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Narratives of Human Rights: Universal Concepts Brought into Focus Through the Lenses of Life Stories

HIV, Stigma and Law in Malawi

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Thesis submitted for the degree of PhD in Development Studies
(SOAS) and Law (Birkbeck College)

7 November 2012

Resubmitted with revisions June 2013

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Declaration for PhD thesis

I have read and understood regulation 17.9 of the Regulations for students of the School of Oriental and African Studies concerning plagiarism. I undertake that all the material presented for examination is my own work and has not been written for me, in whole or in part, by any other person. I also undertake that any quotation or paraphrase from the published or unpublished work of another person has been duly acknowledged in the work which I present for examination.

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Abstract

Background

Law has prominence in the formation and regulation of moral norms—not only in regard to human rights, but also in regard to HIV, health, criminalization, the policing of sexuality and intimate behaviours, and the production of stigma. This research focuses on the potential and impotence of the law to transform social, economic and - to an extent - political inequalities that are limiting the human right to health in the context of HIV in Malawi.

Methods

This one-country qualitative case study (Malawi) action research involved data collection during a 6-month period (October 2010 to March 2011). Datasets include interviews with law commissioners (n=10), opinion leaders (n=22), life story participants who were people living with and closely affected by HIV (n=20), reflections of the action research team (n=6), and a review of the proposed HIV and AIDS (Prevention and Management) Bill, legal and policy documents.

Results

The results showed that while stigma remains a challenge in Malawi, HIV is part of everyday life and only one aspect of nuanced and complex identities of the people whose lives it directly affects. The proposed HIV and AIDS (Prevention and Management) Bill in Malawi manifests a tension between intention and impact—the desire to enact a law to protect human rights and strengthen the national response to HIV, while potentially taking away those rights from certain groups and fuelling HIV-related stigma. Legal consciousness was not apparent in the everyday lives of most of the people living closely with HIV in this research, and significant challenges to law enforcement and access to justice remain. The potential impact of the proposed HIV and AIDS (Prevention and Management) Bill at the personal level could be devastating in creating barriers for testing, internalizing stigma, and limiting opportunities for disclosure for fear of reprisal through the law—for example through the potential application of the criminal law to HIV transmission, exposure and non-disclosure (sections 43 – 5 of the draft Bill). The law does have a symbolic potential in defining aspirations for socio and economic changes that may address the underlying determinants of ill health and protect human rights.

Conclusion

The findings confirm that HIV-related stigma still exists and that stigma is not experienced in a simple way. It is a complex phenomenon expressed both subtly and overtly. Understanding power relations and the complex intersecting dynamics of agency and identity and how they interrelate with law play a vital role in grounding universal human rights principles in the context of the realities of everyday life.

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Moment of Choice

By George Kampango

Birds come and sing
Songs of praise:
The crow, the tit and the owl;
All sing around the flowered tree.

Manly and flat
Sounds Crow's song
And in no time--
Elimination.

Feminine and sweet
Enters Tit's tune
Going deep
Into the heart.

Intermittently
Sings Owl
Plaintive beats
And the tree drops tears.

Is Owl telling a sad story?
Or is it desire for Tree's love...?
I want to know.

The *M'bawa* tree must know
For it has seen
Seasons of dry lands
And seasons of green fields!

ACKNOWLEDGEMENTS

“Laws and institutions must go hand in hand with the progress of the human mind.”

Thomas Jefferson¹

I have always loved to run. Some of my clearest thoughts have crystallized while pounding pavements and fields throughout my life, and the course of this research has been no exception.

I was running recently in Washington DC, on a hot, humid and tiring morning, and serendipitously found myself running up the white marble stones of the grand memorial to Thomas Jefferson. It was at the end of a long week tied up with the international AIDS conference, and the monuments and memorials of the Mall were both a peaceful and inspiring reminder of the grandeur of democracy and great leadership. The long, glaring, hot steps up into the Dome were worth it, as the climb has provided the epigraph for the beginning of this thesis.

This quotation resonated strongly with the core themes of my research—laws, and the principles enshrined in legislation that govern a country. Institutions, and the mechanisms by which laws are translated into practice and that governance is performed in a country. Progress, and the dynamic evolution of life and society. Human, and the irrationality, individuality and lived impact of everyday life. And mind, the rationality of thought and intention.

This quotation, and the inspiration and exhaustion that accompanied my time in Washington DC, provided the final motivation for finishing this thesis. Four of the six partners in the action research team were together at the conference, all of us participating separately in our presentations and dialogues while also connected through the common thread of work that still keeps a piece of us all linked together. It is both my commitment to that very hard working team as well as to ensuring that the results of the research are made public in a timely and useful way that has tipped the scale towards the finish line in the journey of completing the final presentation of this research.

On receiving the Templeton Prize in April 2013, Archbishop Desmond Tutu said “when you are in a crowd and you stand out from the crowd it's usually because you are

¹ Quotation on one of the panels on the wall of the Jefferson Memorial in Washington, D.C.

being carried on the shoulders of others.”² I feel the same, and I am incredibly grateful to all those who have run beside me and guided me throughout the great journey of this research. First and foremost, to all the participants who generously shared their time and insights, and to David Kamkwamba, Ruth Kundecha, Milliam Simkonda Kumwenda, George Kampango and Gift Trapence, whose friendship, hard work and intellect not only contributed to the substance of the research design, data collection and reflection, but also to the collaborative spirit and camaraderie of the entire process. My supervisors in London, Dr Michael Jennings and Professor Matthew Weait, have been a source of guidance, support and constructive criticism alongside Dr Alister Munthali at the Centre for Social Research with University of Malawi. I would also like to extend a special thanks to Kevin Osborne, who helped to connect and create spaces within IPPF to support the research and provided humour and critical guidance, and also Mathias Chatuluka (Family Planning Association of Malawi), Maureen Chirwa (College of Medicine), Safari Mbewe (MANET+), Patrick Brenny (UNAIDS) and Dr Frances Cleaver (University of Bradford). I am also very grateful to the London International Development Centre (LIDC) for the Bloomsbury Fellowship that supported this research.

Last and certainly not least, to my friends and family across many borders whose love and support have nurtured me through the highs and the lows of some very challenging and soul-forming experiences: Sabrina, Kai, Dan, Raoul, Greta, Finn, Keren, and Saku, also for her adventurous spirit and constant supportive good cheer. To Dad, Leanne, Em, Luke, Alex, Patta, Guy, Stewart, Nick and Allan, for their unwavering and unquestioning confidence that the end was possible and in sight. To Karim, for poetry and procrastination. To Jo, for coffee and critical common sense. To Masi, for pots of tea and chocolate at midnight, and infinite patience. To Roo, for always being there. And to Mum, selfless and inspiring, and the world’s most diligent and encouraging proof reader.

It is on these very strong and capable shoulders, each a giant in their own way, that I stand in submitting the ideas in this thesis. Here’s to the spirit of the M’bawa tree within each of us, and the strength to endure the seasons of dry lands and green fields ahead.

Lucy

June 2013

² <http://www.guardian.co.uk/world/2013/apr/04/desmond-tutu-templeton-prize-spiritual> accessed 18 May 2013.

Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ARASA	AIDS and Rights Alliance of Southern Africa
ART	Antiretroviral Therapy
CEDEP	Centre for the Development of People
COWLA	Coalition of Women Living with HIV and AIDS
D4T	The fourth antiretroviral drug available, also known as Stavudine
eMTCT	Elimination of the Mother to Child Transmission of HIV
FPAM	Family Planning Association of Malawi
GNP+	Global Network of People Living with HIV
HIV	Human Immunodeficiency Virus
ICRW	International Centre for Research on Women
ICW	International Community of Women Living with HIV
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICCPR	International Covenant on Civil and Political Rights
IPPF	International Planned Parenthood Federation
LGBT	Lesbian, Gay, Bisexual and Transgender
MANET+	The Network of Networks of People Living with HIV and AIDS in Malawi
MANERELA	The Malawi Network of Religious Leaders Living with and Affected by HIV and AIDS
MBC	Malawi Broadcasting Corporation
MDHS	Malawi Demographic Health Survey
MHRC	Malawi Human Rights Commission
MLC	Malawi Law Commission
NAC	National AIDS Commission
NAF	National HIV and AIDS Action Framework
NSP	National Strategic Plan
OAU	Organization of the African Union
OPC	Office of the President and Cabinet
PMTCT	Prevention of Mother to Child Transmission of HIV
STIs	Sexually Transmitted Infections
UDHR	Universal Declaration of Human Rights
UNAIDS	United Nations Joint Programme on HIV and AIDS
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
UNGA HRC	United Nations General Assembly Human Rights Council
WHO	World Health Organisation

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Watipa
(Hope)

1 | Introduction



Happy, healthy and safe sex may not immediately come to mind as one of the cornerstones of international law and state obligations to promote human rights; nor as one of the primary concerns for international development today. Yet HIV—and the millions of lives it touches—triggers at times uncomfortable or unexpected conversations, and is embedded within many personal, programmatic and policy priorities and agendas around the world. For the estimated 34 million people who are living with HIV today (UNAIDS, 2012), stigma and discrimination pose a real threat to the realisation of the human right to health. As a virus that thrives in the intimate spaces of personal lives, where transmission occurs through blood contact most often during sex or the injection of drugs, HIV spotlights topics that might be hidden or secret, can be difficult to talk about and/or are taboo. As such, it can spotlight previously un-conceived or ill-articulated concerns and emotions for individuals, for communities and for societies, as well as for the dynamic relationships that link them.

Living with HIV today is a different experience for every individual. Life is multi-dimensional, and all individuals will find themselves in different situations where they have different relative positions of visibility and/or engagement and/or power. For some, taking treatment, seeking support, and accessing health services is routine and part of a wide selection of services and choices available. For others, information is limited, support insufficient, or choices denied because of fear or marginalization. Yet stigma relating to HIV remains a significant challenge because it has an impact on the accessibility and orientation of services (not only health, but also legal, care and support services) as well as on self-esteem and general quality of life—which affects people living with HIV,

their families, friends and carers, as well as broader social attitudes reflected in the media, in institutional policies and in political debates.

The research presented in this thesis is interdisciplinary and is a socio-legal study of HIV-related stigma in Malawi that explores the context of the human right to health and the role of legal frameworks in everyday life in the context of HIV. The research is founded on a recognition that people have an intrinsic sense of justice defined by their own complex identities, cultures and contexts. Stigma relating to HIV can be a violation of human rights –undermining an individual’s realisation of “the highest attainable level of physical and mental well-being” (as defined in the WHO Constitution from 1946) and most explicitly in its enacted form as specific experiences of discrimination. This research questions the extent to which initiatives to address HIV-related stigma may have been misdirected in the past by focusing almost exclusively on a person’s HIV status rather than a holistic sense of their identity, and in so doing may have contributed to fuelling rather than abating stigma relating to HIV. The results suggest that in order for the human right to the highest attainable standard of health to be realised for people living with and affected by HIV in Malawi, as promulgated in international law and adopted in national legal frameworks, the underlying inequalities that prevent or perpetuate ill health need to be identified and transformed at the iterative micro and macro levels of individuals within their societies. Without a foundation in the voices and realities of people, and a holistic sense of their lives, the universal principles of human rights risk being distant and abstract from the lives of many, and a blunt instrument for actually achieving human rights.

This action research focuses on the potential and impotence of the law to transform social, economic and - to an extent - political inequalities that are limiting the human right to health in the context of HIV in Malawi. The approach, primarily modelled on Reason and Bradbury (2001), embeds self-critical and applied reflection with the data collection, analysis and presentation of the research results. The planning, implementation and data collection process was founded in the principles of action research (outlined extensively in chapter three). The final analysis presented in this thesis, as well as oversight of the whole research project and management of every stage of executing the research is my own work that demonstrates the required independence, rigor, reflexivity and contribution to a field of a Social Science doctoral research (McNiff, Lomax and Whitehead, 2003; Lomax, 1994; further details presented in chapter three).

Problem statement

More than thirty years on from the first recognition of HIV, there is almost universal consensus that stigma remains a significant challenge.

Internationally, in 1987, Jonathan Mann – the director of the WHO Global Programme on AIDS at that time - identified three phases of the HIV epidemic spanning from HIV, progressing to AIDS, and the epidemic of stigma, discrimination, and denial. Even then, he predicted that this third phase would be as central to the global response to the epidemic as the disease itself (Mann 1987). Almost twenty years later, Peter Piot – the Executive Director of the Joint United Nations Programme on HIV and AIDS at that time – noted the enduring importance of stigma and the lack of due attention and resourcing that had so far been paid to addressing stigma and promoting human rights in the international response to HIV. He lamented that to date there had not yet “never been serious political and programmatic commitment” and that efforts to address stigma had been “relegated to the bottom of AIDS programmes, together with human rights, and often with no funding attached to them” (Piot, 2006). Most recently, in launched the Global Commission on HIV and the Law at a speech in Geneva in 2010, Helen Clarke - the Administrator for the United Nations Development Program (UNDP) and former Prime Minister of New Zealand – said:

“To halt and reverse the spread [of HIV], we need rational responses which shrug off the yoke of prejudice and stigma. We need responses which are built on the solid foundations of equality and dignity for all, and which protect and promote the rights of those who are living with HIV and those who are typically marginalized”.³

In the preface to the landmark report of the Global Commission on HIV and the Law the Chair of the Commission and former President of Brazil, Fernando Henrique Cardoso pointed to the difference but interdependence between stigma, and the process of “respecting human dignity,” and discrimination, “injustice”:

“The end of the global AIDS epidemic is within our reach. This will only be possible if science and action are accompanied by a tangible commitment to *respecting human dignity and ending injustice*.” (UNDP, 2012, p 4, my emphasis)

Nationally, in Malawi, when Bakili Muluzi – the President of Malawi at that time – launched the official AIDS programme in 2004, he did so by urging all Malawians to tackle

³ Press release on the launch of the Global Commission on HIV and the Law: <http://www.undp.org/content/undp/en/home/presscenter/speeches/2010/06/24/helen-clark-on-the-occasion-of-the-launch-of-the-global-commission-on-hiv-and-the-law/> accessed 25 May 2013.

stigma relating to the disease by commemorating his brother who had died three years earlier of an AIDS-related illness⁴. Almost ten years later, both the Presidents during the period of this research also spoke out about the need to “not be complacent about fighting stigma”⁵ (Bingu wa Mutharika, 2011) and continuing to “address the legal environment to ensure that people living with HIV are neither stigmatized nor discriminated”⁶ (President Joyce Banda, 10 October 2012). In terms of rhetoric, in Malawi and around the world, stigma and discrimination remain at the top of the political agenda in responding to HIV.

Stigma is an inherently personal experience that is driven by social and cultural norms and values (as reviewed in chapter two). These norms and values are demarcated in the laws, policies and traditions that govern a society. A lived experience of stigma – just like beauty – is in the eye of the beholder. The literature to date includes multiple analyses of where, how and if HIV-related stigma occurs at a moment in time. While some studies have explored notions of layered identity and how the complexity of identity may have an impact on an individual’s experience of stigma relating to HIV at one moment in time, no other known research has explored the dynamics of stigma as it may be experienced, perceived and change over time within the life of one individual, and very little research has documented experiences of HIV-related stigma through a methodological approach that is by and for people living with HIV.

Increasingly the law has been engaged – either through old laws or through the creation of new HIV-specific laws – in the response to HIV and also identified as having a critical role in shaping the extent to which an environment is enabling in the context of universal access to HIV prevention, treatment, care and support (UNDP, 2012). The law, as mechanism of establishing or sedimenting societal governance, has an influence in shaping normative attitudes towards HIV and potentially fuelling or abating HIV-related stigma. Internationally, the last decade has seen a trend to apply the criminal law (prosecuting HIV transmission, and in some cases HIV exposure and/or non-disclosure of an HIV positive status) as part of national responses to HIV and to promoting public health (GNP+ 2010, OSI 2010). Yet the law, on its own, is limited in its capacity to capture and

⁴ News coverage of the launch in 2004: <http://www.iol.co.za/news/africa/muluzi-urges-malawians-to-end-aids-silence-1.205773#.UaCKvRyth24> accessed 25 May 2013.

⁵ In a statement with the UNAIDS Executive Director, 2 February 2011.

⁶ News coverage of the Annual AIDS Conference on the website of the National AIDS Commission in Malawi: <http://www.aidsmalawi.org.mw/index.php/8-news/13-no-more-stigma-and-discrimination-says-president-joyce-banda> accessed 21 October 2012.

engage the complexity of an individual situated within their wider social context (Freedman, 1999). For example in many countries, criminal prosecutions relating to HIV are being brought under laws that have only recently been enacted (for example HIV specific legislation), or under old laws that have only recently been applied to HIV transmission or exposure (such as public health laws relating to contagion, or criminal laws relating to assault and/or grievous bodily harm) (Pearshouse, 2007). It has been suggested that one of the reasons for the recent proliferation of laws relating to HIV transmission and exposure has been that politicians have been seeking to do something proactive, concrete and publicly visible in response to HIV (Pearshouse, 2007). Very little research to date has explored the potential role of the law in the national response to HIV while also considering its utility and accessibility in the daily lives of people living with HIV, or reviewed the intentions of lawmakers involved in the drafting and proposing new HIV specific legislation. It complements the submissions to the recent Global Commission on HIV and the Law (UNDP 2012) in providing a national summary of HIV and the law in Malawi—one that includes the element of legal consciousness alongside an analysis of the role of the law as part of the national response to HIV (as reviewed in-depth in chapter seven).

The overarching research question explored in this research was the extent to which it may be possible to achieve human rights affirming individual and social change, through law grounded processes in the context of lives and societies affected by HIV. Three specific research questions were identified within this framework as the basis for the results presented in this thesis: first, the extent to which experiences of stigma relating to HIV change over time and alter in relation to the multiple layers that comprise individual identities. Second, an inquiry into aspects of the law and legal consciousness that may affect the usefulness of the law in the daily lives of people living with and closely affected by HIV. Third, the extent to which the normative or symbolic potential of the law frames social attitudes towards HIV and engage stigma relating to HIV.

Throughout the research process there was sustained critical reflection about the role of a participatory process of exploring a human rights concern (in this case stigma relating to HIV) and the potential contribution of the process to protecting human rights for those directly involved. As such, this research methodology is reviewed as a model an effective approach for reducing stigma (see chapter three).

The research presented in this thesis responds to these gaps in the literature by recognizing, analyzing, and documenting links between the complexity of individual experiences of living with HIV and the laws and policies that govern a national response to HIV. The contributions to knowledge can be identified in five key areas. The first, by extending the critical legal notion of intersectionality to an in-depth review of HIV-related stigma, the research presented in this thesis makes a significant contribution to conceptual notions of stigma in terms of both its complexity, as it morphs in relation to permeable layers of individual identity, as well as its temporality as it sediments, erodes and/or embeds over time. This is generated through an in-depth review of life stories explaining instances of when stigma occurred as well as equally when they did not (see chapter six).

Second, this research adds contextual depth to considerations of the normative role of the law and its purchase in daily life. By applying a research approach that focuses on legal consciousness, the research findings illuminate critical areas where there are challenges and/or disconnection between how the laws are conceived on paper and how they are realized in daily life (see chapter seven). A legal consciousness approach is relatively unusual in the study of law in an African setting and is one that has not systematically been undertaken outside North America.

Third, the research also makes an important contribution to documenting and analyzing HIV in the context of Malawi – a country with a relatively high HIV prevalence rate (currently estimated at 10.6% in the latest Demographic Health Survey in Malawi; NSO, 2011) that has been researched less than some of its neighbours (see chapters four and five).

Fourth, this research is the first known instance where a legal consciousness approach has been applied to exploring the role of the law in relation to the experiences of people living with HIV in Malawi. By focusing on the life stories of people living with and closely affected by HIV, the research illuminates notions of the law in everyday life and legal consciousness alongside experiences of HIV and incidents that could be considered examples of HIV-related stigma or discrimination as well as though that are examples of resilience where stigma has been averted (chapters five and six). This aspect of the research links conceptual notions of the potential role of law in demarcating social norms and in governing aspirations for social and economic change that may address the

underlying determinants of ill health and protect human rights with the intentions and actions of the law commissioners involved in drafting the proposed HIV Bill in Malawi. This research in Malawi captured a rare opportunity to document the perspectives on this issue from commissioners involved as part of the Special Law Commission on HIV who drafted the proposed HIV and AIDS (Prevention and Management) Bill in Malawi in 2008, hereafter referred to as the draft HIV Bill) (MLC, 2008) (see chapter eight).

The fifth key contribution of the research to filling gaps in the literature related to the self-reflective critical engagement with an action research methodology that has modelled the Meaningful Involvement of People Living with HIV and AIDS (MIPA) principle in action—according to the literature reviewed, and to the best of my knowledge, this is the first qualitative action research about HIV and stigma in Malawi to undertake such an approach (see chapter three).

The research presented in this thesis links the personal with the political at all levels. These five critical areas to knowledge about HIV, stigma and the law have been documented, understood, and analyzed in this thesis to inform and generate action through both the dissemination of the research results and the enhanced critical reflection of practitioners involved in the action research process.

Conceptual foundations

As Amartya Sen said, “it would be silly to build an ambitious structure on the foundations of quicksand” (Sen, 1999, 249). Five key terms and concepts underpin this research — law, development, HIV, stigma, and the human right to health. However by way of brief introduction, the core definitions are outlined below to set a strong foundation for the analysis and investigation that follows.

The first concept is that of law. In this research I have followed the direction of Ewick and Silbey to define law as more than statutes and legislation, and see it as more of a social interaction that embodies daily activities, structures and implementation (1998). Focusing on legal consciousness rather than on legislation and policies per se also enables an understanding of different legal frameworks and ideologies that might be influencing perceptions of law in everyday life, by examining law in its social context, and considerations of the challenges of enforcement as well as barriers prohibiting access to justice. Given the grounding of this research in life stories, “law” is broadly used to reflect

the meanings that participants ascribed to it rather than a clear delineation between formal, customary and other traditional legal systems.

Second is the concept of development. Given the fundamental importance of people and humanity in the context of HIV, and indeed of development in general, my definition of development incorporates social dimensions as well as economic ones. Drawing on notions of Sen (1999), Stiglitz (2002) and Schumacher (1973), development can be defined as a process of expanding the freedoms, choices and opportunities that people enjoy. In the context of HIV, this translates into freedom to implement HIV preventative practices; freedom from stigma, discrimination and violence; and opportunity to cultivate human capital and economic growth. The methodology adopted for this research also reflects this definition of development, which has been inspired by Paulo Freire's focus on self-critical awareness (*conscientização*) and a belief that "reflection—true reflection—leads to action" and that "oppressed" people themselves hold the key to their own empowerment and have the potential to generate sustainable social change (Freire, 1972, 48; Freire, 1974; Chambers, 1997; Chambers, 2008). Reflection and notions of praxis are imbued with the potential to generate change, assuming a connection between the past and the future, and incorporating actions or aspirations for change—at the individual or social level. As such, this definition of development has shaped both the process as well as the findings of this research.

The third concept concerns the definition of the human immunodeficiency virus (HIV). From a biomedical perspective the research is based on the standard definition of HIV as the virus that weakens the immune system, ultimately leading to AIDS (UNAIDS, 2011). I enhance this perspective by taking a socio-cultural perspective about HIV, which takes into consideration the structural determinants of health that create and/or perpetuate vulnerability to HIV (Marmot, 2007; WHO, 2008). In addition, this research embodies the GIPA Principle (The Greater Involvement of People Living with HIV) that was formalised in the Paris AIDS Summit Declaration in 1994 and is now a core criterion for policy consultations, international grant applications and organising committees relating to HIV (GNP+, 2009). As with the definition of development, the notion of GIPA (and in fact MIPA – since adapted to ensure the meaningful involvement of people living with HIV) has equally shaped the process and substance of this research and analysis, and the action research methodology.

Fourth, stigma, commonly understood as a process of devaluation or as a 'mark' of discreditation (Goffman, 1963), can be productive, and is imbued with power (Parker and Aggleton, 2003). Different types of stigma have been differentiated as enacted stigma (actions resulting from stigma, also known as discrimination), perceived stigma (fear that stigma will be experienced), stigma by association (stigma experienced because of perceived association with a stigmatised group or discredited behaviour) and internalised stigma (the internalisation of negative or devaluing attitudes) (Parker and Aggleton, 2003; Link and Phelan, 2001). Stigma attaches itself not only to individuals but also to specific social contexts (Goffman 1963; Manzo, 2004).

Last but not least, the final key concept that forms the foundation of this research is the notion of the human right to health. The human right to health has been defined from the outset as a holistic concept in international law, framed within a wider consideration about the social determinants of health and the promotion of human rights, dignity, equality and freedom (WHO, 2008). The right to the highest attainable standard of health as a "state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity," and as "one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition," was recognised in 1946 with the adoption of the Constitution of the World Health Organisation (WHO, 1948). The WHO definition also articulates the importance of health promotion and the process of enabling people to gain control over decisions and access to information that will benefit their health (Mann et al., 1999).⁷ General Comment 14 provides an international framework that defines State's obligations to respect, protect and fulfil the human right to health as a broad, multi-faceted and enforceable right (UN, 2000). Participatory approaches to understanding the human right to health (such as the results presented in this thesis) can provide in-depth and contextualized insights into the multiple dimensions that enable and hinder health in everyday life (Kesby, 2005).

Just as the human right to health is inter-connected and mutually dependent on other human rights (Gruskin, Mills and Tarantola, 2007), these five key concepts are interlinked and mutually critical for understanding the dynamics of this research topic and process. It is necessary to also maintain focus on a structural understanding of stigma that

⁷ These principles were echoed two years later in article 25 (1) of the Universal Declaration of Human Rights (UDHR) which adopted an equally holistic definition of health 'including food, clothing, housing and medical care and necessary social services' and is founded on concepts of inviolable human dignity and freedom, alongside justice and peace (UNDHR, 1948).

includes a recognition of the dynamic interplay between an individual and the social determinants and power structures that influence their lives (Parker and Aggleton, 2003). As such, HIV and happy, healthy and safe sex are in many ways central to international, national and personal conversations, decisions and interactions in the world (both conscious and those less so).

Human rights in reality

International declarations have successfully raised awareness about human rights and placed issues of social justice, (in)equality and obligation firmly on the table of international relations and national government policies. Yet their very indiscriminate universality means that they risk losing purchase in assisting the struggles of individual lives.

Law, on its own, is limited in its capacity to capture and engage the complexity of an individual situated within their wider social context: “a legal system premised on a strict dichotomy between individuals and the collective ignores the extent to which individuals define themselves through, and take meaning from, their relationships with others” (Freedman, 1999, p 237). By understanding perceptions and consciousness of law in everyday life, the complex relationships between individuals (in all our inconsistency and complexity) and society are illuminated. Likewise, individual agency, community based action and/or social mobilisation is limited by the institutional and societal reception it generates. The life stories that are at the core of this research contribute depth, nuance and diversity to understanding the dynamics of a wider environment that can both facilitate as well as impede agency, human rights and quality of life at different times and in different circumstances for individual lives. By understanding the diverse and at times competing dynamics of individuals within social contexts, we can piece together an understanding of possible ingredients that together can produce rights-based and health-promoting individual and social change (Englund, 2012).

Research and social change

This research involves a naturalistic inquiry and a case study exploring the human right to health within the context of lived experiences of HIV, the law and stigma relating to HIV in Malawi (Yin, 2009; Lincoln and Guba, 1985). It investigates how an empowering process of documenting human rights (their conceptualisation, as well as moments of

realisation and violation) can contribute to development and a *conscientization* of human rights—a Freirean notion of consciousness that is embedded with action and the potential for personal and social transformation. This thesis is structured to review the research of others while also distilling the critical results from this research along the key themes of HIV and daily life, stigma, and the law in Malawi. After this introduction, chapter two establishes the critical theoretical foundation for the research. The framework is original and innovative in the extent to which it draws on critical race theory, legal theory, power and agency and applies it to the conceptual area of the human right to health. The literature reviewed in the chapter also serves to situate this research within the context of other studies that have looked at HIV-related stigma, law and human rights within a relevant context.

The third chapter describes the methodology adapted for the research and establishes the rationale and consistency inherent in adopting an actor-oriented approach to documenting human rights through participatory action research with people living with and closely affected by HIV in Malawi. The methodological approach adopted for this research – participatory action research – is flexible, narrative-focused and actor-oriented in order to capture the nuances and depth of the murkiness of everyday life. It includes a critical reflection about the implications from the lessons learned about the potential of the action research process modelled in the data collection process of this thesis to be a new/ innovative/ holistic approach to a stigma reduction intervention by engaging and working with people in their daily lives and not only focusing on their HIV status.

The fourth chapter provides a contextual introduction to Malawi, drawing on both a current overview of relevant literature, international indicators and the latest national demographic information, as well as descriptions from the participants in the research about the most pressing priorities in the national HIV response. Using the typology of Sandelowski and Barroso (2003), this chapter builds the foundation of a thematic survey of the important contextual and social issues relating to HIV and Malawi.

Chapter five introduces the life story participants that are pivotal for the analysis and results presented throughout the thesis. This chapter builds the foundation of a thematic survey of the important individual and experiential issues relating to HIV and Malawi. Read in conjunction with the empirical component of chapter three (part B), these two chapters provide the grounded context for the theoretical and conceptual analysis presented in the remainder of the thesis.

Chapters six, seven and eight present the details of the main thematic findings and conceptual implications of the research. Chapter six presents the results that extend the notion of intersectionality to the dynamics of stigma and daily living with HIV, and provides the in-depth analysis relating to the conceptual contribution of the research findings that highlight the complexity of identity, layering, and temporality in understanding HIV-related stigma. The chapter begins with an overview of the life story interviews and an exploration of the meaning of HIV in the lives of people living with and closely affected by HIV in Malawi. It includes an analysis of the extent to which people describe their experiences of HIV-related stigma. However by taking an approach based on life stories and a holistic view of people, it seeks to counterbalance the majority of research about HIV-related stigma that tends to focus solely on HIV and/or on stigma as an issue in isolation – that is, devoid of the context and experiences of the whole person. This chapter situates the findings in relation to the meaning, understanding and conceptualisation of stigma and the consciously proposed solutions for overcoming it. Other research investigating HIV-related stigma has not taken into consideration the different meaning and perceptions of stigma held by the participants in the research. The findings outlined in the chapter indicate that this dimension is critical for understanding stigma as well as interpreting the most effective locus of action and interventions to overcome it.

Chapter seven explores the extent to which the formal legal system is present in the everyday lives of Malawians and the potential utility of the proposed draft HIV Bill as part of the national response to HIV. The chapter presents insights into law and legal consciousness, and utility of law in the everyday life of people living with HIV. It reviews the report of the Special Commission on HIV and AIDS and the subsequent proposed draft HIV Bill, which embodies the paradox of a legal framework that is founded on principles of non-discrimination (in terms of the national Constitution as well the defined premise for the proposed draft HIV Bill), yet includes controversial and stigmatising provisions. It explores the extent to which the law can engage, and respond to, the multiple facets of a person's identity. Globally there is a paucity of information relating to the motivations and aspirations of lawmakers and the rationale behind legislative provisions relating explicitly to HIV. The timing and framing of the research has provided a rare opportunity to document and analyze the intentions and perceptions of the individuals involved in drafting the proposed HIV legislation in Malawi.

Chapter eight analyses the results in terms of the potential dualism of the role of the law – its symbolic potential in defining aspirations for social and economic changes that may address the underlying determinants of ill health and protect human rights and also its potential through the criminalization provisions to create barriers for testing, internalizing stigma, and limiting opportunities for disclosure for fear of reprisal through the law. The chapter focuses specifically on one aspect of the draft HIV Bill – the criminalization of HIV transmission – as a lens to analyze the confounding nature of criminalization, stigma and vulnerability to HIV. It does so in relation to other prevalent notions in law such as the Constitution of Malawi and situates this research in light of other scholarship about the justiciability of social and economic rights in Malawi.

The conclusion summarises the main arguments and contributions of the research, and brings back together the interwoven Jeffersonian elements of laws, institutions, progress, humans and the mind.

The research underpinning this thesis is self-reflective, applied and collaborative, founded on core principles central to both action research and stigma interventions—that change starts with each one of us.

“Stigma begins and ends with each one of us. As the triple combination of ignorance, prejudice and fear creates a nurturing avenue for HIV’s continued spread, so openness, acceptance and accessible services are the key to its containment. Shame and fear can be defeated, the chains that link HIV to racism and inequality can be broken and the HIV epidemic can be turned back. The fight against HIV will be won by a unique combination of increased political commitment, adequate resources, sound policies and robust health systems. This much we know. But fundamentally, however, the fight must be won at the personal level. The real battle must be fought by ensuring individuals—be they policymakers or the poor; presidents or patients—have the ability and skills to live, love and find the light that glows in the very shadows of this epidemic. That is where the real battle is. For in truly embracing HIV we can begin the journey of honest reflection and concerted action” (Osborne, 2009, 37).⁸

The process of telling and listening to stories, and reflection on individual lives and situated selves within the dynamic intersections of identity and society, can become one of the cornerstones promoting individual and social praxis. In turn, this could contribute towards the liberating individual and social change necessary to both overcoming stigma and promoting the human right to health.

⁸ Kevin Osborne is a friend and mentor, as well as the Senior Advisor for HIV at the International Planned Parenthood Federation (IPPF) and is the person who first thought of the idea for *The People Living with HIV Stigma Index* in 2005 (in the shower!).

By understanding and being conscious of the dynamics within and between individuals and societies, and privileging individual reflection and undertaking social action, this research suggests that a kaleidoscopic process is needed to mediate power inequalities and generate the kind of social and individual transformation that can translate the human right to health from rhetoric into reality.

2 | Kaleidoscopes of identity:

Self, society and the power to change

Theoretical Framework and Literature Review



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INTRODUCTION | Life, Self, Stigma and Society

Life's murky inconsistencies create puzzles that are difficult to capture in a single theoretical framework. In this chapter, I explore the literature relating to the relationship between self and society, and how it affects the realisation of the human right to health at the individual and structural level. In isolation, each of the core theoretical frameworks seem to be missing an intrinsic dynamism—a dynamism that can reflect and capture the nuanced, complex and layered realities of individual lives. Yet combined, they enable a kaleidoscopic image that both illuminate broader social patterns while also bringing the individual into focus. Significantly, this image in the kaleidoscope presents a dynamic, reactive and transient image that changes (and changes back) depending on the context (such as the light) but the actors (individual focus within different patterns) remain the same.

To give a practical example, this approach could provide a framework to explain why and how a man can be stigmatised at breakfast, can discriminate at lunchtime, and find solidarity in the evening. He has a complex identity as an individual man, who is well educated, employed, Christian, living with HIV and married with three children. He is quintessentially human, shaped by attitudes and beliefs and moods that can be inconsistent, and who can simultaneously feel empowered and disempowered depending on the context. This man might experience stigma at breakfast, when his mother-in-law serves his coffee in a cup that has been separately washed and marked for him because she (irrationally) fears HIV transmission. This same man might tease a colleague at work, because his colleague is gay and is wearing a pink shirt, and who also happens to be living with HIV but has not disclosed his status in the workplace. The same man in the evening may attend a meeting of a support group, for people living with HIV, organised by his Church, where he feels included and shares common beliefs and a sense of solidarity with the other members of the group. At night, even though his wife is supportive and they have been married for 5 years, he often fears that she will reject him sexually. The experiences and attitudes of this one man is beyond the sum of its parts—neither the different 'categories' of his identity (e.g. man, living with HIV, employed, Christian) nor the intersection of these identities sufficiently explain how this man can simultaneously experience power and powerlessness in different moments in the context of his daily life.

The literature reviewed in this chapter also situates the analysis outlined in the remainder of the thesis within the context of other relevant studies about human rights,

legal consciousness and stigma in relating to HIV, where such studies exist. The literature review also spotlights gaps in the literature that I seek to address through the analysis presented in this thesis. The approach I have taken can be described as grounded theory, whereby the analyses of the ideas generated by participants in this specific research provide the foundation for the interpretation and broader conceptual implications transferable from this research (cf Sandelowski and Barroso, 2003; Lincoln and Guba, 1985). This is consistent with the approach proposed by Ife (2010) in the study of human rights from below, both in terms of identifying thematic concerns as well as interpreting the results to have broader conceptual transferability (Shenton, 2004).

By drawing on theoretical frameworks relating to power, structuralism and intersectionality, a synthesis of the critical elements of each framework offers a possible lens through which to usefully understand the relationship between self and society, and to unpack the underlying determinants of health, human rights and social justice. I explore theories of power, identity and triggers of change for the future that can provide insight into why someone—with all the complex intersecting layers of their identity within the competing structural dynamics of the society in which they live—can feel powerful and powerless, potentially within moments, in different contexts; how this transient or ephemeral power relates to different layers of complex identities, and/ or different layers of competing structures; the extent to which an individual's capacity to act, to perceive power, and to have the freedom to exercise that power exists beyond the rational realm and is influenced by feelings, emotions and sub-conscious experiences of self in relation to society; the difference between power and agency; and how even when someone is and/or feels powerful they may not have (or choose not to exercise) that power (which is their agency); or vice versa, when someone has or feels they have all the agency in the world and yet does not have power to complete that act as desired; and, how change is triggered (and by whom or what) at the individual and social levels that can facilitate first the imagination and then realisation of aspirations for more equitable and empowering realities for individuals and societies in the future.

Building on the review of power and the relations linking individual agency and structural and cultural dynamics, the remainder of the chapter explicitly situates this research within existing literature and current gaps of research relating to the specific areas of relevance for this research project within broader consideration of the dynamic relationship between self and society. The literature was robustly reviewed using common

search terms in public health and legal databases such as *PubMed*, *JSTOR*, *LexisNexis* and *WestLaw*. Specific journals such as *Social Science and Medicine*, *Journal of the International AIDS Society*, *Health and Human Rights*, *Development in Practice* and *Action Research* were also searched for specific references. Keywords searched included *HIV*, *Malawi*, *stigma*, *discrimination*, *law*, *legal consciousness* and *criminalization*. Key authors known to have published specifically on these issues were also directly searched by name in various databases. Relevant articles were reviewed, and included as appropriate in the literature review as described in the sections below. The literature review presents an in-depth conceptual review of theories and relevant bodies of scholarship, to facilitate the interpretative and conceptual analysis of the specific data collected as part of this research. The literature review did not seek to include an exhaustive description of other contextual studies, as the intention has been to adopt a form of grounded theory approach and situate the analysis within the perspectives, opinions and experiences of the participants directly involved in this research.

The literature review is divided into two main thematic areas. The first, the law, including considerations of legal consciousness, perceptions of human rights and the discursive tension between the universal and the individual, and the sociological framework for critiquing the normative relationship linking the law and stigma through in the example of the criminalization of HIV. The review lays the foundation for the 'human rights from below' approach of this research (cf Ife, 2010) by exploring perceptions of human rights, notions of law, linked with a self-reflective process of community mobilisation through participatory inquiry. There is a gap in the literature relating to the intentions and motivations of lawmakers in applying legal mechanisms to national responses to HIV, which highlights the opportunity of this research to address that gap in the context of Malawi given the context and timing of this research in relation to a proposed HIV Bill in Malawi (see chapter three). The review also highlights the dearth of research about access to justice in the context of HIV and legal consciousness in an African setting. This section of the chapter provides the foundation for the subsequent grounded theory analysis of research questions two and three (i.e. the extent to which law and legal consciousness useful for seeking redress for HIV-related discrimination in the daily lives of people living with and closely affected by HIV, and the extent to which the normative or symbolic potential of the law frames social attitudes towards HIV and engage stigma relating to HIV).

The second area of literature reviewed is stigma and processes of stigmatisation, and the interplay between internalisation and socialisation of complex processes and attitudes of devaluation. This section lays the foundation for the exploration of the first research question (i.e. the extent to which experiences of stigma relating to HIV change over time and alter in relation to the multiple layers that comprise individual identities) and includes a review of the nature of stigma, the differences between stigma (a process) and discrimination (and action); current literature that has analyzed HIV-related stigma and existing reviews of stigma-reduction interventions. The review identifies two critical gaps in the conceptualisation of stigma and the locus of stigma-reduction interventions that the analysis presented in this research seeks to address through the presentation of results relating to the first research question. It also helps frame some of the critical reflections about the process undertaken in this action research project as a holistic model and stigma reduction intervention in its own right. The review also highlights the dearth of research about HIV-related stigma in Malawi and indicates the important contribution this research makes to providing contextual knowledge relating to a developing country with a significant HIV prevalence.

The literature is vast, and in particular I focus on exploring the questions of perception, contextuality and temporality which are central to understanding processes of stigmatisation and the realisation of human rights—both of which I argue are intrinsically determined by power and the interrelationship between individuals (in all our complexity) and the society (in all its different guises) in which we live. The chapter concludes by exploring implications for change that take into consideration the dynamic notions and the complex power dynamics that link the individual, social and cultural across the temporal spaces of past, present and future.

One overarching challenge remains, which is to extend this theoretical approach to delve beyond the 'conscious' to explore the underlying dynamics and relationships and prejudices that may remain hidden to the individuals and societies in which they operate. How does someone recognise the external dynamic power relations that are affecting their being in and perceiving of the world? To what extent might someone have or desire agency to then change that dynamic once aware of its presence? What are the triggers that bring these power dynamics into consciousness for an individual so that they may choose to act, resist and/ or overcome? Or do nothing? These questions are particularly

significant for understanding process of stigmatisation, which deeply live in the souls, attitudes and cultural beliefs of individuals as well as societies and its institutions.

1 POWER| Self, Structures and Societies

There are numerous aspects of power at work in regard to human rights and the ability—either individual or collective—to realise these rights and to exercise free will or agency. Dimensions of power and powerlessness are embedded in the contested identities of individuals and groups according to gender, race, sexuality, religion, education level, employment, institutional affiliation ... and the list seems endless. Addressing the relational and situational nature of power provides a framework for understanding that any one individual or group can simultaneously be powerful and powerless depending on the context.

This section first explores the conceptualisation of power that situates the agency of the self—the ability to exercise power—within a wider context of social and cultural structures that influence power relations. The concept of intersectionality and the complex layers of identity, and the inability of the law (as traditionally defined) to respond to that complexity is added to provide a more comprehensive theoretical foundation for the power analysis to follow. The second focus is on the temporal nature of power, and how power changes and evolves over time and is exercised differently in different contexts. This concept is explored in relation to legal mechanisms that limit or facilitate this recognition of temporality. The third section focuses on the power to transform, the triggers of change at the individual and social level, and the opportunities to aspire and imagine social justice. The fourth section explores the productive aspects of power and its potential to generate resistance and opportunities for transformation.

Several authors have looked at dimensions of power, dissecting it into distinctions between ‘power to’, ‘power over’ and ‘power from within’ (e.g. Rowlands, 1998; Chambers, 2000; Chambers, 1997). Steven Lukes usefully invokes the need to conceptualise power in three dimensions, incorporating decision and policy making power (first dimension), attempts to control agendas (second dimension) and the capacity to frame public issues in a way that distorts or suppresses people’s perceptions of their interests (third dimension) (Hayward and Lukes, 2008; cf Lukes 1974; Lukes, 2005). Lukes argues that the third dimension of power is one that governs the perceptions of power

and the internalisation of disempowerment—it is “the power to prevent people, to whatever degree, from having grievances by shaping their perceptions, cognitions and preferences in such a way that they accept their role in the existing order of things” (2005, p 11). There is a fourth possible dimension, which Lukes presents and rejects, that could be drawn from Foucault, and has subversive implications for how we think about rationality and freedom. For Foucault, there is a deep and intimate connection between power and knowledge (Lukes, 2005)—“power is not built up out of ‘wills’ (individual or collective), nor is it derivable from interests” but is constructed and functions on the basis of myriad issues and effects (Foucault, 1980, p 188). Foucault provides a theoretical analysis of the web of human and institutional relationships with a relatively simple point overall: power is not only “built up out of ‘wills’”, but is rather a relational force constructed along various axes of individual identities, collective identities and environmental circumstances (Foucault, 1980).

“Between every point of a social body, between a man and a woman, between the members of a family, between a master and his pupil, between everyone who knows and everyone who does not, there exist relations of power” (Foucault, 1980, p 187).

It is this third and fourth dimension of power that explicitly touches on the internalisation of power and how it affects an individual’s perception and being in the world that is of particular significance for understanding stigma, and will be explored in more detail later in the chapter.

Power both represses (desire, agency) and produces (pleasure, knowledge, discourse) (Foucault, 1984; Lukes, 2005). Power can be seen as a process, as a potential, and as a capacity. Foucault explains, “power is neither given, nor exchanged, nor recovered, but rather exercised” (1980, p 89). Lukes extends this further by suggesting that power is “a capacity not the exercise of that capacity” (2005, p 12) which significantly provides an opportunity to articulate the difference between agency and power at the individual level. Cleaver also reminds us that there is a need to distinguish between the choices that people make and their ability to make (and exercise) those choices (2007, p 224). In this research, especially as it relates to stigma, power is taken to mean both the capacity to exercise power as well as the action itself—in some ways this reflects the relationship between stigma (process that limits capacity) and discrimination (an action inhibiting the exercise of power).

Structure and Society

Power is relational, and is shaped both by the existence of structures as well as an individual's engagement with those structures. The law is one such structure that has an influence in the governance of society. Archer (1988) develops a link between focusing on individual agency and power, with broader social and cultural structures that affect how that power is embodied in different contexts and visible in different patterns. She stresses the dynamic and temporal nature of culture and refers to it as a "shapeless, seething and shifting thing" (Archer, 1988, p xxii). Archer argues in favour of an 'analytical dualism' that distinguishes between systems and the relationships between agents in those systems and facilitates a cultural or structural analysis that also responds to the dynamic relationship between self, selves and society (p xvi). The first component of the analytical dualism refers to the cultural system integration which has a logical consistency and explores the relations between components of culture—in other words, a macro level that positions culture without a knowing subject. The second component refers to socio-cultural integration and focuses on the micro level and the individual knowing subject that exists within culture. This level is outside logic and facilitates exploration of social cohesion (or lack thereof) and the dynamic relationships between different agents. Although not explicit, Archer's distinction between the 'knowing' and 'unknowing subject' also points to a space beyond rational consciousness where there is a need to enhance the conceptualisation of power dynamics between individuals, structures and cultures (similar to the Africanist literature on human rights summarised below).

By focusing on the structural determinants of power, Foucault and Archer both distinguish dynamics of power that are systemic and operate potentially outside the reach of any one individual's life. Significantly however, Foucault and Archer also take account of individual agency and ability to exert free will as well as the environmental or contextual relationships that may either facilitate or impede that ability. As Foucault poignantly summarises, as one who is more concerned with the structural relationships of power rather than the individuals involved yet also considers the real life implications "power" has on someone's life:

"In thinking of mechanisms of power, I am thinking rather of its capillary forms of existence, the point where power reaches into the very grain of individuals, touches their bodies, and inserts itself into their very actions and attitudes, their discourses, learning processes, and everyday lives." (Foucault, 1980, p39, cited in Lukes, 2005, p88-9)

Foucault suggests that power's success is proportional to its ability to hide the mechanisms by which it operates, and notes that undermined or disempowered agents are evidence of the effects of – and significantly not absence of – power and domination (Lukes, 2005). Tension remains between focusing on an agent-centric or a structural conceptualisation of power, and there is a need to take both into consideration (Hayward and Lukes, 2008). By adopting the analytical dualism proposed by Archer (1988) it is possible to bring both processes into necessary focus for understanding the dynamics and interrelational aspects of power. In other words, a kaleidoscope.

Gregory Bateson adds a further focus for understanding power dynamics. He suggests that it is in fact the interrelationship between individuals that is the locus of power. He describes a theory of dependency or symbiotic relationship between individuals and society—taking in both a focus on individual identity as well as the inter-relationship between individuals comprising society:

“You are the company you keep. Your identity, yourself, depends upon the people and the things that compose your associations. And perhaps even more important, *your knowledge of yourself* and your development as a person are both predicated on those same associations.” (Bateson, 1982, p3, *my emphasis*)

Bateson suggests that emotions or experiences are not internal to a single person, such as pride, anger, or stigma, but in fact have “roots in what happens between persons” (ibid, p 5). He also links this to a self-critical awareness—a self-knowledge. Implicitly he is suggesting that there is a space beyond the rational consciousness of any one individual that shapes the form and locus of power, social attitudes and relationships. Individuals or agents interact within structural limits while also developing expectations about actions and reactions of others in particular contexts—and highlights the need to understand the inter-subjective as well as subjective understanding of the meanings of actions in different contexts (Hayward and Lukes, 2008). There is a need therefore not only to understand power dynamics by focusing on individual agency (and their capacity to exercise that agency) as well as the structural and cultural forces affecting that agency, but also to focus on the relationships between individuals (and within groups) that also have the potential to generate or constrain power.

By recognising and disentangling different power relationships, as well as the broader social and cultural context in which these dynamics operate, a dualistic approach to power analysis facilitates the recognition of the overarching concepts critical for understanding the dynamic interrelationship between self, selves and society and the

underlying determinants affecting the realisation of human rights for different individuals in different contexts. Archer cautions against taking a “theoretical stance which embraces its eternal duality but then ends up unable to specify under what conditions we are condemned to reproduce our culture versus which conditions allow us the freedom to transform it” (Archer, 1988, p xx iii). The results in this thesis suggest that an approach based in ‘human rights from below’ may enable such freedom. The elision described in this chapter, of components of ‘Western’ and ‘African’ theoretical concepts of human rights, creates a cross-cultural opportunity to facilitate the freedom to critically reflect on the relationship between self, others and society.

Heeding Archer’s advice, the remainder of this conceptual section of the chapter focuses on the application of the theoretical conceptualisation of agency and power to real life complexities, and an exploration of the opportunities that can trigger the freedom and possibility for transformation.

Deepening conceptualisations of ‘self’ and intersectional identities

One area where the literature relating to power is lacking is in regard to the complexity of individual identities. There are multiple axes of identity that may influence an individual’s engagement with—and treatment within—law and law enforcement, such as gender, age, race, class, and the extent to which that individual may be ‘outlawed’ on a basis of their identity (for example because they earn money in a manner deemed illegal or their sexual orientation is not acceptable in law).

The concept of ‘intersectionality’—to borrow from critical race theory and feminist legal studies—adds complexity, layering, categorisation and solidarity to the notions of individual power and agency explored above. In essence, intersectionality describes the coming together of dynamics of inequality centred on the complexity and layering of identity. Echoing Bateson, the concept is built on recognition of identities that exist apart from each other, within and shared between individuals, acting like a “fastener” that “presumes the gaps that it attempts to close” (Grabham et al, 2009, p2). As a concept to focus political critique, intersectionality has directed a spotlight onto multidimensional aspects of individual identity, where axes of power meet, as well as the discourse of structural regimes that produce, recognise and/or ignore relationships between self and society (Cooper, 2009).

The concept has gained momentum (and criticism) since 1989 when 'intersectionality' was first coined by Kimberle Crenshaw in a seminal article that dissected the dual axes of race and gender and showed how women of colour can be marginalised within patriarchal anti-racism movements and/or racist feminist movements (Crenshaw, 1989; Davis, 2008). Crenshaw is responding to "the elision of difference in identity politics" (1995, p 357). She suggests that sometimes women of colour may experience "double-discrimination" which is unique and is the combined effects of race and sex based discrimination, even though they may also experience discrimination that is similar to white women (sex discrimination) or men of colour (race discrimination) (Crenshaw, 1989, p 149). This naming and recognition of the different and compounding axes of discrimination lays the conceptual foundation for analysis of layered stigma relating to HIV that is discussed later in this chapter.

Intersectionality has been welcomed as a seminal contribution to feminist theory in two ways (Davis, 2008). The first, by exploring how categories of race and gender are intertwined yet distinct; and the significance of asking questions to disentangling the social processes (Matsuda, 1991). The second, by contributing to the postmodernist search for alternatives to static conceptualisations of identity and developing Foucauldian perspectives on the dynamic processes of power (Davis, 2008). The evolution of the concept of intersectionality has enabled recognition of relationships between self and society that are not spatially or temporally separated, but are in fact simultaneous, mutually reinforcing and intertwining (Cooper, 2009; Archer, 1988).

Several metaphors have been used to capture and elaborate the concept of 'intersectionality'—all of which mark the quest for a more nuanced dynamism within the concept that can more adequately reflect the complexities of real life. While heeding concern that metaphors can be reductionist and simplistic (Kwan, 2002), a comparison of three of the key metaphors relating to intersectionality and its critics highlight the on-going evolution of the concept to more adequately reflect the complex relationships between layered selves and society. In many ways, each new metaphor highlights the deficiencies of the one preceding it, and none to date satisfactorily capture the dynamism and temporality that I argue is essential for understanding how one person can simultaneously experience feeling powerful and powerless in different moments in the same context. It also alludes to recent discussions of agency, which differentiate different models of self and reflexivity over time, and in different contexts (cf Greener, 2002).

The first metaphor used to represent the concept of intersectionality was that of the intersection or the crossroads (Crenshaw, 1989, p 149).⁹ The strength of this foundation metaphor is in its promotion of the recognition of difference within groups and processes of discrimination. By naming categories of race and gender, Crenshaw provides a framework that enables the enhanced visibility of women of colour within both the feminist and the anti-racism movements. However the concept is limited in that it oversimplifies identity (implicitly to an intersection of two streets—race and gender, although in principle an intersection could have many streets or be a roundabout) and provides only one site of intersection. For example once a vehicle leaves the intersection it is implied that it is limited to continuing along the ‘patriarchy’ or ‘colonial’ or ‘racism’ street. Similarly, the term ‘intersection’ implies stasis rather than movement (Grabham et al, 2009) and fails to transcend difference (Nash, 2008).

The second key metaphor used to represent and further develop the concept of intersectionality was that of the “Koosh ball”—a popular children’s ball with intersecting and stretchy rubber bands (Wildman and Davis, 1995, cited in Kwan 2002).¹⁰ The authors go on to draw out the analogy to emphasise the risks of categorical thinking, stressing the need to focus on the complexity of the individual. They argue that societal efforts at categorization are dynamic like the Koosh ball, and as such it is the perfect post-modern ball given its ability to capture the interaction between contexts of privilege and of subordination (ibid.). The strength of the Koosh ball metaphor lies in its ability to capture the different ‘strings’ of identity that can be strong or weak but still present in different contexts. As others have noted, context is critical for understanding oppression, subordination, and indeed privilege (Chang and Culp, 2002). Crenshaw focused on the dual axes of race and sex, which is constrictive, and this development in the concept of intersectionality highlights the numerous other competing aspects of someone’s identity

⁹ Full quotation: “Black women can experience discrimination in any number of ways and that the contradiction arises from our assumptions that their claims of exclusion must be unidirectional. Consider an analogy to traffic in an intersection, coming and going in all four directions. Discrimination, like traffic through an intersection, may flow in one direction, and it may flow in another. If an accident happens in an intersection, it can be caused by cars travelling from any number of directions and, sometimes, from all of them. Similarly, if a Black woman is harmed because she is in the intersection, her injury could result from sex discrimination or race discrimination.” (Crenshaw, 1989, p 149)

¹⁰ Full quotation: “The Koosh ball is a popular children’s toy. Although it is called a ball and that category leads one to imagine a firm, round surface used for catching and throwing, the Koosh ball is neither hard nor firm. Picture hundreds of rubber bands, tied in the centre. Mentally cut the end of each band. The wriggling, uniform mass in your hand is a Koosh ball, still usable for throwing and catching, but changing shape as it sails through the air or as the wind blows through its rubbery limbs when it is at rest. It is a dynamic ball.” (Wildman and Davis, 1995, cited in Kwan, 2002, p 327-8)

and their interactions in different circumstances. The focus, however, remains on the individual, the ball itself, without engaging with how the wider social and cultural context may influence the dominance or repression of different 'strings' of identity.

The third key metaphor used to represent and further develop the concept of intersectionality was that of a house of cards, to depict the symbiotic nature of relationships among systems of subordination while also recognising the individuals that make up those systems (Ehrenreich, 2003. p 279).¹¹ The strength of Ehrenreich's metaphor is in her effort to depict the mutual dependency between individuals and society that can both reinforce subordination as well as give strength. It highlights the deficiencies of the other metaphors in capturing a sense of a relationship between individuals—a relationship that in itself is imbued with power dynamics (Bateson, 1982). Ehrenreich's view is that unlike the separate vehicles operating independently and coming from different directions in the concept of intersectionality, "the sets of cards exist in relation to each other and are mutually reinforcing; they hold each other up. They also overlap ... [I]ike individuals they exist in a complex web of relationships in which they sometimes are dominant and other times subordinate" (Ehrenreich, 2003, p 279). However, unlike the vehicle or the Koosh ball, the house of cards metaphor lacks a sense of movement or transition. But it does suggest balance and fragility. Even though Ehrenreich does describe a possible way that the cards might 'move up' (in a fairly laboured extension of the metaphor), she does not develop the point to show how the symbiosis between the cards could change from a dominant to subordinate position of dependency in different circumstances.

To an extent all the metaphors and the concepts they represent¹² focus on the individual and the categories (even when multiple) that contribute to defining their identity. The discourse relating to intersectionality risks overlooking the agency and individuality of people—both in and between many—groups (i.e. the individuality and

¹¹ Full quotation: "A house of cards is composed of many individual cards, each the same sex and shape as the others, but each with a different design. Like human beings, they are all similar, yet different. They also belong to groups, both by number and by suit. All the members of a particular group are similar, but they are not identical to each other, just as not all African Americans are heterosexual and not all women are white. Most of the cards are positioned above some cards and below others in the structure. Individually, none of the cards would be able to stand up on its own, but together they can form quite an edifice—a structure that is composed of cards supports the other groups (whether they are touching or not), giving them strength they would not otherwise have." (Ehrenreich, 2003. p 279)

¹² Kwan (2002) notes that there has been an over-abundance (rather than a paucity) of 'new' terminology in the evolution of concepts building on "intersectionality" including symbiosis, co synthesis, interconnectivity, post-intersectionality, multiplicity and others (p 237)

personalised performance of intersecting identities). Only the original image of intersectionality, where a woman drives the vehicle, is there a sense of the agency of the individual who creates, perceives, performs and embodies the multiple layers of her dynamic identity. A similar silence exists in relation to the structural dynamism within which these complex individuals are engaging. As one possible antidote, Staunæs (2003) suggests instead that it would be beneficial to focus on the sites where discrimination occurs, not on the categories themselves, in order to critique the broader social determinants and dynamic social processes involved.

While acknowledging the contribution of intersectionality and related concepts (including symbiosis and social dynamism)¹³ of vast analytical frames and terminology to facilitate the articulation and recognition of power structures that marginalise and discriminate, three significant omissions remain which risk perpetuating the very subordination that, through naming they seek to overcome. The first is an absence of agency on the side of the individual to perceive, react to, perpetuate and/or overcome the situation in which they experience discrimination. Nash (2008) notes that the concept of intersectionality still needs to grapple with the ways in which individuals experience subjectivity or strategically deploy identity in particular circumstances. By linking the discourse relating to intersectionality with that relating to power (as I attempt to do here), there is potential to deepen the conceptualisation of both. The second is a sole focus on the marginalisation aspects of identity and social dynamism (relating to subordination or privilege) rather than on celebrating difference and championing diversity. Crenshaw (1995) alludes to empowerment for women of colour, as the other side of the coin of subordination, and notes the potential of strategic coalitions formed along identity lines. Ehrenreich also mentions the sense of strength that can come from mutual dependence. However this is not the focus of her argument nor is it celebrated, and generally the authors frame their exploration of the complexity of identity glumly in terms of processes of marginalisation, subordination and discrimination. The third is a failure to recognise that the relative power or subordination of someone may change over time—within the

¹³ A social dynamics approach, which incorporates structural and systems based processes as well as relations of inequality, but enables the domain's relative autonomy to slide apart or join in different ways, enables an exploration of the competing or symbiotic processes within alternative social spaces (Cooper, 2009; Nash, 2008), recognising a need to broaden the concept to necessarily encapsulate and visualise the construction of the social in an active sense—through dynamics that sexualise, engender, marginalise and racialize individuals in different and overlapping contexts (Grabham et al, 2009).

same group identity—or change at the same time but in relation to different aspects of identity (cf Archer, 1988).

Mindful then that race, gender, and aspects of identity are not things as captured by metaphors, but rather constructs of identity that are apparent and performed within systems of power, culture, language and society (Kwan, 2002, p 329), the contested concept of intersectionality offers relevant insights to this exploration of self and society, the law and human rights. One of the fundamental contributions of intersectionality is the challenge it creates relating to homogeneity, by spotlighting potentially uncomfortable disunities within groups that allows for a much richer and robust conceptualisation of the dynamic nature of self, relationships and society (Nash, 2008).

Combining this with theories of power, structure, agency and identity then begins to resonate more accurately with the realities of everyday life—and the variation between contexts and over time. This provides a useful analytical framework for exploring HIV, law and stigma in Malawi because it facilitates an analysis that takes complex individual identities into account, while also allowing for recognition of a dynamic relationship with others people and within society. In other words, the framework allows the kaleidoscope to change and to come into focus and understand why an individual can simultaneously—and not contradictorily—experience stigma, exclusion, resilience, power, and agency.

2 | LAW AND LEGALITY

The central area of inquiry explored throughout this thesis is the extent to which it is possible to achieve human rights affirming individual and social change, through law grounded processes, in the context of lives and societies affected by HIV. This section reviews literature about the law and legal consciousness and research that has explored plural legal systems as they related to HIV particularly in an African context. The research presented in this thesis presents results from the first known study of legal consciousness in the context of HIV and the law in everyday life in Malawi, and as such contributes an in-depth analysis of potential barriers for people to access justice and/or for the law to be implemented in reality (i.e. beyond the statute books or mindsets of the traditional authorities).

Demand and supply: the transformative potential of law

In the context of the law and the human right to health, Paul Hunt, former UN Rapporteur for Health and Human Rights, argues that substantive equality was essential for removing and compensating for the discriminatory laws (Hunt, 1996, p89).¹⁴ Hunt notes the interplay between social, economic and political power structures as part of the bigger and complex web of factors that need to be addressed to overcome the discriminatory and unequal legacy of the past—a transformative process that will promote human rights and public health. Hunt articulates a difference between equality (linked with material redistribution) and dignity (linked with a broader philosophy of equality and substantive attention to past injustices). Ramphela raised a similar notion, that more than material, and in fact transcendent elements are needed if the law is to provide a framework for repairing historical inequalities (Ramphela, 2008, op cit). Ramphela argues that an intense and even spiritual approach to transformation is necessary—a transcendence—for achieving meaningful social, economic and political change:

“Embracing a comprehensive framework for transformation that reflects the indivisibility of freedom requires a focus *beyond the material domain of life* on which major revolutions tend to concentrate. Shifting the frame of reference is about transcendence. It is a deeply spiritual matter that forces one to be true to deep convictions even if one may be going against conventional wisdom. *It is about making oneself vulnerable by abandoning known ways of seeing the world and engaging with others to explore different approaches.*” (Ramphela, 2008, p 27, my emphasis)

Is it possible then to achieve dramatic social change through law-based processes? I argue that more than the law and formal legal processes are necessary for realizing transformation—it is what the law can inspire for human beings and what spaces it can open up for human societies, that facilitate social change, and achieve a constitutional democracy that promotes dignity, equality and freedom.

This section explores notions of human rights, positioned in the context of African legal philosophy and the concept of *ubuntu* (a Southern African ethos of ‘togetherness’ as

¹⁴ Hunt writes: “formal equality required nothing more than the repeal of apartheid’s discriminatory laws and the prohibition of direct discrimination on the grounds of race. It ignored the actual social and economic conditions which continued to structure land, education and so on, on a racial basis. In contrast, substantive equality mandated the removal of apartheid’s discriminatory laws, the prohibition of direct discrimination, and the eradication of social, economic and political barriers impeding access to land, education and other services. Formal equality alone could not dismantle the social, economic and political structures erected by years of apartheid” (Hunt, 1996, p89).

explained below), and lays the foundation for the discussion in chapter seven about the extent to which the law is conscious in the everyday lives of the people living with HIV.

The literature reviewed in this section further contextualises the issues raised about the law and legal consciousness, by exploring in depth the literature relating to the criminalization of HIV transmission, exposure and non-disclosure. The conclusion of this section links conceptual notions of the potential role of law in demarcating social norms and in governing society, its potential to fuel stigma and as a result act as a structural determinant of health. The literature review situates the results presented in this thesis within current international discourse and national studies about the application of the criminal law to national responses to HIV.

2.1 Human Rights: The universalised and the contextualised individual

Human rights—codified in national and international statutes—extend well beyond the courtroom or legislative papers and encompass thoughts, freedoms and opportunities reflecting the breadth and diversity of many different individual yet universally connected lives. The law can have a pivotal role in protecting, promoting and fulfilling these rights. Yet on its own, the law is limited in its capacity to govern the necessary transformation and politicisation that is needed to address the underlying inequalities that impede social justice, fuel ill-health and impede the realisation of the human right to health.

Human Rights, Agency and Identity

Douzinas suggests, “post modern human rights define the fluid relation between power blocs and the contested identities of individuals and groups” (2000, p 344). Yet the spirit of universalism and the language of the international declarations explicitly disregard consideration of relational notions of power in the pursuit of human rights: it is a “common standard of achievement for all peoples and all nations” (UDHR, 1948). Or, as the name and spirit of universalism implies, it provides a timeless, context-free, universal list of the rights that are the entitlement of all human beings. “The universal man of the declarations is an unencumbered man, human, all too human” (Douzinas, 2000, p 187). By being all too human, to what extent can universal principles of human rights and the legal mechanisms that enforce them be useful tools for realising the human rights of people living amid the grey areas of real lives, struggles and identities?

This research is founded on an inclusive notion of the theories of human rights, rooted in both ‘Western’ and African traditions. Ife (2010) describes three main notions of human rights—natural rights, based on the philosophy of John Locke, as something universal that all humans are born with by the nature of each individual’s very humanity (cf Donnelly, 2003; Douzinas, 2000). As described below, stigma attacks at the heart of this natural notion of human rights, as defined by Goffman (1963), in the marking of ‘spoiled identity’ and devaluation of aspects of being human. The second type of rights are those traditionally defined in a legal sense, as the obligation of the State to govern in a way that respects, protects and fulfils rights (cf Gruskin, 2004). The third notion of rights is of a process of constant negotiation, at all levels of society, that evolves and constructs assumptions about rights and responsibilities. Ife’s third notion of rights includes a sense of human agency, within the context of a dynamic society, in the definition of human rights (Ife, 2010; Archer, 1988). This thesis works with a combination of all three notions of human rights, as well as the fourth relational dimension added by Africanist philosophers as described below, in that it incorporates notions of intersecting identities, pluralistic notions of law and access to justice, and the dynamic and temporal relationship between individuals and societies in the analysis of the realisation of human rights within the context of HIV in Malawi.

In terms of natural rights in international laws and covenants, Article 1 of both the Universal Declaration of Human Rights (UDHR) and the International Covenant on Economic and Social Rights (ICESCR) start from a statement about the centrality of power, free will and agency for all human beings:

“All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.” (UDHR, 1948, article 1)

“All peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.” (ICESCR, 1966, article 1)

In essence both documents advocate the empowerment of individual human beings as the primary foundation for the realisation of human rights. Yet according to theorists of power (such as Foucault, Archer, Bateson and others) this is not in fact possible without taking existing hierarchies and power relations into account. Are the international human rights declarations—useful as they may be for consolidating the human rights response—abstract lists of aspirations that are distant from the realities and contested identities of

individual lives? If law without justice is like a body without a soul (Douzinas, 2000), what good then are universal human rights if they are words without meaning?

Modern concepts of human rights build from the natural, individual and communal sources of rights and espouse the rights of the individual within a symbiotic relationship with the rights of others, and also include an implicit recognition of the obligations (individual and state) necessary to achieve them. They take into account the differences between civil and political rights and economic and social rights, formalised in the Universal Declaration of Human Rights (UDHR) (1948) and further articulated in the International Covenant on Economic Social and Cultural Rights (ICESCR) and the International Covenant on Civil and Political Rights (ICCPR) (1966), but fundamentally delineate that human rights are indivisible, de-contextualised and universal. These rights are implicitly deserved by all simply for being human, regardless of whether or not that is the current situation in reality. As Jack Donnelly summarises:

“Human rights are equal rights: one either is or is not a human being, and therefore has the same human rights as everyone else (or none at all). They are also inalienable rights: one cannot stop being human, no matter how badly one behaves or how barbarously one is treated. And they are universal rights, in the sense that today we consider all members of the species *Homo Sapiens* ‘human beings’, and thus holders of human rights” (Donnelly, 2003, 10).

Beyond Donnelly’s definition is a reference to legal documents, mechanisms and treaties that are there to defend human rights. In a sense, Donnelly prioritises the definition of human rights according to its presence for individual people, but omits a discussion of the rules (law) by which they will be enforced.

Other common modern definitions of human rights instead focus almost entirely on the law, or State’s rights as Ife (2010) refers to them, defining them in terms of international conventions and treaties, and focusing on the governmental and legal mechanisms through which they are at first drafted, agreed and then supposedly enforced. For example, one leading scholar of health and human rights defines human rights as the “norms and standards that tend to be drafted by government representatives, negotiated in political fora, and incorporated in the body of international law in the form of international treaties which impose legal obligations on the governments that ratify them” (Gruskin, 2004, 329). Yet this definition of human rights, even though accurate in terms of the mechanisms by universal human rights as enshrined in the Universal Declaration of Human Rights (UDHR) (1948), the International Covenant on Economic Social and Cultural

Rights (ICESCR) (1966) and other international declarations, overlooks the intensely aspirational elements of agency, free will and human dignity.

Human Rights and Power: Whose Reality?

“People are acutely aware of the injustices inflicted upon them. Knowledge of the contents of the Universal Declaration will hardly advance their condition. What they need is a movement that channels these frustrations into articulate demands that evoke responses from the political process. This the human rights movement is unwilling or unable to provide. In consequence, the real life struggles for social justice are waged despite human rights groups—not by or because of them—by people who feel that their realities and aspirations are not adequately captured by human rights organisations or their language.”

(Chidi Anslem Odinkalu, *Why more Africans don't use human rights language*, 1999)

Universalist declarations and the concept of human rights have been criticised for being shaped by a distinctly Western experience and for not being inclusive in terms of gender, race, religion and ethnicity in terms of those involved in drafting and agreeing the UDHR (Merry, 2006; Nyamu-Musembi, 2002). They have been criticised for not speaking to the reality of the people in different countries, cultures and livelihoods around the world, and for legitimising a platform for privileged altruistic people to continue to meddle in the lives of the poor and marginalised (Odinkalu, 1999). Yet it has also been argued that even though human rights can be deemed European in origin and inspiration, they are at the same time some of the only tools available for use in the struggle for the rights of disenfranchised people in some parts of the world and have at the very least symbolic value for those who have heard of them and can identify with the language and the aspirations (Merry, 2006; see also Grewal, 1998 cited in Merry, 2006).

The international declarations have generated a shared language of rights and provided a universal (or regional in some cases) point of reference to inform “rights-based approaches” to development, to policy making, to program planning, and in some cases to living. Douzinas suggests that in the process of drafting the UN Charter and subsequently other international declarations, distinction between people and states converged as ‘the people of the world’ and distinctions between individual agency, state power and oppression were dissolved (2000, 117). Their universality meant that no individual, no country, no corner of a community could be excluded. The perceived deficiencies of the UDHR in speaking to the specific needs of specific cultures paved the way for and stimulated subsequent regional declarations (such as the African Charter in 1981, the Bangkok Declaration in 1993 or the Asian Human Rights Charter in 1998) or for other

declarations or covenants to explicitly define the rights of specific groups (such as the UN Convention on the Rights of the Child in 1959, the Convention on the Elimination of All Forms of Violence Against Women in 1979, or the drafting of a UN Declaration on the Rights of Indigenous Peoples in 1994). These can all be seen as positive attempts to give meaning to the concept of the universality of rights within specific cultural or thematic or geographic contexts.

Other criticisms have taken a different approach to criticising the cultural relevance of the declarations by questioning instead their ability to speak to the realities of people who are struggling most to realise their rights (i.e. the poor or marginalised). Such criticisms raise more fundamental questions about how the rights were defined and who was involved in the process of defining them. Chidi Anselm Odinkalu criticises the international treaties and human rights movement for no longer having currency or relevance for the lives of individual people (1999). This is what the development economist Amartya Sen refers to as a “terrible irony of good intentions” (cited in Farmer, 2005, xxv). Even though the delegates may have perceived that the peoples of the world were speaking through them and the other government representatives involved in drafting documents such as the UN Charter (Douzinas, 2000), it seems that the international charters and declarations may lack currency with the poor or marginalised individual people for whom they have been designed to protect. Specifically in relation to health, recent attention to the notion of ‘decent care’ has attempted to overcome a cultural relativist critique of what is essentially a human rights based notion, that uses the language of ‘decency’ and principles of reciprocity between individuals and societies, that are found in many of the main religions of the world (Ferguson *et al*, nd).

African Philosophy and Human Rights

To study human rights in an African context provides a further complexity to the perspective in the kaleidoscope through the consideration of legal pluralism. It has been argued that colonization brought with it the first wave of legal pluralism, and the second wave is now coming in two forms related to global capitalism and liberal democratic norms (Tamanaha, 2012). As Mamdani eloquently described, the bifurcation of power that colonization triggered and that is sustained in legally pluralist societies, influence the relationship and constructions of citizenship and subjectivity between individuals and the State (Mamdani, 1996). The legal consciousness approach taken in the research presented

in this thesis offers an opportunity for understanding the nature of individual subjectivity and how it interrelates with the dynamics of law in a legally plural field. Although not the focus of the results presented in this thesis, such an approach could in turn be useful for further analysis of what identifies and differentiates various legal spheres (cf Merry, 2012). Specifically in terms of human rights, as Kinley describes and is consistent with the approach taken in this research, they are “are not above, beyond, or separate to any of these pluralizing forces, but constituted by them” (Kinley, 2012, p 60).

African philosophers – especially those who have engaged reflected on the translatability of ‘Western’ concepts of rights to different contexts in Africa – have tended to focus more on the relationship between individual and collective rights, and debate the prioritisation or not of one over the other (Gyekye, 2003; Mamdani, 2000; Shivji, 2000). Englund explored a concept of the “relational aesthetic of recognition” (2004, p 17) to add a dimension of the relationship between self and society to the other notions of human rights outlined above (cf Ife, 2010). Bujo (1998) notes that in principle human rights should only be considered universal if all cultures have entered into a dialogue in their formulation (cf Odinkalu, 1999). Notions of rights, to ensure their relevance in an African setting, should be rooted in existential and daily experiences so that they can be useful in generating meaning in the lives of African people (Bujo, 1999, p 155; Bell, 2000). As such this prevents the imposition of notions of rights or justice that may be incompatible “with realities on the ground” (Englund, 2004, p 23).

In Southern and Eastern Africa in particular, notions of human rights (or more accurately equivalent concepts) embody a more relational recognition of the individual rights-bearer in the context of his or her society. For example, by spanning the past, present and future, for an individual in relation to others, the Southern African¹⁵ legal tradition ‘ubuntu’ transcends a legal system premised only on a dichotomy between individuals and the collective — a limited, binary legal system and destined to be ineffective in securing human rights because it ignores the extent to which “individuals define themselves through, and take meaning from, their relationships with others” (Freedman, 1999, p 237; cf. Bateson, 1982). Ubuntu can be described as ‘the African principle of transcendence through which an individual is pulled out of himself or herself

¹⁵ The concept of ‘ubuntu’ has been most widely documented, researched and formerly explored as a philosophy in South Africa. However the central principles have been traced across borders in Southern and Eastern Africa as well (Cornell and Van Marle, 2012), and specifically in Malawi (Nkhata, 2010; Tumbulasi, and Kayuni, 2005), only the scholarly tradition is less developed on this issue outside South Africa.

back towards the ancestors, forward towards the community, and, towards the potential each one of us has' (Cornell, 2008, p 5-6). It extends beyond a simple dichotomy between individual and a collective, and includes a potential for transformation that embraces a relational (individual and the world), temporal (past and future), and aspirational (dreams and ambitions) notion of self—the kind of changes necessary for meaningfully facilitating the realization of human rights (Cornell, 2008; Van Marle, 2006; Klare, 1998).

Ubuntu is founded on a prioritization of the notion of individual and collective dignity—a tradition in different African cultures that can be seen as central to notions of democracy and progressive governance in Africa. Ramose has termed this 'bantocracy' highlighting the links between ubuntu, democracy and the philosophy of the Bantu tradition (Ramose, 2009). The legal scholarship concerning ubuntu emanates predominantly from South Africa, however the concept does resonate across borders. While ubuntu has not been formalized in any African Constitution, however it was included as a formal note in the drafting stages of the South African Constitution (Bekker, 2012). Yet as Ramose suggests, however, just because it is not written does not mean that it is unknown:

“Just like the British, *ubuntu* constitutional law is unwritten. But this does not mean that it is unknown. Nor does it mean that it is no longer practiced. One of the basic principles of *ubuntu* constitutional law is that *Umuntu ngumuntu ngabantu (Motho ke motho ke batho)*. Reciprocity in the concrete form of recognition, protection and respect for the individual right to self-defence is the core meaning of this principle” (Ramose, 1999, p 120).

One of the foundations of ubuntu is the primacy of the legal subject – and the role of the individual in constructing the process of attaining or ensuring collective justice. For example Ramose (1999) states, “according to ubuntu philosophy, the authority of law is by definition derivative. Law is dependent upon the prior active presence of umuntu. Without the living umuntu law cannot arise” (Ramose, 1999, p 118). Specifically in Malawi, although not explicitly cited as ubuntu, the link is clear between civic participation and collectivity and the foundation notion of justice. For example Chirwa, in his review of the Constitutional protection of social, economic and cultural rights in Malawi, notes “the Malawian conception of justice emphasizes participation of everyone in judicial proceedings ... The participatory approach draws its legitimacy from communitarian ideals prevalent in African societies where an individual is regarded as part of a larger community and not an island” (Chirwa, 2005, p 238).

In summary, the two main contributions that a review of African philosophy and notions of human rights provide for this thesis are first, a conceptual clarity linking individual and social dynamics, and second, a consciousness of imposition and recognition of the relevance of lived experience in understanding human rights in an African context. As John Murungi very eloquently surmised, “*What is essential to law is what secures human beings in their being*. The pursuit and the preservation of what is human and what is implicated by being human are what, in a particular understanding, is signified by African jurisprudence.” (Murungi, 2006, cited in Cornell and Muvanga, 2012, p 1, original emphasis)¹⁶.

Human rights from below

With the emergence of participatory development and other more iterative practices in international and social development, human rights have been reframed as “shaped through actual struggles informed by people’s own understandings of what they are justly entitled to” (Nyamu-Musembi, 2002, 1). As noted above, Ife has reviewed the links between community development and the need to generate ownership for human rights, and termed the phrase ‘human rights from below’ (Ife, 2010). This is consistent with legal consciousness approaches that focus on the real life experiences of law in everyday life (as well as its absences) rather than focusing on statutes and legislation (e.g. Ewick and Silbey, 1998). Nyamu-Musembi presents an actor-oriented perspective on human rights which is an “understanding of human rights needs and priorities that is informed by the concrete experiences of the particular actors involved in and who stand to gain directly from the struggles in question” (2002, 1). She situates this new discourse within four key debates: the universal validity of human rights, liberal individualist conceptions of rights and recognition of groups, the hierarchy between rights (civil-political and social-economic), and the extent to which non-state actors should be

¹⁶ Full quotation: “Each path of jurisprudence represents an attempt by human beings to tell a story about being human. Unless one discounts the humanity of others, one must admit that one has something in common with all other human beings. To discount what one has in common with other human beings is to discount oneself as a human being. *What is essential to law is what secures human beings in their being*. The pursuit and the preservation of what is human and what is implicated by being human are what, in a particular understanding, is signified by African jurisprudence. Being African is a sign of being African, and being African is a sign of being human. African jurisprudence is a signature. In this signature lies not only what is essential about African jurisprudence, but also what is essential about the Africanness of African jurisprudence. To learn how to decipher it, which, in a sense, implies learning how to decipher oneself, paves the way to a genuine understanding.” (Murungi, 2006, cited in Cornell and Muvanga, 2012, p 1)

responsible for realising human rights. She argues that “looking for the meaning of rights from the perspective of those claiming them transforms defined normative parameters of human rights debates, questions established conceptual categories and expands the range of claims that are validated as rights” (ibid, 1). She argues that the legal framework should become one that does “not disregard the community context in which people are embedded, but at the same time does not legitimise a narrow definition of personhood that is based on status in hierarchical social relationships” (ibid, 10, cf Murungi, 2006; Chirwa, 2005). Specifically in terms of realising the human right to health, De Vos et al (2009) proposed a framework that recognized the importance of people’s empowerment (i.e. engaging wider structural issues relating to power) in seeking participation and also ensuring State accountability in the practical achievement of universal access to primary health care (p 26). In so doing, a virtuous relationship has been identified between individual identity and community mobilisation, power and empowerment, and States’ obligations and the law in the realisation of human rights (Ife, 2010; De Vos et al, 2009; Vincent and Stackpool-Moore, 2009; Nyamu-Musembi, 2002).

For human rights to have purchase and meaning in the complex lives of individual people requires a delicate balance, since although failure to fully contextualise universal human rights may impede their realisation in reality, to undermine their universality may simultaneously undermine their potential to generate change (Merry, 2006). Given that people may “feel that their realities and aspirations are not adequately captured by human rights organisations or their language” (Odinkalu, 1999, op cit), the underlying question therefore is one of representation, and the extent to which the codified principles of human rights speak to the realities (conscious and unconscious) of people struggling to realise their human rights. To maximise the positive potential of the law to contribute to (and not undermine) the response to HIV, to enable both rights and responsibility in a way that does not stigmatise or disempower, and facilitate the realisation of the human right to the highest attainable standard of health for all, individual and societal change is needed to address the underlying causes of vulnerability to ill-health (Mann, 1999).

The Human Right to Health

The human right to health has been defined from the outset as a holistic concept in international law, framed within a wider consideration about the social determinants of

health and the promotion of human rights, dignity, equality and freedom (WHO, 2008). The right to the highest attainable standard of health as a “state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity,” and as “one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition,” was recognised in 1946 with the adoption of the Constitution of the World Health Organisation (WHO, 1948). The WHO definition also articulates the importance of health promotion and the process of enabling people to gain control over decisions and access to information that will benefit their health (Mann et al., 1999).¹⁷ It was reinforced and further particulars were defined in article 12 of the ICESCR in 1966, which made the principles legally binding for the 149 States who have now become party to the ICESCR (UNHCR, 2004).¹⁸ The Alma Ata Declaration (the outcome of an international conference on Primary Health Care in 1978) more explicitly defined health as a socio-economic issue and as a human right (WHO, 1978). The declaration reaffirmed the definition of health from the WHO constitution in 1948 and described health as a “social goal whose realization requires the action of many other social and economic sectors in addition to the health sector” (WHO, 1978, p 1) including education, housing, food security and employment opportunities (Gruskin, Mills and Tarantola, 2007; Mann et al, 1999).

As concisely summarised by Jonathan Mann, one of the pioneers of the health and human rights framework, there is a dynamic interconnection between disease and society that any “attempt to deal with one, the disease, without the other, the society, would be inherently inadequate” (Mann, 1999).

“When and where human rights and dignity are respected, there will still be rich and poor, Mozarts and people who cannot carry a tune, but all will be ensured of a basic minimum in which their individual potential can be freely and fully developed. ... We propose that, as respect for human rights and dignity is *sine qua non* for promoting and protecting human well being, the human rights framework offers public health a more coherent, comprehensive, and practical framework for analysis and action on the societal root causes of vulnerability. ... [P]romoting and protecting human rights is therefore inextricably linked with our ability to promote and protect health.” (Mann, 1999, p 223)

¹⁷ These principles were echoed two years later in article 25 (1) of the Universal Declaration of Human Rights (UDHR) which adopted an equally holistic definition of health ‘including food, clothing, housing and medical care and necessary social services’ and is founded on concepts of inviolable human dignity and freedom, alongside justice and peace (UNDHR, 1948).

¹⁸ The ICESCR clarifies and refines the concept so that the full realisation of the right to health includes ‘the prevention, treatment and control of epidemic, endemic, occupational and other diseases’ (12c) and ‘the creation of conditions which would assure to all medical services and medical attention in the event of sickness’ (12d).

In other words, promoting and protecting health requires explicit and concrete efforts at the individual level to promote and protect human rights and dignity, while also facilitating change to address the structural and societal determinants of health (Mann et al, 1999, p 5; cf Ferguson *et al*, nd). Realising the right to the highest attainable standard of health therefore necessitates a comprehensive approach that incorporates promoting rights to education, information, privacy, decent living and working conditions, participation, and freedom from discrimination (Braveman and Gruskin, 2003).

Therefore in order to realize the human right to the highest attainable standard of health, and indeed to facilitate the realization of human rights in general, health-promoting societal change is needed to address the underlying causes of vulnerability to ill-health, and the inequalities that impact the wider social determinants of health. The significance of this holistic conceptualisation of the human right to health is threefold: first, health is defined in a holistic sense, encompassing emotional, spiritual and physical well-being; second, health and human rights are defined as mutually inter-related; and third, the realization of the individual right to health is intertwined with broader social determinants of health and human rights.

The articulation of a specific health and human rights framework was crystallized in the 1990s and explicitly demonstrates the symbiotic dependency of one on the other. Minimum core State obligations to respect, protect and fulfil the right to health were established by the United Nations Committee on Economic, Social and Cultural Rights in General Comment 14 (UN, 2000). It paved the foundation for the recognition of structural determinants of health by focusing more broadly than only on access to health services (Stuttaford, Harrington and Lewando-Hundt, 2012; Mchangama, 2009; cf WHO, 2008). This breadth of scope has been praised by some for setting an ambitious and normative guide for system-wide rights-based responses to promote public health (Patterson and London, 2002), but it has also been criticised for being too wide-ranging, venturing beyond what could be considered plausible from a legal basis, and distracting from arguably more important (in their opinion) efforts to secure other rights such as freedom of speech (Mchangama, 2009).

Questions have also been raised about the justiciability of social and economic rights (Gloppen, 2007) and elitism in accessing legal services to pursue the right to health through legal mechanisms (Ferraz, 2009). Other criticism has suggested that in fact rights-

based approaches to health have reduced the role of public health in response to HIV, have not achieved any health benefits, have worsened inequalities and have overburdened national legal systems (Reubi, 2011; Mchangama, 2009; Ferraz, 2009; De Kock, Mbori-Ngacha and Marum, 2002). Additional critique has also suggested that this has specifically impeded the response specifically to HIV in Africa, either because it was not sufficiently framed as a public health emergency in the early days (De Kock, Mbori-Ngacha and Marum, 2002) or because there may have been initial scepticism about the relevance of a narrow sense of a human-rights based approach that had been closely associated with civil liberties and the gay rights movement in North America (Patterson and London, 2002).

These criticisms of a human-rights based approach are salient, however the only take into consideration tangible benefits and health outcomes for evaluating the role of human rights in achieving public health outcomes. However, if the normative potentiality of human rights is taken into consideration, then the symbolic valuation of equality and access to the highest attainable health for all and privileging of social and economic rights to equal standing as civil and political rights can be seen as important outcomes in their own right (London, 2008). A perspective that recognizes and values the normative potential of international and national human rights frameworks (the perspective adopted in this thesis) enables due attention to be given to the process by which human rights are respected, protected, fulfilled, that in turn spotlights underlying considerations of inequality in accessing justice, exerting agency and the visibility of human rights violations.

Gaps and contribution of this thesis—human rights

According to the literature reviewed for this thesis, there has not yet been a ‘human rights from below’ approach to understanding human rights in Malawi in general, nor specifically in relation to HIV. Recently the results from *The People Living with HIV Stigma Index* in Malawi in part addressed this gap, however there is neither a detailed analysis nor exploration of perceptions of legal or human rights concerns even though this is one area of results briefly mentioned in the final report (Chirwa, Kamkwamba, Umar, 2011).

The research presented in this thesis contributes to filling this gap by providing ‘thick descriptions’ of perceptions of justice and human rights in the daily lives of people living with and closely affected by HIV (methodology explained in chapter three). The

research models the process of human rights from below while also contributing in-depth information about human rights in the context of HIV in Malawi.

2.2 LAW AND LEGAL CONSCIOUSNESS | Responsibility, rights or social control?

“There has developed a universal ache ... [for] not being alone, of being part of the community, [which] should be seen as the central and precious core of traditional African law.” Justice Albie Sachs (1999)¹⁹

“Law could not be law at all if the legal subject were permanently deleted from its vocabulary.” Mogobe Ramose (1999)²⁰

“Legality is embedded in and emerges out of daily activities...[it] is enduring because it relies on and invokes commonplace schemas of everyday life.” Patricia Ewick and Susan Silbey (1998)²¹

It is not immediately apparent what a Justice of the South African Constitutional Court (Albie Sachs), a Zimbabwean philosopher (Mogobe Ramose) and two American sociologists of law (Patricia Ewick and Susan Silbey) have in common. Yet as these extracts indicate, each one of them places the individual person – and their lived experiences in relation to others – at the heart of understanding the law and legal processes.

Law and Legality

As one of the structural elements that shape power relations, law is challenged in its ability to respond to and have meaning in the fluid and contested identities of real lives. Increasingly the notion of human rights has been reframed as “shaped through actual struggles informed by people’s own understandings of what they are justly entitled to”

¹⁹ “Throughout the globe, people exist in atomized and anomic societies where personal wealth and individual autonomy have become inseparable from personal loneliness. By way of response there has developed a universal ache for the experience of what our Constitution calls *ubuntu*. The concept of not being alone, of being part of the community, should be seen as the central and precious core of traditional African law.” (Sachs, 1999/2012, p 310).

²⁰ “Law could not be law at all if the legal subject were permanently deleted from its vocabulary. Western legal thought accords primacy to the legal subject as a concept: an abstract entity. *African legal philosophy understands the subject as a living and lived experience*. Both contrasting views show that the legal subject is ineliminable from the vocabulary of law.” (Ramose, 1999, p 102; *my emphasis*)

²¹ “As a constituent of social interaction, the law—or what we will call legality—embodies the diversity of the situations out of which it emerges and that it helps structure. Because legality is embedded in and emerges out of daily activities, its meanings and uses echo and resonate with other common phenomena, specifically bureaucracies, games, or ‘just making do.’ Legality is not sustained solely by the formal law of the Constitution, legislative statutes, court decisions, or explicit demonstrations of state power such as executions. Rather, *legality is enduring because it relies on and invokes commonplace schemas of everyday life*.” (Ewick and Silbey, 1998, p 17; *my emphasis*)

(Uvin, 2004; Nyamu-Musembi, 2002, p1; Wilson, 1997). In this way, the paradigm of documenting human rights therefore needs to focus on individual realities and socio-historical relationships—perhaps viewed within the tradition of legal consciousness, recognizing individuals as agents of change within their own contexts (Harding, 2006; Wilson, 1997; Ewick and Silbey, 1995). The exploration of legality in Malawi in this research grows out of the enunciated perceptions of the life story participants—one of only a few research projects that adopts such an approach outside North America—and as such is an attempt to promote an actor-oriented and socially active approach to documenting law and human rights in everyday life in Malawi (Nyamu-Musembi, 2002; Ewick and Silbey, 1998; Tuhiwai-Smith, 1999).

Focusing on legal consciousness rather than on legislation and policies per se also enables an understanding of different legal frameworks and ideologies that might be influencing perceptions of law in everyday life while also engaging in the intersectionality of people’s identities. In Malawi, as in many countries in Africa, this approach allows for a combination of traditional, constitutional and/or colonial legal traditions.

Legal Consciousness

Grounding universal concepts in the legal consciousness of individuals and their everyday lives is challenging but ethically imperative since it reveals difficult issues concerning the legitimacy of action, the empowerment of people to exert agency within their complex realities and the lines of accountability, while also facilitating the way for sustainable change (IDS, 2003). As Nyamu-Musembi states, this shift “explicitly acknowledges the reality of power differences and hierarchical relationships in society, and therefore points to the need to look beyond abstract formal equality principles to the effect of those principles in entrenching or challenging hierarchy—from the perspective of the subordinated” (2002, p 2).

Transformative jurisprudence—the potentiality of the constitution

There is an implicit tension in the idea of a ‘transformative constitutionalism’—on the one hand, transformation demands massive change; on the other, constitutionalism

delineates guidelines for stability.²² Many authors have explored the symbolic as well as real significance of a constitution as both memorial and monumental, but to date no one has applied this frame to an analysis of HIV specific legislation.²³ As a memorial, it acknowledges and commemorates the past, ritualizes remembrance and demarcates the end of something that should not happen again (Le Roux, 2007; citing Snyman, 1997). As a monument, it celebrates a triumph or victory, solidifies a sign that one can take pride in remembering, and demarcates a new beginning (ibid). More concisely, “monuments celebrate, memorials commemorate” (Van Marle, 2006, p 37). Nkhata has explored this notion specifically in relation to Malawi and explored the proposition of social-trust based governance and constitutionality (Nkhata, 2010).

Can an inspiring document inspire a sense of the rule of law and a sense of the aspirations for the transformation that the rule of law seeks to achieve? In this thesis I explore the extent to which transformative constitutionalism can ignite, inspire and sustain the civic mindedness, dignity, and spiritual transcendence of individuals and institutions to embrace democratic principles. For the words to have real purchase and to have meaning in the lives of people, communities and nations, they need to be interpreted and applied and tested in the political and individual complexities of real life. The results presented in chapters five and seven of this thesis also attempt to ground the concept of monumentalism and memorialism in the lives of individuals living with HIV (in how they make meaning out of an often transformative experience of an HIV positive diagnosis) and the dynamics of normative laws (such as the constitution or the proposed draft HIV Bill) that are intended to demarcate and/or respond to moments of important social change in Malawi.

HIV and law

HIV is a public health issue that provides an illuminative lens to critique the law and notions of human rights because it is an entry point to explore the interconnections between disease and society (Mann, 1999, p 222). Mann describes how vulnerability to HIV reflects the extent to which people are, or are not, engaged in and visible in society

²² Van der Walt (2006) explores this apparent contradiction explicitly in regard to legal culture, and asks: ‘is a democratic constitution that seems to entrench existing privilege and power workable in a political, social and economic context that so palpably requires urgent and radical transformation? Conversely, can a democratic constitution that so clearly demands and legitimizes large-scale social transformation really deliver on its promises of stability and continuity?’ (p. 4-5)

²³ In the example referred to here, Le Roux is referring to the South African Constitution (2007).

and capable of making and enacting free and informed choices about their health (Mann, 1999). It is widely accepted that to establish a health-promoting environment, strategies must empower individuals while also addressing broader social determinants of health such as power inequalities, access to clean water, nutrition and safe housing (WHO 2008; Hassim et al, 2007; Marks, 1999).²⁴

The law in relation to HIV has prominence in the formation and regulation of moral norms—not only in regard to human rights, but also in regard to criminalisation and the policing of sexuality and intimate behaviours. While my research focuses on the intersection of rights and responsibilities relating to expressions and consciousness of human rights principles in everyday life, it includes a broader awareness of the paradoxical role of law in undermining and promoting human rights in the context of HIV. This includes action to overturn the deeply-rooted social and political structures that perpetuate and produce ill-health (Freedman, 1999; WHO, 2008)²⁵ as well as the provision of a legislation environment that is enabling—and consistent, between different aspects of the legal system and its enforcement—not inhibiting the realisation of the human right to health (UNAIDS, 2008b).

Gaps and contribution of this thesis—legal consciousness and HIV

The research presented in this thesis works outwards from the starting point of diverse and contextualised individual perspectives and experiences, facilitating an understanding of how people understand and access information relating to law and their actual understanding of law as it relates to themselves, society and governance in Malawi.

An important contribution of this research is that it addresses two interesting dimensions that emerge when considering the role of law, in response to HIV, in its analysis through the lens of the dynamics between individuals and societies (be they local, national or international). Intersectionality therefore not only has an impact on an individual's experience of stigma, over time, relating to multiple axes of their identity (as further explored below), but also on consciousness and engagement with legal systems and access to justice. The first dimension is a challenge for universalised and rigid principles to respond to and have meaning in the fluid and contested identities of real

²⁴ Hassim, Heywood and Berger (2007) explicitly highlight the importance of a substantive and redistributive element to the law in the context of HIV, and make a direct link between health and broader safeguarding of social security.

²⁵ Freedman (1999) suggests that this transformation necessarily requires subversive action (p 228).

lives. The second is the division or sharing of the responsibility between individual and institutional or state structures to enforce, enact, police or regulate the law.

According to the literature reviewed for this research, to date no studies have been undertaken to explore notions of legal consciousness in Malawi, nor explicitly in relation to people living with or closely affected by HIV. The Global Commission on HIV and the Law released a landmark Report, which drew from expert contributions and submissions from people around the world (UNDP, 2012). The Report pays great attention and due respect to life experiences—both those of the Commissioners as well as those of the people who submitted testimonies and reflections through the regional dialogues—recognizing the role of individual perspective, experience and consciousness in understanding the role of the law in relation to HIV. The report is comprehensive and diverse in the perspectives it includes and the recommendations it makes. One shortcoming however is that by definition the submissions focused on experiences that people had when they engaged the *formal* legal system, including the police and other law enforcement agencies, as well as through the courts. Submissions were not solicited from people who were not conscious of the role or relationship between the law and HIV, acknowledging that it would be nigh impossible to do this on a regional or global scale. In many respects, the perspectives documented and analysis provided in this thesis compensate for this shortcoming at the global level by offering a national summary of HIV and the law in Malawi—one that includes the element of legal consciousness alongside an analysis of the role of the law as part of the national response to HIV (as reviewed in-depth in chapter seven). TO achieve this, my research facilitates an understanding—from diverse and contextualized individual perspectives—of how different legal traditions can engage and respond to the transient relations between individuals and society at different times and in different contexts.

One of the factors limiting the transformative potential of the law in Malawi is the “muted” legal voice of many people in Malawi. In her study of the courts, marginalization and vulnerability in Malawi, Siri Gloppen writes that there are “various factors combining to mute the legal voice of poor people in Malawi, preventing them from pursuing social transformation though [sic] the courts” (Gloppen, 2007, np). The methodology undertaken in this research was designed to amplify those voices. These factors can be categorized into two main areas—structural and psychological. Even though these formal mechanisms exist, ‘law’ in its formal sense is often either absent from or misunderstood in the

everyday lives of Malawian people. At the structural level, Gloppen suggests that the reasons include the cost of litigation (prohibitive in one of the world's poorest countries), the limited capacity of civil society to provide legal support, and that "institutions with a pro-poor agenda do not prioritize litigation in their pursuit of social rights" (ibid). Banda (2009) supports this notion, particularly citing the financial incapacity of the majority to afford formal legal redress, and also includes physical distance as a barrier that separates a tenant worker, for example, from seeking justice in a court of law. At the psychological level, Banda also suggests that as a result, the law seems foreign and "is often obscure and remote to those upon whom it impacts" (Banda, 2009, p 169). Gloppen goes further to suggest that there is a "distrust and fear" among poor people of the legal system because the "law reflects the power relations in society and often has an anti-poor bias, if not formally, then in its application" (Gloppen, 2007, np). As a result, and also because of a long history of reliance on traditional and other customary sources of justice, people continue to seek redress and have their rights reaffirmed according to traditional norms. The findings of this research illustrate and extend the structural and psychological barriers to accessing formal justice that the studies of Banda and Gloppen identified, including knowledge and awareness.

A third possible barrier limiting legal consciousness in everyday life is that the formal legal system and its laws are not relevant because they are out of touch with the daily realities of most people.²⁶ As Yash Ghai argued, also an argument developed by Banda (2009): "the common law does not touch the lives of many people, its ideologies assumptions and rationalizations have little relevance for them" (Ghai cited in Banda 2009, note 122, p 169). As explained in chapters seven and eight, the findings from this research challenge Ghai's proposition and indicated that even though law was seldom enforced, it was perceived and relevant and imbued with a symbolic power linked with notions of governance.

The results of this research highlight a disconnect between the potential of the law (in both its positive and negative hypothetical impact) and the actual invisibility of the formal legal system in the everyday lives of many Malawians. It has also been suggested that this is equally the case for ubuntu, which is more effective as a guiding principle that

²⁶ This may not be the case for customary and traditional laws; however that was beyond the scope of enquiry for this research. Given that the analysis is based in the language and descriptions participants themselves gave about the role of the 'law', the term is used to encompass the multiple meanings and perceptions of the 'law' described by the participants.

necessarily enforced in dispute resolution (Cornell, 2008). The results from this research support the hypothesis that both structural and psychological barriers are limiting the transformative potential of the law in Malawi—yet also that people in everyday life perceive (or have learning to perceive) that the law nevertheless has a role in governing issues of their concern.

2.3 CRIMINALIZATION | Normative power of law and potential influence on stigma

In the context of HIV, a dualism emerges where the law is imbued with both a positive and negative potential role, and can both empower as well as disempower or stigmatise as a result. The law acts as a benchmark imbued with a symbolic significance in demarking and controlling wider social standards (Garland, 1996).

HIV provides a vivid lens through which to investigate the opportunities and limitations of national and international law in supporting individuals to realise the human right to health. HIV illustrates how the law can both facilitate and impede this process—through provisions that could potentially protect rights and challenge stigma, such as in a progressive constitution, human rights and/or anti-discrimination legislation (cf Hassim, Heywood and Berger, 2007; Cameron, 2005; Welbourn and Cornwall, 2002; Klare, 1998); or through potentially undermining provisions that perpetuate stigma and re-enforce barriers for accessing health services, such as the criminalisation of HIV transmission, exposure or non-disclosure (cf Weait, 2007; 2001; IPPF, GNP+ and ICW, 2008). The dualism is apparent when considered in the context of someone who is living with HIV—on the one hand championed as the cornerstone of the response to challenge stigma, supporting peers and informing an effective response to HIV, bearers of human rights and citizenship; on the other, labelled as a potential criminal who may—through reckless or intentional actions—transgress the criminal law and transmit or expose another person to HIV.

A sociological litmus test to explore law and stigma

Criminal law in essence provides a mechanism for the deterrence and/or punishment and/or retribution of those that violate established social norms through legal action such as imprisonment, probation, community service, fines, or probation, warnings or cautions. Specifically in the context of HIV transmission, exposure and non-disclosure,

this raises questions about the interface between constructions of responsibility, harm, consent, and the delineation of attitudes towards disease and society (Weait, 2007).

Although his sociological analysis was grounded in a different era and different reality (from 21st century Malawi), Emile Durkheim's framework is often cited as one of the foundations of the sociology of law. Despite the narrow, positivist and moralistic interpretation of law, his framework nonetheless provides an appropriate lens through which to examine the relationship between crime, punishment, social control and society (Cotterrell, 1999; Lukes and Scull, 1983). Durkheim, writing in his specific social and cultural context at the end of the nineteenth century, proposed three hypotheses about penal law: the first, that it provided an index that symbolizes social solidarity; second, that in its progression from collectivism to individualism and the evolution of commercial, procedural and other types of law, it represented an advancement in society; and third, that crime was a violation, and punishment, an expression of collective sentiments (Lukes and Scull, 1983; Spitzer, 1975). He said:

“[One] should not say that an act offends the common consciousness because it is criminal, but that it is criminal because it offends that consciousness. We do not condemn it because it is a crime, but it is a crime because we condemn it.”
(Durkheim, in Cotterrell, 1999, p 66)

The extract shows that there is an active process of consciousness in delineating what is 'criminal'. In other words, agency—and in this case productive stigma—connotes what counts as a crime. Weait has more recently conceptualised this specifically relating to HIV: “criminal law serves a very distinctive function for states...it articulates the sensibility, culture and values of those states” [Weait, 2011, p6]. In this sense, what is deemed 'criminal' could be viewed as a yardstick for understanding social stigma in a specific place, time and cultural context.

It is exactly because (not in spite) of Durkheim's unashamedly moralistic view of law that it transcends history and is useful for analyzing law, stigmatization and the criminalization of HIV transmission or exposure in the world today (Cotterrell, 1999). The extract shows that there is an active process of consciousness in delineating what is 'criminal'. In other words, agency—and in this case productive stigma—connotes what counts as a crime.

Neither crime nor criminality are an objective entity in reality, they are in fact something that is the product of a common consciousness. Therefore for Durkheim the link between stigma and crime is explicit, and both were seen as an expression of shared

beliefs—a collective consciousness—defined not in terms of harm but rather in terms of offence to sentiments or beliefs (Cotterrell, 1999; Lukes and Scull, 1983). More recently, Weait has stated this concept in specifically to applications of the criminal law to HIV: “criminal law serves a very distinctive function for states...it articulates the sensibility, culture and values of those states” (Weait, 2011, p6). In this sense, what is deemed ‘criminal’ could be viewed as a yardstick for understanding social stigma in a specific place, time and cultural context.

While Durkheim suggests that the law is a barometer of the collective consciousness, Garland (1996) argues that strategies of crime control can in fact simultaneously be working to devolve the responsibility of the law to constrain or punish ‘deviance’. New modes of exercising power and control have been developed, for example a strategy of ‘responsibilization’ that devolves responsibility for crime prevention on to agencies, organizations and individuals (Garland, 1996, p 452). Ironically, individuals are on the one hand encouraged to take responsibility for their behaviour in the devolution of observation and policing to neighbourhood watch schemes, local organizations and institutions; yet on the other hand, state control, policing of ‘deviance’ and a general increase in incarceration is also prevalent in some jurisdictions (Garland, 1996; Sudbury, 2000).

For an individual, this is a bittersweet transformation—by becoming what Rose (2000) describes as “ethical subjects of freedom”, while empowered as a responsible citizen—any deviance renders the perpetrator of crime not only indictable by the rule of law, but also reprehensible as an individual who has failed to accept his or her responsibilities as a subject of a moral community (Rose, 2000, p 205). In other words, it is an explicit invocation of stigma through a re-moralization of the role of law within a broader context of state control and regulation of society, morality and the delineation of ‘deviance’. It could be seen as an internalization of punishment, similar to the pitfalls of “subjection” Foucault warned against, with the realization of power imbalances among those lacking the potential to change them (see chapter two).

In a very bold, simple and stark way therefore, building on the analyses of social control offered by Garland (1996) and Rose (2000), Durkheim offers an explicit and seminal description of the link between the law, morality and stigmatization for both an individual as well as for society.

Context: Criminalization delineating social parameters

Internationally, the last decade has seen a trend to apply the criminal law (prosecuting HIV transmission, and in some cases HIV exposure) as part of national responses to HIV and to promoting public health (Global Network of People Living with HIV (GNP+) and the HIV Justice Network, 2013; OSI, 2008; IPPF, GNP+ and ICW, 2008).²⁷ In many countries, criminal prosecutions relating to HIV are being brought under laws that have only recently been enacted, or under old laws that have only recently been applied to HIV transmission or exposure (Pearshouse, 2007; IPPF, GNP+ and ICW, 2008; Human Rights Watch, 2008). It has been suggested that one of the reasons for the recent proliferation of laws relating to HIV transmission and exposure has been that politicians have been seeking to do something proactive, concrete and publicly visible in response to HIV, when other efforts to prevent and halt the spread of HIV are failing (e.g. Pearshouse, 2007), conceived “with the blinded ire of legislators, frustrated by the complexity of the AIDS pandemic and desperate to show results” (Eba, 2008, p 9). This argument supports the theoretical positions of Garland and Durkheim, who suggest that although the punitive may masquerade as a symbol of strength, it should in fact be interpreted as a “symptom of weak authority and inadequate controls” (Garland, 1996, p 445).

Difficulties emerge relating to evidence, the burden of proof, and differentiating between negligence, recklessness and intent (UNAIDS, 2013; IPPF, GNP+ and ICW, 2008). Because it is unclear (and to date there is no universal legal standard) what a ‘reasonable person’ should do to prevent transmission of HIV, the translation of criminal law from statute into practice is susceptible to interpretation by police, lawyers, juries and judges in each stage of the prosecution, trial, conviction and sentencing (de Haann and Loader, 2009; Weait, 2001). In other words, the agency of the lawmakers and law enforcement actors is critical in determining the nature and impact of the application of the law. The conviction, sentencing and imprisonment of people living with HIV is likely to exacerbate the already high prevalence of HIV in prisons (already a high-risk environment) where access to condoms, ART, support and other health services are severely compromised and limited).

²⁷ Although difficult to know exactly, and specific research into national legislation and policy frameworks is currently underway, recent reviews indicate that 58 countries worldwide have laws that criminalize HIV or use existing laws for the prosecution of people for HIV transmission or exposure and another 33 countries are considering similar legislation (IPPF, GNP+ and ICW, 2008; Chenge, 2008). See www.criminalisationscan.org, and initiative of the Global Network of People Living with HIV (GNP+) to document the situation in many countries around the world and their legislation relating to prosecution of HIV transmission or exposure.

HIV testing and knowing one's HIV status is a critical component of any response to HIV (personal, societal, national and global). It has been shown that the highest HIV transmission rates occur among people who do not know their HIV status (UNAIDS, 2012) and that fear or anticipated stigma can create a barrier for testing (Rankin et al, 2005). Recent research has demonstrated the effectiveness of ARVs in both treating HIV and preventing the progression of HIV to AIDS, while also decreasing 'infectiousness' and preventing HIV transmission (HPTN052, 2012; Vernazza et al, 2008). Criminalization provisions create a disincentive and in fact limit consciousness of HIV status. By paradoxically creating evidence of *mens rea* in a potential crime (e.g. should have known HIV status and/or should have disclosed HIV positive status), it incentivizes individual agency in a direction that directly undermines HIV prevention efforts and potentially fuels HIV transmission. In other words it creates a perverse incentive for not "being responsible" and for not knowing ones HIV status.

Even though it has been widely recognized that the cornerstone of any local, national and international efforts to effectively address HIV is to empower people living with HIV and those in the most vulnerable communities (DfID, 2008; UNAIDS, 2009), the criminalization of HIV transmission can undermine the response by perpetuating and re-enforcing stigma and exaggerating agency by placing sole responsibility for HIV transmission with people living with HIV (UNDP, 2012; Weait, 2011; GNP+, 2010). This can occur through its symbolic potential as well as through its enforcement.

Gaps and contribution of this thesis—criminalization and normative role of law in governing social attitudes

As noted in the literature, the application of the law to HIV is a relatively new development in the global response to HIV, and imminent in Malawi with the anticipated tabling of the proposed draft HIV Bill. The research presented in this thesis provides a rare opportunity to explore and analyse the perceptions and intentions of the lawmakers involved—in an almost real time capacity—in the drafting of a proposed HIV Bill. The results from this research have already been directly fed back in the revision process to the lawmakers and key stakeholders to inform the revision of the Bill before it goes to parliament (see chapter three). In addition, no other systematic empirical research was available in the literature review about the perceptions of people living with HIV about the potential impact of criminal provisions in their life, or in relation to the implications for the

governance of society. The results presented in chapter eight of this thesis contribute to filling this gap.

3 STIGMATISATION| Self, society and complex processes of devaluation

Stigma attaches itself to not only to individuals but also to specific social contexts (Goffman 1963; Manzo, 2004). As such, it can be attached to any one or many of the axes of individual identity, which in turn can be felt and experienced privately or publicly in group or social settings (Crenshaw, 1989). It can also be attached to sites where these identities are embodied (Staunaes, 2003). Parker and Aggleton (2003) note that Goffman has often been interpreted to frame stigma as a relatively static characteristic—as a thing—even though stigma is culturally constructed (Parker and Aggleton, 2003, p 14). They suggest that Goffman’s conceptualisation of stigma can in fact be integrated and building on the relational lines of Foucault and Bateson, provides a theoretical framework that relates stigma to cultural and social determinants of health. Parker and Aggleton also argue that stigmatisation can be purposive and can be used as a mechanism for maintaining social power and marginalisation in different contexts:

“While Goffman’s work on stigma hardly even mentions the notion of power, and Foucault’s work on power seems altogether unconcerned with stigma in and of itself, when read together their two bodies of work offer a compelling case for the role of culturally constituted stigmatization (i.e. the production of negatively valued difference) as central to the establishment and maintenance of the social order.” (Parker and Aggleton, 2003, p 17)

As such, combining Goffman, Foucault and Bateson provides an enhanced understanding of stigma as well as human rights—one that situates an individual within a “political economy of stigmatisation and social exclusion” (Parker and Aggleton, 2003, p 19)—one that recognizes the dynamic interplay of an individual within their wider context, shaped by agency and cumulative experience as well as wider social determinants, and recognises real barriers and opportunities to promoting the human right to health.

Addressing the relational and situational nature of power and indeed stigma therefore provides a framework for understanding that any one individual or group can simultaneously be powerful and powerless depending on the context, and why someone may be both stigmatising and stigmatised at the same time in concurrent situations (cf

Connell and Messerschmidt, 2005; Connell, 1987).²⁸ Realising human rights (including individual empowerment and knowledge of rights, as well as legal frameworks and structural issues) depends on facilitating change at different levels (the individual as well as the interpersonal and structural) level that can endure and is sustained in different contexts.

Process of devaluation

Stigma is imbued with power and is commonly understood as a process of devaluation or as a “mark” of discreditation (Goffman, 1963). Different types of stigma have been differentiated as enacted stigma (actions resulting from stigma, also known as discrimination), perceived stigma (fear that stigma will be experienced), stigma by association (stigma experienced because of perceived association with a stigmatised group or discredited behaviour) and internalised stigma (the internalisation of the negative or devaluing attitudes) (Stangl et al, 2010; Parker and Aggleton, 2003; Link and Phelan, 2001). It is important to note that stigma is different from discrimination, in that it is a process that can be difficult to pinpoint, recognize and/or articulate (Stangl et al, 2010). Deacon (2006) emphasizes that there is a value in analytically separating stigma from discrimination in order to best understand the relationship between them.

Stigma is layered and complex and can feed off other attitudes or prejudices relating, for example, to homophobia, racism or sexism (Mahajan et al., 2008; Nyblade 2006; Dodds, 2006). In other words, stigma can attach itself to one or more axes of a person’s intersecting identities, including HIV but not excluding other dimensions such as race, gender, and/or sexual orientation, for example. Stigma can have many outcomes and can adversely affect how and when someone accesses services (including testing, support and treatment), how people interact with each other (including friendships, intimate partnerships, within communities and professional relationships), and how someone perceives themselves and their self-esteem (Maman et al, 2009; Genberg et al, 2009; Simbayi et al, 2007).

²⁸ Connell explores this notion in relation to gender, looking explicitly at ‘hegemonic’ masculinities that can disempower some men in specific contexts even within a patriarchal society.

HIV-related stigma as a human rights violation

Just as the human right to health is interconnected and mutually dependent on other human rights (Gruskin, Mills and Tarantola, 2007), there is a need to focus on a structural understanding of stigma that includes a recognition of dynamic interplay between an individual (and all the intersecting layers of identity) and the social determinants and power structures that influence their lives (Mahajan et al, 2008; Simbayi et al, 2007). Stigma cuts across all elements of the human right to health because it impacts the physical, mental and social well being of individuals in the context of their societies.

Given the holistic understanding of the right to health as a 'state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity' (op cit), stigma poses a real threat to the realisation of human rights. While most would agree that enacted stigma (or discrimination) is unquestionably a human rights violation, I suggest that all forms of stigma are a human rights concern with direct consequences for the realisation of the right to health.²⁹

In the context of HIV, there are three main ways that stigma can impact the human right to health. Firstly, when it is internalized, stigma can negatively affect the quality of life and self-esteem of people living with HIV and can create barriers to realising other human rights (Cameron, 2012; Hasan et al, 2012; Li et al, 2009; Simbayi et al, 2007). Stigma has been shown to be associated with stress, depression, and lower perceived quality of life among people living with HIV (Simbayi et al., 2007; Brouard and Wills, 2006). People living with HIV can feel dirty, ashamed, or guilty because of their HIV status (ibid) and it is uncontroversial and well evidenced that stigma exacerbates the already-heavy burden experienced by people living with HIV (Li et al, 2009). Even though stigma is collectively constructed, institutionalized and embedded within social and political relationships, there is an agency involved within the person who experiences stigma and attention should focus on the interaction between individual and collective processes in the construction of stigma (Howarth, 2006). Stigma is difficult to predict, and it can attach and/or be related to multiple layers of a person's identity just as it has an impact in multiple aspects of a person's life (Maughan-Brown, 2010).

²⁹ In fact the first worldwide public-health strategy to explicitly engage human rights principles was the Global Program on AIDS at WHO, directed by Jonathon Mann, in the late 1980s (Gruskin, Mills and Tarantola, 2007). Mann also suggested that stigma and discrimination would be the 'third wave' of the HIV epidemic, enduring longer than other issues relating to prevention and access to treatment (cf Parker and Aggleton, 2003).

Second, stigma creates barriers for accessing health and other services (Maman et al, 2009). This can be a product of internalized stigma (cf Cameron, 2012; Hasan et al, 2012) as well as linked to the experiences and/ or anticipation of experiences within a health care setting (Turan et al, 2012; Nyblade et al, 2009; Mahendra et al, 2007; Greeff et al, 2008). As result, research has indicated that stigma affects HIV prevention and treatment efforts, including the use of condoms, HIV testing uptake, and uptake of prevention of mother to child transmission programs (Maman et al, 2009; Genberg et al, 2009; Simbayi et al., 2007; Rankin et al, 2005). Stigma has been identified as a factor contributing to the refusal to return for the results among people who have tested, to low HIV disclosure rates and to affect adherence to antiretroviral therapy (ART). Some research has indicated that ART is associated with new types of stigma (Roura et al, 2009; Maughan-Brown, 2010) and disproves assumptions that treatment is a 'magic cure' for HIV-related stigma (Makoe et al, 2009). Research has also found that experiences of stigma in a health care setting limits the uptake of these services by people living with HIV (Engender Health, 2004).

Third, stigma can re-enforce power inequalities and processes of social marginalisation (Mahajan et al., 2008; Smith, Rossetto and Peterson, 2008; Parker and Aggleton, 2003). It touches on intimate behaviours, decisions and moralities that are accompanied by a minefield of personal and societal attitudes, perceptions and principles (Dodds, 2006). As such, stigma relating to HIV is often conflated with others such as racism, homophobia or sexism (Herek, 1999; Nyblade, 2006). A relationship between disclosure, social support and stigma has also been observed, where people living with HIV reported less social support when they also felt that HIV carried a greater stigma (Smith, Rossetto and Peterson, 2008). This example explicitly highlights the potential influence of internalized stigma and social engagement including access to sources of support.

Stigma-reduction strategies and interventions

Strategies to address HIV-related stigma benefit from being informed by theory and evidence (Bos, Schaalma and Pryor, 2008). A review undertaken in 2003 suggested that few interventions have been undertaken to address HIV-related stigma in Africa and that few studies have assessed sustained changes in stigma-related attitudes over time (Brown, Macintyre and Trujillo, 2003). However the last decade has seen an increase in

international and national impetus to address HIV-related stigma (as noted in the introduction), at least in terms of political rhetoric. As one review of stigma reduction strategies and interventions noted, people are not passive agents in the stigma-reduction process and the most effective interventions should be oriented at multiple target groups and different levels including the intrapersonal, interpersonal, institutional, community and structural (Heijnders and Van Der Meij, 2006). Even though these authors considered the intrapersonal level, which included the internalization of stigma and interventions aimed at individual behaviour change, they do not document or discuss layers of stigma or notions of intersectionality. Nevertheless the review does highlight the importance of linking individual level transformation with wider social change to mitigate the impact of HIV-related stigma. Other studies have made a similar connection, highlighting the potential role of interpersonal communication and relationships, community action and social mobilisation in overcoming HIV-related stigma (Vincent and Stackpool-Moore, 2009; Bos, Schaalma and Pryor, 2008; Campbell et al, 2005; Parker and Aggleton, 2003). Several studies and frameworks indicate that there is a need not only to tackle experiences of stigma but also to address the drivers of stigma, such as fear (Stangl et al, 2010; Rankin et al, 2005; Brown, Trujillo and Macintyre, 2003).

Gaps and contribution of this thesis—stigma

Gaps in the literature reveal that to date there have not been enough interventions targeting HIV stigma; where these interventions have been undertaken and monitored, this has been done with inadequate measures that have not shown enough evidence of statistically significant change, and there is a general lack of internally valid (good quality) studies (Sengupta et al, 2011). Greater attention should be paid to perceptions of stigma (Yang et al, 2007), robust monitoring (Maughan-Brown, 2010) and rigorous evaluation (Sengupta et al, 2011) to enhance the evidence base for understanding stigma and better-informing effective actions to overcome it (Campbell and Deacon, 2006). Several authors have noted the complexity of the social environment and its impact on HIV-related stigma (Heijnders and Van Der Meij, 2006), and human rights (Ife, 2010), layers of stigma attached to different aspects of a person's identity (Dodds, 2006; Nyblade, 2006; Herek, 1999), and the need to bridge individual and social dimensions (Deacon, 2006). However, to date the literature review indicates that no authors have yet

linked the two – namely a recognition of the complexity of social dynamics (multisectionality) with the multiple layers of individual identity (intersectionality). The results presented in this research attempt to contribute to knowledge by filling this gap, as noted in chapters five and six.

There is also the need to consider how stigma is embedded within “moral life” of people (Yang et al, 2007, p1528), and “how stigma threatens moral standing [has been] ascertained by eliciting the actual words used by informants to describe their stigma experiences” (ibid, p 1532). To date there has been a gap in listening to “insiders’ perspectives” about stigma and the social, cultural, psychological and everyday conditions in which it is experienced (Howarth, 2006, p449).

The literature review indicates that only recently has attention been paid to an empowering process of documenting and understanding HIV-related stigma (for example recent publications presenting the national and regional results from *The People Living with HIV Stigma Index*), and highlights a significant methodological contribution made by the research process and results outlined in this thesis (Stackpool-Moore et al, 2013).

The kaleidoscopic process and methodology described in this thesis locates it importantly within the wider literature about effective interventions for overcoming stigma and the broad reaching potential of participatory interventions in responding to issues relating to HIV, individuals and the dynamism of relationships within their social context. This provides the foundation for the critical reflection outlined in chapter three, that highlights aspects of the action research process modelled in the data collection process of this thesis to be a new, innovative *and* holistic approach to a stigma reduction intervention by engaging and working with people in their daily lives and not only focusing on their HIV status.

4 CHANGE | Engaging the hearts, minds and actions of individuals and societies

Realising human rights requires enabling factors at the individual, social and cultural levels—including legislative frameworks and enabling environments. Given that the human right to health remains elusive for vast numbers of the world’s population, how can human rights (and the processes of documenting the lived experiences of the presence/ absence of these rights) facilitate the kind of individual and social transformation necessary to translate these rights from rhetoric to reality?

Many of the authors writing about power or structure tend to describe each as abstract, static and monolithic, individually and collectively. Likewise, many of the authors discussing identity fail to recognise how layers of identity change over time and also can gain/ lose power and symbolic meaning in different contexts. Keeping the textured focus provided by intersectionality in mind, and applying it to the temporal and dynamic conceptualisations of structure, agency and power outlined above (cf Archer, 1988), a more nuanced picture of the interaction between self and society begins to come into focus. Originality of this research is evidenced in its highlighting of how strategies and efforts to reduce HIV-related stigma have not yet taken into consideration the kaleidoscopic relationship between layers of individual identities (intersectionality) and social dynamics (multisectionality).

To return briefly to the discussion about power, Archer succinctly refers to the “dialectical interplay of culture and agency over time” (1988, p xxii) which both provides a connection between the present and the process by which the power structures have been constructed while also alluding to the possibility for building the foundations of change for the future. She notes that the cultural future is made in the present—a “future which is forged in the present, hammered out of past inheritance by current innovation” (Archer, 1988, p xxiv). Foucault also touches on this concept, when he describes the chain and fluid relation of powers and the movement of individuals:

“Power must be analysed as something which circulates, or rather as something which only functions in the form of a chain. It is never localised here or there, never in anybody’s hands, never appropriated as a commodity or piece of wealth. *Power is employed and exercised through a net-like organisation. And not only do individuals circulate between its threads; they are always in the position of simultaneously undergoing and exercising this power. They are not only its inert or consenting target; they are always also the elements of its articulation.* In other words, individuals are the vehicles of power, not its points of application” (Foucault, 1980, p 98, my emphasis).

Both Archer and Foucault articulate a temporal nature to power structures that are non-linear and can be shaped over time in response to the actions of individuals within the systems of power. Both use active metaphors—hammering, innovating, vehicles moving—to capture the active role of agents and individuals in experiencing, responding to, recreating, perpetuating and challenging power relations.

What is it then that can enable an agent, within these structural systems of power, to hammer or to innovate or to understand their position of subordination in order so that

they can transform and overcome it? Or as Archer refers to it, how can the experiential problem be solved as to “how we can simultaneously feel bound to plod round the cultural treadmill yet also brim over with criticism and creativity” and to overcome the “tension between being conditioned to do things one way but being able to conceive of doing them differently” (Archer, 1988, pxxii)? Building on the combination of agency and structural determinants of power, what triggers change social meanings that shape power structures, which are iteratively and continually interpreted and re-interpreted (Hayward and Lukes, 2008)? Questions remain as to how individuals can conceive of doing things differently, why individuals stop consenting or willingly complying with processes that are against their interests, and when individual and/or collective resistance can spark change in structures of power.

This final section situates this action research and the methodology I have undertaken within other literature as well as within its potential to model an innovative approach to reducing stigma, by exploring triggers that can transform human rights (and the legal mechanisms in which they are enshrined), power relations and processes of stigmatisation to enable meaningful realisation of the human right to health, in the context of stigma and discrimination relating to HIV, for individuals and societies in the future.

Resisting power and reflecting to achieve change

Power can generate resistance, and compliance, as well as producing other dimensions of power (Lukes, 2005; Mamdani, 1996; Foucault, 1984). Several authors suggest that through triggering opportunities for reflection, action, and imagining change, individuals can develop both a consciousness of their subordination as well as an aspiration to transform it. For Archer, the “quintessential reflection ability of human beings” is centrally linked with the temporal nature of power and the context of self in society and is the key to fighting “back against their conditioning ... giving them the capacity to respond with originality to their present context” (Archer, 1988, p xxiv). Freire also addresses this question in detail, focusing on notions of self-critical awareness (conscientização) and a belief that “reflection—true reflection—leads to action” and that “oppressed” people themselves hold the key to their own empowerment and have the

potential to generate sustainable social change (Freire, 1972, 48; Freire, 1974; Chambers, 1997; Chambers, 2008).

Reflection and notions of praxis are imbued with the potential to generate change, assuming that they are linking both the past to the future and incorporate actions or aspirations for change—at the individual or social level. Underlying Freire’s concept of liberation and social change is recognition that both the ‘oppressors’ as well as the ‘oppressed’ hold the key to their liberation, since both perform roles that perpetuate power inequalities (Freire, 1972). A process of self-critical awareness, reflection and action could catalyse the individual and society to overcome stigma and enable the realisation of the human right to health. This also builds on Foucauldian notions of knowledge, and the possible fourth dimension of power, which focuses on a reactivation of local knowledge or challenge relations of power in the production of (new, alternative, diverse) discourses of truth (Foucault, 1980, p 93).

Drucilla Cornell further developed this notion of self-reflexivity as part of a process of change by more explicitly focusing on the notion of possibility and aspiration. Cornell has written extensively on the notion of dignity as another way to frame the possibility for self-reflection and imagination about transforming inequalities and injustices in the relationship between self and society (2002). She focuses on the difference between dignity and equality in defining a spiritual dimension to the pursuit and realisation of dignity. She describes a space—the imaginary domain—that refers to the “moral and psychic space to reimagine and express the person whom we seek to be” (Cornell, 2002, p xx). For Cornell, the notion of dignity includes a notion of the self in relation to the world, and also in relation to a temporal connection with the past and the future. Dignity is therefore inspired by dreams and aspirations as well as reactions to repression or failures of the past: “our dignity and the demand for its respect stem from actual resistance, but also from the broken dreams that are turned into hopes” (Cornell, 2002, p xviii). Cornell suggests that a more intense and even spiritual approach to transformation—or transcendence—is necessary for achieving meaningful (social, economic and political) changes in individual lives that challenge broader structural power dynamics. It requires a focus beyond the material domain and is a deeply spiritual matter that forces one to be true to deep convictions even if one may be going against conventional wisdom (Ramphela, 2008). “Imagined autonomy” is critical for a person’s conceptualization of their own agency (Cleaver 2007). It is also fundamentally important for imagining and

feeling empowered to contribute to effecting change towards realising the redistribution of power and aspirational reality imagined for the future.

Decency and reciprocity—understanding ourselves and others to overcome stigma

Stigma relating to HIV not only spotlights issues that may be uncomfortable or difficult to talk about but also may highlight attitudes, behaviours and prejudices that may or may not be conscious to the agents driving them—be they individuals, institutions and/or the socio-political environment.

There is an implicit reliance within the notions of reflective action, and even within the more spiritual dimensions of transcendence and action, on rationality and conscious awareness of power dynamics in order to be able to overcome or change them. Yet individual lives and realities are much more than rational, including how we emotively respond and engage with the intersecting layers of our identities in the different contexts and moments of our lives. Many of the social theorists recognize the importance of unconscious motivations of conscious actions, the unconscious self-disciplining of agents and their internalization of hegemonic norms (Clever, 2007). Bourdieu (2001, cited in Lukes, 2005) refers to a cognitive relationship that shapes perception and action yet is “profoundly obscure to itself” (p 37). Identity and consciousness are therefore the product of power relations and it is essential to understand the way in which agency is shaped by the actions of others (Bateson, 1982). Not all individual acts are the product of conscious choice, but can rather stem from habit, routine, unarticulated but felt peer pressure and the workings of the unconscious mind (Clever, 2007). How people feel, think, perceive themselves, imagine the future, define themselves in relation to communities to which they experience themselves as belonging, and participate in social and political spaces, is shaped by the conscious as well as unconscious dynamics and influence of the fluid relationship between self and society.

Two principles seem critical for overcoming stigma—the first, listening to and amplifying the voices of people most affected by HIV; and the second, challenging ourselves to reflect and illuminate the corners of our own consciousness and confront our own values, attitudes and behaviours towards others. The conceptual and literature review suggests that potential for transformative change at the individual and social level in the future requires a shift beyond dualisms (violator v violated; oppressor v oppressed;

powerful v powerless) to recognise the agency and proactively engaging people most affected by an issue (in this case HIV) in the process of defining the shape of the response. As such, the process (of participation, of consultation, and of understanding documenting human rights realities) and the privileging of what could be seen as ‘alternative’ or ‘subaltern’ perspectives, becomes just as important as the product or outcome and participation becomes a demonstration of consciousness, reflexivity and imagination (Kesby, 2005; cf Cornell, 2002).

As one of the structural elements that shape power relations, the law is challenged in its ability to respond to and have meaning in the fluid and contested identities of real lives. Increasingly the notion of human rights has been reframed as “shaped through actual struggles informed by people’s own understandings of what they are justly entitled to” (Uvin, 2004; Nyamu-Musembi, 2002, 1; Wilson, 1997). The paradigm of documenting human rights – and the process of research adopted in this thesis – mirrors this ethical preference to focus on individual context and socio-historical relationships, viewed within the tradition of legal consciousness, recognising individuals as agents of change within their own contexts (Harding, 2006; Wilson, 1997; Ewick and Silbey, 1995).

“By situating social persons in communities and contexts, and furnishing thick descriptions of acts of the violent exercise of power, it can be seen how *rights themselves are grounded, transformative and inextricably bound to purposive agents rather than being universal abstractions.*” (Wilson, 1997, p 155, my emphasis)

As Wilson explains, documenting the realisation and violation of human rights in a way that also embraces the agency of the rights-bearers, is a mechanism for bridging the distance between abstract universal principles and everyday realities.

Honouring these theoretical underpinnings, this thesis attempts to fill this gap. The research is based on the deliberate choice of an action research life-story-based methodology. As such, this research is part of a tradition where it is recognized (and valued) that the process of storytelling can itself trigger a consciousness and can be a form of social action (Ewick and Silbey, 1998):

“As a form of social action, stories thus reflect and sustain institutional and cultural arrangements, bridging the gap between daily social interaction and large-scale social structures. In other words, stories people tell about themselves and their lives both constitute and interpret those lives; the stories describe the world as it is lived and is understood by the storyteller.” (Ewick and Silbey, 1998, p 29)

An actor-oriented approach to understanding stigma and documenting human rights – the legal consciousness – offers an organic and grounded perspective of how ordinary people approach, use and think about law and justice in everyday life (Harding, 2006). This research not only recognises but also proactively seeks to understand the relationship between individuals, their identities and their societies, their perceptions of and experiences of stigma, and the actual words they use to convey their meaning.

LIMITS| Power, Consciousness, and Complexity

Three important caveats are therefore relevant in understanding the power relations that shape self, selves and society and that also underpin the opportunities for transformation and realising the human right to health in the future.

The first are the limitations that an analysis of power illuminates about the potential for meaningful transformation. A conceptualisation of power and identity that fails to take the boundaries of reflexivity into account will form an incomplete foundation for understanding processes of individual empowerment and social transformation (Cleaver, 2007).

The second is that it emphasises the risk of unfairly charging individuals with the responsibility of triggering their own liberation and bearing an undue burden for challenging the power dynamics that affect their lives. Foucault (1979) argued that an individual becomes “the principle of his own subjection” if he recognises, perceives and inscribes in himself the power relations to which he is subjected (Foucault, 1979, p 202-3; cf Lukes, 2005). The critical notion therefore is to address both the processes of internalisation of subordination within the individual as well as within the wider structural and social dynamics (Hayward and Lukes, 2008). Even though Freire (1972) focuses on the link between reflection, action and change, and as such relies on triggering consciousness as a precursor to effecting change, he does implicitly promote a solution for also tackling the irrational or unknown effects of power. By suggesting that the “oppressors” as well as the “oppressed” need to be liberated, and that all should reflect on and take action to address the power dynamics that they are all responsible for perpetuating, Freire’s notion of praxis still maintains the potential to tackle the underlying powers exerted beyond the logic of consciousness.

The third insight gleaned from a focus on the limitations of consciousness is a respect for the disillusionment that can accompany realisation and the burden that participation can create. Sen refers to a quiet acceptance of deprivation that shapes the lives of many poor people around the world (1984). There is a dignity in acceptance, and in an on-going self-reliance to live, work, provide food and overcome in the face of adversity. As argued by the former President of Tanzania, consciousness can become a burden; and freedom a luxury.

“What freedom has our subsistence farmer? He scratches a bare living from the soil provided the rains do not fail; his children work at his side without schooling, medical care, or even good feeding. Certainly he has freedom to vote and speak as he wishes. *But these freedoms are much less real to him than his freedom to be exploited.* Only as his poverty is reduced will his existing political freedom become properly meaningful and his right to human dignity become a fact of human dignity” (Julius Nyerere, in Shivji (1989), p 26, my emphasis).

The literature highlights the importance of conceptualising human rights and the power relations imbued in the relationships between individuals and society as dynamic, multi-layered, contextual, temporal and more than what can immediately be perceived. It also highlights that for change to be triggered at the individual and social levels, we need to first understand the complexity of the power dynamics at work in order to imagine and then realise the aspirations for more equitable and empowering realities for individuals and societies in the future. As such, there are significant implications for conceptualising the complex power dynamics that link the individual, social and cultural levels across the temporal spaces of past, present and future—and the role of the law in the process of individuals conceiving and realising their human rights.

One of the conceptual limits of the theoretical framework—linking power, layers of identity, structuration and social dynamism—is that while it addresses the what and the how, it lacks further analysis about the why (Cooper, 2009). Stigma offers one (of many possible) lenses for interrogating and understanding more of the why—significantly, because it lives in the hearts as well as minds of individuals and societies, it necessarily demands attention to the conscious as well as sub-conscious experiences, expressions and production of power.

CONCLUSION | Beyond Rights: Realising the 'Fact' of Human Dignity

Realising human rights and overcoming stigma is a complex process that is determined by dynamic and ever-changing interrelationships between self and society. By drawing on theoretical frameworks relating to power, structuralism and intersectionality, I have outlined a possible lens through which to view the relationship between self and society, and to unpack the underlying determinants of health, human rights and social justice. My research focuses on the dynamics between self and society, the role of the law in expanding or constraining freedom, and the representations of temporality and consciousness that affect stigma and the human right to health.

The methodology adopted for exploring these ideas further seeks to mirror the principles outlined above and seeks to generate spaces that could trigger critical self-reflection and potentially bring into consciousness and support the local production of knowledge about critical aspects of self, society and power dynamics. This knowledge could simultaneously document, subvert and/or reinforce conscious narratives of real life experiences of human rights and stigmatisation. Adopting a process that can engage an individual, while simultaneously working within the wider socio-historical structural reality in which we live, creates not only immense potential for unearthing new insights but also can act as human rights promoting intervention in itself. Jonathan Mann summarises this most articulately when he reflects on the lessons learnt from the response to HIV:

“... empowerment, which is a critical concept not only for others, but also for ourselves. This empowerment rests on two pillars. One is knowledge: an understanding of the importance of societal determinants of health...The second pillar is equally critical: the belief, faith, and confidence that the world can change... That next step, that possibility for change toward a more human world, will require a leap of confidence based on analysis, reflection, and hard work. Only we can empower ourselves” (Mann, 1999, p 225).

Overcoming stigma and enabling human rights therefore is a challenge and opportunity for all of us, regardless of how or when we find ourselves stigmatising or being stigmatised, since equalising power relationship is at the core of addressing stigma and realising human rights (Osborne, 2009, op cit).

By addressing the gaps in literature, and working with the empirical data collected as part of this research, the results presented in this thesis contribute a 'grounded theory' approach to understanding the potentiality of law in achieving human rights in the context of HIV in Malawi. The results presented in this thesis, combined with the conceptual notions that are transferable for other contexts, establish a basis of what could be

considered dignity jurisprudence in the context of HIV, health and human rights in Malawi. The notion of dignity embraces both a relational notion of the self in relation to the world, a connection between the past, present and future, the privileging of lived experiences in understanding law in daily life, and a recognition of agency, resilience and aspiration in social processes of (de)valuation.

There is no magic bullet, no single intervention nor one public policy that can generate the transformation necessary to make rights a reality—or in the words of Nyerere, to realise the fact of human dignity for all. Understanding difference, power relations and the complex intersecting dynamics of agency and identity can play a vital role in grounding universal human rights principles to meet the needs and desires competing among the realities of everyday life.

3 | Methodology and Methods

Championing a Self-Reflective Community Action Research Model



“Narratives are socially organized phenomena which, accordingly, reflect the cultural and structural features of their production... as socially organized phenomena, narratives are implicated in both the production of social meanings and the power relations expressed by and sustaining those meanings.... [W]hen narratives emphasize particularity, and when they efface the connection between the particular and the general, they help sustain hegemony. Conversely, when narrativity helps bridge particularities and makes connections across individual experiences and subjectivities, it can function as a subversive social practice.” (Ewick and Silbey, 1995, p 200)

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CORE PRINCIPLES

The research methodology I have chosen seeks to model the core principles of self-reflection, inclusion and participation. It is a naturalistic inquiry, informed by the axioms and characteristics outlined by Lincoln and Guba (1985), recognizing that the approach incorporates both the actions of the investigation as well as the degree of influence imposed by the investigator. The focus of inquiry as well as the presentation of results is based in a natural setting; within the dynamic and unpredictable context of human lives; is inductive and includes conceptual generalizations that are intuitive and empirical, drawn from personal and vicarious experiences; and embraces the “everyday consciousness of reality and its chameleonlike quality” (Lincoln and Guba, 1985, p 70).

As a non-African researcher exploring issues (human rights, stigma, HIV and the law) that are deeply rooted within individual, social, cultural and philosophical context, I followed the advice of Richard Bell and designed a three step approach (Bell, 1997). The first: engaging in discussion with African intellectuals and reflecting on each of our self-understanding about the issues. The guidance of my research by the action research team as well as my local supervisor with the University of Malawi was designed to facilitate this engagement. The second: to listen to oral narratives and lived experiences, which formed the majority of the data analyzed in this research, both in the life stories and key informant interviews. And the third: to participate in various cultural, artistic and ritual traditions, which I did during the period of fieldwork as well as in subsequent visits back to Malawi (and as the opportunities have arisen in London).

The research process is seen as an outcome that is just as important as the research results and analysis (Heron and Reason, 2001; Lincoln and Guba, 1985). The process of narration and of documenting human rights concepts is seen as a form of social action in itself (Ewick and Silbey, 1998), and as a way of exploring the fourth dimension of power that explicitly touches on the internalization of power—and potential subversion of power—and how it affects an individual’s perception and being in the world (cf Lukes, 2005). Building on Ewick and Silbey (1995), my methodology involves a convergence of both a political and epistemological commitment to ‘giving voice’ and understanding multiple subjectivities:

“Indeed, the *political* commitment to giving voice and bearing witness through narrative is underwritten by the epistemological conviction that there is no single, objectively apprehended truth. Conversely, the *epistemological* claim that there

are multiple truths is based on the recognition that knowledge is socially and politically produced.” (Ewick and Silbey, 1995, p 199)

A peer-interviewing approach and life history style of interviews forms a significant part of the methodology, which allowed narrators to describe issues, concepts and priorities in language and a sequence that is of most meaning to them in the presentation and analysis of the results presented in this thesis.

As such, I aspire to amplify and understand the nuances and complexity of potentially subversive stories recounting both the mundane and the magnificent experiences of everyday life, to contribute to understand HIV, stigma and the law.

Power to Change

Recent shifts in approaches to community development, to understanding human rights, and to valuing the perspectives of people most affected in policy debates have begun to recognise the agency and integral role that actors have in their own development and processes of change (cf Ife, 2010).

For valuing the perspectives of people most affected in policy debates, programming and all areas relating to HIV, the GIPA Principle (The Greater Involvement of People Living with HIV) was formalised in the Paris AIDS Summit Declaration in 1994 and is now a core criteria for policy consultations, international grant applications and organising committees relating to HIV (GNP+, 2009). The GIPA principle - based on principles of community organising and community building - is central for effective interventions, and new models are emerging for advocacy and social change in response to HIV related stigma (Mahajan et al., 2008: S75). More recently, responding to some experiences of tokenism, it has become known as the MIPA principle—the Meaningful Involvement of People Living with HIV.

All three areas are relevant for influencing the methodology underpinning the research presented in this thesis, in proactively engaging people most affected by an issue (in this case HIV) in the process of defining the shape of the response to HIV and the process of national development.

Participatory Action Research

This research is an attempt at participatory action research, although in some aspects it is more of a collaborative hybrid approach as outlined in Table 1 below. Co-inquirers documented the evolution of each of our reflections, understanding, challenges and visions for the research process. It is based on Freirean principles of conscientization and praxis that is an iterative cycle of action, reflection, change and action.

"Liberation is a praxis: the action and reflection of men and women upon their world in order to transform it." Paulo Freire (1972)

In the context of addressing stigma and discrimination relating to HIV, it is rare that interventions have been designed with social transformation or community mobilization in mind, and have often been based instead on practices targeting behaviour change (Parker and Aggleton, 2003):

"Only more rarely have interventions been designed with the goal of unleashing the power of resistance on the part of stigmatized populations and communities—in spite of the fact that empirical studies of empowerment and social mobilization in response to HIV and AIDS have clearly demonstrated that the most effective and powerful responses to the epidemic ... have taken place precisely when affected communities have mobilized themselves to fight back against stigmatization and oppression in relation to their lives." (Parker and Aggleton, 2003, p 21, op cit)

Responding to this, I have designed a methodological approach where the process (of participation, of consultation, and of understanding documenting human rights realities) becomes just as important as the product or outcome (see chapter two, cf Ife, 2010; Nyamu-Musembi, 2002).

As a research approach that seeks to promote inclusive, non-stigmatizing, collaborative and self-reflective ways of working, grounded in the life experiences and subjectivities of the co-inquirers (including myself) as well as the participants, the methodology strives to translate some of the theoretical concepts into practice—to generate spaces that can privilege local knowledge, trigger consciousness, and recognize and celebrate the complexity and diversity of identity. As such, it could be seen as part of an evolving research paradigm—performative social science—that essentially seeks to perform the desired outcomes of the research while also reporting on the process and results (Stackpool-Moore et al, 2013; Haseman, 2006).

In essence the methodological approach seeks to facilitate and document praxis among individuals in the context of their everyday lives. As such it seeks to listen to, capture and illuminate some of the complexities of intersectional identities, the temporal

experiences and perceptions of human rights amid the daily realities of life. To an extent I follow Bevir (2006), who discusses the validity and concept of narratives in relation to interpretation and 'situated agency' in research³⁰:

"In explaining change, interpretivists do not privilege their academic accounts of the world; rather, they again offer interpretations of interpretations, concentrating on the subjective and intersubjective understandings of the actors who bring about the change" (Bevir, 2006, p 289).

The process created opportunities for an individual and shared "praxis in the determination to make a change in the troubled time and space and on the contested land" (Madison, 2008, p 404). The process of telling and listening to stories, and reflection about our own lived experience, became one of the cornerstones to our own praxis and to confront stigma.

Much of the language used to describe participation reflects the necessarily energetic and contested dynamism of the process—such as 'liberation' (Freire, 1972), 'struggle' (Wilson, 1997), 'subversion' (Freedman, 1999) or unleashed 'resistance' (Parker and Aggleton, 2003). In many words, the change (for the individual and for wider society) will come from an at-times uncomfortable and confronting praxis that engages self-reflection and action within the context of the lived experiences, social and historical determinants of real life.

METHODS

"Good participatory processes are predictably unpredictable"
(Chambers, 2002, xiv)

"Central to any social scientific analysis ... in human rights (as in any topic) is the need for good method... Methods establish the ground rules of any inquiry, specify the types of knowledge that are possible given the theoretical expectations and assumptions of the researcher, and set the parameters for how evidence is collected and analyzed." (Landman, 2009, p20)

The methods used straddle an aspiration to implement participatory action research tempered by the limitations of a relatively short time period and fulfilling the requirements of doctoral research (cf McNiff, Lomax and Whitehead, 2003; Lomax, 2004). The process of inquiry remained firmly based in my independent aims, research questions

³⁰ Note Bevir is referring only to subject of research rather than situated agency among research participants in the act of telling their stories.

and analytical frames throughout, while simultaneously honouring a genuine process of action-oriented critically self-reflective collaboration with co-inquirers.

One country case study: Malawi

As Yin (1994) proposed, a case study approach is best suited for “contextual” research, and the focus of this study is people living with and affected by HIV in one country in Sub-Saharan Africa—Malawi. Although each of the participants and co-inquirers (including myself) have complex identities and personal life stories, these were taken into account in the research process, our “bounded phenomena” are common personal interest and experience of HIV (Cohen *et al.*, 2000, 79). The elements of action research adopted for this study are based on the objectives of linking research with professional practice, promoting collaborative problem solving, and promoting reflective practice (*ibid.*). Overall, my research design could be described as an in-depth case study guided by the principles of participation, mutual reflection and interaction (as opposed to extraction).

The research was concentrated in one country and serves as a case study that reveals contextually—grounded insights relating to the research questions. As such the findings and discussion are rich, nuanced, indicative and informative, and the conceptual implications could potentially be transferable for other settings.

Malawi was chosen based on key considerations including:

- 1) HIV prevalence,
- 2) Enthusiasm and availability of local co-inquirers to participatory in the action research,
- 3) Experience in implementing *The People Living with HIV Stigma Index*,
- 4) Existing relationships between myself and key potential partners and participants in the research, and
- 5) Timely relevance given the context with the proposed draft HIV Bill.

The presentation of findings also includes an embedded case study design, as in an incorporation of multiple units of analysis within a single case study design (Yin, 2009, p 46). In the presentation of results in this thesis, this includes specific focused analysis of two specific aspects of the law in chapter seven (the Constitution and a proposed draft HIV Bill) as well as in-depth presentation and discussion of specific life story testimonies (Inserts 3 and 4) and an opinion leader interview (Insert 5).

The thick descriptions presented in the embedded case studies as well as the provision of the widest possible range of information for inclusion (relevant to the research questions and describing the context), provides the reader the opportunity to probe for internal consistency and make necessary judgments about transferability. This contributes to providing the details for assessing the trustworthiness of the naturalistic inquiry (cf Lincoln and Guba, 1985; Shenton, 2004).

Research questions

The methods and research questions are derived from each other, given that process and product were both important considerations in the design and implementation of the action research project. As Landman (2010) notes, “method is a function of the research question that is posed, the theories used to help answer the question, and the epistemological orientation of the researcher” (p20).

At the beginning of the research process, the research questions were reviewed³¹ by the action research group. After the first year of my doctoral studies, where I was based in London reviewing literature and conceptualizing the research approach, I arrived in Malawi with a starting point for discussion with the action research team about research investigating HIV-related stigma and human rights. On arrival and after initial discussions with the action research steering group and life story interviewing team, the research questions were finalized in October 2010 as follows:

- 1) How can processes of documenting human rights contribute to development and the realization of human rights?
- 2) To what extent does HIV-related stigma create barriers for realizing the human right to health?
- 3) What are the similarities and differences between the impact of HIV-related stigma on the human right to health at the personal, service and structural levels?
- 4) What are the strengths and limitations of the role of the law in promoting the human right to health as part of a national response to HIV?

³¹ In this case, it was not action research in its pure sense because I already had a loose framework for enquiry in my mind already when arriving in Malawi and approaching/ inviting colleagues to participate in the action research.

In retrospect, these questions could be grouped under one overarching research question:

In the context of lives and societies affected by HIV, to what extent is it possible to achieve human rights affirming individual and social change, through processes grounded in law?

The timing of my research was serendipitous given the status of the proposed draft HIV Bill at that time in Malawi. The existence of this proposed draft HIV Bill and the outcomes from the Special Law Commission on HIV and AIDS was unknown to me when I first arrived in Malawi, and it soon became clear that research focusing on HIV, stigma and the law at that time must also include an intense focus on the details, perceptions of and intentions behind the draft HIV Bill. This topic of inquiry was timely and of contextual importance in Malawi. The recently disbanded group who had been involved in the Special Law Commission on HIV and AIDS also provided a unique opportunity in an almost “real time” setting to document, understand and explore the intentions of the individuals involved in drafting HIV-related legislation. This provided a rare opportunity that has not previously been documented in another setting. The fact that at the time of research the draft HIV Bill had not yet been before parliament also created an entry point for action and for the outcomes of this research to be useful in informing advocacy efforts to influence the potential directions (if any) and shape of the process by which the draft HIV Bill may become enacted into legislation.

After I had left Malawi and returned to London to undertake the transcription, coding, analysis and writing up of the results from the research, I had a greater opportunity to reflect on the key emergent themes, to update the literature review, and subsequently to revisit the research questions to more closely match the critical areas of enquiry that had evolved in the research process. The process involved identifying key themes from the data, and then coding the data according to the themes that had emerged. The research questions were then reformulated which became the basis of the analysis and grounded theory presented in this thesis (Walker and Myrick, 2006).

On reflection, the focus of the research remained an exploration of the extent to which it is possible to achieve human rights affirming individual and social change in the context of lives and societies affected by HIV through law grounded processes. Specific

research questions that more closely match the areas of enquiry and questions asked of the data during the collection and analysis phases of the research are:

- 1) To what extent do experiences of stigma relating to HIV change over time and alter in relation to the multiple layers that comprise individual identities?
- 2) Is the law and legal consciousness useful for seeking redress for HIV-related discrimination in the daily lives of people living with and closely affected by HIV?
- 3) To what extent does the normative or symbolic potential of the law frame social attitudes towards HIV and engage stigma relating to HIV?

The results presented in this thesis in chapters six, seven and eight are structured to respectively respond to each of these research questions. The reflections included in this chapter also consider the extent to which a participatory process of exploring a human rights concern (in this case stigma relating to HIV) contribute to protecting human rights for those directly involved, and in so-doing if this research methodology model an effective approach for reducing stigma.

ETHICAL CONSIDERATIONS

Confidentiality and Informed Consent

Every possible step was taken to ensure that confidentiality about the details of their interview was assured for all participants and particularly those who shared their life stories. Some desired this more strongly than others. Specific steps were taken to prevent any personal information from being known to people outside the research team:

- All participants signed an informed consent form permitting the inclusion of their interview in the research (see Annex 1).
- All consent forms were kept separate from all other documents relating to the research.
- All members of the Action Research Team and Interviewers signed a confidentiality agreement (see Annex 2).
- Each interview was recorded, translated from Chichewa (unless the interview was conducted in English) and transcribed, and given a non-identifying marker as described below, to ensure that the research and analysis was based on true representations of the participant's perspectives.

Some participants explicitly wanted their names and their stories to be included and identified in the research. However for consistency, and to prioritize the wishes of those who requested anonymity, all interviews have been treated the same way.

- All interviews have been anonymized and coded as life story participants (LS), opinion leaders (OL) or law commissioners (LC) and numbered sequentially.
- Attempts have also been undertaken to remove any identifying characteristics from each interview (such as very localized place names).
- Some identifying features were listed alongside the interview codes for the life stories, such as MN (representing Male from the Northern Region) or FC (Female from Central Region), and document the demographic breakdown of participants in this chapter.

In the reporting of extracts, quotations and embedded case studies in this thesis, all identifying features have been changed and the participants anonymized with two noteworthy exceptions. The first, is in relation to the members of the action research team –the steering group as well as life story interviewing team. As is the practice in action research, to recognize and acknowledge co-collaboration, the action research team have been named, are visible, and have been duly acknowledged for the contribution they made to this research (cf Brydon-Miller and Greenwood, 2006).

Explicit consent was sought and informed consent and confidentiality forms were signed at the beginning of the process (in October 2010, as described below) and again in critical reflections at the end (in March 2011), and in subsequent follow-up meetings with the team (in May 2012; and in May 2013). The second exception is in relation to the description of the Commissioners and staff from the Malawi Law Commission who were involved in the Special Law Commission on HIV and AIDS. While the identities of the commissioners and opinion leaders from within this group has been kept anonymous, the list of the whole group is public information and published in the report (MLC, 2008) as explained in chapter seven. The specific extracts and responses included have however been completely anonymized, as for all participants except in the sections that directly and solely draw from the reflections of the action research team (see below).

As part of the process of establishing the trustworthiness and reviewing, revising and ensuring the rigour of this research, due attention has been paid to ensure that

promises of confidentiality and anonymity have been honoured and adequately protected (Lincoln and Guba, 1985; Shenton, 2004).

Photographs

Some participants were offered the opportunity to have their photograph taken alongside their life story interview. The rationale for this, having been considered by the action research team, was that pictures can speak a thousand words (and visual images might add another layer of insight to the more rational language-based descriptions of the life story interviews) and also that participants might like a photograph of themselves as a souvenir from the interview and an opportunity to visually represent oneself, one's world, and potentially foster self-esteem (cf Prins, 2010). In this way the photographs presented in this thesis and collected as part of this research became part of a culturally informed observation (cf Harper, 1998).

As there was only one camera, not all 42 life story participants had the opportunity to participate in the photo collection process. However all of the 20 life story participants included in the final analysis presented in this thesis were photographed. Decisions were made on an individual basis, modelling what Harper describes as ethical decision making and the images presented have been understood within an awareness of the power dynamics of the research process (Harper, 1998). In addition to the informed consent reviewed and signed by all participants, explicit verbal consent was sought for the photographs, and the use was clearly described as to accompany their interview for the purposes of this research and for potential inclusion in the thesis document that would be archived in the library at the University of London. Photographs were taken on a digital camera, and each participant was shown the photographs and given the choice about which one they preferred to be included in this research. Additional consent will be sought if the findings and stories are to be published in a book for the general public.

Given that this study is about people living with or closely affected by HIV in Malawi, and given the high prevalence rate of HIV in Malawi, a participant's HIV status cannot be inferred from the inclusion of their photograph in this thesis.

The photographs presented compliment the details in the qualitative analysis; however they have not been linked directly to any specific testimony or detailed analysis of the responses given in an interview. Photographs have only been included where the explicit consent of the participant was given for their inclusion.

Ethical approval

The ethics for the research was founded on the guidelines of the British Oral History Society³² at that time—although the Society indicated that these need to be updated. I also drew from the protocol for informed consent and confidentiality outlined in the guidelines for *The People Living with HIV Stigma Index* (IPPF *et al*, 2008).

Having been closely involved with the research and rollout of *The People Living with HIV Stigma Index* in Malawi³³, as a member of the Taskforce steering the project and also one of the co-authors involved in the data analysis and drafting of the national report, the exchange of ideas between my PhD and the Stigma Index in Malawi has been iterative and continuous.

Ethical approval for my research was gained from the Committee for Ethical Research at the Royal College of Medicine, where my PhD research was included as one of the contributing sources of data for case studies to enrich the findings from the Stigma Index (see Annex 3, reference P.08/10/974 and Annex 4). The research was affiliated with the Centre for Social Research, Chancellor College, University of Malawi, and Dr Alister Munthali agreed to be my local supervisor (see Annex 5 for proposal accepted).

SAMPLE

As with most naturalistic inquiries, the sampling approach was purposive and focused both for the constituency of the action research team as well as for the participants interviewed (cf Lincoln and Guba, 1985). Even though a grounded theory approach has been adopted for the coding, analysis, interpretation and presentation of results, this was not in tension with the purposive and snowball sampling undertaken during the data collection stage of the research because it was conceptually informed (Curtis *et al*, 2000).

The selection of participants was designed to be indicative not representative, recognizing the truly subjective and individual stories and opinions shared through each of the research methods. As such, the members of the Action Research Team, Interviewers and participants represented a cross-section of people living with HIV and key stakeholders in the national response to HIV.

³² Oral History Society Ethical Guidelines available at <http://www.oralhistory.org.uk/ethics/index.php#eg> accessed 13 May 2010

³³ I have also been involved in directly supporting the national rollout of *The People Living with HIV Stigma Index* in the UK, Dominican Republic, Swaziland, Ethiopia, Mexico and Bangladesh.

According to the National HIV Prevention Strategy 2009 – 2013 (NAC, 2009), there are some specific characteristics about HIV prevalence in Malawi that were taken into consideration and reflected in the sample:

- Gender: HIV prevalence is significantly higher among females than males, except in the 30+ age bracket (where it is approximately equal) (p4). However transgender is not included in the breakdown of figures.
- Geography: HIV prevalence is significantly higher in urban compared to rural areas, and highest in the Southern region compared to Northern and Central (p5).
- Employment: The highest HIV prevalence is among female sex workers (estimated at 70.7%). However male sex workers are not included in the breakdown of figures (p8).

The Strategy also notes that men who have sex with men (MSM) are a ‘well-known high-risk group with very high incidence’ (p 9) and also have a prevalence of almost double the national average.

A combination of sampling approaches was used to ensure that a diverse group of participants was represented. The sampling included purposive and snowball for the key informant interviews, focusing on a range of leaders from five main broad sectors influencing the role of the law in response to HIV in Malawi. These included healthcare providers, lawyers and legal service providers, policy makers, people living with HIV and the organizations that support them, and other key civil society or opinion leaders. Probability-based random selection was used to identify some of the life story participants as follow up from the national survey *The People Living with HIV Stigma Index* (Chirwa et al., 2011).

The total number of interviews was in part determined by timing and in part by theoretical saturation (Sandelowski and Barroso, 2003). Every effort was made to interview all of the Commissioners involved in the Special Law Commission on HIV (as listed and identified in the front of the Report from the Special Commission, MLC, 2008). Beyond that, within the categories informing the selection of key informant interviews, I sought to reach as many diverse perspectives as possible. This phase of data collection was stopped once the responses on the common themes seemed to be repeating patterns of responses from other interviews and no new insights were emerging. However this was difficult to determine because some of the questions were specifically about opinions and

individual understanding of key issues, often evoking stories of personal experience from the participants. Each of the key informant interviews was different. This is consistent with my methodological stance that opinions and actions are deeply rooted in individual agency, context and often (but not always) consciousness. Given this position, 'empirical saturation' might never be possible given each life and each individual perception is unique, however 'theoretical saturation' was achieved once no new insights were emerging to inform new ideas for the grounded theory approach. The action research team concluded that sufficient perspectives had been included in the research and that there had been good multi-sectoral inclusion among the participants.

APPRECIATION

I ethically chose to acknowledge and appreciate the time contributed to the research process by members of the action research life story interviewing team (MK 5,000³⁴ per completed transcribed interview) as well as life story participants (MK 1,000³⁵) and records were kept (see Annex 6). Because the key informant interviews were shorter and less personal than the life stories, and because the participants were either professionals and/or follow-up from the life stories, no honorarium was given.

APPROACH: ROLES AND RESPONSIBILITIES

The approach undertaken in this research aspired to be participatory and action—oriented, while also fulfilling the expectations of doctoral research. Overall the methods could be described as participatory action research with elements of more traditional research included to add depth on specific, targeted thematic areas of analysis (in this case, the role of the law and draft HIV legislation in Malawi).

³⁴ Approximately GBP £20 at time of research.

³⁵ Approximately GBP £4 at time of research.

Definitions (adapted from IDS, 2010, p 19)				This research
Stages of research	Researcher-led (traditional)	Participant-led (participatory)	Collaborative	Hybrid, collaborative action research
Identification of research question or problem	Researcher	Community	Joint	Researcher led, and jointly refined in consultation with the action research group
Development of approach/ method	Researcher	Community with researcher assistance	Joint	Researcher led, with refinement and feedback from the action research group and life story interviewing team
Entering the community	Researcher	Researcher invited by the community	Negotiation process	Researcher introduced through professional role and invited by community
Gathering data	Researcher	Community members	Joint – division of labour	Joint—division of labour (all key information and opinion leader interviews done by researcher, and 5 life story interviews; life story interviewing team completed 37 interviews, averaging 6 each).
Analysis of data	Researcher	Community members with health of researcher	Joint	Lead analysis from researcher, informed by key themes identified by action research group and life story interviewing team
Dissemination/ follow-up	Researcher	Primarily for learning and action in the community	For community empowerment and for outside use/ publication	For community empowerment and for outside use (for example through inclusion in the MANET+ <i>Stigma Index</i> research and FPAM radio debates)/ publication (for example through submission of PhD thesis, book chapters, and future articles)
Exiting the community	Researcher	Transfer of skills	Negotiated process	On-going relationship, sustained community of enquiry through co-authorship of publications, joint conference presentations and meetings whenever possible

Box 1: Breakdown of stages of research and comparison between research approaches

DATA COLLECTION

The three main empirical components for the research included reflections from the Action Research and Steering Group (including transcripts from meetings, notes, and research diary entries), life story interviews, and key informant interviews with opinion leaders. Additional insight was also gained from a review of grey literature and media coverage during the research period.

Method	Person responsible	Outcome	Data included
Action research	Lucy	Steering group guidance, training of peer-interviewers, reflections recorded and transcribed	Reflections from review meetings, research diaries
Life stories	David, Ruth, Gift, Milliam, George and Lucy	42 life story interviews completed and transcribed	20 life story interviews
Key informant interviews	Lucy	58 interviews completed and transcribed	22 opinion leader interviews; 10 law commissioner interviews; 20 additional materials to complement life story interviews
Review of laws and policy documents	Lucy	Policy review	Analysis of Draft HIV Bill and relevant aspects of Constitution

Table 1: Summary of data collection methods and data collected

In total 52 interviews have been selected for inclusion in the final analysis and presentation of results, from a combination of methods described below. These interviews were part of the total 100 interviews. Selection was based on discussions within the action research group and on criteria relating to relevance to the main research questions, depth of content and seniority of the participants. Further details about the selection and exclusion process are detailed below.

The demographics of the participants whose interviews are included are as follows:

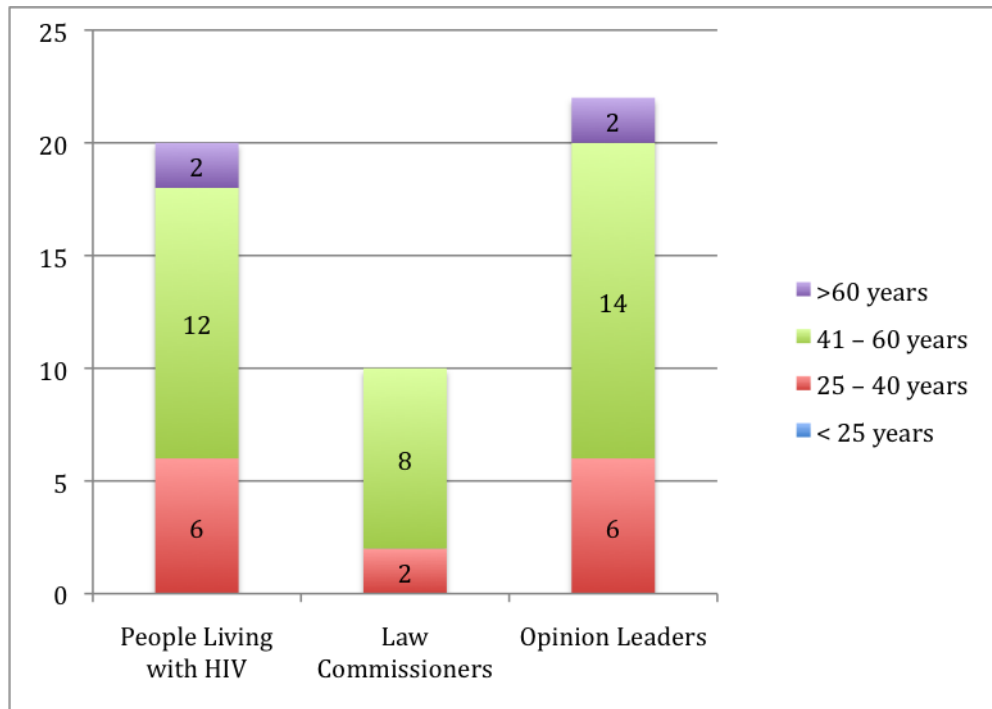


Figure 1: Age breakdown of participants (n=52)

The breakdown between men and women was almost equal for the life story interviews. For the Law Commissioners, the bias towards female participants reflects the constitution of the Special Law Commission on HIV/AIDS and its majority of women as the Commissioners appointed. The bias towards men for the Opinion Leader interviews reflects a general bias in Malawi towards appointing men to positions of leadership and authority in institutions. For example, at the time of interviewing, the acting executive director for one of the networks supporting women living with HIV was a man.

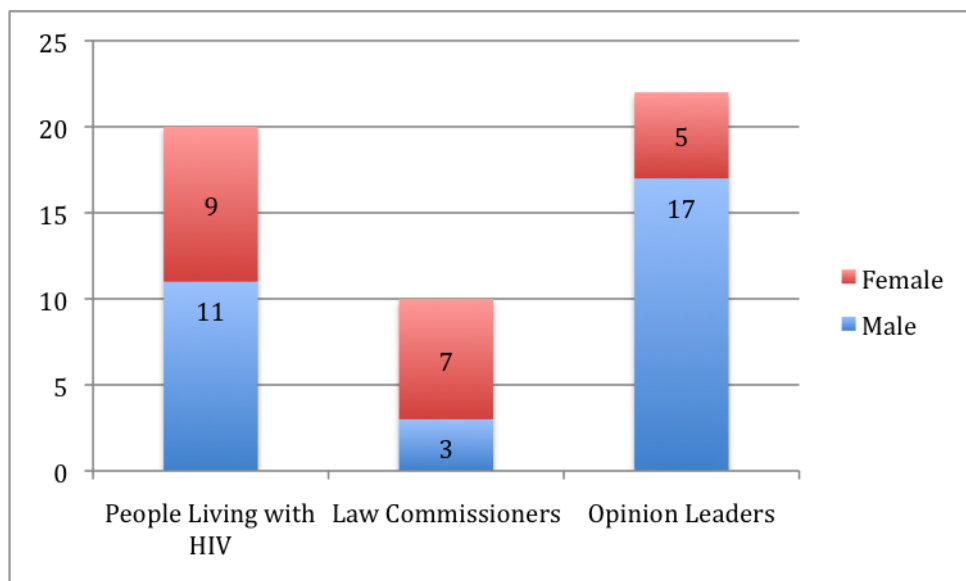


Figure 2: Gender of participants (n=52)

The breakdown of participants between regions is shown below. For the Life Story interviews, the team purposively sampled participants across all three regions. However the bias towards the Central Region for the responses included reflects the concentration of decision makers (both from Law Commissioners and from the Opinion Leaders) in Lilongwe, the Capital City, which is in the Central Region.

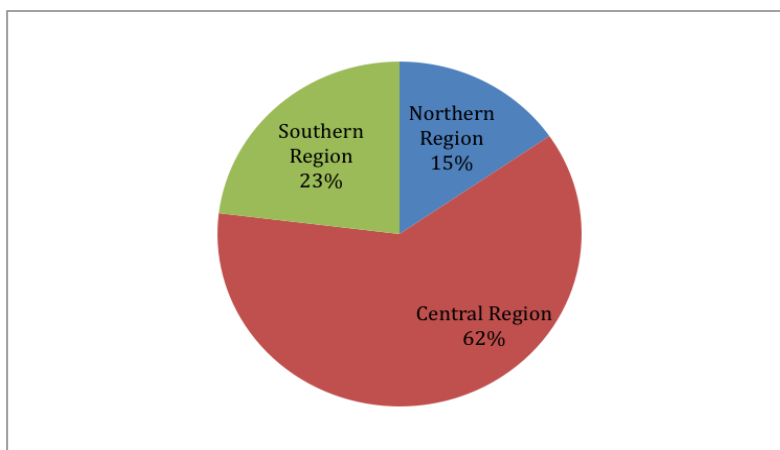


Figure 3: Regional distribution of participants (n=52)

Perspectives were explicitly sought from people living with HIV and those most affected by HIV in Malawi, including women, people in sero-discordant relationships, prisoners, sex workers and MSM.

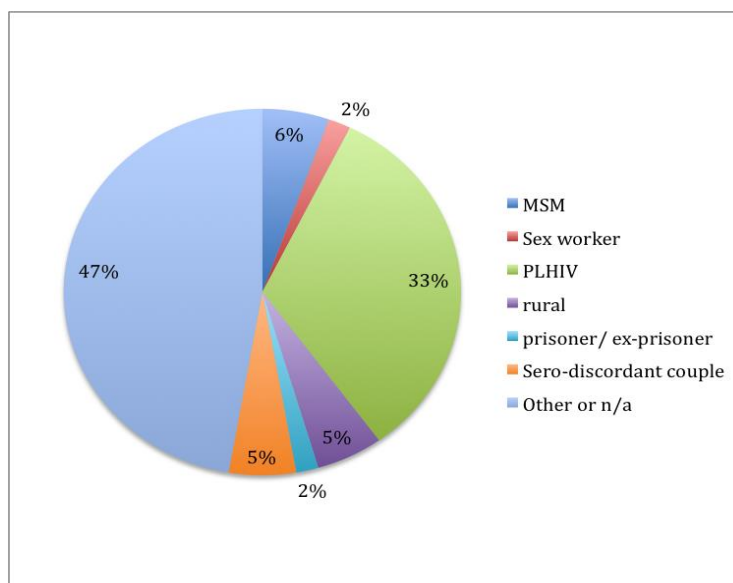


Figure 4: Identity groups of participants (n=52)

N/A in this graph means not disclosed and/or not identified with any group or characteristic listed

1) Action Research team and peer-interviewers for life story interviews

The Action Research process started in October 2010, when a team of practitioners joined together to guide my research and to reflect on HIV-related stigma in the context of their own work during the duration of the research. Individuals were identified and invited to participate in the process, based on their interest and existing familiarity with the loose frame of the research into HIV, stigma and the law. All were associated in some way with *The People Living with HIV Stigma Index* in Malawi.

The team comprised of Safari Mbewe, Executive Director of the Malawi Network of People Living with HIV and AIDS (MANET+), Gift Trapence, Executive Director of the Centre for the Development of People (CEDEP), Ruth Kundecha, District Manager for the Family Planning Association of Malawi (FPAM), Dr Roberto Campos, Partnership Officer with UNAIDS Malawi, Dr Maureen Chirwa from the Royal College of Medicine, and David Kamkwamba, Chair of the national network of journalists living with HIV (JONEHA) and Controller of Programmes for Radio 1 with the Malawi Broadcasting Corporation (MBC) (see image 1). The group met three times during the course of the research to help refine the research questions (October 2010), to discuss key themes and emerging findings (February 2011), and to review initial findings (October 2011). Notes and recordings were taken during the meetings, and some of the team also shared extracts from their diaries that have been included in the analysis. All members signed an agreement of confidentiality at the first meeting.

The team of Life Story interviewers was formed at about the same time (October 2010), with overlap of two of the members from the Action Research group. The team comprised of five people, all of whom are living closely with HIV (see image 2). The team selection was through nomination from institutions associated with the Action Research. Key criteria included education, listening skills, sensitive manner, and interest and availability to be part of the project. Initially I had excluded people not living with HIV from being part of the team, but on further consideration and reflecting the importance of exploring the layers of stigma and stigma by association, this criterion was expanded to also include people closely living with or affected by HIV. This facilitated the inclusion of life stories from MSM as well as from people in the Northern Region, where recruitment of an interviewer living openly with HIV had been challenging. Each of the life story interviewers also signed an agreement of confidentiality.

I had hoped to also include a young person living with HIV as one of the life story interviewers. One young person attended the initial training however it became clear that unfortunately he did not understand the concept of research (he thought it was like a role play interview for radio). After discussions with others in the team, we agreed that it wasn't only a challenge because of language (the same issues were evident when he was working in Chichewa) and I decided not to retain him as one of the researchers in the team. However we have maintained communication and he expressed gratitude at having been included in the initial training and for having learnt from the other participants who were such confident and inspiring elders openly living with HIV in Malawi.

The team were trained in life story research and supervised during the data collection and transcription process (see images 3 and 4). To prepare the team and finalize the research design, a two-day training and planning meeting was held at my house in Lilongwe, 23-24 October 2010. I facilitated the training, which included the principles of good research, rationale behind a life story approach, listening skills (and how the life story approach is different from things like radio interviews), transcription, communication and follow-up. I developed a checklist, and also a referral sheet (to be completed by each interviewer as appropriate to their specific location) to prepare interviewers share knowledge and information about sources of support if necessary after the interview (see Annexes 7 and 8). We workshopped and collaboratively agreed on a draft question guide, as a prompt for the life story interviews (see Annexes 9 and 10). This question guide was then piloted on the second day of the training when the team interviewed each other, marking the first life stories collected as part of the research. Additional changes were made to the guide after the piloting, which was then finalized for use in each of the regions. One of the team, Gift, was unable to attend this initial training and a follow-up training was done one-on-one with him on 13 November. Approximately two weeks after the training I visited each of the team to review their first transcripts and give feedback about the interviews. A mid-collection review meeting was held in Lilongwe in December 2010, where in addition to checking in about progress and challenges with the research, the group shared reflections and started discussing initial themes emerging across the interviews. An end of collection meeting was held in Lilongwe in March 2011 to review the whole collection, discuss and agree the framework for analysis, and to celebrate the hard work and achievement of the team (see image 5).



Image 1: Action Research Steering Group
Maureen Chirwa, David Kamkwamba, Gift Trapence, Ruth Kundercha, Safari Mbewe, Lucy Stackpool-Moore
(Area 10, Lilongwe, 21 October 2010)



Image 2: Action Research and Life Story Interviewing Team



Image 3: Side-by-side interviewing



Image 4: Action Research Steering Group meeting and Interviewer training (Area 10 Lilongwe, 22 October 2010)

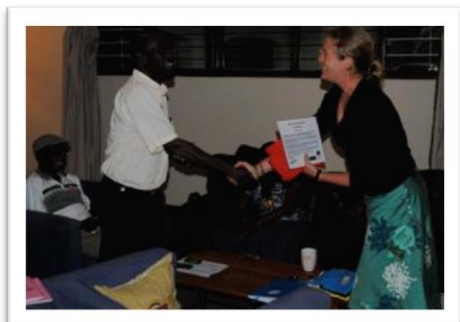


Image 5: End of collection meeting and appreciation ceremony (Area 10, Lilongwe, 9 March 2011)

	Northern Region	Central Region	Southern Region	Total
Age				
< 25 years	-	-	-	-
25 – 40 years	1	2	-	3
41 – 60 years	-	1	1	2
>60 years	-	-	-	-
Gender				
Male	-	2	1	3
Female	1	1	-	2
HIV Status				
HIV positive	-	2	1	3
HIV negative	1	-	-	1
No known/ not disclosed	-	1	-	1
Location				
Rural	-	-	-	-
Urban	1	3	1	5
Key population group				
MSM	-	1	-	1
Sex worker	-	-	-	-
PLHIV	-	2	1	3
Sero-discordant couple	1	-	-	1
Total per region	1	3	1	5

Table 2: Demographics of Life Story Interviewing team (Total = 5)

2) Life story interviews

The participants who were interviewed for the life stories were recruited in three distinct phases. The first, to practice interviewing skills and to pilot the question guide, was to interview other members of the team. The interviewing team was diverse, encapsulating very different life experiences, men and women of differing ages and from opposite ends of Malawi. The team also understood the rationale behind a life story approach, and as such their stories provided an important foundation for the collection.

The second phase involved snowball sampling at the discretion of the interviewing team. Three loose criteria were agreed to guide the selection of life story participations: gender, diversity of respondents (including working situation, gender, and age) and living with or closely affected by HIV. Each of the interviewers completed between 4 and 6 interviews according to their own selection.

The third phase involved purposive sampling to focus on case studies identified for follow-up based on the results from *The People Living with HIV Stigma Index*. This sample was generated from respondents and was then ranked according to key criteria (see Chirwa at al., 2011), looking for geographical diversity as well as those who had a key story to tell (an experience of stigma or discrimination) and who had indicated willingness to be

approached for a follow-up interview. During an intensive week in February 2011, David and I visited 9 people across the country. The follow-up interviews included a life story interview (if not already completed), a case study interview recorded broadcast quality to contribute to a radio documentary, focused questions specifically about the law, and a photograph. Participants could discontinue the interview at any stage. In total 42 life stories were collected, of which 20 have been selected for inclusion in the final analysis. The final selection of life stories included for analysis in this thesis were nominated and discussed by the team, and selection for inclusion was based on gender balance as well as life stories that were particularly different from the others, and also the personal satisfaction of the interviewer with the interview. There was no disagreement about which ones to include, as the lead interviewer's judgment was followed in all cases.

As part of the follow-up to the life story interviews, the participants were asked if they would like their photo taken and included alongside their story. Where possible I followed up on this, documenting both a profile as well as a photograph of the participant within their environment. Unfortunately due to some challenges of access (cell phone reception, the rainy season and many participants moving to tend to their gardens, and limited time) I wasn't able to follow-up with all the participants who wanted to be involved in the photo collection (almost everyone expressed an interest to be included!). Before each photo shoot, the use of the photos was explained and additional consent was sought specifically in relation to the images. During the photo shoot, if the participant didn't wish their face to be shown, a more artistic image was taken (for example in silhouette, from behind, or in abstract). Each participant was then asked which photo was their favourite, and where there was a preference, these images have been selected to accompany the story collection. The rationale behind including the photos alongside the life stories is the old idiom that "a picture is worth a thousand words," and participants appreciated the opportunity to share visual depictions of their life story alongside the verbal narrated description.

"The camera makes everyone a tourist in other people's reality, and eventually in one's own." (Sontag, 1974)

In all but one case, repeat interviews were undertaken over a period of 3 months. The maximum number of contact with any one participant was 3 interviews.

	Northern Region	Central Region	Southern Region	Total
Age				
< 25 years	-	-	-	-
25 – 40 years	2	1	3	6
41 – 60 years	4	4	4	12
>60 years	-	2	-	2
Gender				
Male	3	4	4	11
Female	3	3	3	9
HIV Status				
HIV positive	5	6	7	18
HIV negative	1	1	-	2
Location				
Rural (defined as village or remote setting)	1 (F)	1 (M)	1 (M)	3
Urban (defined as proximity to a city, including suburbs)	5	6	6	17
Key population group				
MSM	-	1	-	1
Sex worker	-	-	1	1
PLHIV	5	6	7	18
Sero-discordant couple	2	-	1	3

Table 3: Demographics of Life Story Respondents (Total = 20)

Code ¹	Born	Current region (at time of interview)	Diagnosed HIV positive?	On ART?	Other significant characteristics	Age at 31 Dec 2012 (years)	Time since HIV dx ²
1 MN	14 September 1971	Northern (Mzuzu)	2005	Yes	Workplace discrimination; celebrity	41	7
2 MN	16 March 1970	Northern (Rumphi)	2007/8/9	2007/8/9 (same)	Father stigma; self-stigma; family	42	5/6/7
3 MN	19 January 1965	Northern (Mzuzu)	2007	2007	Discordant relationship; JONEHA	47	5
4 MC	23 October 1950	Central (Lilongwe)	1994	2008	MANET+; AR team	62*	18*
5 MC	26 May 1968	Central (Dedza)	2006	Yes	NAPHAM chair	44	6
6 MC	1983	Central (Lilongwe)	No	No	MSM; ex-prisoner; didn't know father	29	n/a
7 MS	6 April 1958	Southern (Blantyre)	2003	2003	AR team	54	9
8 MS	1976	Southern (Blantyre)	2009	2009 (same)	Sister stigma; education	36	3**
9 FN	16 February 1975	Northern (Mzuzu)	No	No	Discordant couple; AR team	36	n/a
10 FN	8 October 1958	Northern (Mzuzu)	1995	2006	Activist	54*	17
11 FC	3 February 1963	Central (Lilongwe)	1988	2003	Activist; mother 2, grandmother 1	49	24*
12 FC	12 January 1971	Central (Salima)	2006	2006	COWLHA; single mother 4 boys; gender violence	41	6
13 FC	1973	Central (Dedza)	2008	Yes	FPAM; AR team	39	4**
14 FS	-	Southern (Zomba)	1999	No	Sex worker	-	13
15 FS	1966	Southern (Zomba)	1999	Yes	Author; academic; law commissioner	46	13
16 MS	10 February 1986	Southern (Nsanje)	2005	2005	Unemployed	26**	7
17 MC	6 June 1950	Central (Mitundu)	2004/ 2002	2004/ 2002	Arson story; family stigma; chief	62*	8/10
18 FN	1972	Northern (Nkotakhota)	1997	Yes	Land grabbing; chief and police	40	15
19 MS	14 July 1958	Southern (Nsanje)	2008/9 (tested twice)	2009	Discordant couple; self-stigma; stigma in relationship	54	¾
20 FS	28 March 1973	Southern (Mangochi)	2006	2006	Stigma in relationship; no teacher stipend; police and gossip	39	6

** Youngest/ least time since HIV diagnosis, identified within each gender group

* Oldest/ most time since HIV diagnosis, identified within each gender group

Box 2: Breakdown of life story participants' characteristics, age and time since HIV diagnosis

¹ As noted, the additional coded reflects gender and region e.g. MN = Male Northern; FC = Female Central etc.

² 'Dx' is an abbreviation meaning diagnosis, as at 21 Dec 2012 (years).

The youngest male interviewed was 26 years and youngest female 36 years; and the older men interviewed was 62 years (2 participants) and oldest woman was 54 years.

	Overall	Men	Women
Range (yrs)	26 – 62	26 – 62	36 - 54
Mean (yrs)	44	45	43
Median (yrs)	42	43	40

Table 4: Life Story participant's age (as at 31 December 2012)

In terms of time since HIV positive diagnosis, the longest time was 24 years (for a woman). Specifically for men, the longest time since diagnosis was 18 years. The most recent HIV diagnosis was 3 years (a male) and for a female it was 4 years.

	Overall	Men	Women
Range (yrs)	3 – 24	3 - 18	4 – 24
Mean (yrs)	10	7	12
Median (yrs)	7	7	13

Table 5: Life Story participant's time since HIV positive diagnosis (as at 31 December 2012)

3) Opinion Leader interviews

The third component of the empirical research involved key informant interviews with opinion leaders. The interviews were semi-structured based on a question guide workshopped and agreed by the Action Research Steering Group. I piloted the question guide and it was revised after the first 4 interviews (and subsequent follow-up interviews arranged with the first four participants). A total of 58 key informant interviews were completed during the 6 months, of which 36 were excluded or re-categorized for inclusion in the final analysis. Of the 58 interviews, 18 were with people living with HIV and the responses were incorporated alongside the life story interviews for those that were selected for inclusion; 10 were from Law Commissioners involved in the Special Law Commission on HIV/AIDS and have been separated out as their own notated group of participants; and 8 were excluded on the basis that the participants were either not senior enough in their organization to be considered an 'opinion leader' and/or someone else more senior from the same organization was included. In total 22 opinion leaders were selected for inclusion in the final analysis.

	Northern Region	Central Region	Southern Region	Total
Age				
< 25 years	-	1	-	1
25 – 40 years	4	14	4	22
41 – 60 years	4	22	5	31
>60 years	-	3	1	4
Gender				
Male	4	25	7	36
Female	4	13	5	22
HIV Status				
HIV positive	6	6	7	19
HIV negative	-	2	1	3
No known/ not disclosed	2	30	4	36
Location				
Rural	3	2	1	6
Urban	5	36	11	52
Key population group				
MSM	-	1	1	2
Sex worker	-	-	1	1
PLHIV	6	6	7	19
Sero-discordant couple	1	-	-	1
Total per region	8	38	12	58

Table 6: Demographics of total Key Informants interviewed (Total = 58)

	Northern Region	Central Region	Southern Region	Total
Age				
< 25 years	-	-	-	-
25 – 40 years	2	3	1	6
41 – 60 years	-	13	1	14
>60 years	-	1	1	2
Gender				
Male	1	14	2	17
Female	1	3	1	5
HIV Status				
HIV positive	-	-	-	-
HIV negative	-	2	-	2
No known/ not disclosed	2	15	3	20
Key population group				
MSM	-	1	1	2
Sex worker	-	-	-	-
PLHIV	-	-	-	-
Sero-discordant couple	-	-	-	-
Total per region	2	17	3	22

Table 7: Demographics of Opinion Leaders interviewed and included (Total = 22)

	Northern Region	Central Region	Southern Region	Total
Age				
< 25 years	-	-	-	-
25 – 40 years	-	2	-	2
41 – 60 years	-	6	1	7
>60 years	-	-	1	1
Gender				
Male	-	2	1	3
Female	-	6	1	7
HIV Status				
HIV positive	-	-	1	1
HIV negative	-	-	-	-
No known/ not disclosed	-	8	1	9
Key population group				
MSM	-	-	-	-
Sex worker	-	-	-	-
PLHIV	-	-	1	1
Sero-discordant couple	-	-	-	-
Total per region	-	8	2	10

Table 8: Demographics of Law Commissioners interviewed and included (Total = 10)

While all 100 interviews have informed my understanding of the issues, for the purpose of analysis I have categorized the interviews into three categories: Opinion Leaders (OLs, 22 participants, including politicians, directors of civil society organizations, and heads of department), Law Commissioners (LCs, 10 participants, specifically those directly involved in the Special Law Commission on HIV and AIDS chaired by the Malawi Law Commission), and people living with HIV (LS, 20 participants, including those who had given their life stories and then were interviewed in a follow-up session specifically on issues relating to the law).

The People Living with HIV Stigma Index in Malawi

Although it is not the primary focus of my analysis, the research draws on some of the quantitative data generated from *The People Living with HIV Stigma Index* in Malawi. This is to further strengthen analysis outlined from my qualitative research with reference to national responses generated during the same research period. The combination also further strengthened the complementarity of the data generated by the two processes.

The People Living with HIV Stigma Index in Malawi was rolled out in 2010-11, with 2272 participants from 15 districts around the country. The research used an international

questionnaire (already implemented in more than 25 countries around the world³) to establish baseline data about the experiences of people living with HIV of stigma and discrimination. The questionnaire primarily focuses on experiences within the last 12 months, so that when repeated, it will provide a useful measure to monitor change over time. *The People Living with HIV Stigma Index* is comprehensive and covers many more aspects than are drawn out in my analysis – I have chosen to focus on parts of the Index that are relevant to illuminate debates generated in response to the Special Law Commission of HIV.

The Report from *The People Living with HIV Stigma Index* concludes:

“It is evident that HIV related stigma and discrimination remains a potent stressor to PLHIV in Malawi, nearly three decades since the advent of HIV. The case study component demonstrated various lived experiences where PLHIV have faced abject discrimination at personal, household, community and institutional levels. Apparent in this study, stigma and discrimination are impacting negatively on aspects of prevention, care and treatment as these limit PLHIVs accessibility and utilization of health services thereby increasing the suffering associated with living with HIV.

Provision of ART, decreasing human rights violations and increasing practical-awareness about stigma and discrimination with an active involvement of all stakeholders and PLHIV is not only critical in the reduction of stigma and discrimination but also in slowing the impact of the epidemic. Integrating consistently and explicitly into AIDS programming stigma and discrimination preventive elements is pertinent in Malawi.” (Chirwa, Kamkwamba and Umar, 2011, p110)

On a national scale, the survey highlighted two aspects relevant for my research and approach: the first, that several of the areas identified in the life story interviews also emerged in the qualitative sections at the end of the questionnaire (which were not explicitly asked about in the questions. For example there was a section at the end of the questionnaire that included open-ended spaces for people to comment about their experiences in a health setting. The results from the Stigma Index showed that similar issues emerged at a national scale as those from the life stories (presented in chapter five) such as concerns about lipodystrophy, experiences of gossip in waiting rooms, and access to quality ARVs. The second, that the MIPA principles can be modelled and implemented at a large scale in a national scientific survey by and for people living with HIV.

³ In 2012, *The People Living with HIV Stigma Index* has been and/or is currently being undertaken in more than 44 countries internationally. In 2013 it is reported that more than 70 countries have now rolled it out.

ANALYSIS

An inductive analytical approach was undertaken based on 5 central areas of inquiry (Maykut and Morehouse, 1994, 126; Lincoln and Guba, 1985). The 5 areas were deduced from the research questions as well as from emerging results from the interviews, in an iterative process, and in conversation with the action research and life story interviewing team. Given the nature of the research and the extended time span of my data collection process, I both consciously and subconsciously used a “constant comparative method” in all stages of the research process (Glaser and Strauss 1967, cited in Maykut and Morehouse, 1994, 134; Walker and Myrick, 2006; Bryman and Burgess, 1994).

Initial ideas for analysis were discussed with the Action Research Group, the Life Story interviewing team, and with the Department of social science at the University of Malawi in March 2011. The 5 areas are generally the breakdown of chapters five, six, seven, eight and nine, including the meaning of HIV in everyday life, understanding stigma, the meaning of law in everyday life, criminal justice, and reflections on the process of the action research. The interview transcripts and notes from the action research meetings (including transcriptions from the meetings, notes, research diaries and reflective SMSs and emails) were also reviewed and thematically analyzed according to these 5 areas.

Where relevant, I have focused on critical incidence and unusual responses to add depth and insight to the analysis (Cohen *et al.*, 2000). I followed the advice of Maykut and Morehouse (1994) and equipped myself with pen, pencil, scissors, glue, highlighters, coloured chalk, and an open mind. I initially attempted to code the data using Nvivo software, however after an initial trial period I reverted to using crayons, colours and sticky notes to code and re-code the data. This at times included writing over, in different colours, aspects of my analysis to also record and reflect my evolving ideas over time (cf Marshall, 2001). The responses on the specific themes were first extracted from the complete interviews and listed, in sequential order, and grouped according to participant group (LS, OL or LC). Analysis was subsequently done within participant group as well as thematically across all interviews.

While the process of analysis in qualitative research is a constant and evolutionary process, I also agree “it is difficult to make a clear-cut distinction between the process of analysis and the process of writing up” (Potter and Wetherell, 1994, 64). Although many of the key ideas and connections emerged throughout the process, it was not until I had to

first present them and then write them in some kind of coherent report that the main ideas, concepts and patterns all began to link together to form a web of meaning. As Oakley (1994) commented, there are serendipitous connections to be made if one is open to them, and throughout the qualitative research process and I (and the process as a whole) have tried as much as possible to be open to these ideas, while also discussing them iteratively amongst the action research team and with other colleagues.

PRESENTATION OF RESULTS IN THIS THESIS—A grounded theory approach

It is a methodological approach and a presentation of the research results in this thesis that seeks to engage the hearts, minds and self-reflective inconsistencies of complex real lives of many different individuals from within and sitting between different community groups, including but by no means emphasizing my own. While I will offer my own interpretation and make connections between the stories and findings, to explore dimensions of the hegemonic and the subversive in the narratives (Ewick and Silbey, 1995), I also let the words, perceptions and stories speak for themselves in the presentation of the research findings in this thesis. This is consistent with ensuring trustworthiness in the presentation of results, as Lincoln and Guba note, it is best to err on the side of over-inclusion and provide a clear audit trail of results (1985). This presentation style is consistent with a grounded theory approach (cf Ife, 2010; Sandelowski and Barroso, 2003; Lincoln and Guba, 1985).

The results presented in this thesis span the three typologies of qualitative research described by Sandelowski and Barroso (2003) in their review of qualitative health research relating to women living with HIV. In this thesis, chapters four and five could be considered as presenting a thematic survey of the qualitative results, in their attention to describing key findings in relation to the context of Malawi (description of society) and personal histories among the life story participants (description of self). Chapters six, seven and eight could be considered as conceptual/ thematic descriptions, in that they include descriptions with a more in-depth reflection about the potential conceptual implications and transferability of the issues analyzed according to the three revised—grounded—research questions. The final typology – that of interpretative explanation – applies to the normative conclusions summarized in the concluding chapter of this thesis.

The images from the research have been included throughout the presentation of results to honour the spirit of experiential interaction among the team and the dynamics and physicality of the interviews themselves. Consistent with principles of action research and naturalistic inquiry, it adds another dimension to include a range of different methods of inquiry spanning the experiential, aesthetic and presentational (cf Heron and Reason, 2001).

While following the structure of the research questions, the presentation style also strives to honour the ideal that hearts and minds need to be engaged to effectively open up spaces for reflection and dialogue in order to understand and overcome stigma. In so doing it also links with quotations and poetry (some of which was composed by one of the life story interviewing team, George Kampango) to also convey some of the broader meaning of the concepts and ideas.

Through the emic and inductive approach and broad inclusion of research findings included in this thesis, I have adopted a grounded theory approach in both the presentation of the findings as well as in drawing the interpretative conclusions from the research results.

VALIDATION AND FEEDBACK

All interviews were transcribed verbatim, with the exception of one of the follow-up interviews (with LS 8, who has a stutter so the quality of the recording left many of his sentences inaudible). Where possible, a copy of the transcript from the interview was shared with the participant and their feedback sought. This was not possible for some of the life story participants who lived in remote areas and there were challenges in terms of a) providing a copy of the transcript back and b) of it being accessible to them in terms of literacy in a language (English) that they may not be comfortable in. As much as possible, follow-up phone calls or emails were sent following the interviews to check if the participants would like to add or change any aspects of their interview.⁴

At the end of collection meeting, one of the life story interviewers suggested that an audio copy of the interview be made available to all of the life story participants who had shared their story. However the most feasible way to achieve this has not yet been

⁴ Few participants responded to this opportunity. And of those who did, only a minority added or suggested changes to the interview. Where this occurred, all communication in relation to the research was included for analysis.

resolved, given that many of the participants only have access to radio rather than to a cassette or CD player.

Copies of the photographs taken alongside the life story interviews have been given to the participants for their record wherever possible. Again, for the participants in the hardest to reach areas this has not yet been possible.

The initial findings and themes for analysis were reviewed and discussed among the action research group and life story interviewing team in group meetings between October 2010 – March 2011. Additional clarification of ideas and direction was attained through on-going email dialogue as well as the drafting of collaborative and co-authored publications (such as a book chapter published in 2013, an article submitted following a conference presentation to the Journal of the International AIDS Society, and preparation of abstracts and posters for conference presentations).

External opportunities to review and discuss initial findings included the presentation of the evolving results in two 'brown bag' lunchtime sessions at IPPF (London office), and more formal presentations at the International AIDS Conference for AIDS in Africa (ICASA, Addis Ababa, Ethiopia, December 2011) (Annex 11); at the Socio-Legal Studies Association Conference (Leicester, UK, April 2012) and the International AIDS Conference (IAC, Washington DC, USA, July 2012) (Annex 12). The National AIDS Commission of Malawi requested the two presentations from the IAC at a national research and dissemination meeting in November 2012 (Ruth Kundecha and George Kampango each presented the research findings, see Annexes 13 and 14).

The final results were disseminated in a summary policy brief emailed to all key informant participants in May 2013 (Annex 15), and other key stakeholders such as the SADC parliamentary forum, UNDP Malawi and the Malawi Law Commission. The results were discussed with the action research life story interviewing team at a meeting in Lilongwe on Tuesday 7 May 2013. Copies of the final thesis will be given (along with everlasting immense gratitude) to all members of the life story action research team, and for archiving in the secretariat of the Family Planning Association of Malawi (FPAM), and the country offices of UNAIDS and UNDP in Malawi.

POSITIONALITY, REFLECTIVITY AND POTENTIAL BIAS

In the spirit of action research, naturalistic inquiry and feminist research, in this section I am transparent about my own lens as a researcher and I present how I understand stigma (Lincoln and Guba, 1985; Marshall, 2001). I reflect on my position in relation to the central themes of this research, reflections about my life and its influence on the research process, and outline my awareness and mitigation of potential bias in the research process.

The approach I adopted for the methods, questions asked, and the composition of the action research team were all closely linked with and informed by *The People Living with HIV Stigma Index* in Malawi. As noted, prior to this research, I had been working to mentor the development of the proposal for implementing the Index in Malawi through my role as HIV Officer with IPPF. It was in this capacity that I first met David Kamkwamba, one of the co-investigators for the Index and Chairperson of the National Network of Journalists Living with HIV and AIDS (JONEHA), while facilitating a regional training workshop to catalyze the roll out of the *Stigma Index* held in Nairobi, May 2008. In many ways it feels lucky that I chose Malawi or that Malawi chose me.

A friend advised me, when I was finalizing my decision about which country to choose for the case study, that the kind of introduction I am given—to the place and to the people—makes all the difference (cf Heron and Reason, 2001). I think she was right, and I was fortunate to have a very warm welcome in Malawi. At the first Stakeholders meeting, attended by representatives from leading HIV organizations, policy makers, donors and healthcare professionals in Malawi, David introduced me as follows:

“I am glad to introduce Lucy, and I think we can clap hands for all these people [applause]. Clap your hands. Sometimes I like to say she looks so ordinary but she has a big head [laughter]. Since I met her in Nairobi she is such a wonderful person and when we didn’t know what she was doing for Malawi. I mean when you have people who can do things for you I think it’s really pride worthy... So we became more confident that Stigma Index would be done. So we are very thankful, and I am sure it’s the feeling of every Malawian beyond who is here. You have the gratitude of Malawi behind you. So we very much appreciate that Lucy.”

[Lilongwe Hotel, Lilongwe, 22 October 2010]

In my notes in the margins, I had also comments on the experience from the Taskforce meeting the previous day:

“I feel very privileged to be here, reading some of my own words recycled in Terms of Reference for the Taskforce, having very much of a back seat. I feel proud. It has been a long journey since May 2008. Way to go David!”

[MANET+, Lilongwe, Taskforce meeting, 21 October 2010]

I was very fortunate in my introduction in Malawi, and the synergies between work and research, and past and present connections, helped to create a strong and ethical foundation for this action research process.

A touch of irony and humility

As someone who is not living with HIV, and passionately committed to the principles of participation, I find myself in an ironic and at times uncomfortable situation. According to the principles and approaches of my methodology, it would be more consistent for the person undertaking this research to be from Africa and living with HIV.

Goffman (1963) divides the support sought by people who experience stigma into two types—support from other people who share that common experience of stigma, and support from “wise” people who empathize without directly experiencing it (p 41).⁵ The notion of “wise” (although seemingly presumptuous as a word) struck a chord with me, since the emphasis on the importance of being accepted as well as reaching out seems to capture a sense of humility, hesitancy, privilege and reciprocity that maintains recognition and respect for the value of lived experience (in this case twofold, the experience of receiving an HIV positive diagnosis and living in Malawi).

Although Mies (1983) might have overstated the duty of feminist researchers to integrate “their own experience of oppression and discrimination into the research process” (p68), I see my position as paradoxically both central and peripheral to the

⁵ The complete quotation from Goffman (1963, p 41) is below. Despite using horribly stigmatising language (!), Goffman outlines a framework for the difference between ‘in-group’ support and solidarity for people living with HIV to overcome stigma and ‘out-group’ support from people who empathise—the key being the offering and acceptance of that support from someone ‘outside’ the group. He writes: “I have considered one set of individuals from whom the stigmatized person can expect some support: those who share his stigma and by virtue of this are defined and define themselves as his own kind. The second set are—to borrow a term once used by homosexuals—the ‘wise’, namely, persons who are normal but whose special situation has made them intimately privy to the secret life of the stigmatised individual and sympathetic with it, and who find themselves accorded a measure of acceptance, a measure of courtesy membership in the clan. Wise persons are the marginal men before whom the individual with a fault need feel no shame nor exert self-control, knowing that in spite of his failing he will be seen as an ordinary other. ... Before taking the standpoint of those with a particular stigma, the normal person who is becoming wise may first have to pass through a heart-changing personal experience... And after the sympathetic normal makes himself available to the stigmatized, he often much wait their validation of him as a courtesy member. The self must not only be offered, it must be accepted” (Goffman, 1963, p 41, my emphasis).

research process. The combination of a 'feminist' and participatory approach means that although my own background and professional experiences will influence both the process and product of the research, so too will the ideas and priorities of the action research team of co-inquirers and indeed also of the participants. My approach is feminist in the sense of privileging 'subaltern' voices—that is voices that might otherwise be overlooked within unequal power structures in society (not only patriarchy, but also relating to wealth, geographical location, and literacy):

“Feminists don't need a doctrine of objectivity that promises transcendence, a story that loses track of its mediations just where someone might be held responsible for something, and unlimited instrumental power. We don't want a theory of innocent powers to represent the world, where language and bodies both fall into the bliss of organic symbiosis. We also don't want to theorize the world, much less act within it, in terms of Global Systems, but we do need an earthwide network of connections, including the ability partially to translate knowledges among very different—and power-differentiated—communities. We need the power of modern critical theories of how meanings and bodies get made, not in order to deny meanings and bodies, but in order to build meanings and bodies that have a chance for life.” (Haraway, 1988, p 580)

Beyond feminist however, my stance is participatory, in essence striving to invert the power relations in more traditional research approaches by “handing over the stick” of the process to facilitate a research process that is meaningful in its own right, driven by the priorities of the participating individuals, and illuminative of ideas identified and important to (and potentially not thought of by myself) the participants (Chambers, 1997).

Positionality

In this section I reflect on the practice of research, my place within it and the construction of the fields of inquiry presented in this thesis (May, 2011).

How or why did I become focused on stigma? Like stigma itself it is difficult to pinpoint. But for many years I have been interested in a range of things that essentially concern individuality and are nevertheless connected with the wider social, cultural and structural environment. As an educationalist, I have been interested in informal learning and how to teach in a transformative way that engages the heart as well as the mind. As an activist, I have sought to listen to people most affected and support efforts to eliminate inequality and barriers to justice. As a manager, I have developed projects done in partnerships with people living with HIV in many corners of the world, learning from experiences and stories that both separate and unite. As a friend, I have listened, worried

and supported through the ups and downs of life's rollercoaster including moments of testing, diagnosis and treatment challenges. And finally, or perhaps first and foremost, as an individual I have loved, cried, worried, been tested, judged, been judged and overcome challenges (some more quickly than others) as I navigate through my own life journey.

I am passionate about alleviating stigma – and also about open-mindedness, justice, and human rights for all. In my opinion, stigma is at the heart of determining how we can triumph over the transmission of HIV and provide suitable care and support to those living with HIV. Stigma is very different from discrimination, in that it is quintessentially subjective and difficult to articulate or measure – where discrimination is an action that could be more objectively observed and/or verified, stigma is profoundly an experience within the eye of the beholder. To answer one of the questions I asked many participants, how do I understand stigma? Stigma to me is a shadow – one that casts darkness over someone's sense of self and their own value, and one that equally can shade how others are perceived. It is also a shadow out of which anyone can step, and likewise, help others to do the same. My passion for stigma does not however mean that I seek out stigma or impose it as a lens to interpret other people's experiences. Rather it fuels determination to better understand if, how and when stigma is experienced; what factors foster resilience against experiencing stigma; and what actions can be taken to overcome and alleviate the negative personal impact that stigma can trigger.

I have chosen three quotations from the life stories that crystallized my own thoughts about a theme that also resonated with my commitment to a self-reflective action-oriented process. The first, a professional motivation as a manager and researcher, to find a more grounded, effective and relevant way to address stigma within our workplaces and projects:

“We need to address stigma. We need to find a way of talking about it and not just talking about it as a job but something that is part of us.” (OL8)

The second, a thematic motivation to interrogate the relationship between the actions and perceptions of stigma, and how they both intersect with identity:

“Stigma is the self feeling you are feeling which you have because of things which have happened to you or because of the things which you are.” (LS6)

And the third, a personal motivation relating to agency, and an acknowledgement that the both the sources and solutions for stigma start from within:

“I understand stigma as something which is – which starts from within. It can start *by me.*” (LS12, my emphasis)

These quotations resonated closely with me and my values. I was conscious of this resonance during the interviewing process but it was only in the processing of these ideas through my writing in my research diary and in the subsequent data analysis process did the connection become clear. I have include these examples to illustrate the iterative cycle between the interviewing process (in which my role was primarily to listen, document and enable the conversation), my own self-critical reflection through my research diary and conversations with others in the action research team, and generating conscious notions of key themes in this research (in this example, relating to stigma) that formed the basis of the results presented in this thesis (cf Marshall, 2001).

Reflexivity

In this section I include some reflections about if or how my position and experience with stigma is related to the process, results and outcomes of the research presented in this thesis. My more in-depth life story is included as an afterword. The collision of my personal values and professional experience most explicitly influenced the research presented in this thesis in two critical ways: first, the thematic focus on HIV, stigma and the law; and second, the participatory, action-oriented and reflective methodology undertaken.

What is relevant and important about me that might have influenced how I carried out this research? I am a young, single, open-minded Australian woman who was both a professional (a project officer and manager with IPPF supporting the rollout of *The People Living with HIV Stigma Index* in Malawi) and doctoral student (conducting the research presented in the thesis) throughout the period of data collection. These are labels I have chosen to give to myself, as it is all a matter of perception – for example in Malawi, I could have been considered middle aged given the relative life expectancy in that country compared to Australia or the UK (I was 30 years old at the time). The combination of the two roles – as a professional and as a doctoral student – was complementary and helped facilitate my connection to many of the key informants and members of the action research team. I was always very clear when I introduced myself in a meeting if I was participating in the meeting in a professional capacity or when I was there as a student conducting my doctoral research.

I consider myself to be quite a private person. While the data analysis and process of working closely with the other five members of the interviewing team was intensely personal and reflective, I tried to be as consistent in the information and my own presence in the process of conducting the interviews as possible. In the course of the interviews most participants would be introduced to me in my research capacity, and of course what could be observed about me and my background in the interview. This was not to deny the presence of the personal in each and every interview, but rather to try to militate against any potential bias that could result from my own identity and circumstances of the interview (further details discussed in the following section).

There was however a conscious exception – among the action research life story interviewing team – given that our team and individual reflection meetings would at times become very personally reflective (cf Brydon-Miller and Greenwood, 2006; Heron and Reason, 2001). In the first meeting of the action research life story interviewing team we deliberately situated ourselves within the journey of this research process through an activity called “rivers of life”. In this activity each participant drew a “river” that symbolized the journey of their life, key moments where the river had turned or changed direction, and that had influenced their arrival as part of the team associated with this research (see image 4). This was significant in the process of the research for three main reasons—the first, it helped introduce the team to each other by establishing a tone of self-critical reflection and created a foundation of trust among the group; the second, it helped to introduce me and establish a legitimacy for my interest in HIV-related stigma in Malawi; and third, by having gone through the process ourselves, it introduced a consciousness about the process of sharing a life story that aimed to prevent an objectification of the participants we each then interviewed.

Potential bias

Conscious effort was made throughout the research process to identify possible bias through frank and open conversations, research diaries and critical reflection. This was particularly important given the deliberately subjective nature of the data collection process and core data set – founded in individual reflections and life story interviews.

Given the rigorous approach to informed consent adopted by the action research life story interviewing team, all participants were fully aware that this research was about stigma and the law relating to HIV. The potential bias this could have triggered was

mitigated by the questioning approach adopted for all the interviews—one that started with general questions to first make the participant at ease and comfortable in starting their description of their life from a point of their choosing. As shown in the life story interviewing question guide (Annex 9), the first questions were always enquiring about how the participant felt on the day of the interview and with a very broad question asking them to describe their life (sometimes also including prompts to reflect on childhood, schooling or family life to help trigger the description). This was a deliberate sequencing of questions, that I had initially proposed, was discussed, reviewed, revised and agreed by the action research life story interviewing team at the first meeting (October 2010), to try and ensure that the participants would tell their life stories from an open mind – one founded in the memories of their childhood and early life experiences, rather than one where the starting point was founded in the central areas of inquiry of the research.

I adopted an equivalent approach in the interviews with the key informants, by first starting the interviews with a question asking them to introduce themselves and their experiences, as well as some broad questions about the most pressing concerns in the national response to HIV, before continuing with specific questions about HIV-related stigma and the role of the law in Malawi (see Annex 10).

Among the action research team, based on our own self-critical reflections and sharing of life experiences in the review meetings, we were aware of each of our positions in relation to stigma. As a group, there was a mixture of people who described experiences of stigma within their own life stories (3 members of the team) and those who could identify where stigma occurred but felt that it was something that they had ever directly experienced (3 members of the team). I fall into the second group, as someone who has not directly experience stigma relating to any aspect of my identity, but like the other 2 in this group, I can identify moments where it could have occurred. Our personal experiences and perceptions was actively discussed in the life story training process as well as in the mid-point collection meeting, as well as the individual review meetings, to ensure that the team were always alert to the possibility of if and how these might influence the interviewing process. The verbatim transcription of all interviews also provided a rigorous source to check and validate the questioning process, so that answers given by participants were always analyzed in the context of the questions to which they were responding. For example as part of the training in the life story methodology, I individually visited each of the interviewers after they had completed one interview in the

weeks following the initial training I conducted on the data collection methods in October 2011. At that time each of the other life story interviewers had completed a full interview and transcript, which we reviewed together, discussing key themes emerging, what the process had been like for the interviewer. I noted any areas for improvement in questioning approach (such as asking more follow-up questions to get additional depth in the responses, and/or not asking leading questions) and discussed these with of the action research interviewers individually.

In undertaking this research, we were not looking for experiences of HIV-related stigma. Rather, by taking a life story approach, we were seeking to document and understand the experiences of living closely with HIV in the context of someone's life, and then equally to analyze experiences of stigma, recourse or redress sought as well as incidents where stigma could have occurred but was averted (for example, when it could be judged to have occurred by another person, such as the interviewer, but where the participant did not identify that moment as one in which they had experienced stigma). As noted earlier in this chapter, this formed the basis of a critical incident approach to data analysis that forms the basis of the results presented in chapter six.

In a similar vein, to ground the interviews in the participant's own understanding of the law (not one imposed by the interviewer), as the conversation moved towards the legal questions the participants were asked first to explain their perception of the law in the national response to HIV in their own words. Often this included elements of the customary and formal legal system, and at times also aspects of policing and law enforcement. The individual's notion of the law then became the foundation for the conversations about law in the remainder of the interview (see chapter seven). We did not presume that participants had any understanding or engagement with any legal system. In this way the research presented in this thesis allowed for pluralistic concurrent conceptualizations of law as well as none at all. The research also complements the testimonies collected for the national and regional dialogues for the Global Commission on HIV and the Law where the starting point was based on people's experience (i.e. presumed legal consciousness) of the law and HIV, rather than as in this thesis, where the methodology also allowed for an absence of legal consciousness. I have tried to compensate for bias (at least to recognize and identify where it occurs most) by combining methods (life story and key informant interviews, and action research reflection discussions) to ask similar questions as well as to include repeat visits to the same

participants to check for change of opinion over time. The documents reviewed (such as the Constitution, and the Report from the Special Law Commission on HIV and AIDS) were also used as a trigger for questions in the opinion leader interviews as a common reference point. The combination of interviewing approaches—the more loosely-guided life story interviews alongside the more directed key informant interviews – also sought to test dominant themes and check for validation on common issues (see Annexes 9 and 10).

The London International Development Centre (LIDC) at the University of London funded this research through a Bloomsbury Studentship, did not influence the process of results from the research presented in this thesis. The research was undertaken without any conflict of interest.

The sustained guidance from my thesis supervisors at the University of London (SOAS and Birkbeck College) and the Centre for Social Research at the University of Malawi, as well as from the action research team, provided a continuous feedback loop to contribute to ensuring the rigour of the research process and validation of the results.

CHALLENGES

The research—like any process grounded in real life experiences—was not without its challenges.

Diversity of participants

One of the challenges was ensuring a diverse range of participants. I proactively sought the involvement of key populations (such as men who have sex with men and sex workers), for example through the involvement of representatives of support organizations in the action research group and through the configuration of the life story interviewing team. Gender, age, reaching rural as well as urban communities as well as other aspects of identity (such as education level, sexual orientation, employment status, and religion) were taken into consideration in inviting participation at all stages in the action research process.

Consideration was given also to the selection of life story participants to include those living closely with HIV (not only those living with HIV) such as partners in sero-discordant relationships. The most challenging group to reach out to was young people; this would have been easier had the capacity of the young person who attended the life story interviewer training been suitable to continue with the interviews.

The life story interviewing team members were self-critically aware about the voices included and we reviewed the diversity of the range of participants at the mid-term review meeting as well as through individual check-ins.

Terminology

In the local languages in Malawi, there is not a clear word to differentiate between stigma and discrimination like there is in English (cf. Chinouya and O'Keefe, 2006).⁶ Even though many of the interviews were conducted in English, this is a limitation in terms of analysis, since it is not possible to attribute the lack of clarity expressed by participants to language barriers or to a lack of understanding of the difference between the two concepts.

Transcription

To facilitate the comfort and handing over of power in the interview process, my intention had been to enable participants to respond in the language that is most comfortable for them (and paired with an interviewer who is also comfortable in that language) (cf. Bennett, 1999). The interviews I conducted were all in English; however the life story interviewing team were fluent in a range of local languages including Yao, Tumbuka and Chichewa. However the additional time for translation in the transcription process, and the self-selecting nature of the life story participants by the life story interviewers, meant that after the first round many of the life story interviews were conducted in English (at the choice of the interviewers). The exceptions were those participants in the very rural areas, most of whom had been identified for follow-up interviews through the identification process from *The People Living with HIV Stigma Index*.

Sensitivity

Recognizing that HIV touches on topics that people often don't want to talk about (such as intimate behaviours, sexual relationships and other topics that may be considered taboo), and similarly that stigma touches on personal values, beliefs and morals (in all

⁶ As noted, in Chichewa however it can be difficult to distinguish between stigma and discrimination, so for the life stories that were conducted in Chichewa or Tumbuka and then translated into English (n=9), this may have contributed to the high number of participants who have stigma and discrimination in their responses (see chapter 3, Methodology, for further details about the translation of interviews) (cf Chinouya and O'Keefe, 2006).

their potential inconsistency), at times it was challenging for the team to establish spaces where participants felt comfortable and safe to share their experiences and perspectives openly (cf Cornwall and Welbourn, 2002).

We anticipated this challenge, and in the interview training reviewed the sequencing of the questions (for example starting with the concrete/ descriptive and following-up with questions that are more emotive, analytical or reflective), shared ideas about establishing rapport with participants, discussed empathetic and active listening, and recognized the importance of acknowledging emotions in the interview process.

Self-critical awareness

An on-going challenge throughout the research was not assuming that because we were researching 'stigma' that we were all automatically liberated from our own judgments and pre-suppositions. The interviews did provide a mirror up to ourselves, and we discussed the challenges of tapping into attitudes and behaviours that participants (and indeed ourselves) might not be aware of ... that is potentially the presence of stigma beyond the conscious.

Using my own experience as an example, I am aware in retrospect of interviews where I felt more or less comfortable, and more or less agile in responding to the dynamics of the interview. Things like weather, mood, and time of day affected this for me as much as for the participants. This may constitute a limitation of this research project, as with all qualitative research, and all the more so because of the prominence of self-critical reflection as part of the action research process. I have not tried to offset this possible deviation through the inclusion of more psychoanalytical methods (such as by including participant observation or discursive analysis) in the analysis process, since that would undermine the core ethos of my research design as participatory and empowering for participants. However I have tried to be as transparent about the 'audit trail' as possible and all members of the interviewing team recorded critical incidents and reflections on each interview in a research diary.

Commitment and motivation of interviewing team

With Julius Nyerere in mind (Shivji 1989, op cit), another challenge related to sustaining the engagement and commitment of the action research team and peer-interviewers in the research process. The core team remained committed and motivated

throughout, genuinely interested in the results of the research and knowing more about the outcomes from the analysis. However given the “burdens” of participation and limited compensation available, as well as the juggling act that the team was doing to make time for this work amidst very busy daily lives, timelines slipped and the transcription in particular took longer than anticipated. Likewise for myself, my early departure from Malawi and other life concerns meant that I also was delayed in delivering some of the stages of a fairly ambitious timeline for the research.

LIMITATIONS

The research is rich in depth and detail, and is indicative. It recognizes its limitations and the presence of the researchers as an integral part of the process. The main limitations are outlined below, and also the strengths, since many of the limitations are the flip side of some of the strengths.

Following the framework established by Lincoln and Guba (1985) and further described by Shelton (2004), the research is credible, transferable, dependable, and to an extent confirmable⁷, and as such as be considered trustworthy in its contribution to knowledge as well as rigorous as a specimen of naturalistic inquiry.

Insider interviewing approach

The majority of life story interviews were completed by 'insiders' – proactively—to try to equalize the power dynamic in the interview, facilitate peer learning and sharing through a “side-by-side” interviewing technique, and to enable the participant to feel comfortable and open during the interview.⁸ This approach generally was successful in achieving these intentions, however on two occasions members of the action research team reflected that it may have in fact made it more difficult for the interviewer to open up completely since they had common connections and knew some of the same people.

To validate the interviews, I personally met and did as many follow-up interviews as possible. All of the 20 included in the final analysis had at least 2 points of contact with the research team – with one of the life story interviewers, and with me.

⁷ Triangulation and reflexive journals were undertaken as part of the research as already noted, and the details for an audit trail presented, which meets three of the four key criteria for confirmability in Lincoln and Guba’s framework (1985). However within the scope, timeframe and primary purpose of independent doctoral research, it is not feasible to also undertake the fourth stage of an external audit process.

⁸ This is modelled on the approach promoted by *The People Living with HIV Stigma Index* (IPPF, GNP+. ICW and UNAIDS, 2008).

The presence of the personal

By design, the interviews were designed to be subjective and emotionally evocative for the participants as well as the interviewers. As Reason and Bradbury note, “relationships, practical outcomes, extended ways of knowing, purpose and enduring consequence, are quite demanding on action researchers,” but this is compensated for by the fact that action research is emergent and focused more on one broad issue over another along the way (Reason and Bradbury, 2001, p 449). The critical reflections and insights from the team were invaluable in deepening the analysis of the results (Brydon-Miller and Greenwood, 2006).

This process is valued as part of the iterative analytical discussion. Yet as a check and to identify the extent to which this may have excluded other important themes, key contacts were contacted to review the outline and summaries of key findings as a final review and validation process (Bell, 1997).

Oral history

The limitation of oral history is that it is dependent on memory, and recollection, as told at a fixed point in time. The framing of the story is influenced by mood, time of day, and other factors that affect the frame of mind and comfort levels of the narrator (cf Bennett, 1999). Another concern is the “presentism” of oral histories in that they often view past events in light of current concerns (Khalili, 2007).

The results were triangulated with the findings from *The People Living with HIV Stigma Index* (restricted to the 12 month time period immediately before the time of interview, i.e. 2009 – 2010). As presented in chapter four, for example, the results from *The People Living with HIV Stigma Index* relating to law, consciousness of the national policy and international human rights frameworks (in this case the UNGASS Declaration) and seeking legal redress were reviewed and compared with the central findings emerging in this thesis. Unfortunately the *Stigma Index* did not explicitly ask participants about their knowledge and/or experience of the Special Law Commission on HIV and AIDS not the proposal draft HIV Bill. The results analyzed in this research were also triangulated with other available literature including other national studies of HIV, stigma and the law in Malawi (or aspects of these), as well as UNAIDS, NAC and other civil society position papers relating to the issues of HIV, stigma and the law in Malawi. As noted earlier, the focus of the literature presented in chapter two as well as the results presented in this

thesis is to enable a grounded theory approach for the analytical basis of the results presented.

Sampling limitations

The analysis draws on a foundation of 100 in-depth qualitative interviews, with targeted analysis on 52 of these (including 20 with people living with HIV; 10 with Law Commissioners; and 22 with Opinion Leaders). Good representation was achieved between gender, region of Malawi, age and sexual orientation. Religious affiliation was not a question that was asked of participants.

In terms of representativeness of people living with and most affected by HIV in Malawi, the life story collection includes at least one story from most of the groups most affected: women, mothers, men, sex workers, men who have sex with men, and young people. In addition the collection includes a cross-section of participants currently living in all three regions of Malawi (noting that some had migrated during their life time, originating in a different part of the country). One limitation however was to include the life story of an openly HIV positive man who has sex with men. All of the 6 participants who identified as MSM who were interviewed for this research were either HIV negative or did not know or disclose their HIV status.

In terms of the Opinion Leaders, it was possible to achieve a good range of depth and breadth for the sectors and perspectives included, spanning multiple institutions involved in health, human rights, and the law in Malawi. However efforts were made to also interview representatives from four other pillars of the community, namely the arts, the trade unions, the traditional leadership, and the Malawi Business Coalition against HIV/AIDS. Unfortunately it was not possible to complete these interviews during the period of data collection.

I have taken these limitations and possible biases into account when considering the implications of this study, and perceive the contribution of this research as highlighting conceptual and thematic areas for further research, as well as showcasing the strengths and weaknesses of an action research initiative applied in the specific context of human rights, stigma and HIV in Malawi.

CONTRIBUTION OF RESEARCH

The research makes significant contribution in five main areas: first, conceptual, by inductively generating a theory of law and jurisprudential insight informed by the lived experiences of individuals and communities; second, contextual, and potentially political, by building a significant collection of evidence from specific community groups not often asked about their perceptions of law and access to justice; third, methodological, as an action research initiative focusing on legal consciousness to bridge legal and social science research (an approach that has to date mostly been limited to studies within North America); fourth, applied, social and economic, by generating analysis with the potential to inform more effectively targeted community interventions and policies to enable access to justice and ‘good’ governance; and fifth, personal, by raising consciousness within and among the collaborative action research team(s), enabling sensitization to intersection of ethnicity and HIV, and ‘transformative’ reflections at multiple levels. These are reviewed and interpreted in more depth in the concluding chapter of this thesis.

PERFORMATIVE AND IMPURE: REFLECTIONS ABOUT THE ACTION RESEARCH PROCESS

“No action research project can address all issues equally and that choices must be made about what is important in the emergent and messy work of each action research project.” (Bradbury and Reason, 2001, p 454)

The final section of this chapter explores the extent to which a participatory process of exploring a human rights concern (in this case stigma relating to HIV) can contribute to protecting human rights for those directly involved. In light of other approaches to stigma reduction, that have tended to focus solely on a participant’s HIV status, this chapter also examines if this research methodology models – as one based on a holistic sense of self and life stories beyond moments explicitly relating to HIV – an effective approach for reducing stigma. In addition to the review of the trustworthiness of this research as a naturalistic inquiry (Shenton, 2004; Lincoln and Guba, 1985), this final section evaluates the integrity, quality and validity of the research explicitly as action research.

Reflections from the action research process offer an opportunity to hold a mirror up to nature. It challenges us all—practitioners, policy makers, advocates, and people living with HIV—to recognize that people living with HIV are not a homogenous group and

to critically question pre-conceived notions about the process of research (participation, consultation or extraction) and the role of the law, everyday life, and the national response to HIV in Malawi. Olav Eikeland has suggested that action research is normative in that it enables people to safely “*observe, tell, understand, and change what is actually done by power, neighbours, colleagues, themselves, or anyone, not only espouse declarations of values, but the details of actual practices and events...and the possibility to learn individually and collectively*” (Eikeland, 2006, p 232, original emphasis).

Following a framework developed by Bradbury and Reason (2001), five “choice-points” are outlined for reviewing quality are outlined in Table 9 below, which provides the framework for the reflections on the research and learning process that follow.

Is the action research:
1) Explicit in developing a praxis of relational-participation?
2) Guided by reflexive concern for practical outcomes?
3) Inclusive of a plurality of knowing? - Ensuring conceptual-theoretical integrity? - Embracing ways of knowing beyond the intellect? - Intentionally choosing appropriate research methods?
4) Worthy of the term significant?
5) Emerging towards a new and enduring infrastructure?

**Table 9 Choice-points and questions for quality in action research
(Based on Bradbury and Reason, 2001, p 454)**

This chapter consolidates some short reflections and insights about the process of working and learning together, and individually, through the process of the action research. It explores the notion of performative research through a discussion of power, participation and social change. The quotations presented in this chapter come from the notes, diaries and reflections documented from the team members.⁹ These inform a review of the process of implementing an action-oriented research initiative, by and for people living with and closely affected by HIV, as a model for both understanding and addressing stigma.

1) Explicit in developing a praxis of relational-participation?

The main criteria defining this quality indicator for action research revolves around the accessibility and meaningful nature of participation. I tried to establish this from the outset with the formation of action research and life story interviewing team, and the

⁹ From a mid-process and end of collection reflection meeting held in November 2010 and March 2011 respectively, as well as emails and personal journals kept by members of the team (and extracts that they chose to share with me).

respect for diversity and divergent skill sets held within the group. From a practical point of view, it also meant that the style and location of action research meetings varied between ones centralized at my house (where participation costs were reimbursed for travel and accommodation for the members of the team who lived in other regions) and ones that were located more conveniently for each of the team members (meaning I was the one who did the travelling).

The design of the action research process mirrored that of *The People Living with HIV Stigma Index*, in that from the outset it aspired to be by and for people living with or most affected by HIV.¹⁰

“It was unique that we had people who are positive collecting the data. Talking to people through the training helped them reflect on their experiences and helped them to have certain explanations about their feelings and experiences.” (David, April 2011)

From a peer-interviewing or “side-by-side” interviewing dynamic for the most part, the process sought to create a safe space for listening, sharing information, and open dialogue (see image 3, chapter three). George referred to this idea as the importance of “mutual trust” in the environment of the interview (March 2011). In other words, the process sought to invert imbalanced power dynamics that often accompany a more traditional interview (for example where a very well educated person is interviewing someone who may be illiterate, and is literally holding the pen and controlling the notation of their opinions).

Listening

The researchers appreciated the opportunity to listen to the stories of others. In many of the interviews, having an HIV positive diagnosis was the only common ground linking the researcher and participant who might otherwise have very different lives. This revealed to all members of the team the diversity of HIV and how it reaches different people within their community.

“I felt like I could be part of the audience to hear their story and also to be accorded that opportunity where they can share with you their story. It also helped me to have some insights on what is going on currently and the issues of HIV, both levels, depending on where I did the interviews. But more so also to have a perspective because I think I had always thought that maybe when we were on ARVs [antiretroviral drugs] these are my rights. Like me I look at my rights and I

¹⁰ See methodology chapter for reflection about the considerations in expanding the criteria for researchers to participants closely affected by HIV as well as living with HIV.

safeguard them. But then you go somewhere else where they don't even look at those things – to them they don't matter, you know? To them it's just if I have to go to a clinic and get the drugs, that's all I need for now, and to me that's OK. So you are also able to appreciate the other side of life where people don't ask for too many things, all they want is to make sure they get their ARVs and they're OK with it. So we are able to appreciate the other side of life and see how people are managing in very underprivileged circumstances (Ruth, March 2011).

Empathy

“Some people were very shy at first ...but after the knowledge I shared with them on issues of HIV and AIDS they began to be free and open to me. The skilful art was to make them feel that you are part of them.” (Milliam, November 2011)

The common ground made easier by the shared reality that both interviewer and participant were closely living with HIV not only facilitated empathy in the interview process but also helped enable a feeling of trust and openness. This led to some surprising sharing even among people who knew each other quite well, and a sense that the researchers were privileged to hear some of the more 'hidden' dimensions of the realities of HIV.

“When I went to start hearing the stories of people it helped me see the other side of life” (Ruth, March 2011).

“Again for me it was a learning experience. It gave me an opportunity to understand the life of the person living with HIV. A deeper understanding of the person living with HIV – the Malawian person living with HIV. That the person living with HIV is not the one my eyes see, it's not the one that my eyes see, but it's someone that is the inside self, the one that like he puts it, the hidden aspect of the epidemic” (David, March 2011).

The physical approach to the interviews (side-by-side) and the spirit of the approach (diversity of the team, listening and empathy) enabled as much as possible for meaningful participation both for the team and participants in the research.

2) Guided by reflexive concern for practical outcomes?

In this research project, two aspects stand out as relevant for this quality measure—the sense of social action and potential change (through advocacy as well as a result from an empowering process) that could come from the story telling (Ewick and Silbey, 1998), and the livelihood opportunities that were generated through the honoraria

and capacity development associated with the process of preparing for and doing the interviews.

Social action

This included not only empathy with others directly involved in the national research initiative, but also with others around the world—both part of the global initiative as well as more generally affected by HIV and involved in understanding and responding to HIV-related stigma.

“For me it means a lot but to mention a few [aspects] it gave me a wide range concerning [that] HIV is real. And that HIV is affecting or infecting people all over the world. Be it in town or villages. And it also gave me a wide range to realize that the world is concerned about HIV and AIDS.” (Milliam, March 2011)

It also resonated at the national level, illuminating to David that more meaningful spaces should exist for people living with HIV to engage in national decision making processes:

“People living with HIV do not seem to have a forum where they can be expressing their feelings and aspirations.... There was this last question, ‘do you have anything else to say at the end?’ And you see somebody expressing their expectations about this to say I wish this was happening every day, I wish people would just listen to how we want things to be. I learnt that mobilizing people living with HIV would strengthen their voices.” (David, March 2011)

At a final reflection and review meeting in May 2013, both Ruth and George remarked on how proud they had felt to be able to present the results from the research to the NAC in November 2012. George even described how he did it in his ‘pastor’s costume’ (also highlighting his multiple identities). Ruth mentioned that she has felt part of a family in this action research project, “working on an issue and seeing where to go. It has ignited that fire and I want to go out there and do more” (Ruth, May 2013). David also expressed an awareness and ambition to contribute more to social action based on his role in the research: “I can see my bigger role in society and it is based on this knowledge” (David, May 2013).

Livelihoods

The action research also pragmatically provided training and income generating opportunities for people living with HIV (as researchers and also through the honorarium for sharing their life stories). Most of the team expressed gratitude and also the utility of

the “skilful art” in interviewing, recording and documenting that they gained through the action research process.

“After the research I have taken on the skills to apply in the another studies [sic] that I have participated on family planning user dynamics for long term contraceptive decision making The skills have been very helpful and I will continue to use them. My involvement in that research also helped me negotiate my own life. I was able to re-strategize in life and moved on with some challenges that I encountered. Dealing with the team and sharing the experiences also helped me to relieve some of the challenging emotions I had.” (Ruth, August 2012)¹¹

This last reflection from Ruth illustrates how some of the practical skills had value for her (in terms of research and documentation) as well as some of the interpersonal connections with other in the action research team. Likewise for George, the interviewing skills were practically useful to support his work and professional advocacy, as well as the interpersonal connection with others in the action research team and participants who he had interviewed as part of the research:

“The research techniques helped me in implementing the GIPA Report Card, an advocacy tool that sought to measure the applicability of the GIPA Principle and the perceptions of people and what government can do to promote the principle. I shared this at the International AIDS Conference in Washington DC in July 2012. The Life Story Interviews also strengthened my relationship with fellow PLHIV in Malawi, especially those I worked with as data collectors. I have become a trusted friend of those I interviewed.” (George, August 2012)

The team also hopes that the findings from this research will be useful to inform parliamentary deliberations about the draft HIV Bill which has happened in 2013. The research brief (Annex 15), and publication of the findings in a peer-reviewed academic journal¹² (Stackpool-Moore, 2013) have been sent to the Law Commissioners, and UNDP and UNAIDS Malawi, who are involved in the final revision to the Bill before it goes to parliament¹³.

As a team we would also like to establish “Life Malawi” a small charitable organization that could try to provide some on-going support for the people who shared their life stories. We have drafted the Constitution but have yet not been able to obtain official registration (Annex 16). We discussed editing the stories into a publication that could be sold, and all the profits would go to Life Malawi. The Trustees would be the members of the action research team, who would administer the transfer of the support

¹¹ Details of the specific studies removed.

¹² Stackpool-Moore, 2013.

¹³ Personal communication has indicated that this may happen in mid 2013.

to the life story participants. It is still an idea that we committed to getting started, and I hope will be successful in the near future.

3) Inclusive of a plurality of knowing?

Many levels of “ways of knowing” were included in the action research process, which could be categorized as collective, self and sensory. The challenge is often that “voices” and “photographs” may be perceived as weakness in the research design, and as already noted, various forms of communicating the research results have so far been adopted to be effective and persuasive for policy makers while remaining true to the spirit and process of the research (Scott-Villiers, 2012, p 29).

Collective knowing

At the implementation level, the process helped to foster connections between individual people living with HIV.

“It gave others confidence through me because when I was with somebody, be it ... whoever I was relating with, because they knew that they are talking to a fellow person living with HIV, and I knew that I was talking to a fellow person living with HIV, so there was this companionship. There was this cross-fertilization of confidence.” (George, March 2011)

Self-knowing

We all found that in listening to the experiences of others, parts of our own story and experiences were reflected (reflections from the team are included below, and my own in the Afterword).

“When people are saying their story I can see my story in it.” (David, March 2011).

The research also enabled all members of the team to reflect on each of our own pre-conceptions about the nature of research and the nature of the issues we were researching.

“It was a learning experience; I had never done research before. I learnt how to collect data through structured questions... and to relate my life with what others have gone through” (David, March 2011).

Sensory knowing

It was also a sensory experience, as many of the reflections from the group referred to the sites, sounds and smells of the interview experiences, as well as an

interpersonal insight about how the participant appeared or acted during the interview (for example at ease, distracted or apprehensive).

The inclusion of photography as part of the data collection process also added a different dimension to documenting the life story participants in the context of their daily lives, and added an opportunity to clarify the extent to which they gave consent for the inclusion of their image and story as part of the documentation for this research.

4) Worthy of the term significant?

Of the five criteria outlined by Bradbury and Reason (2001), this one is the least well defined. It includes notions of the extent to which the process evoked questions about the values each member of the team holds and the kind of processes we engaged, as well as the quality of the research questions and contribution of the research results. They ultimately conclude, “it can of course be argued that any participative form of inquiry, well-grounded in the everyday concerns of people, will necessarily be worthwhile” (Bradbury and Reason, 2001, p 453).

Contribution to forms of knowledge

From the action research process specifically, in addition to the conceptual contribution from the analysis presented in the body of this thesis, there were three critical new areas of knowledge discussed and generated from the reflections of the team. The action research process, and conversations with the action research team throughout 2010 – 2013, has informed the grounded theory approach presented in this thesis.

The first was regarding how HIV is considered in someone’s life, and that it should be framed in terms of a whole person and not obscure other aspects of someone’s life and identity:

“I learnt that HIV is just an aspect of the problems we go through in life. Like poverty. When you know somebody has lived for 23 years and they are still kicking, they still have hopes, and they are still studying beyond first, second degrees, and then you say ‘how possible.’ So I looked at HIV as just like any other problem we go through—poverty, low education.” (David, March 2011)

A second specific conceptual contribution from the action research process was a consciousness of differential access to and knowledge of rights. This was present in the life story interviews, as well as in the results from *The People Living with HIV Stigma Index*, and discussed often by the team. For example,

“I think what really stood out for me in the life stories is the levels of knowledge on the issues of rights. I think we take things for granted and we are seated in town and we talk about the issues—you think everybody else has the same level of understanding. I think generally Malawians, especially Malawians that are living in the rural areas, they don’t know. And then because they don’t know they way they are handled, they might not even appreciate if they are being violated.” (Ruth, March 2011)¹⁴

The third area related to the potential connection between individual reflections and national concerns. For example, David explained how the process of self-reflection and finding connections between one of the participants he interviewed with his own life, also generalized these to deduce significance for the national HIV response:

“I have also found that voluntary testing is still a challenge. Joseph¹⁵ came just like myself. I didn’t go for testing voluntarily – I had to be sick, and very sick, that almost what you call near death sickness. So when Joseph was talking about that I could relate with what I went through... Because when I look back, when these people were telling their stories, *I was trying to look back at myself*” (David, November 2010, my emphasis).

These critical new areas of knowledge were generated during discussions among the team, and contributed to the analytical foundation of the results presented in this thesis.

5) Emerging towards a new and enduring infrastructure?

For the team, more than anything the experience left a taste of how addressing HIV-related stigma—in terms of both the personal and social response it demands—is complex and all encompassing. To “perform” the kind of personal and social change necessary to overcome stigma, our efforts need to engage conscious attitudes as well as those less conscious.

Individuality and the team— ubuntu in action

In many ways, the action research team was a microcosm of the spirit of ubuntu. We were working together on a common initiative, yet also responsible for our individual actions, and reflecting on both the process and broader implications of the research

¹⁴ Although Ruth does not mention a specific example in this context, however in personal communication she had mentioned that she had been alarmed to discover that one of the participants she interviewed had felt that she was receiving good health services, and yet in her interview had described at least 3 visits to received CD4 testing from the clinic, where she would wait, and return without a test or analysis of the staging of her HIV because the machine was not in order. Ruth perceived this as a violation of the participant’s rights to access health care, which was different to the framing of the experience by the participant.

¹⁵ Not his real name.

results, such as the detail the interviews were unearthing about HIV, stigma and law in Malawi.

Recognizing that people living with HIV are not a homogenous group, neither was the team, and a continuing challenge was engaging a cross-section of people living with HIV as researchers and participants in the initiative.

For David, Ruth, Milliam, George, Gift and myself, the process of working together on the action research was both challenging and rewarding, offering an opportunity to learn about the complexity of identity, identification (or lack of) with any one identity-based movement, whether based on gender, age, sexuality or nationality, and principles about modelling or “performing” the change envisaged for the world. The teamwork dynamics, combined with the results and the process of implementing the research in Malawi, offer a model for further analyzing the kind of individual and social transformation necessary to tackle the underlying causes of stigma and structural determinants of health.

Lasting impact?

In September 2012, more than 18 months since our last action research meeting and since the last interview was completed, each of us has internalized the experience in a different way.

George:

“18 months since our last action research meeting and the end of the interviews, the process has contributed a lot in my life, especially looking at how the process empowered me to share with comfort the experience of living with HIV and what it really means, what other people think about PLHIV and how valuable it is getting other people to understand that the story is more than just living with HIV.”
(George, August 2012)

Milliam:

“One and half years later since our last action research meeting and the end of the interviews, there is a lot that I learnt. One was that my husband fell very ill and was sent on sick leave by MBC his employer for six months. In the first 3-months, he was given full salary and in the last three was on half pay. Thereafter, he was sent and told to meet a medical board at the Mzuzu Central Hospital on 3rd August 2006. During that medical board appointment he was told as per Doctors recommendation that he be retired on medical grounds. But after that meeting on that day, one Doctor asked my husband if he could make it to go to Ocean Road Cancer Institute in Dar es Salaam in Tanzania to meet with some Doctor there of which he did upon borrowing money from banks and getting loan from his employer. He started going there immediately and his condition apart from his

positive living with HIV began to surely change for the better. I could not leave him because I vowed to love him come what may, in sickness or otherwise, in poverty or whatever the case might be.

And when I was involved in the action research, it gave me more and more in-depth love, care and concerns over him to support him the much more I could. With what has been happening, it gave me even much love in that although he was in the state of what other people thought he was useless, it was a blessing to me because since then, I have been tested negative yet he is on ART treatment day in day out.

With the skills I learnt it brought me to realize that there is no need to stigmatize and discriminate him in any way as it made me bear in mind that he is like any other person. Positive living is one thing that encourages me and makes me to feel that HIV and AIDS is like any other disease.” (Milliam, 6 September 2012)

This reflection from Milliam points to some of the unexpected outcomes of collaborative working, and potentially some of the more profound and life-long learning of compassion and acceptance that could be an antidote for stigma. In some ways, perhaps for Milliam (as she explains herself), the opportunity of working as part of the action research team created learning that engaged her beyond her existing belief systems. Perhaps, as Archer implied (1988), this was an example of stepping outside the existing boundaries of culture and consciousness to become aware of (and in this case transform) existing beliefs.

In May 2013, the team were still reflecting on how their involvement had (or not) a lasting impact for each of them since we first came together in October 2010. I asked each of them if it was a good thing to do and if they would get involved in something similar again—and they said yes. Ruth described how the process had helped her to run the ‘young positives’ programme more effectively for FPAM, and also had connected her to being involved in the UNDP review process in the revision of the draft HIV Bill (Ruth was connected with UNDP through one of the meetings I had organized relating to conversation with key stakeholders about the research findings, in May 2012). George noted that his credibility as a research and advocacy officer had been enhanced by his involvement in the research, and on a personal note he felt “elevated” that his poems were printed in the thesis¹⁶. David reflected that although he had been involved in other global initiatives, he had felt “used” in the past and not paid or duly respected in the research process. He said:

¹⁶ He took a photograph of it on his phone, quietly during our meeting, in May 2013.

“There was a dynamic difference in the way we have been treated in this. I want to appreciate your leadership. I feel I have a stake in this. Your participatory leadership has been a lesson to me—it has given me a tool. We are a toolkit now. This thing has given me a name—my activity comes from it.... It has encouraged me even at a personal level. We know who we are. We know how we live. It’s been very inspiring—sustaining in my life” (David, May 2013).

The value of the friendships and on-going connections between members of the team and some of the participants will perhaps only really be felt—or even come to fruition—in years to come.

ACTION RESEARCH—AN IMPURE AND VALUABLE SCIENCE

Taking “science” from its Latin origin meaning “knowledge”, this action research was both impure and valuable from start to finish. The approach undertaken in this research was a hybrid of collaborative and action research, even though very strongly based in commitment to principles of participation and social action in research¹⁷.

The process has both generated a new and interesting contribution to the body of knowledge relating to HIV, stigma, and legal consciousness in Malawi through its conceptual, contextual, methodological, pragmatic and personal contributions. It has also had an impact on the lives of the members of the action research team, on which they have all commented even more than two years after the end of collection meeting in March 2010. I anticipate that additional effects will be felt in different ways in years to come, as yet opaque to the members of the team. It provided timely evidence about law and legal consciousness in the context of HIV and may also have contributed to raising awareness about stigma and the potential impact of the HIV Bill in Malawi.

The action research approach is ambitious in its attempt to engage individuals within the context of our own lives, to shape the reflection, action and vision for change—an approach that straddles deeply personal feelings and wider social attitudes. Yet, for lasting change, the momentum and ideas generated through community action need to be supported and reinforced by wider institutional, policy, social and legislative

¹⁷ As already noted, there are some shortcomings of this research as an action research undertaking in its purist form. Although the analysis outlined in this thesis is informed by the one-to-one debrief meetings with each member of the team, the mid-collection and end-collection meetings, and sustained communication with the team via email and in person whenever possible, in reality the structure of the arguments and key analytical findings laid in this thesis are my own. While this is in compliance with the regulations and framework of a PhD submission, it goes against the grain of pure action research, which would model collaborative co-inquiry throughout the process of writing and presentation of analytical results as well.

structures—either strengthening existing ones to be more supportive, or generating systemic change to create new ones where this is needed. Community-based action (of which this research is one of many examples) is only one part of a multi-faceted and complex picture needed for facilitating individual and social change.

To return to the notion of subversive stories and the potential of narrative to catalyze social action explored at the beginning of this chapter:

“ [W]hen narratives emphasize particularity, and when they efface the connection between the particular and the general, they help sustain hegemony. Conversely, when narrativity helps bridge particularities and makes connections across individual experiences and subjectivities, it can function as subversive social practice.” (Ewick and Silbey, 1995, p 200, op cit)

Stories and conversations are implicated in both the production of social meanings and the power relations expressed by and sustaining those meanings. In the diversity of the team and the individual and collective learning that was associated with the action research process, we embraced difference yet also sought to generate a wider reaching understanding of the critical issues.

The process of undertaking this action research project models a notion that to effectively address a complex multi-level concern like HIV-related stigma, a complex multi-level solution is needed. In essence the ingredients of an effective ‘anti-stigma’ intervention include bringing different people together, bridging diversity, addressing the personal, service and structural levels of stigma, and enabling the total value of the process to be much more than the sum of its parts.



Image 6: Action Research Team Lilongwe, May 2013

4| Malawi: A snapshot

The leaders of tomorrow are here;
The torch flickers,
And the darkness tears apart...
No Longer dawn!

This is the time,
Tomorrow is here now
For the children of yesterday,
The one time leaders of tomorrow
Are here now...
To sort out the injustices
Hitherto covered up
With cleverly moulded deceit.

Lower your colours,
You, leaders of yesterday;
No one-man word will be final—
It's pluralism now...
And today is the tomorrow.

No Longer Dawn, by George Kampango



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HIV IN THE SOCIO-POLITICAL CONTEXT OF MALAWI

“I want to agree with the Chairperson of MANET+ that stigma and discrimination against People Living with HIV (PLHIV) still exist in this country. Therefore, the government will continue to address the legal environment to ensure that People Living with HIV are neither stigmatized nor discriminated” (President Joyce Banda, NAC, 10 October 2012¹⁸).

The theme of the most recent annual national AIDS conference in Malawi was “Putting Research Findings into Practice” and was held 10-11 October 2012 in Lilongwe. President Banda called for an end to stigma and discrimination (op cit). It seems that at least in terms of rhetoric, stigma and discrimination remain at the top of the political agenda in the national response to HIV in Malawi. Addressing stigma and discrimination was identified as a priority among participants in this research¹⁹—second only to HIV prevention—in the national response to HIV, which is consistent with recent political rhetoric confirming the government’s commitment to ending HIV-related stigma (NAC, 2012).

Malawi is one of the poorest countries in the world, and is ranked 171 out of the 187 countries ranked in the UNDP Human Development Index in 2011. Almost three quarters of the population (currently estimated at around 14 million) live beneath the poverty line and earn less than USD\$1.25 a day (UNDP 2011). There has been a history of food insecurity and widespread poverty in the last decade (UNAIDS, 2008c), and in this context it is noteworthy that the political responsibility for the national response to HIV and AIDS has been grouped with nutrition, and that the portfolio has been located within the Office of the President and Cabinet since 2004.

This chapter presents a short history of Malawi and situates the current national response to HIV within its broader socio-political context. It also presents the latest national statistics and policy responses in relation to HIV and human rights. Recent submissions as part of the Universal Periodic Review and other correspondence with the United Nations General Assembly and the Office of the High Commissioner on Human Rights indicate significant differences in the connotation of the human right to health as well as a divergence from the priorities identified in recent policies and reviews from the

¹⁸ News coverage of the Annual AIDS Conference on the website of the National AIDS Commission in Malawi: <http://www.aidsmalawi.org.mw/index.php/8-news/13-no-more-stigma-and-discrimination-says-president-joyce-banda> accessed 21 October 2012.

¹⁹ This is not surprising given that all participants knew there was a research focus on HIV-related stigma.

National AIDS Commission. These differences suggest that greater synergy could exist between the two different national policy processes to strengthen collaboration and effectiveness in the realisation of the human right to health in the context of HIV in Malawi. The second section reviews jurisprudence in Malawi and provides background information about the two embedded case studies that are reviewed in detail in chapters seven and eight—the Constitution of Malawi and the proposed draft HIV Bill. The final section of the chapter reviews the empirical responses from the participants in this research, and notes differences between the priorities identified in this research with those dominant in the current national human rights and HIV policy documents in Malawi. The empirical component of this chapter can be seen as thematic survey of results about society and social dynamics of HIV in Malawi that is complimented by the thematic survey presented in chapter five that focus on the individual and personal dynamics of HIV as part of the life (cf Sandelowski and Barroso, 2003).

Insert 1: Map of Malawi



²⁰ Map downloaded from <http://www.world-atlas.biz/images/malawi-map.gif>, accessed 30 May 2013.

A| HISTORY, HUMAN RIGHTS AND HIV IN MALAWI

Brief historical context

Malawi is often referred to as the warm heart of Africa²¹. Almost a third of the country is the lake that borders Mozambique and Tanzania, and which symbolically and literally has a powerful presence in Malawian culture. The official national languages are English and Chichewa, and other languages include Yao and Tumbuka. There is a strong regional pride particularly in the North, and the main religion is Christian with a strong Muslim representation found particularly in the Southeast of the country.

Malawi has an interesting and rich history that includes human evolution, trade, slavery, colonisation, dictatorship and democracy. Formerly known as Nyasaland, it was formalised in 1907 when the British Central African Protectorate was divided into Northern Rhodesia (now Zambia) and Nyasaland (now Malawi). Nyasaland was granted full independence and renamed Malawi on 6 July 1964, under the leadership of Hastings Kamuzu Banda (UNGA HRC, 2010). He governed autocratically for more than 3 decades until a referendum was held in 1993, political transformation ensued, and the first multi-party elections were held in March 1994 (UNGA HRC, 2010).

The current president is Joyce Banda (from 7 April 2012) – the first female president of Malawi. During the period of the research, the president was Ngwazi Professor Bingu wa Mutharika, who was first elected in May 2004 and although initially widely praised for his anti-corrupt and democratic principles, he was criticised for authoritarianism (HRW, 2012). Unprecedented nationwide protests (sometimes referred to as riots) broke out in several cities in Malawi in July 2011. Nineteen people were killed and scores wounded, when police fired ammunition and tear gas on unarmed demonstrators and bystanders in Lilongwe, Blantyre and Mzuzu (HRW, 2012). Mutharika died suddenly in April 2012 and Joyce Banda, the Vice President at the time, was appointed to take over the leadership of Malawi until the next elections (forecast for 2014). The national and international response to President Banda has been initially positive, as she has publicly indicated her commitment to human rights, anti-corruption and tolerance in contrast with her predecessor.

²¹ Physically, looking at a map of the African continent, Malawi sits right in the place where the heart would be if the continent were to be personified. While this is a stereotype, it had currency among many of my colleagues and also participants in the research, who explicitly welcomed me to, and/or checked to see if I was enjoying my time in, the “warm heart of Africa.”

The first diagnosis of HIV in Malawi occurred in 1985, and initial prevention efforts focused on migration and border routes with neighbouring countries which were the sites “blamed” for bringing HIV to Malawi (Lwanda, 2001). The first national AIDS control initiative was established by the Ministry of Health in 1987, and by 1991 AIDS was acknowledged as a major cause of death in the country (ibid). However definitive political action was not taken until eight years later in 1999 when the government launched a variety of initiatives to tackle HIV. This was in part to do with the arrival of multiparty democracy and “free” media post -1994, and the President at the time, Elson Bakili Muluzi, became increasingly (in)famous and criticised in the press for attending funerals and honouring the dead, while “leaving the living to suffer” (ibid, p161). Tellingly, a book compiled between 1995 and 1998 that was co-authored by Muluzi, thought to contain a synthesis of his personal views on health and governance in its epilogue, is “noteworthy” for its exclusion of HIV—one of the three major health concerns at that time (ibid, p162; citing Muluzi et al, 1999). Both the Banda and Muluzi administrations have been criticized for not awarding HIV the priority and political attention it deserved in the early years of HIV in Malawi (Lwanda, 2001).²²

Human Rights in Malawi

Language plays a significant role, and Englund (2012) has explored transliteration and understanding human rights specifically in relation to Malawi, where he notes the subtle differences in meaning in the Chichewa translation of human rights into local notions of birth freedoms and dignity. He concludes by suggesting that the most accurate terminology is “relationship rights” rather than human rights, to capture the symbiosis between a person and others in the protection and realisation of the kind of freedoms the villagers were demanding in rural Malawi.

The 1964 Constitution contained a Bill of rights that guaranteed human rights (UNGA HRC, 2010). However, significantly, these were limited solely to civil and political rights, and it was not until the new Constitution was adopted in 1994 that social and cultural rights were also included (Chirwa, 2005). Malawi has also been recognized for a landmark case within the African Court of human rights, where in *Achutan (on behalf of Banda) and Amnesty International (on behalf of Orton and Vera Chirwa) v Malawi* in 1995

²² See Annex 17 for a timeline of key dates in the history of Malawi and this Action Research Process.

under article 59 (1) of the African Charter on Human and People’s Rights, the decision held that a new government inherits the previous government’s international obligations, including its culpability for human rights violations and mismanagement from previous regimes (Ndulo, 2008, p 189).

Table 10 outlines the scope of Malawi’s international obligations as a signatory of core universal human rights treaties:

<i>Core universal human rights treaties and national constitution</i>	<i>Date of ratification, accession or succession</i>
Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)	12 March 1987
African Charter on Human and Peoples' Rights (Banjul Charter)	1989
Convention on the Rights of the Child (CRC)	2 January 1991
International Covenant on Economic, Social and Cultural Rights (ICESCR)	22 December 1993
International Covenant on Civil and Political Rights (ICCPR)	22 December 1993
<i>New Constitution (full Bill of Rights)</i>	<i>1994</i>
International Covenant on the Elimination of All Forms of Racial Discrimination (ICERD)	11 June 1996
Optional Protocol to ICCPR (ICCPR-OP1)	11 June 1996
Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT)	11 June 1996
African Charter on the Rights and Welfare of the Child (ACRWC or Children’s Charter)	1999
<i>Reviewed and Revised National Constitution</i>	<i>2004</i>
Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Women in Africa (Maputo Protocol)	2005
Protocol African Court on Human and Peoples’ Rights	2008
Optional Protocol to CRC on the sale of children, child prostitution and child pornography (OP-CRC-SC)	7 October 2009
International Convention on the Rights of Persons with Disabilities (ICRPD)	27 August 2009

Table 10: Malawi’s international and national human rights obligations²³

In terms of human rights and HIV, HIV is mentioned only twice in the latest National Report submitted to the Human Rights Council Working Group on the Universal Periodic Review in 2010 – once, as the seventh national priority (grouped together under the enormous umbrella of “public health, sanitation, HIV and AIDS management”) and the second time, under a section on children’s rights (UNGA HRC, 2010, p 4; p 9). HIV is not mentioned at all in the section on the “right to health” in this National Report. However an “Essential Health Package (EHP)” is identified as the implementation mechanism for the right to health in Malawi, and described as a package that “contained the priorities of the Ministry which addresses major causes of morbidity and mortality that disproportionately affect the poor and most vulnerable groups in society” (ibid, p8). In

²³ Adapted from UNGA HRCb, 2010, p2 and from <http://www.claiminghumanrights.org/malawi.html> accessed 30 May 2013.

other words, according to the National Report, the EHP is designed to address the wider structural determinants of health that have been linked with vulnerability to HIV (cf WHO, 2008). Similar language was reported back from the meeting almost verbatim, in the Report of the Working Group on the Universal Periodic Review for Malawi (UNGA HRC, 2011, p 5).

Notably however, in none of the 100 interviews undertaken as part of this research, was the EHP mentioned. This is surprising, given that the issue of the human right to health was explicitly discussed in the interviews, which were held with Ministry representatives who were included in the sample, including from the Ministry of Health, Gender, Agriculture, Justice and the Office of the President and Cabinet. While this finding is not the focus of the analysis that follows, it suggests that there is a disconnect between the notions of the policy framework enabling the human right to health and how it is implemented and perceived in reality.

National HIV and health context

According to the latest Demographic Health Survey in Malawi (MDHS), conducted in 2010 and published in 2011, the national HIV prevalence has reduced over the last 6 years from an estimated 12% in 2004 to 10.6% in 2012 (NSO, 2011; Malawi Government, 2012). The estimated HIV prevalence remains highest in the southern region, doubling the estimated prevalence of the central and northern regions (Malawi Government, 2012). HIV remains a feminized epidemic in Malawi in 2010 as it was in 2004, with HIV prevalence estimated as 12.9% among women and 8.1% among men (NSO, 2011). It also remains urbanized, with HIV prevalence in urban areas double that of rural areas (Malawi Government, 2012). The MDHS also indicates that malaria remains a serious public health concern in Malawi, with six million cases occurring every year. The results indicate that high proportions of the population are married, 60% of women and 50% of men aged 15 – 49 years (recognizing both formal and informal unions), and that gender based violence also continues to pose a serious challenge (NSO, 2011). In terms of employment levels, the MDHS shows high youth unemployment that reduces over time, and is particularly high for young women aged 16 – 19 years (ibid). The MDHS also reports differences in earning, and types of earning (in-kind, cash, and unpaid) between men and women. These factors and others presented in the MDHS suggest a complex picture of how demographic factors

such as gender, marital status, and type of employment may intersect in relation to vulnerability to HIV—and potentially also resilience in responding to HIV related stigma.

Accurate estimates of HIV prevalence and incidence remain a challenge in Malawi as in every country. In terms of stigma, the MDHS interestingly notes that there is little alignment between current HIV status as determined by the MDHS HIV test compared with self-reported HIV status of participants (NSO, 2011, p 214). For example among women, 9% indicated that their last HIV test had been negative but the HIV test undertaken as part of the MDHS was in fact positive. This was even higher for women who had declined to disclose their HIV status in the interview or had said it was unknown, where 12% were HIV positive according to the HIV test undertaken as part of the MDHS (p213). It is noted in the report that this could be for a number of reasons beyond the scope of the MDHS, including an allusion to the potential role of stigma, which was referred to as “a discomfort about disclosing” HIV positive status to an interviewer (ibid).

The main policy document which currently governs the national response to HIV is the extended National HIV and AIDS Action Framework (NAF), designed initially to cover the period 2005-2009 but has been subsequently extended to include 2010-2012. A new National Strategic Plan (NSP) that will cover 2012 – 2016 is anticipated for release. The seven priority areas identified in the extended NAF are 1) prevention and behaviour change; 2) treatment, care and support; 3) impact mitigation; 4) mainstreaming and decentralisation; 5) research, monitoring and evaluation; 6) resource mobilization and utilization; and 7) policy and partnerships (Malawi Government, 2012, p 9). Access to ART was identified as both a success and a priority in the recent report from the Malawi Government, celebrating that the number of people receiving ART increased from 10,761 in 2004 to 322,209 in 2010 (Malawi Government, 2012, p ii).

Recent research has highlighted some critical areas of concern in the national response to HIV.

Gender differences were apparent in many of the studies, such as cultural trends to link blame and stigma for HIV to women (Peters, Kambewa, and Walker, 2010), and a higher propensity for interpersonal discrimination for women compared with men (Neuman and Obermeyer, 2013). White (2010) has considered possibilities through the courts to secure positive law reform for women in Malawi, particularly in relation to land and inheritance rights. A descriptive analysis of HIV-related stigma in comparison with the Universal Declaration of Human Rights in five African countries found that the human

rights of people living with HIV are violated in a number of ways. Critical areas related to income opportunities, verbal and physical abuse, and experiences in health and dental services (Kohi et al, 2006). Another study however questioned the appropriateness of ‘Western’ individual rights-based public health norms in relation to localised concerns for communities in Malawi. The case study focused on issues of HIV testing norms and messages in Malawi (Angotti, 2012). Communities, peer-groups, and leadership from affected communities have also been identified in recent studies in relation to a successful national response to HIV (Trapence et al, 2012; Kaponda et al, 2011). Stigma and health care settings—both in terms of creating barriers for seeking services (such as for MSM and people living with HIV) as well as in terms of health care workers accessing HIV-related services—is a critical issue (Fay et al, 2011; Bemelmans et al, 2011; Namakhoma et al, 2010). Challenges relating to internalized stigma and fear of disclosure were identified among pregnant women, indicating concerns relating to gender inequality and questioning the effectiveness of HIV prevention among sero-discordant couples (Hardon et al, 2012). As with the data presented from the MDHS, and indeed from the life stories that follow in chapter five, the recent research about HIV and stigma in Malawi indicates a complex picture of intersectional identities spanning gender, marital status, fertility and sexual orientation may conflate vulnerability HIV and HIV-related stigma. My research is novel within this field.

Significantly for this research, the latest report from the Malawi Government on HIV does make explicit links with the Constitution, the proposed HIV Bill, and generally refers to some of the challenges in implementing international human rights principles in practice (Malawi Government, 2012, p 10 – 11). The report states that the national HIV policies have been “aligned with the Constitution” whilst also acknowledging the challenges of a lack of “operative legislation aimed at ensuring protection, participation and empowerment of individuals within the context of the HIV and AIDS epidemic” (ibid). The report does not mention limited access to justice for many Malawians, the lack of consciousness of legal frameworks in everyday life in Malawi, nor the challenges of law enforcement that features so prominently in the findings of this research (see chapter seven). The report draws on evidence from the MDHS as well as the findings from *The People Living with HIV Stigma Index* in Malawi to indicate that stigma “exists” and remains a “potent stressor” to people living with HIV in Malawi, and calls for “multifaceted

strategies that include protecting human rights and provision of high quality health services sustained over time” (Malawi Government, 2012, p 29).

The policy frameworks guiding the national response to HIV in Malawi recognise that HIV is a social and cultural issue, and that health and well-being is embedded within broader development concerns such as nutrition, food security, economic livelihoods and gender dynamics—in other words, determined by the realities of everyday life.

This opening section has presented an historical, legal and socio-political outline of key contextual issues relevant to the research questions explored in this thesis. The remainder of the chapter builds on this secondary review by including a presentation of the critical issues in the national response to HIV that were identified by the participants in this research.

B | JURISPRUDENCE IN MALAWI

This section explores the historical and jurisprudential foundation for the analysis of the two legal case studies – the Constitution of Malawi and the proposed draft HIV Bill – that offer a context for these ideas in the chapters seven and eight.

Transformative constitutionalism

Malawi has a Constitution that came into provisional force on 18 May 1994 and definitive force one year later. Having been colonized by Britain in 1889, with no formal constitutional framework established by Britain to regulate colonial rule, the 1964 first written Constitution was adopted in Malawi in 1964, on independence (Chirwa, 2005). It did not contain provisions to protect any socio-economic rights and was superseded as planned in 1966 (ibid). The Constitution was revisited following the transition from a single-party system of government to a multi-party democracy in 1994 (Government of Malawi, 2004).

In 1994 therefore, there was a real need to demarcate social and political transformation. The former president, who had been designated a life president and had ruled for three decades in a one-party system, was likened to other African ‘dictators’ such as Idi Amin (Muula and Chanika, 2004). As Gloppen noted, the adoption of the 1994 Constitution represented “the most radical reform of formal law in Malawi’s history, establishing a legal regime on principles that claimed to transform society and promote

the welfare of all sections of the population, particularly those hitherto marginalized” (Gloppen, 2007, np). The Constitution of Malawi was imbued with the great potential and great hope of the nation to codify human rights, citizenship and democracy. Its potential has been likened to the South African Constitution in its transformative vision for the future:

“The Malawi Constitution, as with the South African Constitution, was intended by its drafters to provide a basis for the development of a transformative jurisprudence. This aspect of the Malawi Constitution, coupled with specific provisions that call for the horizontal application of the Bill of Rights to the common law, places the onus on the common law court to contribute effectively to the political goal of positively transforming the lives of the economic and social underclass.” (Banda, 2009, p 169)

The Constitution has been seen as an aspirational document that enshrines human rights and which embodies the collective desires of the Malawian people. Justice Msosa, a judge in the Supreme Court of Appeal in Malawi, says that this spirit is obvious in the preamble of the Constitution, which “clearly shows the aspirations of the people of Malawi and their ownership of the constitution” (Justice Msosa, in Ott (ed), 2003, p 164). The notion of human rights enshrined in the Constitution is akin to the collective values of ubuntu. It is unlike the African Charter, which defines the right to development as people’s rights, in that the Malawian text refers “to the right of ‘all persons and peoples’ to development, is open to individual as well as collective claims” (Gloppen, 2007, np).

The Constitution is long and detailed, perhaps setting a precedent for the drafting of other laws such as the proposed draft HIV Bill, which while having the potential to be comprehensive, also has some disadvantages. For example in purely numeric terms, the original Constitution of the United States of America has seven articles and twenty-one sections. The Malawian Constitution has twenty-three chapters, and two hundred and fifteen sections. As Dodge et al have suggested, there are three main pitfalls of a detailed Constitution:

“First, it tends to bind the political branches of government more tightly, which may decrease their ability to respond to changing conditions at the same time that it guards against the abuse of power. Second, the more the Constitution consists of specific details rather than general principles, the less dignity it may have in the eyes of the people and in the eyes of the government officials who are to be bound by it. Third, the longer the Constitution is, the less accessible it becomes to ordinary citizens on whose support the vitality of the Constitution ultimately depends.” (Dodge et al, 1994, p2)

The extract highlights the importance of dignity in inspiring people and government officials, and the risk that this notion is obfuscated amid a detailed and elaborate law. The extract also emphasizes the risks in making a law that is inaccessible to 'ordinary citizens' and, in other words, is pinpointing one of the reasons why the Constitution is seldom meaningfully present in the everyday lives of Malawians (see chapter seven).

The Constitution has been heralded as "propitious for the emergence of transformative jurisprudence" in that it was pro-poor, protective of human rights, had the potential to alter structural inequalities, challenge power imbalances, and improves the situation for all Malawians including the poorest and most marginalized (Gloppen, 2007, np). Chirwa has deemed it to be as "revolutionary" as the South African and German Constitutions, in that it allows the Bill of Rights to apply in the private sphere (Chirwa, 2005). Chirwa argues that this goes beyond more traditional Constitutions and is transformative in its conceptualization (ibid). The 1994 Constitution included a comprehensive Bill of Rights that created an environment conducive to ratification and domestication of the most important international human rights treaties (Kanyongolo, 2006, p 29). Yet as Kanyongolo has noted elsewhere, the illusion of transformation held within the spirit and potential of the Constitution may have in fact deceived people from seeking and achieving real material and meaningful redistribution of power and resources:

"While conceding that the promotion, protection and enforcement of human rights have brought some demonstrable benefits to the people of Malawi, the ultimate irony is that by creating the illusion of transformation – 'transition' – the rhetoric of human rights in Malawi contributes significantly to the cauterization of a genuine transformation of class and gender relations." (Kanyongolo, 2004, p 79)

The potentiality of the Constitution is tempered by the impotence of law, and its enforcement, to legislate social change. Chirwa (2005) suggests that the socio-economic rights enshrined within the Constitution are inadequate to redress the historical and current inequalities in Malawi. Even so, the enforcement of socio-economic rights (even in their limitations) under Malawian law has not been forthcoming. Eloquently put by Chirwa, "without litigation, the Constitution will remain a paper tiger" (Chirwa, 2005, p 241). Gloppen demands an explanation as to why, "in a contract where the need for social transformation is striking, and the legal basis for social rights litigation reasonably promising", legal voices and transformative justice for those in the greatest need has not been forthcoming (Gloppen, 2007, np).

Private consciences and collective wisdom—HIV, personal and social transformation

When the Constitution of Malawi came into provisional force on 18 May 1994, it was 9 years after the first diagnosis of HIV in Malawi. The Constitution is founded on principles of human rights and non-discrimination, and although it references some groups directly it does not include any explicit mention of HIV.

The Preamble distinguished between individuals and collective society, explicitly linking consciences (personal) and wisdom (collective).

“The people of Malawi - recognizing the sanctity of human life and the unity of all mankind; guided by their *private consciences and collective wisdom*; seeking to guarantee the welfare and development of all the people of Malawi, national harmony and peaceful international relations; desirous of creating a constitutional order in the Republic of Malawi based on the need for an open, democratic and accountable government: Hereby adopt the following as the Constitution of the Republic of Malawi.” (p 11, my emphasis)

It is clear from the Preamble of the Constitution in Malawi that the dualism of agency between individuals and communities is central to the manner in which notions of citizenship are defined in the Constitution (cf Gloppen, 2007, op cit). “Relationship rights,” a more accurate interpretation of an organic understanding of human rights in Malawi, was implicit within the Constitution of 1994 (Englund, 2012).

The Constitution contains definitive language in relation to equality and human rights for all, such as:

“All the peoples of Malawi are *entitled* to the equal protection of this Constitution, and the laws made under it.” (p 11, my emphasis)

“The dignity of all persons *shall* be inviolable.” (p17, my emphasis)

“Inherent dignity and worth of each human being *requires* that the State and all persons *shall* recognize and protect fundamental human rights and afford the fullest protection to the rights and views of all individuals, groups and minorities.” (p 13, my emphasis)

These extracts showcase legal *obligations* within the Constitution of *entitlement*. The Constitution also clearly articulates that all people would have equal status before the law and access to legal remedies (p13)—covering all four types of human rights reviewed in chapter two: natural, State’s, constructed and relational rights (Englund, 20012; Ife, 2010).

“41. (1) Every person shall have a right to recognition as a person before the law.
(2) Every person shall have access to any court of law or any other tribunal with jurisdiction for final settlement of legal issues.

(3) Every person shall have the right to an effective remedy by a court of law or tribunal for acts violating the rights and freedoms granted to him by this Constitution or any other law.” (p 22)

Health is covered within the Constitution, which outlines standards for universal access to adequate health services “to provide adequate health care, commensurate with the health needs of Malawian society and international standards of health care” (p 14).

The Constitution explicitly prohibits any form of discrimination:

“Discrimination of persons in any form is prohibited and all persons are, under any law, guaranteed equal and effective protection against discrimination on grounds of race, colour, sex, language, religion, political or other opinion, nationality, ethnic or social origin, disability, property, birth or other status.” (p 17)

It is interesting to consider, although outside the specific focus of this research, why HIV was not included in this list as a potential source of discrimination, and also to speculate about the potential symbolic influence such an inclusion may have had on – and changed - the evolution of the HIV response in Malawi.

Finally and of particular interest for subsequent laws introduced in Malawi (such as the draft HIV Bill), the Constitution includes a clause that invalidates potential laws that constrain fundamental principles, “rights and freedoms”, because they would be in contravention of the Constitution:

“46 (1) Save in so far as it may be authorized to do so by this Constitution, the National Assembly or any subordinating legislative authority shall not make any law, and the executive and the agencies of Government shall not take any action which abolishes or abridges the fundamental rights and freedoms conferred by this Chapter, and any law or action in contravention thereof shall, to the extent of the contravention, be invalid.” (p 28)

This has implications for considering the draft HIV Bill, which explicitly contains some provisions that undermine human rights for people living with HIV. However, as this research demonstrates, the everyday purchase of the Constitution is limited and the likelihood of financial and human resources being invested in a challenge to the draft HIV Bill in Malawi on constitutional grounds is unlikely.

Draft HIV and AIDS (Prevention and Management) Bill

The Special Law Commission for HIV and AIDS ended in 2008 with a Report (Malawi Law Commission (MLC) report number 20) that included a proposed draft HIV and AIDS (Prevention and Management) Bill (draft HIV Bill) (Annex 17). The draft HIV Bill is yet to be

tabled in Parliament even though the Commission concluded and submitted the Report in 2008. The “submissions acknowledged that HIV infection in Malawi has risen rapidly necessitating the adoption of a legislative framework to protect individuals infected and affected by the HIV and AIDS epidemic in view of the current constitutional order which is human rights based” (MLC 2008, p 9).

In August 2006, the Malawi Law Commission received two submissions requesting attention to the ‘development of a comprehensive legislative framework to govern issues relating to HIV and AIDS’ (MLC 2008, p 9). One submission, from the Department of Nutrition, HIV and AIDS, requested legislation to realize the principles outlined in the National HIV and AIDS Policy which had been adopted by the Government in October, 2003; the other, from the National AIDS Commission, requested the enactment of an institutional framework to allow ‘for the proper and effective functioning’ of the NAC (ibid). The different priorities of the combination of the two submissions are evident in the diverse provisions covered in the Draft HIV legislation at the end of the Report of the Special Law Commission.

The purpose of the Bill as stated in opening of the draft HIV Bill is:

“An Act to make provision for the prevention and management of HIV and AIDS; to provide for the rights and obligations of persons infected and affected by HIV and AIDS; to provide for the establishment of the National AIDS Commission; and to provide for matters incidental thereto or connected therewith.” (MLC 2008, p89, my emphasis)

This notion is particularly interesting in light of the balance between rights and responsibilities (or obligations) explored in chapter eight, especially in relation to how that balance might be weighted differently for people living with HIV compared with the rest of society.

The proposed draft HIV Bill in Malawi embodies a paradox. It is a legal initiative that is founded on principles of non-discrimination (in terms of the national Constitution as well the defined premise for the proposed draft HIV Bill), but includes and embraces controversial and stigmatising provisions. It contains several self-identified “thorny” issues such as the proposal for the mandatory or compulsory testing for some people (Section 19), the criminalization of HIV transmission and exposure (Section 44—deliberate transmission, Section 45—reckless transmission, analyzed in detail in chapter eight), the forced disclosure of HIV status by a healthcare provider regardless of a client’s consent (Section 10), and other controversial provisions regulating polygamy and other “harmful”

cultural practices (MLC, 2008, p17). The main justifications given for the Bill, including its “thorny” provisions such as the criminalization of HIV transmission, includes protecting the public “at large” and balancing the rights and obligations of people living with HIV as stated early in the Report:

“The Draft Bill proposed by the Special Law Commission seeks to introduce a comprehensive law to regulate the prevention and management of the HIV and AIDS epidemic in Malawi. Further, the Bill seeks to provide for the institutional framework for effective regulation of the prevention and management efforts including the establishment, powers and functions of the National AIDS Commission. The Bill takes a multi-dimensional approach by combining public health, human rights and criminal law issues. The Bill, further, seeks to balance rights and obligations of people infected and affected by HIV and AIDS on the one hand and obligations of the State to protect the public at large from the epidemic.” (MLC 2008, p 17)

Note that this does not explicitly mention the rights and responsibilities of “the public at large” towards people living with, nor the obligations of the State to protect people living with HIV, indicating an implicit bias against people living with HIV in the foundation of the Bill from the outset.

In contrast, The SADC Parliamentary Forum adopted the Model Law on HIV in Southern Africa on 24 November 2008. It was drafted as a guide to legislative efforts in Southern Africa on issues relating to HIV. It is fundamentally rights-based, where half of the primary objectives are devoted explicitly to protecting human rights. It’s stated aims in the preliminary section are to “provide a legal framework for the review and reform of national legislation related to HIV in conformity with international human rights law standards” and to “ensure that the human rights of those vulnerable to HIV and people living with or affected by HIV are respected, protected and realized in the response to AIDS” (SADC PF, 2008, p 5).

Some of the reaction to the SADC Model Law from Malawian legislators was very favourable, as noted in media sources:

Malawi’s Justice [sic] Isaac Mtambo, who is also a Judge with the SADC Tribunal, also welcomed the SADC Model Law on HIV and said although it was not binding, it was “persuasive”. “It is the kind of law that we would feel persuaded by when we make our judgments. We can allude to it occasionally but it is not binding on us, no doubt,” he said. Justice Mtambo said the workshop had succeeded in bringing together people from various jurisdictions to exchange views on the SADC Model Law on HIV. His considered view is that more than 70 per cent of the SADC Model Law on HIV is relevant and could be incorporated into domestic legislation if member states so wished. Justice Edward Twea of Malawi described the SADC

Model Law on HIV as “all encompassing”. “Even a country that would wish to take it as it is can do so. However, the essence is not to have one law but to be uniform in our approaches. The SADC Model Law on HIV is pointing the direction for us. How far we go is up to us,” he said.²⁴

However—and it would be interesting to explore why not—the SADC Model Law was not adopted for Malawi and instead a different and more “organically grown” draft HIV Bill was proposed. The draft HIV Bill in Malawi would have avoided the contentious pitfalls of the “thorny” issues had it been more effectively guided by the SADC Model Law. For example, the provisions relating to criminalization of HIV transmission and exposure explored in chapter eight were excluded from the SADC Model Law after consultation and debate. The Human Rights from the AIDS and Rights Alliance of Southern Africa (ARASA) notes that even so a number of countries in the region were considering criminalization provisions, and the reasons behind this were unclear for a number of persuasive reasons: all SADC countries have existing, broad common law or penal code crimes which could be used to prosecute persons who deliberately transmit HIV; the SADC model law does not provide for any criminal offences; and multiple efforts regionally and internationally were raising awareness about the potentially harmful impact the criminal provisions could have on the national response to HIV (UNAIDS, 2013; ARASA, 2009, p27; IPPF, GNP+ and ICW, 2008; OSI, 2008).

Instead, it seems that the Malawian law commissioners undertook study visits to the UK, Tanzania and Singapore (the current relevance of at least two of these three countries to the Malawi context is questionable), and sought to develop legislation that attempted to incorporate the very broad and diverse administrative and public health measures anticipated from the two different submissions.

Criminalization of HIV transmission in the proposed HIV Bill in Malawi

The draft HIV Bill is full of contradictions as a proposed legislation that is, on the one hand, based on principles of human rights and non-discrimination, and yet restrictive, punitive and discriminatory on the other. Criminalization provisions in relation to HIV have been scrutinized in other specific HIV laws in other countries, for example in the N’Djamena model law on HIV from 2004. In an effort to galvanise law reform advocacy to improve the law, UNAIDS published recommendations for alternative language in 2008

²⁴ AfricaFiles, 27 October 2009, <http://www.africafiles.org/article.asp?ID=22152> accessed 19 August 2012.

that described the link between punitive laws and stigma, and the potential to undermine national HIV responses:

“Punitive approaches that involve mandatory HIV testing, disclosure or treatment, or that criminalize HIV transmission, exacerbate already existing HIV stigma and discrimination and drive people away from HIV prevention and treatment into greater fear, secrecy and denial. As a result, people may be afraid to be tested, afraid to disclose their status and afraid to take up HIV prevention and treatment lest it reveal that they are HIV positive – all of which maintains a spiral of more infection, less treatment and more infection.” (UNAIDS, 2008d, p 2)

A close reading of the specific articles of the Bill relating to the criminalization of HIV transmission, exposure and non-disclosure in Malawi highlights how it includes elements of the criminal, the maternal, the banal, the exceptional and the conceptual.

When criminalisation of HIV is referred to here, as elsewhere in much of the scholarly literature, it does not imply that all people living with HIV will necessarily be investigated, prosecuted and convicted. It is rather a term that conveys the potential of laws criminalising HIV non-disclosure, exposure and transmission to only apply selectively to certain segments of society (in this case people living with HIV) based on one aspect of their identity. In this sense it could be seen as analogous to the “criminalisation of homosexuality”—in that the commonly used phrase does not necessarily imply that being homosexual is an offence (typically there will need to be proof of acts or behaviour associated with homosexual identity before an offence is committed). Therefore the analysis of the draft HIV Bill and interviews that follow does not suggest that each and every one of the people who could face prosecution under the proposed provisions in the law would be formally processed in the criminal justice system. Rather, the analysis seeks to emphasise the number of people who, by virtue of their HIV status, could be rendered susceptible to prosecution and to explore the link this may have on HIV-related stigma.

The following section includes a close analysis of the relevant provisions of the Bill, and establishes the foundation for the focused analysis of the normative potential influence of the criminal law and stigma explored in chapter eight.

The criminal

The criminalization of HIV transmission and exposure serves as a microcosm of the paradoxical role of the law in relation to human rights, and the relevant provisions are found in sections 43-45:

“43 (1) A person who knows that he is HIV positive shall *not do an act or omit to do an act* which is likely to transmit or spread HIV infection to another person unless, before the act or omission takes place, the other person—

(a) has been informed of the risk of contracting HIV from him or her; and

(b) has voluntarily agreed to accept that risk.

(2) Any person who contravenes this section shall be guilty of an offence and shall be liable to to [sic] imprisonment for *five* years...

44. A person who *deliberately* infects another person with HIV shall be guilty of an offence and shall be liable to to [sic] imprisonment for *fourteen* years.

45. (1) A person who *recklessly or negligently* infects another person with HIV shall be guilty of an offence and shall be liable to imprisonment for *ten* years.”

(MLC 2008, p 101-2, my emphasis)

These sections of the draft HIV Bill could apply to HIV transmission, either intentionally (section 44) or recklessly/ negligently (section 45), as well as non-disclosure or exposure of HIV positive status (section 43). By implication, failing to disclose HIV status and likewise not using a condom could incur between 5 and 10 years in prison, depending on the extent to which the non-disclosure is also deemed reckless; and intentional HIV transmission could incur up to 14 years in prison.²⁵ Prisons in Malawi are already overcrowded²⁶, and the passing of this legislation means that many HIV-positive individuals could be at risk of criminalisation for failing to disclose their HIV status in their sexual relationships.

²⁵ Although it was beyond the scope of this research, it is interesting to note that sentencing seems inconsistent in Malawi through the court system. For example recent media coverage of two court cases involving stealing, one man was sentenced to 5 years in prison including hard labour for stealing a police date stamp (September, 2012, see <http://www.nyasatimes.com/malawi/2012/09/11/jail-for-stealing-a-malawi-police-date-stamp-five-years/> accessed 31 October 2012) and another man sentenced for 18 months including hard labour for stealing just over GBP£1,000 in cash and cheque from a bar (September 2012, see <http://www.malawidemocrat.com/national/man-sent-to-jail-for-theft-of-cheque-belonging-to-novelty-bar/> accessed 31 October 2012).

²⁶ While doing my research, I heard an anecdote from a friend who used to work in Maula Prison in Lilongwe, who said that the overcrowding is so endemic that the prisons have to sleep in a ‘spoon’ position, and can only roll over when the whistle is blown periodically through the night. One of the key informants interviewed (but whose interview was excluded from final inclusion because her boss was interviewed as well for the research, and the inclusion criteria was one representative per organisation based on superiority) also vividly portrayed the overcrowding by describing the last prisoner in the cell has to sleep with his/her arms wrapped around the bucket that is used as a toilet, so that they can all fit inside the cell.

The other relevant provisions include the discussion in regard to the defence of informed consent. Interestingly Malawi, is proposing to allow informed consent as an acceptable defence²⁷.

“Informed consent or marriage, according to some jurisdictions, has been acknowledged as a defence. The Commission noted that the defence of informed consent acknowledged the privacy and autonomy of individuals being able to choose to engage in sexual activities without fear of reprisals from the State. The Commission noted that to decline consent as a defence might undermine public health efforts on counselling, testing, treatment and support. The Commission observed that to impose marriage as a defence might put women at a greater risk of failing to negotiate for safe sex generally and use of protecting measures. The Commission therefore recommends that only informed consent as opposed to marriage should be recognized as a defence.” (MLC 2008, p 75)

This extract shows that marriage was rejected as a potential defence in order to protect the rights of women, recognising some of the challenges Malawian women face in negotiating safer sex within marriages (Bonga and White, 2000). This is interesting because while the Report acknowledges the challenges of gender inequality, and the vulnerability of women within some marriages to acquiring HIV and potentially also gender violence, the deliberation is incomplete. The logic underlying this decision is assuming that the women being protected are those who are HIV negative – the assumption being that it is the husband who would bring HIV into the relationship. It fails to acknowledge that is often women who know their HIV status first, through antenatal testing for HIV, and can be blamed and punished for bringing HIV into the household (Ahmed, 2011). A defence relating to marriage would under these provisions not protect a woman living with HIV who may equally find it challenging to negotiate safe sex within her marriage.

The maternal

This devaluing of the rights of women living with HIV is apparent in other parts of the law, such as the provisions relating to the potential criminalization of vertical transmission of HIV and mandatory HIV testing for all pregnant women.

“The first case identified for compulsory testing is that of pregnant women. The Commission considered that if Government were to demonstrate its commitment to protecting the life and health of the unborn child then it would be appropriate

²⁷ This is different from many other countries around the world where HIV transmission is criminalized using legislation relating to grievous bodily harm (like in England and Wales) and it is not possible to consent to a harm as ‘grievous’ as acquiring HIV.

that the current Routine Offer of HIV testing to pregnant women should be made compulsory. The Commission was aware that the routine test offered in health centres for pregnant women has led to negative social and economic consequences for many women where marriages end in divorce. The Commission however considered this negative consequence as a *lesser evil* compared to transmission of the virus to the unborn child.... The Commission therefore recommends compulsory testing for both pregnant women and their sexual partners.” (MLC 2008, p 53; my emphasis)

Even though the law recognises the potentially discriminatory nature of this provision for women and mothers living with HIV, it disregards those in favour of preventing HIV transmission to the “unborn child”. This is reviewed in detail in the broader context of criminalizing sexual and reproductive health in the analysis of the interview with OL15 (see insert 5). Therefore the construction of harm in this case, in terms of the greater ‘evil’, weighs in favour of the foetus as opposed to the mother—that is being born without HIV is seen as a stronger ‘good’ at the expense of denying mothers who are HIV positive the right to choose whether to be tested for HIV. The Report also fails to note the potential disincentive compulsory testing might create, which was noted by a number of participants in this research, given human nature and a tendency to resist things that are mandatory. The current uptake of HIV testing, even when offered by providers during antenatal visits is very high, which could be jeopardised by the introduction of mandatory testing for all pregnant women.²⁸

The banal

The only other explicit route of transmission singled out for criminalization in the draft HIV Bill in the section on ‘transmission and exposure’ was hair cutting.

“The Commission also noted that the enterprise of operating barber shops also increase the risk of exposure to HIV infection... The Commission concluded that in case a barber does not exercise his duty to ensure that risk of exposure to HIV infection is removed, criminal sanctions should ensue” (MLC 2008, p 76).

The extent to which HIV transmission within barber shops is unclear (!), given that the most common mode of transmission analysed and addressed in the national HIV strategic plans related to heterosexual transmission. This example highlights the pedantic detail that is included regarding some of the sections, whilst simultaneously demonstrating the lack of relevant attention that is missing from the levels in between.

²⁸ During this research, a Ministry official indicated that the rates were as high as 97% uptake of testing in antenatal facilities. Personal communication.

The exceptional

The draft HIV Bill also demarcates that HIV is somehow exceptional, and therefore not adequately covered under existing laws such as section 192 of the Penal Code.

“The Commission observed that it is an offence under section 192 of the Penal Code when any person unlawfully or negligently poses the risk of spreading the infection of any disease dangerous to life. ... Nevertheless, the Commission considered that the *peculiar nature of HIV* and AIDS requires a specific penal provision and recommends accordingly.” (MLC 2008, p 74-5; my emphasis)

As reviewed further in chapter seven and noted in one of the participant’s responses outlined in chapter eight, section 192 of the Penal Code has already been used to prosecute some people directly (selectively targeting sex workers in Mwanza District in 2009).

The “peculiar” nature of HIV – somehow more grave than “any disease dangerous to life” - renders it exceptional and needing of special attention according to the findings from the Special Law Commission (MLC, 2008, op cit). In this case, it seems that the perceived exceptionality of HIV has created a justification for promulgating a specific law, with harsher sentencing and punishments, with explicit provisions regarding different modes of HIV transmission. Other authors have argued that the emphasis on peculiarity or exceptionality has fuelled stigma (cf. De Kock et al, 2002). As explored in chapter eight, the combination of experienced stigma as well as the perceived or anticipated potential stigma through the application of criminal provisions in the response to HIV, and other provisions within the law, could fuel a vicious cycle of devaluation of individuals within society.

The conceptual

The framing of HIV transmission in the draft HIV Bill is one of death. For example, in terms of economic aspects of HIV, the Report notes:

“As such, loss of life to HIV and AIDS is a loss of all that investment made on each and every individual and their unrealized potential... As such, economic prosperity becomes a pipe dream. Individuals who are infected and affected with the HIV and AIDS epidemic are, in most cases, people who have social and financial responsibilities over their households...In many cases, such individuals are heads of households and sole breadwinners whose *death* often leaves the survivors destitute.” (MLC, 2008, p10, *my emphasis*)

While there is some truth in this statement, the framing is one of hyperbole and negativity. In a country where approximately one million people are living with HIV (estimated at

approximately 10.6% of the population as already noted), and by extension a significantly larger number of households are directly affected by HIV, there are likewise many stories of survival. As the life stories demonstrate, many people living with HIV are living productive and fulfilling lives, providing for families and relatives, and planning for the future. In another example, echoing the alarmism of LC4 (op cit), the link is over-emphasized with dramatic language between promiscuity and ‘rampant’ exploitation of women, resulting in death.

“The Commission further observed that HIV and AIDS permeates every aspect of human life such that human rights mechanisms are essential in the fight against the epidemic ... Alongside the new responsibilities brought by HIV and AIDS, exploitation of women and girls becomes *rampant* especially when they are forced into risky and promiscuous behaviour to make ends meet thereby facing greater risk of HIV infection. The natural consequence of this scenario is faster progression of AIDS and *death*.” (MLC, 2008, p36, my emphasis)

Other examples of the melodramatic used to describe HIV included in relation to increased death rates and the impact on land grabbing (and the criminalization of that) (p 48) and the attrition rate among education professionals who die from HIV-related illnesses (p 70). Even though this occurs, as noted in the life stories, the Report presents the negative aspects of HIV disproportionately in relation to the multiple daily realities of living with HIV.

In contrast, living healthily is seldom referred to and usually in relation to justifying a limitation of rights for people living with HIV. For example, the Report was informed by stories from rural areas where Chiefs, custodians of customary land, prefer to give land to people “who are perceived to be healthy” (MLC, 2008, p48). While the Report rightly recognises the links between these discriminatory actions, vulnerability to HIV, and poverty, it nonetheless is silent on correcting the misperception in regard to health and HIV status.

For comparison, 73% of the people who completed *The People Living with HIV Stigma Index*²⁹ in 2010 indicated that they were in good to excellent health at the time of completing the survey (Chirwa et al, 2011). As demonstrated for example by LS14, it is possible to live a healthy life for many years with HIV before even starting ARVs, and other participants indicated that they were living happy, healthy, productive and ‘positive’ lives.

²⁹ The total sample size was 2272 participants, all living with HIV (see chapter 3).

The proposed inclusion of provisions to criminalize HIV transmission, exposure and non-disclosure in the draft HIV Bill goes directly against the grain of the latest international standards as well as the SADC Model HIV Law (see above). For example the Report from the recent Global Commission on HIV and the Law explicitly recommends warns against applying punitive sanctions against HIV transmission. Recommendation 2.1 states:

“Countries must not enact laws that explicitly criminalise HIV transmission, HIV exposure or failure to disclose HIV status. Where such laws exist, they are counterproductive and must be repealed. The provisions of model codes that have been advanced to support the enactment of such laws should be withdrawn and amended to conform to these recommendations” (UNDP 2012, p 25).

UNAIDS has produced a series of briefings, and held two expert meetings in 2011 about the latest technical (e.g. in proof, evidence, case law) and advocacy relating to provisions criminalizing HIV transmission, exposure and non-disclosure around the world.³⁰ A UNAIDS Guidance Note released in 2013 highlights critical scientific, medical and legal considerations and warns against the use of overly broad criminalisation of HIV non-disclosure, exposure and transmission in the law (UNAIDS, 2013). The Guidance Note suggests that two key scientific and medical developments relating to HIV treatment that necessitate a revision of the application of criminal sanctions to HIV transmission, exposure and non-disclosure—namely the significant reduction demonstrated in AIDS-related deaths and the extension of the life expectancy of people living with HIV to near-normal lifespans; and the reduction of the risk of HIV transmission due to effective treatment (UNAIDS, 2013, p 9). HIV has been transformed from “a condition that inevitably resulted in early death to a chronic and manageable condition” (ibid).

Worthy of note but unfortunately beyond the scope of this research are the numerous civil society consultations, letters, facsimiles and other correspondence sent to the Malawi Law Commission, the Chair of the Special Commission, and the Office of the President and Cabinet registering concern at the more problematic provisions within the draft HIV Bill. Concern was raised about the punitive, stigmatizing and detrimental criminal provisions and mandatory testing provisions repeatedly (cf Dignitas 2010, Canadian HIV/AIDS Legal Network 2010, ChristianAid 2010, MANET+ 2010; UNAIDS, 2010).

³⁰ See for example UNAIDS press release about the expert technical meeting, September 2011: <http://www.unaids.org/en/resources/presscentre/featurestories/2011/september/20110907criminalizationmeeting/> accessed 27 October 2012.

In Malawi, a context where almost every family is affected by HIV and almost 1 in 6 people live with the virus (NSO, 2010), universal access to first line HIV treatment is assured in the national policy (Malawi Government, 2012), policy makers are leading the world in the progressive rollout of programmes to prevent HIV transmission from mothers to their children (Schouten et al, 2011), and HIV is resultantly perceived by many participants in this research as more of a chronic disease than the ‘death sentence’ it may have once seemed (as outlined in chapter five), reasonable doubt exists as to whether HIV ‘offends the common consciousness’ at all (see chapter two for review of sociology of criminalization).

The application of the penal law to HIV transmission and exposure—a relatively recent development around the world, and brand new in Malawi through the drafting of the proposed HIV Bill—can be seen as indicative of the problematic role of the law in social control, stigmatization and the policing of ‘deviance’ (Weait, 2007; Garland, 1996). Criminal law in essence provides a mechanism for the deterrence, punishment, or retribution of those that violate established social norms through legal action such as imprisonment, probation, community service, or fines. Specifically in the context of HIV transmission, exposure and non-disclosure, this raises questions about the interface between constructions of responsibility, harm, consent, and the delineation of attitudes towards disease and society (Weait, 2007).

C| CURRENT CHALLENGES IN THE NATIONAL RESPONSE TO HIV

Malawi is relatively under-researched in terms of social science in general as well as on specific issues and concerns relating to HIV. This research provides in-depth results exploring HIV-related stigma, complimenting other current national research about HIV and the structural determinants of health. Noteworthy differences emerge between the participant’s perspectives (including people living with HIV, the opinion leaders, and law commissioners) about the current priorities in the national response and those articulated in the national policy documents. Although this was not the primary focus of this research, each participant was asked a “diagnostic” question about their opinion regarding the “biggest challenge” or “most important priority” in the national response to HIV. When participants identified more than one challenge or priority in their response, each theme was noted separately. This ensures that the analysis presented throughout this thesis is as

authentically inductive as possible, and informed by the priorities and issues identified by the participants themselves in addition to the secondary literature reviewed in the first half of this chapter.

According to the participants interviewed as part of this research, the three biggest challenges in the current response to HIV in Malawi are prevention, stigma and health infrastructure. Other significant issues identified included resources, the framing of HIV in the national response, political leadership, culture and the law. Even though a few participants noted the higher HIV prevalence among certain groups, such as prisoners, MSM and sex workers, none explicitly recommended the need for specific, tailored responses to meet the prevention, treatment, care and support needs of these groups.

The following section reviews the details of the three most prominent themes identified as the current challenges in the response to HIV: prevention, stigma and health services/ infrastructure (see Annex 4|1). It concludes with a review of other important themes raised in the interviews, and a discussion of the similarities and differences with the national policy documents.

Prevention

The most common issue participants identified as the biggest current challenge in the national response to HIV was HIV prevention, with more than two-thirds identifying HIV prevention as the priority concern. This included a range of practical issues such as positive behaviour change, condom use, information and civic education, and promoting understanding about HIV to respond to perceived gaps in knowledge (see Annex 4|2).

It is interesting to note that within the largest sub-group, relating to condom distribution and usage, there was a wide variety of both understanding of the issues as well as knowledge relating to condoms. One participant, for example, who was in a senior position within a Ministry, appeared to be ill-informed about condoms:

“People should have more knowledge with regard to HIV/AIDS; how to prevent [it] and everything else. And well the prevention, people – they emphasize so much about condoms, but you know there is a disadvantage in Malawi with the use of condoms. Well I think, because I haven’t looked at condoms as such, but I think condoms have got one size. And yet people have got different sizes. And that’s one thing, so if the condom is too big, what happens? If the condom is too small, what happens? There is no alternative to size. I don’t think in condoms there is small, medium and large and extra-large. But I think human beings are different. So with that I wonder if condoms are really a solution. And secondly condoms are rubber, and in Malawi we have got hot seasons and cold seasons, and you find that there is

no information on how to keep and preserve condoms. I don't know what happens when they are exposed to extensive heat, and I don't know what happens when they are exposed to extensive cold. We don't have very very cold conditions but the heat can be quite a lot. And in certain places if you have been to Chikwawa, what happens to condoms in shops that are displayed openly – at a Filling Station there is no Air Con, it is too hot, or expose to the sun as such. So if people think that condoms are a solution in Malawi the fact that there is one size and there is no information on preserving them, I don't think it's a solution to many people.” (OL7)

This extract from OL7 illuminates some concerning misinformation and value judgments about condoms held by a senior government official. This comment is particularly interesting in light of the analysis below relating to political leadership and the "othering" of HIV, and the perceived need for a greater ownership and leadership of HIV among public figures including senior civil servants, Traditional Authorities, and Members of Parliament. Likewise recent efforts to catalyze family planning in Malawi (such as the national conference held in July 2012) have been viewed as a reaction to a legacy from the past that rejected contraception as a concept foreign for Malawi (cf Lwanda, 2001).

Prevention was almost unanimously framed in terms of preventing HIV transmission and protecting people who are HIV negative. Only one participant made reference to prevention of “infection” for people living with HIV, indicating recognition of the sexual health of both partners. However even in this instance, this was framed in terms of responsibility for people living with HIV to protect others, and as noted in chapter eight also framed in terms of a tension between the rights of people living with HIV and the rights of others. Throughout all of the interviews, there was no indication of an awareness to protect the sexual health of people living with HIV as a priority in and of itself.

Finally, prevention was often not mentioned in isolation, and many of the participants drew connections between prevention and other important aspects of the national response – such as addressing stigma and discrimination. One such example is:

“For me I would say prevention, but for me prevention inherently deals with our conceptualization of HIV in this nation. And as and until the Stigma Index totally disabuses me of my pre-conceived notions of what stigma represents in this country, I would still tend to strongly think that stigma and discrimination is so fundamentally intertwined. You – we can't achieve universal access to prevention, to care, to treatment and support as long as stigma and discrimination exist. Therefore addressing stigma and discrimination is a fundamental component of any of the things we do. But in terms of if I have to pick a programmatic component, it's HIV prevention. We're looking at 70+ thousand new infections a

year in a country of 13 million people? I mean how sustainable is that? I was very pleased that one of the... representatives from OPC* stood up at the National AIDS Review and said ‘how long before we’re all HIV infected at this rate?’ which is a very intelligent observation. This is not sustainable.” (OL3)

However, none of the participants mentioned combination prevention, which was formalized as the recommended approach to HIV prevention by UNAIDS in 2010 (UNAIDS, 2010). It is also interesting to note that my research pre-dates the attention to treatment as and for prevention, which was catalyzed by the publication of the findings from the HPTN052 trial (which included 481 couples in Blantyre and Lilongwe in Malawi) in 2011.³¹

Stigma

The next most prominent challenge participants identified was stigma. Taking into account that most participants were aware that the research was investigating stigma and HIV in Malawi, which might have contributed to the large numbers, it is nonetheless worthy to note that almost two-thirds of participants identified stigma as a main concern in the national response to HIV. The sub-categories described relating to stigma included stigma and discrimination in general, denial and internalized stigma, acceptance and the need to accept HIV, othering and a culture of silence. Conversely, one participant explicitly mentioned that stigma was no longer a big challenge in Malawi (see Annex 4|3).

One participant summarised concisely, suggesting that the HIV response needs to be re-framed to focus on a holistic notion of a person:

“To me the biggest challenge is the focus – focus as far as HIV programmes are concerned, focus has been on the physical part of the being, and forgetting the emotional part and the psychological part of the being.” (OL13)

This quotation highlights the importance of (and rationale behind) an approach such as the life story methodology undertaken in this research, that can encompass the emotional and perceptive dimensions of people as well as the rational (see chapters three and five).

Several participants highlighted issues relating to denial, acceptance and the internalization of stigma as a primary concern. For example,

“Issues like stigma, like self-denial, those are some of the things that up to now some people haven’t realized that by denying themselves they are in the unfortunate circumstance of being found HIV positive – diagnosed HIV positive. For

* Office of President and Cabinet

³¹ Details of study protocol available on the HIV Prevention Trials Network website: http://www.hptn.org/research_studies/hptn052.asp accessed 22 October 2012.

them they think that's the end of life. And it might not be discrimination coming from a third party but from within. That's the bottom line of stigma, so self-denial, saying 'no I don't think I can belong to this society because I am HIV positive.'" (LC2)

Denial was also explicitly linked to concerns relating to different groups within society, and a sense that it was greater among those who are professional, well-educated, or part of the so-called "elite" of Malawian society:

"[What] I would rate top would be the issue of denial. Previously it was denial across the board, at different levels, and now we still have denial at the top level – the elite level. At the grassroots don't have as much denial as we used to in the past, but these days you still have people in denial at top level. Maybe... it's the fact that people would be ashamed to maybe to lose face or to regret their status I am not sure, but you still find people who have all the necessary resources and they know where they can get assistance in terms of therapy for HIV/AIDS, but still people don't go there." (LS15)

"The professional person should come out in the open and talk about the epidemic. I have already said that HIV does not choose. So since it does not choose it is not only for road cleaners. HIV is not for people who mop. HIV is not only for the messenger alone. It is there for even bosses in the offices. It is there even for... those highly educated people.... the elite. So.... what is needed is for people should understand that HIV does not discriminate." (LS4)

These extracts highlight another dimension of intersectionality (as explored in chapters five and seven) – relating to class – that may have an influence on experiences of internalized and externalized stigma relating to HIV (cf Cameron, 2012). It is interesting to note, as developed further in the section on leadership below, that all of the participants who identified stigma among the "elite" of Malawi as one of the biggest challenges were people living with HIV who could be considered themselves as peers within this group. Other research has pointed to a history of classism in the response to HIV in Malawi, in part due to the limited access to treatment restricted to only those who could afford to pay, and potentially the discussion relating to stigma and elitism is in part embedded within that historical context (cf Lwanda, 2001).

A prominent theme amongst those who identified stigma as a primary concern was the notion of acceptance and the need to encourage greater comfort with HIV. For example,

"The biggest challenge I think is still the inability to make people comfortable with the whole subject matter about HIV/AIDS. The information is there now. In terms of contracting AIDS, in terms of management of AIDS I think the biggest challenge is still the inability to make it one of the diseases. It is still a special disease in terms of people wanting to keep it to themselves or people not trusting each other about

disclosure. So even within families people are still unable to come out in the open.” (OL4)

This challenge of making HIV “one of the diseases” or in other words normalizing HIV is one of the paradoxical questions of stigma explored in this thesis (see chapter six), given that stigma can be productive to guide behaviour and add meaning to some people’s lives (in terms of feeling included and part of an HIV movement for example), while also entrenching a sense of devaluation and shame in the lives of others (who may be struggling to come to terms with an HIV-positive diagnosis).

A few participants noted a kind of extreme acceptance or culture of silence within Malawian culture that may in fact on the other hand impede an effective response to HIV. This kind of acceptance would disempower people from confronting situations that perpetuate vulnerability to HIV (for example power imbalances within relationships due to gender inequality).

“The other thing is I think the silent syndrome. You know in our culture people don’t want to talk about the issues. That’s why in terms of gender-based violence, in terms of that stigma we are talking about, people want just to remain silent. So although they have issues they just want to remain silent. So there is that silent culture, even in meetings where people, you see people don’t want to raise issues which they think are controversial.” (OL10)

From combining the different participant’s perceptions, it therefore seems that acceptance can be important as part of the response to overcoming stigma but only in so far as it does not disempower people from challenging experiences of discrimination or from confronting stigmatizing behaviours (see chapter six).

It is important to note that one participant explicitly commented that stigma is no longer a concern in Malawi in his opinion. Unlike other participants who referred to some of the barriers to acceptance and overcoming stigma (such as a culture of silence) in Malawi, he referred to the positive social structure and response to HIV in families and the community:

“Stigmatization can be there but what I have seen is that culturally Malawians would like to live together; they would like to support the patients. So stigmatization is not really very serious in Malawi. You see with the norms of the extended family, I think we have built a structure where we say if one is sick in a family it means the whole family is sick and therefore we need to look after our friend. So I don’t think stigmatization is an issue especially when we look at these terminal illnesses, like HIV/AIDS is one of them, so there isn’t much stigmatization. Of course there could be in other families we could sense it, but I think there is a lot of messages of awareness, you know, sensitization you see that we need to

have those who are sick but also I see that there is a lot of counselling among those who are positive. So stigmatization in my view, discrimination in my view, is not really a big issue.” (OL1)

In some ways, OL1 here could be referring to a notion of ubuntu, in his perception (and wish) that “culturally Malawians like to live together” (see chapters two and seven).

These articulations of stigma as one of the current biggest challenges in the national response to HIV in Malawi are interesting in light of the conceptualization of stigma among participants, reviewed and analyzed in chapter six.

Health services and infrastructure

The third most prominent challenge identified by just over half of participants related to health services and infrastructure. One participant did directly link the challenge of infrastructure and equipment back to stigma against people living with HIV:

“The biggest challenge that I see in 2010 is stigma and discrimination against people living with HIV... Talking about stigma starts with government up to the community in the village. I mention government because it puts in place policies and program. It does not know that those programmes are fuelling stigma. But to us, to me, who is HIV positive, I am able to see that such and such programmes are facilitating stigma.... One example that I have seen to facilitate stigma is... lack of proper equipment in our hospitals.” (LS5)

Another participant also noted the quality of care for people living with HIV as the main challenge. However most who noted challenges in this area referred to aspects of ART, capacity of health care providers, their workload and distribution of the workforce, health systems in general, infrastructure in general, and alternative models of care such as through NGO or CBO providers (see Annex 4|4). Within the group who noted ARVs as the biggest challenge, the priorities were drug supply, quality of drugs and the alternatives relating to side effects and treatment access. As reviewed in chapter seven, this is particularly interesting in light of one of the main perceptions of the potential role of the law in Malawi as being the protection of access to treatment for people living with HIV (which in reality in Malawi is provided according to national policy rather than related to the law).

Regarding infrastructure, participants noted technology (for example access to and maintenance of viral load testing machines and machines to check CD4 count) and the physical structure of healthcare facilities as a key challenge. The most common example given was the location of the window for accessing and collecting ARVs, as some

participants noted that this could be improved to mitigate stigma in healthcare facilities and remove a barrier for people accessing health services. For example, one participant spoke of her personal experiences in accessing ART:

“The biggest problem would be my visit to the hospital. As I said I am a teacher and I sometimes leave my students to go to the hospital. The reception by the doctors is sometimes bad; they curse and use offensive language, which is hurtful and results in tears sometimes. But since we have no choice, we wait it out until we get the ARVs.” (LS20)

Another participant spoke of the same issue from a policy perspective, clearly having not been personally affected by any direct experience, and also evidently confused about how to negotiate or rationalize quality of care that respects privacy and confidentiality with issues of discrimination and the provision of integrated and/or specialized or separated health services.

“Another area with I see as another challenge is the separating the HIV treatment from the *normal* treatment because that also brings its own stigma... when people are getting ARVs they go to face the window. When people are getting tested they go to a *special* room. Those also are forms of discrimination you see. They are forms of discrimination but it’s because people wanted to hide... And the integration would be very difficult because when you are talking about it on the open because somebody will feel ‘oh my rights have been violated.’ Why are we not doing the *same* when somebody has hypertension and diabetes? Because both conditions, you take treatment for the rest of your life. So what is special with HIV? So this is the challenge? It’s a very big challenge. And when they go to the hospital and they are told ‘all those who have come to get ARVs, this line’. They feel so offended.” (LC4, my emphasis)

This response from LC4 highlights how subliminal messages can be conveyed in the words (or tone) used, contradicting the apparent meaning of the statement.

In terms of health systems, a few participants noted that the systems in general need to be strengthened. One participant suggested that the biggest challenge is the capacity of NGOs to provide services and referrals, since he perceived them as the current (and future) main entry point for people to access testing, treatment, care and support services. On the other hand, another participant noted that one of the main challenges is the proliferation of “fraudulent” community—based organizations who misuse funds and do not actually serve the needs of people living with HIV even though that is their stated objective.

Funding and resources

The fourth most pressing challenge identified by almost half of participants related to resources, and in particular to current levels of funding. Two participants also explicitly mentioned the potential impact of the new WHO guidelines³² and the funding gaps in relation to providing ART to an expanded group of people.³³

“More resources are needed ... because life is not cheap - life itself is not cheap. People expect you to use small resources towards responding to HIV, which should not be the case – that should not be the case. In as much as life is expensive we should expect something that supports the support the life to be expensive as well.” (LS4)

In an opposite sense to Goffman’s notion of a ‘spoiled identity’, LS4 is in fact arguing for the investment and valuation of human life and living with HIV. Other key considerations within resources that emerged from the interviews included monitoring and evaluation, agenda setting, sustainability and the reliance on international funding, as well as the allocation and/or mobilization of national funding to support the national response.

Nonetheless, even though most resources for HIV in Malawi comes from foreign aid, several participants also noted that the challenge in Malawi is one of both the magnitude of HIV as well as the framing of HIV as a holistic issue. For example, OL8 suggested that the biggest challenge is both the scale of HIV as well as the impact it has on (and demands from) health systems:

“The biggest challenge in the response? One I think is the magnitude of the problem itself, that’s where the challenge is. If there were only 3 or 4 people infected it would have been a smaller challenge. But it’s the fact that it is quite a big chunk of the population that is infected and affected. In fact that also it’s the people who are of reproductive age, people who are in productive age, economically active population that are being affected... HIV carries a face of a woman, a young woman to be specific. So these are things that pose a big challenge for the country in terms of trying to surmount the repercussions of the epidemic. Yeah. So this has implications in terms of resources, although we need more resources, many people are wanting to access treatment, the health system now, human resources for health, the infrastructure itself, all those things they pose a challenge to the epidemic. And we don’t know what the future holds in

³² It is important to note that since the time of interviews, new WHO ART Guidelines are expected to be launched in June 2013 that will increase the suggested initiation point for example to a CD4 count of >500, and treatment for life for all infants born with HIV and for all pregnant women living with HIV.

³³ During the period of research, one of the main areas of discussion/ contention involved the changing of the WHO guidelines for when someone should start ART (from having a CD4 count of <200 to <350). This is evident from the responses of the participants below, who may have been influenced by media coverage and national Country Coordinating Mechanism (CCM) for the Global Fund meetings at the time (for the opinion leaders), and mentioned access to treatment and resources as the most pressing concern in the national response to HIV.

terms of resources. And our response is still dependent on external support so these are challenges that we need to surmount if the response is to be sustainable.” (OL8)

A few participants mentioned the need for a holistic framing or broad focus of the national response to HIV as the biggest challenge. For example,

“It’s something that I think we are now coming out of just looking at it as a disease – it’s a social problem, it’s a social issue, it’s a rights issue and there is just so much that you can address administratively. You rely on people’s attitudes and consent and agreement.” (LC3)

“It’s difficult to say one thing would be the biggest challenge I think HIV cuts across too many areas and because it cuts across too many areas that makes it very challenging for the national response because then the national response has to tackle all the various facets that it hinges on.” (LC9)

The notion of HIV cutting across many areas and being a “social problem” is consistent with the conceptual framing of HIV in terms of structural determinants of health (WHO, 2008), and also with recent government framing of the core issues (Malawi Government, 2012; MLC, 2008). In a similar vein, OL1 noted that HIV must be viewed within the context of the wider implications for the wealth and economic development of Malawi:

“HIV definitely has been a challenge because it is taking the lives of many young people who would be leaders of tomorrow, contribute to economic and such development of this country.” (OL1)

Other participants drew links to specific structural drivers of HIV such as access to education and illiteracy (one participant), access to livelihoods and poverty (3 participants), food security and nutrition (2 participants).

Governance and leadership

Another challenge mentioned by some participants concerned national leadership in the response to HIV. This was particularly apparent in the challenges identified by the life story participants, and perhaps expectedly, concurrently absent completely from the national policy documents. A typical response highlighting leadership as a critical challenge was:

“The biggest challenge facing Malawi in response to HIV is aah turning knowledge into positive change because what Malawi as a Nation has been grabbing over the years we tend to say awareness is at about 98-99% but you still have people who can’t translate that awareness into positive behaviour change in order to stop the spread of the virus and may be contain it. That’s the biggest challenge of Malawi.

That's how I look at it and also we talk of leadership unless leadership is there but then I always argue to say why should it always be people - why don't we have people in leadership coming out in the open to say they HIV positive because those people would act like role models to everyone else. If one day a Minister we have a Minister coming out to say 'I'm HIV positive' that would act as an encouragement to other people but then as it is HIV is looked as at as a disease of people that are poor, illiterate and what have you professional." (LS11)

"Leadership" included a desire for more role models among ministers and traditional authorities, as well as comments that professionals and other "elite" members of the community were reinforcing stigma by remaining silent about the extent to which HIV was present in their lives (see discussion earlier in this chapter relating to class and intersectionality). One participant explicitly turned this notion around, and in fact encouraged other people living with HIV and leading advocates within the national response to HIV to more proactively engage leadership:

"We have not been honest with ourselves. For example, it's only this year that I got to know that in this country that we have a Traditional Authority living with HIV, because of the Stigma Index. And that is a big problem and when I was asking him, he says his subjects don't know. No other Traditional Authority apart from himself knows. That tells you where we are. But this in Malawi doesn't come as strange; culturally we are very conservative people ... The biggest problem we have now is the educated people themselves, the people who have money, and these are the people who are continuing to die – up to as even I am talking to you, now this is 11 January 2011, the elite continue to die. Just two weeks ago we buried two elites in the media. Parliament, have we gone to members of parliament? Forget everything, let's just talk about HIV: 'How do you think first how does it affect you – you yourself, you as a person, you as a family, you as blah blah blah? What do you think we should do?' Have we done that? We haven't. So, members of parliament they don't want this thing. They don't want this thing apart from moving with files, whatever we call it legislation, they don't want this thing." (LS7)

In contrast, one participant noted that there is effective and strong political leadership against HIV in Malawi, and instead suggested that the main challenge related to structural issues, in this case nutrition and food security.

"We have a political will, the President of this country would like to see that HIV/AIDS is completely reduced in this country and hence we're strengthening on food production because from food production we can address the issue of nutrition you know if we had a lot of food in the country, I think we [should] improve nutrition, and nutrition is critical, because of those HIV positives get better diet I think they live longer and even the ARVs, the drugs they take, since they get food, I think they sustain – their health can be sustained." (OL1, op cit)

The last two main challenges identified were culture and the law. Of the few who mentioned culture, four participants referred in general to cultural norms and three explicitly cited gender as the main challenge.

Of significance for this research, only four people identified the law as the biggest challenge in the current national response to HIV from different angles in response to the open-ended question about the biggest challenge in the national response to HIV. Of those who indicated that the law was one of the most important challenges in the response to HIV, one suggested that there was a conducive legal framework and the biggest challenge is implementation and enforcement. However two others indicated that the biggest challenge was that there is not a legislative framework for HIV, and that all issues relating to HIV need to be 'legalized'. One participant noted that in terms of human rights, there is a conflict between the rights of people living with HIV and those of everyone else, creating a tension in the implementation of the law.

Even though at first few participants cited the law (unprompted) as one of the main priority areas in the national response to HIV, later in the interviews, when asked directly about the role of the law, it was almost unanimous across all participant groups that the law had an important role to play in the national response to HIV (see chapter seven). This supports the notion that the association between HIV and the law in response to HIV is not obvious for most participants, suggesting that the real purchase of the law and formal legal mechanisms is either weak and/or underutilized in the enforcement of national policies relating to HIV in Malawi.

CONCLUSION

The history, politics and cultural context of HIV and human rights in Malawi, spanning the national policy documents and participant's responses, suggest that research into stigma and the law in Malawi is timely. The current national mobilization and commitment to addressing stigma, identified as the second biggest challenge by participants and cited as critical in the recent National AIDS Commission conference and endorsed by the President, indicates that the findings from this research may be useful to inform interventions to address stigma in the new National Strategic Plan 2012-2016.

The current political attention to enacting HIV legislation in Malawi, despite the fact that the link between the law and a national HIV response was not immediately apparent to most participants, and that the proposed law is actively triggering resistance

by its controversial provisions (see chapter eight), also suggests that detailed and in-depth research on this aspect is timely and useful.

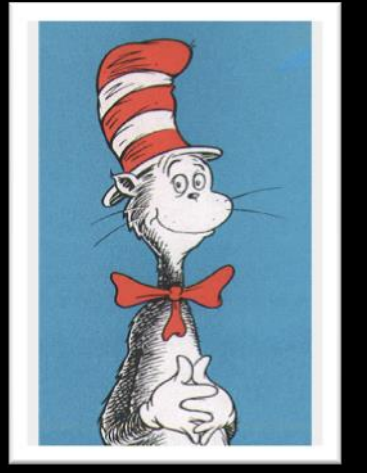
Priority areas identified in the Extended National HIV and AIDS Action Framework (NAF) 2010 – 2012 (Malawi Government, 2012, p 9)	Biggest challenges identified by participants in this research (October 2010 – March 2011)
1) Prevention and behaviour change 2) Treatment, care and support 3) Impact mitigation 4) Mainstreaming and decentralization 5) Research, monitoring and evaluation 6) Resource mobilization 7) Policy and partnerships	1) Prevention 2) Stigma 3) Health services and infrastructure 4) Funding and resources 5) Governance and leadership

Table 11: Comparison of priorities in the national response to HIV between policy documents and participant’s responses in this research

This chapter has sought to demonstrate the importance of listening to people to better understand and set priorities in the national HIV response. As the results demonstrate, while there is some overlap there are clear differences between the priorities identified by the participants in this research and those stated in the national policy documents. The general lack of consensus on one priority – or conversely the identification of many priorities – in the national response to HIV also serves to highlight the complexity of HIV and how it intersects with multiple aspects of an individual’s life, of society, and of national governance.

5 | “HIV IS NOT THE WHOLE STORY, IT IS PART OF LIFE”

“Sometimes the questions are complicated and the answers are simple.” --Dr Seuss



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HIV IS PART OF LIFE

HIV has different meanings in everyone's life, ranging along a spectrum from very positive to very negative. Just as there are more than 7 billion people in the world living varied lives in very different places, with different sounds and smells and daily routines, so too is the diversity in the daily realities of the 34 million people estimated to be living with HIV around the world, including the one million living in Malawi.

This may seem a very obvious starting point, but one which all too often is overlooked in efforts to address HIV-related stigma and discrimination. Initiatives to address HIV-related stigma have often focused (arguably in a blinkered way) almost exclusively on a person's HIV status. To date most interventions overlook this contextualized complexity and focus on individuals, in assumed 'static' situations, aiming to increase the knowledge and empathy of potential stigmatizers or improving the ability of people living with HIV to cope (e.g. Earnshaw and Chaudoir, 2009). Few social programmes that address stigma promulgated by structural and institutional factors were identified in a recent review of peer-reviewed literature (Mahajan *et al*, 2008). Yet the life stories presented in this chapter illuminate much more complicated, passionate and nuanced lives in terms of the highs and lows of life, including living with HIV. So while the questions may be very complicated, the starting point and in fact the answers, may be simpler than at first appears imaginable.

This chapter presents an analysis of the life stories to lay the foundation for the discussion of research questions two and three—that is, the extent to which experiences of HIV change over time and alter in relation to the multiple layers that comprise individual identities and the role of law in the daily lives of people living with and closely affected by HIV. This section is foundational for further analysis of these issues in relation to stigma in chapter six, and legal consciousness and access to justice in chapter seven.

One of the challenges of qualitative research is knowing when to stop, and when to recognize a saturation point when common themes begin to recur and the interviews stop illuminating new insights. This is fundamentally impossible in life story research (as noted in chapter three) given that every life and every person is different. Therefore this chapter does not pretend to be exhaustive or representative of the multitude of realities of living with or being affected by HIV in Malawi. On the contrary, it seeks to present the lives of a few to highlight the nuances and diversity that must be at the forefront of our collective consciousness in considerations relating to responding to the lives of many, in the context

of living with HIV and experiences of HIV-related stigma. It includes a description thematic survey and individuals, as per the typology of the presentation qualitative research (see chapter three), and builds on the descriptive analysis of society outlined in chapter four (Sandelowski and Barroso, 2003).

This chapter presents a summation of the selected life story interviews included in the final analysis of the research.³⁴ The chapter then discusses the results through an exploration of the meaning of HIV in the lives of people living with and directly affected by HIV in Malawi. It includes an analysis of the extent to which people described their experiences of HIV-related stigma as well as a review of the individual experiences and motivations in relation to three key areas: testing, disclosure, and acceptance (or not) of an HIV positive diagnosis. In conclusion the results suggest that efforts responding to HIV, particularly those targeting HIV-related stigma, need to place a holistic conceptualization of a person at the centre of the response—as an active agent in their own processes of individual and social change—and not only as a person defined in terms of an HIV positive status.

A strong foundation

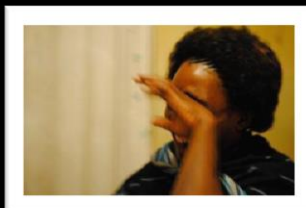
The following section introduces personal and situational aspects of the people whose life stories form the foundation of this research.

The life story participants were a diverse group spanning across age, gender, livelihoods, education levels, religious beliefs and sexual orientation (see chapter three). The group of 20 includes people from across the 3 districts of Malawi (see Insert 1).

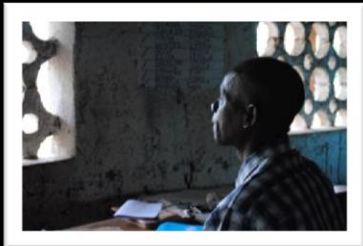
³⁴ As described in chapter three (methodology), these 20 life stories were selected from the complete collection of 42 stories.

INSERT 2—A STRONG FOUNDATION

Introducing the Life Story Participants



<p>I am... LS 1 (MN)</p> <p>Born: 1971</p> <p>Diagnosed with HIV: December 2005, on ART</p> <p>Experienced stigma?</p>	<p>a TV presenter and journalist.</p> <p>“I am a celebrity and my celebrity status sometimes would get into my head.... I would like to think I am bigger than life itself.”</p> <p>Proud? Of my creativity.</p> <p>Future? “Everything is possible... I am positive today but I am living. I messed up but I am living.”</p> <p>Yes – demoted at work and forced to re-locate, he thinks because of his HIV status.</p>
<p>I am LS 2 (MN)</p> <p>Born: 1970</p> <p>Diagnosed with HIV: 2007, on ART</p> <p>Experienced stigma?</p>	<p>A professional in Environmental Health.</p> <p>“I should really thank god. I have a wife who is very courageous. She said ‘I know what you are thinking, you are thinking of your status because you are now reactive. Can you stop doing that? This is the time we should start thinking of our future. And the fact that we have HIV status doesn’t mean we are dead, we can do something.’”</p> <p>Proud? Of being on ARVs and looking healthy.</p> <p>Future? “HIV to our family, that is my wife, I myself, and the kids, it has really influenced us to plan for the future.”</p> <p>Yes – anticipated stigma from father, who responded negatively to brother’s disclosure of his own HIV positive status.</p>
<p>I am... LS 3 (MN)</p> <p>Born: 1965</p> <p>Diagnosed with HIV: 2007, on ART since 2007</p> <p>Experienced stigma?</p>	<p>a Radio producer.</p> <p>“When we talk of a journalist, a journalist is maybe a very difficult animal on earth. And as journalists we sometimes like to just point fingers at some people...We must face it the way it is, not just talk about it... Let us be the leading example to others so that in the end we happen to be at least a bunch of journalists that can speak a good language.”</p> <p>Proud? Of promotion at work.</p> <p>Future? “Life is just normal. It only becomes hard on the daily intake of medicines otherwise life is just normal. In fact, the truth is that because my wife took my problem to be hers as well it gives me strength and courage to live... I am still handsome.”</p> <p>Yes in the workplace, made redundant because of HIV status.</p>



I am... a pastor, journalist, former air-traffic controller, and advocacy officer for NGO.

LS 4 (MC) “I am born of old times. I have done some education, which I am still continuing even if I am of the old times. I am married. I am working.”

Born: 1950 Proud? Of influencing national HIV policy.

Diagnosed with HIV: 1994, ART since 2008 Future? “I must be like an ambassador of hope. I should be giving counseling or informing those not much knowledgeable about HIV... so that they should not be seeing that in HIV is the end of life. No, but that HIV is the beginning of another life.”

Experienced stigma? No.

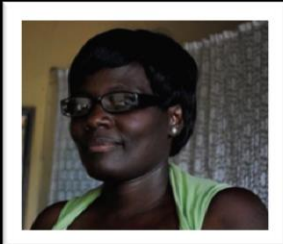
I am... a District Coordinator for NGO.

LS 5 (MC) “As a person living with HIV myself, I see that our life is not getting 100% of the necessary support in our hospitals. For instance, as I said, I tested for HIV but our hospitals do not have all the necessary equipment to help monitor progress of how the ARV medication is making in our health condition. Such equipment is not there. I don’t know whether our country/ government is too poor to afford them. Because of that, I see that things are not going on well. We are taking the drugs all right, I feel I am fine, but I don’t know what else is happening in my body as I am taking these drugs.”

Born: 1968 Proud? Of my wife and children.

Diagnosed with HIV: 2006; on ART Future? “I see that my future is very bright. That is why I am able to continue with my studies for more education so that me and my family are happy and enjoy life even though I am HIV positive.”

Experienced stigma? Yes – from some relatives, when disclosed HIV status, so he moved cities.

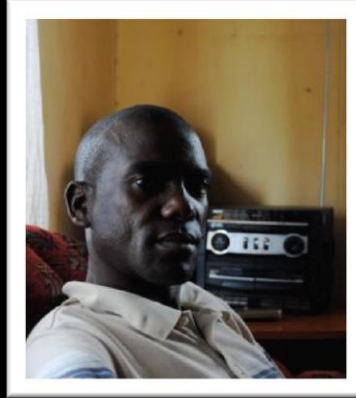
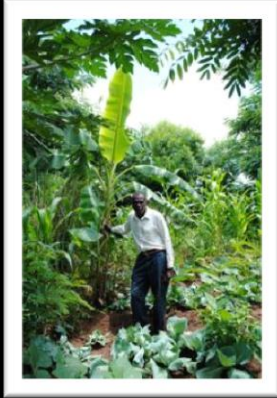


I am...	a former prisoner, domestic worker and peer-educator.
LS 6 (MC)	“My biggest memory from my childhood days, I would say it was something which is about I should say it is about my sexual orientation. Back then I was schooling at a boy’s primary school. Yeah it is right here in town, right here in Lilongwe. Then since it was a boys’ primary school, I realized that I had a certain feeling towards my fellow men. You know we are putting on shorts, we are not putting on trousers, but we are putting on shorts. So each time I saw a leg of my fellow boy I had some sexual feelings towards that thing, towards seeing my fellow leg. Then you know I realized OK what is happening to me? At first I thought it was something that was out of childhood, no, then later on then as I grew up I realized that it was still like anchoring in me—it was like pulling yeah I should say it was anchoring in me.”
Born: 1983	Proud? Of living independently.
Not HIV positive at last test	Future? “My hope mainly is to get a stable job yeah and live freely without any hassles”
Experienced stigma?	Yes – relating to his sexual orientation, internalized and also gossip from other MSM in his community.

I am...	a former radio controller, activist and researcher.
Ls 7 (MS)	“I have a passion for education... I believe God still wants to use me to save lives, to improve lives, to educate my children... I would like to see my children graduate, get into jobs and yeah I believe if my rights are provided, if the environment around me, I still feel I have life, I still feel I have life.”
Born: 1958	Proud? Of a productive, successful career.
Diagnosed with HIV: 2001, on ART	Future? “I want people to be comfortable, to talk comfortably about HIV whether they are managers or what – we don’t have that environment now. Most of the elites, they don’t want to hear about HIV; they externalise HIV and because of that, programmes are suffering... I want to see HIV, people living with HIV, representing all cadres.”
Experienced stigma?	Yes – from doctor when diagnosed and from wife in coming to terms with her own HIV positive status.



<p>I am... LS 8 (MS)</p> <p>Born: 1976 Diagnosed with HIV: 2009; on ART since 2009</p> <p>Experienced stigma?</p>	<p>a university student.</p> <p>“If people can have the knowledge that oh...I am positive. I think that it can bring some consciousness in their memories and their minds.”</p> <p>Proud? Of silencing my critics and going back to my studies.</p> <p>Future? “My hope is to get my bachelor’s [degree] and help other people you know. Problems are there in this world. I still feel like HIV is not a big problem, it only needs some support.”</p> <p>Yes – from his immediate family; rejected by his wife’s family and his sister forces him to stay in the basement and not interact with the rest of the family.</p>
<p>I am... LS 9 (FN)</p> <p>Born: 1975 Not HIV positive at last test</p> <p>Experienced stigma?</p>	<p>a shopkeeper and researcher.</p> <p>“Now I have just accepted even though I am negative I still carry myself about as person who is HIV positive.”</p> <p>Proud? Of my family.</p> <p>Future? “I cannot dictate about my future but you just plan only God knows our future... I know I have a future and I always pray that God look after our health and we can raise our child together. I think the most important thing is as long as you are healthy there is a better future waiting.”</p> <p>Yes – anticipates stigma from family so has not disclosed her husband’s HIV status to them.</p>
<p>I am... LS 10 (FN)</p> <p>Born: 1958 Diagnosed with HIV: 1995; on ART since 2006</p> <p>Experienced stigma?</p>	<p>an HIV activist and former bank clerk.</p> <p>“I wrote a letter to the President last year because he said on television that anybody who has a problem should write him. So yes, I did it and wrote a letter of about two to three pages telling him about my status and many other issues about HIV and AIDS. I wanted him to support people who are HIV positive especially we activists! This should even reach out people who are in very remotest areas and villages. The Principal Secretary on Nutrition, HIV and AIDS told me that the President has seen my letter but up until now, there is no answer.”</p> <p>Proud? Of my volunteerism and contribution to encouraging people to test for HIV.</p> <p>Future? “My hope for the future is to be someone the world can depend upon when it comes to advocating for HIV and AIDS in whatever forums. And they are bright! .. So, my hopes for the future are to have a beautiful posh car and to live in my own house and I want someone to help me buy the house I am living in. I also want to see many people who are HIV positive to live healthy lives.”</p> <p>Yes – at Church some people stopped talking to her after she disclosed she was HIV positive.</p>



I am... an HIV activist, former bank clerk and former UN volunteer.

LS 11 (FC)

“Because of the way I was brought up, I like referring to myself as a natural fighter... I was brought up by a single parent but then I’ve always been focused... I don’t like people looking down upon me or being put as a second class citizen because I was born female. I like also setting up goals and doing whatever I can to achieve these goals because I don’t sit back and say wait for somebody to do something for me because I say I am an able bodied person, I have everything that it takes to achieve what a person can achieve in life.”

Born: 1963

Proud? Of having fought and known my HIV status in 1988, and being an ambassador to the Global Fund in 2010. “I’ve brought those kids up through college and I’ve lived to be a grand mum — something I never dreamt of — that I’ve lived to be. I take that as some of my greatest achievements and that even in 2011 as I said I just last week clocked 48 you can imagine the first time when I knew my HIV status. I was 25, now I am 48, 23 years down the line. I’m still here. I take that as an achievement.”

Diagnosed with HIV: 1988,
on ART since 2003
Experienced stigma?

Future? “I am the same person, HIV positive or not... I’m not handcuffed anyway simply because I carry this virus with me.”
Yes – in accessing ARV medication through employer’s insurance program.

I am... studying to be a nurse, founder and chair of support group

LS 12 (FC)

“I am thinking that it has to be in the heart of the person listening - there is a lot that is to be done in order to win this war of fighting HIV and AIDS. So there is a lot happening; and there is a lot also that is needed.”

Born: 1971

Proud? Of my leadership.

Diagnosed with HIV (&
Meningitis): 2006; on ART
since 2006

Future? “Then I can say there is no problem on being HIV positive. I can do anything I want. That’s what...that’s why I said I went to school. And also there is this local government elections, I would also want to stand as a Ward Councilor. So to me HIV is not an issue.”

Experienced stigma?

Not much – once only from pharmacist when receiving ARVs.



I am...	a manager with a health NGO, former nurse and researcher.
LS 13 (FC)	“HIV has brought so many problems in my life especially when I was not working I had no money to support my family. The money which I kept in my Bank Accounts was used for school fees for my children. I was taking ARVs but had little or no money to buy food. My body was very weak...you know my family also depends on me. This was also a reason why my brothers and sisters failed to show stigma on me because I am a bread winner. I have accomplished so many things in life so this makes me feel good.”
Born: 1973	Proud? Of taking care of my life and children, and of being myself.
Diagnosed with HIV (& TB & Meningitis): 2008, on ART since 2008	Future? “I hope to live for a long time because when I started taking ARVs my CD4 count was at 35...but after barely seven (7) months it was 350; this gives me hope. I choose to follow Doctors’ advice; I don’t miss my dosage.”
Experienced stigma?	No – she is a bread winner and knows details of HIV from her training as a nurse.

I am...	a volunteer with local NGO and sex worker.
LS 14 (FS)	“As a woman living with HIV, yah, I am found to be HIV positive, it does not mean that I cannot have a feeling for sex. I must have it because I am a human being – it is nature.”
Born: c. 1968	Proud? Of volunteering; and ensuring my son got an education.
Diagnosed with HIV: 2000; not on ART	Future? “I want my health to continue being this good, yah, free from frequent illness. I also want to reach out to some of my friends, those that are still experiencing fear... I want people like those ones that one day they should accept and go for HIV testing to know their status.”
Experienced stigma?	Yes – “For me, I understand stigma because as I explained earlier I do not talk about somebody; I talk about myself because I have gone through some difficult times and I have evidence. Stigma and discrimination exists.”



<p>I am...</p> <p>LS 15 (FS)</p> <p>Born: 1966</p> <p>Diagnosed with HIV: 1999; on ART</p> <p>Experienced stigma?</p>	<p>a student, university lecturer and former commissioner.</p> <p>“Life is basically what you make. So if you want to make it gloomy or sad indeed life will be gloomy. If you want to make you know jovial it will be like that. It’s - nobody has control over your life other than yourself.”</p> <p>Proud? Of managing life, of professional success, and of designing and building my own house.</p> <p>Future? “The only difference [with HIV] is just the medication. So what...whatever ah...hopes I had you know for the future that has been maintained; and I still hope that life will continue. I [hope to] continue with my work and the career path in the university.”</p> <p>No.</p>
<p>I am...</p> <p>LS 16 (MS)</p> <p>Born: 1986</p> <p>Diagnosed with HIV (and TB): 2005; on ART</p> <p>Experienced stigma?</p>	<p>unemployed.</p> <p>“Freedom is important to me because if I’m not free to my friends, it might happen that I could be worried and not happy but there is need for me to be free as some of my friends are.”</p> <p>Proud? Of going for HIV testing and knowing my status.</p> <p>Future? “My future right now, I see that it is my life only since I have nothing to do that I do that I can say is mine... Taking care of my life so that my everyday life is strong.”</p> <p>Yes – being laughed at while collecting ARVs at hospital; gossip and name-calling from friends.</p>
<p>I am...</p> <p>LS 17 (MC)</p> <p>Born: 1950</p> <p>Diagnosed with HIV: 2004; on ART since 2004</p> <p>Experienced stigma?</p>	<p>a subsistence farmer.</p> <p>“My childhood was that I grew up very well without any problems, my father raised me up very well; sending me to school though I didn’t do much on education but still everything was good until I got married without problems.”</p> <p>Proud? Of gardening and gardening well.</p> <p>Future? “I want to tell everybody in Malawi that I discovered that I was HIV positive in 2004 but I want to tell you that whosoever has HIV will not die today ... I went for HIV testing and I was counselled and I want to appeal to all those who haven’t gone for testing to do, as this disease is coming in different ways because you can be flattered that you don’t have the virus because you are fat.”</p> <p>Yes – house burnt down by brother-in-law and forced to move to another village.</p>



I am...	a subsistence farmer.
LS 18 (FN)	“I’ve reached point that I don’t get worried, I am encouraged, I am free, I don’t get worried that I’ve been found to be HIV positive.”
Born: 1972	Proud? Of keeping chickens and goats.
Diagnosed with HIV: 1997;	Future? “In the future I think that I should continue farming as I do little by little until I will achieve what I want.”
on ART	
Experienced stigma?	Yes – land snatched by husband’s relatives when she was widowed and forced to move to another village.

I am...	a headmaster of a school and teacher.
LS 19 (MS)	“There is no one helping me because in our family I am the first born child. Every problem in our family I have to solve it and also the problems that the orphaned children are facing. There is no one I could turn to for assistance. All my siblings and my family depend on me for support. I have all the responsibility.”
Born: 14 July 1958	Proud? Of buying a piece of land and building a house.
Diagnosed with HIV 2009;	Future? “I would like to do my job with perseverance and diligence because as a teacher, I could assist children so that they can live a proper independent life. And also I would like to see the children listening and changing their attitude because times have changed since we were young.”
on ART since 2009	
Experienced stigma?	Yes – from wife, who withheld sex and made him feel ashamed about his diagnosis (wife was HIV negative on last test).

I am...	a school teacher.
LS 20 (FS)	“We were 8 children in the family but the first born, our oldest brother who put us through school, died. He died as a result of HIV, both him and his wife. I am now the guardian of their children. My other siblings are working.”
Born: 28 March 1973	Proud? Of the fact that I work and support my children.
Diagnosed with HIV: 2006;	Future? “I would say there is some hope but it is hard for those people in the village because medication usually gets there late or in little amounts after their days have passed... My hope is that when people write their MSC examinations this term that the next term, which is the first, I should join school again so I can realize my dream of being a nurse.”
on ART since 2006	
Experienced stigma?	Yes – at hospital, when seeing a dentist, was seen by another provider once the first had seen HIV status in health book.

'HIV is not the whole story'

Life is diverse, and HIV is present within the lives of diverse individuals across different corners of all societies. In this regard, Malawi is no exception and the people who shared their life stories in their research are archetypal of the humanity that 'hosts' the virus. Taking a collective view of the life story collection, this section highlights some of the themes about life and living with HIV in Malawi—and explores the notion of monumentalism and memorialism, and transformation, at the individual level as a foundation for the analysis of these themes in terms of the law (see chapter seven).

The most resonant quotation, connecting the stories, experiences and biographies of all the participants, was that 'HIV is not the whole story, it is part of life' (LS7). Echoing the notions of intersectionality, from all participants it was clear that the presence of HIV in their lives was only one dimension of their identities that also included gender, sexual orientation, sense of self, ambition and connections with others (for example through community groups, intimate relationships and/or religion).

The following sections outline recurrent themes about life, HIV and the personal reflections of individual change over time that were documented in the interviews.

LIFE

Some participants framed HIV simply as part of life – a life that is what you make of it. Like anybody or everybody, participants were reflective and philosophical about their various life journeys:

“Life is basically what you make [of it]. So if you want to make it gloomy or sad indeed life will be gloomy. If you want to make it you know jovial it will be like that. It's.. nobody would...has control of ...over your life other than yourself.” (LS15, op cit)

“My work has been very productive. I think when I look back I have had a successful career, very successful career. I think it has given me what I thought life can give me. Aah it has allowed me to know lifestyles in other countries, it has allowed me to know lifestyles in our country, it has allowed me to know other countries in Africa. I think I have a better understanding of life because of my job.” (LS7)

“[What] I have discovered is you know life is a learning process. And is ... this process takes people who are keen in understanding situations that they are. At...at the moment I was at secondary school ah...there were people with problems at secondary school I was not able. And now that I am at the university I have also discovered that there are problems at the university that people are having. And

people out there in the world they seem not to...to know or to – to realize that problems exist in the process of life.” (LS8)

These three quotations touch on three themes that recur throughout the life stories—the notion of making or carving out a life from different experiences (agency); the notion of work and productivity (livelihoods); and the notion of getting to know oneself and life-long learning (consciousness).

Notably, for some participants HIV came to symbolise knowing oneself more honestly or truthfully. It was linked to a sense of consciousness about one’s place in the world and in society. This was most commonly found in regard to testing, and knowing one’s HIV status, as a symbol for really knowing oneself. For example,

“The impact has been ah...ah...that it has built in me some....courage that I never had ...some strength that I would have lost.. unknowingly or knowingly. Ah...but *to be ignorant about yourself is the worst thing in life. You better know yourself.*” (LS1, *my emphasis*)

“I am also advocating for legalizing the thing. Because you legalize... you understand... everybody will have understand his status. Oh I am...*I am positive. How do I do... you will have self-consciousness you know.* My understanding is that God everybody gave them self-consciousness. Conscious... so whether...whether you are not educated or you are educated but conscious. The moment you have the knowledge the consciousness automatically comes into your mind.” (LS8, *my emphasis*)

For some participants HIV came to personify both an opportunity for and result of expressing individual agency. An example of this agency, linked also to a sense of responsibility for becoming HIV positive, was the metaphor of a journey into the path of a lion described by one participant:

“People should learn to value life. It takes somebody who values his/her life to find ways of protecting self. You mean... you can’t... follow a path. If somebody tells you this path leads to a point where a lion resides and you deliberately take that path. I mean... that doesn’t make sense. If they have [been] told there is a lion... then there is a lion and you avoid using that path.” (LS4)

The metaphor encapsulates this notion of a complex and intricate life (self), full of contradictions between common sense and decisions made (such as walking towards a lion), that is shaped by the journey (movement over time) along a path that is interrupted by other beings and events (society).

For many of the participants, their HIV diagnosis marked a turning point for change or re-direction in their life as well as coming to symbolize a moment of realisation about themselves as individuals as well as in terms of themselves in relation to the world.

BEING HUMAN

Several of the participants framed HIV as something that is part of their life, and that does not make them (or others who are living with HIV) any different. A typical example of this kind of response is:

“I have good health; I am gaining weight; I am happy, and I am doing my studies. It will be the same with anybody who goes for an HIV test and is HIV positive – they can emulate my example, that they can do any kind of work like anybody else that is HIV negative.” (LS5)

This notion of the sameness between people who are HIV positive and those who are HIV negative was particularly clear when participants were discussing human rights for people living with HIV, for example:

“We are all human beings. Because it is also possible that some of those that are accorded the rights have not gone for the test. We are better off because we know our status when the others do not know. So, human rights should be enjoyed by all alike—no difference.” (LS14)

“Human rights are the same because every human being is born with all available human rights. But HIV comes later in life after taking the test that determines you are infected with the virus. So, there is no way human rights can be different because of HIV status. They are all the same and equal, and must be applied equally.” (LS5)

A few participants used examples of other aspects of life – such as employment, health, sexuality and family - to further elaborate the point of “sameness” with others. For example:

“As a woman living with HIV, yah I am found HIV positive, it does not mean that I cannot have a feeling for sex. I must have it because I am a human being—it is nature.” (LS14, op cit)

“The other impact I can deduce out of this is that... knowing my status...makes me live free and better life...whenever I feel sick, I rush to see my Doctors. In fact, on my relationship it is normal, on having children it is normal depending on how or what we agree upon with my wife as I earlier on stated. On lovemaking with my wife it is normal safe sex. On employment I just talked about what happened to me 12-months ago when I got promoted to this position of Chief Programmes Producer. So my hopes for the future are just bright! I believe that where there is

life there is always hope! In fact, I am sooner or later going to be a manager of my own and live a good life.” (LS3)

One participant went further, emphasising the point by describing how she employed people and contributed to national development and that HIV is no barrier to success:

“I advise them to work hard as I do because HIV is not a block, it is not something to make someone fail to advance in any form; HIV is not a gap to success! As for me, I have employed workers at home, my garden, I pay them a salary, which means that I am contributing to development and I pay tax through my business! Is this development? So that’s exactly what other people that are HIV positive should do as they earn their living.” (LS10)

In light of the ‘sameness’ that was almost unanimously emphasized by participants in regard to living with HIV and equity in the entitlement of human rights for all, the contradictory responses on the question of criminalizing HIV transmission or exposure (explored in chapter eight) pinpoints an example of how or where stigma lives. As outlined in detail in chapter eight, many participants argued that HIV transmission should be considered a criminal offence for example because it was like giving someone a ‘death sentence’. The contradiction between the egalitarian values outlined in response to notions of human rights, yet the differential punishing values outlined in response to notions of criminality, highlights how contradictory values can co-exist within individuals (not necessarily consciously) and be held simultaneously.

HIV

People living with HIV are obviously not a homogenous group, in fact quite the opposite, with heterogeneous personalities, livelihoods, lifestyles, belief systems and ways of living and being in the world. Equally within the individual lives of people living with HIV, the meaning and role of HIV in their life changes over time. Chapter six offers a more detailed exploration of the temporality and transience of HIV and its meaning (particularly in relation to stigma).

In terms of the meaning of HIV in the lives of the life story participants who were HIV positive (18 of the 20), their responses can loosely be grouped under those who described aspects of their experience living with HIV as a positive, a negative or a neutral attributes at specific moments in time. While this is a simplistic grouping, it does help to frame the more in-depth discussion below about the potentially transformative nature of an HIV positive diagnosis in certain circumstances.

Some typical examples of those who framed HIV as having a negative meaning in certain aspects of their life included those who expressed a desire to have avoided it or those who explained that it has brought worries or anxiety into their life. For example:

“It’s not something good. If I had a chance of avoiding it...I would ah...always want to you know go back in life. And ah...start all over again. And make sure I try as much as I can to avoid it. But it’s something which I have accepted. Because that’s the situation now; so instead of looking may be looking back...just say okay let’s look for solutions. And because of that that ah...I find that it’s something I can live with. And continue with the...the normal life.” (LS15)

“The impact is not good at all. I always have worries especially when I think about my son who is positive because he is in standard eight (8) and he might be selected to go to Secondary School. Will he manage to take ARVs on his own? Because right now, he does not know he is positive. Secondly, HIV has made our family change in terms of sex, we always use condoms. We can’t have children anymore. Right now I am working tirelessly so that I can find money to build a house to live in that anytime I die my children must have a house to live in. I would have done this but not now. These are the impacts of HIV on my life.” (LS2)

The life story participants had nuanced reflections about their HIV status, and at specific points in their life story narratives, some focused on more positive outcomes than negative or neutral ones. For example:

“To me to be positive in this country. It has bad and good effects. Good is the sense that after being...sss... declared positive now I can...I can see my body healthily. I...I am much better. Because then I we.....used to suffer headaches...headaches not knowing that ehhhh...my immediate system was declining little by little. Yah...so positively that’s the other. But negatively there I think there is...there a lot of stigma you know. Stigma from my relatives.” (LS8)

In this example, one can almost hear how difficult it is for LS8 to rationalize the opposing meanings of HIV in his life.

Of those who framed aspects of their experience of living with HIV as positive at certain times¹, it was generally relating to a better understanding of themselves (holistically) and specifically of their health status (and reasons for ill-health, since the majority of participants had been tested for HIV because they have been experiencing symptoms of sickness).

Some participants explicitly linked their coping with an HIV positive status to physical recovery and the benefits of ART, for example:

¹ This is not to suggest individuals saw their status in inherently positive terms, but rather at specific times they focused on what are more positive outcomes than negative or neutral ones.

“As I am HIV positive I see nothing different but by the time I was sick that’s when I realized that this a big problem but now I am strong because I am taking medication, there is no problem which I am facing ...” (LS16)

These findings are interesting in light of results from recent research in Tanzania (Malawi’s neighbour to the North) that indicated that in fact HIV-related stigma increased *after* clients were accessing ART even though HIV-related stigma was declining in the general community (Roura et al, 2009) and other studies with similar findings from South Africa (Maughan-Brown, 2010). Even though the participants in this research suggest that the onset of ‘universal access’ to ART had a positive impact on acceptance levels relating to HIV, they are consistent with other studies that indicate that stigma relating to HIV has become more nuanced rather than necessarily having been abated by the availability and accessibility of treatment (Roura et al, 2009; Maughan-Brown, 2010). For example one participant indicated that for him, given the side effects of his treatment regime, his HIV status was visible through physical signs such as the glossiness of his eyes and the distribution of fat in his body. For him, this was particularly problematic since he was a TV presenter, and he attributes some of the discrimination he experienced in the workplace and his relocation to the North of Malawi, to HIV and its physical visibility:

“My job is a TV job, people have to see me. So in the process of taking my drugs I could have some physical changes which people would say ‘you know that guy is not OK’. When you are actually told to move you feel it, and your programme is taken away from you unceremoniously, it hurts. It hurts. It does hurt. “ (LS1)

This example further illustrates the complexity and dynamic nature of HIV in someone’s life. Even something as seemingly straightforward as lifesaving medication can in fact be a catalyst for stigma. Further research could delve into this specific area in more detail, potentially exploring the evolving dynamic of treatment, side effects and adherence among people living with HIV – particularly in a country like Malawi where access to quality ARVs is still limited.²

² Some of the life story participants described how they were concerned that they only had access to low standard medication, d4T (Stavudine) which the WHO recommended be phased out from first line treatment in 2009: “[The WHO] recommends that countries phase out the use of Stavudine, or d4T, because of its long-term, irreversible side-effects. Stavudine is still widely used in first-line therapy in developing countries due to its low cost and widespread availability. [Zidovudine](http://www.who.int/mediacentre/news/releases/2009/world_aids_20091130/en/index.html) (AZT) or [Tenofovir](http://www.who.int/mediacentre/news/releases/2009/world_aids_20091130/en/index.html) (TDF) are recommended as less toxic and equally effective alternatives.” WHO, 2009, news release: http://www.who.int/mediacentre/news/releases/2009/world_aids_20091130/en/index.html . The policy guidelines have since changed in Malawi from 2013.

TESTING AND DIAGNOSIS

It is important to note that the majority of life story participants had been tested for HIV because they were unwell or had symptoms of opportunistic illnesses such as meningitis, tuberculosis and open sores. Some had been diagnosed HIV positive during their pre-natal care. Only two participants sought an HIV test purely because they wanted to know their status and not because they were unwell, showing symptoms, or offered by a provider during pre-natal screening.

Several of the participants recalled their experience and emotional response at receiving their HIV positive diagnosis. Again, loosely speaking, the response could be categorized as negative, positive or neutral. An example of a negative response, which was the most common, is:

“At first ah... I couldn’t believe it... When it turned to be positive I just knew aha...this thing those doctors were just running away from the truth. The reality is this. Let me just accept. Although part of my heart was in anger.... really in anger.”
LS14

Some of the attitudes described which could be classified as ‘negative’ included anger, regret and guilt. A few participants expressed a kind of guilt and viewed their HIV diagnosis as a product of their lifestyle. For example,

“I had already lost a brother, that first born—and a second born brother—we had lost—and then the other brothers the other side in the other house who were part of me in Blantyre. So I was asking—what’s this thing, what’s this thing? Until I got to know. And-but somehow looking at where I have come from, which I have explained, I thought yah I am a victim of my lifestyle.” (LS7)

On the other hand, some examples of positive responses to an HIV positive diagnosis include³:

“When I heard the results I was a very happy person that after such a long period of suffering I decided to be tested to know exactly what was giving me problems in my body.” (LS5)

“[When] I was told that ‘you are HIV positive’ I was very happy. I did not feel sorry for myself—I did not feel anything bad to my life. Even when I was coming out from the room, my friend who escorted me to the clinic told me ‘what is it?’ I told her that ‘aaaa I am found’ (laughs). ‘So how do you feel?’ ‘Nothing bad, yea’. Nothing bad—I was very happy and I lived the whole day thinking that ‘oh am I HIV positive? Ok, where is it?’ Aah, I was as I am is the way I was yesterday and the way I was yesterday is the way I am today.” (LS22)

³ For me, as an activist and researcher in issues relating to HIV for a number of years, this was the most surprising and unexpected ‘learning’ from the life stories. I had never before come across (and perhaps I had never asked) people who were relieved and pleased to have been diagnosed with HIV.

Only two of the participants said that they sought an HIV test simply because they wanted to know their HIV status. One, in 1994, was tested because he felt disingenuous working as a peer educator for an HIV organisation, encouraging others to test, without knowing his own status:

“It was here in Lilongwe in the year 1994. And why I tested...it’s like I have explained that I was in.... I was a Programme Officer in Media and AIDS Society in Malawi. And our workpart of our work was to encourage people to go for their blood testing. So that they can know their body status. But I was doing this work of encouraging my friends to test their blood for HIV before I myself had tested. So I felt that there was no justice in this. There was no justice. So I took the initiative to test my blood. And that time it was very difficult. It’s not like now that you just go to a testing centre and get in. You are counselled and then when they have taken your blood sample then after fifteen minutes you know your results. That time we could wait sometimes for two weeks before the results would be in. And during that period it was very difficult. A lot of worries indeed. But when you know what you are doing and you have done it and the desire of your life ah...it’s not often to feel disappointed with the results. So even if I was HIV positive...I wasn’t disappointed with the results. I *just accepted* that things are what they are.” (LS4, my emphasis)

The other, was tested because she had volunteered for a local HIV service organisation and understood that as a sex worker she was at high risk for contracting HIV:

“It was during this time that I heard about VCT. That was around 1999/2000. I was keen to see what happens at the VCT. When I went to Zomba Central Hospital I met the doctor because it was very confidential at that time. He explained to me about HIV, everything else that happens. He then asked me if I were prepared to take the test. I told him I was ready. He wanted to know why I had decided to be tested for HIV. I told him that I had done quite a lot of prostitution and so I wanted to know my status, if I had the virus. ‘What if you test HIV positive?’ I said there was no problem. He tested me and informed me that I was HIV positive. ‘How do you feel?’ he asked me. I told him *I did not have any ill feelings*. He explained to me that there were no drugs at the time. If they were available I would be told when to start taking ARVs, and from which centre. ‘But since you say you are staying nearby, keep checking with us so that you can start taking the ARVs as soon as we receive them,’ the doctor said, because that time I was not looking as healthy as I am today. My body was very weak, so weak that even when I took a bath, it was like I had not done so.” (LS14, my emphasis)

Although these are only two examples, it is interesting to note that for both, their reaction to the positive diagnosis was neutral or ambivalent – “just accepted” and no “ill feelings.” Further research could investigate the correlation between motivation for testing (and potential differences between testing that is voluntary, mandatory or provider initiated) and the psycho-social outcomes for the person receiving an HIV positive diagnosis – both

at the individual level as well as how they disclose their status to others and frame the meaning of HIV in their life. This has potentially significant ramifications for considering the types of testing and degrees of consent (or lack of) in national strategies to promote HIV counselling and testing (HCT). The potential impact for the client, particularly in terms of their emotional response to an HIV positive diagnosis and the extent to which they internalise stigma, may vary depending on the conditions under-which they were tested (i.e. provider initiated, mandatory or compulsory).

It is important to note that the emotional experiences recalled from the time of HIV-positive diagnosis did not necessarily correlate for each individual with how they framed the meaning of HIV in their life overall. This in itself illustrates how the framing of HIV in someone's life can change overtime, and suggests that other factors (such as support or other aspects of someone's life) may influence the positive, negative or neutral presence of HIV at any one moment in time.

DISCLOSURE

The participants had different experiences with disclosing their HIV status. They expressed different perspectives about the extent to which someone should disclose, and their choices in when, whom, how and if they disclose their HIV status. For some, stigma remained a barrier to disclosure, for example:

“The biggest challenge I am facing is to overcome stigma and disclose my status because right now I only target people who are in need.” (LS2)

For others, it was about the timing and choices of different communication mediums for disclosing, such as:

“I first disclosed to my nearest and dearest one ...my wife and later on it was my employer who I disclosed to. The rest heard it from me indirectly speaking on radio Programmes broadcast on MBC and other relevant networks. And when we talk of stigma and discrimination this is where things get into deep waters when people do not necessarily understand what it means to carry the virus that causes AIDS. Like as I said before, *you might accept it yourself but the society you are living in might not.*” (LS3, *my emphasis*)

This extract is interesting also because it highlights the different levels of acceptance and judgment, the personal and the social, and the dynamic interplay between the two. Particularly on the issue of disclosure, which by its very nature involves a conversation between at least two people, the responses and reflections of the participants highlight

the extent to which any efforts to overcome stigma must engage both the individual as well as the transitory and kaleidoscopic communities and societies in which they live.

Some participants discussed the benefits of disclosure, which can be categorized into three main areas. The first, benefits for others, such as promoting knowledge and diminishing stigma relating to HIV. For example,

“I choose to continue disclosing my status so that I educate them on the benefits of testing for HIV” (LS5)

“[I disclosed] at my church and my office. This was so because I wanted to help some people especially at work because they used to mock me. If they only hear me coughing, they laughed at me and told me to go for TB test otherwise I may die like someone who died of TB. So I decided to disclose my status to them and to the youth in order to encourage them.” (LS13)

“I have always wanted to do this... tell the world...who I am and what I think about HIV. Because that’s the only way that people would save their own lives and live longer.” (LS1)

The second area is in relation to concrete benefits that can come from disclosure, such as nutritional support, fertilizer subsidies (although these were also identified as a site of discrimination, as noted in chapter five), connections with peer support and other networks, and income supplements. For example,

“There are programmes that target people living with HIV in the workplace of village/ community. If you do not disclose your status you will not benefit from those programmes. In addition you may not be reached with relevant messages for your good health.” (LS5)

One participant noted that another concrete outcome of disclosure would be better government tracking of HIV in Malawi and also a greater consciousness of ‘self’ for the person living with HIV:

“It can help for the part of the government for the sake of statistics. And it can help for the part of the individuals. So they can have some consciousness eh? Then they can control... self-control. It can help them to have self-control you know.” (LS8)

Thirdly, some participants saw disclosure as an empowering experience that benefits the individual person living with HIV. For example,

“Disclosure is so empowering. Ah...with the sign starter... it brings in you confidence. To say I have told them the truth about me. And I don’t know why they tell... they are not telling me the truth about themselves. Yah...I just...it just put me somewhere ah...on a safer place...because I know who I am. What is happening to me. So I am enjoying every single day.” (LS1)

“It’s like treatment. It’s like a remedy. When you become free to disclose to others it means your burdens are lifted in the heart. So all the worries get away from you.” (LS4)

“I disclose my status, even when I go to a group of people, I find it difficult to give examples of somebody else saying ‘they say’ because you do not have evidence. I give my own life examples because it is something I cannot forget or go wrong; it will be as it is.” (LS14)

Some participants discussed the extent to which the perspectives and/or stigma of others (such as intimate partners) can have an influence on choices relating to disclosure. For example,

“Before you...before you go open about your HIV status ah...you have to consider certain things. That person with HIV... You as a person with HIV positive. You are a family person...this is the first thing...you are a family person. So what kind of respect does a family person require? And with the HIV issue under discussion...that if family members know that you go out to disclose your status. How will your family members feel? Your wife.... how will she feel. How will your children feel? When these children go to school with other children ...with other children...what shall they be saying? You have to consider that. At church you pray with people...an HIV positive person gathers with others at church. Eh...what...what will that message trigger in the minds of those that he/she prays with? And an HIV positive person is at work. What will it mean there if you go out in the open about your status? And you a village person...you live in the village...you are in a community. Whether here in town...you are in a township. You go out disclose your status... what will people be saying? You have to consider all those things. But above all you need to consider the value of life... the value of life. That’s what you need to consider first.” (LS4)

This extract highlights the extent to which disclosure may be affected by someone’s identity – as a family person, a husband or wife, a parent – and equally the extent to which someone may disclose (or not) in different settings – such as at school, a religious setting such as a church, at work, or in the village or town centre. It also highlights the importance of relationships, and interpersonal power in disclosure, by his consciousness of the potential impact of disclosure on the other person.

For others, disclosure was linked to the strength and trust in personal relationships. One participant describes the dynamics within different relationships in his life, and how his decision to disclose (or not) varies. He begins by praising his courageous wife, who was the impetus and encouragement that enabled him to be tested for HIV in the first place.

“I should really thank god. I have a wife who is very courageous. She said ‘I know what you are thinking, you are thinking of your status because you are now reactive. Can you stop doing that? This is the time we should start thinking of our

future. *And the fact that we have HIV status doesn't mean we are dead, we can do something.*' It took me two weeks, so confused, but she would still more encourage me – 'if this will make you not eat as a result you will die faster.'" (LS2, *my emphasis*)

This extract illustrates a sense of agency that individuals articulated in contrast to a notion of death. This is significant for two main reasons—the first, as alluded to earlier, the notion that HIV is no longer considered a death sentence in Malawi (even though, as noted in chapter eight, HIV still carried these connotations regarding the application of the criminal law), and the second is a sense that life can be shaped and made into a positive direction for the future. He continues to explain that he and his wife were tested HIV positive, and one of their two sons. They all started ARVs almost immediately, trying out the starter pack within three weeks of their diagnosis.

"I think I am now OK. Yeah so I take my drugs regularly. So it was quite the challenge to accept but I feel if you the quicker you accept the results the more the better, because you remove the fears, you know for sure this is my status, what else can I do? The only thing now I should do is to plan for my future. So I tell you it was quite a challenge." (LS2)

After taking considerations of his health, his families' health, and their stability for the future, he continues to talk about disclosing to find sources of support. Yet there is a history of HIV, disclosure and stigma within his family. LS2 expressed concern about disclosing to his father, based on the experience of his older brother who had told him he was HIV positive a few years earlier. However he was encouraged to disclose his status to someone, and so he trusted his news with a friend ... only to find out that the friend felt honoured and trusted to know his status, and that they had something in common:

"Now the next thing was who should we tell about our status. This was a discussion between me and my wife. Then my wife said can we tell our parents? I said no ways I cannot tell my parents..... Then she said OK but you should choose a friend so that we keep on sharing knowledge on HIV/AIDS issues. I have a best friend, and fortunately I didn't know about his status. When I went there I was so surprised to hear 'I am also HIV positive' so we work together. He is also working in the same team so he said 'Oh' but he really appreciated to say 'I didn't expect you to tell me this, because you are saying when did you get the test?' then I told him. He said 'I think me, I was tested much earlier than you. So for you to come to me and tell me you are HIV positive I have been overwhelmed, I really feel you are a true friend. Your status is my status.' So I said 'OK therefore what do we do?' We keep trying to encourage one another." (LS2)

This example of LS2 highlights the extent to which disclosure can be both a choice and privilege, as well as how even within close personal or family relationships, the dynamics and responses to HIV can be very different.

As with the other dimensions of HIV in people's lives, the experiences of the life story participants and their choices relating to disclosing their HIV-status are different. This difference is not only apparent between the experiences of different individuals but also within an individual's life, and their experiences of disclosure – and the reactions it brings – in different moments and circumstances throughout life.

TRANSFORMATION

Several participants also noted how their HIV diagnosis was a transformative moment in their life – that it in some way triggered an opportunity for reflection and change in their values, habits, and/or choices for living life. These results concur with other life-story-based analyses of the meaning of HIV in life, such as Robbins (2005) that talk about transitional moments and rites of passage triggered by an HIV diagnosis. Some participants noted transformations in quite concrete ways, for example by enabling them to use and promote condoms:

“Being HIV positive changed my life because I am able to use a condom. I am also able to tell the men that want to have sex with me all about the condom and its benefits. I also talk to my children at home about condoms... they feel free with me... Even at school where they go there are children that got HIV from their parents or they were raped, they know they are HIV positive, they chat with them. Some people discriminate against those children but my children do interact with them because they know they have the thing in their home. So I see that this HIV has changed my life.” (LS14)

For some participants, the HIV diagnosis was seen as a call to appreciate the opportunities and goodness in life. This was often accompanied by gratitude to God. For example:

“I have been looking up to God to say that everything is possible. Everything is possible. And God never meant life to be so formal. And to be...to have one kind of a tradition... that this is how you are going to live life. If you don't live life like this then you know... look at me I am positive today but I am living. I messed up but I am living. But I think God...God has been so good to me.” (LS1)

Some people translated the experience of an HIV positive diagnosis into a call to action – both in terms of empathy and understanding others, as well as a call to disclose and educate others to prevent further transmission of HIV:

“I would say it’s made me reflect on life more. Not just on my life per se but on life of others. Because the fact that it happened to me it had made me you know think about others. For example immediately when I knew my status first thing which came to mind is oh...I think I need to open up. And you know tell particularly students at college. Eh...that they ...they need to be careful about you know their lives. Ah...the reason why that was the case is because my first sexual relationship was the time I was in College. So I thought okay...looking back...reflecting on my own life. May be this could also happen to a lot more others and ah...it could be avoided if they are aware. So if I use my experience may be it might help one or two you know ah...people not to contract HIV.” (LS15)

Another participant framed a similar idea in terms of being an ambassador of hope – an ambassador against stigma, and to ensure that HIV remains framed simply as one aspect of someone’s life:

“I must be like an ambassador of hope. I should be giving counselling or informing those not much knowledgeable about HIV and AIDS. So that they should be knowledgeable so that they can see... they should have a blessed hope in future...ambassador of hope. So that they should not be seeing that in HIV...that it’s the end of life, no. But that *HIV is the beginning of another life through which you have to look after your life.*” (LS4, my emphasis)

For the two life story participants who are HIV negative (at the time of the interview) yet whose lives were directly affected by HIV, their discussion of the meaning of HIV in their lives was also interesting in their differences, and in highlighting dimensions and processes of empathy. For one participant, HIV was very much something that she had internalized in a holistic way, and saw herself as someone living with HIV just like her husband:

“Now I have just accepted even though am negative I still carry myself about as person who is HIV positive. I must confess that it was not easy at first, I remember when I came to know the results of my husband I cried the whole night... So yes HIV has affected us in so many ways. I cannot deny it. Everybody is affected and in my case I cannot say am not.” (LS9)

For the other, even though he belongs to the group of people with the highest HIV prevalence of HIV in Malawi (MSM)⁴ and is a peer-educator, he views HIV in more purely medical terms:

“About HIV I would say it has, it has a meaning of course it has a meaning to my life simply because it’s a disease which so far has no cure and it is a fertile disease yeah which has claimed many people’s lives. So it has a meaning to me that I try my level best not to acquire the virus through ... my sexual orientation I try.” (LS6)

⁴ According to the Director of CEDEP, the only Malawian NGO working with lesbian, gay, bisexual and transgender (LGBT) communities, the estimated HIV prevalence among MSM is almost double the national average, estimated to be approximately 21% (compared with just under 11% for the general population). Personal communication, March 2011.

Even though LS6 and LS9 were not personally living with HIV at the time of the interview, HIV was very present in their lives—and had meaning—by the nature of their personal relationships and intimate partners.

One common message to appear in many of the reflections about the role of HIV in the participants' life related to a notion of acceptance. This resonates strongly with the outcomes from the study of stigma and how it operates (described in chapter six), and some of the suggestions for strategies for overcoming stigma. But the notion of acceptance was present more strongly than only in relation to stigma, and it was discussed in terms of overall embracing and coming to terms with an HIV positive diagnosis across the many dimensions of someone's life. For example,

“So acceptance is like a major step to ...to everything else. Eh...because once you accept your status then you can already start looking for... for solutions.” (LS15)

“It is good to accept it yourself so that even if people can talk about it then you are free at homeno worry about it” LS3

“One thing I think which has helped me is that I accepted it—eh, I think that's what has helped me because even when I knew my status, I have seen people that continue to die, and I have discovered the reason is eh they are not accepting—they are still fearing.” LS7

The life stories indicate that HIV does not have a static presence within someone's life. Likewise, the experience of stigma and the impact that it causes can change overtime, occupying a variety of large or small spaces in terms of the influence it has on the framing and nature of people's everyday experience of living with HIV.

Conclusion

The diversity between and nuances within these personal responses about the meaning of HIV illustrates the intensely personal, contextual, transient and evolving relationship that individuals have with a virus that is part of their life, and not the whole of life. The results from the life stories enforce notions expressed by Sontag (1977) and others about understanding illness as metaphor and one that has a dynamic presence in individual lives. Metaphors were not however apparent in the descriptions the life story participants gave of HIV and its meaning in their lives. All the same, the descriptions given and the individual reflections about how HIV has been present or absent in different ways in different moments of their lives encapsulate the essence of what Sontag was describing

in her idea of illness as metaphor. Illness, as something that can take on an identity or a symbolism, that comes to embody something to reflect values, judgements and projections much more than the biomedical aspects of the virus or disease.

In the opening of *Illness and Metaphor*, Sontag frames her ideas in terms of temporality and transience of health and life and its relationship with illness (ironically, through metaphor):

“Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.”
(Sontag, 1977, p3)

Just as life morphs in different directions and through moments of exultation and despair, sickness and well-being, along with the shades of grey and the more mediocre emotions in between, so too does a person’s relationship with a virus such as HIV in their life. As indicated above, in fact the life stories illuminated how HIV can become personified to reflect meaning in someone’s life—to embody a moment of transformation, an opportunity to know oneself, and/or a turning point to decide on life’s future directions.

There are significant implications of these results both in terms of how we conceptualize HIV as well as how collectively we frame responses to engage, support, provide services and generate leadership as part of national responses to HIV. The three main findings from this analysis could be summed up as comprising both simple and complex messages (in the Dr Suess sense). The first, the simple one and also the starting point, that HIV is part of life and is present in diverse and dynamic lives around the world. The implication as argued above is that interventions to overcome HIV-related stigma should be founded on a holistic notion of people and societies, not only channelled into a narrow specific focus solely on HIV. To be successful, interventions should encompass whole people in terms of livelihoods, belief systems and worldviews.

The second and third are less simple, or less obvious, and centre on notions of agency. On the one hand there is the agency of the individual to shape the direction of their life as well as perceive and re-construct over time the meaning of HIV in their life. The results point to notions of agencies at two levels – both in terms of the trigger of an HIV positive diagnosis to take stock of life and make conscious decisions to guide its future direction, as well as in terms of a sense of responsibility (sometimes connoted as guilt) for becoming HIV positive. For many of the participants in this research, their HIV positive

diagnosis marked a distinct transformative turning point in their life. For the two individuals who had voluntarily sought an HIV test (i.e. not the majority who had been tested because they were unwell) it seemed that this act of agency in seeking to know their HIV status may have had a mitigating influence on their reaction to receiving an HIV positive diagnosis. That is, those participants seemed more readily accepting of their HIV positive diagnosis than others. One hypothesis to emerge from these two stories could be that the initial acceptance of an HIV diagnosis (which could be framed as a reduced internalization of stigma) may be enhanced with a greater readiness and willingness to know. This has significant implications for national policies to promote HIV testing for example, that from an efficacy perspective as well as from one founded in principles of human rights, should rather focus on cultivating a demand for voluntary testing rather than mandating testing through legislation (as proposed in the draft HIV legislation, reviewed in chapter seven and eight) or even provider—initiated counselling and testing.

The third notion is that there is the agency of communities and societies to be AIDS competent and to militate against the devaluing and marginalizing power of stigma. The implications of the findings from the life stories, particularly in relation to experiences of disclosure given that is the area that most explicitly relates to interactions between people, are consistent with other research that has focused attention on the competencies of societies to respond to HIV within their communities in an embracing, empathetic and stigma-alleviating manner (cf Campbell et al., 2012).

Recognizing history (looking back) and the future (looking forward, effecting change), as well as the individual in relationships with others (self and society), are the key ingredients for the kind of transformative strategy needed to tackle the underlying social determinants of health. Initiatives to address HIV-related stigma may have been misdirected in the past by focusing almost exclusively on a person's HIV status—the life stories illuminate much more complicated, passionate and nuanced lives in terms of highs and lows of living with HIV. Efforts to address HIV-related stigma should focus on love, compassion and wider issues relevant in someone's life beyond the positive diagnosis (as modelled through the process of this research, and reflectively evaluated in chapter three). In so doing, efforts to address stigma must engage the whole story.

6 | UNDERSTANDING STIGMA: NATURE – NOTIONS – NEXUS



“We should not be complacent about fighting stigma.”

(The late Ngwazi Professor, former President of Malawi, Bingu wa Mutharika, 2011)

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⁵ The image is a representation of LS 8 in his current ‘home’. He chose to photograph his hand opening the door to his room (in a basement behind the main house where his sister lives in Blantyre) as a symbol both of the current stigma he is experiencing from his family as well as an opening of hope for things to improve in the future. He would like to be reunited with his wife in the North of Malawi and be able to return to finish his university studies.

INTRODUCING STIGMA

Just like beauty, stigma can be said to be in the eye of the beholder. Stigma happens, but the degree of its intensity and impact is as much within the anticipation and perception of stigma as in the act itself. This chapter presents insights and relevant results for the first research question, exploring the extent to which experiences of HIV-related stigma change over time and alter in relation to the multiple layers that comprise individual identities.

As reviewed in chapter two, HIV-related stigma is layered and complex and can feed off other attitudes or prejudices relating, for example, to homophobia, racism or sexism (Mahajan et al., 2008; Nyblade, 2006; Dodds, 2006). Stigma can have many outcomes and can adversely affect how and when someone accesses services (including testing, support and treatment), how people interact with each other (including friendships, intimate partnerships and professional relationships), and how someone perceives themselves and their self-esteem (Maman et al, 2009; Genberg et al, 2009; Simbayi et al, 2007).

HIV-related stigma cuts across all elements of the human right to health because it affects the physical, mental and social wellbeing of individuals in the context of their societies. HIV-related stigma can have an impact at three key levels. As a starting point, it can impact the personal level. Internalized stigma can negatively affect the quality of life and self-esteem of people living with HIV and can create barriers to realizing other human rights (Li et al, 2009; Simbayi et al, 2007). Secondly, stigma can create barriers for accessing health and other services (Maman et al, 2009)⁶. And finally, at the structural level, stigma can reinforce power inequalities and processes of social marginalization (Mahajan et al., 2008; Parker and Aggleton, 2003), for example limiting access to economic opportunities, education and/or livelihoods.

Two pivotal concerns are missing from this summary breakdown of the levels of impact of stigma: first, the temporal, that is recognition of the extent to which stigma can intersect across all three areas in different ways with a different impact at different moments in time. And secondly, the conceptual, that is, a conceptualization of stigma and the extent to which the impact of stigma as well as efforts to mitigate or alleviate stigma

⁶ HIV-related stigma also creates barriers for people accessing other services (such as legal, employment, psychosocial care etc) but for the purposes of this research I am focusing specifically on health services.

are dependent on a conscious (both individual and collective) understanding of what stigma actually is. One of the main findings emerging from this research is that different people understand stigma differently. This is hardly surprising, but in fact little other research has looked at conceptual understandings of stigma amongst people whose lives stigma directly affects.

The analysis outlined in this chapter attempts to integrate both temporal and conceptual dimensions into an analysis of HIV-related stigma in Malawi. The results presented are based in an inductive analysis of key themes emerging from the responses of participants when asked a question about describing what stigma means to them in their own words. All participants in the research were asked to define, in their own words, how they understand the term “stigma”. It is important to note that the question that prompted the response relating to the definition of stigma was not always asked in the exact same way. However the question was usually phrased as a follow-up question from something the participant had already said. For example a question was commonly asked following the first time the participant had used the word stigma with a follow-on question such as “you mentioned the word stigma – can you describe in a sentence what stigma means to you?” or “can you please explain to me what stigma means in your own words?” or “if I had to ask you to describe stigma just in a sentence, how would you describe it?” (see Annexes 9 and 10). Some participants were also subsequently asked as a follow-up question what they would see as the solution for overcoming stigma (detailed in Part III).⁷

This chapter is divided into five sections, which explore the nature and notions of HIV-related stigma in Malawi. The first two sections, Part I, focus on the nature of stigma, exclusively drawing from the experiences of stigma described by people living with and affected by HIV in the life stories. Section one describes the settings of stigma identified, which is consistent with the three levels identified in the literature review. Section two deepens the analysis by adding a new dimension of the temporal nature of stigma and experiences over time. The remainder of the chapter draws from all three sets of interviews (the life stories, as well as the interviews with the opinion leaders and law commissioners). Part II focuses on notions of stigma, exploring definitions and the origins

⁷ In a self-conscious moment about the process of the research itself, one participant even commented that it was good to be asked to define stigma, recognizing that the term itself is often loosely applied: “I must admit to you that I think the way we use the word stigma and discrimination, I think it is loosely applied – what it means and those things and I think that it is important for you to ask that question and to see how people perceive stigma and these sort of things.” (OL9)

of stigma and how participants understand the term. Part III explores the proposed solutions for overcoming stigma. Both Part II and Part III conclude with an analysis of the actions and actors identified as being both a part of the problem as well as part of the solution.

Understanding how people understand stigma is crucial in terms of how to address something that encompasses both action and perception. The results suggest that to be effective, efforts to overcome stigma need to noticeably have an impact on both the concrete aspects of stigma (outcomes, triggers and experiences) as well as on the perceptions of stigma (feelings, attitudes and expectations). The results indicate that the temporal nature of stigma – how it sediments over time and how different experiences of HIV-related stigma compound over time – is also an important conceptual consideration when understanding stigma.

PART I

I| Nature: Experiences of stigma

The life stories indicate how one individual may experience stigma in multiple settings concurrently and/or sequentially during their life—sometimes consciously, and sometimes unaware. In each of the three levels outlined in the literature, participants described experiences of stigma in specific settings, including at the personal level (as explained in chapter four, in relation to people who had negative feelings about the meaning of HIV in their life), feeling ashamed or afraid of disclosing their HIV status, experiencing rejection or the withholding of sex within intimate relationships, and exclusion from family settings.

At the service level, this includes the attitudes of the doctor on communicating an HIV positive diagnosis, the response of the pharmacist when asked for ARVs, and the response of the police to incidents of stigma and discrimination. One participant described experiences of stigma when receiving health care, for example collecting his ARVs:

“We feel ashamed of the place where we get medication because the place is near the antenatal ward, so when going there we pass-by the women and everybody knows that this one is going to get ARVs because when we are passing the women laugh at us...They don’t speak anything but they laugh whilst looking at you... The problem is that you feel ashamed why are these laughing at me? What have I done? You have questions which you fail to answer yourself.” (LS16)

For someone living with HIV who is on ARVs, the experience of collecting drugs from the pharmacy becomes significant since repeat visits are necessary sometimes as frequently as every month.⁸ Treatment adherence be challenging not only because of possible side effects and fatigue of taking pills each day, but also if the process of collecting those pills involves a repeated stigmatizing experience.

Some participants also described experiences of HIV-related stigma in settings other than those relating to health care, such as in community settings or through interactions with the police. One participant described how she and her friends had been bullied by the police, however she attributed this more to her work as a sex worker than to her HIV status (see Insert 4 for further details). This is one example of how HIV-related stigma can be attached and/or attributed to intersecting characteristics of someone's identity and also how groups particularly vulnerable to HIV (in this example, sex workers) are also vulnerable to harassment, criminalization and stigma linked to other aspects of their identity. Another participant described how she had experienced stigma in a religious setting, in this case her church, for example,

“Yes! Like at Church, you find that somebody does not talk to you probably because you are HIV positive.” (LS10)

At the structural level, participants described how HIV-related stigma had limited their access to livelihood opportunities (such as obtaining fertilizer, farming and/or withholding applications for employment) because of HIV status:

“The thing which has come in my life because I am HIV positive is poverty because as I have HIV some things which I was doing, I cannot do them and when I look into that HIV has brought this in my life.... What I mean is that sometimes we can have people to assist us but when they learn that we are HIV positive they say I cannot continue to assist you because you are HIV positive, we have friends whom that time we were chatting together but now they discriminate us [sic].” (LS16)

The two extracts presented here from LS16 also highlight how stigma relating to HIV can be experienced in multiple settings and cut across different aspects of his daily life – for example as a friend, in social settings, in accessing health services and in his sense of pride in himself.

Others described how they had experienced stigma and discrimination directly from family members, for example through the snatching of land from an HIV positive widow or through the burning of a house of an HIV-positive relative:

⁸ Thanks to colleagues at IPPF who pointed this out during recent conversations about the characteristics of a 'stigma-free' setting (July 2012).

“My sister’s child came from work and started shouting at me saying you want to trouble us, *you came here already dead*.... when I opened the door I found him with some fire in his hands saying I’m standing in this side so that fire should spread quickly, I told my family members to get out of the house to prevent them from being burnt right in the house... no one came out to assist us... He said that ‘after a dead body has been removed from the house it is never returned back’.” (LS17, *my emphasis*)

“I found a man and got married, I’ve been from 1997 until I had four children with him but one passed away, when my child passed away it was found that my husband was getting sick frequently and I was also doing the same... In 1997 my husband was sick ... and on 7th January he passed away then I went home for his burial after his death I stayed there for about 4 months, while I was staying there I discovered that his relatives were torturing me but I was not worried... When my husband was sick he called his relatives and my parents to say when I die my wife should be staying here don’t let her go to her village because she is often sick don’t snatch the farm and the garden from her. But when he passed away I was chased in an unpolite [sic] manner and now I am facing a lot of problems.” (LS18)

In both cases, LS17 and LS18 sought redress through traditional authorities and were supported to relocate to other villages with rental plots to help re-build their livelihoods. Notably, in both the cases, the formal legal system (police, lawyers or courts) was not engaged even though extreme examples of dispossession were involved. The implications of this are examined in more detail in chapter seven, which explores the presence and absence of formal legal traditions in the everyday lives of people living with HIV in Malawi.

Some participants described discrimination in the workplace. During the time of the interviews, some participants (LS1, LS7 and LS3) described how they had lost their jobs, been demoted, or been relocated by their employer. All three attributed this to their HIV positive status and the fact that they had disclosed openly in the workplace.

“At one point Mzuzu was known as Guantanamo Bay because that’s what I think ‘if they send so and so there they are punishing you for whatever reason.’ So there is a group of us at the office, we meet, we talk. When you are staying as a family you have a lot of care – love, care, you live a happy life. But when you are separated you are all alone, it’s not easy. So I’m trying to go through like the same process. Now 9 months later I am still alone, yeah. So I risk, we talked about it, and I was told there could be some help. The only thing is if you take the guys to court looking for justice, obviously you may lose your job, so we would think let’s keep our jobs by being silent but that really just don’t work. That really just doesn’t work out. Personally I would love to get some help, get some justice, but I am always sometimes I am scared because I have got kids to look after. So our justice system may take a bit long, in the process we could be suffering even more.” (LS1)

He continued to recognize the courage it takes for someone to invoke the law and speak out against discrimination in the workplace:

“So there is that kind of provision that employers who are found to be abusing or to stigmatise or to discriminate, you’ve got first the law and there is a fine of about one million kwacha. So sometimes you think ‘is that enough for you to go for it?’ But I haven’t heard of anybody who has tried to go and you know to look for their rights so far. And I was saying that I think we need to have the courage to see justice being done. Although in the process we can have some problems because they will always have some excuses.” (LS1)

However as with the examples of land grabbing and dispossession above, LS1 did not seek redress through the formal legal system for his experiences of stigma and discrimination in the workplace.

As outlined in the methodology section (chapter three), the goal was to document experiences of stigma, recourse or redress sought as well as incidents where stigma could have occurred but was averted (for example, when it could be judged to have occurred by another person, such as the interviewer, but where the participant did not identify that moment as one in which they had experienced stigma). As noted in chapter three, a critical incident approach to data analysis that forms the basis of the results presented in this chapter.

A minority of participants showed great empathy for people who had experienced stigma and could describe examples of stigma in different settings, yet insisted that they had never experienced stigma themselves. LS15 for example did not deny that stigma existed, even in her life, but rather framed it as something that had not affected her personally—by defining that being strong enough, and determined, one can prevent stigma from “happening to me” by being strong and assertive:

“If people do stigmatize against me then it’s something I don’t notice.... It just needs, you know, one being assertive and having that strong will that ‘okay I am not letting this happen to me’...I know stigma happens but I wouldn’t say it has ever happened to me.” (LS15)

In this extract LS15 is suggesting that an almost exaggerated sense of agency can prevent stigma—a determination that it will not happen to her.

Consistent with the literature, the life story participants explained experiences of stigma in different settings—within themselves at the personal level, as well as in external environments in accessing services and other structural health-determining areas such as access to economic opportunities and livelihoods.

The following section deepens this analysis of the nature of stigma by incorporating a dimension of temporality and the extent to which stigma can be

experienced by one individual in various ways over time. Like a scar, the scar tissue left behind from a stigmatizing experience may remain, hardening or diminishing over time. By exploring the temporal dimensions of stigma, the chapter offers a more subtle and complex analysis of the triggers and definitions of stigma as well as seeking to find examples of what mitigates the impact or, in other words, dissipates, the scar tissue.

II| Nature: The temporality of stigma

The following section provides some illustrations of how stigma was described in different experiences at different times by the life story participants. Some participants described how they had experienced stigma at all three levels. For example, LS7 describes experiences of stigma in himself, and in different settings, in his interview. Notably LS7 at the time of the interview was one of the leading activists in Malawi for HIV. In his interview, he describes his initial feelings about an HIV positive diagnosis:

“I should say first, around this time I was suffering. I had already lost a brother, that first born, and a second born brother – we had lost – and then the other brother, the other side in the other house, who were part of me in Blantyre. So I was asking ‘what’s this thing, what’s this thing?’ ‘Til I got to know. And somehow, looking at where I have come from, I thought yah, I am a *victim of my lifestyle*.... I thought there are things I have done which have exposed me...” (LS7, *my emphasis*)

It is clear from this extract that he was blaming himself, feeling a *victim* of his lifestyle and choices. LS7 then describes his experience receiving news of his diagnosis, and how he felt stigmatized by the doctor, in the health care setting:

“The Project Manager said ‘let’s go to the hospital.’ So for the first time I landed at this top facility in Blantyre. She said ‘the project will pay for you because we can’t afford to lose you.’ And I was being examined by a white doctor... So this white doctor says ‘yah you see why you are suffering it’s because of this other disease’. I said ‘what?’ He said ‘this other disease.’ So I was interested. I said ‘what do you mean?’ That time looks like even doctors had problems to say. But because he was a white man, eh, he said HIV. I said ‘you mean I have HIV?’ He said yes. Ah then I asked myself, so I said, all these places I have been going to for medical support, it means they knew about me and they couldn’t tell me ... Stigma, I’ve told you about the doctor, I didn’t like it (the way he told me) because HIV is not something you lightly tell somebody. I don’t think so ... he brought fear in me, it’s like I had something strange, had something unique, but I thought as a doctor he just needed to tell me in a way that I accept it. But, he brought fear – you have, you have this strange thing in you – and I didn’t like that. I felt stigmatized.” (LS7)

In his story, LS7 felt that the way he had been told by the doctor had triggered fear in himself—not necessarily the nature of the diagnosis per se. LS7 relates to the way in which the news was told—not in a way that made it easy for him to accept but in a way that made him feel strange—that LS7 perceives to have been stigma. He notes that the way the doctor had presented the news meant he felt fear. That is not to equate stigma with fear, but rather to recognise that LS7 remembers something about the process by which the doctor communicated the news that made him feel “strange.” Other dimensions of power seem to have come into play as he recollects the experience, such as the high quality (and expense) of the clinic and the racial differences between himself and the ‘white’ doctor. This suggests that perhaps other dimensions of disempowerment and feelings of alienation or isolation within that setting may have exacerbated the stigma experienced by LS7 at that time.

LS7 also reflects on how he feels that he has experienced stigma from his wife, and how he feels responsible for her HIV positive diagnosis, which is limiting the extent to which he be as open as he feels he would like to be about HIV in his life:

“I can stigmatise myself, but the challenge I have been having is the more I want to be open, for example, I have to say even up to now I don’t think my wife is really not quite there – you see and this is stopping me from even discussing this at length with my kids. She is still not there. Aah she doesn’t want me to, to really be as open as I feel” (LS7)

LS7 highlights the impact he feels on himself, and the degree to which he can be open about his HIV status.

In a later part of the interview, LS7 draws explicit comparisons himself between feeling stigmatised by the doctor and by his wife.

“Eeh my wife is very critical – very critical of me, critical of what I do – and I think I also appreciate the state in which I found her as a virgin. And she was equally an innocent girl. So, I told, I tell, I – we left that place. We went home and in our bedroom, I tell her that I am HIV positive. Oh she cried – she cried – she did what, and it was my first test of – in fact second test because the way the doctor told me, I didn’t like it – of stigma. The way the doctor told me, I didn’t like it. It didn’t give me confidence; it didn’t tell me anything.... The day I told her, she was like ‘what is this you have brought?’” (LS7)

And then also,

“[The doctors] knew something about me but they couldn’t tell me. So, this created a shell in me. And then the way my wife responded to me because I thought she would be accommodating. This created a shell to me.” (LS7)

These extracts from the life story of LS7 highlight the temporal overlap of experiences of stigma. The story also illustrates how the 'scar tissue' from one experience can carry over to another, and frame the process by which an individual makes sense of their experience of stigma. In this example, the links LS7 has made between the emotional response and stigma experienced from his doctor on one hand (at the specific moment of diagnosis), and his wife on another (on-going), and subsequently articulated in the interview, highlights the active process by which he has understood his experiences, and how the former adds to the hurt or pain or confusion of subsequent experiences.

In another example, the life story of LS13, a female nurse from the Central Region also describes the dynamic and evolving relationship between an individual, her HIV diagnosis and her experiences of stigma as they have changed over time. Upon hearing her diagnosis, she remembers feeling neutral and almost clinical about the news:

“My reaction was not very bad. I knew that my mother might have heard it from the Doctor in confidence because she was my parent, my mother. The other factor was that it was so calm on me because of the nature of my job as a Nurse; so I already knew about it after being on TB treatment.” (LS13)

In this extract LS13 herself makes sense of her reaction according to her profession, indicating an awareness of some of the layers of identity that were influencing her response. Later in the interview, she describes and rationalizes how the doctor broke confidentiality and disclosed to her mother, and she also describes some moments where she has experienced stigma from within her immediate family.

“My mother was a little bit shocked because some of her relatives also died of HIV and AIDS ... And one of my younger brothers did not accept me. I remember one time he refused to use the toilet which I was using. I know this was so because he was told about my status.” (LS13)

In LS13's description, issues relating to employment and financial security feature throughout her rationalization of the experience of living with HIV and overcoming stigma.

“HIV has brought so many problems in my life especially when I was not working I had no money to support my family. The money which I kept in my Bank Accounts was used for school fees for my children. I was taking ARVs but had little or no money to buy food. My body was very weak. This made me to think more than I could think.⁹” (LS13)

⁹ A subtle reference here is made to a moment in her life when LS13 was considering suicide. This inclination, like her experiences with stigma, has changed over time and is very far from her current reality and frame of mind.

LS13 equates her own self-reliance and responsibilities as a bread winner in the family as one of the main reasons that she has been able to overcome stigma, and attributes a change in her own process of coping with living with HIV to the moment when she was employed by an organization in Lilongwe.

“But when I was employed my life changed; my body was strong. ...You know my family also depends on me. This was also a reason why my brothers and sisters failed to show stigma on me because I am a breadwinner. I have accomplished so many things in life so this makes me feel good.” (LS13)

Finally, looking back, LS13 is proud and strong in how she frames her life and all its dimensions – in terms of her experiences with HIV, relationships and looking after her family. Again for LS13, it is clear that livelihood and employment is closely linked with her sense of self and her sense of life’s achievement at the moment of the interview.

“I have managed to take care of my life and children; I am working and I am proud of being myself what I am.” (LS13)

These two examples from the life stories of LS7 and LS13 highlight three things. First, stigma can be present in different facets of someone’s life, at different intensities, at different moments in time. Second, the stigma experienced from others can generate or compound stigma (such as guilt, responsibility or shame) that has already been internalized. And third, participants describe a kind of ‘scar tissue’ or ‘shell’ as LS7 calls it that develops in relation to stigma. Repeat experiences of stigma, from the same or different sources, can potentially influence coping mechanisms and/or perhaps early warning signs, that people like LS7 are consciously aware of and able to articulate.

These findings are significant in shaping and adding to how stigma is understood, since existing research tends to focus solely on a snapshot in time without consideration of factors that might compound or potentially abate stigma that has occurred in the experiences that have preceded the moment of enquiry.

PART II

III | Notions: Defining stigma

The participants had very different ways of describing and understanding stigma. An inductive approach to the research analysis illuminated three main categories to describe stigma were as an outcome (such as social exclusion), as triggered by moral judgments (such as social norms) or physical ‘blemishes’, and as a process (such as devaluing attitudes or feelings). The results suggest that to be effective, efforts to overcome stigma need to noticeably have an impact on both the concrete aspects of stigma (outcomes, triggers and experiences) as well as on the perceptions of stigma (feelings, attitudes and expectations).

The participant’s definitions were almost equally split between the three primary areas of definition (see Annex 6 | 1 for a detailed breakdown). The categories are not mutually exclusive, given that many participants covered multiple themes in their definition of stigma. In the results, participants articulated the importance of considering both the actual experiences of stigma (defined as an outcome, and solution as openness) as well as perceptions of stigma (defined as a process, and solution as acceptance and transformative education).

The majority of participants defined stigma in terms of an outcome, such as social exclusion or discrimination. This may reflect a blurring of the distinction between stigma and discrimination that is common, or it may relate to challenges in translation noted in chapter three.¹⁰ The next most common was defining stigma in terms of its triggers, which can be grouped into two main categories relating to moral triggers (such as fear of HIV transmission, self-denial, a sense of judgment that behaviours have transgressed moral norms or contravened moral belief systems) and physical triggers (relating to the visibility of the cause of stigma). This grouping of definitions can be seen as an amalgamation of Goffman’s notion of a ‘spoiled identity’ (1963) combined with the ancient Greek origins of the notion of stigma as a mark or blemish. The third most common definition of stigma was in terms of a process, which included definitions with key words such as labelling,

¹⁰ As noted, in Chichewa however it can be difficult to distinguish between stigma and discrimination, so for the life stories that were conducted in Chichewa or Tumbuka and then translated into English (n=9), this may have contributed to the high number of participants who have stigma and discrimination in their responses (see chapter 3, Methodology, for further details about the translation of interviews) (cf. Chinouya and O’Keefe, 2006).

perceptions, feelings and attitudes. This grouping of definitions is the most aligned with Goffman's definition of stigma as a process of devaluation (1963).

A few participants defined stigma in more unique ways that lay outside these broad categories and have been grouped as other, including in terms of openness, power dynamics, as something that is avoidable, in terms of its manifestations at different levels and as something with multiple layers.

Before delving into the more detailed breakdown of how participants defined stigma within each of the main categories, one important cross-cutting theme was recognition of the distinct yet symbiotic dynamic of internalized and externalized stigma. That stigma can be both an internal and external process was articulated by a few participants. For example,

"So you're there's a feeling of being denied or you know of certain opportunities or you know you deny yourself opportunities. It doesn't have to be, it's two way really, it can be self-imposed or it can be imposed by others." (LC8, my emphasis)

Or put another way, stigma is a combination of internalized and external feelings and actions:

"Stigma is the self-feeling you are feeling which you have because of things which have happened to you or because of the things which you are." (LS6, op cit)

Few participants explicitly defined stigma in terms of an awareness of both internal and/or external process, however the distinction between the two elements becomes more apparent in analyzing the different actors and direction of action (see part II and III).

Participants also described an active process in understanding specific experiences or an element of consciousness in terms of being or becoming aware of moments of stigmatization. One participant highlighted how someone might experience stigma without realizing it:

"I understand stigma because as I explained earlier I do not talk about somebody, I talk about myself because I have gone through some difficult times and I have evidence. Stigma and discrimination exists. I do understand and I am able to see it because there comes time when they put a cross on your plate or cup. When you ask for water, you see that each time they bring you the same cup so that nobody else uses it. Or sometimes when you go to a funeral in the village you will see people eating together in groups of two and so on. You would think it is honour when they say to you 'aah madam, come and have your meal here freely'. You would think it is an honour and respect, not realizing they are discriminating against you on the basis of HIV, with the perception that you will pass it on to them when you eat from the same plate." (LS14)

This extract illustrates how experiences can be framed in different ways, at different moments in time, to have opposite meanings. LS14 describes a moment, a realization, an active process of becoming conscious that stigma is taking or has taken place. This echoes some of the stories outlined in chapter five that pointed to an agency or self-awareness involved in constructing the meaning of HIV within one's life, and how agency and also stigma may evolve in positive and negative ways over time, based on accumulated experiences. One participant went further to explain that the internalized dimensions of stigma can be overlooked because it is most commonly the external that is talked about:

“Stigma is like maybe when one has an attitude which is more of demeaning because of somebody's condition, which then maybe would lead to the fact that one starts discriminating the other individual [sic] ... Yeah but it could also be within one's health ... maybe the other people are not looking at you in that way but because you know your status you just feel, ah, maybe ... [it] could also be *you seeing things which others are not even thinking about*. Yeah so, but I think that one is the type of stigma that is mostly talked about is when it is from somebody else.” (LS15, my emphasis)

LS15's comment further emphasizes the role of a process of becoming conscious about stigma—in terms of both becoming aware of the dimensions of stigma that are internalized and perceived from within (whether or not these are in fact triggered by external factors) as well as learning to recognize externalized stigma when it is taking or has taken place (as elucidated by LS14 above).

The following section provides further detail about the main categories of the participant's definitions of stigma. Within the different categories, participant's responses were phrased differently but could be grouped according to some key words and themes as outlined below.

Stigma as an outcome (discrimination or enacted stigma)

The most common understanding of stigma expressed was in terms of the outcomes associated with it, namely exclusion and/or discrimination, and just over two-thirds of participants included the outcomes associated with stigma as part of their definition of stigma. Slightly more people referred to discrimination than social exclusion within these participants. Some of the definitions given referring to discrimination include:

“Stigma is the worst form of discrimination. Yah... it's the worst form of discrimination. It really adds ... really puts you up hard from the rest of the community.” (LS1)

“Those who discriminate us, they think that will transmit the virus to them I don’t know because the way they discriminate us [sic]... someone doesn’t want you, doesn’t want to see you.” (LS17).

Some examples of the responses that referred to social exclusion include:

“It’s like you are *not taken as part of the community*. So much as you are supposed to be involved in social activities you are not involved.” (LS2, *my emphasis*)

“Stigma to me, I would look at this word as meaning being *abandoned by the society* or the environment or the people that you work with because of what you are suffering from.” (OL13, *my emphasis*)

“Stigmatization is avoiding a person with HIV, *leaving them out of any activities happening in that community* because they are infected” (LS20, *my emphasis*)

The elision between stigma and discrimination in the participant’s responses, even when considering the challenges of translation, illustrates that the outcomes of stigma (i.e. discrimination) is much easier to pinpoint than the related processes.

Stigma as defined by a moral or physical trigger

The second grouping of participants’ understanding of stigma related to the trigger or origins of stigma: just over half of those who gave a definition. These spanned two key categories—those relating to moral judgments and transgression, and those relating to physicality.

The main theme related to transgressing social norms or being seen as morally reprehensive. Some of the phrases used included being seen to be “careless” (LS1), “not upright” (LS4), “not a straightforward person” (OL11), and “the moment you are thought to be HIV positive you are promiscuous, you are sinful, you are a sinner, you are unfaithful” (OL19). Five participants also used similar descriptions of “negative behaviours” as the jumping off point for defining stigma.

“So because you are a sinner. You are somebody who undresses anywhere anyhow. You have bad morals. So because you have bad morals you are not following the discipline of good morals. So because you are not following good morals ... morals that are good and acceptable. You don’t qualify to live the way they live ... no. Or receiving things like anybody. Or doing things together with them as people who are HIV negative. That’s stigma and discrimination.” (LS4)

Stigma was often defined in terms of transgressions against so-called normative or desirable social behaviour:

“Stigma is an abstract concept but if you are looking at how I understand it you know it’s something that labels somebody as someone who did something bad. Somebody who did not respect the culture. Somebody who did something to the extent that he deserves some kind of punishment – this is a bad person who is not wanted in society. It is an *evil for society*.” (OL8, op cit, my emphasis)

This notion was reinforced by a participant who defined stigma relating to men who have sex with men, who he saw as stigmatized because they transgressed social norms relating to men and masculinity:

“Stigma you could feel in a way that maybe you feel like an outcast, yeah, feeling like what you are doing is *not normal*. Something which can affect you psychologically, yeah, I would say that is stigma... for example for one being maybe gay that can happen, but from the people around you. Yeah. Because they will feel like you are doing something which is *contrary to what the society, yeah, expects from you* as a male person.” (LS6, my emphasis)

These two examples from LS6 and OL8 directly link with the analysis in chapter eight, that explores the deliberate production of stigma through the law to delineate limits of what is socially acceptable.

Given the origins of the word stigma in ancient Greek, as meaning a mark or a blemish, it was interesting to note that several participants defined stigma as something that is triggered by something physical or visible.

“So in the process of taking my drugs I could have some physical changes which people would say ‘you know that guy is not OK’.” (LS1, op cit)

Interestingly, some participants noted that the visual association for HIV has changed with the increased availability of ARVs and has gone from being one of wasting and thinness, to being one of a certain look in the eyes or a redistribution of fat (lipodystrophy) or other side effects associated with d4T, the most widely available ARV in Malawi.¹¹ For example,

“The starting point for stigma is where you think somebody is looking different. So if someone is looking different maybe they have side effects and the like, of poor quality treatment then I think that is also not helping matters. So if we could improve the quality of the services, so if someone is HIV positive, whether they are on ARVs they should look as normal as anyone else so there is no difference in terms of the looks. That would also help in reducing stigma.” (OL6)

Finally, one participant saw the fear of stigma and the threat of physical changes that could induce stigma as a good motivation to encourage people to test – and test early – for HIV:

¹¹ See chapter 5, note 1, p 140, at the time of research.

“A lot more people who start noticing that there is a change in you. And you can find people you know talking about you. May be ah...discussing something about you; the changes you are having in your body because you delayed to go for a check-up. And sometimes if one moves on and gets really sick ah...chances are he might you know be discriminated against or stigmatized because people notice that the person is not in health.” (LS15/ LC6)

The understanding of stigma as something triggered by physical changes associated with HIV is something that stands out as different from the most common notions of stigma. This notion of stigma would engender very different interventions to overcome it, such as ensuring availability of a greater variety of ARV drugs and different combination therapies. These kinds of interventions are markedly different from those addressing internalized and socialized moral judgments associated with definitions of stigma as either a process of devaluation or an outcome of social exclusion or personal isolation. Only two participants referred to quality of care (LC5) and access to ARVs (OL9) as relevant for their suggestions for overcoming stigma, which implies that further attention is due to the visible and physical ‘markers’ of HIV in Malawi.

Stigma as a process

The third most common understanding of stigma was as a process. This included a broad grouping of definitions, as outlined in Annex 6 | 1. Within this grouping of responses, the most common definition related to stigma as a process of labelling (8 participants), for example,

“Stigma would be something which is labelled because it would be in general terms.” (LC10)

“Stigma is an abstract concept but if you are looking at how I understand it you know it’s something that labels somebody as someone who did something bad... Somebody who did not respect the culture. Somebody who did something to the extent that he deserves some kind of punishment – this is a bad person who is not wanted in society. It is an evil for society. And nobody wants to be labelled as such and that’s why stigma is an issue.”(OL8)

This last definition, by OL8, is a good example of how a response can fall into multiple categories, such as defining stigma in terms of process (labelling) as well as in terms of outcome (social exclusion).

Labelling was closely followed by descriptions defining stigma in terms of attitudes and perceptions as the next most occurring terms defining stigma in terms of process. For example,

“People have negative attitudes about something or about somebody on the basis of maybe cultural beliefs and practices or on the basis of status (whether they are HIV positive) or they are people living with disabilities or because they are commercial sex workers or because they belong to a certain sect which people are not happy with – certain people are not happy with – they would be stigmatized. So this is what I would say is my understanding of stigma.” (LS4)

“Stigma. I’m actually surprised, that one is quite a tricky question. Ah what do I mean when I say stigma? It’s loaded. You are looking at an attitude towards a person, which is probably unreasonable to what they actually are. A negative – a negative outlook on someone which is baseless, discrimination. It’s really unjustifiable attitude towards another individual. Because when it is justified it can’t be stigma. It has to affect them negatively I suppose, and psychologically and mentally.” (LC3)

“I think being discriminated against just on a perception that I might be HIV positive, or that even if I – or if someone knows I am HIV positive, I am being denied services, or association with people and so on just purely on the fact that I might be HIV positive.” (LC4)

The definition by LS4 also highlights different triggers of stigma (see below), and both LC3 and LC4 conflate definitions of stigma and discrimination (i.e. the terms appear to be mutually synonymous for them), which was not unusual. As indicated above, 19 participants defined stigma either as the same as discrimination (and used the terms interchangeably in the definition) or in terms of its difference from discrimination (which was not always an accurate distinction).

Another description defining stigma within the process category referred to feelings. These most often included notions of negative feelings or denial, such as,

“So you’re – there’s a feeling of being denied or you know of certain opportunities or you know you deny yourself opportunities. It doesn’t have to be, it’s two way really, it can be self-imposed or it can be imposed by others.” (LC8)

“Stigma I would just describe it, in simple terms, I would say having a negative feeling towards someone with HIV.” (OL6)

Some participants, as highlighted in the responses by OL6 and LC4 above, made a clear link between feeling and identity – in other words that stigma was attached to or the result of an aspect of someone’s being.

The final definition included within this category was more closely linked to processes of action, whereby stigma was defined in terms of treating someone differently. For example,

“Well stigma is treating somebody differently you know in a negative way because of their status.” (OL7)

While this is similar to those who saw stigma as an outcome (above), the difference is that focus in this case is on the process—“seeing someone differently”—rather than on the outcome per se.

Finally and perhaps most memorably, two striking metaphors and descriptions used to describe stigma referred to notions of humanity and to notions of death. Three participants noted that the origin of stigma was related to notions of sickness and death. For example “people saying ‘you are already dead’” (LC4), “they automatically take away from the book of life and say ‘ah this one is already dead’” (LS8), and “you discriminate someone just because you think he/she is sick, is terminal illness [sic] and therefore will not be useful in the community” (OL1). Two participants explicitly defined stigma as triggered by a view of a person who has been devalued of their humanity—a kind of ‘spoiled identity,’ to borrow Goffman’s terminology (1963). On the one hand, one participant referred to a phrase in Chichewa that likened such people to dogs; the other participant instead defined herself in terms of not having any “less” humanity than someone who is not living with HIV:

“That’s stigma and discrimination. It means they don’t value you as a person...they have removed you from the level of a human being. You are putting him/her on something. Like this one ... as we say in Chichewa to say ‘ah, this one, what this one is doing is doggish’. It means there that they have removed from the level of what; from the level of a human being.” (LS4)

“Stigma to me is like you put it on being treated differently because you have got HIV. But as I said earlier on that I always argue to say having HIV doesn’t make me less human. I’m still a human being, full stop. That’s how I look at it. So nobody should treat me differently when I come out in the open and tell people that I’m HIV positive.” (LS11)

These definitions of stigma are most closely aligned with Goffman (1963)—the theoretical basis for understanding stigma in this research as outlined in chapter two—who defined stigma as a process of devaluation that often involved labelling.

Other definitions of stigma

The final collection of responses was somewhat disparate and they could not be grouped into any of the other categories. Loosely speaking the concepts all objectified stigma in different ways, personifying the term with a specific characteristic or metaphor. One participant defined stigma in terms of openness:

“Stigma is that you have to be open enough – you have to be open enough to tell the people who are you. You see, you have to tell the people who are you – whether you are a robber, you have to tell the people you are a robber because of ABCD. So if there are people who can help you they can come close to you to help you, but if you remain silent then it’s a problem.” (OL2)

One participant, even though she stressed that stigma to her is both an outcome (people treating someone differently) and a process (feeling stigmatized), also emphasized the point that, as an entity, it can be avoided.

“Stigma - I must say I have a completely different perspective of stigma. Particularly because I relate it to other factors, and I always strongly feel stigma is something which can be avoided... Being stigmatized is like when somebody may be some people are shying away from you or it could be yourself.... yah. May be feeling that people are stigmatizing you. And they...you know they are like treating you the way they are because of your status. So I feel it’s something which can be avoided” (LS15/ LC6)

One participant defined stigma in terms of the different levels in terms of its different manifestations:

“I think it’s if you are excluding or if you have some bad assumptions of people and those attitudes or practices leads these people to be excluded from either activities or services I think that is what I would call stigma. And that can be manifested by either *words, actions or policies*, or yeah I think that’s what I can – yeah. So stigma is around what people can talk about others, whether that kind of need for them to be excluded from all various you know developmental issues in the country.” (OL10, *my emphasis*)

This framing of HIV indicates that participants project or personify metaphors onto HIV, rather than the other way around. Unlike the arguments proposed by Sontag, for many of the participants interviewed in this research, HIV has gained a meaning in their lives (which was often expressed in the form of a personification or at times a metaphor). It did not ever appear the other way – that is, none of the participants used a metaphor to stand for or explain the presence of HIV in their lives.

Defining stigma – what was not said

Two key aspects of stigma were mentioned by surprisingly few people. Even though the layers of identity (or intersectionality) came out very strongly through the life story interviews, few participants made an explicit connection between multiple aspects of identity about which stigma could be experienced. Only one person described different layers of stigma and the confounding impact that might have, and he did so in relation to stigma experienced by people living with HIV who have served time in prison and go back into the community:

“The prison service is quite problematic because you know a prison society is quite different from the outside society, you see. You can see this person has got two problems. One is in prison. Being in prison alone is something that the society and even the prisoner himself do not want society to know that he is in prison, that he is serving a sentence because maybe he robbed or he did whatever. That is a problem again, that is a stigma as well. He want to hide himself keeping quiet until the time the sentence is expired and goes home without the society not knowing that he – why because he would want to be accepted by the society as a good person... Now if he is tested in prison he has been tested and he is HIV positive. He will make sure that he starts getting the ARVs inside you see and he would not want the society to know that he is HIV positive. When he goes out he would want to be taking the drug secretly. Secretly without anyone knowing that he is taking the drug but at the same time he is the one who can spread, because he is just coming from prison and people out there will not know that he is HIV positive. But if he can be open enough to tell the people that I am HIV positive, obviously people will not allow him for any kind of contact.” (OL2)

On this point, the methodology (life story interviews) and the actual definitions of stigma articulated by the participants diverged and illuminated a critical difference in the conceptualization of stigma. On the one hand, the life stories in their very nature revealed the unique, complex, and intersecting layers of multiple identities of all of the participants. On the other hand, almost all of the participants did not consciously¹² make a connection between the complexity of themselves and different aspects of their daily lives, and an association with different aspects of those layers or situations.

The other noticeable absence was that only one participant viewed stigma as something that might be determined by different power dynamics by the relative equality in the power relationship between the individuals involved:

“Presuming that we are in equal levels of authority power or whatever in that I can try and you can stop me, then that’s that. It doesn’t go any further. But when you create imbalances in the relationship and it’s usually various aspects of a power

¹² As noted during the interviews.

relationship and that's usually the way it is, then the one who has the power and is able to do that and the person being bullied or abused or discriminated or stigmatized has really no alternative but to take it – there is no immediate recourse – you can't push back – you can't stop me OK. So in that sense then, yes. So if it's totally equal, I would say no, you stand up for yourself: If I'm a jerk you tell me I'm a jerk and defend yourself and your rights. You don't let me take your rights away from you. And if you let me do it, that's bad on you – bad on me too but bad on you. But certainly within the context of HIV those power relationships are very infrequently equal.” (OL3)

This is the opposite of the definitions that objectified stigma, because in one sense this definition constructs stigma as something that is totally relational and determined. It is surprising that only one participant viewed stigma in this way.

In other words, conceptually stigma remained predominantly a mono-dimensional concept for participants (as for the literature) – even though the life stories and their articulation of identities and experience of stigma in daily life demonstrate that in reality, it is much more nuanced.

Analysis – differences between groups

The implications of the different articulations of stigma are wide reaching, incorporating both the extent to which stigma is currently being experienced by people living with HIV and the experiences that are most conscious to them, as well as signposting the kind of areas that would need to be addressed to overcome stigma. For example an effort to address processes of devaluation (in attitudes, internalized feelings and perceptions) would encompass a very different approach from one that would focus on addressing the outcomes of stigma (social exclusion, isolation and discrimination). The former would call for efforts promoting psychosocial support whereas the latter would be more effectively addressed through policies that outlaw discrimination.

Differences are apparent between the participant groups in terms of their overarching understanding of 'stigma'. As shown in detail in the chart in Annex 6|2, distinct differences between the participant groups exist in terms of how they understand stigma. For the life story participants—those most likely to have direct experiences of stigma—the most common understanding of stigma was first in terms of its outcomes and then in terms of its triggers (both over two-thirds), with less than one quarter referring to stigma as a process. For the opinion leaders the results were much closer, indicating perhaps that they gave more comprehensive definitions of stigma that incorporate more

than one aspect of stigma. The process was the most common definition (over three-quarters), followed closely by the triggers (almost two-thirds) and then outcomes (just over half). Finally for the law commissioners, it was the inverse of the people living with HIV, who defined stigma most commonly in terms first of the process (more than three quarters), then the outcomes (over two-thirds), and finally the triggers.

The following section compares the definitions of responses between participant groups, exploring differences between how people living with and affected by HIV, lawmakers, and opinion leaders understand stigma.

IV| Nexus: Direction of action in conceptualizing stigma

A review of the direction of stigma (as coming from external sources or from within) and the main actors who are stigmatizing (either self or others) extends the analysis further to reveal and explore differences between participant groups. An analysis of the direction of stigma highlights divergent sources of stigma – or in other words, who participants attributed as the cause of stigma or identified as the primary agents in generating stigma. This analysis differs from the definitional responses, which describe where stigma occurs (at the personal, service and structural level) and what stigma means. The analysis outlined in this section cuts across all definitions and rather looks at who is taking the action in generating or triggering stigma. The analysis explores the extent to which stigma comes from within, or if it is something that is conceptualised as being imposed on/ from someone/ something external.

The majority of participants saw stigma as something coming at least from an external source, with almost two-thirds defining stigma purely as something done by other people or to others. Just over a third saw it is something that originates from within, with a few defining stigma solely as an internalised process. Just over a quarter identified stigma as coming from both directions, and two participants did not identify any actors or directions in their definition of stigma (see Annex 6|3).

Some of the definitions of stigma described by participants attributed action only to an external source—another person or an action that is done to other people. For example,

“Stigma and discrimination means *they look at you* as being different because of what you are.” (LS4, my emphasis)

“Stigma is something that results in *some people isolating you, talking ill of you* in a way that is not pleasing in your life. *They take you* as unacceptable to some people with regard to the bad things they say about you.” (LS5, my emphasis)

“To me stigma means *connoting somebody, hmm, as ‘the HIV’*. And discrimination is denying somebody who has the virus to access certain services. For example we have the work for work programme – work for cash, work for food, work for this, or even agriculture subsidies. Some of the HIV positive people are denied saying ‘you are already dead. After all you are dying tomorrow so why should we give you fertilizer? Let us give it to those who are OK.’ That is discrimination. Stigmatizing saying ‘yeah the whole of your house is HIV positive’ or ‘you are the HIV’ or ‘they are the HIV’. So to me those are the two. And the language being used also matters. *‘They have AIDS’ but remember these are saying ‘you have AIDS.’*” (LC4, my emphasis)

Between these first two and the last examples, even though the actors are external, the direction of stigma is very different. The first two, from the life story participants, define stigma in terms of what ‘they’ do to ‘you’; whereas the third example, from one of the law commissioners, constructs stigma as something that is done to others, or in other words in terms of what ‘you’ do to ‘them’. Stigma therefore is still portrayed as something from other people, and even within the group who defined stigma in terms of external actors there were some nuances in terms of explaining the course that stigma took.

Fewer participants identified stigma purely as an internal process, but some did:

“I understand stigma as something which is – which starts from within. It can start *by me.*” (LS12, my emphasis)

“Stigma I think it’s – it could be a perceived or an inherent feeling that because of what I have *I will not be accepted* by others.” (LC9, my emphasis)

“Stigma to my own understanding stigma is that *you have to be open enough* – you have to be open enough to tell the people who are you.” (OL2, my emphasis)

These extracts also clearly illustrate the distinction between the internal direction of action for stigma (stigma as something that “starts from within,” LS12) and the experiences of stigma at the personal level (stigma as a feeling of being “ashamed,” LS16, reviewed earlier in the chapter).

Several participants articulated that stigma was a combination of both internal and external processes. For example,

“Stigma would be denial of some kind... It can start by yourself; sometimes it can start with some other.” (LS3)

“Stigma, sometimes as I said there is internal and external. So the internal one is something like you might just think that if I go to the hospital, I am going to be judged, I am going to be – not to be taken care of because I think that I am the most sinful person. But the external one is really to see that you can really see that it is happening.” (OL9)

Both extracts illustrate a generative process that combines the external experience with the internal perception in the construction of stigma. Another participant said this even more clearly, when he noted that you are simultaneously “marginalized somehow” and you also “feel” and become aware of the experience of “being marginalized”:

“The way I understand the word stigma, we are looking at should I say the social mark associated with a person which causes marginalization, I think you *are marginalized* somehow, and you *feel you are being marginalized*.” (LC7, my emphasis)

This notion suggests a reciprocity or symbiosis involved in both the action and perception of stigma for these participants. Some participants identified that there are multiple directions of action involved, suggesting that perhaps the distinction between the internal and external while illuminative, might also be too crude. In the quotation below, OL11 refers not only to internal and external processes of stigma, but also to how individuals interact with and create social values, indicating more than one plane of action (like the “koosh ball” of intersectionality, see chapter two).

“You know the way we see and perceive and things might end up stigmatising someone and might end up that person not being productive. Others can even commit suicide because they feel ‘I’m useless, I don’t add any value to this world because the society looks at me in a negative way’. Because *in society we look at people negatively* actually. I think I should say the way we look at others, other things, other people negatively. For example people living with HIV and AIDS. First thing you say ‘I am positive’. Then other people will say ‘oh this one is positive and think he is not a straightforward person, he was moving around with women.’ But you know you can contract HIV anyhow. But at the same time we need to look at HIV as a disease like any other disease. Because if you look at HIV and you think ‘ah no he didn’t have morals that’s why he has got HIV and AIDS’. Ahck no it means I wasn’t take caring of myself and how is society going to look at me? Then that also ends up confusing you and you become isolated – *you isolate yourself actually because of how people view you*.” (OL11, my emphasis)

The self-isolation OL11 describes is an example of how the internal reacts to the external triggers of stigma, and potentially how the two can reinforce each other in a vicious cycle.

Two participants described stigma in neutral terms, as something without attributing action or a sense of direction to either internal or external sources.

“Stigma is the worst form of discrimination. Yah... it's the worst form of discrimination. It really puts you up hard from the rest of the community.” (LS1)

“And if I had to ask you to describe stigma just in a sentence, how would you describe it?”

Fear – fear of the unknown.” (OL4)

As noted above, across all groups the most common understanding of stigma articulated it as an external process. This was particularly true for the opinion leaders, of whom two-thirds described stigma in this way compared with exactly half of both the life story participants and the law commissioners.

Analysis – implications of different interpretations of the direction of action of stigma

As with the definitions of stigma, differences emerged between how different participant groups attributed the direction of action. The most striking difference between the participant groups relates to internalized stigma or the direction of action that was attributed to the self. Within each group, one of law commissioners, two of the life story participants and only one Opinion Leader viewed stigma solely as an internalized process. In other words, although the numbers are small but taking the group size into account, the opinion leaders were the least likely to define stigma as an action purely from within. However when looking at the proportion of each group who identified that stigma was both an internal and external process, it is in fact the life story participants who emerge as the least likely to consider the internalized dimensions of stigma: fewer than a quarter of life story participants, compared with almost half of the law commissioners and a third of the opinion leaders.

As with the differences in the conceptualization of stigma already noted, there are important programmatic and policy implications for overcoming stigma that can be deduced from the attributions of direction of action in generating stigma. On the one hand, an intervention that is founded primarily on a notion of stigma that starts from within may be centred on the personal, with efforts to empower or counsel individuals, link them to support and other services, and potentially provide some kind of individual nutritional or economic support. The focus is on self-perception, self-reliance and self-esteem. On the other hand, an intervention founded on an externalized notion of the direction of action may focus on the public, that is, on efforts to respect other people, to

protect against discrimination, and to enable social inclusion. This focus is on actions towards others.

Recognizing the extent to which responsibility for stigma – for stigmatizing – is attributed to internalized or external sources is just as important as understanding the nuances of what stigma means to key actors within the national response to HIV in Malawi. By focusing on the links and differences between the two, this analysis seeks to simultaneously consider notions and attributions of agency for stigma alongside notions of how stigma is present in people's lives. The methodology undertaken for this research also sought to explore this dynamic interaction between the self, the themes and the research process (see chapter three). The following section extends the same parallel analysis to a review of the nature and nexus of proposed solutions for overcoming stigma.

PART III

V | Nature: Proposing solutions

Two key angles to understanding stigma have been explored so far in this chapter – the nature of stigma and where it occurs over time, and the direction of agency involved in those stigmatizing actions. This section concludes with the third key angle applying this analysis to possible solutions for overcoming stigma. The ways in which participants suggested stigma could be solved also provides insight into how they conceptualized stigma, as well as the areas of inconsistency in how they described their understanding of stigma.

The three main solutions for overcoming stigma were openness (being and becoming open minded), acceptance (both of an HIV positive diagnosis as well as HIV in society), and education (civic awareness and knowledge sharing). Although not necessarily given the same credence, it is generally apparent how the proposed solutions seem to respond to the perceptions of what stigma means. As in the definitions of stigma already outlined, participants articulated the importance of considering both the actual experiences of stigma (defined as an outcome, and solution as openness) as well as perceptions of stigma (defined as a process, and solution as acceptance and transformative education).

Openness

The most common solution for overcoming stigma suggested by just over three-quarters of participants related to either being open or encouraging openness. Almost half of the participants within this group suggested that the solution for overcoming stigma was encouraging and supporting people living with HIV to disclose their HIV status, with two participants also explicitly recognizing the courage that this takes on the part of the individual (details in Annex 6 | 4).

“Maybe if more people were open like that then it’s more out there yeah, then you tend to accept because it becomes the norm. If everybody came ‘well by the way I have got HIV’ it becomes the norm is that people have it. Not that they have to disclose it, but if they are comfortable enough to accept their situation and tell people, because it is in your face every day then you get to accept it. But if it is hidden because of the stigma as I was saying, when somebody comes to you and says it you still think ‘oohh’.” (OL12)

One participant explicitly defined his own sense of stigma, and the possible solutions for overcoming it, in terms of his own learning and appreciation of the openness and public disclosure of the interviewer (in this case, both the interviewer and the participant were members of the action research team). He reflected,

“I’ve learnt that those people who are courageous, for example, you yourself¹³, I knew about you being positive before I knew about me being positive. So, whether knowingly or unknowingly you were also a source of inspiration because I was saying that there are people that I heard, before I knew that they are positive and they are still living.” (LS7)

Other suggestions included being open-minded, having reflection and deep conversations, and promoting more open and courageous leadership in talking about HIV.

“We need to find ways of unravelling or like getting down. You have to really use other methods of digging deeper, penetrative sort of methods that will make people open up. That would allow people to open up and dialogue more, talk more about the issues so that they know – because you can change their mind easily, issues can be changeable, by time and even by the way you look at them. Over time they should be able to change and you know look at them differently so that the stigma will no longer be their stigma.” (LC8, my emphasis)

On leadership, the suggestions included a mix of different kinds of community champions and called for leadership at many levels. This included the so-called ‘elite’ and influential people, including people living with HIV within these categories (see chapter four).¹⁴

¹³ In this case the interviewer was George.

¹⁴ Personal communication with Justice Edwin Cameron about the findings from the research reaffirmed the importance of further research and/or analysis on internalized stigma according to class.

“If we could be more open with our status I think that would help. Especially people that are in authority, I guess what we might call *elite*. Then we would feel – it would demystify the whole issue of HIV.” (LC1)

“I think for me it is to have an open dialogue and this dialogue must start from the secretary – the sub-sector themselves, the religious institutions, from the youth, from the different sectors and then tie up together so that we know the issues.... We need *those people who matter* to talk about it openly.” (OL8, my emphasis)

The desire for openness was expressed at many levels—including the “elite” and the leaders of the country, as well as including peers and mentors in speaking about HIV in their lives. Some participants acknowledged the courage this takes from all, in becoming leaders in the response especially for people openly living with and affected by HIV. Participants also perceived the symbiotic nature of their leadership for all to speak more openly, disclose and have in-depth conversations with friends, peers and relatives as part of daily life so that HIV becomes common parlance among their church groups, communities and schools.

Acceptance

The second most common solution for overcoming stigma suggested by participants was acceptance. This included acceptance at the personal level and coming to terms with an HIV positive diagnosis, for example,

“One thing I think which has helped me is that *I accepted it*—eh, I think that’s what has helped me because even when I knew my status I have seen people that continue to die, and I have discovered the reason is eh they are not accepting – they are still fearing.” (LS7, my emphasis)

“One thing is to *accept it yourself*. You start accepting it. When you accept it then things will go well. Because when you accept it, even if people talk about it in your presence, you hear about it, they talk about it, they talk about you, because you have accepted it, it will be very normal. But when you start denying it yourself and they talk about it, it will be very painful. So first of all accept it, when you accept it makes things go smoother than when you deny it.” (LS3, my emphasis)

It also included acceptance at the societal level in terms of embracing HIV as ‘among us’ and part of Malawian society, for example,

“Acceptance, [HIV] is amongst us, then I feel stigma is gone.” (LS2)

“Solution for stigma? Because if I look at it from the issue of acceptance then I think the more discussions we have about what is causing it, the more acceptance there will be and therefore the less – the less segregation there would be of people, the less ignoring of people that would be there.” (LC9)

It is interesting to note that of those who suggested that acceptance was a solution for overcoming stigma, three times as many focused on acceptance at the personal level as opposed to the societal level.

Four participants suggested that overcoming the “othering” of HIV, that is, breaking down the distinction between those who are living with HIV (and know their status) and those who are not or those who have not yet tested, should be one of the strategies to overcome stigma. Three participants suggested that a greater understanding of HIV was needed, and that this also called for greater personal reflection about the extent to which HIV has or could touch individual lives. One of the participants who focused on the societal level of acceptance stressed the need for greater empathy and more personalized understanding of HIV, to forge a stronger solidarity between people living with HIV and those who are not.

“I think the solution is—I would say—is us, meaning everybody, should understand HIV – that I mean it is here until we find a vaccine, we can say that it is here to stay with us, so we should be empathetic in the way we treat one and another. Because today it is my friend, tomorrow it may be me. So whatever we are doing to those who are infected we should imagine if it was – if I was in their place, would I be happy if I was treated that way, so we should not stigmatize one another. Let us just live as one and enjoy life as it is.” (OL15)

Two participants also focused on cultivating love and compassion as part of the solution for overcoming stigma.

“And another solution is again love and maybe compassion, I feel if one has love then definitely for the ones who is HIV positive, he or she can care for a person. So I feel maybe love is not there, acceptance is not there. So if we have acceptance, we accept first, and then love one another, then I feel that would be OK.” (LS1)

“HIV is real and it comes from something that we have all experienced, because HIV is about love. Let’s face it.” (OL8)

The recognition of different levels of acceptance—internally as well as in communities—highlights a tacit and sometime explicit acknowledgement among participants about the interrelationship between self and society in shaping attitudes and responses to HIV.

Education

The third most common suggestion for overcoming stigma was education (21 participants). Those who suggested solutions based on education included notions of civic

awareness and information-sharing about HIV and access to health services (such as testing). For example,

“Civic awareness. Every person I think needs to know what their responsibilities are to a person infected or living with HIV/AIDS, to a person just affected by HIV/AIDS. I think that if everybody would be aware that they have a duty to perform to themselves, to people living with HIV/AIDS, I think that would be – it’s about changing attitudes in my view. That’s the start.” (LC3)

Several participants also referred to education and information in terms of increasing knowledge about HIV and the routes of transmission. For example,

“We should try to emphasize more on how this disease is passed on. I don’t know in terms of what percentage is passed through sexuality, but still if we can also highlight these other areas then people would feel comfortable to say after all one gets the disease from any other form. You know you don’t feel ashamed if you suffer from measles for example, because you know it is airborne [laughs]. You get it – you don’t have to choose to get it. Unless if you are not immunized, you can get it. So one doesn’t feel ashamed, but the stigma comes because of this sexuality.” (LC7)

This example also clearly shows the distinction between participants who framed their solutions to overcoming stigma in terms of openness (as outlined above) and those who did so in terms of knowledge. In this example, instead of suggesting the efforts be tailored to change or broaden those norms, LC7 instead suggests that by broadening the base of knowledge about routes of transmission the association with sex and sexuality would be deflected. Even though she recognizes that morality and norms about sex and sexuality may be the cause of stigma, she does not suggest that the solution is to broaden or reframe the moral norms about sexuality, but rather to deflect attention away from the association between sex and HIV.

Several participants also noted specific comments that the tone of the messages should be positive, framing key messages in terms of living with HIV and clarifying that an HIV positive diagnosis does not equate with death, and specifically to promote greater awareness about access to ART.

Other solutions

The main other categorization of suggestions for overcoming stigma can loosely be grouped as referring to creating an enabling environment. This included suggestions such

as the law and human rights and listening meaningfully to people and hearing their stories.

For example,

“It requires interventions that would change people’s attitudes. It requires strong cases that people listen to.” (OL22)

One participant specifically suggested creating safe spaces for people to share, listen and reflect:

“I think the other thing how we can deal with stigma is I think listening to the stories of those affected ... people can learn from those experiences and start you know building on those stories. Because people do face a lot of issues on stigma but they don’t have the space to tell their stories...People have stories but they don’t know where to put their stories – a safe space where they can talk their issues... and the story is being listened to. I think we can move forward but we don’t have those kinds of spaces. Even if in the village you would think, in the rural areas, if someone is in this case HIV positive, where can she or he take her story without facing discrimination? So to me I think that has been a challenge. Maybe we have talked a lot in towns because of the technology...but what about the common person who is in the rural areas? Does he or she have enough information? ... There are not those spaces.” (OL10)

Of the few participants who explicitly mentioned law and human rights, it was generally as an important concern rather than as an actionable possible solution for overcoming stigma. For example,

“If there is stigma and discrimination, human rights have no room in a person living with HIV. If there is no of human rights [sic], it means that there is a wind of stigma and discrimination. Yes what do I mean? A person has the right to receive treatment from the hospital for healthy living. A person has a right to life. If he/she does not get assistance from the hospital which is his/her right...it means he/she can’t have life. They have cut off his/her right. They have removed his/her right to life. Because of what? Because of stigma and discrimination.” (LS4)

One participant did explicitly reflect on the utility of the law in responding to stigma:

“For me one of the relevant issues is you know whether or not the law as a law – it maybe a necessary but I don’t know that it’s a sufficient condition to deal with stigma and discrimination. You know you pass a law that says ‘thou shalt not ... thou shalt not commit adultery!’ and we know how well that one works in this country, right. But you know ‘though shalt not discriminate against people living with HIV.’ OK fine you have a law that says that, remedies, you have fines, you know you have imprisonment etcetera, but by passing the law that doesn’t mean stigma disappears from one day to the next. Nor does it necessarily mean that people are going to start getting prosecuted for it or start complaining for it, and so the law would be a good step but in and of itself it’s still – it doesn’t necessarily change anything. It doesn’t change the attitudes it doesn’t change the behaviours. What else has to happen and how else do you have to do that? *So it can be useful to have the law, as it can be problematic to have the law depending on what it says,*

but in and of itself – on its own – the fact that it exists doesn't necessarily at the end of the day mean all that much.” (OL3, my emphasis)

In this extract, OL3 questions links between a law on paper and its efficacy in changing attitudes and behaviours in practice. This opinion is very interesting in light of the results presented in chapters seven and eight. These illustrate the extent to which the law was perceived to have a normative and symbolic potential in delineating social values and thus the relationship between the law and stigma. OL3 is implicitly aware of the link between law and governing social values as he equivocally comments that it can be both useful and problematic to have a law “depending on what it says” (op cit). It is therefore even more interesting that he concludes that the existence of a law per se does not in fact “mean all that much” (op cit) – when in fact, as indicated in his previous comment, he clearly thinks that it may.

Throughout many of the suggestions relating to the enabling environment there was a strong sense of openness and depth of conversation. Although one participant suggested that there was in fact no solution to overcoming stigma, she continued to explain how deep personal reflection and change may in fact be possible (see OL 12, op cit). Likewise OL3 suggests that is interventions that can generate a change in actions and behaviours that are the solution for overcoming stigma. Combined with those outlined in the openness and acceptance categories, these suggestions point to the kinds of interventions that unravel or dig down (to borrow metaphors from the participants) in a transformative way that somehow engages a person in a way that goes deeper than the rational or logical level within their dynamic social context.

Analysis – differences between groups

On looking at the breakdown of suggestions for the solution to overcoming stigma between the participant groups, some noticeable differences emerge (details in Annex 6|5)¹⁵. The law commissioners suggest openness, acceptance and education in almost equal measures. Approximately two-thirds of opinion leaders favour solutions relating to education and openness over acceptance (just under half); whereas almost half of the life story participants strongly favour acceptance and then openness (around one quarter), with none of them suggesting education or civic awareness.

¹⁵ As explained above, the categories are not mutually exclusive. Proportions are given in relation to the total group, not of only those who answered the specific question.

Given the smaller numbers of life story participants who responded to this specific question, it is more challenging to draw out meaningful insights from the differences between the groups. However the most significant difference centres on the solution of education. For the group of people more likely to have had direct experience of or exposure to stigma, solutions that addressed attitudes and behaviours (acceptance and openness) were conclusively favoured over solutions that focused on knowledge and information (education). For the other two groups, education featured much more prominently as the preferred solution (over half of law commissioners, and two-thirds of opinion leaders). This could be for a variety of reasons, such as the fact that the results indicated that stigma is predominantly viewed as a mono-dimensional process. This could be linked to an oversimplified perception that stigma is founded on a lack of knowledge. However as argued throughout the more recent literature on stigma and supported through the findings of this research, stigma is interlinked with power and productive measures to delineate social control (Parker and Aggleton, 2003). Another possible reason is that many of the law commissioners and opinion leaders were in a position where they were responsible for drafting and implementing policies and programmes to address stigma.¹⁶ From an implementer's perspective, it is much easier, cheaper, and more publicly visible to deliver an education campaign in schools, through the media (television, radio, print and online) and/or through public service announcements in public spaces (through leaflets, billboards and clinic waiting rooms). It is significantly more costly and more challenging to facilitate transformative educational processes that can empower people and stimulate positive change within the individual in the context of their environment (Stackpool-Moore et al, 2006).

Further research could more definitively explore the differences outlined above, pursuing in more detail the possible reasons for the variations between the groups.

VI| Nexus: Direction of action in overcoming stigma

As with the meaning of stigma, it has been possible to identify directions of action from the participant's responses and suggestions for overcoming stigma (detailed breakdown in Annex 6|6). An analysis of the direction of the proposed solutions for

¹⁶ This was explicit, and due to the selection criteria for opinion leaders as policy and programme leaders related to HIV, law and human rights in Malawi. The law commissioners, by virtue of having been part of the Special Commission on HIV and the Law, were integral in the process of drafting the proposed HIV legislation.

overcoming stigma further explores the potential differences between the identified source of stigma and the primary agents in generating stigma in how participants articulated their ideas for solutions to overcome stigma. The locus of action for the solution gives an insight into how the “problem” is perceived. But the analysis of responses reveals an inconsistency between the understandings of stigma as a “problem” compared to how it is understood as the basis for the “solution.” This inconsistency sheds light on one of the concluding recommendations from this analysis, that the understanding of the three key areas – the understanding, the action and the solution – should be aligned to ensure that both the action as well as perception of stigma is addressed effectively if stigma is to be alleviated.

The results were mixed, but almost half of participants suggested that the solutions would be determined by a symbiosis of both internal and external processes. Some focused on linking education and awareness on ‘both sides’ including for those living with HIV and others, such as,

“We have to educate people because even if you put penalties, penalties is the last resort [sic]. Yeah but people have to understand – they have to understand the disease itself – I mean the HIV/AIDS epidemic, the impact it has, how you can get it, how it can be controlled, and give hope because what is important is people should be told that it is not the end of their life. I know if people are given the hope that you know if you have this disease, because the stigma is from your side and from the other side. You can be – you know – stigma by yourself and those others. So on both sides people should be able to – be made to understand that there are rainy days, there’s hope, and because at the moment there is no cure, but still life can be perpetuated or prolonged to maybe even 20 years or more.” (LC7)

Another participant suggested that it necessarily needs to engage both individuals and the structures that make up society, and argued that education alone is not enough for overcoming stigma – as shown by the fact that stigma still exists in Malawi after some years of public awareness campaigns:

“Awareness has been there anyway but maybe the question is why are we still having stigma after all these years? People have talked about stigma and discrimination but after all these years why are we still facing the issues? What is it that we are failing to challenge stigma? So I think to me the issue is that maybe we have been looking at the issue of stigma from only maybe one angle, yeah, only one angle. People if we talk about stigma only, people will think – a person is known to be living with the virus and that’s the end but from the individualistic centre, we have to also look at other structural you know issues influencing stigma.” (OL10)

One participant made this point in relation to perceptions and being open to change, for example in not only perceiving the problem as one that is external but also being/ becoming aware of how the individual is part of that problem. In so doing he suggests that it is a symbiotic engagement between the personal and social that can generate the solution for overcoming stigma:

“In counselling we are meeting different people from different backgrounds; others are having relationship problems in their families; others are having relationship problems in their workplaces. And whoever comes for sessions usually will say ‘I look at so and so as having problems relating to me or dealing with me’ but in the course of helping him in the counselling process you would discover that he is also playing a role in that – in the issues that he is presenting. At first I may say ‘Lucy has a problem’. OK? Now within the counselling process this person is also assisted to look around and see his own contributions towards that problem. *What part am I playing there for the maintenance of the behaviour or for the onset of the behaviour?* What part do I play? And then it goes on and on and it helps the client to see how best can I improve this situation, OK. It is not up to Lucy to improve this situation but what part can I play to improve this situation. It’s the whole dynamic of the whole person.” (OL13, my emphasis)

A large number of participants identified that the solution for overcoming stigma was primarily in focusing on individuals in terms of how they are open to HIV, how they accept their own and other people’s status, and the extent of their own knowledge about HIV and how it is transmitted. Several participants identified focusing on personal reflection and change as the key for overcoming stigma. For example,

“It takes change, personal change, yeah because if you have I mean we need to understand that we have some people with strong opinions and a strong way of thinking that you can’t just sway them with a new legislation. It needs – you need to personally accept that this is the world we are living.” (OL12)

One participant, while suggesting that the solution rested at the individual level, also expressed dismay that stigma was still present in a country with a relatively high HIV prevalence like Malawi (i.e. where most people would have direct exposure to people living with HIV in their homes, workplaces and other social spaces). He commented,

“One of the things that I still struggle with is how do you begin in every setting and in every context help to put people on that road towards normalization in a sense. In their own individual, personal understanding. And there really doesn’t seem to be – there is no magic bullet, there doesn’t seem to be some pill that we can slip in the water supply. Um it is almost an individual-by-individual, person-by-person process. And what I find most striking in Malawi is that - in other places I have been one of the key factors in getting people to start changing the way they think about it is because they have been directly, personally touched – someone in their family has been affected and that has made it more of an ‘us’ than a ‘we’ and

‘them’ kind of perception. And to a large extent that seems to not have really happened in this country.” (OL3)

Following OL3’s logic, nor will HIV become normalized, and accepted in society, if stigma is entrenched within the new HIV Bill (see chapter eight).

One participant spoke specifically about how people living with HIV can inspire those who may have become sick or in more advanced stages of disease progression. She suggested that acceptance and avoiding self-pity for those “just” living with HIV could help to motivate others to recover and become healthy again (by implication encouraging them to adhere to their ARV treatment).

“Avoid...self-pity. And when you speak with one voice, and at the same time [you are] proving that you are capable of doing what everybody else is doing...If you are just positive and you can...you can do as much as anybody else. Let’s go for it and then that would also act as an encouragement. To those who are bed-ridden to see that ‘okay I can also, you know when I get better I can also live a normal life’. Just like anybody else.” (LS15/ LC6)

One fifth suggested that the solution for overcoming stigma rested solely with external processes. For example,

“I think we still need more sensitization campaigns and we also need people to go in the open and tell them about their experiences with HIV and AIDS. Something like holding something on a screen – they should be watching as if they are watching a film.” (LS12)

“My personal opinion is that we need to play it in a more simplified manner. I think the manner in which HIV and AIDS were introduced, right from the onset, was like bringing in threatening messages and that has created a very negative impact because someone with HIV, people think he has been very immoral in terms of morality you know. So it is a question of maybe trying to bring people in terms of how they understand HIV gets transmitted, how it can be prevented.” (OL5)

Three participants noted no specific focus on either external processes or individual processes as the target for solutions to overcome stigma, for example,

“It’s a broad thing that can be dealt from different angles so as I said; to fight stigma is not maybe one thing. There have to be several approaches that work in harmony to at least bring it down – to bring down the stigma itself.” (OL16)

On looking at the direction of action within the suggestions for the solution to overcoming stigma between the participant groups, some noticeable differences emerge. None of the law commissioners suggest a focus solely on external processes, and instead they focus on internalized processes or those that incorporate both directions. This is somewhat surprising, given that as the drafters of the proposed HIV legislation, they were

involved in proposing a legal framework that was explicitly designed to address stigma and discrimination relating to HIV and their views are likely to have a direct impact on external processes and the extent to which the environment is an enabling one for overcoming stigma in Malawi. The opinion leaders were the most equally divided between the actions, with the highest number suggesting bi-directional processes and equal numbers suggesting either internal or external processes. For the life story participants, even though the majority did not address this question in their responses, more expressed a greater emphasis on internal processes than external processes as an important focus in overcoming stigma. This was perhaps due to the fact that the majority of life story participants had described personal experiences of stigma in their lives, and is consistent with the findings from this group in the other key areas for understanding stigma described above. It also suggests that the life story participants may have felt that they “deserved” stigma, having internalized the negative associations with HIV, and could identify sources of stigma within themselves.

In sum, the results spotlight that it is misleading to assume that all people share the same conceptualization of stigma. The differences identified in these results showcase the need for consciousness about the conceptualization of stigma – in general, as well as the differences between different constituents, and including awareness of the direction of action involved. As noted, due attention needs to be directed on the conceptual notions of stigma to guide effective and appropriately targeted policies and programmes to mitigate the impact of stigma on communities and within individuals.

VII | Nexus: Direction of action—meaning versus solution

One final comparison crystallizes the importance of paying attention to notions of understanding stigma. A significant difference emerges when comparing the actors identified in the conceptualization of stigma (how people defined stigma as outlined in the first part of this chapter) and the solutions suggested for overcoming stigma (see Annex 6|7).

In defining stigma, the majority of participants described it as an externally-driven process – something that is done by other people or to themselves or to other people. In addition, several participants also saw stigma as both an internal and external process, and identified external processes such as structures, power inequalities, and social norms as critical drivers in terms of how they understand stigma. However, when it came to

suggesting solutions, only a minority of participants focused on external processes. Some said it was bi-directional, involving both internal and external processes. More than one third of participants suggested that the focus for overcoming stigma should in fact focus on internal processes, and the highest proponents of this solution were people most closely affected by HIV themselves—the life story participants (see detailed breakdown in Annex 6 | 8).

The differences are stark, and the results suggest that efforts to address stigma may need to take into consideration equally the external drivers as well as internal drivers to more closely correspond to how stigma is experienced. Recognizing the extent to which efforts to overcome stigma focus on individuals or external sources, and the extent to which these correspond with the conceptualization of stigma, may also add important insights for how efforts to overcome both the actions and perceptions of stigma should be targeted in Malawi, in particular how these interact with the different laws and different provisions within the proposed draft HIV Bill (see chapters seven and eight).

CONCLUSION

The results presented in this chapter outline various understandings about the nature, notions and nexus of HIV-related stigma, direction of action and solutions for overcoming stigma in Malawi. The findings provide insight into the nuances of this understanding within and between individuals and groups. By breaking down an analysis of stigma from multiple angles, the results have indicated the extent to which the devil is in the detail. Much more critical attention is needed to ensure that efforts to address stigma are actually being targeted in the most appropriately directed way. Questions are also raised as to the extent to which policies and legislation are in fact ill-equipped to deal with the multiple dynamics of stigma—and indicate that alternative actors, actions and approaches might be needed for effectively alleviating the negative impact of stigma.

There are two main conceptual contributions to knowledge from the analysis and results presented in this chapter—the first relates to considerations of the temporal nature of stigma, and how it compounds over time; and the second relates to the importance of understanding how stigma is perceived (particularly in terms of the exertion of agency and responsibility for stigma) before being able to effectively alleviate experiences of stigma. The first half of the chapter focused on individual stories and experiences of stigma, documenting the results from the research in terms of common

reporting of stigma and where it did or did not occur, at the personal, service delivery and structural level. The second part sought to deepen this analysis at the personal level, by adding in the dimension of temporality and compounding experiences of stigma over time. It continued then to build on this foundation to explore three angles to further deepen the analysis of the understandings of stigma documented in this research. Part II looked at definitions of stigma, and at directions of action. Part III on proposed solutions, and actors and also the direction of action.

In conclusion, the findings indicate that there are significant differences in conceptualizations of stigma between individuals, and that experiences of HIV-related stigma change over time within the lifetime of one individual. These differences need to be understood to more effectively research, design programmes, consult on policies and support individuals, on order to more consciously engage with the realities of stigma. The results show that both the process and outcomes of stigma should be considered and addressed (as a concept) while also addressing the agents responsible for the actions associated with stigma. Thus a dimension of agency (in actioning or inflicting stigma) as well as one of conceptualizing (in perceiving where and if stigma has taken place) are relevant considerations. This is particularly true for guiding efforts to solve stigma appropriately, at both levels, so that both the impact and perception of stigma can be mitigated. Both types of focus are necessary to achieve an actual and perceived success in response to stigma.

The absence of much discussion relating to layers of stigma or multiple triggers of stigma indicates that perhaps the nuances of how stigma intersects with other aspects of identity (such as gender, sexual orientation or source of income) was not conscious among the participants interviewed in this research. This was equally true for those experiencing stigma as well as for those stigmatizing, since in many of the interviews both dynamics were visible within the one individual (arguably to be expected, and very human). In response, as a possible solution, educational efforts might be well placed to broaden an understanding of stigma, to also help people most vulnerable to experiencing stigma to recognize when, why and how it is occurring. The results suggest that greater attention could be paid to the complexity of stigma, the aspects of identity to which it attaches, and its evolution over time in efforts to alleviate HIV-related stigma in Malawi. It also suggests that conceptually the application of notions of intersectionality could usefully be applied to stigma reduction efforts and civic education initiatives.

These understandings of stigma also preface the analysis in the following chapter, which explores the extent to which the law is useful in the daily lives of people living with HIV for example in securing redress for experiences of stigma or discrimination. As the solutions proposed for overcoming stigma indicate, a transformative process of individual and social change is needed to foster the kind of acceptance and openness to stifle stigma. Yet if stigma remains conceptually mono-dimensional, devoid of the complexity it absorbs from the everyday realities, layers of attachment, and accumulated experiences over time, it will forever lurk as the Achilles heel, which destabilizes fragile yet vital responses to HIV.

7 | LAW AND LEGALITY IN EVERYDAY LIFE



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LAW AND LEGALITY IN MALAWI

This chapter explores the second research question—the extent to which law and legal consciousness is useful for seeking redress for HIV-related discrimination. The chapter presents results relating to insights about law in daily life and access to justice for people living with and closely affected by HIV. As outlined in chapter two, HIV is a public health issue that provides an illuminative lens to critique the law and notions of human rights because it is an entry point to explore the interconnections between disease and society (cf. Mann, 1999, p 222). Vulnerability to HIV reflects the extent to which people are, or are not, engaged in and visible in society and capable of making and enacting free and informed choices about their health. It is widely accepted that to establish a health-promoting environment, strategies must empower individuals while also addressing broader social determinants of health such as power inequalities, access to clean water, nutrition and safe housing (WHO 2008; Hassim et al, 2007; Marks, 1999).¹⁷ HIV is not just a health/ medical issue, but also a phenomenon that requires deep inquiry into structural factors of inequality, power, and personal and social dynamics.

The analysis in this chapter stems from two conceptual elements – first, the law and the jurisprudence on which it is founded, and second, legality and the currency of the law in daily life. The focus of the legal analysis is on two specific ‘laws’¹⁸: the Constitution of Malawi and the proposed draft HIV Bill, and the perceptions of the potentiality and role for the law as a whole in the national response to HIV. For the discussion of legality, the analysis is based on the day-to-day experiences of the participants of the research and an analysis of some of the challenges to enforcement and implementation of the law.

As outlined in chapter two, one of the factors limiting the transformative potential of the law in Malawi is the “muted” legal voice of many people in Malawi (Gloppen, 2007, np). This factor can be categorized into two main areas—structural and psychological. Even though these formal mechanisms exist, the ‘law’ in its formal sense is often either absent from or misunderstood in the everyday lives of Malawian people. Yash Ghai had suggested a third possible barrier limiting legal consciousness in everyday life—that the formal legal system and its laws are not relevant because they are out of touch of the daily

¹⁷ Hassim, Heywood and Berger (2007) explicitly highlight the importance of a substantive and redistributive element to the law in the context of HIV, and make a direct link between health and broader safeguarding of social security.

¹⁸ The draft HIV Bill has not yet been enacted and is likely to undergo revisions before it is tabled in parliament and during the ensuing parliamentary dialogue.

realities of most people.¹⁹ This third barrier was definitely not substantiated by the findings from this research, as described below. From the interviews with life story participants, all perceived that the formal legal systems and laws had an important role to play in protecting people in Malawi and in various ways had a specific part to play in the national response to HIV. However, in the same breath, the majority of these participants had never themselves invoked the formal legal system to seek redress for incidents when their rights had been abused and/or they had experienced discrimination based on their HIV status. The results of this research highlight a disconnect between the potential of the law (in both its positive and negative hypothetical impact) and the actual invisibility of the formal legal system in the everyday lives of many Malawians.

There is an old African proverb that says one cannot build a house from the roof down, so to commence the analysis I will begin by looking at the foundations: the legality and the impact of the law in everyday life in Malawi.

Law and legality

The law can have a profound impact on the lives of people – especially those who are vulnerable and marginalized. For example, this can be a positive force for change; through judicial and legislative action has improved access to life-saving treatment and protected people living with HIV against discrimination (UNDP, forthcoming; Cameron, 2005; Hassim, Heywood, Berger, 2007). Or where the law has guaranteed equal inheritance and property for women and girls, it has helped to mitigate the social and economic burden caused by HIV and AIDS (Ahmed, 2011b; Chiweza, 2005). Increasingly attention has been paid to creating enabling legal frameworks to mitigate the causes and consequences of HIV, yet in many countries, legal frameworks that further entrench structural inequalities persist (UNDP, 2012).

The degree to which people living with and closely affected by HIV are conscious of the law and enforcement mechanisms – including the various laws that could protect as well as those that could punish – has not been extensively reviewed to date. The Global Commission on HIV and the Law attempted to do this to some extent, by focusing on collecting stories and experiences from people who had direct experience of HIV-related

¹⁹ This may not be the case for customary and traditional laws, however that was beyond the scope of enquiry for this research. Given that the analysis is based in the language and descriptions participants themselves gave about the role of the 'law', the term is used to encompass the multiple meanings and perceptions of the 'law' described by the participants.

legal processes, mechanisms and discrimination through the law (UNDP, 2012). This Commission started however from a position of assuming legal consciousness from the testimonies on which it was based. *The People Living with HIV Stigma Index*, which has now been implemented in more than 70 countries around the world, began to systematically look into this issue by including a few specific questions about knowledge of laws and policies, and access to legal redress for experiences of discrimination (IPPF, GNP+, ICW and UNAIDS, 2008c). To date however, no in-depth interrogation of the specific results relating to legal consciousness among people living with HIV have been consolidated across countries or analyzed in great depth. All the same, programming tools promoting HIV-related legal literacy (for example with women and girls, or relating to stigma and discrimination) are currently being developed by UNDP and others to address the perceived need to support people living with and affected by HIV have access to justice in daily life.²⁰

The research presented in this chapter explores the context of the human right to health and the role of legal frameworks in everyday life and as part of the national response to HIV in Malawi. I have applied a lens of legal consciousness to explore the extent to which the law may impact real people involved in their daily life struggles in realizing their human rights (Ewick and Silbey, 1998). As noted in chapter two, and in the writings of Albie Sachs, Mogobe Ramose and Patricia Ewick and Susan Silbey, the research presented in this chapter places the individual person – and their lived experiences in relation to others – at the heart of understanding the law and legal processes.

At an empirical level, this chapter analyses the presence and absence of the formal legal system in the narratives of the life story participants and the responses of the opinion leaders. Nestled within the conceptual framework of transformative legal potential – transformative constitutionalism, the philosophy of *ubuntu* and new legislation relating to HIV – the perspectives of law commissioners, people living with HIV and opinion leaders from civil society in Malawi form the basis of a critical review of legal concepts as well as the laws themselves (see also chapters two and four). There is a paucity of research about HIV, the law and legality in Malawi, and the research findings presented in this chapter contribute to filling that gap. The analysis therefore draws parallels more broadly with recent literature that explores the justiciability of socio-

²⁰ Personal communication, UNDP, September 2012.

economic rights, gender, and jurisprudence in Malawi (cf Gloppen, 2007; see also chapter four).

The chapter is divided into four main sections—what the law is, what it is perceived to, what it could be, and what it is not. Part I, what the law is, explores two different dimensions of the law broadly in the Malawian context – the first, the Constitution that came into provisional force on 18 May 1994. Echoing and building on the arguments of Karl Klare, the major question is whether the kind of dramatic social change needed and wanted in Malawi with the introduction of the Constitution at the end of the Banda era can possibly be achieved through a law-grounded process—transformative constitutionalism (Klare, 1998). The second is the proposed draft HIV Bill that was finalized in the report of the Special Law Commission on HIV in 2008 and has yet to come before parliament for debate and potential enactment. While this Bill does not of course yet have case law or parliamentary commentary to provide a context in which it can be evaluated and assessed, it can nevertheless be analyzed for the extent to which it embodies the symbolic power of the law’s ability or limitations in triggering transcendence, or individual and/or social transformation in light of a contemporary health and human rights concern.

Part II, what the law is perceived to be, reviews the legal consciousness of the life story participants and their perceptions of the link between HIV and the law. The results indicate that for most, there was little understanding and/or a misunderstanding about the role of the law in response to HIV even though they unanimously hoped it could have a role.

Part III, what the law could be, explores the potentiality of the law in Malawi. It reviews the responses from participants about the potential positive and negative impact of the law in the national response to HIV.

Part IV, what the law is not, reviews two main limitations of the law in Malawi—challenges of enforcement, and the difficulties of responding to the intersecting and multiple identities in everyday life.

In conclusion, I explore the extent to which the law is absent or present in the everyday lives of people living with and closely affected by HIV in Malawi, and argue that in the current context it would be challenging to achieve human rights affirming individual and social change through processes based in law. Many authors have explored the symbolic as well as real significance of a constitution as both memorial and monumental, but to date no one has applied this frame to an analysis of an HIV specific legislation (see

chapter two). To repeat Van Marle, “monuments celebrate, memorials commemorate” (2006, p 37, op cit). At the micro level as explored in chapter five, an HIV diagnosis becomes a metaphor for this in different ways in the lives of the life story participants. At the macro level, as explored in the pages that follow, I argue that at the macro level, the Malawian Constitution and the draft HIV legislation achieve this to varying degrees, but are limited within their potential to be the monumental and memorial foundations of individual and social transformation.

Transformative justice in Malawi?

In Malawi, even without the enactment of a specific HIV legislation, there are numerous laws that have the potential to affect the national response to HIV. This includes through the general criminal and civil provisions of the formal legal system (much of which has been inherited from the colonial period and borrows from British law) as well as through traditional systems where the chiefs and local courts are still identified as a source of justice. This research supports that of others, such as Gloppen, who argue that the law is a critical component of the structural determinants of health and human rights (cf Gloppen 2007; WHO, 2008): “In Malawi, as elsewhere, law is an important element in the dynamics of economic marginalization that produce and reproduce poverty. The role of the law may be positive or negative” (Gloppen, 2007, np). As outlined in this chapter and chapter eight, these include laws that protect (such as the Constitution and the non-discriminatory sections of the proposed draft HIV Bill) and those that punish (such as the Penal Code and its application to groups vulnerable to HIV, the criminalization sections, and the discriminatory sections of the proposed draft HIV Bill).

As such, the law has potential for both a positive and negative impact on the national response to HIV in Malawi. The results outlined in this research suggest that even though the implementation of the law is limited and on the whole absent in the everyday lives of Malawians, the symbolic power and potential impact of the law is present and relevant to their daily lives and expectations.

Gloppen asks why a legal framework “clearly favourable to litigation that would advance the social rights of marginalized sections of society - has not, in twelve years, produced significant transformative jurisprudence?” (Gloppen, 2007, np). She then offers two dimensions for analysis: demand-side failure (litigation not forthcoming) and supply-side failure (courts not willing to take cases on). The empirical findings presented in this

chapter focus primarily on the demand-side failures and some of the barriers rendering the law impotent within its transformative potential.

PART I: WHAT THE LAW IS

The relationship between law and legality is investigated through two case studies in the following section—the first, the Constitution of Malawi, and the second, the proposed draft HIV Bill, the first law explicitly referring to HIV in Malawi. The case studies portray the intersection of law and legality, the challenges of implementation, and highlight the potential of the law, given its limitations, to achieve the kind of social transformation on which both laws are founded.

Case Study 1: The Malawi Constitution

This case study presents the concept of constitutionalism in the history of Malawi, the specific provisions of note from the Constitution of Malawi, and an analysis of the results from the interviews with participants about their perceptions and notions of the Constitution in everyday life in Malawi. The analysis suggests that the Constitution could provide a stronger base for achieving the social, economic and political potential of transformative governance and protecting human rights for all in Malawi.

Role of the Constitution in response to HIV

In this research, several participants cited the constitution as an important ingredient in the legal response to HIV. Many saw this as a normative legal framework to protect human rights for all (including people living with HIV, who were often cited as an example in arguing for rights) and for law and order. Some participants noted that laws relating to HIV should be consistent with the basic principles enshrined in the Constitution. For example,

“International law...the law itself is supposed to come from the Constitution. If anything else around law is being established as law and not consistent with the Constitution or the Constitution is not being reviewed on how things should be or that it is wrong to do things in a certain way...that is not law.” (LS4)

One participant did question why HIV had not explicitly been included in the language of Constitution of Malawi when it was drafted (and also revised) since HIV was already of serious concern in Malawi at that time.

“Our constitution says nobody should be discriminated, discriminated on any basis but may be when this was being drafted the HIV wasn’t taken - wasn’t there. Maybe, but they mentioned about the race, the colour and what have you, I would love it if HIV came out prominently as to say nobody should be discriminated based on HIV sero positive status because if you just take it it’s like in a blanket form and people tend to forget that this blanket form is aah includes ABCD.

So has HIV changed the way you think about the law and its role in your life?

I remember when Malawi had the first constitution review conference. I was there primarily for the sole reason of wanting to argue to say why is HIV silent in our constitution but then there argument was why should we specifically mention HIV because they argued that way because they are the people who haven’t experienced what having HIV living with HIV is and coming out in the open in Malawi is like they don’t know what we are going through they haven’t experienced what we go through so maybe they don’t feel they don’t see the necessity of having HIV spelt out to say nobody should be discriminated on the basis of HIV sero status.” (LS11)

Many participants indicated that people living with HIV have the same rights as everybody. This was generally framed in a positive light, seeing HIV as just one part of people’s lives and highlighting that people living with HIV are the same as everybody else (see chapter five).

The most common understanding of human rights was as freedom, akin to Amartya Sen’s iconic conceptualization of development as freedom (Sen, 1999). A quarter of participants directly used the word freedom in describing how they understood human rights. Phrases included “to live freely in working places” (LS20), to have “the freedom to do what you want to do without disturbing other people” (LS19), “the freedom to live” (LS13), and “to give freedom” (LS3). The notions of freedom incorporate elements of rights, of responsibilities, and of enabling the realization of rights for others. Even the notions described by participants of human rights as freedom encapsulates the duality of the individual and as well as the collective. Several participants also described that human rights are applicable to all people, from birth, by virtue of being born a human being. For example, LS4 described human rights as “things that a human being is born with” and went on to discuss how the government “had the responsibility, the obligation, to see that its citizens” enjoy those rights. By implication, and linked with the discussion of perception of stigma in chapter six, Goffman’s notion of a ‘spoiled identity’ could be construed as a denial of rights related to the intrinsic worth of being human (1963).

A few participants noted a direct link between human rights, health, and their right to access ARVs. This was also a common theme when the life story participants were asked to explain their ideas in relation to the role of the law in response to HIV in Malawi (see below). One indicative example that makes this explicit link between law, human rights and accessing treatment was from LS2:

“I know something about human rights and they are good to my life because I have the right to access ARVs or the right to any health services I want.” (LS2)

Or as LS19 links together, human rights enable him to be proud, responsible and healthy:

“[Human rights] are what make me stand tall. I have the right to stay with my family, to have a job, to receive free ARVs. All these are important.” (LS19)

However, five participants indicated that although principles of human rights were important, either the law was unclear in how they could be realized or it was not enforced to translate the aspirations of the law into real human rights protections in reality. For example, LS8 felt that “on paper you have got 100% rights. But when you go on the ground it’s 50% is taken away.” Stating a similar sentiment to OL14, who had identified the three key challenges of enforcement as knowledge, reporting and structural barriers (op cit), LS9 felt that “human rights are basic but ... not fulfilled. A lot of people do not know and that is why people are denied their rights.” In the most despondent example, LS12 said that human rights are “just a name...it doesn’t work...because people do not understand their rights, they do not know what their right is.” Only one respondent (whose interview was not included in the final selection²¹) commented that human rights were a ‘Western import’, and she was one of only two non-Malawi born respondents who were interviewed.

The consciousness of human rights that the life story participants described, which some linked explicitly to the Constitution, illustrates the main arguments developed so far—the interrelationship between law and legal consciousness in determining the impact of the law in everyday life, the combined spirit of the individual as well as the collective underlying the legislation, and the potential as well as the impotence of the law to demarcate individual and/or social transformation.

²¹ I interviewed her boss subsequently, and included only the most senior respondents from each organisation represented in the final selection of interviews.

Enforcing Human Rights: "If all else fails then we have to go to the Constitution"

Some participants noted that human rights, while in principle are there for all, in practice are not realized in the lives of people living with HIV. The distinction between the extent to which human rights for people in general in Malawi were limited, and the extent to which the limitations specifically related to HIV status, was not often clear. For example,

"Human rights and HIV and AIDS? I think that it is just a name, yeah. I don't think it works; it doesn't work.

Is there a reason it doesn't work?

Yeah because people do not understand their rights, they do now know what their right is.

For you what do human rights mean to you?

Human rights is something I get just when I am born [sic]." (LS12)

This example shows how even though this participant thinks rights are just a name, not a reality, in her life, it is not clear whether this is attributed to her HIV positive status or whether it is relating to other factors of her life – such as living in a rural area, as a woman, with limited access to education.

In a different way, another participant highlighted a similar point about the limitation of human rights – as enshrined in the Constitution – as abstract concepts, difficult to translate or utilize in actual legal disputes. He describes how for the cases that have Legal Aid representation, even among the few people who seek legal redress and who are able attain support from Legal Aid (apparently demand exceeds supply), rarely is a rights-based or Constitutional argument put before the Court:

"Like for instance we have a progressive constitution in terms of human rights but I always tell my officers not to come to me with a constitutional provision as a basis for assisting someone. Go and look in the laws! Look at the particular legislation— look at the affiliation act, look at the marriage act—for solutions. *If all else fails then we have to go to the Constitution.*" (OL4, my emphasis).

In this extract, it appears that OL4 does not consider the Constitution to be a law that is enforceable like other laws.

This case study is significant for three main reasons; first, it highlights the many challenges facing the realizing of human rights in the day-to-day lives of Malawians through legal means, even though they are recognized and protected in the Constitution.

Ironically, if the Constitution was in fact upheld more vigorously and more proactively engaged in legal proceedings, then perhaps there might be a greater visibility and realization of the foundational principles of non-discrimination. In so doing, the legal realism of the idealistic principles might become more present in the lives of Malawians (either through direct exposure or indirectly such as through media coverage), which may in turn diminish the motivation for a separate HIV specific Bill founded on principles of non-discrimination in the following section.

Secondly, it confirms the reservations expressed relating to the challenges of enforcing law in relation to HIV. These results are also consistent with the findings from *The People Living with HIV Stigma Index* in Malawi that indicated that although 20% of people living with HIV had recognized that their rights had been violated in the previous 12 months, and of these 70% had not sought any legal redress (Chirwa et al., 2011, p76). Of those who sought legal redress, less than a third achieved a resolution of the issue (ibid).

Thirdly, it demonstrates the symbolic power of the law (i.e. Lukes' third dimension of power, chapter two, Lukes 2005). Even though few participants mentioned having been involved in any formal legal process and none mentioned being involved in a Constitutional challenge, many referred to the Constitution as a point of reference. This is further explored in chapter eight, with a comparison with the potential normative power of criminal provisions if applied to HIV. As presented in this chapter, even though participants noted their lack of experience in seeking legal redress, this did not seem to curb their enthusiasm in their responses about the potential role of law in the national response to HIV. Whilst HIV is not explicitly referenced in the Constitution, many people may not have read or understood the details, and it seems to be rarely invoked in the courtrooms of Malawi, the Constitution and its principles of non-discrimination and equality is nevertheless important in the legal consciousness of some people living with HIV and opinion leaders.

Case Study 2: The proposed Draft HIV Legislation

The Constitution poses an interesting comparison for the following review of the proposed draft HIV Bill. In different ways, both laws seek to delineate a set of moral norms for society. This case study reviews the proposed draft HIV Bill in Malawi in the context of the rest of the world and the role of the law in response to HIV, and in light of the

reflections of the participants interviewed in this research. The draft HIV Bill has some commonalities with the Constitution of Malawi – it is also very long and detailed, it includes aspirational principles of non-discrimination, and even though it is in draft form (i.e. not yet enacted like the Constitution), as a concept it has limited purchase among the people whose lives it is directly trying to impact and is likely to face significant challenges of enforcement.

The proposed Draft HIV legislation in Malawi: “The intention may not be cruel and unhuman [sic] but the impact may be”

As reviewed in chapter four, the Special Law Commission for HIV and AIDS ended in 2008 with a Report (MLC, 2008) that included a proposed draft HIV and AIDS (Prevention and Management) Bill. The purpose of the Bill as stated in the report of the Special Law Commission is:

“An Act to make provision for the prevention and management of HIV and AIDS; to provide for the rights and obligations of persons infected and affected by HIV and AIDS; to provide for the establishment of the National AIDS Commission; and to provide for matters incidental thereto or connected therewith.” (MLC 2008, p89, my emphasis, op cit)

This notion is particularly interesting in light of the balance between rights and responsibilities (or obligations) explored in chapter eight, especially in relation to how that balance might be weighted differently for people living with HIV compared with the rest of society.

However, in the interviews undertaken in this research, some of the law commissioners expressed slightly broader reasons for why the Special Law Commission had been convened and why it had seemed necessary to draft an HIV-specific legislation. One of the commissioners emphasized that the environment or legal context had changed, hence specific issues relating to HIV needed to be addressed in the law. She also indicated that this would help to systematize and standardize how HIV is treated in legal proceedings:

“The situation...the terrain where the law was operating before HIV has changed. And whatever issues have come up with it needs to be ah...taken care of. So that ah...if such situations arise they know how to handle it. Instead of doing it there and then.” (LS15/ LC6)

Building on this idea of consistency, yet also invoking extreme examples of HIV transmission (that are not the primary mode of transmission in Malawi in 2011-12), another Commissioner commented that the main role of the law was to provide guidance – practical and moral – for Malawi’s response to HIV:

“The coming of HIV brought in its own challenges because culturally as I told you earlier on, some people believed that if somebody is HIV positive, they have sexual intercourse with a young girl, that girl after sexual intercourse – because the young girl has not reached puberty – it will solve the virus. At puberty it will take the virus out. So the man will be alive, the girls will be alive, while it was the opposite. Ok. Those were some and there were others who were violating the situation left and right, and in the process transmitting the HIV. So with that you could – they ended up having a lot of problems and it created its own problems among the population. So because of this that’s why it was felt that we needed the Act. And that we didn’t want the treatment to be ad hoc.” (LC4)

This sentiment reinforces the notions identified earlier about the potential of an HIV-specific legislation to strengthen the administrative and enforcement of HIV policies. It also illustrates the point of OL14 who had suggested that even people who make the laws do not necessarily understand them (op cit), and it is clear from this extract that LC4 has a very narrow and specific conceptualization of the rationale for the HIV Bill in Malawi which is very different both from the reality of HIV transmission and prevalence as well as from the more comprehensive stated intentions of the proposed law itself.

Unexpectedly, and perhaps contradictorily, in the glossary that accompanies the Bill, discrimination seems only to be defined in terms of so-called positive discrimination – that is favouritism or affirmative action that might privilege people living with HIV:

“‘Discrimination’ means any prejudicial act of making distinctions or showing partiality in the *granting of privileges* or benefits to any person on the basis of actual, perceived or suspected HIV status.” (MLC 2008, p 89, *my emphasis*)

From the life stories and interviews with people living with HIV in this research, it was not apparent that ‘positive’ discrimination – or the ‘granting of privileges’ - was practiced much, if at all, in Malawi in relation to HIV status²². There were, however, two policies and practices that policies had been designed to help protect the nutrition and food security of people living with HIV, in relation to fertilizer subsidies or salary supplements for government staff living with HIV. However, as seen in chapter five, these policies were

²² While the extract is ambiguous in referring to HIV ‘status’ (i.e. not HIV positive status), the implication would seem to be HIV-positive, given that it would be a very unusual turn of phrase to “suspect” someone of being HIV- negative. While not the focus of the research presented in this thesis, it would be interesting to undertake a discourse analysis of the language used throughout the draft HIV Bill and related Report (MLC, 2008).

often sites of stigma or discrimination when implemented, and often not implemented at all in practice.

Furthermore, the draft HIV Bill claims to be founded on notions of anti-discrimination and protecting the human rights for people living with HIV as enshrined in the Constitution. This is especially interesting given the challenges in translating 'discrimination' into local languages (see chapter three) and the ambiguity of a distinction between stigma and discrimination.

"6. (1) Any form of discrimination on the basis that another person is infected with HIV or is suffering from AIDS or is perceived to be infected with HIV or perceived to be suffering from AIDS is hereby prohibited" (MLC 2008, p91).

Unfortunately the draft HIV Bill expressly pits human rights against public health, and provisions (such as those regarding compulsory medical examination and isolation) in the Public Health Act, and in so doing seems to contradict the Constitution.

"Due to the peculiar and unique nature of HIV and AIDS, these modes of prevention seem to violate some human rights provisions enshrined by the Constitution" (MLC 2008, p 16, op cit).

Some participants referred to this as the giving of human rights with one hand, and the taking away of those rights (for certain people) on the other. For example,

"Because you have the more universal very positivistic protectionist language and rights of those living with HIV. You have a whole section, which is nothing more than administrative or bureaucratic reconstitution of NAC [National AIDS Commission]. Which is you know totally unrelated in that sense to the more lofty principles that are espoused in the law. And then you have those few problematic sections which are effectively 'I give you the right with my left hand and take it away with my right one'. It's like everyone has universal rights except you, you, you, you and you, right? So besides the potentially problematic content from a legal standpoint (having studied constitutional law at one point in time) the fact that you create a universal right and then restrict it immediately by saying 'except for these folks' is just also totally incoherent and inconsistent, and so it doesn't make a lot of sense to do what they're trying to do in the way that they're trying to do it because also just legally – and legally philosophically – it's inconsistent with what they are trying to do." (OL3)

This extract highlights how the proposed law is inherently contradictory in purporting to guarantee universal human rights protections for all while simultaneously restricting them for some.

The draft HIV Bill is paradoxical in that it would simultaneously protect and prohibit human rights. The inherent contradictions spotlight entrenched stigma against people living with HIV (or those most vulnerable to HIV) by prioritizing the rights of others (the

general public) over their rights such as to privacy, to the highest quality standard of health, to non-discrimination in seeking employment, and their rights to receiving quality, confidential health treatment (see chapter eight).

The contradictions within the provisions of the draft HIV Bill were mirrored in the different participants' perceptions of the potential role and impact of the law if passed in Malawi. The following section explores the perception of its potential as well as its limitations in having an impact (either positive or negative; or both) on the national response to HIV in Malawi.

PART II: WHAT THE LAW IS PERCEIVED TO BE

Through the lens: legal consciousness and the law in everyday life

To return then to the overarching question of this thesis — is it possible then to achieve personal and social change through processes grounded in law? In Malawi, while it seems that the law is premised on fundamental notions of humanity, for the law to achieve its transformative potential, greater synergies need to be made between customary and formal legal traditions and interventions made to overcome the structural and psychological barriers to accessing justice (cf Merry, 2012; Mamdani, 1996).

This section looks at the presence of the law in the lives of the life story participants interviewed and their legal consciousness (research question two). None of the participants had effectively engaged the formal legal system to seek redress for episodes of injustice or discrimination they had experienced. Their life stories indicate that the traditional authorities are a much more prominent source of justice in their lives. Most of the participants were asked about where they get a sense of justice in their lives as one of the final questions in the interview²³, and as with the other results presented throughout this thesis, the discussion in this chapter is founded in an inductive understanding of how participants themselves understand and interpret the law. Consciousness of the direct link between law and HIV was not always clear for participants. For example the exchange in the interview with LS20, reviewed in more detail below, clearly shows that the link between HIV and the law was not obvious at a conceptual level:

²³ The question asked was deliberately vague, and when participants sought clarification or guidance on how to answer the question, I would explain a short scenario that if they had felt they had been wronged by someone in some way, where would they go to seek justice.

“Can I ask, just from your own, experience have you ever gone to the law to help solve any issues you have had relating to HIV?”

Not at all.

By law I mean traditional chiefs, village headmen, police or anything?

No.

Not for HIV then but have you for any other reason?

For any other reason? Yes, sometime ago when I informed my husband that I am HIV positive... “(LS20).

This extract illustrates that even when pushed to consider the law broadly, including traditional authorities and the police, LS20 still does not make a connection between HIV and the law. However in the very next question, when asked if she has ever sought redress for another reason, she answers in the affirmative and gives an example relating to her HIV status. Paradoxically, as outlined in the section that follows, nonetheless when asked a different question, explicitly asking about the role of the law in response to HIV, almost all participants perceived the law (including traditional authorities and a sense of legal pluralism) to have an important role in the national response to HIV.

The perceived role of traditional authorities (such as village headmen or chiefs) in providing justice is clear. Six participants explicitly referred to the important role of traditional chiefs in providing justice if they had been wronged. Two participants indicated that the traditional processes were the first port of call, and if those failed then they would receive a letter to go to the police. In other words, the initiation process with the formal legal system (the police) was seen as a fall back option by some when the traditional mechanisms had not been effective. Two of the participants had direct experience of conflict resolution by the traditional chiefs as described in chapter five. Both LS17 and LS18 had experienced stigma and discrimination at the hands of their relatives, and had lost land and livelihood because of their HIV status. In both cases, the traditional authorities found alternative living and farming arrangements in other areas for the families to relocate to. Another participant indicated a demographic difference relating to where someone lives as opposed to where they seek justice:

“Ah sense of justice. It depends on where you are. If you are in the village then there’s also systems there and where you – through the village headmen where you get a sense of justice. And then if you are in the urban areas, in the cities, then you can even you can call for a lawyer, you know, so it depends on where you are

and at what level. But at each level you get some sense of justice. In the communities, in the villages the village headmen are crucial in terms of justice and then urban settings then it's the lawyers." (LS15)

The results outlined here support this claim, as both LS17 and LS18 live in rural areas. The two participants who indicated a mistrust of the traditional justice system and/or a preference for the formal legal system were living in cities. LS3 preferred the courts because he feared bribery was more common among the process of settlement by traditional leaders. In regard to the courts, he commented that "it is very straight there, you would get a good judgment out of whatever issues you bring forward" (LS3). Another participant indicated that he preferred the courts, "because the people who discuss issues in court are educated" (LS5). These examples and the links to demographic characteristics such as geographic location and education, highlight how the presence of the law in everyday life can be affected by structural factors and influence a sense of justice found in different potential sources of legal remedies (see chapter two).

Conversely, two participants had sought help from the police, although arguably the police were not the appropriate source of support in both examples. In the first, even though LS16 identifies that the traditional authorities are the first place someone will turn when they have experienced a threat to justice:

"According to the law, if I have offended somebody, in your village, the first thing you will take that person, the person who has offended you, to the chief. So unless that level fails that's when you go to the police." (LS16, op cit)

Paradoxically, he also describes how he went to the police when he had been stigmatized because of his HIV status. He had been gossiped about by someone in his community who had seen him collecting ARVs from the local hospital:

"Yes I have had a problem, and that's what I said, that I was being gossiped about by somebody, that you have HIV/AIDS. I went to the police, supported by my parents. And I was advised that this issue needs to be referred to organizations.

Which organizations?

NICE – National Initiative for Civic Education. And I didn't pursue it further based on that advice.

How did the police respond—were they supportive or were they not supportive?

I think what I can say is that police just called that person, and on this issue when they asked him, he accepted. And so he was just advised that you wronged him.

This is a case and you can be prosecuted. And so you the accused was asked to apologize.

When you decided to go to the police did you decide to do that instead of going to the chiefs or the village headman?

Ja it is true, I didn't go to the traditional leader because I just felt this could be more of a police case. It is an issue that I have to take the police rather than to the traditional leader.

And you mentioned that the police said the other person could be prosecuted for something, do you remember under which law, what the crime was?

They were using the law which says that anyone who discriminates a person living with HIV, *if that person complains*, then the one who was gossiping about him could be prosecuted." (LS16, *my emphasis*)

The actions and reflections of LS16 illustrate four key points. LS16 was one of the few participants who had sought to engage the formal legal system to redress an experience where he felt his rights had been violated. In so doing, his actions directly cut across his rational identification of the traditional authorities as the first port of call for conflict resolution. Second, LS16 describes an understanding of the legal framework that protects his rights that is incorrect, and there is no such law currently in Malawi outlawing discrimination against someone because of their HIV status nor is there one that states someone can be prosecuted for gossiping. Thirdly, LS16's final comment indicates a sense of agency held by the person whose rights had been violated, in bringing justice. In his comment, "if that person complains" is imbued with the power to name and identify the incident, and thereby transform it from one of "gossip" to one of "accusation" of discrimination demanding further investigation. Finally, the police refer LS16 to a local NGO and community support group to seek redress. Even though LS16 does not take up this option, it does indicate the role that community organizations play in providing a supportive space and restoring a sense of justice. Three other participants had sought comfort and found a sense of justice from peer support (such as Church groups, support group of women living with HIV, and a sense of solidarity within a community).

The other participant (LS20) who had direct experience with the police explained that it had also been ineffective for different reasons, mainly because of gender inequality and the fact that the police favoured her husband, and highlights some of the challenges and inconsistencies of law enforcement.

“Can I ask, just from your own experience, have you ever gone to the law to help solve any issues you have had relating to HIV?”

Not at all.

By law I mean traditional chiefs, village headmen, police or anything

No.

Not for HIV then but have you for any other reason?

For any other reason? Yes, sometime ago when I informed my husband that I am HIV positive, he used to be with me without a condom, but I have been insisting him to use a condom. Just because I was not able to do sex without a condom, I was being chased away and I was sleeping outside. That time I went to the police to report it. But the police did nothing just because most of the policemen here are his friends.

And he was saying those things?

Yeah.

And so the police in their reaction were they supportive of you?

They were not supportive. They just wrote me a letter saying that you should both report on such and such a day. When that day came he didn't report, he was saying that 'all the policemen there are my friends, they cannot do nothing'. And it's true, they did nothing for me, they didn't give me any support until now." (LS20, op cit)

For LS20, the experience is cast rather in terms of her unequal relationship with her husband (where HIV is an example of that), rather than attributing the experience directly to her HIV status.

Gender inequality as a barrier for seeking formal justice was mentioned by another participant, LS13, who explained how her former husband had beaten her. This is an example of how lawyers of identity might influence access to justice – an example of the concept of intersectionality in action. She said that she had never used the law to help her, “but I wanted to use law when my husband mistreated me. I wanted to go to court to sue him but I never did that.” The experiences of both LS13 and LS20 corroborate other research findings that have identified gender inequality as one of the barriers preventing women from seeking justice through the court system (cf. Chiweza, 2005; Bonga and White, 2000).

Three participants indicated that there was no source of justice in their lives, on a spectrum of extreme reasons. At one end, one participant explained that she is very forgiving and does not need to seek support externally if or when she has been wronged (LS6). Another participant indicated that she feared beating or violence if she goes to the police and so remains silent (LS14). LS11 indicated that because there were no specific laws, it was impossible to protect human rights in practice: “practically we don’t have anywhere to turn to because there is no law that is covering us” (LS11).

Finally, one participant expressed an accurate knowledge of the law, but recognized that for personal reasons, the stakes may be too high to take action. LS1 attributed his demotion in the workplace (in part when he was redeployed from Blantyre to another smaller city, which he likened to Guantanamo Bay in the interview) to the fact that he was open with his boss about his HIV positive status.

“We know what’s there, the universal human rights they provide for freedom for all, and that there should not be any discrimination whatsoever. We know that. But I think because we cannot take an action I always tell my friends in Mzuzu because most of the people who have declared their status to one or another, they have been pushed to Mzuzu as a dumping place ... At one point Mzuzu was known as Guantanamo Bay because that’s what I think ‘if they send so and so there they are punishing you for whatever reason.” (LS1)

He goes on to describe that it takes courage to take action, and that there are risks involved.

“The only thing is if you take the guys to court looking for justice, obviously you may lose your job, so we would think let’s keep our jobs by being silent but that really just don’t work. That really just don’t work out [sic]. Personally I would love to get some help, get some justice, but I am always sometimes I am scared because I have got kids to look after. So our justice system may take a bit long, in the process we could be suffering even more.” (LS1)

These extracts from the life stories illustrate the extent to which the formal legal system is either invisible or misunderstood by the participants. In practical terms, even though many express a perceived role of the law in their lives, none had effectively engaged it to enforce their rights. They also illustrate how intersecting and complex nature of individual identity – including gender, employment, rural/ urban characteristics – also influence notions of and access to justice. A strong bias remained in the most part towards first seeking justice from traditional means or by simply remaining quiet. Structural barriers such as gender inequality and educational levels, distance to the courts, and geographic location were also identified as factors influencing the legal consciousness

of participants. The examples also indicate that the few times when the police were involved, it was not necessarily in relation to an infringement appropriate for police intervention and supports the notion that participants were generally unfamiliar with or ill-informed about the details of the scope and specific framework of their rights as currently protected under Malawian law (for example through the Constitution). The final element again is one of agency, and the capacity and motivation to take action. As LS1 sums it up, “I think we need to have the courage to see justice being done” (LS1).

Building on this foundation, the following section explores the knowledge, perceptions and aspirations for the laws of Malawi within the national response to HIV. The juxtaposition of the laws and the legality outlined highlights the extent that the expectations for the role of law are out of sync with the real life experiences of the law among people living with HIV.

PART III: WHAT THE LAW COULD BE

Almost all participants expressed an opinion that the law had a role to play in response to HIV in Malawi. The analysis outlined in this section draws on the responses from all participant groups, focusing first on the responses from the life story participants, and then broadening out to include general perceptions from the opinion leaders and the law commissioners. The most interesting difference is found between the perceptions of the life story participants and the law commissioners relating to the role of the law in securing access to ARVs, highlighting a clear difference in perception regarding the scope of legal impact.

The main reasons cited for there being a role for the law in response to HIV can be grouped into three main themes. The first theme is about the normative nature of the law, and the role of the law in generally providing symbolic guidance about how life should be lived in Malawi. This resonates with the results about the perception of human rights and the constitution presented earlier in the chapter. The second relates to protecting people living with HIV. The third main reason is to provide a stronger mechanism to support the implementation of the national policies relating to HIV, such as facilitating provision of ART rollout and access to health services.

Only two participants (one of the Life Story participants and one Opinion Leader) explicitly questioned the relevance of the law to HIV specifically. One indicated that the

law might be ill equipped to meet the personal and cultural context that is critical to the dynamics of HIV in Malawi:

“What would that law tell us? That’s one thing. Because one you would look at marriages, you know, you look at cultures, you look at various aspects. So I don’t know how the law can come in.” (OL1)

The other one who questioned the role of the law in relation to HIV made a distinction between the law in general and the proposed specific HIV Bill. He did this on the basis of wanting to “normalize” HIV and suggested that paying special attention to HIV in the law (or through other specialized settings such as standalone clinics) might perpetuate stigma:

“It’s very tricky because we have to start from Constitution – eh we have to start from the Constitution. I think the Constitution stops everybody from discriminating irrespective of the status bla bla bla. If we start from there, then HIV stigma will not be there. But unfortunately we want to isolate HIV as a social problem. But HIV is a social problem – it is more of a social problem than a medical. Hmm? I am for other people who saw we should normalize – what I’m saying is when I go to the hospital I don’t have to go to a special clinic... So that’s my view about the law, we should look at the law holistically. We should look at the law holistically like it applies to anybody.” (LS7)

These two dissenting views are suggesting that the law may not have a role to play in the response to HIV because things like culture and “social problems” are bigger concerns than could be addressed by legal attention specifically to HIV. They are not suggesting that a legal framework (such as the Constitution) does not have a role in Malawi, but rather that specifically it would be limited in its impact on HIV.

The following section presents further details of the perceptions of what the role of the law could be in response to HIV in Malawi. First, the positive potential impact is explored, looking at the normative power of the law and its capacity to protect people living with HIV. Second, the potential negative impact of the law is explored through some of the “thorny” provisions of the draft HIV Bill (laying the foundation for the detailed exploration in chapter eight) as well as relevant sections of the Penal Code that have an impact relating to HIV in Malawian society. And third, differences of opinion between the lawmakers and people closely affected by HIV are explored in more detail by looking at the role of the law in ensuring access to ART.

Potentiality: Perceptions of the role of the law in response to HIV

The two most common potentially positive roles of the law in response to HIV in Malawi was in terms enforcing good governance (in general) through setting norms and standards for society, and in terms of protecting the rights of people living with HIV.

Role of the law: normative power

Several participants expressed a view that the law had a role to play, because like all Malawians people living with HIV needed to be governed by the rule of law. In other words the law in general had a role to play in maintaining law and order for all, which inclusively affects the lives of people living with HIV.

“To the extent that we live in a society where the rule of law has meaning and where we attach value to the law and what the law does or says – the protections or prohibitions that the law provides – yes, to the extent. Now do we live in a society that respects the rule of law and respects laws and which gives mean to laws? Aeeh, you could get a lot of different answers to that question I think very honestly and it depends very much on which law you are talking about. So yes and no, in a very abstract sense of the rule of law. This clearly is a country where for some individuals in some instances, hopefully for the majority of time if we’re lucky, the rule of law both has meaning and has value.” (OL3)

There are already laws in place, such as certain sections of the Penal Code and the Constitution that are designed to govern the national response to HIV. In their responses to the role of the law and HIV in Malawi, many participants linked the existing situation and actions under the existing laws with ideas for the ideal purpose of the draft HIV specific legislation. At the time of interview however, a number of participants (mostly the life story participants and also representatives from the legal sector other than the law commissioners) had not heard of the proposed draft HIV legislation.

In describing the normative power of the law, some participants made explicit links between health and human rights, including for people living with HIV as citizens within the wider social environment:

“If we talk about the law...it is not limited to a place. It is everywhere. And even what we say, human rights it’s for everybody irrespective of where they are... HIV must be relevant to the law, because the law relates to what? To human rights, which is health... So it really affects the life of the law of the nation. And it is necessary that *the law should be consistent with the aspirations and needs of Malawians. So that they can live as people who respect human rights. The human rights that can enable them to enjoy rights even when they are HIV positive.*” (LS4, *my emphasis*)

This example illustrates the desire for the law to uphold egalitarian principles and guide both the aspirations and daily needs of all Malawians, regardless of their HIV status, as it protects the life and enforces the law of the nation. In an indirect way, LS4 is also alluding to the notions of rights upheld in the Constitution of Malawi.

A few participants made a distinction between the guiding philosophy of the law and how it relates to HIV, either protecting or punishing people, as determining the impact of the law:

“There should be some guidance actually. There are actually I think there are some things – without the law actually because things just fall over and things. I think there should be some guidance from the law, which says actually the way you would handle things. The way one would be mandated in order because the law is like a guiding principle and you know you should follow this. ...what I would want is that once you are taking the law *it should be a law of protection and guidance rather than a law of punishing.*” (OL9, my emphasis)

This is an inherent tension within the normative and symbolic power of most laws, and the draft HIV Bill straddles both as explored in the case study. The draft HIV Bill contains provisions that explicitly protect the rights of people living with HIV as well as those that explicitly punish people living with HIV (for example through the criminalization of HIV transmission as reviewed in chapter seven).

Role of the law: protecting people living with HIV

Several participants indicated that having a law explicitly articulating the rights of people living with HIV not to be discriminated against or stigmatized would have a positive role in the response to HIV in Malawi. One participant, a university student, expressed great hopes for specific legislation relating to HIV as a way to ensure that his rights were protected. To illustrate his point, he compared his right to life (and experiences of stigma as a person living with HIV), with his right to education. Both of these he saw as being strengthened in reality – not only on paper – with specific legislation relating to HIV.

“So this... the right to having life in Malawi, it’s like you have got the right to anything else. The right - you can go to the hospital, go to education, go to do but it’s like eh...for example me I have to go to university, now I can’t go finish my education. I feel like my right to education is being constrained there. Is short...is being shortened. So the right is there but then the right is with some conditions...

And eh do people living with HIV have the same human rights as others?

I feel yah! On paper yes they have. But when you go practically they don't. Until it's legalized the way I look at it. On paper yah, they have got all the - it's everybody has got equal rights. But when you go on the ground people they know that you have – mentally - you have got HIV then those rights are taken automatically. Yah so it varies; on paper you have got 100% rights. But when you go on the ground it's 50% is taken away." (LS8)

This extract from LS8 is illustrating the exact arguments put forward by Chirwa (2005) and Gloppen (2007), indicating that without litigation – and particularly without litigation on human rights and socio-economic issues – the law will remain nothing more than a 'paper tiger' (Chirwa, 2005, op cit).

"Human rights and HIV and AIDS? I think that it is just a name, yeah. I don't think it works; it doesn't work.

Is there a reason it doesn't work?

Yeah because people do not understand their rights, they do now know what their right is." (LS12)

LS12 is describing a sense of human rights similar to Freire's notion of conscientization—the need for a consciousness of rights to exist as the first step in order for them to be protected and or realized in reality.

A difficult conundrum is revealed however, as explored at the end of this chapter in the discussion of intersectionality, when the different aspects of the law—the Constitution and the Penal Code for example—are mutually contradictory, just like the inconsistent provisions within the draft HIV Bill that are explored further in chapter eight. In both cases, the law is on the one hand giving rights while on the other taking them away. In these cases, Foucault might trump Freire, in his notion that further entrapment or subjection ensues when one realizes ones rights but is not in a position to realize them.

In summary, the potentially positive impact of the role of the law in response to HIV was identified as protecting the rights of people living with HIV. These included in the workplace, in experiencing health services free from stigma, and in governing processes to safeguard access to life saving medication. It was also articulated that the enactment of a law would strong-arm the implementation of HIV policies by the addition of an enforceable legal mechanism, indicating a general confidence in the perceived strength of the formal legal system and in the symbolic power of the law to shape social norms.

Impotence: Potential negative impact

Several participants also identified a potentially negative role of the law in the response to HIV in Malawi. Even though the participants did indicate that the law has a role to play in the response to HIV, they include caveats in their responses about the potentially negative impact (especially the “thorny” provisions within the draft HIV Bill, for those who were familiar with it, as detailed in chapters four and eight). Some framed the role of the law as a negative one – one that fuels stigma, one that does not meaningfully challenge harmful cultural practices (for example those entrenching gender inequality), and one that reinforces marginalization or social exclusion for those vulnerable to contracting HIV.

This was specifically noted in relation to the targeted enforcement of the law for some populations vulnerable to HIV (such as sex workers or men who have sex with men) or through the application of provisions with the Penal Code to reprimand, forcibly test, and stigmatize key populations (for further details explored from the perspective of two life stories later in the chapter). For example,

“Specifically for HIV I would say that the law has got a part to play, since as I am saying the law doesn’t recognize homosexuality in our country so if the law is maybe not recognizing homosexuality to happen in this country which means that those people are prone to disease like HIV.... So you could say that it is playing a role, yeah, but negatively towards – with this sexual orientation, yeah.” (LS6)

One participant also expressed distress at the extension of the Penal Code to explicitly include the criminalization of sex between women (formerly the law was limited to homosexual behaviour between men). Section 153 of the Penal Code criminalizes “unnatural offenses”. OL3 was exasperated in November 2010 when this provision was clarified in an amendment to the Penal Code, as well as one more explicitly criminalizing sex workers as individuals (formerly the law criminalized the work not the identity). With a touch of irony, he commented that the development was “another wonderful step forward for human rights in Malawi” (OL3)²⁴.

Two participants, LS14 and OL18, referred to a recent incident where sex workers in Mwanza District had been arrested and forcibly tested, their HIV status disclosed

²⁴ Since the time of the interviews, the President of Malawi has changed and Joyce Banda, who was inaugurated in April 2012, has indicated that she will de-criminalize homosexuality and be more amenable to supportive legislation that enables human rights for all. However no direct action seems yet to have been taken to follow up on this stated intention.

without their consent in open court, and some were charged and sent to prison in 2009²⁵. This occurred pursuant to Section 192 of the Penal Code, which states that “any person who unlawfully or negligently commits or does any act which is, and which he knows or has reason to believe to be, likely to spread the infection of any disease dangerous to life, shall be guilty of a misdemeanour”. These examples highlight how different laws, such as certain provisions with the Penal Code and to an extent the Constitution, are already having an influence on the national response to HIV (further explored in the section on intersectionality at the end of this chapter).

To avoid fuelling marginalization and the potential compounding stigmatisation that the law could have, particularly for communities most vulnerable to HIV, participants suggested the solution should be ensuring that a specific HIV law would treat people equally. For example,

“Let’s have a programme which tackles all of us as Malawians. In that way I think we are going to. But if you say ‘no me I think I am OK but that group is the one that is messing up is spoiling up’ then *I think no, why am I excluding myself?* So let’s look at sex workers, let’s look at prisoners; let’s look at everybody as citizens. Then in that way it will be easier to come up with – of course you might know others are more risky – populations which need special attention – we should not have laws to victimise them. Because if the law is going to go the way it is, you will find that most of the sex workers - ok they are going to be found positive – they will be sent to prison. Now do we have space in prison to keep [them]? The prisons are already overpopulated. We have a population issue in prison, overcrowding. Now every day you are taking sex workers, testing them, whether they are positive, and if they are positive you will take them to – and where are you going to keep them? They want [them] to go to prison. But in prison also the conditions are terrible. So you just say well OK we are sending you to prison to die. One won’t have direct access to the treatment actually in terms of the drug itself, so really we need to be careful as a nation in terms of what law do we need.”
(OL11, my emphasis)

This extract not only illustrates a sense of the unequal enforcement of the law, and the potential ramifications of that (such as overcrowded prisons and death from the conditions inside prison), but it also includes a dimension of empathy and self-reflection

²⁵ Since the time of the interviews there has subsequently been a successful legal challenge launched by some of the sex workers. In November 2011, the group of 14 sex workers sued the government for “unfair action and violating their privacy”. According to an article in the Nyasa Times (an online newspaper of Malawi), the sex workers had all tested positive and filed for a judicial review of their case in 2009, but were only given permission by the court to proceed with their action in 2011. The article quotes the sex workers standing up for their rights, citing the constitution, as one of the spokespeople for the group is quoted: “This was violation of our constitutional rights to privacy and liberty, non-discrimination, to freedom from cruel, inhuman and degrading treatment and to dignity of the person”. See ‘Sex workers sue govt after forced HIV test’, Nyasa Times, 13 November 2011 by Agence France-Pres (AFP).

from the Opinion Leader (see chapter six, where empathy was suggested as one of the possible antidotes for overcoming stigma).

The debate regarding the proposed HIV Bill illuminates both the inconsistent application of the current laws (the Penal Code and the Constitution) and how they potentially target and/or further marginalize those already vulnerable to contracting HIV (as in the examples above, relating to MSM and sex workers). It also illustrates how the criminal law embodies intersectionality, by potentially punishing one or multiple axes of a person's identity.

As argued later in the chapter, it is perhaps within these inconsistencies that stigma flourishes (see case study in Insert 5, chapter eight). The proposed draft HIV Bill may further entrench those inconsistencies. This includes inconsistencies in the proposed law, the application of the current law (and disproportionate impact it may have on certain groups of people), failure of the law to protect some people (such as key populations, women, people living with HIV, and/or people in rural areas), and inconsistencies in the hearts and minds of people living and working with HIV around the meaning of HIV in people's lives (see chapters five and eight).

Different perspectives: the role of the law in ensuring access to treatment

In comparing the responses between the life story participants and the law commissioners, an interesting difference emerged as to their perceptions about the impact of the law in ensuring access to ART in Malawi.

The life story participants unanimously felt that the law had a role to play in the response to HIV. The most common reason identified was to ensure they could access treatment. More than a quarter of the people living with HIV interviewed indicated that guaranteeing access to treatment (ARVs) was a critical role for the law:

“Of course the law has got a role in the response as I said they have to do what is right think of what is good to a person that is living with the virus he has to be prescribed the right drugs of which they could make that person feel better and also on the part of nutrition something has to be the role of the government that the food supplement should be given to a person who is I don't know who is very sick “ (LS12)

One participant noted that even despite the potentially problematic provisions of the proposed HIV Bill, it was still valuable for ensuring access to treatment:

“Like this Bill which is being prepared which says that everyone should go for testing and that if you transmit HIV to someone then that should be a crime. But...these things will not help us. People must not go for testing in fear of being arrested but to help improve their lives. But if you talk about ARVs the law can help us because if you go into so many hospitals, you find ARVs available.” (LS13)

A few participants also linked access to treatment and the enforcement of this through the law to combating stigmatizing attitudes and behaviours of health care providers:

“Government laws are important in that we should get medication without problems since there are some doctors who speak some bad words to people who are HIV positive so if these laws could be adhered to we can be getting medication freely.” (LS17).

The life story participants drew direct connections between the law and their access to treatment.

On the other hand, the law commissioners indicated that the greatest role of the law was to support the implementation of policies relating to HIV. For example, one of the commissioners indicated that the law would have a more symbolic and effective power to guide policy implementation:

“There are a lot of measures are that could probably be better managed and effectively enforced or implemented if they were not administratively done. And I think the legal framework would go a long way to addressing a lot of the issues ... We need a framework to actually give the government and maybe authorities the power to actually enforce certain things.” (LC3)

Illustrating one angle of the policies this Commissioner was referring to, some of the life story participants link their understanding of human rights to something that ensures their access to ARVs and lifesaving treatment with the role of the law to enforce access to treatment. For example LS2 said that human rights are good in his life because he has “the right to access ARVs or the right to any health services” that he wants. This sentiment is shared by two of the law commissioners, who explicitly indicate that the role of the law is to protect people living with HIV, both through ensuring the provision of services and treatment, and through preventing stigma and discrimination:

“The law for example can ensure that the government provides services for those who are HIV infected, for those who wanting to access them, the law can provide and ensure that those services are available to everyone, and so on. The law could also protect those people who might be suffering from stigma.” (LC5)

“Bringing justice and the protecting those for instance who are HIV positive - I hope this is what the law is to do and also to help us understand our own culture...

the law would challenge us Malawians to look at ourselves but also challenge us Malawians to look at individuals who are HIV positive in a different way.” (LC10)

Notably in this last example, one of the commissioners aspires for the law to be used as an opportunity for people to reflect on themselves and Malawian culture, to be more mindful or conscious of the treatment of people living with HIV. Both commissioners suggest that the law has a role to play not only to protect people living with HIV but also in providing broader benefits for everyone, including the normative potential of the law to trigger a self-critical reframing of Malawian culture.

Another Commissioner suggests that the law, and in this case a specific HIV Bill, could clarify certain aspects of other laws and policies as they relate to HIV:

“It is making clear some of the issues that are not stipulated anywhere. Yeah it is adding value to the existing different agendas in the response. So this one is adding more clarity in other areas that are not clarified already.” (LC1)

The perspectives of the commissioners indicate both a desire for consistency and stronger power of the law to support national policies in their governance of the national response to HIV in Malawi.

The difference therefore between the two groups is one of attribution of impact—the life story participants perceive a direct link between the law and access to treatment whereas the law commissioners tended to add an extra step, perceiving a direct link between law and policy, and then between policy and access to treatment. This is significant for two main reasons—the first, that the life story participants were actually correct in their understanding of the potential role of the law in safeguarding their access to ART. The relevant provision is outlined in section 7 of the proposed HIV Bill:

“7. (1) A person who is infected with HIV or is suffering from AIDS, shall have the right to__
(a) dignity of his person, physical integrity, life and health;
(b) practice a profession of choice;
(c) compensation associated with the restriction of his enjoyment of rights; and
(d) free medication, at the expense of the State at any State medical institution, necessary for the treatment of any HIV-related disease listed in the Second Schedule.” (MLC, 2008, p 92)

This is ironic given that most of the life story participants were not familiar with the draft HIV Bill in general, let alone specific provisions within it, compared with the law commissioners who had actually drafted its provisions. The second significance of this finding is that it suggests that the law commissioners were not familiar with processes of

law enforcement and/or had little regard for the likelihood of case law to enforce the provisions within the draft HIV Bill. This finding is consistent with other research that has pointed to the paucity of case law on social and cultural rights in Malawi (Gloppen, 2007; Chirwa 2005) as well as to the criticisms outlined in particular by some of the opinion leaders about the impracticality of the Bill and the lack of due consideration to mechanisms of enforcement in its conceptualization.

The participants' perceptions of what the law could be in response to HIV, as explored in this section, highlight elements of both the positive and negative potential impact it could have in the national HIV response if passed in its current form, and also illuminate an interesting difference of perspective between everyday people and lawmakers about the links between law and policy implementation. The results speak to both the impotence and potential of the law in the response to HIV in Malawi (cf Van Marle, 2006).

PART IV: WHAT THE LAW IS NOT

This section explores the limitations of law in response to HIV in Malawi. The participant responses indicated two main concerns—the first being that the law is not often enforced, and the second that the law is not able to engage or consistently respond to the multiple intersecting layers of someone's identity.

Challenges of enforcement: "We make laws but we don't follow them"

As one participant surmised, problems arise in implementing the laws and the way the laws are (mis)represented by people.

"The laws are there, they are good laws. The problem is we make laws but we don't follow them ... the laws are there, they are good, but the problem is we have not accepted to say HIV is among us, this is the situation just like other diseases. I think we are not yet there. Sure. But the laws, I understand them, they are good, they are fine, but the problem is the people." (LS2)

It is the human translation of the law into reality, if or when that occurs, that constructs the meaning and presence of the law in everyday life. As other authors have noted in response specifically to gender inequality, and the issue of protecting women's rights to inherit property, greater attention is needed to enable the people and processes within the administrative systems of implementation to be more effective (cf Chiweza, 2005).

A few participants noted challenges relating to enforcement and/or people whose lives are affected by HIV with reference to knowing the details of the law and processes to seek legal redress. Quite apart from the “thorny” elements of the provisions themselves, a number of practical considerations affect the enforcement of the law and its presence in daily life, such as access to information, infrastructure (including access to batteries as well as legal services!), literacy and attitudes towards the visibility of the law. For example, one of the participants cited differences between rural and urban areas, and the challenges for people in rural areas to access information about the laws, and the impact the laws may have on their lives:

“I, as a woman that lives in the village, I do not have a chance to know what the law says because I rarely find batteries for my radio. And when we go to support groups where we meet we don’t discuss such things. We do not have that chance. We only talk about positive living, not about the law.” (LS14)

This concern was echoed by one of the opinion leaders, who managed an organization that supported peer networking for people living with HIV:

“Yeah surely the law has a role to play. But I think this is my opinion in Malawi we have laws but we have problems with enforcement of those laws and as a result no matter how much we would craft a piece of legislation if our enforcement mechanisms as they are at the moment I think they we still would not be getting what we want to get from such legislation...So the laws are important. But the other question is how many people would know the laws that are covered in this country? Not many. How many people are able to report violations of these laws? I am afraid very few. And this to me has also a lot to do with illiteracy levels in the country, so people are not literate enough to understand that we have laws to protect every Malawian, then we have a problem. So much as laws would be an ideal way or sorting out some of the challenges, then they are not going to be effective because people don’t understand the laws, including the people who pass those laws.” (OL14)

This extract disaggregates three important areas that create barriers or challenges to enforcing the law—one, knowledge that the law exists; two, awareness of to appropriate process to seek legal redress; and three, structural barriers such as illiteracy and access to legal recourse mechanisms. OL14 also makes reference to the fact that even some lawmakers do not fully understand legal processes, which is explored further through the analysis of paradoxical criminalization provisions within the proposed draft HIV Bill reviewed in chapter eight.

In summary, in its combination of the (lack of) knowledge of the laws, challenges of access and reporting, and multiple levels of human agency, the challenges of law

enforcement contribute to the absence of the law in the everyday life of many Malawians. This is due to a range of reasons that include dimensions of the law as well as legality more broadly, and the challenges of law enforcement span both.

Through a kaleidoscope: Intersecting identities and layers of the law in everyday life

Law and legality relating to HIV, such as the Constitution and draft HIV Bill outlined above, have a varying impact in the day-to-day lives of Malawians. And as noted, this is due to a range of factors such as knowledge of the law, access to legal services, and other structural barriers such as cost, distance, gender inequality and literacy.

Not only is the convergence of law and legality relating to HIV ill-defined and not apparent in day-to-day lives in Malawi, but so too are the intersecting layers of identities that are also policed and regulated by other aspects of the legal system. Other legislation that has already had an impact on communities of people and individuals living with and most vulnerable to HIV include Section 153 of the Penal Code that prohibits ‘unnatural offences’ (and has been used to arrest and imprison men who have sex with men), Section 156 that protects ‘public decency’ (and has been used to arrest sex workers) and Section 192 which is a public health law that has been used to arrest, forcibly test, and imprison sex workers (see earlier extract). The Section provides that “any person who unlawfully or negligently commits any act which is, and which he knows or has reason to believe to be, likely to spread the infection of any disease dangerous to life, shall be guilty of a misdemeanour.”

This final section of the chapter delves further into questions about the interplay of law and legality by adding a lens of complexity – and grounded reality – of dimensions of intersectionality (Crenshaw, 1989). The analysis addresses this in three sections: an overview of the responses from participants that recognized the nuances of intersectionality, followed by two in-depth life stories that complexify these issues. One is from the life of a man who feels the law has not allowed him to live freely with his sexuality in Malawi; and one from the life of a woman who has experienced stigma and violence at the hands of law enforcement personnel because of her work as a sex worker.

Policing sexuality: Layers of persecution in enforcing and regulating the Penal Code

One of the themes emerging from the interviews with opinion leaders relates to how other aspects of the Penal Code and law enforcement have an impact on vulnerability to HIV:

“When we talk with these policy makers, people think that the law – they think that the law has nothing to play you know, in terms of HIV/AIDS response. What I am telling you, sometimes one feels you know sad. Because people are dying, people are affected by this legal environment, whether sex workers or what. Every day we have these HIV/AIDS infections. So it’s the law that hinges the interventions. I will tell you we have very good policies in place that also include MSM, sex workers, but as of now as a nation you think there is actually nothing in terms of a national programme targeting these communities.” (OL10)

Participants referred to specific sections of the Penal Code to make this point, as well as to ways in which particular groups have felt the brunt of the existing legislation more than others:

“The current status has pushed people underground, because it is criminal, that’s what I am saying. So what I was saying if we have a welcoming legal framework for these groups, I mean these people, sex workers, MSM, will come out. Will be visible enough. Because the law is at least protecting them from being discriminated or from being stigmatized. From programming to access to services.” (OL10)

As noted above, some participants elaborated on the link between law, what is regarded as illegal behaviour, and vulnerability to HIV. The two most commonly referred-to groups among participants were men who have sex with men (MSM) and sex workers.

“For example the current HIV and AIDS prevention strategy talks about the most at-risk populations in Malawi, but when you look at some of the laws, some of the statements that are coming out are at times disjointed from the policies themselves. Like in this regard I will give you an example of men who have sex with men. This is another group of people who are prone to high infection rates and the little research we have has already tended to give us evidence towards that direction to say that the prevalence among them is above 20% and so are commercial sex work. But commercial sex work in Malawi is still illegal. Men who have sex with men although the law does not say it explicitly they are people who are considered to be citizens who are turning against the law.” (OL19)

OL19 is recounting how in Malawi, homosexuality is against the law and therefore men who have sex with men—a group also at higher risk of being HIV positive—can be criminalized on at least two axes of their identity. Notably however, of the total participants, relatively few discussed nuances of stigma and vulnerability to HIV, and how stigma might impact on different groups of people most affected by HIV.

Some participants indicated the stigma and the law might create a barrier for some people in accessing health services:

“When you know MSM cannot access services in a hospital or talk about access to information in terms of how they can prevent themselves from the virus, so if people do not have enough information because of their sexual practices, then it’s a – you are not doing good to them. It’s a human rights issue because people cannot access information for their own better health ... we need to look at these issues critically, because it is hinged on people’s lives, they are saving lives, people are dying, the MSM are dying. We don’t know that they are dying because we are denying them services because of the laws that we have.” (OL10)

One participant gave a recent example of the experiences of a group of women who were sex workers, and how laws relating to venereal diseases had been used to detain them, test them for HIV without their consent, and publicly disclose their sero-status (and breach confidentiality) as part of the court proceedings:²⁶

“HIV is being criminalized right now in Malawi. This is through the Penal Code – Section 192. It states that ‘any person who unlawfully or negligently does an act which is or is likely believed to spread the infection of a disease dangerous to life shall be guilty of a misdemeanor.’ So, we have seen cases in Malawi where the courts have interpreted the venereal diseases to include HIV.

One example from 2009 relates to a number of ladies defined as sex workers were charged with negligent act (contrary to section 192 of the penal code) in Mwanza district, for ‘unlawfully and knowingly doing an act likely to spread infection of the disease HIV and AIDS by practicing prostitution’. I was not representing these women directly – we got the information from the newspapers, and once reading the details the Malawi Human Rights Commission had to get involved.

What happened was that a number of ladies had been arrested at a drinking place, taken by the police, with men accompanying them. All the men were released – only the ladies remained in custody. The ladies were ordered to board a police vehicle. They didn’t know where they were going and they were taken to Mwanza District Hospital. When they arrived at Mwanza District Hospital they were put in a building with a corridor and they realized they were in a hospital. There were two police officers in the corridor and two in the room, and every lady was being told to go into the room. When they arrived in the room they saw two medical officers and two police officers, and were simply told ‘can we have your hand’. So then the blood was taken from them and the medical officer was writing their name and other details. And the same thing happened one after one, but they didn’t know what the blood was being taken for - until they were taken to court. When they arrived in court was when they were charged with the offence of spreading a venereal disease and specifically referring to HIV. These women didn’t have legal representation so they pleaded guilty because the police intimidated them. As part of the facts, the court read out their HIV status, and that was then these

²⁶ For further details see Annex 12.

women realized that the blood that was taken from them at the hospital was meant to determine their HIV status. It was the first time that the women were hearing the results from the HIV test and it were so many people [sic].” (OL18)

This example highlights concerning human rights issues relating to coercive testing for HIV, non-confidential disclosure of HIV status or test results (in this case in a court of law in front of the media), and the targeting of laws to prosecute specific groups of people (in this case a re-conceptualization of an old law to target sex workers in the context of HIV).

Links were described between the law, stigma and the quality of health care provided and received. Two of the participants interviewed specifically noted how the provision of health services should be open to all, treating people appropriately for what they present to the clinicians, regardless of their sexual orientation or source of income. For example,

“Well here it for me is really when I said that what is the relevance of human rights is that it is our mandate here as the Lighthouse, our role is provide the service, and to us regardless – we need to provide the service when it is required and how it can be provided regardless of who is – who and how they are. I was asked a question ... by one of the strong journalists who just said ‘what is your opinion about Malawi putting people in jail because they are homosexuals and things, what is your personal opinion? Do you think that is discrimination and those issues? What are you doing about it?’ So I was like well ‘I am a clinician and to me if someone comes with a TB or with HIV, they come in, whether they are homosexuals or not, their presentations are going to be the same. And to me I provide the care.’ And if somebody actually says you should not treat this person because they are homosexual, I would disagree with that. Because that’s not - my role is to treat someone who has come in ... I would like to know if someone is a homosexual because if I think they have gonorrhoea I need to know where to look for it. That’s the only reason – but not to say how but it’s like where should I be looking, because I would be looking in the wrong place. The anus, and we don’t usually do that.” (OL9)

Some also argued that perhaps a health-oriented approach rather than human rights based approach might be more persuasive for politicians and other cultural leaders who may otherwise resist tailoring policies and programmes to reach out to key population groups:

“The preferred strategy is to take it as healthy – what – public health approach. Because you are saying if ‘I don’t protect you, you are going to give it or you are going get it from somebody’ and transfer it to you wife. Because and then you are saying ‘we can’t let people get sick’ you just have to treat them. People are people, no matter who they are they have to be treated.” (OL17)

However, even though the ideal is for stigma-free services, both in terms of the quality of care the client receives as well as ensuring that as many barriers as possible for accessing health services are removed, it seems that in practice this is not necessarily the case (as described in Felix's story below).

Another key population group in terms of vulnerability to HIV as well as stigma for "taboo" sex was prisoners. Even though one participant stressed that prisoners living with HIV are treated equally and are eligible to receive a nutritional supplement (much needed for anyone surviving on prison rations) (OL2), another participant noted that prisoners who are HIV positive might experience discrimination in prisons (OL10). In Malawi, ART is available in prison but condoms are not, even though it is tacitly acknowledged that (male) prisoners have sex with other (male) prisoners. The rationale given for this is that because same-sex sexual relations are outlawed in Malawi, under Sections 137A and 153 – 156 of the Penal Code, then the prisons cannot controvert the national law. This indicates how in this context, the national criminal law is actually placing men at greater risk of contracting HIV because a known prevention intervention is being withheld from a population group known to be at high risk for contracting HIV and other STIs:

"Condoms are available but they are not issued during the tour of their status in prison. They are issued on release. You see we are afraid because in Malawi homosexuality is a crime, one thing. Secondly if it is a crime if we mean to give them condom, among men, what will that imply. And are we not going to be challenged by the inmates to say 'you gave us a condom in order for us to practice what? Homosexuality.' Instead they are sensitized on the dangers not to do ABCD just to ensure they are protected up to the end of their sentence. But when they are released they are given a condom, because we do not know what will happen out there. They have to be protected whenever they want to do that. And again homosexuality up until now it's not yet legalized. It is still in our laws of Malawi. Yeah." (OL2)

"People don't want – they know people are having sex in our prisons, so if you wanted to get through that message then we can start with the prison and say 'ok, we want to protect people who are going in prison' and people would say 'ok if you are protecting the prisoners, why can't you protect the guy on the street' but we don't even want to protect the prisoner although we know that they are having sex there." (OL17)

In light of these perspectives, I have chosen to focus on two of the life stories in particular to explore the intersection of different layers of identity and different interactions with the symbolic or real impact of the criminal law.

1) Felix, whose story is one of a gay man who spent time in prison in South Africa, is HIV negative, and discusses how both his time in prison and his experiences of health services in Malawi have been affected by his sexual orientation.

2) Saidi, who shares a story of motherhood, sex work and volunteerism, is living with HIV, and has limited knowledge of law and legal redress even though she has had direct involvement with the police.

Both stories illuminate the nuances of the presence and absence of law in their lives, in ways that directly and indirectly related to HIV.

INSERT 3: Felix's life story (LS6)

"The law is there somewhere, somehow guarding us not to live freely in our country"

The following life story is taken, almost verbatim only edited slightly, from an interview in Lilongwe on 9 March 2011. The participant wanted to remain anonymous, so his name and other identifying features have been changed. The column on the right hand side includes reading notes I have annotated alongside the life story, which are summarized in a discussion section after the end of the narrative. See Insert 3 (below) for annotated edit of the interview.

I can say my life is good. No problem. I am Felix Elias Kamwenda²⁷. I stay at Likuni, and I can say I was born in a family of five, I am the second one, and there are three boys in that family and two girls. Yeah I come from the central region of Malawi. Both of my parents died and I am living with my siblings. I grew up in town; it can be exactly where in Lilongwe that's where I have spent most of my life.

I was brought up under the watchful eye of one parent, only my mother, because my parents divorced when I was four years old. She is the one who I can say who educated me, because I only did up to Form Four—that's Malawi School Certificate of Education—MICE, until the time that she died that was 2004.

My father died in 2003, but still I never knew my father. I knew my father when I was twenty; all these years he was nowhere to be seen; that one conversation. The time I saw him that was the time also that he died—right after—some days after the day we met. The next time I saw him was in the coffin. It was like we had met after such a long time. Imagine I grew up under one parent so I was feeling somewhere somehow unhappy because I never knew the love of a father; I never experienced the love of a father. It was like we could do – have that feeling that when we hear about our friends talking about their daddy, we could ask ourselves questions 'ach what about me?' Then anyway

*Orphaned now,
and grew up
knowing his
mother only*

²⁷ Not his real name

something which never existed in me, it went out, and I was almost like those children who leave their parents—both of their parents—simply because *my mum, she possessed, she possessed all what it takes. Yeah even though there was no father, but she had a quality also of what—she had the qualities of both father and mother.* So to me it wasn't that experience. Of course I was just happy to have met him at last.

A lovely compliment to the parenting, care and support he received from his mother

[I am the] second born, my sister is the first-born. The other three they are here in Malawi. There are two boys and the other one is a girl—the last one in schooling, the girl. The two boys, the other one, the one who is after me is just staying but he left school at Form Two, yeah he has got a junior certificate only. The fourth one, she did school the way I did up to Form Four, but she's also just the same. So it's like they rely on that sister of ours.

The first introduction to his sister, on whom he and his siblings rely on for support

Childhood

My biggest memory from my childhood days, I would say it was something, which is about I, should say it is about my sexual orientation. Back then I was schooling at a boy's primary school, right here in Lilongwe. Then since it was a boys' primary school, I realized that I had a certain feeling towards my fellow men. You know we are putting on shorts, we are not putting on trousers, but we are putting on shorts. So each time I saw a leg of my fellow boy I had some sexual feelings towards that thing, towards seeing my fellow leg. Then you know I realized OK what is happening to me? At first I thought it was something that was out of childhood, no, then later on then as I grew up I realized that it was still like anchoring in me—it was like pulling yeah I should say it was anchoring in me. Then afterwards as time went on I realized that it was affecting me so much that I couldn't take it anymore that each time I saw that I could go maybe to the toilet and do what we call masturbation just to get relieved of what I saw. Then that went then it reached a time when I reached adolescent age, then I was at secondary school. Then I realized that even though I was attracted to girls because I would say most of my friends were females, if I was to chat with a boy I would say that was the time maybe when I had gone to play football, yeah, but when it comes to things concerning maybe education or friendship, I preferred to stick to females than my fellow men. That even my Mum would ask me questions—'ah why do you like sharing your time with females?' I would say 'ah no I would say that is how I was made, that is how I was born.' Then she would say 'how could you say that?' She liked to say, there is no such a thing, 'you cannot say this one is a friend' meaning someone of the opposite sex. I insisted 'that was your time then but these days you can talk to someone who is of the opposite sex.' Then but still I was not sexually attracted to those females, I was just attracted to them. But I realized that those feelings which I had when I was in my childhood days I realized that they were getting more and more that I went to secondary school and even though it was a co-education school, but still I had no feelings towards females.

He describes his first inklings of feelings for other men

At first he doesn't understand it, finds it alienating, and then eventually realizes it is central to his identity

Love

Until when I reached Form Four. That's when I had fallen in love with a friend who was of the opposite sex. I was 18 years old. I would say she was the one who forced me to fall in love with her, but as I have already spoken, due to my orientation what I was feeling inside me was far from what was happening. So it didn't last long.

I met my what I would say my first experience when it comes to—that is if I can talk of my sexual orientation—that's when I first met my, what I would say, my real thing. What I had been looking for. So it was somebody else from Blantyre, he just came right here in Lilongwe, then it was like he took me to a certain place of course we were drinking, after that then we went to a certain place. And then when we had reached there it was like he was caressing me, ah-hah, touching me here and there, then he was like what we call talking some words, lovely words to me. Then I realized OK, because then I was just hearing about homosexuals or whatever. Because what I would say even though I was feeling like that, I had feelings towards my fellow men, but actually I didn't know that such things exist until when I first heard about homosexuals. So after realizing, after experiencing what that man was doing to me, that's when I connected the feelings which I had towards my fellow men and the story which I was hearing about falling in love with people from the same sex. I was just combining the three and I realized that I think this is what is all about me. This is the thing that I have been looking for.

Then it happened that I moved from here I went to South Africa. When I went there I met some other people, of course the first group when I went to South Africa, I was taken by a friend of my sister, together with her family—that was her husband and her son. I used to go to a certain bar when I was there in South Africa, then there was this other man who was a friend to me and we were attracted to each other. According to my side I was just attracted to him in the normal way. But I realized that his attraction to me was somewhere somehow sexually. Until one day when I went there he kissed me publicly. Then I realized that 'oh so these things are all over—it's not only happening in our home country.'

Prison

Then in 2008 when I was still there it happened, something happened, that I got jailed. So I went to prison in South Africa. Of course I was arrested not that my case was related to the story that I was talking about. I was arrested for being an illegal immigrant. For being an illegal immigrant and the other story of course was just fabricated by the one who made me to be known to the police that I was living there illegally. But the main thing that started all this was like there was like a verbal what, there was some quarrels I should say, I had a friend with whom we were living together, then we exchanged some words to a point

First love with a woman – a good friend

First exploration with a man... and he realizes he finds what he has been looking for

Cultural experience outside Malawi, in South Africa, where there is a greater acceptance (although still limited) of homosexuality

He also realizes that he can have feelings across borders—and that same-sex feelings also happen outside Malawi

Describes an encounter with the law (assault and immigration) and a bitter row with a friend

that we fought. So he went to the police and reported for me that I assaulted him. But actually it was not much of an assault but if I can recall what happened he was the one who assaulted me. He bit me.

The quarrel was about the house rent. After realizing that he had not paid for maybe some months, that's when I started like demanding my payments because I was paying on his behalf. In fact it was like then he was not working. So I said 'OK remember when you start work remember to give back my money.' So when he started working it was like he was just busy out boozing you know whatsoever. When I approached him and asked him for my money we started exchanging words then we fought. So he reported me to the police and I got jailed, so it was like two cases – assault and being an illegal immigrant. In fact he had also added that I had stolen his phone, so it was like theft, illegal immigrant, and the assault. But the other two I would say, especially the last one, was not true. So he was like cooking stories.

So in fact I've got my sister there, we hired a lawyer, then that lawyer told me 'you know what your case is not difficult, you can win it, but still it will take time, maybe two years. They will still keep you on remand maybe for a long time because they will just be saying they are still investigating, still investigating. Why don't you just accept? Why don't you accept the what, the accusations against you? Why don't you just accept—I will talk according to my profession, I will talk in a professional way that the magistrates should consider giving you a short period of what, a sentence, or not give you that stiff sentence. That maybe you can get what we call, you can get a fine maybe, to pay to create the what.'

When we first entered the court I [had] said 'no' because then I had not yet found a lawyer. I was soon taken myself as innocent until when that lawyer came telling me that I should accept the accusations. Then the court was adjourned to the following day. Then I accepted the accusations and then I was charged to be in prison for let's say 18 months which is almost a year and 6 months, a year and a half. Then they said since you are like a first offender, it's your first time to be in such a situation, then we are trimming—then they trimmed to a year—which is like 6 months in prison. Then they said there is but an option, if you can pay a fine of 3,500²⁸ Rand you can walk about of prison.

Since I had no money to pay by then I still went to prison. But then my sister was planning to pay the fine for me on my behalf so that I could walk out of prison. So it happened that I walked out of prison but after staying there for a month and 18 days. I stayed 18 days when I was at remand, then one month I was behind bars.

I would say life is hard in prison. Since in fact that was my first time

Challenges of law enforcement and decent legal representation—cost, time, money and sound counsel (structural determinants)

Counselled to plead guilty—a potentially innocent man in prison because of structural determinants of law enforcement

²⁸ By the October 2010 exchange rate, this is approximately £267 GBP

that I got jailed. I had never been in prison. That was my first time but still I realized that a prison life is hard. It is hard in a sense that there are many things that happens when you are there. There are a lot of things that happens. In fact looking at the way the story was cooked up against me, I was psychologically affected to a point that—I reach a point where I could think of committing suicide but I think that the ones who were building the prison, they knew there would be some other people who could have ideas like those of mine. Then they built it in a way that nobody could maybe think of throwing themselves down because it was like maybe three or four stories.

So it happened that I stayed there—after having stayed there for three to four days with the people which I met, I mean there are those who I met whilst there, especially those from Malawi, they were like encouraging me ‘no you don’t have to do that, anyway it’s life, after all you are telling us that you have got a sister who could maybe come any day to pay the fine for you so why are you telling us you are getting worried to the point that you are not eating and you are saying that at one point you were thinking committing suicide? No. Just take it, just accept it, it’s life.’ So as time went on I got used to it but still not getting used to it to a point saying I was happy with what was happening there. No I wasn’t happy but I just let it go.

Then there was this other thing that was happening there which is about my sexual orientation. The thing which of course I was just here learning at first that homosexuality is at a peak in certain environments, in such places, prisons. So I saw it with my eyes. I could see—in fact they told us at the time we were entering the prison that ‘you know, when you get inside there, you will meet some other people who will be telling you like maybe to offer them some services, sexual services, in return to what they can give you like protection from the people who have been there for a long time, they do things as if it’s their home.’

So when we were going inside I realized that such things really exist in I should say they happen most in prisons, yeah, because I could see that the people who had been there for a long time they could do such things with people who were like new. Then I said but even though my sexual orientation is similar to what these guys are doing but still I will not show up that I am one of them. I don’t know what exactly made me to not actually feel for them because somebody, a certain friend, just told me that I don’t know what kind of food is eaten while I was there in prison. Somebody was just telling me that they put something inside there so that people should not have feelings. I don’t know if it’s true but it might be, because I could see that even though I was there and even though I was a person who was with feelings towards my fellow men, but I never cannot remember any point whereby I – of course I could admire, I could get attracted, but not to a point of thinking of having sexual act with that person. So anyway but the other

Prison life—not easy, and he is suicidal.

Finds support and a community form other Malawians within the prison

Acceptance and life

Economies and exchange within prison

He is cautious about showing his sexual orientation in prison, and even though he likes having sex with men, he finds it alienating in prison and is not attracted to violence and ‘economic’ nature of the exchange in prison

thing the main thing that made me not to show up was like since it was happening it was happening in a strange way—in I don't know which word should I use—it was happening in a ... I am about to ... it was happening in a way that one could actually think that yeah, but is this the normal thing which I know? Is this the normal thing happening in a strange, in a violent way? Somehow that it was like terrifying. So I said ah anyway let me not show up that I am into that because I knew that many people would like flock to me because I was seeing it was like more violent. So I decided not to show up until when I came out of prison.

The other thing that made me not to show up because I knew that I would be prone to diseases like STIs, HIV/AIDS and all that. So that's why I decided not to show up because there were no condoms, there were no lubricants, the things which can help one not to get affected. That was the other thing that made me not show up because no such things were there, they were no there, there were no such services.

The day I left prison I was happy to be out of jail. Then in fact we were just outside by the time my name was called. Then I just moved from where I was at the time with my friends and I just went straight to the reception and just realized that—my what—my brother in law had come to pay the fine for me. Then right away I was told to go into the changing room where I went to change the what, the foyers, which I was putting on the clothes I came with at the time I was entering prison. Then we were just taken straight in immigration cars and we were just handed over straight from prison officers to immigration officers.

Family

My sister is the first-born in our family and is married to a Malawian. She has got one children, but she's caring I would say she is the one who played a big role when I was in prison. I had a lot of friends who were outside of prison but neither of them came to see me. She was the only one coming to see me almost each and every weekend, bringing me some things, of course food. But because food was not allowed to enter inside the prison she would bring maybe money so I could buy whilst inside there. But she was coming to see me each time, week. She is such a good and say caring mother I would say.

My relationship with her has changed slightly mainly because when I was there I was like I am somebody who takes alcohol so when I was there she was like putting the blame on me for all the things which happened. She was saying if you were not into alcohol I would not think you were jailed today. To her she thought maybe it was the effect of alcohol what made me to engage in a fight with that friend. But it wasn't like that. So up to today she takes me as somebody who is into beer, that's all. That is what she has towards me; that's what she feels. She doesn't give me room maybe to do things maybe on my own as an

No access to condoms in prison, and he wanted to prevent contracting HIV and other STIs

Deportation back to Malawi after financial but no longer emotional support from family in South Africa

Relationship cools with his sister, as he feels she judges him for his lifestyle and drinking alcohol

Feels restrained to live his life

adult. She's just there maybe to—no when I said maybe I am trying to look for support from her, she says 'no maybe you want to use this money for beer, you want to do this.' It's no longer the intimacy which was between us. So all this is dragging from the issue that happened when I was there. So currently I even stopped calling her.

I don't know. So anyway it's like I just felt like I was forsaken, yeah so, it's just and anyway let me live my life, sure. But about my sexual orientation she doesn't know anything about that and I don't even think that there has been a day that she has come across or she has seen some suspicious things towards me about this.

Home

I came back straight to Lilongwe. Since the experience, which I have gone through, especially the prison life, made me not to have plans to go back again. Home is best; let me stay home for some time.

And I happened to meet the friends which I had left and met new ones. Of course I was like the moment I reached here I found out that there are those feelings which I had towards my fellow men had now, I don't know what to say, they shoot—like I should say if it was like a flower I would say it blossomed. So that's when I started saying maybe it's true that the food which is there that they have in prison so that people should not have feelings towards their fellows.

When I reached home I started working of course. Since I was like, most of my things like my clothes and my school papers were still there in South Africa so I just communicated with my sister that she should bring them back. Since the experience I went through when I was there, especially the prison life, made me not to have plans to go back there again. I went to somebody else and asked for a job as a housekeeper. In fact I was told that they were looking for a housekeeper. Then I went there to ask if they could offer me the job. They offered me the job and I worked with them for 7 months. After that I stopped working there simply because they were saying that they were moving to South Africa. And they were even telling me that I should go together with them but I said no I would not be able to go with you because those memories were still fresh with me.

I was lucky because I only stayed there for a month and 18 days so it was a short period of time. But it's true I would say for people who stay in prison for a long time. When they come out it's hard for them to look for a job or do something which can earn them money.

I am working but voluntary with an NGO, as a peer educator. But since it was a project so it has just expired so I understand that maybe there would be like a Phase II, yeah, so currently I would say since it has expired then I would say I am not working.

He has not spoken with his sister about his sexual orientation

Happy to be home!

He is embracing his attraction to men

Some independence from working

Empathizes with people who are 'ex-prisoners' who may find it Peer educator with local LGBTI organization, CEDEP

Sexuality

There hasn't been anyone whom I have told about my sexual orientation. But those younger brothers of mine I think they have a suspicion towards maybe my sexual orientation. I am saying this because when I'm home sometimes there can come somebody who – a male friend, maybe when I am in my sleep maybe somebody would just come and pick me up, go up, without coming maybe in the morning. So these things are – has been happening for a long time, so it's like I am realized that they are suspicious somewhere somehow about my moves, but actually they haven't yet found out what is actually happening.

I would, I can and it has been my want to disclose about my sexual orientation but first you consider the things, the consequences which would come after you revealing that. But once I know that at least at this point if I can tell them about my sexual orientation they would be able to understand, I would do that, but for now from what I have seen it is not possible. There's not a positive relationship between me and my relatives, so yeah you can imagine that what if I bring this issue on top of that it would be something like worse, un-understandable.

Last December, a friend of mine, somebody who has been a friend of mine for a long time. Yeah he is such a person who is involved into relationships between people of the same sex I should say. But there was this other day when we were at the pub drinking, then he same, he was amongst us. As we were drinking it happened that I was talking like a she and he started saying 'how come you are talking like a she are you gay?' I said 'ah do mean all the people who talk like females are gays? There are some other people whose voices are like females, that doesn't mean that they are gays. How dare you say such a word to me.' Then after taking this story to my fellow people who also practice homosexuality, they said 'how come he was talking in such an insult to you yet he is also like that.' So it was something which still puzzles me up to today, how come a person who also does that but is trying to discriminate [against] you. I realize that maybe he was doing that out of jealousy.

I would say I am lucky because I am somebody who is like when somebody who has wronged me I take I can have a grudge of course with that person but it cannot last long. I easily forgive and I easily forget. But for somebody else if somebody else I mean if I have done wrong to somebody else I also go to that person for to ask maybe to plead for an apology. But I still give room to that person if he doesn't want to take my apology I leave but as long as I have expressed my what my apology, to me I feel like free, I feel freedom in my heart.

I am in a relationship yeah I would say so yeah I have a fellow man. I wouldn't say much about him because it's a for like confidentiality one

He has not spoken with anyone in his family about his sexual orientation, but he thinks they may 'suspect'

Thinks through the consequences and factors influencing his decision not to disclose his sexual orientation

Gossip and suspicion among men who have sex with men (internalized stigma and fear of being made public)

Forgiving personality

Happy in current relationship, still keeps quiet about it though to

because of his status, yeah, since he is somebody who is big holding a high profile position so I won't talk much about it, but I am in a stable relationship with somebody else. It's not long time it's just I should say it's 6 months now, 4 to 6 months for now. I met him through because of a certain friend of mine who is also like me, so he is the one who introduced me to that person. So since that time we have been in touch we have been conversing through the phone, but there hasn't been much of meetings between him and me but of course we do meet but often not frequently but it's like something – I take it as something which is stable. And unlike how I have been going about this in the past, it was like meeting this one today the other day you meet another person, and so I would say I finally am in a relationship with that person.

HIV and sexual health

HIV has a meaning to my life simply because it's a disease which so far has no cure and it is a fertile disease yeah which has claimed many people's lives. So it has a meaning to me that I try my level best not to acquire the virus through my what - because I mean through my sexual orientation.

I have been there for more than 5 [HIV tests] I would say. Because I am speaking I am a blood donor, I do give blood after each and every three months I go to give out blood.

STI screening-frankly I have never gone for that but I wish to go but still I am worried simply because of course so far I won't say I haven't yet experience to find out any sign that would say it's a sign of STIs but since I realized I read that in some other people there might be no signs that this person is infected with STIs but still I am afraid if I can go there because maybe they will start asking me questions like how come you are having this problem, maybe on the side that is not – I know – I think you know what I am about to say. I mean maybe for example you develop like STIs maybe from your back so imagine you go to the hospital and they will start asking you many questions like how come you are having this from the back because from my view as being a man you are supposed to have this maybe from your front.' So that makes me a bit worried. But still besides that I am still thinking of going there but that means that I will not be able to express the true self about my sexual orientation. I will just go there as another person.

Since the law of Malawi doesn't recognize homosexual or I should say doesn't recognize yah actually doesn't recognize homosexuality, so this is really a factor which is affecting my sexual orientation since it's like you are living like oppressed. So you cannot do that publicly. Once you do that you should know that you are ready to face the what, to face the police or whatsoever or even homophobia, things like those. So I would say *the law is there somewhere somehow guarding us not to live freely in our country.*

protect his partner (he is a public figure)

Even though not living with HIV, he is aware of its presence in his life and his higher risk of contracting it as a man who has sex with men. He tests repeatedly and uses condoms.

Challenges of regular STI screening— difficult to ask for anal screening without disclosing sexual orientation to a health care provider. Fear or anticipated stigma from healthcare provider (and possible arrest).

Law oppressive because criminalizes same sex sexual acts

Pride and independence

One thing I would say that I have been proud of in the last 12 months is that I have been able; I would say that I have never led a life on my own. Living a life not depending on anybody else but this year I have spent I would say most of the last 12 months on my own, doing my own things, not depending on anybody else, sure, so I would say that has been in my most proud thing in the past 12 months.

Hopes

My hope for the future is mainly is to get a stable job yeah and live freely without any hassles.

The government should consider I mean they should consider establishing an environment which would allow people I mean like people who fall into sex with their fellows, yeah, they should consider an environment which like free to them. They should review the laws which criminalize homosexuality—they should consider reviewing those laws.

Proud and aspirations to be independent

His hopes for the future have nothing and everything to do with his past and his sexual orientation

Felix's story touches on several of the key issues identified by the opinion leaders relating to intersections of identity, stigma, accessing health services and the compounding factor that criminalization of HIV and related risk behaviours can have in a context like Malawi.

Felix is a young and thoughtful man, who has a diverse life story brimming with experience already. He has multiple identities as a man, who is attracted to fellow men, who is Malawian, a former prisoner, younger and older brother, an orphan, a divorcee, and a domestic worker and peer outreach worker. His story highlights various elements of the challenges of legal consciousness and challenges of law enforcement reviewed throughout this chapter.

His story touches on the challenges of legal consciousness in that he describes only ways that he feels that the law is impeding his ability to live his life freely (through its oppression of homosexuality) but not how the law could protect his rights. He also has direct experience of the law in a foreign country (South Africa) where he was arrested for assault and subsequently deported as an illegal immigrant. Even though he has direct experience with the law, as a defendant, these are not the provisions of the law that are most present in his life story. He is more taken with the oppressive potential of the law to limit his ability to be free in his expression of his sexuality. This juxtaposition indicates that

the law can have a very powerful presence, even if not directly implemented, when it is linked to an aspect of someone's identity (rather than to an action such as assault).

The challenges of law enforcement highlighted in Felix's story centre on questions of access to quality legal representation. As illustrated by his experience in South Africa, there are several structural dimensions that affect the process, such as cost of legal representation, cost of fines (if found guilty), time to undergo a legal challenge (Felix was advised that it was quicker and cheaper to plead guilty even though he feels he was innocent), and the subjectivity and questionable quality of legal advice received. His story also touches on some of the hardships of prison life, such as violence, rape (inferred), different economies of exchanging and securing services, isolation and suicidal feelings, threat of ill-health (for example from lack of condoms). It also touches on aspects of individual identity and alienation (from his sexual orientation) as well as collective identity in the support and solidarity that he found among the sub-community of prisoners also from Malawi.

Felix's story touches on the layered and temporal dimensions of stigma that he has faced at different times in his life from both internal and external sources, and in the form of anticipated and/or received, for his behaviours (drinking alcohol), sexual orientation (attraction to fellow men), for his poverty (in his dependence on the financial help of his sister) and for his past (as a former prisoner). It also illuminates the multiple sources of support that he has benefitted from that also has temporal or transient dimensions to it, for example from his mother as a child, from his sister to an extent during his time in prison, the Malawian community within prison, his peers who are also attracted to men in Malawi, and his employers who encouraged him with an opportunity to generate his own income and work towards his personal independence.

INSERT 4: Saidi's life story (LS14)

"I, as a woman that lives in the village, I do not have a chance to know what the law says because I rarely find batteries for my radio. And when we go to support groups where we meet we don't discuss such things. We do not have that chance. We only talk about positive living, not about the law."

The following life story is taken, almost verbatim only edited slightly, from a combination of two interviews—one in Zomba on 31 October 2010 and the other in Zomba on 1 March 2011. The participant wished for her real name to be used; however her name and other identifying features have been changed for consistency with other participants. The column on the right hand side includes reading notes I have annotated alongside the life story, which are summarized in a discussion section after the end of the narrative. See Insert 4 (below) for annotated edit of the interview.

My name is Saidi. I live here in Zomba. Actually my real home is Ntcheu.

Zomba is my home because I came here when I was very young. I came here with my parents but they died in 1994. In our family there are 3 young children and I am the first-born. The other two are boys. At the time of my parent's death, the second born was one year and 9 months old. The other was about 12 months. Life was difficult because none of my parent's relatives volunteered to take care of us the way things happen that when parents die, their relatives share responsibilities over the children. So, we continued to live a difficult life in Zomba. That time I was in Standard 8. It was difficult for me to finish or continue with school because there was no support at all.

Survival

In those days there was a bottle store on the road out of town, known as Zomba Inn. There was also another bottle store right there. The only way of helping things that I could see in my life, because government could not offer me employment due to inadequate education and young age. So I would lock up the children – my two brothers – in the house and go to the bottle store to look for men with whom I would have sex for money. I did not even have the idea that when you have sex with a man you charge some [different] money, for a short time or nightlong. I didn't know anything. As a result, I found myself having sex with older men ignorantly throughout the night without even using condoms; without any protection, and sometimes without any money paid to me. Getting back home in the morning, I would find the children already awake, sometimes in a terrible mess, as they were too

The first introduction to Saidi's work as a sex worker is for survival. She is herself a vulnerable young person, who has been orphaned and responsible for looking after her two young brothers, also vulnerable young people

young to take care of themselves. That was my way of life.

We continued living such kind of hard life.

There was no relative I could go to for help or live with. My parents had built a house at home but my aunt who was living there demolished it and used the bricks to erect a fence. She donated the iron sheets to the Church. Since I was young I did not say anything to her. They used to mock me, saying I was too young and they could give me AIDS through witchcraft. Because I was indeed young, I did not understand what they meant. I continued with my way of life and the children continued to grow up.

Lack of help and stigmatizing perceptions of extended family

Then I found **employment** with a certain Indian of Malawi origin as a minibus conductor. I used to be on the Blantyre and Lilongwe routes. But the minibus got involved in a road accident, and the owner of the minibus relocated to Blantyre before paying me my salary, which at that time was 350 kwacha²⁹. From this amount I had to pay rent for the house; buy food for the children. Not only that, the children had to go to school. It was a hard life but there was nothing else I could do.

She shows initiative and resourcefulness, but remains underpaid

I had stopped to work for the minibus and through my commercial sex work I got some little money. I saved the money until I had just enough to start a tomato business. Tomatoes are seasonal. Sometimes it would all go bad or it would all be broken. I stopped doing that business. I started going to Ntcheu where I would order Irish potatoes. I used to travel on a minibus to go to Ntcheu, not on trucks as other women were doing. What puzzled me is that people used to ask me how I got there. I would then tell them I got to Ntcheu by a minibus. They wondered why a minibus and not by lorry. 'You come today, ordered potatoes, and you are going back today?' I told them I had to rush back for my children. Still, they did not understand why I had to spend money ordering the goods and minibus fare. I did not know the business techniques.

She is naïve but showing entrepreneurship, and always prioritizing care for the children

First love?

At about that time there was a boy who proposed to marry me. I agreed and explained to him how I live my life as an orphan and that I have dependents whom I cannot send home because there is nobody who can take of them. He did not seem to be happy with the children. I became pregnant and gave birth to a baby boy who never had his father's care. He had left for Karonga where road construction work had started. He told me that he would write to inform me if he will be lucky with employment, and that he would send some money for transport so that I follow him. But instead of writing me a letter or sending the transport money for me to follow him in Karonga, he wrote only to tell me there were beautiful women from Tanzania,

²⁹ In 2010 exchange rates (the kwacha was devalued in May 2012), 350 kwacha is approximately £1.35 GBP.

Tarifas, they go swimming at the lake and that he was very much enjoying himself.

At the time we had been living in a rented house, and so I decided to follow him in Karonga but did not have any money for transport. I went to Blantyre where I made some money from sex work. Luckily or unfortunately I met a truck driver who asked me where I was going. He told me he was going to Lilongwe and that he could drop me there. He gave me a lift to Lilongwe and gave me money amounting to 800 kwacha. That's what I used for transport from Lilongwe to Karonga.

I found the same man married [to another woman]. He booked a room for me and after a week he gave me 2000 kwacha to take me back. I pleaded for him to give me money to pay the rent and leave the house, but to no avail. Thinking about my children who were all by themselves, I decided to come back to Zomba. That marked the end of the marriage.

Responsibility

The children continued going to school while I continued sex work and selling chips. I used to sell the chips until around 9 o'clock in the evening, the time people usually go out for beer, some knocking off from work, others watching videos – that was the time I would knock off from my chips business. So because I used to stay long hours close to the fire, I developed stomach pains. When I went to the hospital they asked me what work I do. I told them that I fry chips. They told me the pain was due to the heat from the fire. They advised me not to be close to the fire, but it was still difficult for me. There was no other way for me. Because of the sickness the little money I had got used up, but the children got their household needs.

The children never gave up on school. By God's Grace they listened to me. They understood – if I had nothing they would understand, because there [was] no other relative to turn to for help.

Testing for HIV

It was during this time that I heard about VCT. That was around 1999/2000. I was keen to see what happens at the VCT. When I went to Zomba Central Hospital I met the doctor because it was very confidential at that time. He explained to me about HIV, everything else that happens. He then asked me if I were prepared to take the test. I told him I was ready. He wanted to know why I had decided to be tested for HIV. I told him that I had done quite a lot of prostitution and so I wanted to know my status, if I had the virus.

"What if you test HIV positive?" I said there was no problem. He tested me and informed me that I was HIV positive. 'How do you feel?' he asked me. I told him I did not have any ill feelings.

Her sex work is her most reliable source of income

She experiences consequences to her health from the 'risky' work where she tries to earn a regular income—heat from the frying oil, and HIV from sex work

She is proud of the children, and indicates they appreciate her sacrifices to send them to school

She is one of the few people interviewed in this research who went for a test to know her status (not because she was experiencing symptoms and feeling unwell)

He explained to me that there were no drugs at the time. If they were available I would be told when to start taking ARVs, and from which centre. “But since you say you are staying nearby, keep checking with us so that you can start taking the ARVs as soon as we receive them,” the doctor said, because that time I was not looking as healthy as I am today. My body was very weak, so weak that even when I took a bath, it was like I had not done so.

OK of course after I had tested for HIV of course I was worried when I got home, because I didn’t know much about HIV, its nature, and its progression stages. However, little by little through my participation in the support groups I started gathering knowledge about HIV – at what stage you get ill and so on. I was also able to learn, through the support group work, how to cope with the issue of living with HIV.

I saw it as a big problem in my heart, that I was HIV positive because in the case of sudden death my children would think I had been bewitched.

One day I prepared the food that my children like. I cooked rice, beans and meat. I also bought Maheu for them. I asked them a question: ‘if I were diagnosed HIV positive how would you feel?’ They said there was no problem and they encouraged me not to worry – they continued enjoying the rice. We stopped there on that day. After two weeks had passed I brought up the issue again. ‘Aah children, did you say if somebody in this house....?’ One by one the children gave their thoughts. It was at the end of the discussion that I disclosed to them that I went for an HIV test and I was HIV positive. All of them said they did not see any problem with that. They also gave me their thoughts on HIV and living with HIV as they understood it at their age.

Spirit of volunteering

So I kept going to the hospital hoping to hear that the drugs had come. Then he told me about a group where HIV positive people meet. He told me the date when to go to the group and that it was a support group. I was eager to see the place and on the date that I was told, I went. While there I noted there was no one that said they were HIV positive but that it was simply a youth group. I realized that in the group I was the only one that was HIV positive – all the others seemed to be fine but that did not discourage me. I met the Director who said they were looking for volunteers who would be going to the office to water the flower garden and mop the floor. I was one of those that offered themselves. There were six of us.

I used to get to the office at 6am to sweep and mop the floor. At 10am I would prepare tea for the people. What I saw to be a problem is that maybe people do not quite understand what it means to be a volunteer, but I did. The other five volunteers had given up and used to ask me if I had been employed. I told them no – and they wanted to

Always mindful of the children, and she discloses her HIV status to them in a very sensitive way—in a way that they can accept

A remarkable and admirable generosity of spirit in anyone—and even more so when the opportunity cost is so high when no other income is consistent

know what it is that pleases me in doing the work. I told them there was really nothing special. When awareness campaigns were organized elsewhere the people used to take me along. I was asked to share my experiences of living with HIV but people did not believe that I was HIV positive.

Discrimination in the workplace

Now, what used to happen at the office, I mentioned that I joined the support group, I could see elements of stigma and discrimination against me because I was the only one that came out in the open about my HIV status. The others knew each other, how they came to the support group. As I have already said, at 10 o'clock after preparing tea, I would go lie down on the Veranda as the bosses, project officers, drank the tea inside the offices. One day they told me – 'ah Saidi, if you want to drink tea at the office you should bring your own cup from home.' I told them OK I will be bringing my cup but on no single day did I bring a cup in order to partake of the tea. When I got home I thought to myself why they asked me to bring my own cup because there were many cups in the office. I know this was one way of stigmatizing and discriminating against me.

Sometimes as I clean the office, I would notice there was an invitation for training or workshop for volunteers. I was the only volunteer – I knew I would not be the one going but instead a project officer attended that workshop. *I could not ask because I did not have the power and courage to do so.* The office veranda was my place – after cleaning the offices.

People keep wondering and asking me why I stuck there. All I could say is it was out of interest – I didn't quite have a clear answer. But I could also see that I was not going to be a volunteer forever. Someday God will open the gates for me. Indeed after some months, on that day I did not go to the office, I saw a boy coming to my house to tell me that all the bosses wanted me at the office. 'The boss wants me? What is there?' Thinking that maybe something is missing, if I say no people may think otherwise. So, I went and met the Director. 'I sent for you. There is a training where they want counsellors. But the one who was supposed to go is busy writing examinations. So, you are the one going to participate in the training which is for 6 weeks, after which you will be doing VCT.'

I could not believe my ears but I agreed. He asked me if I can speak English. I said I do. 'You also understand the language?' I told him I understand very well.

I went for the training and spent the 6 weeks training in Counselling and Testing. When I came back I continued with my voluntary work because I had no salary. Even as I did the work there was whispering here and there, which showed people were not happy for me to

Discrimination occurs even within the community of people working to support people living with HIV

Agency—in this case limited by her sense of a lack of power and deficit in courage

A well-deserved opportunity, at last!

continue there and providing the HTC service. They thought maybe because I was doing a great job and yet there was no salary I would leave. But I did not give up or complain, I kept on working.

The children, my children, were now grown up – they have gone to secondary school and need school fees. I forced myself to go to a place to have sex with men although I knew I was HIV positive. I had to find school fees. But things were difficult because sometimes some men would not be honest, they would not give me money. Sometimes they would break the condom. Some even would ask me what I was going in such a place. I would tell them off and that they should ask the other girls.

One man said ‘no, these others we have no problem but you – the way you look, you are not supposed to be here at the bottle store. OK when you thought of coming here how much money did you think you would make?’ Childishly and rudely I said 500 kwacha. Then I saw the man produce 500 kwacha and giving it to me and offered to take me home. He dropped me home but did not have sex with me. This turned my heart and sometimes I thought to myself why really I find myself at the bottle store. Because sometimes you would dance until 4am without any customers talking to you – for us we call them customers – customer is anybody who talks to you for ‘short time’ or asks you how much you charge. But it’s difficult.

The children are now grown up – one is a teacher, the other, the last-born, has sat for Form 4 examinations and is waiting for the results. My child, the one who was deserted by his father, is now in Form 3. I cannot say that I do such and such kind of job to pay school fees for the children, aaa it was commercial sex work. I was not even surprised when I was diagnosed HIV positive. I also knew that I got the virus through moving out at night – ignorant and not protecting myself I found myself HIV positive.

Being HIV positive has changed my life because now when I meet a man who would like to have sex with me I force him to use a condom and how to use it properly. I explain to him the benefits of using a condom. I also provide counselling so that they may go and take the test. I have a way of assessing someone and telling if they tested, and if they tested HIV positive can they accept. Being HIV positive changed my life because I am able to use a condom. I can also able to tell the man that wants to have sex with me all about the condom and its benefits.

I also talk to my children at home about condoms. And if you found me with my children you cannot tell that they are my brothers because they feel free with me. I realize that if I am harsh with them and they have sores around their private parts they may not be able to tell me – they will be afraid that I may scold them because that would be

She continues to put her health at risk to earn enough to cover the school fees

Vulnerable to abuse by clients... but some are gentlemen

Pride!

Transformative experience of knowing HIV status—uses condoms

Talks openly in household about HIV and sexual health

Promoting non-discrimination through friendships with other school children

evidence enough that they did not protect themselves, they did not use a condom. But they are free to talk to me. Even at the school where they go, there are children that got HIV from their parents or they were raped, they know they are HIV positive, they chat with them. Some people discriminate against those children but my children do interact with them because they know they have the thing in their home. So I see that this HIV has changed my life.

Proud of her health, and not yet starting ARVs

But honestly, since that time when I was diagnosed, it's now 13 years I have lived with HIV, I am not on ART. I don't even take Bactrin. At some point they put me on it but because I am allergic to it, I stopped taking it. I have never lied down, that I am sick because of HIV. Of course I do have a headache, I am a human being, but I have never lied down and I do not take ARVs. I live a happy life, sometimes I meet disappointment but I never really get worried because of being HIV positive.

Speaks from her own experience to inspire courage in others

Being HIV positive in my life on one hand there is stigma and on the other, human rights. I disclose my status even when I go to a group of people, I find it difficult to give examples of somebody else saying 'they say' because you do not have evidence. I give my own life examples because it is something I cannot forget or go wrong; it will be as it is.

Inspiring others

I came across a certain man whose wife took an HIV test but he was refusing. Many people went but he never listened to them. They got fed up and then they narrated the story to me. 'Saidi there is a certain man who is very ill but refuses to be tested for HIV.' I went to meet the man and had a chat with him. I gave an example of myself – 'Can you see me? I tested for HIV and I am HIV positive. If there were drugs those days, the way I was health wise, I would have started taking ARVs, but because they were not available at the time. But because after testing HIV positive I accepted, I live a happy life without any problems.' The man immediately said 'Aaah, aunt, before you finish your story, come, test me.' Luckily enough I had the testing kit, I tested him after he consented.

Empathy and outreach

The other day I was on a bus from Lilongwe. At 6pm my neighbour on the bus, with whom I was sharing a seat, said 'oh I was diagnosed with meningitis – it is time for me to take the drugs.' When she took out the bottle I noticed written on it 'Triomune 40.' I wondered aaah, medicine for meningitis! Fine. We travelled for some distance and I started talking about HIV – I disclosed to the person about my status. After that she also revealed that the drugs she was taking were not for meningitis – they were ARVs.

The validity, authenticity and power of speaking openly from experience

I understand stigma because as I explained earlier I do not talk about somebody; I talk about myself because I have gone through some difficult times and I have evidence. Stigma and discrimination exists. I

Subjective framing

do understand and I am able to see it because there comes time when they put a cross on your plate or cup. When you ask for water, you see that each time they bring you the same cup so that nobody else uses it. Or sometimes when you go to a funeral in the village you will see people eating together in groups of two and so on You would think it is honour when they say to you 'aah madam, come and have your meal here freely'. You would think it is an honour and respect, not realizing they are discriminating against you on the basis of HIV, with the perception that you will pass it on to them when you eat from the same plate.

So in my view we do not quite understand human rights. When a person is a diagnosed HIV positive, marriage ends. It appears a person cannot get married, cannot find employment, or an opportunity to go to school. It appears that opportunity does not exist when you are HIV positive.

As a woman that lives in the village, eee, to see you, to know you, because I disclosed, everybody knows, as you asked if I am free to disclose, yes I am able to disclose freely. Yes I am able to disclose freely. Those who want to stigmatize and discriminate against me, let them do so, but I must talk about it.

On the issue of coupons, it is the very same people that are supported, sometimes some of them do not even have any land. The coupons are just given or shared among relatives. If somebody outside the circle receives a coupon, it is just by design so that other people should not say much. But to say the truth, the person that is known to be HIV positive in the village stands no chance of being given a coupon. They don't have that chance; they say 'this is already a dead body'. It's the same with some of these offices – that this person cannot go to a workshop or training because when they come back they will be sick and we'll not benefit.

I as a woman that lives in the village, I do not have a chance to know what the law says because I rarely find batteries for my radio. And when we do to support groups where we meet we don't discuss such things. We do not have that chance. We only talk about positive living, not about the law. For us to know what the law says, aaa, no we do not have that chance.

We just hear when somebody breaks the law, yah that section so so in our Constitution, that's when we get to know oh there is such and such a law. But that we have a paper or book to help us know and understand the law here in the village, mmm, we are not that lucky.

Unfortunately we don't know the laws or the policy makers, when they made their laws or policies, I don't know who stands for us. If someone has done some wrong against me, I just keep quiet. You just

of experiences and perceptions of stigma

Another layer of identity – as a woman who lives in a village

Stigma in accessing coupons for fertilizer subsidies

Lack of access to information about the law. Mentions the Constitution but does not know how to use the law to stand up for her human rights.

The law she imagines is not a positive one—it is one that she sees as jeopardizing her rights and her livelihood

keep quiet. Because once you stand out, dodging each other, point your finger at that people, it becomes embarrassing, so you just keep quiet. Even if you are beating me because of HIV, no, it is confidential to my house. I would not go to the police or a traditional chief or anything. For something maybe like stealing from my house, I would go to the chief. And the police. We go to the chief, and the chief gives you a letter to go to the police.

But not for HIV. No. Even if you have a support group in your area and go to the chief, even though the chief is also HIV positive they do not take part. I would never see a chief going to the support group, I would never. The Chief is positive but he is not open. But there is a time we get the coupons and they said 'don't give coupon, she is HIV positive, she can't manage'. So he didn't give my coupon and that was only last year – October.

The police are doing mandatory testing. Once they catch you at night they take you to the cell, then in the morning they went to VCT. As you know that the results should be confidential, but the confidentiality is not there. And before you go to the cell the policeman should sleep with you, compulsory. And they get money from you, and cell phones, without condom.

This happened to 22 of my friends last year, in Mwanza and also here in Zomba. I am the one – I went to the police to follow up this issue up to the station. They forced them to pay money for bail but I know that bail at the police is free of charge – it's only at the courts. And I know this because sometimes I like to work voluntary work, but other people they don't know that it is free of charge. And how much did they have to pay? 4,000 kwacha per person

We don't seek attention or protection from the police. I will give you an example. Sometimes you meet with the customer and the customer don't have money to pay a room. It's night huh. We just go out at the bottle store and maybe just do like this [she stands up and bends forward]. Then the police might be under a tree. Then they say 'what are you doing here? Do you know you are destroying nature.' So they do the police, so we are failing to say I am not supposed to, 'I am drinking beer', you can't say that. You are just for them. Then they are raping you. But they say 'you don't leave just have sex with me', and there are maybe three or four of them at the police station.

Speaking out

But I went to them, after my friends had been arrested, to the prison and they said is there any relationship between these girls and you? Because I had put a piece of cloth on my head, and slippers, and chitenge. They said "who are you?" I said I am Mrs. Phiri. So they said "No maybe you are a journalist, you should go out." I said "OK I go out." Then the next day I went again and I told the police, "I am a sex

Pressure and self-preservation instinct to remain silent to avoid stigma

Lack of openness (stigma?) about HIV among community leaders

Self-imposed silence to avoid persecution at the hands of the police, who are supposed to protect

She refers to the Penal Code and shows how other laws are used to target sex workers

Abuse by police. Rape.

Courage and conviction to speak out.

worker, I am a member of an NGO.” So “what do you want?” “I want to know why you take these girls to the station and why you take them up to the hospital.” I said “OK there is international backup, even in Zambia, even in Zimbabwe, there is this backup. I said OK Do you know that your juniors, I mean the policeman, they rape us, they raped them.” He said “I know, but we are trying to advise them to not do that but we know that they are doing that but of course we don’t know that they still continue or stop.”

I think that my suggestion is, sex work is a work to me, I have a suggestion. Why can’t we make partnership with health workers in hospital, after 3 months or every month, should go for testing? Not mandatory. I said maybe next time when I come back to the police we could action that suggestion. But it is not all of us, or all of the sex workers, that can have that chance to reach the boss – the person in charge of the police.

I want my health to continue being this good, yah, free from frequent illness. I also want to reach out to some of my friends, those that are still experiencing fear, because I have a few friends who when we are together in a group chatting, maybe they do not know about my status, they sometimes say – ‘aaah me, I can’t endeavour to go for HIV testing’ or ‘eeeh, if I go for HIV testing and I am diagnosed HIV positive, and people know that I am like that, I can commit suicide?’ I want people like those ones that one day they should accept and go for HIV testing to know their status.

In addition I wish children whose parents died from HIV-related illness to be treated like all the other children. I don’t know how I can express myself for me to be understood, but they should not be treated differently from those whose parents are HIV negative.

My last words are to thank you for this meeting with you. There are probably a number of things which I wondered where and how I would bring them out but I take this as a great opportunity because I have been able to bring out what has been hurting me inside all along, that is I were somewhere, some position or I had some power and authority, I would have done such and such things – or even thoughts that if I were so and so, I would have done such and such things. But you coming, your visit, has made it possible for something inside me to break.

Sex work is work (no longer framed as for survival)

She shows leadership among the community of sex workers, reaching some people in ‘important’ positions with potential results

Continued determination of spirit and generosity to support others

Hopes for the future

A final comment on the process of being interviewed, and an appreciation of the opportunity to give voice to some of the issues and experiences that have been ‘hurting’.

Saidi is a strong woman with a remarkable life story to share. She has multiple identities—as a woman, as a sex worker, as a vulnerable child, as a parent, as a carer, as a volunteer, as a divorcee, as a community HIV testing and counselling worker, as someone living with HIV, as a spokesperson for her community and as a champion for human

rights... to put categories and a name to some of them. Her life story encapsulates several of the barriers to legal consciousness as well as challenges for law enforcement that have been raised earlier in the chapter.

The challenges to legal consciousness most apparent are her lack of access to information and knowledge about the law. She has not had much education, she has little money and cannot afford batteries for her radio, and her support circles do not discuss issues such as the law. She makes a brief mention of the Constitution but does not see it as a mechanism that can enforce or guarantee her human rights. She knows of some practical elements, such as the “cost” of bail, from life experience rather than from access to information. Likewise she talks of her friends who had been arrested but she does not directly make reference to the specific laws under which this occurred (which was identified by OL18, as Section 192 of the Penal Code).

The challenges to law enforcement that are raised by her life story include the abuse of the law to proactively marginalize groups already pushed to the edge of society (in this case sex workers). She refers to multiple abuses at the hands of the law enforcement agents, the police, who have raped, physically and verbally harassed, forcibly tested for HIV, and breached confidentiality in disclosing the HIV test results, impacting herself and fellow sex workers. At the institutional level, she describes discrimination in the workplace that remained unchallenged because at the time she was not in a position of power to show the courage she has in other circumstances, to raise awareness and address the discrimination. She also cites an example of how internalized stigma within one of the traditional authorities is potentially fuelling discrimination in the distribution of the fertilizer coupons and equally fuelling stigma by not openly addressing the presence of HIV among every level of the community.

Finally, amid a story that describes at times seemingly insurmountable adversity, she shows immense pride, courage, conviction and dignity in her sense of responsibility and generosity of spirit.

CONCLUSION: LAW AND STIGMA – A MORAL BAROMETER

This chapter has reviewed what the law is, is perceived to be, could be, and what it is not, in relation to the current national HIV context in Malawi. Despite the potential challenges of enforcement and implementation of the law in general that were identified in relation to the draft HIV Bill, most participants expressed a desire for the law to provide symbolic guidance and be a positive support for the realization of the national policies relating to HIV.

However the extent to which a law relating to HIV might have a normative power is questionable in a country where there is a limited consciousness of the law in the everyday lives of people living with HIV, a lack of a widespread understanding of the formal legal system and constrained access to formal legal redress for most people, and where the Constitution is seldom enforced. A politicized account of the rule of law is necessary to enable the law to provide an effective foundation for democratic and responsive social and political transformation (Klare, 1998, p 188).

In this chapter I have applied the analytical frame of monumental and memorial aspects of transformative constitutionalism to the context in Malawi, and also to the proposed draft HIV Bill. Klare argues that attentiveness to both the individual as well as the social environment is able to nurture enabling circumstances that can foster freedom, dignity and equality. Guided by ubuntu, for constitutionalism to provide an effective mechanism for meaningful transformation, it must engage the hearts and minds of individual Malawians as well as communities and institutions, inspiring a spiritual transcendence while also delivering material redistribution (cf Ramphela, 2008). Klare recognizes the complexity while also noting the interdependence of the material and aspirational dimensions of the constitution for achieving transformation—at both the individual and collective level, as well as spanning the past to the future, which is embodied in the notion of ubuntu. The results suggest that in order for an HIV Bill to have a positive impact on the national HIV response in Malawi, it must also achieve both material redistribution to alleviate the structural determinants of ill-health while also providing leadership about the norms and notions of HIV in society (see also chapter eight).

The second key finding is that even though the law is ostensibly a lacuna in the daily lives of people living with and closely affected by HIV in Malawi, it is still perceived to have a potential role in the national response. Few people questioned the applicability of

the law to HIV. Further research could explore these results further by examining the origins of this “faith” in the potential role of the law. For example does it come from a conditioned response (such as, because we have laws they should govern all aspects of life) or from a perceived opportunity (such as, clear reasons why the law might have a specific role to govern the national response to HIV that could not be provided for in policies and/or by other social mechanisms).

The third critical finding, linking the methods with the results, was that of a potential “African jurisprudence” centred on the individual legal subject in the context of their interrelationship with others (ubuntu) (cf Ramose, 1999). The focus on legality and daily life illuminated that the law had a symbolic presence, that it was not often engaged and when it was at times in inappropriate circumstances (such as gossip), and that people expressed clear notions of justice and injustice in their own lives and communities. The case study of findings from Malawi presented in this thesis could contribute to illuminate further philosophical and socio-legal thinking about a jurisprudence of dignity, generosity, and reciprocal engagement between individuals and societies.

And finally, the results also illuminated interesting results in relation to agency and the law. It is the human translation of the law into reality, if or when that occurs, that constructs the meaning and presence of the law in everyday life. In other words, human agency is present at many levels that influence the impact of the law in reality. These include agency at level of the citizen, who needs to have knowledge of the law and a grasp of the process involved to seek legal redress. It includes agency in terms of the lawmakers, who discuss, interpret and draft the laws that become enacted. It includes the agency of the lawyers and judges who determine the legal dimensions of each case. And it includes the law enforcement officers such as the police, the prison wardens and the social workers who in various ways are responsible for administering justice.

Agency and the potential for change are the critical determinants on which hinge the potentiality of legal consciousness as a force for transformation or subjection. To avoid becoming “the principle of his own subjection” at the recognition of oppression and power institutionalized through legal mechanisms (Foucault, 1979, op cit), the process of developing legal consciousness ought to be coupled with a process of realization and access to fair and just mechanisms of law enforcement. Otherwise, Freire’s notion of critical consciousness would become an imprisonment of the mind as opposed to an inspiration for resistance and empowerment.

The social action of storytelling and consciousness raising of law in everyday life (Ewick and Silbey, 1995) could be a step in inspiring resistance and social action—providing a stepping off point to understand the law—what the law could inspire, what spaces the law may open that enable the civic participation of marginalized people and spotlight and support struggles for equality, and what debates the law can create for individuals to scrutinize the application of democracy that can give meaning to the legislative aspirational words of equality, dignity and freedom in real life. Perhaps therefore the secret for the future realization of transformation in Malawi rests in the ability of the law—encompassing both its potential as well as its limitations—to inspire the spirit of dignity and equality among all individuals and institutions.



8 | Criminality and HIV

*“I am also looking at the repercussions... I understand the intentions, the intentions are good, but I think the results of that would be very bad.”
(OL 14)*



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³⁰ The image is from World AIDS Day 2010, at a community dialogue in the Central Region of Malawi. The two policewomen were wearing ‘Criminalize Hate Not HIV’ stickers that I had taken to the event, part of the global campaign to raise consciousness of the issue by IPPF.

A PARADOX: CRIMINALITY AND CONSCIOUSNESS

This chapter explores insights relating to the third research question—the extent to which law has a normative power in framing social attitudes towards HIV. The chapter presents results about the criminal provisions within the proposed draft HIV Bill as a litmus test for understanding the symbolic potential of law in productively invoking stigma to define appropriate and moral individual behaviour and to govern society.

The draft HIV Bill embodies a paradox. As already noted, it is a legal initiative that is founded on principles of non-discrimination (in terms of the national Constitution as well the defined premise for the proposed draft HIV Bill), but includes and embraces controversial and stigmatising provisions. This chapter explores one of the “thorny” issues in the proposed HIV Bill, the criminalization of HIV transmission, to analyse issues of stigma, agency, social control and the extent to which the law can engage and respond to the multiple aspects of a person’s identity (MLC, 2008, p 17).

This chapter analyses the criminal provisions of the draft HIV Bill in Malawi through a sociological lens to understand the intentions and potential impact of the criminal law in the national HIV response in Malawi. It builds on the analysis presented in chapter seven that looked at the legal consciousness and potential role of law in the national response to HIV more generally. The analysis reviews individual as well as collective responsibility, internalized and external stigma, and human rights. The following analysis of the draft HIV Bill is based on a sociological view of crime and punishment that is deeply rooted in the structure of society in a specific historical and cultural context (Spitzer, 1975). I argue that the application of the penal law to HIV transmission and exposure—a relatively recent development around the world and one of the contentious provisions included in the draft HIV Bill in Malawi—is indicative of the problematic role of the law in social control, stigmatization and the policing of ‘deviance’ (Garland, 1996). I suggest that in the case of HIV transmission, the application of penal law is detrimental to society as well as to the individuals involved, because it accentuates stigma, undermines the human rights of people living with HIV, and creates—rather than dissipates—barriers to seeking testing, support and other health services (UNAIDS, 2008).

The chapter opens with a review and close reading of the terms of the proposed HIV Bill. The participants’ perceptions of the criminal provisions within the Bill are then analyzed over three sections. The first of these reviews the intentions of the law commissioners in the drafting of the Bill, which is a rare opportunity to understand

processes and motivations behind the law making process. The second section reviews the impact this may have on stigma, focusing on the perceptions of the life story participants, which reveal significant differences from the intentions of the law commissioners. The language and imagery used by both the law commissioners and life story participants was melodramatic and negative connotations expressed about HIV, and over-stated the role of agency in HIV transmission, which I argue was a way to justify the prioritization of the human rights of the general public over those of people living with HIV. The third section reviews the responses from all participants to look at the potential impact of the criminal provisions if the draft HIV Bill were to be passed without amendment. The potential impact was identified at three levels: the personal (in creating barriers to testing and disclosure of HIV status), the structural (in perpetuating stigma, leaving women vulnerable amid gender inequality, and not responding to real life concerns), and the legal (in terms of challenges of enforcing the criminalization of HIV transmission, exposure and non-disclosure, and perpetuation of stigma through the law).

The results indicated that the draft HIV Bill in Malawi manifests a tension between intention and impact—the desire to enact a law to protect human rights and strengthen the national response to HIV, while potentially taking away those rights from certain groups and fuelling HIV-related stigma (Stackpool-Moore, 2013). By incorporating criminal sanctions as part of the proposed HIV Bill, the lawmakers actively seek to engage stigma to shape social attitudes and attempt to guide normative behaviour. This raised the question of whether in fact alleviating HIV-related stigma in Malawi is a real—or only rhetorical—political priority.

The elements of the criminalization provisions with the draft HIV Bill (as reviewed in chapter four: the criminal, maternal, banal, exceptional and conceptual) were described in a variety of ways in the participants' perspectives about the potential role of law (and the draft HIV Bill for those who knew of it) and are presented and analyzed in the remainder of the chapter.

CRIMINALITY AS A LITMUS TEST FOR HIV-RELATED STIGMA

The convergence of criminality with HIV, bringing together notions of illegality, sex, morality and (breach of) trust, provides an informative litmus test for exploring HIV-related stigma. This section consolidates participants' responses in three parts: the first,

based on the responses from the law commissioners, analyzes the intentions expressed behind the drafting of the law. The second, based on the responses from the life story participants, analyzes the potentially stigmatizing connotations of HIV evoked by the application of criminal sanctions for HIV transmission, exposure and/or non-disclosure. The third part draws from all participant responses and evaluates the potential impact of the draft HIV Bill, if passed as is, on the personal, structural and legal dimensions of HIV in Malawi.

Participants were asked about their opinion of the criminalization provisions within the draft HIV legislation (for those who had heard of it) or in general as a punishment for people “passing on” HIV from one person to another (for those who had not heard of the draft HIV Bill). While almost all participants were in favour of equal treatment for all and non-discrimination against people living with HIV, when asked about human rights, two-thirds of participants supported the criminalization of HIV transmission.

Some participants argued both for and against criminalization, and a few chose not to answer the question (see Annex 7|1). There were noteworthy differences between the participant groups. People living with HIV were more thoughtful and more aware of the nuances of arguments for and against criminalizing the transmission of HIV than other groups, with one-fifth expressing arguments both for and against criminalization. Of the law commissioners, only one person argued both for and against (and this was the Commissioner who herself disclosed she was living with HIV); the majority was in favour of prosecuting transmission. Of the opinion leaders, a few argued both sides (i.e. for and against criminalization) with the majority being against it. Women were more in favour of criminalizing HIV transmission than men. Interestingly men also expressed a greater reluctance to give an opinion – all five of those who did not answer or directly address this issue were men (see Annex 7|2 and Annex 7|3).

The participants’ opinions relating to the criminalization of HIV transmission or exposure unveiled inconsistencies in logic and stigmatizing attitudes. These internal contradictions within the opinions expressed during the interviews of participants speak to Durkheim’s notion of the socialization of crime, and the role of collective and individual consciousness (and productive inducement of stigma) to demarcate what is considered ‘criminal’.

Along the lines of the disconnect explored in chapter six between laws, legality and legal consciousness, the responses to criminalization highlight differences between the

opinions of people whose lives are directly affected by the prospect of becoming ‘criminal’ simply because of their HIV status (because the law would not be applicable to someone who does not know or is not living with an HIV positive diagnosis), the people who make the policies, and the policies themselves. Applying Durkheim’s notion of criminality, I suggest that the conceptualization of criminality relating to HIV that was expressed in the interviews spotlights a place of moral judgment, fear, and misconception within participants – a space where stigma ultimately thrives.

INTENTIONS: RATIONALE FOR PROPOSING HIV CRIMINALIZATION

This section is based on the perspectives of the law commissioners and analyzes the intentions expressed behind the drafting of the proposed HIV Bill.

As indicated earlier, one of the reasons for the recent proliferation of laws relating to HIV transmission and exposure represents a last ditch effort of politicians and policy makers to do something visible and proactive when other HIV prevention efforts have been failing (e.g. Pearshouse, 2007; Eba, 2008). Globally there is a paucity of information relating to the motivations and aspirations of lawmakers and the rationale behind legislative provisions that criminalize HIV transmission. It is a rare resource to have the perspectives on this issue from three quarters of the Commissioners involved as part of the Special Law Commission on HIV who drafted the proposed HIV Bill (Stackpool-Moore, 2013). The Commissioners spanned a variety of experience and expertise, and are all explicitly named and are listed as signatories to the Report of the Special Law Commission (MLC, 2008)³¹. The Commission was chaired by Reverend Josph Mpinganjira (Secretary General of the Episcopal Conference of Malawi), and included Mary Shawa (the Principal Secretary of the Department of Nutrition, HIV and AIDS), Janet Banda (Chief Law Reform Officer, MLC), Andrina Mchiela (Former Principal Secretary, Ministry of Women and Child Development), Biswick Mwale (Executive Director, NAC), George Liomba (Chief Executive Officer, Malawi Blood Transfusion Service)³², Fiona Kalemba (Assistance Chief Parliamentary Draftsperson, Ministry of Justice and Constitutional Affairs), Dorothy

³¹ The responses in this thesis have been anonymized, and all identifying features removed from the testimonies of the Commissioners as much as possible, to protect anonymity. This is for consistency with the approach adopted across all interviews, since almost all of the Commissioners expressed a desire not to be anonymous in the interview process.

³² George Liomba is a trained pathologist, and was also the person who diagnosed the first case of HIV in Malawi in 1985.

Namate (Former Director of Health and Technical Services, Ministry of Health), Amanda Manjolo (Executive Director, National Association for People Living with HIV and AIDS), Grace Malindi (Deputy Director, Agriculture, Gender Roles, Extension Support Services, Ministry of Agriculture), Chipo Kanjo (Senior Lecturer in Computer Science, Chancellor College), and Dinah Ntodwa (Retired Civil Servant) (MLC, 2008, p 3-4).

The law commissioners interviewed as part of this research (about two-thirds, as noted above) unanimously identified the criminalization of HIV as one of the most controversial aspects of the proposed HIV legislation. One of the opinion leaders interviewed even cited criminalization as “delaying the progression of the Bill’ through parliament (OL 21). Even though the majority of commissioners were in favour of criminalizing HIV transmission, the awareness of the controversy expressed in their opinions highlights their awareness about the logistical and ethical challenges of enforcing such provisions. Interestingly, although in the background rationale outlined in the Report (MLC, 2008) there is a strong emphasis on the criminal provisions to strengthen HIV prevention efforts (see chapter four), most of the Commissioners cited reasons relating to retribution and ‘justice’ for deliberate infection, rather than prevention per se, as the main reasons for proposing criminal sanctions as part of the Bill. The results from the interviews with the law commissioners indicated that while the stated objective of the HIV Bill in the Report itself was first and foremost founded on intentions of effective and comprehensive HIV prevention. Even though the intentions behind the law were well intentioned, the motivations to include criminal provisions were based on a certain melodrama (i.e. not responding to the primary routes of transmission and portrayed by inflammatory descriptions), desire for retribution, and invocation of moralization in the governance of the national response to HIV.

While acknowledging that it was a controversial issue, the majority of the law commissioners were overwhelmingly in favour of criminalizing HIV transmission without any equivocation. There were two exceptions: one of the Commissioners indicated arguments for and against (incidentally she was the only openly HIV positive member of the Special Law Commission, which is consistent with the findings from the life story participants outlined below) and the other Commissioner who indicated that he had reservations and thought HIV transmission should not be criminalized, even though it was proposed in the draft HIV legislation, primarily on the grounds of enforcement:

“I don’t think [HIV should be criminalized]. I find it difficult how you could get this to prove how somebody could deliberately pass on HIV infection. I think it must be – to prove intent with evidence, that somebody infects someone, would be very difficult. To me anyway, I don’t know how the lawyers would do it.” (LC5)

LC5 suggests the challenges of law enforcement should in fact determine the nature of the law (not the other way around).

Some of the language used to describe the rationale for criminalizing HIV transmission, such as to prevent or deter deliberate transmission of HIV, was exaggerated and arguably melodramatic in some cases. For example,

“Especially if one has the knowledge one knows what HIV does and then intentionally you know by *pure malice* you decide to do that, I think for me it’s criminal. Why would you want to *inflict* somebody with a life long illness that they can actually avoid? Even if we know now there are drugs that alleviate whatever, they are taking these drugs for life, a really long time, why would you let somebody [contract HIV] who otherwise would not have been subjected to that. So that’s where I get the bad feeling that you know you are really not being very good to the other person.” (LC9, my emphasis)

Even though LC9 more accurately portrays HIV as a lifelong illness compared with the evocation of death and destitution outlined in the language of the report, she nonetheless has resource to hyperbole in her evocation of extreme (and arguably exceptional) nature of HIV exposure and transmission. Similarly,

“Or ‘I know I am positive then I say na-huh, I am not dying alone. I know where I got it I will go back there and take everybody who transmit it to me.’ And you go back and maybe in the drinking places and you have sexual intercourse. All the bartenders there, the prostitutes on the street, then that’s deliberate transmission *for heaven’s sake*. You are also re-infecting yourself. I think that when people are arguing, *let’s look at what is your responsibility and what is your rights vis a vis your responsibilities.*” (LC4, my emphasis)

This kind of language could suggest a level of personal judgment or sensationalism behind the motivation for some of the commissioners.³³ As outlined in LC4’s response, the emphasis is firmly on the responsibilities of people living with HIV (and how responsibilities limit their rights) rather than looking at the responsibilities of the general population and also the government, to protect the rights of all. Perhaps the Commissioners in their use of non-judicial (and misleading in terms of public health)

³³ Interestingly, in follow-up questions among all participants (including the Commissioners), only one person had direct personal experience (they had a friend who accused someone) of deliberate transmission of HIV. The others offered examples of stories they had heard (gossip or rumour) or of articles they had read in the newspaper.

language were attempting to justify the proportionate reaction of criminalization. The negative framing of HIV as “death” and a “peculiar” event may be deliberate exaggerations to justify the imposition of criminal sanctions and also to excuse the explicit devaluation of the rights of people living with HIV (for example HIV positive mothers) and prioritisation of the rights of others (such as the unborn child or married women who are HIV negative).

The verdict—conclusions from the opinions of the law commissioners’ opinions

An analysis of the perceptions of the law commissioners in relation to the aspects of the proposed HIV Bill that specifically relate to criminalizing HIV transmission highlight three key aspects that have an impact on stigma. The first concern, the rationale relating to retribution and justice for people in response to incidents of deliberate transmission emphasizes the punitive motivation behind the criminalization provisions in the law. The second, the inflammatory and stigmatizing language used by some of the Commissioners to connote the contagion of HIV and deliberate transmission emphasizes this further. The third key finding related to the framing of HIV in terms of death and illness. Even though some of the Commissioners did refer to HIV as a chronic illness, the sense is that HIV devalues a human life. While most people would agree with the Commissioners that HIV should be avoided, and that HIV prevention is an important goal, to equate the prevention agenda with devaluation of life with HIV is in effect proactively invoking stigma to support prevention efforts. Yet as several studies have shown, HIV-related stigma can in fact be detrimental to HIV prevention in that it creates barriers for people in seeking tests and also for disclosing their status (therefore increasing the likelihood of onward transmission) (cf Mahajan et al, 2008; Simbayi et al, 2007). However in a country like Malawi, with such a high prevalence of HIV and a likelihood that HIV will be present in everybody’s lives at least for a few more generations (even with the most effective rollout of prevention efforts), perhaps a framing of HIV as part of life may be more realistic, less stigmatizing, and ultimately more effective in supporting the national HIV response.

The findings of this research suggest that, contrary to the framing of the Bill in the Report of the Special Law Commission, prevention of HIV transmission may have been a secondary motivation for some commissioners behind retribution, punishment and/or a symbolic demarcation of what is considered moral behaviour.

STIGMA: PERCEPTIONS OF HIV CRIMINALIZATION AMONG LIFE STORY PARTICIPANTS

Turning now specifically to the perspectives of people living with and/or closely affected by HIV, opinion was divided as to whether or not HIV transmission should be a criminal offence (exactly half either way). This section analyzes the potentially stigmatizing connotations of HIV evoked by the application of criminal sanctions for HIV transmission, exposure and/or non-disclosure.

The responses from the life story participants indicated that that people living with or closely affected by HIV showed greater equivocation on the question and demonstrated empathy for the opinions both for and against criminalization. Four of the participants expressed more nuanced opinions, indicating that they would support the criminalization of HIV for some reasons (namely as a punishment or deterrence for deliberate transmission) but not for others (such because of limited access to treatment in prisons, challenges regarding proof, lack of legal enforcement, and consent). Of those participants who did think HIV transmission should be a criminal offence, the primary reason was given in relation to the deliberate transmission of HIV and depending on whether or not someone knew their status. Some discussed certain nuances of the law, in terms of differentiating between deliberate or reckless sexual transmission or another mode of transmission (for example sexual compared with mother-to-child transmission), which is outlined below. Almost two-thirds indicated that HIV transmission should be criminalized given certain conditions and conversely the same number also indicated that it should not be criminalized given certain conditions. Just over a third of participants indicated that it should not be criminalized under any circumstances. Two did not indicate their opinion.

In terms of stigma, some of the participants used strong language associated with killing or death as part of the justification for why HIV transmission should be considered a criminal offence. For example,

“He can come here to the hospital, he can be examined, he can be diagnosed and found with the virus. So I mean that is evidence and he can be prosecuted, because that is *killing*.” (LS16, my emphasis)

“That one who deliberately transmits and infects others, with the virus, must be criminalized because he is doing it deliberately. *Because he has killed the future of somebody*.” (LS17, my emphasis)

“If that person has done it deliberately knowing that he is HIV that one has a crime because he has *killed a person*.” (LS18, my emphasis)

This crescendo of severity showcases how consideration relating to the criminalization of HIV transmission unearthed a framing of HIV as a kind “death sentence” and shows a resonance of the hyperbole of the law commissioners with some of the misperceptions of HIV in everyday life. Even in the minds of some people living with HIV (such as LS16, LS17 and LS18, all of whom are on ARVs and in seemingly good health at the time of the interview); the virus can still be framed as something that will kill rather than as something to live with. Yet in other aspects of the life stories, the life story participants had framed HIV as one aspect of life—that they have the same rights and responsibilities as other people—and as something that they live with. For example,

“I have good health; I am gaining weight; I am happy, and I am doing my studies. It will be the same with anybody who goes for an HIV test and is HIV positive – they can emulate my example, that they can do any kind of work like anybody else that is HIV negative.” (LS5, op cit)

“As a woman living with HIV, yah I am found HIV positive, it does not mean that I cannot have a feeling for sex. I must have it because I am a human being—it is nature.” (LS14, op cit)

These opinions relating to the criminality of HIV transmission indicate an inconsistency relating to the framing of HIV, which in turn highlights the extent to which crime and criminality touch at the heart of stigma.

Perhaps, even though at a rational level all the life story participants indicated that people living with HIV have the same rights as everybody else and can live a healthy life with access to treatment, at a more subtle or subconscious level some still harboured feelings of the gravity of HIV as a virus that literally and metaphorically can *kill*. It is interesting to note the differences in the framing of HIV—on the one hand, more positively, as something *to live with* that does discriminate between individuals when considered in relation human rights; and on the other hand, as something that can *kill* when considered in relation to notions of crime and punishment. The different framing perhaps indicates the connotations that can be conjured up when an issue is considered in light of two different frames of reference—the same issue, but the framing changes according to the association. This difference could indicate an example of how a perceived negative association with criminalization could frame HIV in a more negative way, thus indicating the kind of demarcation of social norms—and arguably proactive engagement of stigma—to which Durkheim was referring.

In addition this conflict of emotions in the framing of HIV signposts elements of internalized stigma, and may explain why people living with HIV were the most equivocal group in their opinions relating to HIV criminalization. The equivocation regarding criminalization may represent a see-saw, encompassing on one side the normalization of HIV and its meaning in life and on the other a potential sense of anger or shame at acquiring HIV, and potential guilt in relation to possible onward transmission. The notion of inconsistency and stigma are explored further in relation to criminality, law and consciousness in chapter seven.

The prevalent framing of HIV in terms of death and killing in the context of the question of HIV criminalization was consistent between the life story participants and the law commissioners. This is a significant finding for three reasons. First, it supports Durkheim's notion that there is a conscious construction of what is considered criminal. Given that the dominant framing of HIV shifted—from something that you can live with, to something that can kill—depending on how the question was asked, indicates that there is a connection between criminality, negative attitudes, and stigma. Second, relating to the law commissioners, was that the extent to which the responses to the “thorny” issues of criminalization revealed disparate motivations behind the drafting of the HIV Bill that contradict those officially stated in the Report (i.e. retribution and punishment as clear motivations, compared to HIV prevention) (cf MLC, 2008). This suggests that the law commissioners are human, and that the motivations behind the drafting of the HIV Bill are more complex, divergent and controversial than those outlined explicitly in the Report itself. It also suggests again that notions of criminality are intrinsically linked with notions of morality, delineating social norms, and consequently stigma. The third main finding, from the responses of the life story participants, suggests that the inconsistencies within the life stories in the framing of HIV (similar to the law commissioners, at times as something to live with but something that can kill, in the context of criminalizing HIV transmission) point to internalized self-stigma about their HIV status. It also suggests that perhaps these inconsistencies were revealed because the connection between the criminal law (closely associated with the formal legal system) and HIV had not previously been contemplated by almost all of the life story participants and thus perhaps triggered a more spontaneous reaction.

The findings highlight that stigma and the criminal law are related and can feed off each other in complex and subtle ways, which appeared to sit astride a tension of that

which was both conscious and obscured to the individual participants (as explored further in the in-depth analysis of insert 5 at the end of this chapter).

IMPACT: A CRIMINAL CONVERGENCE OF STIGMA AND SOCIAL CONTROL

Taking these differences of opinion between the participant groups into consideration, the following section takes a holistic view of the thematic responses from all the participants' perspectives on provisions relating to the criminalization of HIV transmission in the proposed HIV Bill. It explores the responses in three main areas. The first, at the personal level, in terms of perceptions of reasonable behaviour and agency and the perceived or real impact of the criminal law on individual lives of people living with HIV. The second focuses on the structural level, in terms of the impact the provisions may have on structural drivers of vulnerability to HIV and HIV transmission. The third area reviews the responses specifically in relation to the law and legal redress, and includes some analysis of the impact on law enforcement and access to justice in Malawi.

PERSONAL: the potential impact for individual people

At the personal level, many participants commented on the potential normative influence of the criminal law to impact behaviour relating to HIV testing, disclosure and a sense of individual freedom for people living with HIV. Further details of the participants' responses under each of these headings are described below.

Testing for HIV

One of the main concerns cited by respondents was that the provision to criminalize HIV transmission might create a disincentive for people to seek testing. Early testing and encouraging people to know their HIV status is a policy priority in Malawi (Malawi Government, 2012). For example,

“If I know that I will be held accountable for infecting someone then I will opt not to test. That is going to be a defence to say ‘I didn’t test so how do I know that I have HIV?’ So this legislation to me was more or less contravening a lot of other provisions that we already have instead of enriching or building on the legislation that we have.” (OL 14)

“The best is I should not go for a test... If I go to court I will tell them I never tested so I didn’t know that I was positive.” (OL 16)

The link was made between criminalization and creating barriers to HIV testing, with notions of the role of the law in response to HIV. One participant illustrated this by suggesting that the criminalization provisions would render the law as a tool for promoting HIV transmission (rather than preventing it) because of its potential potency in fuelling stigma:

“Being positive doesn’t mean that you are dead, you can still live – the people can still live for years and years – ten, twenty, fifteen, twenty-five years they’re still there. So it doesn’t mean that when you are positive you are dead. But I think to me I feel we should not use the law because the law to me can end up pushing people underground...[L]et’s be clear what law do we have and be sure that at the end of the day we don’t have a law that is victimising people... a lot of people will go underground. And instead of the law being one means of trying to control HIV and AIDS you will find that it will be a tool now of increasing the spread of the disease. So I find that we need to be very cautious.” (OL11)

Very few participants questioned the role of the law in response to HIV, even though some pointed out the potential deficiencies of the incorporation of criminal sanctions. For example OL11, who although argues that criminalization could potentially do more harm than good, but nonetheless contends that the law has a role to play—as a tool in the armoury of the national response to HIV. There was the exception of one participant, who questioned the extent to which the State (through the law) should be intervening at that level of personal relationships, particularly in regard to HIV testing:

“[It’s] very controversial really. If there is wilful intention to infect certainly it has to [be criminalized]. But not many people go for testing. And it is not compulsory, so you don’t know you are and you are in a relationship, certainly from a legal perspective you don’t have a guilty mind. The other side of the coin is if you are going to go into a relationship and not use protection, should the state really come in and defend your rights? It shouldn’t... The state shouldn’t play big brother.” (OL4)

However the point is argued on the basis of principle rather than in relation to the bluntness of the law as an instrument to be responsive to the subtleties and delicacies of disputes in the bedroom (cf WHO 2006).

Disclosure

Criminalization was seen to have a direct impact on disclosure of HIV status for some participants. Some saw it as the premise for the criminal law, for example one

participant stressed the 'duty' of the person living with HIV to disclose their HIV status – and the inferred logical link then to outlaw non-disclosure:

“It’s tied to the right, the obligation, the duty to disclose your status. So if there is a duty on an HIV infected person to disclose then non-disclosure will be proscribed.” (OL7)

One of the law commissioners went so far as to liken non-disclosure as equivalent to deliberate HIV transmission:

“Personally, if I was asked in my own opinion, it depends – it depends in the sense that ‘I know I am HIV positive, I don’t tell my partner I am positive, and I pretend things are OK. Until so many years down the line I am taking ARVs. And when it is discovered there is room for penalizing me. I have deliberately transmitted the virus to this partner. I would have been responsible enough to tell this partner I have been found positive. These are the means of protection. You also get tested – we know what to do.’ The problem in Malawi is that people did not disclose and the majority decided not to disclose, hmm? So that’s deliberate.” (LC4)

On the other hand, a few participants cited the criminalization provisions as potentially creating a disincentive for people to disclose their status.

“It may scare people from disclosing their HIV positive status. I am aware that they say ignorance is not a – what do they say – is not defence in a court of law. But just knowing that transmitting HIV is a criminal offence then it would give a feeling to some people not either to disclose their HIV status or not even to know their HIV status all together. And that would have implications in the national response.” (OL6)

Or more explicitly, one participant elaborated how it opened up the possibility of criminal liability for people who do disclose their HIV status – in other words potentially punishing disclosure.

“It’s like you’re criminalizing this particular individual because he’s got HIV, or because I disclose I’ve got HIV, and in one way or another infect someone and I have to be criminalized. What about those people, maybe they know their sero positive status and they choose to be quiet or pretend to be ignorant about their sero positive status?” (LS11)

Others saw it is a way to guide people to disclose within relationships and prevent transmission of HIV between partners. For example,

“If he knows he has HIV and he loves somebody, he has to explain his status. That even if I love you I have HIV. And then the other person has to agree. So the two who agree to act in such a way that they don’t transmit the virus, they don’t spread the virus, they protect each other from infection.” (LS 17)

This is particularly interesting in light of some of the main reasons people gave in their life stories relating to their decisions to disclose their status and considerations (such as trust) about when, how, if and to whom to disclose (see chapter five).

Agency and consent

Linked to notions of testing and disclosure is the notion of agency and consent—and the extent to which the draft HIV Bill enables that or takes it away. The responses from the law commissioners provide an interesting starting point to consider notions of agency, consciousness and action in the criminal provisions of the proposed HIV legislation. An exaggerated sense of agency is placed on people living with HIV to disclose, to test, and to know their HIV status, without any recognition either of the barriers the criminal law could place on this and/or the agency of people who are HIV negative to remain so and also to know their status. For example two of the law commissioners went as far as to suggest that even those who don't know their HIV status should be liable under the criminal law:

“We thought even those we don't know [that they are HIV positive], that's not an excuse as long as it's proved that you are the one that infected this person. Because some people would say that 'it is better that I don't know' and they don't even know their behaviour. They don't go for the test and they keep on infecting others. Which to us we thought that's not proper.” (LC1)

In more extreme positions, another Commissioners invoked a sense of 'deliberate' not knowing of HIV status as equivalent then to deliberate HIV transmission for someone who “should have taken the initiative” to know their status:

“It would have to be proven if it was negligent or not. For example somebody who has knowledge that they are potentially like that and they probably do not or they deliberately do not go for VCT and they infect someone, there's a way in which evidence would actually be proven on that it was deliberate, because they *should have taken the initiative to actually know.*” (LC3)

In another example, again demonstrating extreme agency on the part of the person living with HIV, the one Commissioner who is openly living with HIV reflected on her own life and her decision not to have sex with any men since the death of her husband and her HIV positive diagnosis:

“Like in my case I am aware that I am positive and if I go ahead and then transmit it to somebody else, then I know exactly what I am doing so that's like a crime. Yeah, because eventually we know that the virus *may* kill somebody. Do we really want to do that deliberately? I mean the answer is no.” (LC6, *my emphasis*)

Despite being very open about her HIV status and very comfortable discussing experiences of stigma in her life as well as aspects of the proposed HIV Bill that may influence stigma, she nevertheless frames HIV as a “virus that *may* kill somebody.” She nevertheless maintains a level of uncertainty by not directly equating HIV directly with death in the inclusion of the qualifier “may”. Compared with, for example, another Commissioner who framed HIV as a “chronic illness” (LC9, see below) highlights the nuances and degrees of positivity or negativity in constructing notions of wellness and fatality in relation to HIV.

Of the total participants (from all participant groups) who supported the criminalization of HIV transmission, all of them specified or justified this primarily in terms of deliberate transmission. Some participants then were less sure when it came to people who did not know their HIV status, indicating an element of agency, consciousness, or *mens rea* to the ‘crime’. For example,

“It can be a criminal offence to me for somebody who knows he is HIV positive and goes around sleeping with women or sleeping with men knowing for sure that he or she is HIV positive. Then that has to be treated as a criminal offence. But if somebody doesn’t know his status and then he sleeps with somebody and then he infects that individual, without knowing his status, then that may not be treated as a criminal offence because he is doing it unknowingly.” (OL 13)

This extract conveys a common sense among participants that linked a consciousness of one’s HIV status—“knowing for sure that he or she is HIV positive”—necessitates a responsibility for preventing onward HIV transmission. The argument links consciousness of an HIV positive status with an assumed enhanced responsibility for preventing HIV transmission. This is logically consistent as the inverse of the arguments outlined above as to why criminalization can impose barriers to HIV testing and the grounds for determining the *mens rea* of a criminal offence. One participant extended this logic to also include a crime before God, in support of his reasoning that HIV transmission should be considered a crime:

“It is wrong because first the person must know about the condition of his/her body. If they know they are positive, it is not right to pass it on to anyone else... if someone voluntarily passes the disease to someone it is a sin and it is wrong.” (LS 19)

The perspective of LS19 further highlights the link between consciousness, and the importance of knowing about HIV (and the condition within a person’s body), and moral

responsibility for preventing HIV transmission. This extract demonstrates clearly the Durkheimian sense of the moral collective consciousness of criminality.

However on the other side of the debate, the notion of consent and agency was also invoked by some participants to suggest that HIV criminalization was not appropriate. For example one participant specifically emphasized the nature of consent to sex from adults (except for cases of rape or defilement), and that the criminalization of HIV unrealistically does not take this into account.

“What we are saying now is that we have given a lot of information to almost the entire nation. We are saying maybe over 90% of the messages have reached people in the system. Now always when we have sex this time it is commonly something that we choose – except for a couple of unlucky individuals who are forced to have sex through raping and the like – but if there is consent then we have to think around that issue before we say this is a criminal, this is what, due to HIV infection. Most of the adults, we choose what we want to do, in the case of sexual contact.” (OL16)

Reiterating some of the discussion in the case studies, the law already targets – either through explicit provisions or through biased enforcement – some key populations vulnerable to both contracting HIV and social marginalization (see chapter seven). The provisions relating to criminalizing HIV transmission could further conflate this stigmatizing effect of the law for certain groups. For example, for sex workers,

“[HIV transmission] it is not [a criminal offence]. For me personally it is not, because until now I haven’t yet come to a clear-cut understanding of how they are going to determine that this criminal act transmitted infection. That’s what I am saying. If it’s sex workers, everyone knows that they are there and it is most likely – what we found is that most of them have HIV. And if a person goes and has sex with a sex worker and later on he claims that he got HIV from the sex worker, what does that mean? To me the problem is the person who did not take appropriate measures to protect himself yet he also enjoyed the sex worker. So in that case the sex workers would not need to be arrested for criminal transmission.” (OL21)

The response from OL21 highlights the on-going question about ‘whose rights count?’ and whose priorities and well-being are prioritized over others, and the extent to which all people have the same entitlement to human rights (cf Ife, 2010). The question is ultimately that in consensual sexual relations between two adults, is it a shared responsibility for the sexual health of both partners—or is responsibility disproportionately placed on the person who is (and/or knows they are) living with HIV? This is explored in further detail on the section below looking at rights and responsibilities.

Therefore the notions of consent and agency strike right at the heart of determining *mens rea* (particularly in cases of accidental or reckless transmission of HIV).

Rights and Responsibilities

The notion of responsibility was often highlighted, and, as noted above, disproportionately allocated to people living with HIV. Across all groups, some participants indicated that criminalizing HIV transmission places greater responsibility for sexual health onto the role of the person who knows their HIV status.

“If someone is transmitting HIV to a person who is not HIV positive that is an offense and has to be prosecuted.

Why?

Had it been that in the first place you discussed with that person that you are HIV positive; the other wouldn't have allowed you to give the virus.” (LS16)

One participant described a notion of shared responsibility for sexual health on the one hand, yet on the other the language and description used seemed to place greater emphasis on the person who is living with HIV.

“There are some people out there who know they are HIV positive and they will not even dare think of how best they can protect themselves and protect other people. Because it is a question of two ways, protecting yourself from getting infected and protecting other people from infecting them. So that is the kind of situation where we should balance the two. And we are saying that if there are individuals who knowingly, know they are HIV positive and they would not involve or *indulge* in protective sex, then something must be done to correct these people so that they *come back to their senses*.” (OL5, my emphasis)

The law commissioners were similar with the other groups in displaying an inconsistency of opinion about the rights and responsibilities of people living with HIV, on the one hand having the same human rights as everyone and yet on the other hand having greater responsibility for protecting the nation from HIV (even though, for example in sexual encounters, it takes two people for HIV transmission to occur). Three of the Commissioners referred to a balance relating to human rights and regulations – a balance either referring to rights and responsibilities, or referring to the rights of certain people over others. For example,

“Whatever we tried to do, it should not infringe – unnecessarily infringe on other people's rights. Of course we always say that rights also come with responsibilities. I think that sometimes it is too difficult to see, to judge, what is right for everybody. This is what is right for the individual. It is always like that – that conflict.” (LC5)

Some explicitly frame a greater responsibility (and in this equation implicitly more limited rights) for people living with HIV.

“Human rights must be practiced with responsibilities. Because I assume if I am positive one of my responsibilities is to accept that I am positive. Another responsibility is for me to break the news to my loved ones. And then the next responsibility is to take action to remain alive. So that I take my treatment properly, and I feel OK about my condition. But then I shouldn’t be demanding for my rights when I am not able to tell my loved ones. I am not able to follow to adhere to treatment. I am not even able to protect myself. Then there is conflict here yeah? And discrimination is coming because we are bringing in all these problems. ‘Ohh it’s this, oh it’s your right’. Where are the responsibilities?” (LC4)

In this extract LC4 is unconcerned by her suggestion that people living with HIV should not be entitled to their rights, without any regard for the potential challenges that disclosure, treatment adherence and other daily realities of living with HIV might entail (including stigma), unless they shoulder the responsibility for the whole of society. In another example, the different responses from the law commissioners illuminated the competing interests identified between the priorities and choices of a mother living with HIV (for example to choose not to undergo an HIV test or not to take medication to prevent transmission to her child) and the “unborn child”. This was articulated most clearly relating to the application of criminal sanctions for the transmission of HIV from mother to child, relating to mandatory testing for all pregnant women (another controversial provision in the draft HIV legislation), where the perceived rights of the “unborn child” (arguably misconstrued as enhanced if born HIV negative) were unanimously prioritized over those of the HIV positive mother. For example,

“That’s where she has been tested, that’s infringing on the rights of the mother. But we are saying no we don’t want this unborn child to be a victim, that’s what we are talking about criminalization.” (LC7)

“When we talked about for example in the rural – for testing – testing women for HIV when they are pregnant. For me it is good for the general good, but when you say whether should somebody have the right to say no or yes, then for me it defeats the purpose of trying to prevent children from getting HIV infection. Because they have no say when they are inside their mother’s womb. So there is that conflict. Now how do you decide – you decide to emphasize on the rural woman’s rights to say no, or do you emphasize on the State’s responsibility to protect the unborn child. That for me is a big conflict in terms of human rights. But I think it is important to ensure that whatever you do does not unnecessarily infringe on other people’s rights.” (LC5)

“If we are going to have a future generation free of HIV we would have protected the unborn babies then it means that it would be something – a goal that would be achievable but they thought that we were violating human rights. So again it is the balance between human rights and doing the most good.” (LC9)

Some but not all of the Commissioners then also thought that criminalizing HIV transmission from a mother to her child should also be made a criminal offence. One clearly articulated a reason not, demonstrating an empathy for the mother, yet also maintaining the logic placing a higher value on a child born without HIV, suggesting that every mother wants a “perfect child” born free from a “chronic illness”:

“I don’t know if I would consider that a criminal offence because a baby can have HIV from the mother even if the mother may have actually taken all precautions that the baby should not – that HIV should not be passed on to the baby. Because even if you know all the precautions that we talk about, there is still a rate of failure, so it may not necessarily be in the mothers control that the baby ends up to be positive. And I don’t think a mother would want her child to have a chronic illness. *Every mother wants a perfect child.*” (LC9, my emphasis)

The responses delineate the element of competing interests in recognizing where the rights of two individuals might be in tension (such as the rights of a woman living with HIV not to take treatment to prevent vertical transmission versus the rights of the infant to be born without HIV) and where the legislative ‘line’ of policy protection might be drawn.

The Verdict—the impact at the personal level

The impact of the criminal law at the personal level touches on multiple dimensions and has the potential to limit the equality and health of many if applied in the context of HIV. The construction of agency and action in relation to HIV expressed in relation to criminalization of transmission and exposure places the responsibility disproportionately among people living with HIV. The potential impact at the personal level could be devastating in creating barriers for testing, internalizing stigma, and limiting opportunities for disclosure for fear of reprisal through the law.

The results spotlight a paradoxical confusion between intent and impact of the law in response to HIV. Criminalization simultaneously exaggerates agency (in defining HIV transmission as the primary responsibility of people living with HIV), misleads agency (by creating barriers and disincentives for testing and knowing one’s HIV status), and denies agency (by failing to recognize equal responsibility in sexual encounters by consenting adults). The responses also highlight an awareness of an imbalance between rights and

responsibilities, competing interests and potential conflict in assuring human rights for all. In many cases, and most notably the example relating to the prevention of mother to child transmission, the rights of people living who are not living with HIV were prioritized and given a higher value.

STRUCTURAL: The potential interrelationship with gender and livelihoods

Several participants indicated that the criminalization provisions within the draft HIV Bill could fuel rather than abate the structural drivers of HIV such as stigma, marginalization and gender inequality.

In terms of stigma, several participants highlighted how the proposed HIV Bill in general could be construed to increase stigma rather than mitigate it. This was linked to two main dimensions – the targeting of individual people in certain groups (such as people living with HIV, sex workers or men who have sex with men) and the association of notions of criminality with HIV. For example,

“The law can play its part but I think we need to be very careful in what we want to be in that law. It can even *victimise innocent* people because of lack of information because even right now we cannot say that people even understand this law that is coming – if it’s going to pass. So we need a lot of public education, civic education, but before we do that we have really to try to see what do we want? What type of law do we need? Because we should not target individuals. We should not target human beings. The best way to me is to intensify in a more broader [sic] way our programmes on providing even HIV delivery services – that’s the most important thing and not start talking about if you infect someone people are going to arrest you, that, is criminal.” (OL11, *my emphasis*)

Note even in this extract notions of stigma are introduced differentiating between ‘innocent’ and by implication then ‘guilty’ people responsible for transmitting or acquiring HIV. Subtle perpetuation of stigma is apparent invoking language of criminality even in an extract that is in fact arguing in favour of non-criminalization of HIV. It highlights just how insidious and contradictory stigma can be.

On the other hand, a few participants suggested that in fact the law could be invoked to generate a kind of productive stigma, delineating ‘desired’ social norms, by outlawing certain acts and groups of people (similar to Durkheim’s notion of delineating collective consciousness):

“If certain acts are proscribed and people are actually, who are in conflict with that particular law, they are prosecuted and convicted and sentenced, it will send a signal to people.” (OL7)

And also as a stronger mechanism to support the kind of behaviour changed sought through the national HIV policy:

“We need a framework to actually give the government and maybe authorities the power to actually enforce certain things... There is just so much that you can change through administrative measures otherwise if you have to enforce behaviours out there you really need something you know that gives you that kind of authority.” (LC3, op cit)

Linked to the review of issues and pressures regarding disclosure outlined above, and rights and responsibility, several participants noted that the criminalization of HIV separates out people living with HIV (as a group) to live by a different standard from others. Some saw this as discrimination. For example,

“Although people would say then you are targeting people that are already HIV positive, so it’s like discriminating.” (LC1)

Some recognized this as a contradiction and potential problem but others were comfortable with using the discriminatory application of criminal provisions (or in other words a productive use of stigma) to justify and enforce greater responsibility for people living with HIV to prevent HIV transmission:

“There is also the argument that we are actually criminalizing people who are living with HIV because the only people who pay out of this law is those living with HIV so you are criminalizing people who are living with HIV as bad people who transmit the disease so you are stigmatizing. I know there is that argument. Yes it’s true but the bottom line is they are transmitting the virus, so people who are not living with HIV don’t transmit the virus.” (OL20)

In both of these examples, the participants went on to conclude that HIV transmission should still be criminalized even though acknowledging the discriminatory and stigmatizing nature of the provisions for people living with HIV. Three of the law commissioners reflected on the potential of the law, and the specific provisions criminalizing HIV transmission, to perpetuate stigma. In different ways however, they each dismissed it, either implicitly or explicitly prioritizing the human rights of people who are not HIV positive (or do not know their status) over those who do.

Other participants noted how the proposed legislation, including the criminalization provisions, might reinforce gender inequalities and potentially fuel some of the structural drivers that render women more vulnerable to HIV (as noted in the law itself relating to vertical transmission of HIV) (UNDP, 2012; Ahmed, 2011) and do not

recognize the challenges women face in accessing justice in Malawi and other countries (Ahmed, 2011; Human Rights Watch, 2008; Bonga and White, 2000).

The responses from the life story participants in particular highlight the extent to which criminalization might impact on different aspects of someone's identity, such as the intersection of gender and HIV. For example, one participant, a married schoolteacher living with HIV, thought that criminalization of HIV transmission was appropriate in some circumstances, depending on marital status.

“[HIV transmission should be a crime] if they are not married. But if they are married it is because all the support comes from the spouse and if they are punished it would not work. Nonetheless everyone is human and by giving them the virus they have *broken their rights and destroyed their lives*. These people should receive a sizeable punishment so they know that what they did was wrong.” (LS20, *my emphasis*)

This extract shows an amount of internalized stigma for LS20, portraying HIV as something that destroys lives. In her own life story interview, she attributes her acquisition of HIV to her husband's infidelity. She also describes how she is dependent on her husband, including for things like receiving her ARVs, which perhaps substantiates why she feels that criminalization within marriage “would not work.”³⁴ Taking her position in the context of her life story and current circumstances has twofold significance in terms of identity and perceptions of the law. Firstly, by drawing attention to marital status as a possible variable in considering the suitability of the criminal law, LS20 is expressing a consciousness of identity and articulating difference in the relevance of the law to certain people in its application. Secondly, by taking into consideration the life situation of LS20, correlations can be drawn between her own personal context and the rationale behind her opinion of the differential applicability of the criminal law.

Other participants articulated concerns regarding access to law enforcement and seeking legal redress (see chapter seven), as well as the provisions of the law per se. For example,

“Enforcement and legal remedy issues to the contrary, um because there are some issues of how you would actually enforce it – there are lots of things it doesn't do: It's not a very engendered draft so all the issues of women's risk and vulnerability perhaps are not dealt with and touched on effectively in the law at all, so there are

³⁴ Alongside the interview, LS20 also asked my advice about leaving her husband. She described how she was unhappy, feared violence, and yet did not have other sources of support to turn to. Although this was outside the scope of the interview (it was during tea back in her house after the interview was completed), it also adds insight into the context in which she holds the position she expressed in response to the criminalization of HIV transmission.

some serious gaps as well. But if you were to pass the law as is with all the problematic provisions in there – it would be a farce.”(OL3)

Linking gender inequality, violence, and some of pitfalls the law could trigger relating to testing, one participant noted the potentially damaging impact the law could have for women.

“There are serious examples of people suffering domestic violence on the basis of HIV status. A woman goes to the hospital because she's pregnant she would have to start antenatal clinics, by chance she gets tested and they realize she is HIV positive. She goes home, tries to explain to the husband, the husband doesn't take it; he beats the wife to death. We have got a law. But what have you done?” (OL19)

Food security and access to nutrition was another theme that highlights both the intersecting daily needs of someone living with HIV (particularly important for those on ART) as well as a hierarchy of concerns in someone's life (of which stigma, the law and even HIV may not feature highly). For example one participant noted that even though he thought HIV transmission should be criminalized, and despite the challenges of implementation, that the issue really would not be a priority for people in rural areas with daily struggles to find enough food to eat.

“[HIV transmission] should be [a criminal offence], because the problem would be how you do implement it. How would you implement it would be the biggest hurdle because I am living in the villages and you will see people there desperate for their daily needs. And sometimes life has no meaning to them if you don't have food, why do you care that you should be healthy? So they would have unprotected sex with whoever gives them money. They are not sex workers but they would still do it because somebody would give them money. And in that case that guy – you prosecute him because he bought a bag of maize for me and infected me. Does he have to reveal that I am HIV positive when he is giving me that bag of maize so that I choose between being infected?’ So um yeah it would be difficult to implement it. For people who are well aware of the consequences, it would be easy but 90% of the population in this country they are poor and live in the rural areas and they have no clues of anything in that Draft Bill. So yeah there would be a few cases that would be coming from the rural areas but people there don't care. They would care what they eat today whether someone has infected them or not.” (OL17)

This response highlights the potential inequalities both in terms or knowledge and awareness of the law, as well as a differentiated sense of a hierarchy of daily concerns – of which HIV (and a desire for retribution) is less prominent than something like nutrition or fundamental food security. It also introduces the notion that it may be a kind of luxury to be concerned about contracting HIV, and indeed from whom, for people who are poor and in rural areas. However, as seen from the life stories (see chapter five), HIV-related stigma

can have a catastrophic impact on the lives of people living with HIV in rural areas – such as losing land, being forced to leave their communities, facing discrimination from relatives and having houses burnt down.³⁵

The Verdict—the impact at the structural level

This intersection of social inequality (in terms of wealth and access to resources), legal consciousness, desire for retribution and stigma is at the crux of the structural, legal and personal dimensions of the role of the law in the everyday life of Malawians, and is explored in more detail in chapter seven. In summary these responses outlined illustrate how the criminalization of HIV is inter-linked and may have an impact on some of the wider social determinants of health and structural drivers of HIV.

GOVERNANCE: Law, stigma and challenges of enforcement

The final and perhaps most obvious level of impact noted by participants of the proposed HIV Bill, and its controversial criminalization provisions, was that of the potential of the law to contribute to good governance, demarcating moral norms, and yet also some of the challenges of law enforcement. Several participants expressed a strong desire that the law could provide guidance to support the national response to HIV (see chapter seven). Some participants felt that the proposed HIV legislation is too broad and potentially covered too many aspects drawing on criminal, public health and administrative law. One participant suggested the opposite; that the law itself needed to ensure that HIV was not viewed too narrowly and in fact saw the diversity of the provisions within the Bill as one of the virtues of the proposed legislation. There was also an explicit recognition by some about the potential of this specific law to fuel—rather than abate—HIV-related stigma.

³⁵ The same participant reflects on his own understanding of discrimination in terms of wealth and independence, and stigma he has experienced relating to sexual orientation: “In the case of MSM there are very few courageous ones who would actually indulge you on one on one. But otherwise because I am – I have – I had a job, I had my own money, I had my car, I had stuff, so it was difficult to notice the discrimination. But every time I took somebody in my car they were asked questions ‘what were you doing in his car?’ and ‘people would ask me – people were asking me what was I doing in your car. What is that supposed to mean?’” (OL17)

Responsible nation

While questioning the impact of the law per se (as OL3, below), some participants suggested that attention should be given to ensure that the law is not only in place for its own sake – rather that, if enacted, that a law should be utilized to support the broader objectives of the national HIV response.

This was done in two main ways—the first promoting positive prevention (prevention efforts that focus on the sexual health and rights of people living with HIV) and those that promote shared responsibility and the notion that everyone should be responsible for their sexual health, a “responsible nation”. This notion of responsibility links individuals and communities in the context of sexual health and the law, in a similar notion to that of ubuntu.

“If you are talking about issues of criminalizing deliberate HIV infection, much as I wouldn’t want people to be deliberately infecting others, I think it is important to have a responsible group of people – *a responsible nation* – but I feel those are some of the issues, which would actually be retrogressive to all the efforts that have been made.” (OL14, my emphasis)

In similar positions, some participants indicated that a better priority for law would be to actually support implementation of a stronger health system, echoing OL3 and the importance of more than just legislation to have a real impact in reality, such as:

“The State should concentrate on service delivery – do an assessment – are we providing condoms? Are people accessing condoms? Are we providing correct information in terms of what I just said? Are we providing treatment? That should be the concern of the state rather than trying to target the criminalization.” (OL18)

One participant pointed specifically to challenges relating to the health system in general, and stock outs of testing kits, condoms and other key commodities that may both hinder the national HIV response while also rendering some people living with HIV as particularly vulnerable to criminal prosecutions (if the Bill were to be enacted).

“Because unfortunately there are stock outs of test kits in Malawi – people can be willing to go and test but when they are going to test they will find that there are stock outs and then you accuse that person tomorrow that you deliberately infected somebody.... You know already we are talking of even stock outs of condoms in Malawi in the most of last year, almost half of last year; there was a chronic shortage of condoms. Are we not as a system perpetuating deliberate infection in that regard? And where who will charge us as service providers or as government, which is mandated to provide services to its population by its own constitution. So basically from that premise that’s where we need to say are we really being proactive in this regard or *are we just making laws for the sake of making laws.*” (OL19, my emphasis)

In this extract, OL19 is echoing current international literature that has suggested a proliferation of application of law to HIV in the absence of other less tenable or less visible clear progress being made (cf Eba, 2008 and Pearshouse, 2007). Also illustrating notions of ubuntu, from the collective perspective, OL19 is suggesting that the State could (and should) be liable for prosecution for failing to deliver health-promoting options (like condoms, ARVs, and counselling that supports disclosure) for people living with HIV.

Stigma and law

Some participants emphasized the importance of the law to prevent stigma, which was seen as critical for achieving the wider goals of the national response to HIV. Framed around limitations to people's access to services (health, nutritional and support), one participant argued that "if there is stigma they will not come" and that therefore "laws are important because they provide the framework within which we can address stigma" (OL8). OL8 argued that because the whole issue of HIV spans a broad and not narrow context—the biomedical, social, political, economic and criminal—so too must the law.

On the other hand, several participants considered the law to be too broad and in fact noted the limitations of the draft legislation (and in particular the provisions relating to criminal prosecutions for HIV transmission) in the drafting or language used in the law itself. The most detailed comment was from OL3:

"There are by my count of I believe it's 67 paragraphs of the law in the report there are 6 I think that are problematic. Two of them dealing with criminalization of HIV transmission and again those are fundamentally problematic because they are just so badly written because they are badly defined that if they were to pass them all hell could break loose quite honestly, and it would thoroughly undermining the national response.... So the five or six provisions don't further and are in fact diametrically opposed to the overall lofty principles that are espoused by the law. So from that standpoint alone they are inconsistent and shouldn't be in there." (OL 3)

OL3 argues that the broad nature of the Bill makes it vulnerable to inconsistency and internal contradiction. He also (unknowingly) rhetorically considered one of the central research questions, questioning the real purchase of the law to sufficiently deal with the attitudes, values and behaviours that perpetuate stigma (op cit, chapter seven). The criminalization and other "thorny" provisions are problematic, tempering the human rights based and administratively useful provisions, all of which are subsumed within the one draft HIV Bill. Even recognizing the normative signal that the law sends to the nation,

OL3 suggests that a lot more needs to happen for the law to have an impact (and especially one that is burdened with internal legal and logical contradictions).

The analysis outlined in this research indicates that it is within this inconsistency between the useful and the problematic that human rights are jeopardized, certain groups of people marginalized, and the core values fuelling stigma are revealed.

Law enforcement

Congruent with the responses about the law in general (outlined in chapter seven), some participants indicated that the interpretation of the proposed HIV law and its related enforcement was subject to individual discretion and agency of law enforcement officers. For example, one participant highlights how the law would be subject to the interpretation of individual lawyers, because the law itself does not provide a clear enough guidance on how it could be enforced.

“Perhaps a lawyer would be able to but it is difficult to demarcate the point at which transmission is illegal and the point at which it is legal, I really don’t understand that. But what we are saying is that the laws are important because they provide guidance in terms of interventions but the laws should not be seen to undermine certain segments of the population to effectively participate in the efforts to manage HIV. I think that’s where the difference is.” (OL21)

In a different way, another participant also suggested that the punishment or sentencing would also be interpreted on a case-by-case basis.

“If it is a crime, how punishable is it? What would be the punishment? I think it has to be case by case.” (OL22)

These examples support the suggestions relating to the challenges of law enforcement more generally (outlined in chapter seven). To make an illustrative comparison, one participant suggested that HIV transmission should be criminalized because adultery is criminalized yet on follow-up questioning revealed that in practice the law is not implemented effectively:

“[HIV transmission should be a crime] because even in our laws of Malawi we have this one, committing adultery, it’s a crime. Committing adultery. So it makes no difference.

The adultery crime is that implemented much?

In fact it is not implemented much because there is no one who reports, because there is need for someone to report you see but with this one, this one of

transmitting – transmitting you know, at least there should be someone to report – how will you know that this one transmitted HIV to this one?” (OL2)

The response indicates some of the challenges relating to reporting the crime as well as evidence to prove direction of transmission.

The responses from the law commissioners also identified a tension between aspirational legislation (in terms of delineating “good” governance) and some of the real challenges of law enforcement. Most of the Commissioners were clear on the question of deliberate or intentional transmission, although several noted that it would be difficult to prove. As noted above, only one Commissioner explicitly spoke out against criminalizing HIV transmission, based on the argument that it would be impossible to prove (LC5). Even though the other Commissioners came to a different conclusion regarding the provision, four others indicated that the issue of proof, and particularly proof beyond reasonable doubt, would be challenging. For example,

“It is very difficult to know whether one has actually passed on the HIV/AIDS directly, so how do you criminalize somebody? Yeah but if indeed it could be proved beyond doubt that one has been infected deliberately, yeah” (LC7)

“I am not sure how it would actually work. It would have to be, because we have criminalized it there has to be proof beyond reasonable doubt but you know the infection came from person A or person B.” (LC3)

Several of the Commissioners commented that even though the transmission of HIV should be criminalized, the enforcement of these provisions would be challenging. One Commissioner stressed that although it may be clear that an offence was committed, the law may be limited in its intended application to the response:

“I think the law can only go so much [sic]. If it is clear that the person actually knew their status and they deliberately do not disclose to a partner and they infect the partner that is a clear case where an offence is committed.” (LC3)

Another Commissioner, highlighting the challenges in relating to proof and evidence, emphasized the impact or autonomy that specific lawyers would have in setting precedents and determining how the law is enforced:

“I find it difficult how you could get this to prove how somebody could deliberately pass on HIV infection. I think it must be – to prove intent with evidence, that somebody infects someone, would be very difficult. To me anyway, I don’t know how the lawyers would do it.” (LC5)

Notions of agency therefore also apply to the role of the lawyers and the courts in translating the legal concept into reality, highlighting the inherent challenges in the

provisions in the law and the scope for flexibility (and potential abuse) in how the laws are enforced by lawyers and in the court systems. All law is subject to interpretation, and the internal contradictions lapses in logic within the proposed HIV Bill render it particularly vulnerable to elastic application.

Another Commissioner extended a similar logic in relation to the ambiguity or subjectivity in how the law would be implemented in practice, ascribing the autonomy more generally to the processes in a courtroom:

“I have difficulties to say how do we prove this. I know it’s unfair for someone to infect the other party knowingly. I think this is criminal. But – that such a person has to face justice. The only problem I had was how do we, how do we get the proof in court. So I think OK that would be part of the court system to find the ways but when we talk of protection and justice, yes this has to be criminalized.” (LC10)

One Commissioner indicated that issues relating to consent (linked to disclosure of HIV status) might complicate the situation, even though she was still in support of criminalizing HIV transmission.

“Of course the certain cases where maybe the partner would be told and then they give consent; I don’t know how that can be handled. Because they had informed – they were informed and they went ahead.” (LC6)

While the role of the law commissioners is not to determine the enforcement of the proposed law, rather to draft it, their responses indicate an implicit motivation to include the problematic provisions despite recognizing the enforcement challenges, because of the symbolic power of the criminal law to delineate social norms.

The Verdict—potential impact on governance and law enforcement

In a country like Malawi, where the challenges of enforcement are large and legal consciousness among citizens relatively low (as shown in chapter seven), the symbolic power of the law is still strong even though the implementation may be weak. The convergence of questions of agency, stigma and coexistence of useful and problematic provisions pinpoints the central tension between law and legality in the national response to HIV in Malawi. Agency, in terms of the reach of the law in dis-incentivizing health-promoting behaviours such as HIV testing; in terms of cultivating a criminalizing and discriminatory environment that fuels instead of outlaws stigma and inhibits individual disclosure of an HIV positive status; and in terms of ill-defined provisions overly

susceptible to subjective interpretation (and potential abuse) by individual law enforcement officers.

The relationship between law and stigma is multi-faceted, balancing the potential to create a framework for challenging stigma, with the power to signal social norms, with the limitations enforcement to have purchase responding to the diverse realities of everyday life. Law itself is ultimately also inherently contradictory in its capacity to straddle tension between provisions that promote human rights—even notions of human rights that equate rights and responsibilities (see chapter two)—on the one hand, and those that take them away on the other.

RESULTS AND REPERCUSSIONS

As the results outlined in this chapter show, the criminalization of HIV transmission, exposure and/or non-disclosure as proposed in the draft HIV Bill could potentially have adverse effects at the personal, structural and legal levels. The analysis of the participants' responses highlights critical concerns of both the intended and unintended potential outcomes of applying the criminal law to HIV transmission. The results also demonstrate a stark and illuminative contradiction between the intentions of the draft HIV Bill and the potential repercussions it may have if passed without amendment. Significant differences of opinion were apparent between the participant groups, with the life story participants showing the most equivocation on the question indicating levels of internalized stigma and competing notions of acceptance of HIV and responsibility, guilt or shame associated with HIV. Inconsistencies within the perceptions of other participants was also evident, suggesting that the lens of criminalization provided a useful mechanism to explore less conscious attitudes relating to HIV than potentially more conditioned responses relating to human rights and access to health services. This notion is explored in more detail in the concluding section of this chapter.

The perception that the criminalization of HIV transmission might create a barrier for people seeking HIV testing is apparent in the responses in this research. Even though this research focuses on the experiences of people living with HIV (i.e. people who have been tested for HIV), the cross-section of their experiences indicates that the criminalization of HIV may have an adverse impact on efforts to encourage HIV testing. This includes both their opinions that it may impede testing, as well as their direct experiences and

reflections on their own motivations for seeking an HIV test. The participants in this research mostly indicated that they went for HIV testing because they were generally feeling unwell or experiencing symptoms of illness (see chapter five). Only two of the life story participants indicated that they went for testing expressly to know their status.

As noted in chapter two, HIV testing and knowing one's HIV status is a critical component of any response to HIV (personal, societal, national and global) and by paradoxically creating evidence of *mens rea* in a potential crime (e.g. should have known HIV status and/or should have disclosed HIV positive status), it incentivizes individual agency in a direction that directly undermines HIV prevention efforts and potentially fuels HIV transmission. In other words it creates a perverse incentive for not "being responsible" and for not knowing ones HIV status. The notions of consent, freedom and responsibility also highlight the unjust and persecutory nature of the criminalization provisions within the draft HIV Bill. Linking back to notions of ubuntu (chapter seven), and indeed the principles and collective ownership espoused in the Constitution, a more progressive HIV legislation could be founded on a more inclusive notion of a sexual community in which HIV is present in the rights and responsibilities of the entire community. Burriss and Weait have expressed a similar sentiment by asking a moral question that links individuals and societies, as well as those who are HIV positive and those who are negative or do not know their status:

"What must all of us do in a sexual community with HIV—we come to an answer that starts with, rather than denies, the real complexity of responsibility. Not one of us can make the community safe; every one of us is compelled to try; no one's obligation is more compelling than any other's" (Burriss and Weait, 2011, p 16).

It is also interesting to note that only one of the law commissioners alluded to the burden of proof (beyond reasonable doubt) that lies with the prosecution. The Bill as drafted poses practical problems for a prosecution and may well be a gift for the defence in terms of raising uncertainty as to the direction of transmission. A similar absence of note was attention to the challenges of evidence, and what may or may not be admissible to "prove" the direction of transmission and/or to demonstrate if, when or how disclosure of HIV status may or may not have taken place.

Specifically on the provisions relating to the criminalization of HIV transmission, as noted in chapter two, even though it has been widely recognized that the cornerstone of any local, national and international efforts to effectively address HIV is to empower people living with HIV and those in the most vulnerable communities (DfID, 2008; UNAIDS,

2009), the criminalization of HIV transmission can undermine the response by perpetuating and re-enforcing stigma (UNDP, 2012; Weait, 2011; GNP+, 2010). This can be through its symbolic potential as well as through its enforcement. Worthy of note but unfortunately beyond the scope of this research are the numerous consultations, letters, facsimiles and other correspondence sent to the Malawi Law Commission, the Chair of the Special Commission, and the Office of the President and Cabinet registering concern at the more problematic provisions within the draft HIV Bill. Concern was raised about the punitive, stigmatizing and detrimental criminal provisions and mandatory testing provisions repeatedly (cf Dignitas 2010, Canadian HIV/AIDS Legal Network 2010, ChristianAid 2010, MANET+ 2010), yet this does not yet seem to have been actioned or responded to in terms of legislative revision.

As other authors have suggested, HIV affects everyone, whether (knowingly or unknowingly) HIV-positive or HIV-negative. The virus—and the law—affects each person in different ways, in different contexts and for different reasons that does not remain stagnant over time (cf Burris and Weait, 2011, p15). Criminalization provisions reinforce gender inequalities and potentially escalate some of the structural drivers that render women more vulnerable to HIV (as noted in the legal provisions relating to vertical transmission of HIV) (cf Weait, 2011; UNDP, 2012; ChristianAid, 2010) and do not recognize the challenges women face in accessing justice in Malawi (cf White and Kachika, 2009; Human Rights Watch, 2008). This echoes the examples of intersectionality illustrated in the life stories and experiences of stigma (chapters five and six) and the extracts relating to legal consciousness (chapter seven). The effect of this layering of potential stigma associated with criminalization is compounded for key population groups (such as MSM, sex workers and people who use drugs) who are vulnerable to HIV and are also may already be criminalized through other provisions of the Penal Code (chapter seven) (cf Weait, 2011; Grover, 2011).

One particularly original contribution of this research is that it has highlighted an uneasy tension between the intended and unintended invocation of stigma in the proposed the HIV Bill. The analysis of the perspectives of the law commissioners, who drafted the provisions, revealed that stigma was consciously invoked to delineate social norms and guide governance of a “responsible nation.” The analysis of the perspectives of the life story participants, whose lives would be most directly impacted if governed by those provisions, reveals the extent to which the stigma associating criminality and HIV is

falling on fertile ground through its engagement and generation of internalized stigma. The results indicate that the criminalization litmus test is illuminative and unearthed the uneasy tension of intentions and perceptions linking stigma and the law in response to HIV in Malawi.

ILLEGALITY AND SEXUAL HEALTH: IN-DEPTH COMPARISON OF CRIMINALIZING ABORTION AND HIV

Of particular interest for an analysis about stigma is the inconsistent logic within individual participant's responses, and how conscious the participants were of the contradictions between asserting principles of rights for all yet insisting on greater responsibilities for people who know their HIV status. While this analysis does not focus on an in-depth linguistic review of individual interviews, the following case study attempts to provide an example and explore the extent to which individuals can apply different standards for different people (perhaps relating to stigma that may or may not be conscious to them). I suggest that it is in such inconsistencies of logic, or the differing expectations or standards for different people, that stigma lives.

The following Insert 5 is a close reading of one of the interviews to further explore the nuances and apparent inconsistencies within one person's rational perspective on the role of the criminal law in relation to sexual and reproductive health. It begins with a detailed extract from the transcript of the interview, followed by a discussion and analysis. The interview took place at government offices in Lilongwe, Malawi, on 7 January 2011. The interview is with one of the opinion leaders, who works for the government and has a long history of supporting sexual and reproductive health and rights as both an influential policy maker as well as a health care provider.³⁶

Insert 5: Criminalizing sexual health: Interview with OL15

One of the provisions in the Bill that I am quite interested in, and I wondered your opinion on it, is around the criminalization of HIV transmission. I just wondered in your opinion do you think that should be a criminal offence?

...I think I would agree if people would actually be criminalized because where you are actually hiding information when you know the truth, you would rather inform the people – I meant the person that you are going to have intercourse with, so

³⁶ For transparency, I have included the questions I asked in *italics* in sequence with the responses from the interview.

that they are not taken unawares. They know their status and they should be able to do the interviews from their own will – they are informed – it's not like they don't know...

OK thank you. And on that one of the different situations, and not so much yet explicit in Malawi but in some other countries the transmission from mother to child is a criminal offence as well, in the US for example there have been many women who have gone to prison on that, what's your opinion on that as well?

OK I think transmission from mother to child, I would in one way agree with the situations where they would actually criminalize it, because nowadays there is just so much information. People know that they should actually go to get tested, so if they go to get tested and then we have got some ARVs that this woman is put on so that the baby should be protected, I know that it's not all the babies born to HIV positive women who will be – and those that have been put on ART – that would come out negative. Still there are those that would come out positive. So maybe it would be 50% because it may not be their fault, they took the ART thinking that the newborn baby would actually be negative but then if they end up positive. So maybe they had that wish for the baby not to be infected. But on the other hand why I am saying yes is because maybe the best would be you know your status, you are HIV positive; maybe why not just not deliver? So that also that you don't make the baby to be born HIV infected? Because I know there was one so and so in the papers, where a boy discovered at the age of 16 that he was infected at birth but then the mother knew that this boy was infected and they started the boy on ARVs but because he was young, the parent was just telling him. 'You know it's because you are having, this that.' But later on because at the age of 16 that's when he really knew that what he was taking was ARVs. The boy really wanted to go to assault the mother – he said 'I would rather she get killed because she is the one who infected me in the first place.' So maybe looking at that situation you would actually want indeed on one side as well to blame the woman – 'you knew you were positive, why should you get pregnant?' because you know from my part I would want if you are positive, maybe I am being not realistic to them, I would rather maybe would just go on family planning and even they shouldn't deliver because if you end up with the infected babies it means the population is still going to continue to be infected later on.

And just a factual question – is access to PMTCT quite widespread in Malawi, or is it difficult for a woman to – a woman who knows that she is positive and knows she will give birth – is it easy for her to access Nevirapine and those kinds of things?

I think that access to PMTCT in Malawi, we have really tried to open a lot of areas – a lot of hospitals – a lot of both in the government and private hospitals, PMTCT which of course falls under the HIV Unit, they have done a lot of training of health workers or personnel to actually dispense with the ART and they have quite intensive supervision. Of course I wouldn't be able to talk of the sites but we have attended several meetings where they are talking of the increase in sites, as opposed to around 2006 or 2007, 2005 or 4, when they were starting the programme, some time back, and they were comparing the numbers, they have really made a lot of progress. Um of course there may be some areas due to the

topography of our country where maybe there are still some women who may find it far to reach a place to get the Nevirapine and AZT, maybe, but otherwise they have really tried and people will go to the nearest health facility to access ART. And actually PMTCT has been incorporated in antenatal clinics, so facilitates even health centres that are offering maternity or reproductive health services; they would have that facility, so I would say that access has really been increased, yes...

Just a couple of final questions then about human rights if I can shift that way, I was just wondering, how relevant are human rights in your day to day work?

Thank you very much. I think human rights are very relevant... because previously we just used to talk about sexual and reproductive health but the rights component has actually been stressed because the – it is a right for somebody to have sexual and reproductive health. Actually the Maputo Plan of Action has really stressed the sexual and reproductive health and rights, because we have the issues of let's say safe abortion – where it is a right for a woman who feels that she really does not want to have that pregnancy, they should be able to have safe abortion so that they get rid of that pregnancy. But we know there have been situations where the woman would want to have that pregnancy terminated but because here in Malawi the law is not clear, of course it says abortion can only be performed to save the life of the mother or the unborn child. And they would criminalize abortion, so people, because they still want that abortion, they procure it in an unsafe way – they go to traditional healers, they go in some places where they may get it unsafe or because it is being done whilst they are hiding so they are not seen. They end up maybe having perforations, they get infected, and then they die. So that's why I feel it should be a rights issue so that if it is clear whether we want people to have that safe abortion so that people do not die unnecessarily, especially like teenagers, they would want to continue with school, they are afraid of their parents, what they had got in a pregnancy, and that's how they would want to terminate it. They are terminating it in an unsafe way and then they die, so and we know complications of abortions also contribute a lot to maternal mortality, like us in Malawi our maternal mortality is very high. And we know that if women did not have unwanted pregnancies or they did not have these unsafe abortions and they died of complications, maternal mortality would have been drastically reduced, yeah. So that's why I think that indeed the law has to be clear on what it says on safe abortion, yeah, so that women should actually have their rights respected... Because in 2007 we approached the law commission about the dangers of unsafe abortion – the complications that are contributing to maternal mortality and we were actually saying if we have to reach our MDGs to reduce maternal mortality by three quarters by 2015, we need to do something about these unsafe abortions. So with the Law Commission that time responded to us to say they needed evidence – have we done any studies that has actually has evidenced to what we were saying... we have done a lot of sessions for journalists, media, on abortion where they do values clarification. When you are starting that meeting everybody's against abortion 'you know that is immoral, that is inhuman,' all those things... in the end of that session people actually have started to understand that I think it is the right of that person – they have made a choice – it should have been respected... parliamentarians in the committee for health were also saying 'what are the women doing? Why are they not demanding to have safe

abortion so that the country should actually say out what the law says?’³⁷ Yeah which means that if you – people are actually explained to properly, they should be aware how we should address this problem. Because much as we say it is illegal, people are still procuring unsafe abortion and they will keep on dying. I think that’s what I can say about the rights issue.

Thank you, thank you and that link with abortion is an interesting one. That last issue you mentioned about why the women aren’t sort of asking or shouting out for more or better provision and things, do you think that there is a stigma around abortion as well that is having an impact?

Yes the stigma is there; of course in our days it’s maybe I would say a lot better, because previously 70s, 80s, 90s it was just that abortion was illegal. If somebody procured abortion they would just – especially if they perforated the vagina, if they perforated the uterus, they would develop sepsis and they would just die of infection they would not even disclose. They would go to the hospital and they would just say they have got malaria. And then they would just be having that fever, being treated with the anti-malarial drugs, and then people would know that maybe there is something wrong when that person is now having sepsis or maybe there is a lot of smell, or maybe they disclose when they see that they are deteriorating and many have died. I personally have actually gone through situations where we lost one of our colleagues when I was at the nursing school. She was our classmate; we went for holidays after our first year of medicine. And then she got pregnant and during that holiday, she went for an unsafe abortion, somebody just inserted a dilator – but I think it perforated the uterus. So later on she became sick, she went to a private hospital here in the Lilongwe. She was just saying malaria. So after one week at that hospital that’s when she disclosed to say ‘oh I think I’ve got it’. Then they went to theatre to try and evacuate but then it was too late. When we came back from our holidays we found her very sick in the central hospital, and she was smelling, she would talk – beneath – the breath that would come out, it was smelling. We lost that girl. After we had completed our nursing course down the line, we lost yet another colleague. Because at that time the moment they knew you had aborted, if people had reported, people would think you would be locked and put into prison. People have now changed because Malawi again started post abortion care services where the women would come, also they would come after they have aborted, if that are incomplete products they actually are – have those products removed through manufactured respiration, so it is a service that is available in the hospitals and people actually come. But previously you have aborted then it means it was a police case – you have to go report at the police, and you know it was not that free and open for people to actually come out. Because the other abortions, it’s not like you have actually induced, you have made them, the others they just come out of their own – the spontaneous ones. So still those people who still abort spontaneously need to be taken care of. So that’s why we really have to clear our law on that so that the women do not die unnecessary.

³⁷ This indicates a clear awareness of the need for greater consciousness among the public about laws and what they delineate in relation to sexual and reproductive health and rights.

And do you think that by making abortion illegal or criminal, do you think that contributes to the stigma?

I think it does, it contributes to making the abortion illegal contributes to stigma because one would not want the other person to actually know that they have procured an abortion. Because these ones are the ones who would report and then you get imprisoned. So yeah but if it was legalized, I think people have the fear they have talked about if it is legalized it means women will be aborting needlessly. But I don't think that will be the situation. Maybe people would now practice family planning more so that they don't have those unwanted pregnancies, I think so...

OK thank you, that's really interesting. One sort of final question on that, just thinking through some parallels maybe between the legal situation and abortion and the draft Bill on HIV, so you think the same argument could then be made about the aspects of criminalization within the proposed HIV Bill but that it might then perpetuate stigma and perhaps then undermine some of the gains made so far in the response to HIV rather than sort of supporting progress?

I know there were reactions of course we haven't asked the whole population –the whole communities. But indeed there were people who really reacted a lot to say if it is criminalized then people would just go in hiding, they would not be disclosed with their status, but I think it's worth finding out. Of course we have made a lot of gains on HIV in that at least people are now free to talk about their status, people are now free to come for testing, but maybe there is need to actually do a study to find out whether indeed it's going to jeopardize the gains made, yes. But like the abortion that I am talking of, because I know that in Malawi most people have actually said this is immoral, but you know arguments that have been made is that we know that there are some institutions, which offer that safe abortion. Even the religious people, who say that it is immoral, have gone to procure abortion services. So it is available for those people who are able to procure it, who can afford, who have the money, but then it means we are doing injustice to the 85% who are in the rural areas and who do not have access to the safe abortions and are the ones who are going to continue dying.

OK, thank you.

This interview is of direct relevance here because it highlights some of the key considerations emerging from the responses on the role of the criminal law in response to HIV. Even though issues relating to abortion (such as degrees of safety, personal choices and post-abortion care) and HIV (such as testing, repeat disclosure, treatment and transmission) are very different. They both concern essentially private matters, where the state intervenes in issues associated with sexual and reproductive health. They are also both issues in which attempts have been made or proposed to use the criminal law to

intervene in Malawi. They are both also areas imbued with controversy, with the potential to stir up public debate, touch on deep seated opinions and beliefs about morality, and are both arenas for nuanced debate about human rights, consent, life, choice and criminality.

The interview highlights some of the challenges of applying the criminal law to something as sensitive and personal as sexual and reproductive health and choices. The participant emphasizes the potentially damaging (and in the example she gives, fatal) impact that the stigma amplified by the criminal law can have on the health outcomes of an individual. In describing the impact of illegal abortion, OL15 highlights the extent to which access to legal support and implementation of new laws and policies (even when they are reformed in efforts to improve health outcomes) is unequal, limited to those with access to information meaning in real terms often those in urban areas and with access to financial resources. In so doing, it touches on some of the key considerations identified from the participants in relation to the potential impact of the criminal HIV provisions within the draft HIV Bill in Malawi—that the criminal law may be ill-equipped to intervene in sensitive areas such as disclosure, that criminality can fuel stigma, and that there are concerns relating to equal access to justice and legal address for example between urban and rural communities.

Beyond the specific areas illuminated by the comparison between the impact of the law regarding abortion and HIV in Malawi, the interview is particularly interesting for three key reasons. The first is that it suggests that personal experience and the evocative power of empathy can have a mitigating influence on stigma. The participant shared a story relating to a friend of hers, a colleague from college, whose experience has clearly touched her life and her perception of the issues relating to abortion and stigma. However, she did not share any similar stories or personal reflections about how HIV has touched her life in the interview even though she did discuss her technical responses and opinion to questions specifically relating to HIV. This could be for a number of reasons, such as she did not feel comfortable to share HIV-related experience in the interview (indicating a greater degree of comfort relating to abortion issues than HIV, since she had felt comfortable to share stories about a similarly sensitive topic) or perhaps because she has not had as evocative a personal connection with HIV as she had with abortion. Yet in a country with HIV prevalence like Malawi, it is highly probable that the participant also

knows and/or is related to and/or may be living with HIV.³⁸ So it is an interesting difference to note regarding the empathy shown in discussing abortion compared to the greater distance indicated when discussing HIV.

The second area relates to the different conclusions – and arguably inconsistency in logic - regarding the role of criminal law between two areas of sexual and reproductive health and rights. On the one hand, the participant emphasizes how detrimental the criminal law has been in Malawi (and on the life of her friend) when it was applied to abortion. Yet on the other hand, even when pushed in specific follow-up questions in the interview, she argues that the application of the criminal law to prosecute HIV transmission, even from a mother to child, would be a useful addition to the national response to HIV and health.

The third reason, illuminated by the contrasting depiction of the ‘mother’ in the two examples, relates to the conceptualization and prioritization of human life. In the discussion relating to abortion, the participant’s arguments point to the role of the law in protecting “the life of the mother” and also that of the “unborn child” when either was at risk. She does not discuss notions of family planning, or contraception, or perceptions of parenting in relation to abortion. She argues that by legalizing abortion, the life of the mother is being saved – in other words that a desired legal environment (in this case one that does not criminalize) would save lives. However, by comparison, when discussing issues relating to the prevention of mother-to-child transmission and arguing that it should be criminalized as part of the proposed HIV legislation, she refers to an example from the newspaper where a son tries to kill his mother in retaliation for giving him HIV. She recalls the story:

“The boy really wanted to go to assault the mother – he said ‘I would rather she get killed because she is the one who infected me in the first place.’”

She continues to elaborate the ramifications for the mother, who in this case is living with HIV, drawing implications that perhaps she should not have had children in the first place (even though prevention of mother-to-child transmission of HIV is possible, as she had previously explained) and that being HIV positive should curtail the fertility intentions and family planning desires of the mother.

“So maybe looking at that situation you would actually want indeed on one side as well to *blame the woman* – ‘you knew you were positive, why should you get

³⁸ From conversations outside the interview per se, I know that OL15 has close experience with colleagues and friends who are living with HIV in her day-to-day personal and professional life.

pregnant?’ because you know from my part I would want if you are positive, maybe I am being not realistic to them, I would rather maybe would just go on family planning and even they shouldn’t deliver because if you end up with the infected babies it means the population is still going to continue to be infected later on.” (OL15, op cit, *my emphasis*)

Despite her knowledge and description of the scale-up of PMTCT programmes around the country that she described in another section of the interview, she explicitly does not consider that relevant in this context. When considering an individual mother in real life situation, she does not entertain access to PMTCT but instead assumes HIV transmission will occur and unquestioningly proposes to limit the reproductive rights of the mother. In summary, she argues that by criminalizing HIV transmission, the life of the child is being saved – or in other words, that a desired legal environment (in this case one that criminalizes HIV transmission) would prevent deaths. The explicit recall of the framing of HIV in terms of death is also particularly interesting given the less direct or less immediate link to death; especially when compared with the example she had given in relation to an unsafe abortion (for both mother and foetus).

The case study illuminates the extent to which stigma relating to HIV can be insidious, perhaps sub-consciously (or not completely consciously) expressed through the inconsistent logic and actions of even the most informed and passionate sexual and reproductive health policy makers and providers. The contrast between the two examples (abortion and HIV) highlights differing amounts of attention and respect for the life of the mother, her family planning choices, and her rights. The contrast also illustrates a judgment regarding notions of the quality of the ‘life’ of the foetus or child—on the one hand, termination from a safe and legal abortion seen as preferred to jeopardizing the rights and health of the mother; on the other hand, the perceived severity of potential life with a chronic (yet manageable) illness as justification for jeopardizing the rights of the mother and denying conception.

The different constructions of life and death in the comparison between abortion and HIV also highlight the importance of framing in overcoming stigma and making sense of, embracing, or empathizing with HIV as part of life – neither as something to be feared, nor a death sentence—potentially for both a mother and her child.

“DISCRIMINALIZATION”:

RE-ASSESSING THE ROLE OF THE LAW IN RESPONSE TO HIV IN MALAWI

Chapters five, seven and eight have reviewed the role of law in the everyday lives of people living with HIV and explored the potential impact of the outcomes from the Special Law Commission on HIV and AIDS and the proposed HIV legislation. There was a limited consciousness of legal processes among people living with HIV, highlighted by the lack or misdirected engagement of formal legal processes to seek redress for infringement of rights. The law is limited in its ability to respond to HIV-related stigma and broader issues of justice, and the example of the potential impact of the criminal provisions, has demonstrated that the law has the potential to do more harm than good in the national HIV response. It seems that a law relating to HIV would have more symbolic than practical power in the Malawian national HIV response.

In a country like Malawi, where legal consciousness and legal redress through formal systems is not prevalent (as seen in chapter seven), the potency of the symbolic power of the criminal law to delineate the parameters of social acceptability is brought into question. Arguably, traditional authorities and other community leaders (for example through the Church and family elders) have more purchase in influencing attitudes, behaviours and moral norms than a statute in the formal legal system (cf White and Kachika, 2009). However given the potentiality of the Constitution, and the references to it evidenced in many of the participant’s perceptions of the role of the law in protecting human rights (chapter seven) despite the fact that it is seldom enforced, suggests that nevertheless the law does hold symbolic power even though that power may exist primarily only on paper. The findings suggest that further research could explore the origins of this perceived “value” for the law in response to HIV and the extent to which this may be a learned response.

Specifically in terms of criminalization, Weait (2012) has speculated that perhaps the dearth of criminal prosecutions relating to HIV transmission or exposure in Africa even where the legislative provisions exist (often explicitly added through HIV specific legislation in a similar process to the draft HIV Bill in Malawi) indicates a lower stigma and lower impetus for retribution through criminal justice systems in higher HIV prevalence settings. He suggests that there appears to be correlation between use of criminal law and wealth of nations, which:

“May be the consequence either of limited resources, or of an unwillingness on the part of people to come forward with complaints to law enforcement agencies. The latter explanation is intuitively compelling: the more normal HIV becomes (the case in higher prevalence countries) the less likely it is to be seen as something that is a harm that warrants state punishment” (Weait, 2011, p29).

However the results from the life story participants in particular, as well as from other recent studies of HIV-related stigma in Malawi (e.g. Chirwa et al, 2011) indicate that stigma is operational in the daily lives of people living with HIV in Malawi. This puts Durkheim in context. For the life story participants interviewed in this research, HIV-related stigma has surely changed over time and evolved according to cumulative experiences and mindset (chapter six). The results from this research indicate that particularly with the availability of ARVs there was a shift in HIV-related stigma that did not equate with a reduction in stigma and may have increased experiences of stigma in a different way (cf Roura et al, 2009; Maughan-Brown, 2010). Particularly from the participants who strongly invoked language of killing, and constructing HIV transmission as passing on a ‘death sentence’ in their opinions, there is a strong inclination and inherent outlet for retribution (and revenge) through the criminal justice system if those provisions were to be included in the HIV Bill that is eventually tabled in the Malawi parliament. As Weait has described elsewhere, in links to research about the criminal provisions of the law in response to HIV in Scandinavia, this may in fact be related to trends in national “trust” of law and legal institutions (e.g. Weait, 2012).

In conclusion, to return to the opening quotation from this chapter, the intentions, results and repercussions of the criminal provisions within the draft HIV Bill are at odds with each other. The research results are consistent with proclamations from recent international protests against the criminalization of HIV transmission or exposure, and its capacity to undermine human rights and public health gains in every national response to HIV. The results from this research about perceptions of the potential impact of the criminalization of HIV in the draft HIV Bill for Malawi are consistent with global arguments in this area that have claimed that potentially the “criminal law is a blunt instrument ... there exists no compelling evidence that it does good, and an increasing amount of evidence that it does harm, especially to those particularly vulnerable to infection” (Weait, 2011, p 7; WHO 2006). The combination of useful and “thorny” provisions also supports the statement of the Global Commission on HIV and the Law that explicitly condemned criminalization as “fundamentally unjust, morally harmful, and virtually impossible to

enforce with any semblance of fairness” (UNDP, 2012, p20). With the practical limitations of law enforcement noted above, and the inequalities and lack of legal consciousness in everyday life (presented in chapter seven), access to justice is very far from equal.

Even though the intentions expressed by the law commissioners behind the provisions they included in the proposed HIV Bill might have been good, some of the provisions – notably the ones criminalizing HIV transmission that were reviewed in depth in this analysis – have the inherent potential to do more harm than good as part of the national response to HIV through the combined power of the intentional and unintentional evocation of stigma.

One of the participants coined a phrase that the criminal law has the potential to “discriminalize” (sic) against people who then internalize that stigma:

“Because they will feel like you are doing something which is contrary to what the society, yeah, expects from you as a male person. So they began to *discriminalize* you in so many ways.” (LS6, my emphasis)

The participants’ perceptions of and their description of the potential impact of the proposed HIV Bill ranged from ridicule, to detrimental, to vital. Across the spectrum, many participants noted the extent to which the criminal law provides the delineation of moral norms to guide social behaviour. In so doing, the criminal law creates punishments constructed on notions of agency and responsibility particularly for people living with HIV, without taking into consideration equality of responsibility for protecting sexual health and/or what may be deemed ‘reasonable’ behaviour. The degrees of what may be considered reasonable are likely to be influenced by the availability of ARVs, the ‘infectiousness’ or viral load of someone who is living with HIV, and the extent to which someone can consent to the notional ‘harm’ of contracting HIV.

The findings of this research suggest that, contrary to the framing of the overall Bill in the Report of the Special Law Commission, prevention of HIV transmission may have been a secondary motivation for some commissioners in light of their opinions relating to the criminal provisions, with the primary motivations being retribution, punishment and/or a symbolic demarcation of what is considered appropriate and moral behaviour. While this may be in line with common perceptions of the role of criminal law, it goes against the grain of existing national policies that have sought to alleviate HIV-related stigma and disentangle HIV from moral judgment. The equivocation regarding criminalization among the life story participants may represent a see-saw, encompassing

on one side the normalization of HIV and its meaning in life and on the other a potential sense of anger or shame at acquiring HIV, and potential guilt in relation to possible onward transmission.

The prevalent framing of HIV in terms of death and killing in the context of the question of HIV criminalization was consistent between the life story participants and the law commissioners. This is a significant finding for three reasons as noted earlier. First, it supports Durkheim's notion that there is a conscious construction of what is considered criminal. Given that the dominant framing of HIV shifted—from something that can be lived with, to something that can kill—in responding to questions relating to criminalization, suggests that there is a connection between criminality, negative attitudes, and stigma. Second, relating to the law commissioners, was the extent to which the motivations behind the drafting of the HIV Bill are more complex, divergent and controversial than those outlined explicitly in the Report itself. The third main finding, from the responses of the life story participants, suggests that the inconsistencies within the life stories in the framing of HIV (similar to the law commissioners, at times as something to live with but something that can kill, in the context of criminalizing HIV transmission) point to internalized self-stigma about their HIV status.

The responses to criminalization highlight differences between the opinions of people whose lives are directly affected by the prospect of becoming 'criminal' simply because of their HIV status, the people who make the policies, and the policies themselves. The construction of agency and action in relation to HIV expressed in relation to criminalization of transmission and exposure places the responsibility disproportionately among people living with HIV. Criminalization simultaneously exaggerates agency (in defining HIV transmission as the primary responsibility of people living with HIV), misleads agency (by creating barriers and disincentives for testing and knowing one's HIV status), and denies agency (by failing to recognize equal responsibility in sexual encounters by consenting adults).

An unusual and potentially controversial outcome from this research is that perhaps it is not in everyone's best interests to reduce stigma. Stigma is a positive force with a productive impact for some people. For lawmakers, who want to delineate acceptable moral norms and social behaviour, stigma is productively used to maintain or establish social control through the law. This is most apparent through the criminal law,

but also visible through other codes and provisions that embody the normative codes of conduct to govern Malawian society.

Further research could explore any potential correlation between motivation for testing (and potential differences between testing that is voluntary, mandatory or provider initiated) and the psychosocial outcomes for the person receiving an HIV positive diagnosis explicitly in relation to the law. It could investigate the extent to which motivations for retribution, protection, and punishment are present within the individual's perception of themselves and/or towards others.

By incorporating criminal sanctions as part of the proposed HIV Bill, the lawmakers constructively attempt to engage stigma to shape social attitudes and attempt to guide normative behaviour. In so doing, they are discriminating—institutionalizing both discrimination and criminalization—against the very people that the law needs to serve if it was to be an effective component in the national HIV response. Only by creating an enabling legal environment, where human rights are protected for all (and not sacrificed for some), can the law support and not hinder public health.

CONCLUSION: An Antidote to Stigma?

Happiness reigns in my heart
That now I must go
As the bugle pronounces in the call...

And do through the years
Perseverance guided us;
Now at the crossroads
... we stand.

Each to take his own way;
Yours goes on;
Mine ends here
Where heavenly angels
Stand in salutation.

Carry on with the cross—
My expecting eye
Will be at the hold gates,
Entry to eternal life...

Last Breath, by George Kampango



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CROSSROADS: GLOBAL AND NATIONAL RELEVANCE OF THE RESEARCH

At the end point of this thesis, which in itself represents the culmination of a journey of reflection, thoughts, conversations and analysis: “now at the crossroads we stand” as in George’s poem above. What conclusions do the findings lead to, what answers have been found to the research questions, and what implications are there for possible antidotes for overcoming HIV-related stigma?

As this thesis has demonstrated, and in line with other research, the perceived impact of stigma remains a critical and evolving determinant of success in responding to HIV. Given the subject matter, and my positionality in relation to the issues being researched (see chapter three for a more detailed discussion on positionality and how this may have impacted upon the research process and steps taken to mitigate against any potential bias), it is worth noting this explicitly before turning to the final conclusions on this once more. The issues being researched – stigma, the relationship between law, HIV and attempts to criminalise certain behaviour in relation to HIV, and the potential impact on the lives of those living with HIV – are intrinsically linked to perceptions, perspectives, and opinions about potential impact. The research methodology undertaken as an action research process founded in life story interviews sought to evoke and analyse potential differences, about stories and experiences that at times were highly personal and emotional. A question might be raised, therefore, as to the risk of the influence of my personal response upon the data generated, and the analysis that flowed from them.

There are perhaps two areas where positionality could most have impacted upon the analysis. First, in the wording of the questions designed to draw out responses to and potential implications around the criminalisation of HIV (a potential area of concern for any research that includes decisions about what to ask, what not to ask, and how to ask). There was a risk that by using the word ‘criminalisation’ in the questioning, respondents could be led to take a particular position in relation to the issue. As explained in chapter three, all efforts were made to ensure that both the methodology and the subsequent analysis were not biased by this factor. Secondly, there is a question as to whether I, as researcher, gave greater weight to the views of some respondents more than others (in other words, did I trust some more than others), allowing my own affective feelings to influence the analysis. For example, in discussing the issue of criminalisation, how did I approach data from lawmakers in ways that differed from those living with HIV? Again, chapter three explores my efforts to overcome and limit any such bias. The research

process was designed to reduce my affective response to these issues as a factor in determining the nature of data gathered and the subsequent analysis, both through a rigorous methodology, but also through various feedback loops to ensure balance and above all fairness. As someone who has worked with HIV for number of years, I am also careful never to assume someone's HIV status if they have not disclosed explicitly if they are HIV positive or HIV negative. I drew on this sensitivity from my professional experience in the process of my research, and was conscious not to presume the nature of someone's HIV status if not explicitly disclosed (for example even though only one of the lawmakers was openly living with HIV, and she discussed this in the interview, I did not automatically assume that the others were not also possibly living with HIV). My reflexivity about my positionality, the rigour of the methodology of the research, as well as the transparency of the description of the research process presented in this thesis equips the reader to be mindful of the complexity of the process and its relationship with issues, analysis and results.

In this concluding chapter I use some of the key quotations from the participants to frame a review of the main results, insights and conceptual implications of this research. The chapter is structured in four sections—the first reviews revisits the research questions in light of the key findings; the second section explores the conceptual implications of the research beyond the specific context of the case study in Malawi; the third sections discusses areas identified for further research; and the fourth and final section includes some final reflections about stigma, law and human rights.

Malawi was chosen as a case study based on key considerations, including high HIV prevalence, the enthusiasm and availability of local co-inquirers to participate in the action research, the national experience in implementing *The People Living with HIV Stigma Index*, existing relationships between myself and key potential partners and participants in the research, and the timely and relevant focus of the research in light of the proposed draft HIV Bill at the time. Issues covered in the research include aspects of life and living with HIV (chapter five), identification of the primary concerns in the national HIV response (chapter four), and perceptions about the law and the “thorny” provisions within the draft HIV Bill (chapters seven and eight). The findings from the process and analytical results presented in this thesis are of vital relevance to the national response to HIV in Malawi.

The research makes a significant contribution to knowledge in five main areas: the *conceptual*, by inductively generating a theory of law and jurisprudential insight informed by the lived experiences of individuals and communities; *contextual*, and potentially political, by building a significant collection of evidence from specific community groups not often asked about their perceptions of law and access to justice; *methodological*, as an action research initiative focusing on legal consciousness to bridge legal and social science research (an approach that has to date mostly been limited to studies within North America); *applied, social and economic*, by generating analysis with the potential to inform more effectively targeted community interventions and policies to enable access to justice and 'good' governance; and *personal*, by raising consciousness within and among the collaborative action research team(s), enabling sensitization to intersection of ethnicity and HIV, and 'transformative' reflections at multiple levels.

The conceptual findings may be pertinent to inform research, policy, HIV-programming and community mobilization around the world and generalisations may be transferable beyond the specific case study of Malawi. These insights can be grouped into three main areas: the first insight, reframing stigma to take dimensions of complexity, temporality and perception into consideration. This conceptual contribution is relevant and useful for understanding HIV-related stigma specifically as well as stigma more broadly as a process attached to other or multiple aspects of identity. The analysis of the realities presented in the life stories and experiences of – and resilience to – stigma illustrate the contribution that this research makes to conceptualising stigma by combining the empirical analysis with relevant theoretical concepts from a range of disciplines including critical race and legal theory, development studies, psychology and sociology. The second insight, drawing from the action research process itself and the lessons learned from a process based in collecting and fostering links between non-hegemonic stories about HIV, stigma and the law in Malawi, can be generalised to more broadly address processes linking research and social mobilisation. The process of undertaking this research in an actor-oriented approach to document human rights issues by a diverse group of people and documenting the reflections from that experience has shown how a process can engage, subvert and potentially transform power relations or individual attitudes. At least for the action research team, and potentially others, the act of telling and listening to stories has catalyzed social action. The third insight, rooted in the diversity the perspectives of the participants in this research, is the foundation of a

notion of a dignity of jurisprudence for further theoretical and empirical development. These conceptual implications of the research beyond the context of Malawi are elaborated in more detail in section two.

SECTION 1: Summary of research findings and revisiting the research questions

The focus of the research was the extent to which it is possible to achieve human rights affirming individual and social change, through processes grounded in law in the context of lives and societies affected by HIV. As described in chapter three, the analysis was framed around three central research questions:

- 1) To what extent do experiences of stigma relating to HIV change over time and alter in relation to the multiple layers that comprise individual identities?
- 2) Is law and legal consciousness useful for seeking redress for HIV-related discrimination in the daily lives of people living with and closely affected by HIV?
- 3) To what extent does the normative or symbolic potential of the law frame social attitudes towards HIV and engage stigma relating to HIV?

In summary, regarding the first research question, the results showed that while stigma remains a challenge in Malawi, HIV is part of everyday life and only one aspect of nuanced and complex identities of the people whose lives it directly affects. Informed by the exploration of theories of power, structure, agency and identity (chapter two), the results depict realities of everyday life and the variation between contexts and over time. This theoretical basis enabled the analysis of HIV, law and stigma in Malawi because it facilitated a framework that took complex individual identities into account, while also allowing for recognition of a dynamic relationship with other people and within society. The framework allowed the metaphoric kaleidoscopic lens of this research to recognise and explore why an individual can simultaneously—and not contradictorily—experience stigma, exclusion, resilience, power, and agency. The results presented in this thesis confirm that stigma is a complex phenomenon expressed both subtly and overtly, and is subjectively experienced in multiple ways that are partially dependent upon the nature of the stigmatizing condition as well as the social circumstances of the individual (chapter six). The research clearly showed that stigma did indeed change over time. Moreover, it also reflected and was shaped by the multiple layers that comprise individual identities. This suggests those working on issues of stigma need to adopt a more complex understanding of how stigma functions.

In regard to the second research question, law was conscious among people living with HIV yet seldom invoked to redress experiences of HIV-related discrimination (chapter seven). Of the few accounts when people living with or closely affected by HIV did described experiences of engaging with law in relation to experiences of HIV-discrimination, traditional authorities were the primary source of support, indicating the importance of recognising legal pluralism in the daily lives of people living with HIV and at a policy level within the national response to HIV. Those who had tried to engage the police had limited success—because of challenges of enforcement (bias and attitudes among the police), or perceived repercussions (such as fear of losing a job), or because the complaint was unsuitable for a legal response (such as gossip). The findings suggest that the practical relevance of law was not apparent in the everyday lives of most of the people living closely with HIV in this research, and significant challenges to law enforcement and access to justice remain; yet the symbolic potential of law was clearly articulated.

In regard to the third research question, my research explored the extent to which a law relating to HIV might have a normative power appeared questionable in a country where there is a limited consciousness of the law in the everyday lives of people living with HIV, a lack of a widespread understanding of the traditional legal system, a constrained access to formal legal redress for most people, and where the Constitution is seldom enforced. The research focused on an analysis of the proposed HIV and AIDS (Prevention and Management) Bill in Malawi, including the perspectives and opinions of the lawmakers involved in drafting the report and proposed legislation. I undertook a sociological critique of the proposed application of criminal law in the context of HIV from the perspective of one of Emile Durkheim's hypotheses about penal law—the construction of crime as a violation, and punishment, as an expression of collective sentiments (see chapter two). Durkheim's framework enunciates the combination of law and social attitudes, and thereby links notions of criminality with processes of stigmatisation. The results revealed a tension between the intention of the law commissioners who had drafted the law and the potential impact of that law in the national response to HIV particularly in relation to the potential application of the criminal law to HIV (sections 43 – 5 of the draft Bill).

The application of the penal law to HIV transmission and exposure—a relatively recent development around the world, and brand new in Malawi through the drafting of the proposed HIV Bill in 2008—can be seen as indicative of the problematic role of the law

in social control, stigmatization and the policing of 'deviance' (Weait, 2007; Garland, 1996). In Malawi, a context where almost every family is affected by HIV and almost 1 in 6 people living with the virus (NSO, 2010), universal access to first line HIV treatment is assured in the national policy (MG, 2012), policy makers are leading the world in the progressive rollout of programmes to prevent HIV transmission from mothers to their children (Schouten et al, 2011), and HIV is resultingly perceived by many participants in this research as more of a chronic disease than the 'death sentence' it may have once seemed, reasonable doubt exists as to whether HIV 'offends the common consciousness' at all. This research examined the extent to criminal provisions are not only potentially overstepping their utility in the context of HIV but also doing more harm than good by fuelling stigma in the national response to HIV. The results suggest that the law is imbued with symbolic power—that can contradictorily both protect and impede rights—a power that in itself may be potent with stigma as a product of collective sentiments.

Key findings and specific implications of the research results

The research has illuminated five key findings from the results in relation to the research questions that are described in further detail in the following section.

LIFE:

"HIV is not the whole story. It is part of life" (LS7)

Key finding: The results showed that while stigma remains a challenge in Malawi, HIV is part of everyday life and is only one aspect of nuanced and complex identities of the people whose lives it directly affects.

Life is diverse, and HIV is present within the lives of diverse individuals across different corners of all societies. In this regard, Malawi is no exception and the people who shared their life stories in their research are archetypal of the humanity that 'hosts' the virus. The results from this research in addressing the first research question showed the stigma relating to HIV is a concern in Malawi, and that stigma is a complex phenomenon expressed both subtly and overtly, and is subjectively experienced in multiple ways that are partially dependent upon the nature of the stigmatizing condition as well as the social circumstances of the individual.

HIV is part of life but it is not the whole picture. The implications from the findings from the analysis of the life stories suggest that contextualizing HIV as only one aspect of someone's identity, which it is, and not amplifying HIV to overshadow other aspects of

identity, might itself militate against the impact of stigma. These findings were analysed in the context of the literature reviewed in chapter two, relating to the relationship between self and society, and the realisation of the human right to health at the individual and structural level. The analytical approach was akin to a kaleidoscopic image that both illuminated broader social patterns while also dynamically bringing individual shapes in and out of focus. The findings, founded in an analysis based on a recognition of intersectionality, suggest that efforts to address HIV could be more effective in reducing stigma if they focused on a holistic sense of self, acknowledging a situated “self” within the context of their life and intersecting aspects of their fluid identity. The results imply that initiatives to address HIV-related stigma that focus almost exclusively on a person’s HIV *status* may have been misdirected— the life stories illuminate much more complicated, passionate and nuanced lives. Not all the life story participants interviewed in this research had experienced stigma, and a close reading of their responses provided insight into some aspects that might mitigate against stigma or enhance resilience to avoiding feeling stigmatised.

The diversity between and nuances within the personal responses in this research about the meaning of HIV illustrates the intensely personal, contextual, transient and evolving relationship that individuals have with a virus that is part of their life. Just as life morphs in different directions and through moments of exultation and despair, sickness and well being, along with the shades of grey and the more mediocre emotions in between, so too does a person’s relationship with a virus such as HIV in their life. The life stories illuminated change over time and how HIV can become personified to reflect meaning in someone’s life—to embody a moment of transformation, an opportunity to know oneself, and/or a turning point to decide on life’s future directions.

There are significant implications of these results. The three main findings from this analysis could be summed up as comprising both simple and complex messages. The first, the simple one and also the starting point, is that HIV is part of life and is present in diverse and dynamic lives around the world. One hypothesis emerging from these results is that interventions to overcome HIV-related stigma may be more effective if founded on a holistic notion of people and societies, not only channelled into a narrow specific focus solely on HIV. The results suggest that encompass whole people in terms of livelihoods, belief systems and worldviews may be more successful in transforming stigmatising attitudes to HIV.

The second and third implications are less simple, or less obvious, and centre on notions of agency. On the one hand there is the agency of the individual to shape the direction of their life as well as perceive and re-construct over time the meaning of HIV in their life. The results point to notions of agency at two levels – both in terms of the trigger of an HIV positive diagnosis to take stock of life and make conscious decisions to guide its future direction, as well as in terms of a sense of responsibility (sometimes connoted as guilt) for becoming HIV positive. For many of the participants in this research, their HIV positive diagnosis marked a distinct transformative turning point in their life.

The process and product of this research, primarily the life stories and the reflections from the action research team, have spotlighted important insights and thick descriptions relating to HIV, life and stigma. Transposing Van Marle's analysis is to recognize that HIV is a transformative experience in someone's life, with elements of both the monumental and the memorial. For almost all of the life story participants, HIV was a metaphor in their lives. This was not, as Sontag theorized, in the sense the people ascribe metaphors to HIV in order to understand or explain the virus in their lives. It was rather as a metaphor in itself, to symbolize a turning point, a moment of reflection, and/or a defining catalyst for change (big or small, positive or negative) in their lives. The monumental could be seen as a demarcation of an opportunity to change (often identified in terms of changing habits that were moralized, and were perceived to have been related to the acquisition of HIV such as drinking alcohol or having multiple sexual partners). It could also trigger moments of despair, shame, self-isolation and ideations of suicide. The memorial could be seen as a commemoration of a previous life or lifestyle before learning of their HIV positive status, recognizing that the diagnosis marks a turning point, for better, worse, or both over time, in someone's life story.

The third notion, on the other hand, is that there may be a relationship between knowledge and readiness to know about an HIV status, and the acceptance of an HIV positive result and potentially the internationalisation of stigma relating to HIV. For the two individuals who had voluntarily sought an HIV test (i.e. not the majority who had been tested because they were unwell) it seemed that this act of agency in seeking to know their HIV status may have had a mitigating influence on their reaction to receiving an HIV positive diagnosis. That is, both participants seemed more readily accepting of their HIV positive diagnosis than other participants. While avoiding to broad a generalisation from these two specific experiences, one hypothesis emerging for further inquiry could explore

if the initial acceptance of an HIV diagnosis (which could be viewed as a proxy measure of the internalization of stigma) may be enhanced with a greater readiness and willingness to know. If further research were to prove this hypothesis accurate, there would be significant implications for national policies to promote HIV testing for example, that from an efficacy perspective as well as from one founded in principles of human rights, should rather focus on cultivating a demand for voluntary testing rather than mandating testing through legislation (as proposed in the draft HIV legislation) or even provider initiated counselling and testing.

LAW:

“We make laws but we don’t follow them...the laws are there...but the problem is we have not accepted to say HIV is among us” (LS2)

In regard to the second research question, law was conscious among people living with HIV yet seldom invoked to redress experiences of HIV-related discrimination. The findings suggest that the practical relevance of law was not apparent in the everyday lives of most of the people living closely with HIV in this research, and significant challenges to law enforcement and access to justice remain; yet as explained below in relation to the third research question, the symbolic potential of law was clearly articulated. This section summarizes the main findings from the research in relation to the second research question that explored the usefulness of law and legal consciousness in the daily lives of people living with and closely affected by HIV and the third research question that explored the extent to which the normative or symbolic potential of the law frame social attitudes towards HIV and engage stigma relating to HIV.

Law in Malawi is at a watershed moment in terms of its role in the national response to HIV. On one hand there is the Constitution, founded on abstract precepts such as principles of equality, citizenship and non-discrimination; and on the other there are “thorny” punitive approach of the proposed HIV Bill that risk embedding principles of deterrence, punishment and retribution based on HIV status.³⁹ Both aspects of law are imbued with symbolic power, which may be enhanced if implemented, and both have a role in shaping moral attitudes and perceptions of Malawian people. Both therefore have a potentially powerful influence – in opposite directions – on the lives and attitudes (of

³⁹ At the the time of revising this thesis in August 2013, it appears that in the review and redrafting of the proposed HIV legislation, all aspects of applying the criminal law to HIV transmission, exposure or non-disclosure have been removed as per the latest draft of the legislation dated 25 July 2013.

and towards) people living with HIV.

Key finding: Legal consciousness was not apparent in the everyday lives of most of the people living closely with HIV in this research, and significant challenges to law enforcement and access to justice remain. Moreover, the proposed HIV Bill in Malawi includes problematic provisions that potentially could fuel stigma.

“As a woman that lives in a village, I do not have a chance to know what the law says” (LS14)

The analysis of legal consciousness of people living with and affected by HIV in Malawi highlighted a significant disconnect between the aspirations for the role of the law in Malawi, expressed through the life stories as well as by law commissioners and opinion leaders, and the real traction of access to justice and redressing for violations through the formal legal system.

The life stories indicate that the traditional authorities are a much more influential source of justice in the everyday lives of people living with and closely affected by HIV in Malawi. For the participants the formal legal system was either invisible or misunderstood in terms of the specifics of its potential role in relation to HIV. Yet paradoxically, almost all participants perceived the law to have an important role in the national response to HIV.

Key finding: The proposed HIV and AIDS (Prevention and Management) Bill in Malawi manifests a tension between intention and impact—the desire to enact a law to protect human rights and strengthen the national response to HIV, while potentially taking away those rights from certain groups and fuelling HIV-related stigma.

“The intentions are good, but I think the ... results would be very bad” (OL14)

The findings from my research suggest that after all, as demonstrated from the internal tensions within the provisions from the focused analysis of the draft HIV Bill, the extent to which alleviating stigma is in fact seen as in the best interests of public health and governance of society remains contested. The draft HIV Bill—the legislative embodiment of the government’s commitment to addressing HIV—protects human rights on the one hand (and appears to outlaw stigma and discrimination), while taking them away for some people with the other (by differentially exaggerating responsibility and limiting rights for certain groups, restricting rights, and fuelling stigma for example the criminalization and mandatory testing provisions).

As analysed in depth in chapter eight, the results highlight five main points: first, that even though the intentions behind the law were well meaning, the motivations to include criminal provisions were not responding to the primary routes of transmission,

and the language used to describe their individual motivations behind the law indicated degrees of desire for retribution and moralization. Second, the construction of agency and action in relation to HIV expressed in relation to criminalization of transmission and exposure placed the responsibility solely among people living with HIV (for example by not acknowledging the shared responsibility for sexual health between two adults in a consenting sexual act). Third, the responses present an element of competing interests in recognizing where the rights of two individuals might be in tension (such as the rights of a woman living with HIV not to take treatment to prevent vertical transmission versus the rights of the infant to be born without HIV). Fourth, HIV was often framed in terms of death and illness in the context of criminalisation but not when referred to in relation to human rights. And fifth, the lawmakers themselves straddled a tension between aspirations of transformation through the law and the tempering challenges of law enforcement.

Key finding: The potential impact of the proposed HIV and AIDS (Prevention and Management) Bill at the personal level could undermine the national response to HIV in Malawi by creating barriers for testing, internalizing stigma, and limiting opportunities for disclosure for fear of reprisal through the law.

In relation to the third research question and exploring the role of law in governing attitudes and social norms, the results showed that the potential application of the criminal law to HIV transmission, exposure and non-disclosure (sections 43 – 5 of the draft Bill) has the potential to limit the equality and health of many if applied in the context of HIV. The analysis of the results drew on a foundation in Durkheim's notion of the sociology of criminality, that views 'crime' as a socially constructed demarcation of acceptable behaviour rather than being an objective or definitive construct (see chapter eight). The findings of this research provides a substantive empirical case study from Malawi that resonates with the policy guidance from UNAIDS and the Global Commission on HIV and the Law, that caution about the interplay between stigma and criminalization in the context of HIV transmission, exposure and non-disclosure and the marginalisation of key affected populations (cf UNAIDS, 2011; UNDP, 2012). Combining the life story research with the perspectives from the law commissioners, with an in-depth review of the proposed HIV Bill itself in Malawi, adds empirical analysis and results that substantiate global concerns, such as that expressed by WHO in 2006, which viewed criminal law as "a blunt instrument that can neither adequately capture the complexity of the contexts in

which HIV transmission occurs nor deal effectively with matters such as the relative probability of transmission” (WHO 2006, p 3). This research adds to the evidence base for national and international organisations that have expressed concern about the recourse to punitive laws in response to HIV.

In this research, the majority of people, including the life story participants, held a view that while HIV could be considered a chronic illness and people living with HIV should be entitled to the same rights and subject to the same responsibilities as others, HIV transmission should also be considered a criminal offence because it was akin to passing on a “death sentence”. Several participants evoked images of death and dying in response to questions relating to criminality, contrasting the framing of HIV in answering questions in other parts of the interviews.

The prevalent framing of HIV in terms of death and killing in the context of the question of HIV criminalization was consistent between the life story participants and the law commissioners. This is a significant finding for three reasons. The first, it supports Durkheim’s notion that there is a conscious construction of what is considered criminal. Given that the dominant framing of HIV shifted—from something that can be lived with, to something that can kill—in responding to questions relating to criminalization, suggests that there is a connection between criminality, negative attitudes, and stigma.

The second, relating to the law commissioners, was that the extent to which the responses to the “thorny” issues of criminalization revealed disparate motivations behind the drafting of the HIV Bill that contradict those officially stated in the Report. This suggests that the law commissioners are human, and that the motivations behind the drafting of the HIV Bill are more complex, divergent and controversial than those outlined explicitly in the Report itself.

The third main finding, from the responses of the life story participants, suggests that the inconsistencies within the life stories in the framing of HIV (similar to the law commissioners, at times as something to live with but something that can kill, in the context of criminalizing HIV transmission) point to internalized self-stigma about their HIV status. It also suggests that perhaps these inconsistencies were revealed because the connection between the criminal law (closely associated with the formal legal system) and HIV had not previously been contemplated by almost all of the life story participants and thus perhaps triggered a more spontaneous reaction.

The differences suggest that notions of law evoke contrasting sentiments (for

example when comparing human rights law and criminal law) in the context of HIV. Two divergent hypotheses emerge from this finding that would warrant further exploration—the first hypothesis could be that the questions on criminality touched a more visceral or unconditioned response from participants, perhaps because it was a question most participants had not been asked before or a connection that is only just coming into the Malawian collective consciousness triggered by the Report of the Malawi Law Commission and debate surrounding the proposed HIV legislation... for those who had heard of it. Alternatively the second hypothesis could be that it was in fact the questioning in relation to crime that evoked sentiments relating to punishment, retribution and death (rather than, as in the first hypothesis, relate to HIV per se), which would confirm Durkheim's sociology of criminal law. The results therefore illustrate a connection between stigma and criminal law, however it is not clear if the trigger for the altered framing of HIV in terms of death and gravity of language is in relation to HIV (i.e. unearthing more instinctive responses) or rather in relation to crime.

The perception that the criminalization of HIV transmission might create a barrier for people seeking HIV testing is apparent in the responses in this research. Even though this research focuses on the experiences of people living with HIV (i.e. people who have tested positive for HIV), their perspectives indicate that the criminalization of HIV may have an adverse impact on efforts to encourage HIV testing. These findings are founded on both their opinions that it may impede testing, as well as their direct experiences and reflections on their own motivations for seeking an HIV test. The participants in this research mostly indicated that they went for HIV testing because they were generally feeling unwell or experiencing symptoms of illness. This would be an interesting area for more in-depth research.

The results spotlight a paradoxical confusion between intent and impact of the law in responding to HIV. Criminalization can simultaneously exaggerate agency (in defining HIV transmission as the primary responsibility of people living with HIV), mislead agency (by creating barriers and disincentives for testing and knowing one's HIV status), and deny agency (by failing to recognize equal responsibility in sexual encounters by consenting adults). The results, building on a Durkheimian framework, indicate that criminalization of HIV can serve as a litmus test for analysing personal and social constructions of crime, criminality, responsibility and the productive evocation of stigma to delineate social norms.

This research unearthed a tension between intentions, perceptions and outcomes, linking stigma and the proposed application of criminal law in response to HIV in Malawi.

Key finding: Law does have a symbolic potential in defining aspirations for social and economic changes that may address the underlying determinants of ill health and protect human rights.

Despite the potential challenges of enforcement and implementation that were identified, and despite the absence of current formal legal interventions in each of the experiences of the life story participants, a value was almost unanimously placed on the symbolic and guiding potential power of law in the national HIV response. The results highlighted in relation to research question three correspond with the complexity and temporality of identity, and stigma, highlighted in the results presented in response to the first research question earlier in this chapter.

The results from this research support the growing international impetus to promote human rights-based legal frameworks to promote public health. In Malawi, the inherent tension within the law between notions of human rights and the problematic provisions of the draft HIV Bill need to be resolved if the proposed legislation is to enhance rather than undermine the national response to HIV and enable a legal environment that can protect all – not punish some. This was most apparent in relation to communities vulnerable to HIV and already marginalized in society, exacerbated by notions of illegality and provisions within the Penal Code, such as sex workers (section 192) and men who have sex with men (section 153). These laws also highlight the potentiality of law to be attached to different intersecting aspects of any one individual's identity (for example a male sex worker, who is living with HIV and selling sex to other men, could be criminalized based on three aspects of his identity). In both cases, the law is on the one hand giving rights while on the other is taking them away.

The results indicate that people living with and closely affected by HIV in Malawi are acutely aware of the injustices inflicted upon them, resonating with the writing of Odinkalu (1999), yet mechanisms for protecting human rights through the formal legal system were of little meaning to them nor effective sources of practical support or redress. The challenges of law and the absence of socially transformative jurisprudence, combined with the challenges of enforcement and the lack of legal consciousness among the citizens of Malawi interviewed for this research, suggest that something different may be needed to realize the principles of rights in reality. The paucity of social rights jurisprudence

compared with civil and political rights cases in Malawi means that questions remain about the justiciability of social rights and the actual potential of law to legislate for individual and social transformation in the context of health. Not one of the life story participants had effectively achieved resolution through the formal legal system to redress even tangible episodes of injustice or discrimination they had experienced, for a variety of reasons, bringing in to question the purchase of law in everyday life in the context of HIV in Malawi. The results imply that more channels to effectively support people living with HIV to seek redress for injustice through the formal legal system, in addition to other customary or traditional means may be necessary to realise the rights codified in the Constitution into reality. The results also suggest that other efforts to support people living with HIV outside the law, such as visibility and connection with other people living with HIV, and leadership and outspokenness about HIV among the “elite” of Malawi, might be more effective than the law per se in shaping positive social norms and perceptions of HIV and diminishing incidents of injustice.

Perhaps therefore the secret for the future realization of transformation in Malawi, as Cardoso suggests in the Report of the Global Commission on HIV and the Law, rests in the ability of the law—encompassing both its potential as well as its limitations—to inspire and entrench the spirit of dignity and equality among all individuals and institutions.

SECTION 2: Conceptual implications of the research findings beyond a one country case study

The research findings contain broader implications for understanding the relationship between law and stigma, law and everyday life, and the extent to which the law can support (and not harm) national responses to HIV. The results highlight a critical need for researchers and policymakers alike to think more broadly about legality and access to justice alongside efforts for law reform and regulation through the courts. Law appears limited in its ability to respond adequately to the multiple layers of identity and complex realities of everyday life. The interaction between notions of agency and consent in law illustrate how despite best intentions, legal proceedings can in fact undermine public health outcomes and repress human rights—in other words impede rather than enable national responses to HIV.

Three main conceptual insights have emerged from the examination of the research questions and could be transferable for other settings outside Malawi, and

beyond the specific thematic considerations relating to HIV, law and human rights. The insights include firstly, re-framing stigma; second, understanding links between research and social mobilisation; and third, providing an empirical springboard towards a philosophical articulations of a jurisprudence of dignity and generosity.

Insight 1: Re-framing Stigma

The findings in this research provide implications for broader conceptualisations and theoretical understandings of stigma. As reviewed in chapter two, other studies have identified that HIV-related stigma is layered and complex and can feed off other attitudes or prejudices relating, for example, to homophobia, racism or sexism (Mahajan et al, 2008; Nyblade, 2006). Stigma is understood as a process of devaluation and can have many outcomes (Parker and Aggleton, 2003; Goffman, 1963). HIV-related stigma can adversely affect how and when someone accesses services (including testing, support and treatment), how people interact with each other (including friendships, intimate partnerships and professional relationships), and how someone perceives themselves and their self-esteem (Maman et al, 2009; Genberg et al, 2009; Simbayi et al, 2007). At the structural level, for example through laws and policies, stigma can reinforce power inequalities and processes of social marginalization (Mahajan et al, 2008; Parker and Aggleton, 2003).

As I understand stigma, it can be the culmination of both conscious experience as well as internalized perceptions of judgments that may remain hidden to the individual experiencing the stigma at that point in time. Stigma is a balancing point that changes over time that can enable or paralyze human potential. Yet conceptually in the literature, stigma remains predominantly a mono-dimensional concept (for participants describing their notions of stigma for this research as well as in the literature) – even though the life stories demonstrate that in reality, it is much more nuanced.

This thesis makes an important contribution to dimensions of conceptualizing stigma in two areas—one of stasis, confirming the timeless and borderless pertinence of the original meaning of the term “stigma”; and one of expansion, whereby the life stories indicate that two additional dimensions of stigma—the temporal and the conceptual—require due attention to meaningfully monitor and understand stigma, to improve research and inform policy and programme interventions relating to HIV. While other research has tended to focus solely on a snapshot in time (either for one individual and/or

for a community) without consideration of factors that might compound or potentially abate stigma over time, the life stories illustrate various examples of how the intensity or degree of stigma felt by people living with HIV, and the place that stigma attaches (as well as those where it is perceived to be attached), and its origins, change over time.

First, the stasis of stigma. The origins of the word “stigma” in Ancient Greek, as a mark or blemish, resonated with the descriptions of the physicality of stigma and the visibility of HIV (such as through the redistribution of fat in the body or the texture of the eyes described by some participants). This suggests a universality and timeless core meaning of stigma—a consistency of meaning across a multitude of eras and contexts, a common usage that remains pertinent to understanding stigma in Malawi today as it did in Ancient Greece. It also suggests that while psycho-social interventions to overcome stigma that focus on self-esteem, confidence and self-perception may be effective, other interventions that focus on visibility, appearance, nutrition and reducing side-effects (to date less commonly framed in terms of stigma reduction interventions) may also counter the impact of and perceived vulnerability to HIV-related stigma. Awareness of perceptions of stigma, and the extent to which stigma—like beauty—is in the eye of the beholder, is also a significant extension this research contributes to the original concept of stigma.

Second, the critical conceptual finding from this research concerns the importance of recognizing three dimensions of stigma that are missing from other theoretical frameworks used to define stigma: the temporal dimension, the attribution of agency and direction of action, and the contextual identification of where stigma exists. Missing from the breakdown of the three main levels of the impact of stigma (personal, service delivery and structural) outlined in the current body of literature (see chapter three) are two key concerns: first, temporal, that is a recognition of the extent to which stigma can intersect across all three areas in different ways with a different impact at different moments in time. And the second, conceptual, that different people understand stigma differently. While this may not be surprising, in fact little other research has looked at conceptual understandings of stigma among people whose lives it directly affects. The contextual analysis highlights important differences between participants in identifying the main sites where stigma is experienced, as well as who were the main perpetrators of stigma.

The duality between agency in and consciousness of stigma highlights significant differences in the conceptualization of stigma, the direction of action, and the solutions identified, and has implications for determining the most effective approach to alleviating

and overcoming HIV-related stigma in Malawi. Differences were present in the identification therefore of the actors and solutions that participants suggested would be most effective for overcoming stigma. Intuitively, the three key areas – the understanding, the action and the solution – should be aligned to ensure that both the action as well as perception of stigma is addressed effectively if stigma is to be alleviated. The differences highlighted between the three key areas in my research suggest that attention to perceptions of stigma is an important dimensions for consideration in research, policy and programme implementation.

Engaging with this duality, and accurately pitching interventions to match the dominant notions and nature of stigma, appears to be critical to engage both the actions and actors that perpetuate stigma. While further research is needed to test the detail of this hypothesis in more depth, the results of this research suggest that the extent to which the impact of stigma, as well as efforts to mitigate or alleviate stigma are dependent on a conscious (both individual and collective) understanding of what stigma actually is, and how and where it occurs.

Insight 2: “It gave others confidence through me” (George)

The process (of participation, of consultation, of exploring legality and of understanding documenting human rights realities) in my research shows a new approach not previously undertaken in Malawi or in many places outside North America, and is as important as a method per se in addition to the research findings. By working in an inclusive and non-stigmatizing way and eliciting stories and perceptions of law in everyday life, the action research was a performative and actor-oriented combination of research and action. My research has contributed methodological insights from its foundation in interdisciplinary social science approaches drawing on participatory action research and legal consciousness. The potential contributions of each member of the action team was considered, and each was selected (or not) after factoring in the wide variety of subjective skills that were needed together to realize novel ambitions of the project. The combination of insights and experiences from each member of the action research team, spanning diverse perspectives rooted in very different identities, genders, cultures, religions, sexual orientations and professional perspectives, facilitated empathy among the team members and a thicker understanding of the framework for research and analysis of the critical issues. By reflecting on the research process itself, I explored its

potential as a transformative model for generating personal and social change in tackling HIV-related stigma—perhaps this process provided an opportunity to trigger change so profound that it takes us outside our conditioned beliefs and view of the world (Archer, 1988).

Perhaps the draft HIV Bill, considering all its contradictions and spanning its imitations as well as its potential, could perhaps serve as the lynchpin for galvanizing community mobilization, resistance and generating the necessary individual and social transformation to overcome some of the legal structural determinants of ill-health and human rights violations (Ewick and Silbey, 1995). As reviewed in chapter eight, reactions to the draft HIV Bill are bringing different civil society groups, religious groups, networks and community support groups together with international NGOs, UNAIDS and others to speak out and advocate against the passing of the proposed HIV Bill in its current form. This is likely to lead to a groundswell of legal consciousness amongst people living with HIV. The “thorny” provisions in the draft HIV Bill in this way may well provide a rallying point to unite civic action.⁴⁰

The research results and reflections from the action research process suggest that law – including the Constitution and other legislation – may just be the beginning. It is what action, reaction, or subversion law can inspire, what spaces it can open that enable the civic participation of marginalized people and spotlight and support struggles for equality, and what debates it can create for individuals to scrutinize the application of democracy that can give meaning to the aspirational words of equality, dignity and freedom in real life.

Insight 3: Towards a Jurisprudence of Dignity and Generosity⁴¹

Responding to other notions of human rights and their jurisprudential potential, the analysis presented in this thesis and indeed in the foundation of a jurisprudence of dignity and generosity is on the dynamic of the relationship between self and society (Ife, 2010; Englund, 2004) as well as on the potential universality of rights to have meaning in

⁴⁰ This appears to have been in the case in the years immediately following the period of action research in 2010-11, lead by MANET+ and the national UNDP office, and has lead to the removal of all mention of the criminalization provisions in the latest draft of the proposed HIV Bill dated 25 July 2013. The brief summary of these research findings, an article published based on the findings presented in chapter eight of this thesis, and key contributions from members of the action research team have all contributed to the process.

⁴¹ With thanks to Justice Edwin Cameron, of the Constitutional Court of the Republic of South Africa, for his suggestions on the ideas presented in this section.

diverse lives if they evolve from dialogue with communities and individuals (Bujo, 1998; Mamdani, 2000). The results of this research contribute towards forming the conceptual basis of a jurisprudence that thinks about the individual legal subject as connected with others—not excluding generality, but still honouring the specificity of individual lives and the workings of social interrelationships. These case study findings from Malawi contributed a foundation for further philosophical and socio-legal thinking about a jurisprudence of dignity, generosity, and reciprocal engagement between individuals and societies, and enable a return to Murungi’s notion of the African tradition of law as *securing human beings in their being* (Murungi, 2006, cited in Cornell and Muvanga, 2012, op cit).

Extrapolating from this case study about HIV, stigma and the law in Malawi, there seem to be four pillars that could form a foundation for a jurisprudence based on dignity and generosity—a jurisprudence that is not only powerful in its justiciability but also in the moral norms it could establish for society. A jurisprudence based on *dignity*, could encapsulate the multiple intersecting layers of self-identity and encourage acceptance. A jurisprudence based on *generosity*, could promote respectful, reciprocal rights affirming relationships between people, facilitating acceptance among and empowerment of diverse and ‘dignified’ individuals. The third and fourth pillars then would denote the responsiveness of jurisprudence to evolve to respond to changing perceptions of justice over time. The third pillar incorporates a mechanism by which law critically reflects on itself, engaging and not denying the agency of lawmakers and law enforcers. The fourth pillar finally encompasses the capacity of law to trigger, catalyse, create a forum for and/or respond to action—action that is subversive, dynamic, resilient and transformative. In other words, a kaleidoscopic jurisprudence that could achieve the potentiality of law in realizing human rights through recognizing, engaging and transforming power dynamics within and between individuals in society.

SECTION 3: Areas for further research and inquiry

Further research could build on the implications from the results outlined in this thesis in conceptual and pragmatic ways. At the conceptual level, further research could investigate the elision of legal theories that could further develop the pillars and refine the foundation for a jurisprudence of generosity and dignity. In addition to concepts such as ubuntu (Cornell and Van Marle, 2012), relationship rights (Englund, 2012), and the

international declarations of human rights (UNHR, 1948; OAU, 1981), to further exploration of the extent to which it may be philosophically conceivable to construct a legal foundation based on non-stigmatizing and inclusive values (reconciliation and restoration) rather than on retribution and deterrence.

At the national level, the findings from this research would merit further examination in broader contexts. For example, research could explore the extent to which the limited legal consciousness of people living and closely affected by HIV is unique to Malawi or is it also apparent in other countries in Africa and around the world, and therefore the impact that has on law and legal endeavours in relation to public health. Research could also explore the extent to which the findings related to the normalization of HIV-related stigma from this research are similar or different in a context where HIV is concentrated among certain groups within the population—perhaps the normalization of HIV in these contexts would in fact miss the target by not appropriately meeting the specific needs of the specific communities most affected by HIV. Additional research could also seek to document and analyze perceptions of trust in law, especially in settings with plural legal traditions, to better understand the symbolic potential of law even when it is seldom enforced in reality. Further national research in the region and internationally could analyse – and continue to question in different contexts – both the justiciability of economic and social rights and symbolic potential of their different representation in laws in plural legal societies.

At the programme level, operations and evaluative research could investigate the extent to which efforts addressing other structural determinants of health (such as income, gender, access to markets, and education) could also be effective triggers for HIV-related stigma reduction. Further research might explore this potential by monitoring the potential stigma reduction effects of interventions that do not directly address HIV at all, but do so implicitly by addressing other structural determinants of vulnerability to HIV such as microfinance schemes, access to safe water, nutritional support or transformative gender initiatives. In so doing, such research would be operationalising an inquiry into the key finding that HIV is only one part of life—and the hypothesis that stigma-reduction intervention may be more effective by not exclusively focusing on HIV. Likewise, one of the interesting findings from the review of the proposed solutions for overcoming stigma indicated significant differences between groups (policy makers and communities most affected). It is much easier, cheaper, and more publicly visible to deliver an education

campaign in schools, through the media (television, radio, print and online) and/or through public service announcements in public spaces (through leaflets, billboards and clinic waiting rooms). It is significantly more costly and more challenging to facilitate transformative educational processes that can empower people and stimulate positive change within the individual in the context of their environment. Further research could explore the reasons for the variations between the groups and come to recommended modalities of interventions that can provide value for money, while ensuring self-affirming processes and meaningful outcomes in alleviating stigma.

At the community level, further research could attempt to identify the determinants of whether an HIV-positive diagnosis is a trigger for positive or negative transformation. This would incorporate investigation of the correlation between motivation for testing (and potential differences between testing that is voluntary, mandatory or provider initiated) and the psycho-social outcomes for the person receiving an HIV positive diagnosis – both at the individual level as well as how they disclose their status to others and frame the meaning of HIV in their life. Van Marle’s framework of the memorial and monumental may provide a useful tool to apply for further research in this area. Such an approach potentially has significant ramifications for considering the types of testing and degrees of consent (or lack of) in national strategies to promote HIV counselling and testing (HCT). The potential impact for the client, particularly in terms of their emotional response to an HIV positive diagnosis and the extent to which they internalise stigma, may vary depending on the conditions under-which they were tested (i.e. provider initiated, mandatory or compulsory).

Another area for further research, at the individual level, would be to explore learnt behaviours and the process of coming to understand and internalise the role of law and human rights. For example, it is likely that one of the reasons why there has been an almost unanimous perception that law has a role in the national response to HIV was not because people believe that, but rather because they are conditioned to think that the law should be the main mechanism for achieving civic governance. In reality, as indicated by the life stories, there may be other more effective or appropriate mechanisms than law, which may be ill-equipped to respond to the nuances and complexity of everyday life particularly in relation to HIV and sexual health. Additional research could also further explore the dynamics of internalized stigma—and the extent to which experiences in

Malawi are similar or different to other countries, what individual and cultural factors may bolster resilience, and also further analysis about other aspects of identity such as class.

One overarching challenge remains, that is, to extend this theoretical approach to delve beyond the “conscious” in order to explore the underlying dynamics, relationships and prejudices that may remain hidden to the individuals and societies in which we operate in relation to stigma in general. What are the triggers that bring power dynamics into consciousness for an individual so that they may choose to act, resist and/or overcome? Research could investigate the processes by which people learn and construct personal and social norms and the role of law in their life, and the broader worldviews that shape these perceptions at the individual level. The research could also explore the inverse dimensions whereby individuals and communities either learn or acquiesce to accepting diminished rights, and what might potentially trigger transformation to empower without endangering those individuals or communities.

SECTION 4: Final reflections and conclusion

The end of stigma?

Stigma has existed for centuries, and certainly throughout the 30-year history of HIV. Stigma can be productive. It can be useful. Stigma may be invoked to delineate desirable social behaviours: it exists because it is thought that stigma can influence people to stop smoking, to use a condom, and in general to be deterred from committing a criminal offence. It is a Sisyphean task—could there ever be an end to stigma?

As is clearly demonstrated through the drafting of the proposed HIV Bill in Malawi, stigma is proactively embedded in aspects of governance (in this case law) to maintain social control and guide the behaviour of “citizens.” There is a perverse dependency between the positive, productive aspects of stigma (its potential to guide behaviour), and the negative, devaluing impact of stigma (its potential to isolate, discriminate and disempower). It is the very existence of that tension, mutually reinforcing, that makes stigma powerful. Stigma is imbued with the power to repress, deny rights, and internalize devaluation; yet it can also facilitate new alliances between individuals, catalyze resistance, and unite the “oppressed” to demand positive change and claim their rights.

Another question to be considered is also if there should be an end to stigma. As explored in the positionality and reflexivity sections of chapter three, this research was not seeking to find experiences of stigma related to HIV, but to document and understand

these when they occurred—and conversely to identify aspects of resilience to potential experiences of stigma when they did not occur. In my opinion, HIV is part of life, and should evoke no more or less stigma than other chronic health conditions. HIV is a virus that is undesired by most, can have negative health implications in terms of side effects, adherence to taking medication everyday once treatment has been initiated, and potential implications for life expectancy and other long term ramifications from ART. Like other viruses, in most parts of the world HIV can be tested for, diagnosed and treated.

Yet unlike other viruses, it has often historically evoked a high degree of moralisation and sensationalisation often attributed to its association with the intimate areas of human life such as sex. That is not to say that any negative association of HIV is stigmatising—but rather that when that you perceive or experience that negative association to have an impact on self-esteem, interpersonal relations and social engagement, or become entrenched through laws, policies and practices in your environment, that demarcates a wider process of devaluation. In the case of stigma relating to HIV, that process of devaluation is attached to the actual or perceived presence of a virus in the blood. The way that HIV has evoked stigma spotlights the moralization of disease, as it is seen as having a negative impact go beyond the purely biological. Thirty years after the first identification of HIV, the stigma ascribed to the potential negative value associated with a virus, HIV, is at odds with the biological effects – especially in a global context where progress continues towards achieving universal access to HIV prevention, treatment, care and support. In my opinion, an antidote is needed to overcome HIV-related stigma because – as a process of devaluation – it has an impact beyond the agency of any one individual to determine the morality of their own attitudes or behaviour, and can systematically marginalize some people based on certain aspects of their identity.

Is stigma being prolonged by those who have the power to end it?

It is clear from the life stories how stigma could be eradicated (even though complex)—by normalizing HIV, by contextualizing it as one aspect of someone’s life, and by routinizing services for HIV life for “any other” chronic health condition. Yet the results have also shown that HIV-related stigma remains a concern in Malawi, as in other countries and contexts around the world, and that stigma is not experienced in a simple or linear way.

An unusual and possibly controversial implication from this research is that perhaps it is not in everyone's best interests to reduce stigma. Stigma is a positive force with a productive impact for some people. For lawmakers, who want to delineate acceptable moral norms and social behaviour, stigma is used to maintain or establish social control through law and enforcement mechanisms—in other terms, stigma is invoked deliberately and productively. This is most apparent through the criminal law, but also visible through other codes and provisions that embody the normative codes of conduct to govern Malawian society. For “development workers” committed to working with HIV, the treatment of HIV as exceptional rather than mundane is potentially a useful trigger in catalyzing funding and securing public attention. For people living with HIV, a positive diagnosis has come to symbolize a range of things that for some has been attributed meaning as a transformative moment in the grand narrative of their life, a catalyst for reflection, a trigger for profound change, and for some an opportunity to find acceptance within a community, and perhaps new leadership roles, identifying as someone living with HIV. Yet some people are negatively impacted by stigma, feel ashamed or judged, and/or experience discrimination or exclusion because of an HIV-positive diagnosis. This can last a lifetime.

Stigma is not experienced—or produced—in a simple way, and can be both subtle and overt. There is a tension between the impetus to normalize HIV and the need to recognize the heterogeneous diversity of people whose lives are most affected by HIV—and the ongoing need for an exceptional response to a pressing health and human rights concern. On one hand, shifting the starting point away from “AIDS exceptionalism” in Malawi to embracing the fact that it is highly probable that every life is or will be affected by HIV could help shift the very foundation on which stigma rests. While maintaining attention to the disparate needs and specificities of the differing dynamics of HIV (adhering to the UNAIDS mantra of “knowing” the epidemic and tailoring prevention, messaging and outreach services accordingly), national efforts could concurrently also normalize HIV as part of everyday life. Such acceptance, which is especially relevant in country with a high HIV prevalence like Malawi, would enable the focus of policy and programme implementation to move towards routinized, sustained, and non-sensationalized provision of testing, treatment, care and support services. On the other hand, HIV continues to warrant an exceptional response. It is morally abhorrent that people continue to die despite the availability of treatment and that the quality of life of

some people living with and closely affected by HIV continues to be jeopardized by stigma, prejudice and ignorance. But this is not what makes HIV exceptional, and the same could be said of other important public health concerns such as tuberculosis or hepatitis. HIV remains exceptional because it forces us all to confront what is quintessentially human—sexuality, morality, intimacy, pregnancy, parenting, lifestyle choices, self-identity, stigma and injustice. HIV provides a litmus test as to how individuals, families, communities, societies, and governments respond to “taboo” and potentially confronting concerns that HIV forces into private consciousness and public discourse. HIV is exceptional in its humanity, and how it strikes at the core of people and societies.

An antidote to stigma?

What then is the antidote for those whose lives it directly devalues and limits the realization of their rights? In conclusion, is it possible to achieve human rights affirming individual and social change through law-grounded processes? The findings from the results and process of my research suggest that there is no magic bullet, no single intervention, no one public policy, nor one law that can generate the transformation necessary to make human rights a reality—or in the words of Nyerere, to realize the fact of human dignity (Shivji, 1989, op cit). Respecting human dignity and ending injustice is morally right, and aspirationally feasible, yet pragmatically impossible until the rights and responsibilities of all are institutionalized and honoured instead of prioritizing the rights of a few. Understanding difference, power relations and the complex intersecting dynamics of agency and identity can play a vital role in grounding universal human rights principles to meet the competing needs and desires among the diverse realities of everyday life.

In a time when resources are precious, and HIV-specific funding is under threat, concurrently with the demand for funding higher than ever to ensure that more people have access to life saving treatment sooner, policies and programmes cannot afford to fail. This research shows us, beyond what it says about stigma, law and human rights, that HIV is a single part of a myriad of identities and life experiences. By moving beyond seeing “people living with HIV” to “people living”, we can more fully understand the complexities of how HIV exists in the social sphere. HIV needs to remain situated in the context—not in isolation—of the complexity of life and other structural determinants of health and human rights. This would ensure that even despite the best intentions, national and international efforts to respond to HIV do not fall victim to the trap of the proposed HIV Bill in Malawi,

and have an impact that is life-affirming and empowering and not potentially cruel and inhuman.

Achieving and securing human rights remains a universal concern. Efforts to mitigate the effects of HIV-related stigma—even if stigma is maintained and invoked to control society as it has done historically and continues to do—would achieve lasting beneficial outcomes if based on principles of a jurisprudence of dignity and generosity, rather than criminality (inducing shame and punishment), spanning wider issues relevant in someone’s life beyond an HIV positive diagnosis in isolation. In so doing, efforts to address stigma would address and respond to the variety of everyday needs and realities of “being human” that human rights are designed to serve.

Afterword

Self-reflections and introducing 'Lucy'



'Between the idea and the reality ... falls the shadow'

T.S. Eliot, *The Hollow Men*, 1925

First and foremost, a health warning: this section is personal, reflective, and an unusual finale for a doctoral thesis in law or development studies... That said, it would seem somewhat hypocritical to undertake research based on life stories without some kind of introduction to myself, the journey of my life so far, and my own opinions, (mis)perceptions and lenses through which I come to view issues relating to HIV and stigma.

I was born in Australia, 4 July 1980, and have been blessed with a loving family and tremendous opportunities even since. Five minutes after me followed my beautiful twin sister, marking a lifetime that would be both individual and independent but also never solitary. Cheeky from the start, we were a month early and gave the doctors a fright when I held my breath while they monitored our vital signs. It was a happy childhood, full of sunshine and the outdoors, and I loved school. Our parents separated when we were young, which opened up our lives to an even more expansive and diverse family web. I have always loved learning, from life as much as from books, and am incredibly grateful for the many educational opportunities I have had in Australia, the USA and the UK, in terms of formal academic opportunities, and in fact throughout the world from the many conversations, bus journeys, sights and smells that have opened my eyes to new ideas and different perspectives.

When I moved to Malawi in September 2010 it was not my first time living in Africa, but it was the first time when I really felt that I became part of local life – or it became

part of me. By the end of the six months I no longer felt self-conscious as the only 'mwazungu' (white person) on a mini-bus or in a local restaurant, and I used my ill-pronounced and very limited Chichewa language skills (or lack thereof) as regularly as I could. I quickly learnt that greetings and appreciation in the national language is not only courteous and respectful, but also a great facilitator for arranging research interviews (for example opening doors to a walk in interview with the Minister of Health).

"I am starting to feel a bit bored in Lilongwe—not with the research, no! But with life...which is good I think because it means that I am feeling relaxed, at home, and not so enamoured with the day to day differences from everyday life in London. To feel so many things, so intensely, and to be learning so much is a remarkable opportunity. I feel very lucky." [My Research Diary, 11 November 2011]

For me personally, the 6 months in Malawi touched my soul. Haruki Murakami has a powerful metaphor at the beginning of one of his novels (*Kafka on the Shore*) where he describes a razor sharp sandstorm, that turns you upside down and pierces into the soul, how grounded in your sense of self you were when coming out the other side. My Malawian sandstorm has many elements. For me personally, these moments are just as significant in terms of learning and life as the analysis and ideas generated by the research. As life would have it, I was witness to some intensely meaningful events while Lilongwe was my home, and I am grateful for the space and the support and the rawness that came with them. These experiences would leave their footprints under any circumstance, but there is something about being far away (from any of my homes) and foreign, on a patch of red African soil under the oscillating rainbow of colours from the Jacaranda and the Flame trees, that magnified the intensity of those emotions.

Of HIV, stigma, people, friends and colleagues, much of this PhD is dedicated to the wealth of learning in this area. In particular though, my mentors in the Action Research team shared wisdom and inspiration for action. As much as I sought to encourage and motivate each of them, it was reciprocal, and this SMS exchange illustrates:

"David safe travels back to Blantyre. Congratulations for today – I felt very proud and very humbled at the same time. See you next Monday, have a lovely weekend"
[SMS, Lucy to David, 22 October 2010]

"Welcome. I have learnt to appreciate those who live to better others. It is a noble cause. I feel not only me but many Malawians are sharing your practical and empowering values."

[SMS, David to Lucy, 23 October 2010]

Of the impact of listening to and sharing stories, that they can be powerful – even when listening second hand to the impact shared by others in the Action Research team. Just as others in the team reported in the mid- and end-of collection meetings, I couldn't help but make connections with my own life during some of the interviews and the ideas discussed. For example during one of the life stories, the participant was talking about growing up with his mother as a single parent (his father had left them when he was very young). He had a beautiful turn of phrase, respectful of his mother and grateful for his childhood, which although in very different circumstances on another continent entirely, somehow resonated strongly with memories of a period of my own childhood.

“Imagine I grew up under one parent so I was feeling somewhere somehow unhappy because I never knew the love of a father, I never experienced the love of a father. It was like we could do – have that feeling that when we hear about our friends talking about their daddy, we could ask ourselves questions ‘ach what about me?’ Then anyway something which never existed in me, it went out, and I was almost like those children who leave their parents—both of their parents—simply because my mum, she possessed all what it takes. Yeah even though there was no father, but she had a quality also of what—she had the qualities of both father and mother. So to me it wasn't that experience.” [LS42]

Another particularly memorable interview was with one of the key informants in the Northern Region. It was New Year's Eve, one of the days in the calendar year particularly ripe for reflection, and I had recently ended a relationship (I was dumped over skype!). The long distance back to London proved to be too difficult. As I was interviewing a psychosocial support counsellor and listening to his perspective, I couldn't help but take in some questions for my consideration and potential New Year's resolutions:

“In counselling we are meeting different people from different backgrounds; others are having relationship problems in their families; others are having relationship problems in their workplaces. And whoever comes for sessions usually will say ‘I look at so and so as having problems relating to me or dealing with me’ but in the course of helping him in the counselling process you would discover that he is also playing a role in that – in the issues that he is presenting. At first I may say Lucy has a problem. OK? Now within the counselling process this person is also assisted to look around and see his own contributions towards that problem. What part am I playing there for the maintenance of the behaviour or for the onset of the behaviour? What part do I play? And then it goes on and on and it helps the client to see how best can I improve this situation, OK. It is not up to Lucy to improve this situation but what part can I play to improve this situation. It's the whole dynamic of the whole person.” [OL 13]

These were two memorable interviews where I subconsciously drew direct comparisons with my own life story. At times I also received direct, encouraging and at times inspiring feedback from some of the follow-up interviews and photo shoots, such as:

“Lucy, I have had pictures before but yours can be described as one of my great pictures. I see some good strength in them, some nice seriousness and most of them all the hope that things will be better for people like me. Thank you so much for talking to me and making such a follow up. My family is just so refreshed by your assurance and please, remember what I really want. A degree in Journalism, Mass Communication or TV Production in Australia! Lol!
You have been a very fantastic person I have ever met in my time.
Have a nice day Lucy”

[Email from LS1, 21 February 2011]

Of uncertainty, I heard some of the most devastating news of my life so far in March, where the day after the End of Collection meeting with the life story interviewers, a close member of my family was diagnosed with a serious illness that required immediate surgery and aggressive treatment. Thankfully the treatment and the surgery since went very well, but at the time it was the kind of shock that shook me to the core, and shone a spotlight on the fragile and precious foundation on which my life is built. I went into total overdrive to arrange flights, complete a final interview and say a quick thank you and goodbye to some of my closest colleagues. It wasn't until I was with a colleague, mentor and close friend, and I tried to explain why I was leaving the next day, that suddenly I felt the weight of the news. Lucky for me, he is a very kind man with a warm and comforting hug. Unlucky for him, he is much taller and ended with a very damp shoulder. The sudden juxtaposition of the hospital in Australia where the treatment was taking place with the health facilities in Malawi was a stark reminder of the immensity of global inequalities and on-going struggles for access to good healthcare in Malawi.

There was another moment that was very definitive for me as a person, as well as for my research in Malawi that has left the deepest of footprints on my heart, soul or somewhere. The first of December 2010, World AIDS Day, was unlike any other I have experienced so far. It's a long story, about risk (my own, helping, with no gloves and lots of blood despite all sorts of first aid training), about inadequate health systems (no ambulances and desolate and overcrowded A&E when we got there), about fate (it was 2 cars in front of ours that had collided with a tractor, that had no lights), about communication (in the chaos of an emergency and not speaking the local language yet somehow everyone getting messages across), about hope (villagers and farmers with

nothing helping to pull people from wreckage and give cloth to help stabilize the injured on the way to hospital), about death (2 people were dead at the scene), about relief (the 3 people - 2 adults and a child - that we drove to the hospital, about 30 kms away, all survived), and about the future (we were on our way back from a rural commemoration of World AIDS Day, which was truly inspiring).

I was deeply moved by the experience, and a day later I felt compelled to try and describe it and share the emotions with my family and closest friends.

So I can remember pretty clearly 1 December for the last few years—maybe because we give it special attention as World AIDS Day, but maybe also because certain things happen that leave a footprint in your heart. Yesterday was one of those days.

Two things in particular stood out – the first, a powerful personal story of courage and strength; the second, an unfortunate road accident the brought unexpected people together in a desperate struggle to save lives. Both somehow were very much about humanity, about blood, and about life.

I spent the afternoon at a World AIDS Day meeting in Mtakatika, a village near Dedza in Malawi that grows delicious mangoes and is not too far from the Lake. The Family Planning Association of Malawi (FPAM) has been working with peer educators on issues of young people and sexuality and is also part of the coordinating group for HIV. I was their guest, and this year the committee decided to host a meeting to discuss the issues rather than have traditional dancing and theatre and celebrations as they have done in other years. The meeting was attended by the Senior Chief Kashintamoto (a woman, which is unusual in Malawi, and she is apparently very strong and highly respected) and other chiefs, men, women and young people from the community. The groups discussed issues of prevention, treatment, human rights, gender and sexuality, and touched on complex areas like the positive but also harmful influence of some traditional practices, drug stock-outs, challenges of giving antiretroviral treatment to children and babies (when only tablets or adult drugs are available), differing acceptance of HIV status by men and women, and the shame or blame that is sometimes related to bringing HIV into a family.

A woman stood up to speak, in response to some questions asked about the presentation from the men's group. She was beautiful, maybe in her late 40s, wearing a sparkly blue hat, earrings, and a matching embroidered yellow skirt and blouse, and our campaign sticker – 'Criminalize Hate not HIV.' She is living with HIV and she spoke about caring for her four children, about her own positive test result, and her husband's refusal to accept HIV or to go for a test himself. She describe how when he got sick, she visited his family who also tried to encourage him to go for a test, but he refused. He passed away, and she wondered had he tested and if he had then received the right treatment, would he be alive today. She then described how she is strong, and also healthy, working the fields each day, and caring for her children. I could feel her strength, even as she described her story in a language I could only understand through translation. She shared a real energy and passion for life. Another person may have farmed the same story as one of hardship, but she framed it as one of courage, strength and everyday life. She was the last to speak,

before the Governor and the Senior Chief, and she received a great and respectful applause when she returned to her seat.

I regret not taking a photograph of her at the microphone - I was too absorbed in the moment – but it is an image that will stay with me for a long time.

The drive home from Mtakataka is beautiful – a steep climb through the mountains back to Dedza, where we dropped my colleague Ruth home, and then a long straight drive back to Lilongwe. It was sunset when we got to Dedza; so much of the last part of the drive was in darkness. The roads are good in Malawi but there are always extra hazards when driving at night – other or slower vehicles on the road, livestock, and limited road markings.

About 15 minutes outside Lilongwe (we could already see the city lights in the distance), there were some hazard lights flashing up ahead. We slowed down and stopped, got out of the car, and saw a horrific road accident that had happened only moments before. A sedan car had collided and rolled somehow with a big tractor, which didn't have any lights, and people were standing around the vehicle trying to pull any survivors from the wreckage. The person in the passenger seat of the car was dead, and there were five others in the car—two women, a man, and two small children. I later found out that the driver of the tractor was also dead at the scene.

Another driver came to us and started speaking. *That car just passed me, he said, maybe half a kilometre ago. It could have been me.* There was that awful sound of metal crumpling and glass shattering as people tried to free people from the squashed car.

Even after years of first aid and rescue training, I felt stuck, not being able to speak the language and not knowing the best way to help. A man asked if we could then transport the injured man to the hospital. Paul hesitated - he was the driver and it was a rental car - but I suggested we should help. A few people gave chitenges and fabric to try and cover the seats, and we tried to lift one of the injured women – now free – into the car. Some people had gloves – I didn't. Years of training tell you to protect yourself and the 'patient' by wearing gloves. I thought twice about it, and it was an informed choice, but there really was no choice. We helped the woman into the car, then the man and one of the small children.

Paul was calm but determined as we sped, high beams flashing and horn blaring, as fast as we could to the central hospital in Lilongwe. *Are you OK?* I asked. *Yes* he said. *Ok drive safely,* and I explained in English to the others that we were on the way to the hospital and would be there as soon as we could. We sped through a police roadblock, ignored a diversion and drove on a half completed road to get to the hospital. It was only when the child started to cry when we turned into the hospital that I realized he was still alive.

When we arrived, people came rushing out – with gloves for us too – and we helped the three into the emergency ward. Once they were inside, some of the people who had helped were asking about the story. They weren't staff either; they were other visitors or bystanders who were able and had wanted to help. Not long after us, maybe 10 minutes, another car, with the other woman and the second child from the accident, arrived at the hospital. It turns out that she was an employee at the hospital.

I am not sure how the story will end – but with life and health for everyone I hope.

Yesterday was a reminder for me of the power and strength of life – yet also its fragility. I am grateful for mine and especially for the special people who share it with me.

This isn't a remarkable story at all, it is actually its everydayness that has left its footprint with me, and I wanted to share it with you.

[Email, Lucy to many, 2 December 2010]

Sadly one of the people who was rushed to hospital did not survive (the woman who was the employee there), but luckily the other 4 did. It was both the extreme and everyday nature of the experience, as well as the web of lives it brought together, as well as the range and history of my own experiences that it called on (as a trained life guard, want-to-be paramedic, foreign English speaker), that left such a powerful impression with me.

Two other moments, much more trivial and yet equally powerful, symbolize the inter-connected and ephemeral dimensions of life. The first was just outside of Zomba, where I went to conduct a follow-up interview with one of the life story participants. We had been trying to connect for many months, but because of travel, cell phone reception and airtime, we had not been able to. My twin sister was visiting Malawi at the time, to share in some of the experiences, and she came with me to the interview. It was one of the most interesting interviews, building on a very powerful life story, and it ended with an open invitation to myself and my sister to stay in the humble and beautifully maintained, half-built house the next time we were in the neighbourhood.

The other moment was a phone call, from Paul, wishing me a safe journey and best wishes for my family as I was waiting to check-in at the airport in my rushed early departure from Malawi. Airtime is not cheap in Malawi, especially for a phone call, it would be more common for someone to 'flash' (send a request to be called back) or send a SMS message. Paul's call was unexpected and very thoughtful, and while we never spoke again about our experience together on World AIDS Day, his gesture showed me that it has meant much to him, as it has also to me.

Somehow both my research and my personal experiences in Malawi, and life journey so far, seems to be very human and founded on the experiences, emotions and dreams of everyday life.

The three things that struck me more than anything during my time in Malawi can be summarized as:

- The inconsistency of humanity, both in the moral narrative underpinning how we describe our lives and in the opinions that we hold
- The power of acceptance, both of yourself by yourself and by others, which may otherwise appear to be a relatively passive action
- The precious, fragile and unpredictable nature of life.

It has been a solitary journey intertwined with the footsteps of others, never alone, and I am deeply grateful for the opportunities to think, listen, learn and experience that I have encountered along the way ... and to the directions it will point me towards in the future.

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ANNEX 1

NARRATIVES OF HUMAN RIGHTS:

Universal Concepts Brought into Focus Through Lenses of Life Stories



INFORMED CONSENT FORM

The research is focused on HIV and The Human Right to Health.

It explores how an empowering process of documenting human rights can contribute to development and the realisation of human rights—specifically in regard to the human right to health and HIV, in the context of stigma and discrimination relating to HIV in Malawi. The research will be narrative-focused and will focus on core aspects of dignity and the aspirations as articulated by individual people, in your own language, recorded by peers, and respectful of your own way of describing and talking about the issues.

The research is part of doctoral studies by Lucy Stackpool-Moore in association with the University of London (School of Oriental and African Studies, Development Studies Department, and Birkbeck College, Law School), supervised by Dr Mike Jennings and Dr Matthew Weait. It is also linked with *The People Living with HIV Stigma Index* in Malawi—an initiative supported by The International Planned Parenthood Federation (IPPF), UNAIDS, The University of Malawi, MANET+ and the Family Planning Association of Malawi (FPAM) (www.stigmaindex.org).

Confidentiality and potential risks of participating. This project is taking every possible step to ensure confidentiality, i.e. to prevent any personal information from being known to people outside the research team. This consent form will be kept separate from all other documents relating to the research, and all members of the research team will sign a confidentiality agreement. Your interview will be recorded and transcribed. This is to ensure that the research represents your story in your words as you choose to describe it and is a research tool to ensure the quality of your response is maintained. If you wish, your name will be changed and other key identifying features of your story to ensure your anonymity. Nevertheless, in all studies like this there is a very small risk that a breach of confidentiality could take place. If this were to happen, your HIV status or other personal information might become known. As a result, it is possible that you could face stigmatizing treatment from someone or unexpected outcomes (in the most extreme cases this could include discrimination in your workplace, loss of access to services, media exposure or physical violence). While this is a very small risk, it is our duty to warn you of this.

You may experience some discomfort in the interview because you will be sharing your personal story. Your interviewer has been trained by national and international researchers and has been selected specifically to interview you as a 'peer researcher' to establish the most comfortable research experience possible. Your interviewer is also someone who is living with HIV.

In case you would like to explore certain issues and experiences in more depth after the interview or you need psychological or physical support, such as counseling or legal assistance or advice concerning educational, health or social support, we have developed a list of professional support services in our community and will be happy to share this information with you.

Potential benefits to you and to your community. We hope that the process of telling your story is an interesting one for you as it might cover some issues that you may not have thought about for some time or in a different way. The interview is designed to give you the experience of being *really* listened to and to tell your story, in your words, as you wish it to be heard.

Your participation in the research is entirely voluntary. You can choose to pause or to end the interview at any time you wish. You will be given a small honorarium as a token of thanks for your time and participation in the research. We will make every effort to share the research findings with you when they become available in 2011.

1) My name is _____ . I have read the information sheet about this PhD research and/or it has been explained to me. I understand how my responses will contribute to the research and how the confidentiality of my story will be ensured. I understand that my interview will be recorded and transcribed.

I consent to participate in the interview and for my responses to be included in the research, and published as part of the findings.

2) Signed: _____, Date: _____
Location: _____

3) Please tick the [YES] box if you would like your name changed and other key identifying features of your story to be changed, to ensure your anonymity.

YES, I would like my name changed and to be anonymous

NO, I would like my name to remain the same and my story to be published as it is

THANK YOU very much for your interest in this research initiative, and for your time to consider these important issues. Through you and other people living with HIV participating in this project, we will be able to produce rich and valuable information that will assist both our national and global efforts to reduce HIV-related stigma and discrimination and ultimately improve the lives of all people living with HIV.

Contact lucysmoore@gmail.com for more information or follow-up.

ANNEX 2

**NARRATIVES OF HUMAN RIGHTS:
Universal Concepts Brought into Focus Through Lenses of Life Stories**

Confidentiality Form
September 2010—March 2011



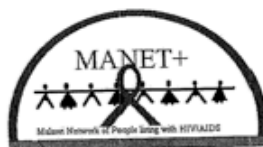
Peer-Interviewers

As a peer-interviewer I agree to take every possible step to ensure that confidentiality is assured for the narrators in the oral history project (if they desire). That is, for people consenting to participate and who wish their stories to remain confidential, I will ensure the following steps are taken to prevent any personal information from being known to people outside the research team:

- Be discreet when discussing the research with people outside the Research Team, and ensure that I do not reveal any information (unless permission explicitly given) that may have been shared in confidence during the interview process.
- Be empathetic and respectful during every part of the interview process (preparation, planning, interview and follow-up).
- Ensure that the informed consent forms explicitly completed by all narrators (including those who do not complete an interview or choose not to participate even after the interview has commenced).
- Ensure that anonymity is ensured for the narrator if they desire (i.e. their name will be changed and other key identifying features of the story to ensure anonymity).

Signed:

Name (print)	Signature	Date



Malawi Network of People Living with HIV/AIDS
Correspondences to be addressed to: Executive Director

25th October 2010

TO WHOM IT MAY CONCERN

PEOPLE LIVING WITH HIV STIGMA INDEX RESEARCH

I write to introduce our research team on Stigma Index Research for People living with HIV & AIDS (PLHIV). The stigma index research aims at collecting information on stigma and discrimination and the rights of PLHIV to help in advocacy efforts.

The study will consolidate understanding of stigma as personally experienced by PLHIV in different settings. The findings will be vital in designing stigma and discrimination interventions thereby improve on operational programmes and services that are rendered by organizations supporting PLHIV.

The findings will also enable the Malawi Network of People Living with HIV/AIDS (MANET+) fulfil its mission which is to advocate for the promotion, protection and respect of human rights and freedoms of PLHIV and affected through their meaningful involvement in issues that affect their lives at individual, family, community, workplace, and national levels.

MANET+ received technical and financial support from the Joint United Nations Programme on HIV & AIDS (UNAIDS) and the International Planned Parenthood Federation (IPPF), to commission a Research on Stigma Index, to measure stigma and discrimination experienced by PLHIV in Malawi.

MANET+ is the umbrella organization for organizations that work with people living with HIV (PLHIV) in Malawi.

The bearer of this letter is a member of the research team from MANET. Please note that this research has been duly approved by the College of Medicine Research Ethical Committee (COMREC). Its Principal Investigator is Dr M.L. Chirwa. See the attached approval letter.

Casa de Shez House, 2nd Floor, Private Bag B377, Lilongwe 3, Malawi. Tel. (265) 01 773 727. Tel/Fax (265) 01770 194 E-mail: safari.mbwewe@manetplus.org

Your support and cooperation in this research process will be greatly appreciated.

Sincerely Yours,

A handwritten signature in black ink, appearing to read 'Safari Mbewe', written in a cursive style.

Safari Mbewe
Executive Director



Malawi Network of People Living with HIV/AIDS
Correspondences to be addressed to: Executive Director

12th October 2010

To Whom It May Concern:

Re: MANET+ Endorsement of PhD Research by Lucy Stackpool-Moore

On behalf of the Malawi Network of People living with HIV/AIDS (MANET+) I am writing a letter of endorsement in support of the research proposed by Lucy Stackpool-Moore as part of her PhD with the University of London.

The thematic focus of the research is timely and important. Stigma relating to HIV remains a significant challenge because it has an impact on the accessibility and orientation of services (not only health, but also legal, care and support services) as well as on self-esteem and general quality of life—which affects people living with HIV, their families, friends and carers, as well as broader social attitudes reflected in the media, in institutional policies and in political debates.

Lucy's research explores how an empowering process of documenting human rights can contribute to development and the realisation of human rights—specifically in regard to the human right to health. The narrative-focus of the research will compliment *The People Living with HIV Stigma Index* initiative that MANET+ is currently coordinating in Malawi. We hope that Lucy's research will contribute even more information to link in and deepened the analysis resulting from the Stigma Index.

Lucy has carefully considered the ethical guidelines as well as the processes to put in place to ensure that interviews are confidential, sensitive, and adequately supported with referral systems should that be necessary.

This is an interesting and timely piece of work, and MANET+ looks forward to participating in the Action Research and Steering Group for the project and to working alongside Lucy to understand more about the complexity of HIV-related stigma in Malawi.

Yours sincerely,

Safari Mbewe
Executive Director

Casa de Shez House, 2nd Floor, Private Bag B377, Lilongwe 3, Malawi. Tel. (265) 01 773 727. Tel/Fax (265) 01770 194 E-mail: safari.mbewe@manetplus.org



UNIVERSITY OF MALAWI

Principal
K.M Maleta, MBBS PhD

Our Ref.:

Your Ref.: P.08/10/974

College of Medicine
Private Bag 360
Chichiri
Blantyre 3
Malawi
Telephone: 877 245
877 291
Fax: 874 700
Telex: 43744

25th October 2010

Dr M. Chirwa
College of Medicine
Public health Department
P/Bag 360
Blantyre 3



Dear Dr Chirwa,

RE: P.08/10/974 – Implementing of Stigma Index to Measure Stigma and Discrimination Experienced by People Living with HIV and AIDS in Malawi

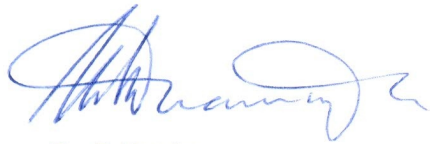
I write to inform you that COMREC reviewed your proposal mentioned above which you resubmitted for expedited review for the following reasons:

1. Specific objectives on page have now been deleted.
2. Confidentiality on using video camera will be observed.
3. A copy of a confidentiality form for a research team member has been included.
4. Informed Consent form and Assent form for minors below 18 yrs have been included.
5. Inclusion of 10% College of Medicine Administration fee
6. The title has been reoriented as suggested and it reads as follows: "Measuring Stigma and Discrimination Experienced by People Living with HIV and AIDS in Malawi by using Stigma Index"
7. Summary of introduction has been inserted at the beginning of the proposal
8. Informed Consent and Assent forms have been attached.

I am pleased to inform you that your protocol **was approved** after considering that you addressed all the queries raised in the initial review.

As you proceed with the implementation of your study we would like you to adhere the amended protocol ICH GCP requirements and the College of Medicine Research requirements as indicated on the attached page.

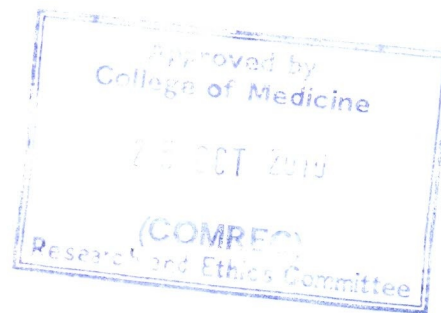
Yours Sincerely,



Dr. S.Kamiza

For: CHAIRMAN - COMREC

SK/ck



REQUIREMENTS FOR ALL COMREC APPROVED RESEARCH PROTOCOLS

1. Pay the research fees as required by College of Medicine for all approved studies.
2. You should note that the follow-up committee will monitor the conduct of the approved protocol and any deviation from the approved protocol may result in your study being stopped.
3. You will provide an interim report in the course of the study and an end of study report.
4. You are required to obtain a continuation approval after 12 months.
5. All investigators must be fully registered with the Medical Council of Malawi.

ANNEX 5

NARRATIVES OF HUMAN RIGHTS:

Universal Concepts Brought into Focus Through Lenses of Life Stories

RESEARCH PROPOSAL—Lucy Stackpool-Moore

September 2010—March 2011



HIV and The Human Right to Health. Happy, healthy and safe sex may not immediately come to mind as one of the cornerstones of international law and state obligations to promote human rights; nor as one of the primary concerns for international development today. Yet HIV—and the millions of lives it touches—triggers at times uncomfortable or unexpected conversations, and is embedded within many personal, programmatic and policy priorities and agendas around the world.

For the estimated 33 million people who are living with HIV today (UNAIDS, 2008), stigma and discrimination pose a real threat to the realisation of the human right to health. Living with HIV today is a different experience for every individual. Life is multi-dimensional, and all individuals will find themselves in different situations where they have different relative positions of visibility and/or engagement and/or power. For some, taking treatment, seeking support, and accessing health services is routine and part of a wide selection of services and choices available. For others, information is limited, support insufficient, access denied or choices obstructed because of fear or marginalization.

Yet stigma relating to HIV remains a significant challenge because it has an impact on the accessibility and orientation of services (not only health, but also legal, care and support services) as well as on self-esteem and general quality of life—which affects people living with HIV, their families, friends and carers, as well as broader social attitudes reflected in the media, in institutional policies and in political debates. Just as the human right to health is inter-connected and mutually dependent on other human rights (Gruskin, Mills and Tarantola, 2007), there is a need to focus on a structural understanding of HIV-related stigma that includes a recognition of dynamic interplay between an individual and the social determinants and power structures that influence their lives (Parker and Aggleton, 2003). As such, HIV and happy, healthy and safe sex are in many ways central to international, national and personal conversations, decisions and interactions in the world (both conscious and those less so).

Human Rights. International declarations have successfully raised awareness about human rights and placed issues of social justice, (in)equality and obligation firmly on the table of international relations and national government policies. Yet the very indiscriminate nature of universal declarations of human rights means that they risk losing purchase in assisting the struggles of individual lives in the realities of every corner of the universe. The law, on its own, is limited in its capacity to capture and engage the complexity of an individual situated within their wider social context. Yet by understanding perceptions and consciousness of law in everyday life, the complex relationships between individuals (in all our inconsistency and complexity) and society become illuminated. If they are to have *real* meaning, human rights need to evolve from and respond to the complex realities of individual lives while also maximising the populism and momentum generated by the universal principles outlined in the international declarations. Without a foundation in the voices and realities of people, the universal principles risk being distant and abstract from the lives of many, and a blunt instrument for actually achieving human rights.

“People are acutely aware of the injustices inflicted upon them. Knowledge of the contents of the Universal Declaration will hardly advance their condition. What they need is a movement that channels these frustrations into articulate demands that evoke responses from the political process. This the human rights movement is unwilling or unable to provide. In consequence, the real life struggles for social justice are waged despite human rights groups—not by or because of them—by people who feel that their realities and aspirations are not adequately captured by human rights organisations or their language.”

Chidi Anslem Odinkalu, *Why more Africans don't use human rights language* (Nigeria, 1999)

Stigma and the Human Right to Health. The human right to health has been defined from the outset as a holistic concept in international law, framed within a wider consideration about the social determinants of

health and the promotion of human rights, dignity, equality and freedom (WHO, 2008). The right to the highest attainable standard of health as a 'state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity,' and as 'one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition,' was recognised in 1946 with the adoption of the Constitution of the World Health Organisation (WHO, 1948).¹ The Alma Ata Declaration (the outcome of an international conference on Primary Health Care in 1978) more explicitly defined health as a socio-economic issue and as a human right (WHO, 1978).

HIV-related Stigma: A human rights violation. Stigma is imbued with power and is commonly understood as a process of devaluation or as a 'mark' of discreditation (Goffman, 1963). Different types of stigma have been differentiated as enacted stigma (actions resulting from stigma, also known as discrimination), perceived stigma (fear that stigma will be experienced), stigma by association (stigma experienced because of perceived association with a stigmatised group or discredited behaviour) and internalised stigma (the internalisation of the negative or devaluing attitudes) (Parker and Aggleton, 2003; Link and Phelan, 2001). Stigma attaches itself to not only to individuals but also to specific social contexts (Goffman 1963; Manzo, 2004).

Given the holistic understanding of the right to health, as a 'state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity' (op cit), stigma poses a real threat to the realisation of human rights. While most would agree that enacted stigma (or discrimination) is unquestionably a human rights violation, I suggest that all forms of stigma are a human rights concern with direct consequences for realisation of the right to health.²

HIV-related stigma is layered and complex and can feed off other attitudes or prejudices relating, for example, to homophobia, racism or sexism (Mahajan et al., 2008; Nyblade, 2006; Dodds, 2006). Stigma can have many outcomes and can adversely affect how and when someone accesses services (including testing, support and treatment), how people interact with each other (including friendships, intimate partnerships and professional relationships), and how someone perceives themselves and their self-esteem (Maman et al, 2009; Genberg et al, 2009; Simbayi et al, 2007).

HIV-related stigma impacts the human right to health at three key levels:

- 1) **Personal:** Internalised stigma can negatively affect the quality of life and self-esteem of people living with HIV and can create barriers to realising other human rights (Li et al, 2009; Simbayi et al, 2007). Stigma has been shown to be associated with stress, depression, and lower perceived quality of life among people living with HIV (Simbayi et al., 2007). People living with HIV can feel dirty, ashamed, or guilty because of their HIV status (ibid) and it is uncontroversial and well evidenced that stigma exacerbates the already-heavy burden experienced by people living with HIV (Li et al, 2009).
- 2) **Service:** Stigma creates barriers for accessing health services (Maman et al, 2009)³. For example research has indicated that stigma affects HIV prevention and treatment efforts, including the use of condoms, HIV testing uptake, and uptake of prevention of mother to child transmission programs (Maman et al, 2009; Genberg et al, 2009; Simbayi et al.2007). Stigma has been identified as a factor contributing to the refusal to return for the results among people who have tested, to low HIV disclosure rates and to affect adherence to antiretroviral therapy (ART). Research has also found that experiences of stigma in a health care setting limits the uptake of these services by people living with HIV (Engender Health, 2004).

¹ The WHO definition also articulates the importance of health promotion and the process of enabling people to gain control over decisions and access to information that will benefit their health (Mann et al., 1999).¹ It was reinforced and further particulars were defined in article 12 of the International Covenant of Economic, Social and Cultural Rights (ICESCR) in 1966, which made the principles legally binding for the 149 States who have now become party to the ICESCR (UNHCR, 2004). The ICESCR clarifies and refines the concept so that the full realisation of the right to health includes 'the prevention, treatment and control of epidemic, endemic, occupational and other diseases' (12c) and 'the creation of conditions which would assure to all medical services and medical attention in the event of sickness' (12d).

² In fact the first worldwide public-health strategy to explicitly engage human rights principles was the Global Program on AIDS at WHO, directed by Jonathon Mann, in the late 1980s (Gruskin, Mills and Tarantola, 2007). Mann also suggested that stigma and discrimination would be the 'third wave' of the HIV epidemic, enduring longer than other issues relating to prevention and access to treatment (cf Parker and Aggleton, 2003).

³ HIV-related stigma also creates barriers for people accessing other services (such as legal, employment, psychosocial care etc) but for the purposive of this research I am focusing specifically on health services.

- 3) **Structural:** Stigma can re-enforce power inequalities and processes of social marginalisation (Mahajan et al., 2008; Parker and Aggleton, 2003). It touches on intimate behaviours, decisions and moralities that are accompanied by a minefield of personal and societal attitudes, perceptions and principles (Dodds, 2006). As such, stigma relating to HIV is often conflated with others such as racism, homophobia or sexism (Herek, 1999; Nyblade, 2006).

HIV-related stigma cuts across all elements of the human right to health because it impacts the physical, mental and social well being of individuals in the context of their societies.

The research explores how an empowering process of documenting human rights can contribute to development and the realisation of human rights—specifically in regard to the human right to health. It is interdisciplinary, drawing on critical legal theory, sociology, anthropology and social psychology for the theoretical framework. It looks at the complex processes of transformation (individual and social) needed to address stigma and in turn to realise the human right to health. The research will focus on a case study exploring the human right to health within the context of stigma and discrimination relating to HIV in Malawi. The methodological approach is self-reflective, applied and collaborative, founded on core principles central to both action research and stigma interventions—that change starts with each one of us. The research will be narrative-focused and actor-oriented to capture the nuances and depth of the murkiness of real life. It will focus on core aspects of dignity and the aspirations as articulated by individual people, in their own language, and respectful of their own way of conceptualising and talking about the issues.

Research Questions

- 1) How can processes of documenting human rights contribute to development and the realisation of human rights?
- 2) To what extent does HIV-related stigma create barriers for realising the human right to health?
- 3) What are the similarities and differences between the impact of HIV-related stigma on the human right to health at the personal, service and structural levels?
- 4) What are the strengths and limitations of the role of the law in promoting the human right to health as part of a national response to HIV?

Research Methodology

The research methodology I have chosen seeks to model the core principles of self-reflection, inclusion and participation, and as such the research process is seen as an outcome in itself, and just as important as the research results and analysis. The process of narration and of documenting human rights concepts is seen as a form of social action in itself, and as a way of exploring the fourth dimension of power that explicitly touches on the internalisation of power and how it affects an individual's perception and being in the world. Building on Ewick and Silbey (1995), my methodology involves a conversion of both a political and epistemological commitment to 'giving voice' and understanding multiple subjectivities:

“Indeed, the *political* commitment to giving voice and bearing witness through narrative is underwritten by the epistemological conviction that there is no single, objectively apprehended truth. Conversely, the *epistemological* claim that there are multiple truths is based on the recognition that knowledge is socially and politically produced” (Ewick and Silbey, 1995, p 199).

A peer-interviewing approach and life history style of interviews forms a significant part of the methodology, which will allow narrators to describe issues, concepts and priorities in language and sequence that is of most meaning to them. As such, the research intends to amplify and understand the nuances and complexity of potentially subversive stories recounting both the mundane and the magnificent experiences of everyday life. The research is also a participatory action research initiative, with co-inquirers documenting the evolution of each of our reflections, understanding, challenges and visions for the research process. It is based on Freirean principles of conscientization and praxis that is an iterative cycle of action, reflection, change and action.

“Liberation is a praxis: the action and reflection of men and women upon their world in order to transform it.” Paulo Freire (1972)

In the context of addressing stigma and discrimination relating to HIV, it is rare that interventions have been designed with social transformation or community mobilisation in mind, and have often been based instead on practices targeting behaviour change (Parker and Aggleton, 2003):

“Only more rarely have interventions been designed with the goal of unleashing the power of resistance on the part of stigmatised populations and communities—in spite of the fact that empirical studies of empowerment and social mobilization in response to HIV and AIDS have clearly demonstrated that the most effective and powerful responses to the epidemic ... have taken place precisely when affected communities have mobilized themselves to fight back against stigmatization and oppression in relation to their lives” (Parker and Aggleton, 2003, p 21).

Responding to this, this research is based on a methodological approach where the process (of participation, of consultation, and of understanding documenting human rights realities) becomes just as important as the product or outcome. As such it seeks to listen to, capture and illuminate some of the complexities of intersectional identities, the temporal experiences and perceptions of human rights amid the daily realities of life. To an extent this approach follows Bevir (2006), who discusses the validity and concept of narratives in relation to interpretation and ‘situated agency’ in research⁴:

“In explaining change, interpretivists do not privilege their academic accounts of the world; rather, they again offer interpretations of interpretations, concentrating on the subjective and intersubjective understandings of the actors who bring about the change” (Bevir, 2006, p 289).

Research Methods

The combination of research methods seeks to engage the ‘situated self’ in the research process—for the co-inquirers, for the participants, for myself, as well as for the thematic focus of the research. Key ingredients include:

- 1) **Participatory Action Research.** The process will be founded on principles of ‘reflective practice’ and ‘praxis’ and sought to provide concrete suggestions for the future as well as creating a space for thoughtful and critical reflection about each of our individual roles as part of the research team (Schön, 1983; Kolb and Fry, 1975; Freire, 1972). According to the framework proposed by Reason and Bradbury (2005), this research will include all three levels of action research practice, where first person action research practice refers to the ability of researcher to foster an inquiring approach to his or her own life; second person action research practice refers to the ability to inquire face-to-face with other people about issues of mutual concern (e.g. improving personal and professional practice) and could include establishing communities of inquiry; and third person action research practice refers to extend relatively small scale projects to create a wider community of interest e.g. writing and reporting or performing results of enquiry and describing process (p xxvi).
- 2) **Life story peer-interviews.** Oral life histories will be digitally recorded and transcribed, which will enable people to participate in the research regardless of their literacy levels. The process will enable a more relaxed setting for the research—removing the physical barrier that a pen and paper can create—and assist in creating rapport between the interviewers and narrators. The life story component of the research will be actively supported by me, but run by the co-inquirers to remain consistent with the ethos of this part of the research being peer-interviews and led by and for people living with HIV. There are some possible limitations of peer- or insider- interviewing, such as bias or disclosure or peer pressure, which will be considered by the action research team in the preparation and design of the life story collection. The peer-interviewing approach was chosen for three main reasons: First, given that HIV is often stigmatised, and touches on issues and emotions that can be difficult to talk about, the peer-dynamics of the interview will hopefully foster openness and a sense of ease, while also enhancing the depth of insight and quality of experience for the participants in the interview process. Second, recognising the differences between people living with HIV, to facilitate space for reaching out to others they might not otherwise have met and opportunities for the interviewers to reflect, share and learn during the interview process. Third, to ‘perform’ the core ethos of the methodological approach as being led by people living with HIV.
- 3) **Policy Level Key Informant Interviews.** Semi-structured qualitative interviews will be conducted with key informants that will complement the insights from the life stories and action research. I will interview representatives from the National AIDS Council, the Ministry of Health, Ministry of Justice, Law Society, lawyers, health care providers, community leaders, representatives from civil society organisations advocating and working on issues relating to HIV, stigma and human rights, and leading national academics.

⁴ Note, Bevir is referring only to subject of research rather than situated agency among research participants in the act of telling their stories.

- 4) **Sites of Stigma (Photo Mapping).** To triangulate the narration of stories (past) with the present, as well as to celebrate the diversity of the narrators and interviewers participating in the research project, I will facilitate an activity to visually depict sites of stigma. This will draw on participatory photo mapping methodologies (cf PhotoVoice, www.photovoice.org) as well as portrait photography.
- 5) **Review of key policy documents and grey literature.** To deepen the contextual understanding of the dynamics of the country's HIV epidemic, key national policy documents will be analysed such as the UNGASS review reports (official and shadow) since 2000 if available, the National HIV Prevention Strategy 2009-2013 (NAC, 2009), the draft HIV Bill, and other key documents relating to HIV, legal frameworks and human rights. This will build on themes discussed in the literature review such as self/society, freedom/constraint, temporality and consciousness. I will complete the document review in consultation with the co-inquirers (if they are interested!) and key themes and/or insights will be discussed among the group. In particular I will review the documents relating to two overarching themes:
 - a. The visibility of people living with HIV and the most affected communities in the language of the documents (for example reference to the GIPA principle and/or the participation of representatives of people living with HIV and the most affected communities in the drafting or reviewing of the documents)
 - b. If and/or how 'stigma' is referred to and identified (or not) as a strategic priority

The findings from the Life Stories and qualitative research will be triangulated with the findings from *The People Living with HIV Stigma Index* (www.stigmaindex.org).⁵ The core principles underpinning *The People Living with HIV Stigma Index* are that it is a research and advocacy initiative that is by and for people living with HIV—the process has been just as important as the product. The international initiative is coordinated by the International Planned Parenthood Federation (IPPF), in partnership with the Global Network of People Living with HIV (GNP+), the International Community of Women living with HIV (ICW) and the Joint United Nations Programme for HIV and AIDS (UNAIDS). Championing a community research model, the power of the research process lies in the community of people living with HIV—those interviewing as well as those participating—in completing the questionnaire and driving each stage of implementation. This peer-interviewing approach puts people living with HIV at the centre of the process, the interviews aspire to be empowering for the interviewers and for the participants. The core of the initiative can be summarised in 4 'P's: that is, the process was just as important as the product, that it was led by people living with HIV, and that it guided by a partnership. The questionnaire captures how people have experienced—and been able to challenge and overcome—stigma and discrimination relating to HIV over a 12 month time period.

In addition the research will be guided by a steering advisory group including representatives from the Malawi National Network of People Living with HIV (MANET+), UNAIDS Malawi, the Family Planning Association of Malawi (FPAM), the United National Population Fund (UNFPA), the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) and IPPF.

Confidentiality and Informed Consent

Every possible step will be taken to ensure that confidentiality is assured for the narrators in the oral history project (if they desire). That is, for people consenting to participate and who wish their stories to remain confidential, I will ensure the following steps are taken to prevent any personal information from being known to people outside the research team:

- Informed consent forms explicitly completed by all narrators (including those who do not complete an interview or choose not to participate even after the interview has commenced)
- All consent forms will be kept separate from all other documents relating to the research
- All members of the Action Research Team and Interviewers will sign a confidentiality agreement
- Each interview will be recorded, translated from Chichewa (unless the interview is conducted in English) and transcribed. This is to ensure that the research represents each story in the words chosen by the narrator at the time of the interview. If the narrator wishes, their name will be changed and other key identifying features of the story to ensure anonymity.

⁵ I have been involved in supporting this project internationally since 2008, and will also be supporting the rollout of the Index in Malawi in 2010-11 led by MANET+.

Ethics

The ethics for the research will be founded on the guidelines of the British Oral History Society⁶ although it has been indicated that these need to be updated. I will also draw from the protocol for informed consent and confidentiality outlined in the guidelines for *The People Living with HIV Stigma Index* (IPPF et al, 2008). The research also adheres to the SOAS Guidelines for Ethical Research.

Affiliation is also being sought with the Centre for Social Science Research (CSR) at the University of Malawi to ensure that any local ethical guidelines are also followed throughout the research process.

Sample

The selection of participants seeks to be indicative not representative, recognizing the truly subjective and individual stories and opinions shared through each of the research methods. As such, the members of the Action Research Team, Interviewers and Narrators will represent a cross-section of people living with HIV and key stakeholders in the national response to HIV.

According to the National HIV Prevention Strategy 2009 – 2013 (NAC, 2009), there are some specific characteristics about HIV prevalence in Malawi that will be taken into consideration and reflected in the sample:

- Gender: HIV prevalence is significantly higher among females than males, except in the 30+ age bracket (where it is approximately equal) (p4). However transgender is not included in the breakdown of figures.
- Geography: HIV prevalence is significantly higher in urban compared to rural areas, and highest in Southern region compared to Northern and Central (p5).
- Job: The highest HIV prevalence is among female sex workers (estimated at 70.7%). However male sex workers are not included in the breakdown of figures (p8).

The Strategy also notes that Men who have sex with Men are a ‘well-known high-risk group with very high incidence’ (p 9) and also have a prevalence of almost double the national average.

Based on these characteristics of the HIV epidemic in Malawi, and taking into consideration the recent legal proceedings relating to Steven Monjeza and Tiwonge Chimbalanga, I will ensure that the Action Research Team, Interviewers and Narrators reflect the diversity of experiences and as closely as possible are proportionate to the national context.

Timeline

	Action Research Team	Life Story Interviews	Policy interviews (Key Informant)	Sites of stigma (Photo mapping)
Oct	22.10.10 Action Research Team meeting (Lilongwe)		Ongoing	
Nov		8.11.10 OT Training (6pm Mon 8 th – 4pm Wed 10 th) 24.11.10 Mid Collection meeting (Lilongwe, ½ day)	Ongoing	
Dec		35 – 40 Life Story Interviews Complete	Ongoing	
Jan		31.1.11 35-40 translated and transcribed stories	Ongoing	
Feb	18.2.11 Action Research Team meeting (Lilongwe, full day)	17.2.11 End of Collection meeting (Lilongwe, ½ day)	1.2.11 30-35 Key Informant Interviews Completed 21.2.11 Gaps identified by Action Research Team	17.2.11 Photo workshop with Interviewers and select participants 19.2.11 Photo work with select

⁶ Oral History Society Ethical Guidelines available at <http://www.oralhistory.org.uk/ethics/index.php#eg> accessed 13 May 2010

				participants (3 days)
Mar			14.3.11 5-10 Additional Key Information Interviews completed as required	
	14.3.11 Photo competition, summary research feedback and appreciation of efforts			

Validation and feedback

I will ensure that the initiative research findings are shared with all participants and direct stakeholders in the research process who will be given the opportunity to comment on the conclusions reached by the action research team and myself. This will include copies of the transcripts of the life stories to be returned to participants (if they wish) and the final executive summary of the results being shared in hard copy with all participants (again, if they wish). This will also include continued collaboration among the research team in the presentation of results in different fora as appropriate, and I will be happy to support the ideas and efforts of others in the team to publish and/or communicate the results and their role in the research process.

Specific external opportunities to review and discuss initial findings will include the end of collection meeting with the peer-reviewers, the ongoing team meetings of the action research team, presentation of initial results at a national AIDS conference, at brownbag sessions with direct stakeholders, and regional and international conferences (such as the International Conference for AIDS in Sub-Saharan Africa (ICASA) in 2011 and the XIVth International AIDS Conference (IAC) in 2012).

Contribution of research

This research will contribute towards a more nuanced and robust understanding of HIV-related stigma at the personal, service and structural levels. It will provide insight into how HIV-related stigma cuts across all elements of the human right to health because it impacts the physical, mental and social well being of individuals in the context of their societies. Moreover the self-reflexive process of collecting the stories and undertaking the research will be illuminative about the extent to which a process can have just as much of an impact on normative value changes (for oneself as well as for society). Methodologically, the research will also contribute to the relatively 'new' community of practice relating to Performative Social Science, share learning with the UNAIDS Monitoring and Evaluation Research Group (MERG), a new technical working group that has been established to develop indicators at the policy and programme level to more effectively measure the nuances of stigma experienced in relation to HIV⁷, and a consultation process just commencing by UNDP about incorporating anti-stigma mechanisms within national AIDS strategies (in addition to anti-discrimination mechanisms which tend to be explicitly designed and implemented). The research findings and methods will also be used to support other national teams working with *The People Living with HIV Stigma Index* by sharing the methodology and collection of stories to support their own advocacy work and deepening their own explorations of the individual nuances of stigma relating to HIV.

Another key contribution will be programmatic implications that can be deduced from the analysis of how HIV-related stigma creates barriers to access and challenges to quality of health services. By working alongside and interviewing healthcare providers—some of whom who are living with HIV—the research will analyse the potential paradoxes within both the individuals and the system that can either reinforce or break cycles of HIV-related stigma.

The research will also provide greater understanding about how individual people view and perceive rights that are very close to them while also illuminating how they generalize and extend those rights to others. The very human and very real inconsistencies that are likely to occur between the two will provide insight into the extent to which the law is limited in its capacity to capture and engage the complexity of an individual situated within their wider social context. In so doing it will provide intensely personalized perspectives about the extent to which the law can effectively ensure human rights and/or be instrumental in responding to HIV-related stigma.

Beyond these ideas, and perhaps most significantly, I hope that the stories and spirit of the research live on and are taken up in unexpected ways by the co-inquirers and participants in the research process.

⁷ This group is part of a partnership between UNAIDS, IPPF, GNP+, the International Centre for Research on Women (ICRW) and Johns Hopkins University (JHU).

Lucy Stackpool-Moore is a PhD student at the University of London—the School of Oriental and African Studies (SOAS) and Birkbeck College—and her research is supported by a Bloomsbury Studentship. Lucy is also an HIV Officer for Stigma with the International Planned Parenthood Federation (IPPF) based in London. She has supported the rollout of *The People Living with HIV Stigma Index* in the UK and coordinated the international partnership that guides the rollout of the Index around the world. With IPPF Lucy also researches and develops advocacy work on HIV and human rights, law and social justice including on issues relating to the criminalisation of HIV transmission. Prior to IPPF, Lucy was with Panos as the HIV Policy and Programme Officer, with a focus on HIV communication, learning and teaching for social change, pastoralism and communication for development. Lucy has worked as youth worker and life skills educator with out-of-school young people in Sydney Australia, as an adult educator in Mozambique and facilitator of outdoor experiential education in the USA, and as a researcher with the Institute of Development Studies and the Sussex University School of Education. Contact lucysmoore@gmail.com; Supervisors at the University of London: Dr Mike Jennings (SOAS) and Dr Matthew Weait (Birkbeck College), and at IPPF: Kevin Osborne.

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ANNEX 6

**NARRATIVES OF HUMAN RIGHTS:
Universal Concepts Brought into Focus Through Lenses of Life Stories**

Honorarium Form
September 2010—March 2011



Interviewer's Name: _____

Location	Name (print)	Signature	Date	Amount received
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				

ANNEX 7

**Referral information sheet
Health Services**

Name of Centre	Location	Contact details	Person to speak to

Sexual and Reproductive Health Services

Name of Centre	Location	Contact details	Person to speak to

Legal Services

Name of Centre	Location	Contact details	Person to speak to

Support Groups

Name of Centre	Location	Contact details	Person to speak to

ANNEX 8

CHECKLIST: PREPARING FOR AN INTERVIEW

1. Confirm the appointment, explain very briefly the purpose of the research, the approach and process that the interview would take (peer interviews, 1-2 hours in length), and that the interview would include an honorarium for transport (MK1,000).
2. Ensure that the agreed place and time for the interview will allow for a good quality interview, free from distraction and disruption and that enough time is available.
3. Confirm the time and location the day before.
4. Charge your digital voice recorder
5. Complete the *Referral List* with relevant local information about services and contact information
6. Take:
 - At least 2 copies of the *Information and Informed Consent Form*, and leave a copy with narrator if they would like.
 - Copies of the *Referral List*
 - Pens and paper or a notebook;
 - Voice Recorder (ensure it is charged)
 - Spare battery for voice recorder
 - Water for yourself and for the narrator
 - Tissues
 - [• Biscuits or sweets if you would like, for yourself and the narrator for energy during the interview]

CHECKLIST: DURING THE INTERVIEW

1. Greet and welcome the narrator and introduce yourself.
2. Give them a copy of the *Information and Informed Consent Form* and read this through with them, answering any questions they might have about the research.
3. If they give their consent for the interview, ask them to sign the form [be sure to complete all sections!]. If they would like, you could give them a copy to keep for themselves.
4. Start the interview. The interview will usually be structured:
 - Welcome
 - Ask how they are today, about their life story and their experiences of HIV ... using the guide questions as needed
 - Ask follow-up questions
 - Provide referrals and *Referral List* if necessary
 - Thank the narrator for their participation.
 - Provide the narrator with an honorarium.
 - Ask the narrator to sign the *Honorarium Form*
 - Thank the narrator again for their time and for sharing their story.
5. If you think a follow-up interview is needed (if the narrator is tired, distracted, upset etc) agree on a suitable time, date and place to meet for a second interview.

CHECKLIST: AFTER THE INTERVIEW

1. Immediately after the interview, complete the *Interview Schedule* (including notes about any referrals made, follow-up meetings agreed, reflections on the interview).
2. Ensure to note if they have requested to be anonymous.
3. Keep the informed consent forms and your interview notes in a secure place that has been arranged for these documents.
4. Spend some time alone reflecting on the interview that you have just conducted: review the notes that you took during the interview, make sure that you recorded all the details that you wanted to and add to your notes if necessary. Write down anything that you feel you need to discuss or need advice about from Lucy.
5. Record your reflections in your *Research Diary*.
6. Transcribe and translate the interview into your *Transcription Notebook*.
7. Keep transcription separate from the informed consent form.
8. Day after interview (or as soon as possible), phone narrator for a quick check about how they are doing and see if they would like to add anything. If need be arrange for a follow-up interview.

ANNEX 9

A) LIFE STORY QUESTION GUIDE (LONG)

Remember this is only a guide – trust your judgment as a trained, empathetic and sensitive interviewer!

Also remember, some of **the best details will come from the follow-up questions**: e.g. 'Can you tell me more about that? How did that make you feel? How has that affected how you are today?'

Thank you for your time, the interview will take approximately between 1 and 2 hours ...

Introduction-Self and someone living openly with or closely affected by HIV, researching with Lucy, PhD Uni London, HIV and Human Rights, Stigma Index

Explain consent form

Is it OK to record? Might need to arrange follow-up interview, break for tea etc OK...

1) How are you today?

How is your life now?

2A) Can you please introduce yourself and tell me about yourself?

Can you tell me a bit about your life history... can you tell me a bit about your childhood?

[Let the narrator choose how they want to tell their story first... Then, if need be, some prompts for areas could be: 'Please tell me about your:

- Childhood – did you have a favourite game to play? What chores did you have to do? Do you have a special memory from childhood?
- Family – parents, siblings
- Education - School experience, favourite subject, most memorable moment from school, university? Did you study what you wanted to study?
- First relationship/ date – where did you go? How did you meet?
- First love – how did you meet? Did it last? Any regrets?
- Marriage... are you married? Single? For how long? Tell me about how you met ...
- Children ... do you have any? Would you like some?
- Employment - are you now doing the things you thought you would when you were younger? If you could be anything what would you be?]

3B) What is the most significant thing that has happened to you in the last 12 months?

a) Can you tell about something you have done that you are very proud of?

4) Please tell me about your experiences of HIV.

a) What meaning you make of HIV in your life?

b) What are people saying about HIV in Malawi these days? Is this different from 5 years ago?

[Let the narrator choose how they want to tell their story first... Then, if need be, some specific questions and follow-up prompts for areas could include on specific themes:

4A: Can you tell me more about your experiences with health services?

- Going for testing ... Why/ when/ where were you tested? Was it your decision?
- Receiving an HIV positive diagnosis ... how did you feel? Do you feel the same now as then about your diagnosis? Had you tested before for HIV before you were diagnosed?
- General experiences ... What services do you use ... where/ when/ how often? What is the quality of the health care you receive? Has HIV affected how you access health services? Experiences of specific services eg prenatal care, GP, emergency, dentist, HIV services, TB etc]
- How did your family welcome the news about your HIV status?

4B: Can you tell me more about who and how you disclosure your status to?

- Do you talk to about HIV... and if so with who and about what kinds of things? How often?
- How open are you about your HIV status?
- Who did you tell first? Why them? What was their reaction? Has anyone ever told someone else about your HIV status without your consent? Do you find disclosure an empowering experience?
- Sources of support ... who do you go to for support relating to HIV? Is this same as for other things in life (like relationship advice, emotional support etc?) Why do you go to them/ there?

- Under what circumstances/conditions/ do you feel that you should disclose your HIV status? To whom? Why/ why not?

4C: Can you tell me more about the impact of HIV on your life?

- Has (or how has) HIV had an impact on how you think about
 - o Relationships
 - o Having sex (with your partner? With casual partners?)
 - o Having children
 - o Seeking employment
 - o Your hopes for the future]

5) What do you think is the biggest challenge facing the response to HIV in Malawi in 2010? Please explain...

- a) What one piece of advice would you give the government of Malawi to improve the response to HIV?
- b) What about to the local authorities?

6) Have you ever experienced being treated differently because of your HIV status?

- a) Have you heard of 'stigma'? If so how would you describe stigma?
- b) Have you ever experienced stigma relating to HIV? If yes, please tell me about it...
- c) Have you ever experienced stigma relating to anything else?
... if no (for either or both of above questions), please tell me about why you think that has been the case
- d) Do you think HIV-related stigma in this region is different or similar from other places? Why/ why not?
- e) Do you think men and women experience HIV-related stigma differently? Please explain...
- f) Do you think things are different now compared with 5 years ago in Malawi?

7) Can you tell me a bit about how or if the law influences your daily life?

[Possible prompts include: what kinds of law? The Constitution? Traditional laws? International laws or declarations?]

- a) Has living with HIV affected how you think of the law and its role in your life? Why/ why not?
- b) Do you think the law has a role in the response to HIV in Malawi? Why/ why not?
- c) What do you think of human rights? Do you think they are relevant for your life? Why/ why not?
- d) Do people living with HIV have the same human rights as others?
- e) Do you think that if someone gives HIV to another person then that is a crime? Why/ why not?

8) Can you tell me about your hopes for the future?

[Prompts could include: for yourself? For people living with HIV in Malawi?]

- a) What advice would you give to someone in the Government to improve national policies relating to HIV in Malawi?
- b) What advice would you give to health care providers to improve their HIV services in Malawi?

9) Is there anything else you would like to say?

THANK YOU for your time

Review consent form and ask for signature.

Would you like to be anonymous? **Y/N**

Would like to receive transcript of interview? **Y/N**. Initial findings will be shared in mid 2011

Would you like to participate in follow-up photo research in February [photos of places where stigma is experienced as well as portrait photos]? **Y/N**

Give your contact details (copy of info sheet also with Lucy's). Indicate you will call in a few days to check in.

B) LIFE STORY QUESTION GUIDE (SUMMARY)

Remember this is only a guide – and some of the **best details will come from the follow-up questions**: e.g. 'Can you tell me more about that? How did that make you feel? How has that affected how you are today?]

Thank narrator for their time (interview takes approximately 1-2 hours)

Introduction of Interviewer, Research Project and complete Informed Consent

Is it OK to record? Might need to arrange follow-up interview, break for tea etc OK...

1) How are you today?

2) Can you please tell me about your life history... can you tell me a bit about your childhood?

2A: What are the main influences in how you live your life?

2B: Who inspires you?

3) What is the most significant thing that has happened to you in the last 12 months?

3A: Can you tell about something you have done that you are very proud of?

3B: What is the biggest challenge you face in your life right now?

4) Please tell me about your experiences of HIV...

4A: What meaning does HIV have in your life?

4B: Can you tell me more about your experiences with health services?

4C: Can you tell me more about who and how you disclosure your status to?

4D: Can you tell me more about the impact of HIV on your life?

5) What do you think is the biggest challenge facing the response to HIV in Malawi in 2010? 5A: What one piece of advice would you give the government of Malawi to improve the response to HIV?

5B: What about to the local authorities?

6) Have you ever experienced being treated differently because of your HIV status?

6A: Have you heard of 'stigma'? If so how would you describe stigma?

6B: Have you ever experienced stigma relating to HIV? If yes, please tell me about it...

6C: Have you ever experienced stigma relating to anything else? If yes, please tell me about it...

... if no (for either or both of above questions), please tell me about why you think that has been the case

6D: Do you think HIV-related stigma in this region is different or similar from other places? Why/ why not?

6E: Do you think men and women experience HIV-related stigma differently? Please explain...

6F: Do you think things are different now compared with 5 years ago in Malawi?

7) Can you tell me a bit about how or if the law influences your daily life?

[Prompts: what kinds of law? The Constitution? Traditional laws? International laws or declarations?]

7A: Has living with HIV affected how you think of the law and its role in your life? Why/ why not?

7B: Do you think the law has a role in the response to HIV in Malawi? Why/ why not?

7C: What do you think of human rights? Do you think they are relevant for your life? Why/ why not?

7D: Do people living with HIV have the same human rights as others?

7E: Do you think that if someone gives HIV to another person then that is a crime? Why/ why not?

8) Can you tell me about your hopes for the future?

[Prompts: for yourself? For people living with HIV in Malawi?]

8A: What advice would you give to someone in the Government to improve national policies relating to HIV in Malawi?

8B: What advice would you give to health care providers to improve their HIV services in Malawi?

9) Is there ANYTHING ELSE you would like to say?

THANK narrator for their time. Check consent. Check if they would you like to be anonymous? **Y/N** Would like to receive copy of transcript of interview? **Y/N**. Indicate you will call to check in.

ANNEX 10

INTERVIEW QUESTIONS – KEY INFORMANTS

Thank you for your time, the interview will take 20-30 minutes...

Introduction-Lucy, PhD Uni London, HIV and Human Rights, Stigma Index... Is it OK to record?

- 1) Describe your experience with HIV and Malawi (how many years, main area of work, job title, motivation for getting involved)
 - 2) How do you understand the term stigma? In general and as it relates to HIV?
 - 3) What do you think is the impact of HIV-related stigma in Malawi? (different levels?)
 - 4) How (or if) do you think men and women experience HIV-related stigma differently? Please explain...
 - 5) How do you think HIV-related stigma in Malawi is different from other countries? Why/ Why not?
 - 6) On a scale of 1 to 10, with 10 being the highest, to what extent do you think addressing HIV-related stigma should be a priority within the national HIV response? Why?
 - a. What do you think should be 10 (if not stigma)? Why?
 - 7) How would you define human rights?
 - 8) How relevant are human rights in your day to day work?
 - 9) Do people living with HIV have the same human rights as others?
 - 10) If you had to choose, what would you say is the most important human right?
 - 11) How do you think that the process of documenting human rights can contribute to the realisation of those rights?
 - 12) Do you think the law has a role to play in the response to HIV in Malawi?
 - 13) Do you think the transmission of HIV should be a criminal offence? Why/ why not?
 - 14) Should there be a specific HIV Bill? Why/ why not?
 - 15) When did the Special Law Commission originate?
 - a. In your opinion, why do you think was it initiated?
 - b. Was there a key action/ incident that you think may have triggered its origin? (please explain)
 - 16) Regarding the consultation process,
 - a. What have been the strengths?
 - b. What have been the weaknesses?
 - c. Were the right people involved in the Commission?
 - 17) Why has there been a delay between the publication of the Report of the Special Commission and it being discussed in Parliament?
 - 18) Do you think impetus is building again now around the Draft HIV Bill? (please explain why/ why not)
 - 19) Do you think reactions to the (idea of the) HIV Bill have changed over time? (please explain)
 - 20) If the HIV Bill is passed into legislation as it is, how do you think it will impact:
 - a. The lives of people living with HIV in Malawi?
 - b. You professionally?
 - c. You personally?
 - 21) Other than the Draft HIV Bill, what other laws currently impact the national response to HIV in Malawi? (please explain)
 - 22) What do you think is the biggest challenge facing the response to HIV in Malawi in 2010? Please explain...
 - 23) Anyone else you would recommend that I also interview?
 - 24) Anything else you would like to add?
-

KEY FINDINGS

1. The meaning of HIV in life is diverse and part of complex lives and identities.

Being HIV-positive, I don't think we should be saying that the person is 'already dead'. No! You are only starting a new life as long as you conduct yourself as advised by the doctor. LS24



The impact has been, ah... ah... that it has built in me some... courage that I never had... some strength that I would have lost... unknowingly or knowingly. Ah... but to be ignorant about yourself is the worst thing in life. You better know yourself. LS33

2. Acceptance of HIV

So, acceptance is a... like a major step to... to everything else. Eh... because once you accept your status then you can already start looking for... for solutions. LS17



We should also see that the top position people should also be exemplary... If the Minister says 'yes, I am HIV-positive', I think the other people may say that 'if this one tested HIV-positive why am I suffering? I should also go for an HIV test.' Sure. LS22

I know that HIV is real. It means that if you have HIV then it is not the end of your life if you only accept you can live.

3. HIV touches everybody's life in Malawi, and courageous leadership is needed at every level to overcome stigma

Most people in policy-making positions, still up to now... my impression is they still have the mentality that HIV is not for them. LS17



HIV IS NOT THE WHOLE STORY, IT IS PART OF LIFE

BACKGROUND

For the estimated 900,000 people who are living with HIV in Malawi according to the NAC, stigma and discrimination pose a real threat to the realization of the human right to health. Living with HIV today is different for everyone - life is multi-dimensional, and all individuals will find themselves in different situations where they have relative positions of visibility and/or engagement and/or power. Yet HIV-related stigma remains a significant challenge in the Malawian national response to HIV.



“ We must continue our efforts to deploy antiretroviral treatment to those affected, and we should not be complacent about fighting stigma”

PRESIDENT BINGU WA MUTHARIKA, 2011



RESULTS

HIV has different meanings in everyone's life, ranging along a spectrum from very positive to very negative. Challenges of addressing stigma include internalised stigma and self-esteem, ongoing incidents of discrimination, and knowledge of and access to laws that could protect people living with HIV (such as the Constitution). The formal legal system as well as traditional system is limited in its ability to respond to HIV-related stigma and broader issues of justice. Access to justice is unequal, and women experience stigma to a greater degree than men in Malawi with less opportunity to seek legal or other redress.



People that are HIV-positive, like me, have the right to do anything... to be employed, to seek medical care at a hospital, or to own a site at the market, or any other right - it exists, like it applies to any other person. LS23

METHODS

Between October 2010 and March 2011, 42 qualitative life story interviews were recorded as part of a participatory action research project that supported *The People Living with HIV Stigma Index* research in Malawi. Peer-interviews were conducted in each region, drawing on an equal number of men and women, and including some men who have sex with men, sex workers and former prisoners, with the exclusionary criteria that all participants were people living with or closely affected by HIV. The participants represented all income levels, ranging from subsistence farmer to national celebrity.



The research explored processes of documenting human rights, the extent to which HIV-related stigma creates barriers for realising human rights, and the role of the law as a mechanism for tackling stigma.

RECOMMENDATIONS

Initiatives to address HIV-related stigma may have been mis-directed in the past by focusing almost exclusively on a person's HIV status - the life stories illuminate much more complicated, passionate and nuanced lives in terms of highs and lows of living with HIV.



Efforts to address HIV-related stigma should focus on love, compassion and wider issues relevant in someone's life beyond the positive diagnosis. In so doing, efforts to address stigma must engage the whole story.

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This research was part of PhD research by Lucy Stackpool-Moore at the University of London (SOAS and Birkbeck College, Dr Mike Jennings and Professor Matthew Weait) and the University of Malawi (Dr Alistair Munthali, Centre for Social Research).


TUPE159



Lucy Stackpool-Moore (IPPP)
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STIGMA
AND THE PROPOSED HIV
LEGISLATION IN MALAWI

"The intention may not be cruel and inhumane, but the impact may be" (117)



"The Commission considered that the peculiar nature of HIV and AIDS requires a specific penal provision and recommends accordingly."
(Malawi Law Commission Report 2006, p. 11-12)

Methodology

Participatory Action Research was undertaken during 2010/11 in Malawi to document the presence/absence of the law in the as part of the national response to HIV. The study draws on legal analysis, interviews with 10 of the Law Commissioners in Special Law Commission on HIV/AIDS, responses from 58 key informants and life story interviews (20 included of a total of 42) people living with and affected by HIV. Participants included an equal distribution of men and women living with HIV, MSM, sex workers, and policy makers. In the study stigma was viewed as a process of devaluation (Goffman, 1963).

Background

The law can have both positive and negative implications for the national response to HIV in Malawi. A Special Law Commission on HIV was appointed in 2006 to develop a legislative framework for the national HIV response but it has not yet been enacted by parliament.

Globally there is a paucity of information relating to the motivations and aspirations of lawmakers and the rationale behind legislative provisions that criminalize HIV transmission. This research draws on the perspectives of the majority of the Law Commissioners involved in drafting the proposed HIV Bill in Malawi.

Protection or punishment? The proposed HIV Bill straddles both, containing provisions that explicitly protect the rights of people living with HIV as well as those that explicit punish people living with HIV.

Results

The Law Commissioners unanimously cited the criminalization of HIV as one of the most controversial aspects of the proposed HIV legislation. Among the Commissioners, while acknowledging that it was a 'thorny' issue, the majority supported criminalizing HIV transmission (89%, n=8). This was consistent with the opinions and perspectives of people living with HIV interviewed in this research.

Most Commissioners cited reasons relating to retribution and 'justice' for deliberate infection, rather than prevention, as the main reasons for proposing criminal sanctions for HIV transmission. Several Commissioners noted that there would be enforcement challenges.

The responses indicate an implicit motivation to include the problematic provisions – using at times sensationalised language – because of the symbolic power of the criminal law. Four key reasons came out from the Commissioner's responses:

- 1) Agency, and escalated responsibility of people living with HIV to prevent HIV transmission;
- 2) Protection for people who are HIV-negative;
- 3) Retribution for people in response to deliberate HIV-transmission; and
- 4) Framing of HIV in terms of death and illness (even though ARVs are available).

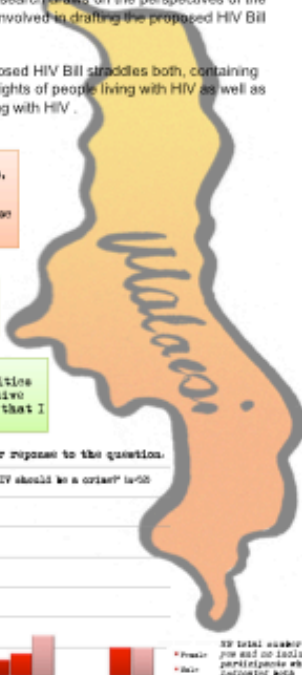
Conclusion

The proposed HIV Bill in Malawi straddles a tension between intention and impact—the desire to enact a law to protect human rights and strengthen the national response to HIV, while potentially taking away those rights from certain groups and fueling HIV-related stigma.

However the extent to which a law relating to HIV might have a normative power is questionable in a country where there is a limited consciousness of the law in the everyday lives of people living with HIV, a lack of a widespread understanding of the traditional legal system and constrained access to formal legal redress for most people, and where the Constitution is seldom enforced. Nonetheless the law is imbued with symbolic power which is imbued with stigma.

Recommendation

To enhance (and not undermine) the national response to HIV, laws should protect all – not punish some.




Malawi

Number participants and their response to the question: "Do you think the transmission of HIV should be a crime?" (n=28)

Response	Yes	No	Agreed	No Answer
Male	10	1	1	1
Female	10	1	1	1
Total	20	2	2	2

38 total number for the set of indicators
 * Male
 * Female
 * Total



"I, as a woman that lives in the village, I do not have a chance to know what the law says because I rarely find batteries for my radio. And when we go to support groups where we meet we don't discuss such things. So do not have that chance. So only talk about positive living, not about the law." (1214)

"It is very difficult to know whether one has actually passed on the HIV/AIDS directly, so how do you criminalize somebody? Yeah but if indeed it could be proved beyond doubt that one has been infected deliberately, yeah" (127)

"Especially if one has the knowledge one knows what HIV does and then, intentionally you know by pure malice you decide to do that, I think for me it's criminal. Why would you want to infect somebody with a life long illness that they can actually avoid? Even if we know now there are drugs that alleviate whatever they are taking those drugs for life—so that's where I get the bad feeling that you know you are really not being very good to the other person." (129, my emphasis)

"That one who deliberately transmits and infects others, with the virus, must be criminalized because he is doing it deliberately. Because he has killed the future of somebody." (137)

"I don't think a mother would want her child to have a chronic illness. Every mother wants a perfect child." (139, my emphasis)

"Human rights must be practiced with responsibility where the responsibility is there. Because I assume if I am positive one of my responsibilities is to accept that I am positive." (134)

"Not only as a human rights lawyer but also from looking at the context of HIV in Malawi, honestly, criminalizing HIV does not seem correct... the issue is when you have a bad law it is more broken than honored" (114)

"It's not only people who are stigmatized each other, even our policies can stigmatize the commission on the ground." (110)

"The intention may not be cruel and inhumane but the impact may be"

Stigma and the proposed HIV legislation in Malawi

Lucy Stackpool-Moore, David Kamkwamba, George Kampango, Ruth Kondecha, Milliam Simkonda Kumwenda, Gift Trapence

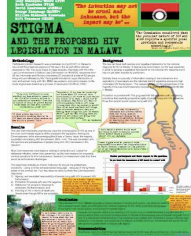
National AIDS Commission
Lilongwe
20 November 2012

"Laws and institutions must go hand in hand with the progress of the human mind."

Thomas Jefferson

Quotation on one of the panels on the wall of the Jefferson Memorial in Washington, D.C.

This presentation—focusing on HIV and the law



- This presentation is based on a poster presentation at the Washington IAC, July 2012
- Focuses on aspects of the research findings relating to:
 - The presence/ absence of law in everyday life
 - The proposed draft HIV
 - The provisions relating to the criminalization of HIV transmission, exposure and non-disclosure
- Outline of presentation:
 1. Summary of research process
 2. Overview methods
 3. Context
 4. Key findings
 5. Recommendations

1. Summary of Research Process Methodology—Action Research

- Action Research
- Interviews conducted 6 months (October 2010 – March 2011)
- Part of research project, PhD, with University of London (Lucy Stackpool-Moore): *"Narratives of Human Rights: Universal Concepts brought into focus through the lenses of life stories"*
- Supporting and part of the national rollout of *The People Living with HIV Stigma Index* in Malawi

1. Action Research team



				
David Kamkwamba Co-ordinator of UNAIDS, partner	Ruth Kondecha Senior National Manager for PMAM	George Kampango Research and Advocacy	Milliam Simkonda Stakeholder and actor	Gift Trapence Executive Director of CDDO

2. Overview of Methods

- A total of 100 interviews, of which this analysis focuses on:
 - 20 life story interviews (people living with and closely affected by HIV) (LS)
 - 22 opinion leader interviews (representatives from health, legal, UN, government and NGO sectors) (OL)
 - 10 law commissioner interviews (involved in the Special Commission on HIV/AIDS 2008) (LC)

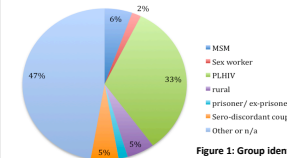
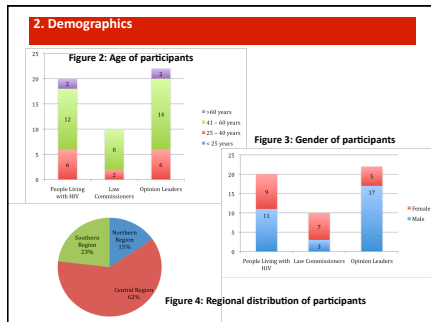


Figure 1: Group identity of participants



3. Context—proposed draft HIV Bill

- Special Law Commission on HIV/AIDS
- Report that included a proposed draft HIV Bill released in 2008
- Founded on principles of non-discrimination and public health
- Yet includes “thorny” provisions that discriminate and undermine public health

3. Draft HIV Bill – protecting rights

“An Act to make provision for the prevention and management of HIV and AIDS; to provide for the rights and obligations of persons infected and affected by HIV and AIDS; to provide for the establishment of the National AIDS Commission; and to provide for matters incidental thereto or connected therewith.” (MLC 2008, p89, my emphasis)

3. Draft HIV Bill – strong foundations

Non-discrimination

“6. (1) Any form of discrimination on the basis that another person is infected with HIV or is suffering from AIDS or is perceived to be infected with HIV or perceived to be suffering from AIDS is hereby prohibited” (MLC 2008, p91).

3. Draft HIV Bill – rights and obligations

“The Bill, further, seeks to balance rights and obligations of people infected and affected by HIV and AIDS on the one hand and obligations of the State to protect the public at large from the epidemic.” (MLC 2008, p 17).

- Whose rights?
- Whose responsibilities?
- Obligations of the ‘public at large’?

3. Draft HIV Bill – Impact?

“The intentions are good... But I am also looking at the repercussions... I understand the intentions, the intentions are good, but I think the results of that would be very bad.” (OL 14)

- Fuel stigma
- Target groups already marginalized through law (e.g. sex workers, men who have sex with men)

4. Key Findings—role of law in response to HIV

- Almost all participants (50 of the 52) expressed an opinion that the law had a role to play in response to HIV
- Three main reasons:
 1. Normative power of law (good governance)
 2. Protect people living with HIV
 3. Implement national HIV policies
- Only 2 participants questioned relevance of law specifically to HIV:
 - Law ill-equipped to meet personal and cultural context
 - Need to ‘normalize’ HIV and no need for a specific HIV Bill (covered for example by Constitution)

4. Key Findings—presence of law in everyday life?

- The formal legal system is often invisible or misunderstood by people living with and closely affected by HIV
- Although all life story participants perceived the law to have a role to protect them in relation to HIV
- All but two had experienced stigma and discrimination relating to HIV
- None had engaged law to effectively seek redress and enforce their rights
- Strong bias remained for traditional authorities
- These results are also consistent with the findings from *The People Living with HIV Stigma Index* in Malawi that indicated that although 20% of people living with HIV had recognized that their rights had been violated in the previous 12 months, and of these 70% had not sought any legal redress. Of those who sought legal redress, less than a third achieved a resolution of the issue (Chirwa et al., 2011, p76).

4. Key Findings—challenges

- 1) The law is not often enforced
"We make laws but we don't follow them... the laws are there...but the problem is we have not accepted to saw HIV is among us" (LS2)
- 2) When the law is enforced, it targets certain people
"On paper you have got 100% rights...on the ground it is 50% taken away" (LS8)
"The law should be consistent with the aspirations and needs of Malawians... even when they are HIV positive" (LS4)
- 3) Law does not easily or consistently respond to different aspects of someone's identity
"As a woman that lives in a village, I do not have a chance to know what the law says" (LS14)

5. Conclusion

"The intentions are good, but I think...the results would be very bad" (OL14)

- Draft HIV Bill: tension between intention and impact
- Desire to protect human rights and promote health
- Yet fuels stigma and undermines rights for people living with HIV through "thorny" provisions

6. Recommendations

1. **Support** efforts that recognize complexity of law in everyday life
2. **Listen** to community resistance to "thorny" provisions
3. **Question** if the law is the most appropriate tool for supporting national HIV response

Be inspired by Thomas Jefferson:

Laws and governance should reflect progress of the human mind and be based on compassion, dignity and generosity (not stigma and punishment)

THANK YOU – ZIKOMO KWAMBIRI

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Special thanks to:
 •College of Medicine: Dr Maureen Chirwa
 •University of London: Dr Michael Jennings and Professor Matthew Weait
 •University of Malawi (CSR): Dr Alister Munthali
 •IPPF: Kevin Osborne

**"HIV is not the whole story,
it is part of life"**

**Universal concepts of human rights brought
into focus through the lenses of life stories in
Malawi**

Lucy Stackpool-Moore, David Kamkwamba, George Kampanjo,
Ruth Kondecha, Milliam Simkonda Kumwenda, Gift Trapence

National AIDS Commission
Lilongwe
20 November 2012

This presentation—focusing on HIV and life

• This presentation is based on a poster presentation at the Washington IAC, July 2012

• Focuses on aspects of the research findings relating to:

- The meaning of HIV in someone's life
- The presence/ absence of law in everyday life

• Includes:

1. Summary of research process
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Figure 1: Group identity of participants

2. Demographics

Figure 2: Age of participants

Figure 3: Gender of participants

Figure 4: Regional distribution of participants

3. Context—HIV and life

- HIV has different meanings in everyone's life, ranging along a spectrum from very positive to very negative.
- Just as there are more than 7 billion people in the world living varied lives in very different places, with different sounds and smells and daily routines, so too is their diversity in the daily realities of the 34 million people estimated to be living with HIV around the world, and indeed of the one million HIV positive people living in Malawi.
- This may seem a very obvious starting point, but one which all too often is overlooked in efforts to address HIV-related stigma and discrimination.
- Initiatives to address HIV-related stigma have often focused (arguably in a blinkered way) almost exclusively on a person's HIV status.
- To date most interventions overlook this contextualized complexity and focus on individuals, in assumed 'static' situations, aiming to increase the knowledge and empathy of potential stigmatizers or improving the ability of people living with HIV to cope.

3. Context—HIV-Stigma remains a challenge in Malawi

The results showed that while stigma remains a challenge in Malawi, HIV is part of everyday life and only one aspect of nuanced and complex identities of the people whose lives it directly affects.

"I want to agree with the Chairperson of MANET+ that stigma and discrimination against People Living with HIV (PLHIV) still exists in this country. Therefore, the government will continue to address the legal environment to ensure that People Living with HIV are neither stigmatized nor discriminated"
(President Joyce Banda, NAC, 10 October 2012)

3. Context—Policy versus participant priorities

- Participants identified different priorities compared with the NAF in the current national response to HIV in Malawi
- Stigma prioritized by participants

Priority areas identified in the Extended National HIV and AIDS Action Framework (NAF) 2010 – 2012 (Malawi Government, 2012, p.9)	Biggest challenges identified by participants in this research (October 2010 – March 2011)
1) Prevention and behaviour change	1) Prevention
2) Treatment, care and support	2) Stigma
3) Impact mitigation	3) Health services and infrastructure
4) Mainstreaming and decentralization	4) Funding and resources
5) Research, monitoring and evaluation	5) Governance and leadership
6) Resource mobilization	
7) Policy and partnerships	

4. Key findings HIV is part of life

"Life is basically what you make. So if you want to make it gloomy or sad indeed life will be gloomy. If you want to make you know jovial it will be like that. It's it's... nobody would...has control of...over your life other than yourself. So yah... I am driving my life with the help of God. So I have to look at life in a positive way." LS15

"As a woman living with HIV, yah I am found HIV positive, it does not mean that I cannot have a feeling for sex. I must have it because I am a human being—it is nature." LS14

"I have good health; I am gaining weight; I am happy, and I am doing my studies. It will be the same with anybody who goes for an HIV test and is HIV positive – they can emulate my example, that they can do any kind of work like anybody else that is HIV negative." LS5

4. Meaning of HIV in life

NEGATIVE "It's not something good. If I had a chance of avoiding it...I would... But its something which I have accepted. Because that's the situation now; so instead of looking may be looking back...just say okay let's look for solutions. And because of that that ah...I find that it's something I can live with." LS15

NEUTRAL "Being HIV positive, I don't think we should be saying that the person is 'already dead'. No! you are only starting a new life as long as you conduct yourself as advised by the doctor." LS240X

"I told him [doctor] that I had done quite a lot of prostitution, and so I wanted to know my status, if I had the virus. 'What if you test HIV positive?' I said there was no problem. He tested me and informed me that I was HIV positive. 'How do you feel?' he asked me. I told him I did not have any ill feelings..." LS14

POSITIVE "The impact has been ah...ah...that it has built in me some...courage that I never had...some strength that I would have lost... unknowingly or knowingly. Ah...but to be ignorant about yourself is the worst thing in life. You better know yourself!" LS1

"When I heard the results I was a very happy person that after such a long period of suffering I decided to be tested to know exactly what was giving me problems in my body" LS5

4. Acceptance

"So acceptance is a...like a major step to...to everything else. Eh...because once you accept your status then you can already start looking for... for solutions." LS17

"It is good to accept it yourself so that even if people can talk about it then you are free at home...no worry about it" LS4.

"I know that HIV is real. It means that if you have HIV then it is not the end of your life if you only accept you can live." LS2

"One thing I think which has helped me is that I accepted it—eh, I think that's what has helped me because even when I knew my status, I have seen people that continue to die, and I have discovered the reason is eh they are not accepting—they are still fearing." LS20

5. Conclusion

- HIV does not have a static meaning in someone's life—it changes over time
- Receiving an HIV positive diagnosis is a transformative experience in someone's life—a moment of reflection (about past and future) and possible turning point
- HIV is part of life.... but it is not the whole story
- People living with HIV are diverse and have multiple identities as fathers, mothers, carers, professionals, politicians, preachers, friends, family, mentors, employees, and lovers...
- Accepting HIV—internally as well as within all levels of society—is a key for overcoming stigma

6. Recommendations

The findings confirm that HIV-related stigma still exists and that stigma is not experienced in a simple way.

It is a complex phenomenon expressed both subtly and overtly, and is subjectively experienced in multiple ways.

Attention should be made to understand perceptions of stigma, the settings in which it is most prevalent as well as the actors most identified as the main stigmatizers, in order to be able to effectively focus efforts to overcome stigma.

Recommendations:

1. Interventions to overcome stigma should focus on the whole person, and not only one someone's HIV status.
2. Efforts to overcome stigma should focus on normalizing HIV...
3. ...While also recognizing the diversity of the lives that HIV affects .

THANK YOU – ZIKOMO KWAMBIRI

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Special thanks to:

- College of Medicine: Dr Maureen Chirwa
- University of London: Dr Michael Jennings and Professor Matthew Weait
- University of Malawi (CSR): Dr Alistair Munthali
- IPPF: Kevin Osborne

HIV, Stigma and the Law in Malawi

Narratives of Human Rights: Universal Concepts Brought into Focus Through the Lenses of Life Stories

Policy Brief

This policy brief outlines a summary of the key findings, results and policy implications from research conducted 2011 – 12 as part of doctoral research by Lucy Stackpool-Moore with the University of London in Development Studies (SOAS) and Law (Birkbeck College) and the University of Malawi Centre for Social Research (CSR). The research was guided by the research assistance of David Kamkwamba, George Kampango, Ruth Kundecha, Milliam Simkonda Kumwenda and Gift Trapence and the mentorship of Dr Alister Munthali (CSR), Dr Maureen Chirwa (College of Medicine), Dr Michael Jennings (SOAS) and Professor Matthew Weait (Birkbeck).ⁱⁱⁱ

“I want to agree with the Chairperson of MANET+ that stigma and discrimination against People Living with HIV (PLHIV) still exist in this country. Therefore, the government will continue to address the legal environment to ensure that People Living with HIV are neither stigmatized nor discriminated.” (President Joyce Banda, NAC, 10 October 2012ⁱⁱⁱⁱ)

PURPOSE OF THE RESEARCH

The underlying hypotheses of the research is that while universal principles of human rights may be *useful* for generating sympathetic international and national policy rhetoric, they may have little impact for *real people* involved in their daily life struggles to realise their human rights. All the same, people have an intrinsic sense of *justice* defined by their own complex identities, cultures and contexts. This research suggests that in order for the human right to the highest attainable standard of health to be realised, as promulgated in international law and adopted in national legal frameworks, the underlying inequalities that prevent or perpetuate ill health need to be identified and transformed at the iterative micro and macro levels of individuals within their societies.

Stigma relating to HIV can be a violation of human rights –undermining an individual’s realisation of “the highest attainable level of physical and mental well-being” (as defined in the WHO Constitution from 1946) and most explicitly in its enacted form as specific experiences of discrimination. The hypothesis underpinning this research is that initiatives to address HIV-related stigma may have been misdirected in the past by focusing almost exclusively on a person’s HIV status rather than a holistic sense of their identity, and in so doing may have contributed to fuelling rather than abating stigma relating to HIV.

International declarations have successfully raised awareness about human rights and placed issues of social justice, (in)equality and obligation firmly on the table of international relations and national government policies. Yet their very indiscriminate universality means that they risk losing purchase in assisting the struggles of individual lives. Without a foundation in the voices and realities of people, and a holistic sense of their lives, the universal principles risk being distant and abstract from the lives of many, and a blunt instrument for actually achieving human rights.

KEY MESSAGES FROM FINDINGS

1. The results showed that while stigma remains a challenge in Malawi, HIV is part of everyday life and only one aspect of nuanced and complex identities of the people whose lives it directly affects.
2. The proposed HIV and AIDS (Prevention and Management) Bill in Malawi manifests a tension

between intention and impact—the desire to enact a law to protect human rights and strengthen the national response to HIV, while potentially taking away those rights from certain groups and fuelling HIV-related stigma.

3. Legal consciousness was not apparent in the everyday lives of most of the people living closely with HIV in this research, and significant challenges to law enforcement and access to justice remain.
4. The potential impact of the proposed HIV and AIDS (Prevention and Management) Bill at the personal level could be devastating in creating barriers for testing, internalizing stigma, and limiting opportunities for disclosure for fear of reprisal through the law—for example through the potential application of the criminal law to HIV transmission, exposure and non-disclosure (sections 43 – 5 of the draft Bill).
5. The law does have a symbolic potential in defining aspirations for socio and economic changes that may address the underlying determinants of ill health and protect human rights.

METHODS

This research focuses on a case study exploring the human right to health within the context of lived experiences of HIV, the law and stigma relating to HIV in Malawi. This one-country qualitative case study action research involved data collection during a 6-month period (October 2010 to March 2011). It investigates how an empowering process of documenting human rights (their conceptualisation, as well as moments of realisation and violation) can contribute towards personal and social transformation. The research is interdisciplinary, drawing on critical legal theory, sociology, anthropology and social psychology for the theoretical framework.

The empirical component of this research is a one-country case study (Malawi) where data collection occurred during a 6-month period (October 2010 to March 2011). An action research approach was undertaken whereby a team of 6 people, guided by a steering group, simultaneously conducted interviews and participated in self-critical and reflective discussions. The analysis draws from a combination of semi-structured key informant interviews with opinion leaders (n=48, 42 of which were included in the final analysis) and law commissioners involved in drafting the proposed HIV Bill (n=10), loosely structured life story interviews (n=42, of which 20 were included in the final analysis), documented reflections from the action research team, and a review of key legal and policy documents. A combination of purposive and snowball sampling approaches was used to ensure a diverse group of participants. Probability-based random selection was used to identify some of the life story participants as follow up from the national survey *The People Living with HIV Stigma Index* [1].

Malawi was chosen as a case study based on key considerations, including high HIV prevalence, the enthusiasm and availability of local co-inquirers to participate in the action research, the national experience in implementing *The People Living with HIV Stigma Index* [1].

BACKGROUND

The law, on its own, is limited in its capacity to capture and engage the complexity of an individual situated within their wider social context [2]. The life stories that are at the core of this research contribute depth, nuance and diversity to understanding the dynamics of a wider environment that can both facilitate as well as impede agency, human rights and quality of life at different times and in different circumstances for individual lives. By understanding the diverse and at times competing dynamics of individuals within social contexts, we can piece together an understanding of possible ingredients that together can produce rights-based and health-promoting individual and social change [3].

The law in relation to HIV has prominence in the formation and regulation of moral norms—not only in regard to human rights, but also in regard to criminalization, the policing of sexuality and intimate behaviours, and the production of stigma. This research focuses on the potential and

impotence of the law to transform social, economic and - to an extent - political inequalities that are limiting the human right to health in the context of HIV in Malawi.

Human Rights in Malawi

The 1964 Constitution contained a Bill of rights that guaranteed human rights [4]. However, significantly, these were limited solely to civil and political rights, and it was not until the new Constitution was adopted in 1994 that social and cultural rights were also included [5]. The 1994 Constitution included a comprehensive Bill of Rights that created an environment conducive to ratification and domestication of the most important international human rights treaties [5].

HIV is mentioned only twice in the latest National Report submitted to the Human Rights Council Working Group on the Universal Periodic Review in 2010 – once, as the seventh national priority (grouped together under the enormous umbrella of “public health, sanitation, HIV and AIDS management”) and the second time, under a section on children’s rights [4; p9]. HIV is not mentioned at all in the section on the “right to health” in this National Report. However an “Essential Health Package (EHP)” is identified as the implementation mechanism for the right to health in Malawi, and described as a package that “contained the priorities of the Ministry which addresses major causes of morbidity and mortality that disproportionately affect the poor and most vulnerable groups in society” [4; p8]. In other words, according to the National Report, the EHP is designed to address the wider structural determinants of health that have been linked with vulnerability to HIV [7].

Notably however, in none of the 100 interviews undertaken as part of this research, was the EHP mentioned. This is surprising, given that the issue of the human right to health was explicitly discussed in the interviews, which were held with Ministry representatives who were included in the sample, including from the Ministry of Health, Gender, Agriculture, Justice and the Office of the President and Cabinet. While this finding is not the focus of the analysis that follows, it suggests that there is a disconnect between the notions of the policy framework enabling the human right to health and how it is implemented and perceived in reality.

National HIV context—prevalence, stigma and daily life

According to the latest Demographic Health Survey in Malawi (MDHS), conducted in 2010 and published in 2011, the national HIV prevalence has reduced over the last 6 years from an estimated 12% in 2004 to 10.6% in 2012 [8, 9]. The estimated HIV prevalence remains highest in the southern region, doubling the estimated prevalence of the central and northern regions [9]. HIV remains a feminized epidemic in Malawi in 2010 as it was in 2004, with HIV prevalence estimated as 12.9% among women and 8.1% among men [8]. It also remains urbanized, with HIV prevalence in urban areas double that of rural areas [9].

Accurate estimates of HIV prevalence and incidence remain a challenge in Malawi as in every country. In terms of stigma, the MDHS interestingly notes that there is little alignment between current HIV status as determined by the MDHS HIV test compared with self-reported HIV status of participants [8; p214]. For example among women, 9% indicated that their last HIV test had been negative but the HIV test undertaken as part of the MDHS was in fact positive. This was even higher for women who had declined to disclose their HIV status in the interview or had said it was unknown, where 12% were HIV positive according to the HIV test undertaken as part of the MMHS [8; p213]. It is noted in the report that this could be for a number of reasons beyond the scope of the MDHS, including an allusion to the potential role of stigma, which was referred to as “a discomfort about disclosing” HIV positive status to an interviewer [8].

Significantly for this research, the latest report from the Malawi Government on HIV does make explicit links with the Constitution, or the proposed HIV Bill, and generally refers to some of the challenges in implementing international human rights principles in practice [9; p10–11]. The report states generally that the national HIV policies have been “aligned with the Constitution” while also acknowledging the challenges of a lack of “operative legislation aimed at ensuring protection, participation and empowerment of individuals within the context of the HIV and AIDS epidemic” [9]. The report does not however mention limited access to justice for many Malawians, nor the lack of

consciousness of legal frameworks in everyday life in Malawi, nor the challenges of law enforcement that was so prominent in the findings of this research. The report draws on evidence from the MDHS as well as the findings from *The People Living with HIV Stigma Index* in Malawi to indicate that stigma “exists” and remains a “potent stressor” to people living with HIV in Malawi, and calls for “multifaceted strategies that include protecting human rights and provision of high quality health services sustained over time” [9; p29].

The policy frameworks guiding the national response to HIV in Malawi recognise that HIV is a social and cultural issue, and that health and well-being is embedded within broader development concerns such as nutrition, food security, economic livelihoods and gender dynamics—in other words, determined by the realities of everyday life.

RATIONALE FOR THE RESEARCH

The law, on its own, is limited in its capacity to capture and engage the complexity of an individual situated within their wider social context [10]. Internationally, the last decade has seen a trend to apply the law as part of national responses to HIV and to promoting public health [11, 12]. It has been suggested that one of the reasons for the recent proliferation of laws relating to HIV has been that politicians have been seeking to do something proactive, concrete and publicly visible in response to HIV [13]. In July 2012, the Global Commission on HIV and the Law released a landmark report, which drew from expert contributions and submissions from people around the world [14]. The Commission undertook a two-year process and the publication of their Report, *Risk, Rights and Health*, marks the latest in a series of publications and consultations about the role of the law in national responses to HIV around the world. In the preface to the report the Chair of the Commission and former President of Brazil, Fernando Henrique Cardoso, writes:

“The end of the global AIDS epidemic is within our reach. This will only be possible if science and action are accompanied by a tangible commitment to respecting human dignity and ending injustice.” [14 p 4]

The report pays great attention (and due respect) to life experiences—both that of the Commissioners as well as that of the people who submitted testimonies and reflections through the regional dialogues. The report is comprehensive and diverse in the perspectives it includes and the recommendations it makes. One shortcoming however is that by definition the submissions focused on experiences that people had when they engaged the formal legal system (including the police and other law enforcement agencies, as well as through the courts). Submissions were not solicited from people who were not conscious of the role or relationship between the law and HIV, acknowledging that it would be nigh impossible to do this on a regional or global scale. In many respects, the perspectives documented and analysis outlined in this research compensates for this shortcoming at the global level by offering a national summary of HIV and the law in Malawi—one that includes the element of legal consciousness alongside an analysis of the role of the law as part of the national response to HIV. It is the first time such an approach has been undertaken in Malawi and in fact in a context outside North America.

Globally there is a paucity of information relating to the motivations and aspirations of lawmakers and the rationale behind legislative provisions relating to HIV. This research in Malawi captured a rare opportunity, to document the perspectives on this issue from three quarters of the commissioners involved as part of the Special Law Commission on HIV who drafted the proposed HIV and AIDS (Prevention and Management) Bill in Malawi [15].

RESULTS

The law in Malawi is at a watershed moment in terms of its role in the national response to HIV. On one hand there is the Constitution, founded on lofty but laudable precepts such as principles of equality, citizenship and non-discrimination; but on the other there are “thorny” punitive approach of the proposed HIV Bill embedding principles of deterrence, punishment and retribution.

Both are imbued with symbolic power, which may be enhanced if implemented, and both have a role in shaping moral attitudes and perceptions of Malawian people. Both therefore have a potentially powerful influence – in opposite directions – on the lives and attitudes (of and towards) people living with HIV.

The challenges of the law and the absence of socially transformative jurisprudence, combined with the challenges of enforcement and the lack of legal consciousness among the citizens of Malawi interviewed for this research, suggest that something different may be needed to realize the principles of rights in reality. The paucity of social rights jurisprudence compared with civil and political rights cases in Malawi, means that questions remain about the justiciability of social rights and the actual potential to generate Malawi's much needed individual and social transformation in real terms [16]. Not one of the life story participants had effectively achieved resolution through the formal legal system to redress even tangible episodes of injustice or discrimination they had experienced, for a variety of reasons. This brings into question the purchase of the formal legal system in everyday life in Malawi.

Perhaps therefore the secret for the future realization of transformation in Malawi, as the Global Commission on HIV and the Law [14] suggests, rests in the ability of the law—encompassing both its potential as well as its limitations—to inspire and entrench the spirit of dignity and equality among all individuals and institutions. The Constitution is just the beginning—it is what it can inspire, what spaces it can open that enable the civic participation of marginalized people and spotlight and support struggles for equality, and what debates it can create for individuals to scrutinize the application of democracy that can give meaning to the aspirational words of equality, dignity and freedom in real life.

“The law should be consistent with the aspirations and needs of Malawians...even when they are HIV positive” (LS4)

Key finding 1: The results showed that while stigma remains a challenge in Malawi, HIV is part of everyday life and only one aspect of nuanced and complex identities of the people whose lives it directly affects.

Life is diverse, and HIV is present within the lives of diverse individuals across different corners of all societies. In this regard, Malawi is no exception and the people who shared their life stories in their research are archetypal of the humanity that ‘hosts’ the virus.

HIV is part of life but it is not the whole picture. The implications raised by the life stories suggest that contextualizing HIV as only one aspect of someone's identity, which it is, and not amplifying HIV to overshadow other aspects of identity, might itself mitigate against the impact of stigma. The findings suggest that efforts to address HIV could potentially be more effective in reducing stigma if they focused on a holistic sense of self, acknowledging a situated “self” within the context of their life and intersecting aspects of their fluid identity. Initiatives to address HIV-related stigma may have been misdirected in the past by focusing almost exclusively on a person's HIV status – the life stories illuminate much more complicated, passionate and nuanced lives in terms of the highs and lows of living with HIV, and the relevance of these considerations in policy or legislative determinations.

The diversity between and nuances within the personal responses in this research about the meaning of HIV illustrates the intensely personal, contextual, transient and evolving relationship that individuals have with a virus that is part of their life. Just as life morphs in different directions and through moments of exultation and despair, sickness and well being, along with the shades of grey and the more mediocre emotions in between, so too does a person's relationship with a virus such as HIV in their life. The life stories illuminated how HIV can become personified to reflect meaning in someone's life—to embody a moment of transformation, an opportunity to know oneself, and/or a turning point to decide on life's future directions.

There are significant implications of these results both in terms of how we conceptualize HIV as well as how collectively we frame responses to engage, support, provide services and generate leadership as part of national responses to HIV. The three main findings from this analysis could be summed up as comprising both simple and complex messages. The first, the simple one and also the

starting point, that HIV is part of life and is present in diverse and dynamic lives around the world. The implication as argued above is that interventions to overcome HIV-related stigma should be founded on a holistic notion of people and societies, not only channeled into a narrow specific focus solely on HIV. To be successful, interventions should encompass whole people in terms of livelihoods, belief systems and worldviews.

The second and third are less simple, or less obvious, and centre on notions of agency. On the one hand there is the agency of the individual to shape the direction of their life as well as perceive and re-construct over time the meaning of HIV in their life. The results point to notions of agency at two levels – both in terms of the trigger of an HIV positive diagnosis to take stock of life and make conscious decisions to guide its future direction, as well as in terms of a sense of responsibility (sometimes connoted as guilt) for becoming HIV positive. For many of the participants in this research, their HIV positive diagnosis marked a distinct transformative turning point in their life. For the two individuals who had voluntarily sought an HIV test (i.e. not the majority who had been tested because they were unwell) it seemed that this act of agency in seeking to know their HIV status may have had a mitigating influence on their reaction to receiving an HIV positive diagnosis. That is, those participants seemed more readily accepting of their HIV positive diagnosis than others. One hypothesis deduced from these two stories could be that the initial acceptance of an HIV diagnosis (which could be framed as a reduced internalization of stigma) may be enhanced with a greater readiness and willingness to know. This has significant implications for national policies to promote HIV testing for example, that from an efficacy perspective as well as from one founded in principles of human rights, should rather focus on cultivating a demand for voluntary testing rather than mandating testing through legislation (as proposed in the draft HIV legislation) or even provider initiated counseling and testing.

The third notion on the other hand, is that there is the agency of communities and societies to be AIDS competent and to militate against the devaluing and marginalizing power of stigma. The implications of the findings from the life stories, particularly in relation to experiences of disclosure given that is the area that most explicitly relates to interactions between people, are consistent with other research that has focused attention on the competencies of societies to respond to HIV within their communities in an embracing, empathetic and stigma-alleviating manner [17].

Key finding 2: The proposed HIV and AIDS (Prevention and Management) Bill in Malawi manifests a tension between intention and impact—the desire to enact a law to protect human rights and strengthen the national response to HIV, while potentially taking away those rights from certain groups and fuelling HIV-related stigma.

“The intentions are good, but I think the ... results would be very bad” (OL14)

The results highlight five main points: first that even though the intentions behind the law were well meaning, the motivations to include criminal provisions were based on a certain melodrama (i.e. not responding to the primary routes of transmission), desire for retribution and moralization. Second, the construction of agency and action in relation to HIV expressed in relation to criminalization of transmission and exposure placed the responsibility solely among people living with HIV. Third, the responses present an element of competing interests in recognizing where the rights of two individuals might be in tension (such as the rights of a woman living with HIV not to take treatment to prevent vertical transmission versus the rights of the infant to be born without HIV). Fourth, HIV was often framed in terms of death and illness. And fifth, the lawmakers themselves straddled a tension between aspirations of transformation through the law and the tempering of the challenges of law enforcement.

The extent to which a law relating to HIV might have a normative power is questionable in a country where there is a limited consciousness of the law in the everyday lives of people living with HIV, a lack of a widespread understanding of the traditional legal system, a constrained access to formal legal redress for most people, and where the Constitution is seldom enforced. Nonetheless the law is imbued with symbolic power—that can contradictorily both protect and diminish rights—a power that in itself is potent with stigma.

Key finding 3: Legal consciousness was not apparent in the everyday lives of most of the people living closely with HIV in this research, and significant challenges to law enforcement and access to justice remain. Moreover, the proposed HIV Bill in Malawi includes problematic provisions that potentially could fuel stigma.

The analysis of legal consciousness of people living with and affected by HIV in Malawi highlighted a significant disconnect between the aspirations for the role of the law in Malawi, expressed through the life stories as well as by law commissioners and opinion leaders, and the real traction of access to justice and redressing for violations through the formal legal system.

“As a woman that lives in a village, I do not have a chance to know what the law says” (LS14)

The life stories indicate that the traditional authorities are a much more prominent source of justice in the everyday lives of people living with and closely affected by HIV in Malawi. For the participants the formal legal system was either invisible or misunderstood in terms of the specifics of its potential role in relation to HIV. Yet paradoxically, almost all participants perceived the law to have an important role in the national response to HIV.

Key finding 4: The potential impact of the proposed HIV and AIDS (Prevention and Management) Bill at the personal level could be devastating in creating barriers for testing, internalizing stigma, and limiting opportunities for disclosure for fear of reprisal through the law. For example the potential application of the criminal law to HIV transmission, exposure and non-disclosure (sections 43 – 5 of the draft Bill) has the potential to limit the equality and health of many if applied in the context of HIV. The construction of agency and action in relation to HIV expressed in relation to criminalization of transmission and exposure places the responsibility disproportionately among people living with HIV.

The impact of the criminal law at the personal level touches on multiple dimensions and has the potential to limit the equality and health of many if applied in the context of HIV. The construction of agency and action in relation to HIV expressed in relation to criminalization of transmission and exposure places the responsibility disproportionately among people living with HIV. The potential impact at the personal level could be devastating in creating barriers for testing, internalizing stigma, and limiting opportunities for disclosure for fear of reprisal through the law.

The perception that the criminalization of HIV transmission might create a barrier for people seeking HIV testing is apparent in the responses in this research. Even though this research focuses on the experiences of people living with HIV (i.e. people who have tested positive for HIV), the cross-section of their experiences indicates that the criminalization of HIV may have an adverse impact on efforts to encourage HIV testing. This includes both their opinions that it may impede testing, as well as their direct experiences and reflections on their own motivations for seeking an HIV test. The participants in this research mostly indicated that they went for HIV testing because they were generally feeling unwell or experiencing symptoms of illness. Only two of the life story participants indicated that they went for testing expressly to know their status.

The results spotlight a paradoxical confusion between intent and impact of the law in response to HIV. Criminalization simultaneously exaggerates agency (in defining HIV transmission as the primary responsibility of people living with HIV), misleads agency (by creating barriers and disincentives for testing and knowing one’s HIV status), and denies agency (by failing to recognize equal responsibility in sexual encounters by consenting adults). The analysis of the perspectives of the law commissioners, who formed the Special Law Commission and drafted the proposed HIV and AIDS (Prevention and Management) Bill, revealed that stigma was consciously invoked to delineate social norms and guide governance of notions of personal responsibility. The analysis of the perspectives of the life story participants, whose lives would be most directly impacted if these provisions came into force, reveals the extent to which the stigma associating criminality and HIV is falling on fertile ground through its engagement and generation of internalized stigma. The results

indicate that criminalization of HIV can serve as a litmus test and unearth uneasy tensions between intentions, perceptions and outcomes, linking stigma and the law in response to HIV in Malawi.

Key finding 5: The law does have a symbolic potential in defining aspirations for socio and economic changes that may address the underlying determinants of ill health and protect human rights.

Despite the potential challenges of enforcement and implementation that were identified, and despite the absence of current formal legal interventions in each of the experiences of the life story participants, a value was almost unanimously placed on the symbolic and guiding potential power of the law in the national HIV response.

“On paper you have got 100% rights... on the ground it’s 50% taken away.” (LS8)

The results from this research support the growing international impetus to promote human rights-based legal frameworks to promote public health [14]. In Malawi, the inherent tension within the law and the problematic provisions of the draft HIV Bill need to be resolved to enhance rather than undermine the national response to HIV and enable laws that can protect all – not punish some.

A difficult conundrum is revealed however, where the provisions within different applicable laws—the Constitution and the Penal Code, for example—are mutually contradictory, just like the inconsistent provisions within the draft HIV Bill. This was most apparent in relation to communities vulnerable to HIV and already marginalized in society, exacerbated by notions of illegality and provisions within the Penal Code, such as sex workers (section 192) and men who have sex with men (section 153). In both cases, the law is on the one hand giving rights while on the other taking them away.

“We should look at the law holistically, like it applies to anyone” (LS7)

CONCLUSIONS

Recognizing history (looking back) and the future (looking forward, effecting change), as well as the individual in relationships with others (self and society), are the key ingredients for the kind of transformative strategy needed to tackle the underlying social determinants of health.

Initiatives to address HIV-related stigma may have been mis-directed in the past by focusing almost exclusively on a person’s HIV status—the life stories illuminate much more complicated, passionate and nuanced lives in terms of highs and lows of living with HIV. Efforts to address HIV-related stigma should focus on love, compassion and wider issues relevant in someone’s life beyond the positive diagnosis. In so doing, efforts to address stigma must engage the whole story.

The results indicated that the proposed HIV and AIDS (Prevention and Management) Bill in Malawi manifests a tension between intention and impact. By incorporating criminal sanctions as part of the proposed HIV Bill, the lawmakers actively seek to use stigma to shape social attitudes and attempt to guide normative behaviour. This raised the question of whether, in fact, alleviating HIV-related stigma in Malawi is a real—or only rhetorical—political priority.

The results indicate that people living with and closely affected by HIV in Malawi are acutely aware of the injustices inflicted upon them, resonating with the writing of Odinkalu [18]⁸, yet mechanisms for protecting human rights through the formal legal system were of little meaning to them. Channels for more effectively supporting people living with HIV to seek redress for injustice

⁸ “People are acutely aware of the injustices inflicted upon them. Knowledge of the contents of the Universal Declaration will hardly advance their condition. What they need is a movement that channels these frustrations into articulate demands that evoke responses from the political process. This the human rights movement is unwilling or unable to provide. In consequence, the real life struggles for social justice are waged despite human rights groups—not by or because of them—by people who feel that their realities and aspirations are not adequately captured by human rights organisations or their language.” Chidi Anslem Odinkalu, *Why more Africans don’t use human rights language*, Nigeria, 1999. [18]

through the formal legal system, in addition to other customary or traditional means, and to translate the rights codified in the Constitution into reality, are needed. The results also suggest that other efforts to support people living with HIV outside the law, such as visibility and connection with other people living with HIV, and leadership and outspokenness about HIV among the “elite” of Malawi, might be more effective than the law per se in shaping positive social norms and perceptions of HIV and diminishing incidents of injustice. If the proposed HIV Bill were to be passed as is, this would be even more problematic for people living with HIV who would paradoxically face additional barriers to seeking protection from discrimination through the law

The research makes a significant contribution to knowledge in five main areas—conceptual (proposing a new way to understand stigma, in terms of layering and temporality), contextual (as a significant empirical research about law, human rights and HIV in Malawi), methodological (as an action research initiative bridging legal and social science research), pragmatic (in offering evidence-informed recommendations for overcoming stigma) and personal (in engaging the diversity of the action research team). The research also draws attention to the importance and relevance of the subjective and contextualized life realities of the individuals interviewed for the study. This technique has not previously been applied to research about law and legality in Malawi, or in fact beyond North America. By centering the personal as an essential element of analysis, a range of sometimes unlikely or surprising materials are introduced which are crucial for management of policy and programme initiatives and legislative implementation.

The findings from the process and analytical results presented in this thesis are of vital relevance to governance and the national response to HIV in Malawi.

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ANNEX 16

Constitution Of The Registered Trustees Of Life Trust Malawi

PART 1

Preliminary

1.0 Name and Establishment

This Constitution establishes a Trust whose name shall be **The Registered Trustees of The Life Trust Malawi**, hereinafter “the Trust”.

2.0 Mission of the Trust

The Trust aims to provide a forum to support people living with and closely affected by HIV in Malawi; specifically those involved in the life story collection research project in 2010-2011. The research took place over six months during 2010-2011 and focused on the life stories of people living with and closely affected by HIV to better understand the experiences of HIV in everyday life. The research contributed to the PhD research of Lucy Stackpool-Moore, a student at the University of London and affiliated with the Centre for Social Science Research at the University of Malawi.

The Mission of the Trust is to:

- Facilitate effective discussion and policy development among people closely affected by HIV in Malawi.
- Contribute to Malawi’s social and economic development by sharing any income generated by the publication of the research (for example if published as a book)
- Sustain appreciation for the research team and the people who shared their life stories
- Ensure that income and assets of the Trust are to be dedicated to the purpose(s) of the Trust

3.0 Location

The registered office of the Trust shall be Plot 123, Area 14, Lilongwe and the registered address shall be F/O Director of Programmes, Family Planning Association of Malawi, Private Bag B424 Lilongwe 3, Malawi.

PART II

4.0 Objective of the Trust

The objectives of the Trust in furtherance of the main aim and purpose in article 2 hereof shall among others include but not be restricted to:

- Contribute to a reduction in HIV-related stigma and discrimination relating in Malawi.
- Develop and maintain lasting relationships between people involved in the research project, their families and support groups—individuals living with and closely affected by HIV.
- Create supportive networking opportunities for the research team and the people who shared their life stories nationally.
- Share experiences from research outcomes with Malawian audiences to inform the national response to HIV.
- Strive to make maximum use of knowledge and skills derived from the research to promote development in Malawi and the region.
- Do all such other things that may be deemed incidental or conducive to the attainment of the above aim and objectives.

5.0 Powers of the Trust

In pursuit of the above objectives and in furtherance of the aim of the Trust to support and enhance the lives of people affected by HIV in Malawi, Trustees and members are designated recipients under this Trust and may be the objects of benefit under this Trust, and subject to the Laws of Malawi, the Trust shall have the following powers:

To open accounts with banking or other financial institutions within Malawi.

To distribute income generated by the publication of the research findings to support people living with HIV in achieving their vision for the future and localized community development.

To source, solicit and receive subscription, grants, funds, donations or legacies in cash or kind from any person

(including the members of the Trust) or body, which it considers necessary for the furtherance of its objectives.

To sell, manage, lease, mortgage, dispose of or otherwise deal with all or any part of the property of the Trust.

To produce and publish books, magazines, leaflets or other literary works and disseminate films, videotapes and audiotapes and such other means of communication the Trust may think desirable for the promotion of its objectives.

To pay expenses incurred in the conduct of the Trust.

To generally do any such other lawful things as are incidental or conducive to the attainment of the above objectives or any one of them.

PART III

Administration

6.0 Membership

Membership shall be open to every participant in the life story collection project associated with the PhD research of Lucy Stackpool-Moore in 2010-2011.

This is limited to the 42 people identified in Annex 2 or an identified beneficiary of their choice to represent their involvement. [Removed from this thesis to protect confidentiality]

Membership shall be by nomination and then appointment to the Trust based on the criteria identified in the research process. The appointment will be overseen by the Trustees.

Every member shall strictly be required to abide by the rules and regulations of the Trust as stipulated by this Constitution or otherwise.

6.1 Termination

Membership shall be terminated by:

Voluntary withdrawal after giving one month notice to Trustees .

A member being expelled from membership if in the judgment of the Board of Trustees.

Death.

A member becoming insane or otherwise incapable of performing the duties of a member.

Nomination of a representative to take the place of the member in the Trust.

7.0 Management of the Trust

7.1 Board of trustees

There shall be a Board of Trustees consisting of not less than three (3) and not more than six (6) persons appointed as those involved in the research process.

The Trustees represent each region of Malawi as well as the founder of the Trust and initial coordinator of the research project, Lucy Stackpool-Moore (an Australian National who has lived in Malawi, including during the research process).

A member of the Board of Trustees shall hold office for three (3) years and shall be eligible for re-election for one additional term of three (3) years.

The Board of Trustees shall apply for the incorporation of the Trust under the Trustees Incorporation Act (Cap 5:03) of the Laws of Malawi.

The funds and property of the Trust shall vest in the Trustees. The trustees shall disperse the movable property of the Trust to the designated recipients and accept, whether subject to condition or not, gifts devices and bequests of any such property.

The Trustees shall elect a Chairperson from amongst themselves.

The Chairperson shall act as Secretary for the Board of Trustees.

The Trustees shall elect a Treasurer from amongst themselves. The duties of the Treasurer may be held by the Chairperson, as combined responsibilities, upon consensus approval of the Board of Trustees.

The Treasurer shall oversee financial transactions of the Trust and prepare annual financial reports.

8.0 Vacancies on the Board of Trustees

8.1 A vacancy on the Board of Trustees shall arise on :

- 8.1.1 The expiry of the term of office of a member, or
- 8.1.2 Resignation of a member after one month's written notice, or
- 8.1.3 The death of a member, or
- 8.1.4 A member failing to attend three consecutive meetings of the Board without valid excuse or reason
- 8.1.5 A member leaving the country for more than three (3) years .

8.2 A vacancy due to any of the above may be filled at the discretion of Lucy Stackpool-Moore.

9.0 No Executive Committee

Given the small and focused nature of The Trust, no Executive Committee is required. The management of the Trust shall be entrusted to the board of Trustees.

10.0 Meeting of the Board of Trustees

The Board of Trustees shall meet in ordinary sessions at least once a year and at such other times as it may determine, or be deemed necessary.

The Trust will cover the expenses for the annual ordinary sessions (return travel and accommodation as needed).

The Board will also have quarterly meetings over the telephone/ skype given the geographical distance between the addresses of Trustees.

The Trust will cover the communication costs of these quarterly meetings.

An extraordinary meeting of the Trustees may be convened at any time at the request of The Chairperson or at the request, in writing, of any two or more of its members.

Half the members of the Board of Trustees shall constitute a quorum.

The Trustees may, from time to time co-opt any person to attend any meeting for a specific purpose. Such co-opted member shall have the right to speak at and take part in the deliberations of such meeting but shall not have the right to vote.

Except as is otherwise expressly provided in this Constitution, the Board of Trustees shall determine its own procedure.

The Chairperson shall preside at all meetings of the Trustees. In the absence of the chairperson, the members present at the meeting shall elect from amongst themselves a member to preside at that meeting.

Voting at all meetings of the Board of Trustees shall be by a simple majority either a show of hands or by secret ballot. In the event of a tie in votes, the person presiding shall have the casting vote.

PART IV

11.0 Duties

11.1 Duties of the Chairperson

The Chairperson shall preside at all General Meetings of the Trust.

The Chairperson shall be responsible for the general running and well being of the Trust.

The Chairperson shall act as Secretary/Treasurer of the Trust.

The Chairperson shall present at the last meeting of a financial year in question an annual report, which shall contain inter alia a summary of the activities of the Trust during the financial year in question and an up to date, financial position of the Trust.

11.2 Duties of the Board of Trustees

The Board of Trustees will attend meetings,.

The Board of Trustees will review applications for assistance and maintain contact and support for the members—people living with and affected by HIV.

The Board of Trustees will be responsible for the distribution of income to the designated recipients of the Trust.

The Board of Trustees will do all such things as are necessary to facilitate the effective operation of the Trust the fulfillment of its objectives and assist the Chairperson in achieving the same.

12.0 Bank Account

12.1 The Trust shall maintain bank account(s) with reputable National Commercial Bank (s) or financial institution(s) in Malawi.

The signatories of the bank account shall be the five (5) founding Trustees.

As or if new Trustees are appointed they will be added as signatories to the bank account.

Withdrawals shall only be effected with signatures of at least two signatories one of which shall always be the Chairperson.

The Trust through the Trustees shall formulate the procedure for authorized payments.

Financial Year

12.2 The financial year of the Trust shall run from 1 December of one year to 30 November of the following year and the Board of Trustees shall see to it that financial statements are prepared at the end of each financial year, showing the trading accounts, profit and loss account, the balance sheet and report of the previous year.

The Trust shall cause its accounting records and annual financial statement to be audited by qualified auditors as required and approved by the Board of Trustees.

PART V

General Meetings

13 .0 Annual General meeting

A general meeting of the Trust shall be held every year not later than 30 September to transact the following business:

- (i) To receive, if approved, the statement of the Trust account for that year.
- (ii) To consider, and if approved make amendments to the Constitution or rules of the Trust;
- (iii) To appoint an auditor or auditors, accountant(s) and lawyers (as required).
- (iv) To deal with any special matters any Trustee may desire to bring before the members; and
- (v) To receive any guidance from members for action by the Chairperson

13.1 The Annual General meeting may be convened in person or through conference call/electronic media depending on circumstances, as determined by the Chairperson.

14.0 Extraordinary General Meeting

An extraordinary general meeting of the Trust shall at the request of The Chairperson or half of the Trustees to transact the following :

- (i) To receive, if approved, the statement of the Trust account for that year.
- (ii) To consider, and if approved make amendments to the Constitution or rules of the Trust;
- (iii) To appoint an auditor or auditors, Accountant(s) and Lawyers (as required).
- (iv) To deal with any special matters any Trustee may desire to bring before the members; and
- (v) To receive any guidance from members for action by the Chairperson

14.1 An Extraordinary General meeting may be convened in person or through conference call/electronic media depending on circumstances, as determined by the Chairperson or at least two members of the Board of Trustees.

PART VI

Miscellaneous

15.0 Common Seal

The Trust shall have a Common Seal which shall be in Square (or circular) form and shall consist of an embossed square (or circular) stamp inscribed with the words **“The Registered Trustees of Life Trust Malawi.”**

15.1 The Common Seal shall be kept in a locked receptacle when not in use. It shall not be affixed to any instrument except by any Trustees for the time being authorized in that behalf by the Board of Trustees, and they shall sign the instrument to which the common seal is affixed in the presence of any other Trustee.

16.0 Amendments of the Constitution

The Constitution shall be amended by a resolution at any Annual or Extraordinary general Meeting of the Trust.

No such resolution shall be passed unless it is carried by a majority of 75 % of voting members present.

17.0 Dissolution of the Constitution

17.1 While Lucy Stackpool-Moore is alive, clause 17.2 shall not operate and the Trust shall not be dissolved without the express prior written consent of Lucy Stackpool-Moore.

17.2 The Trust shall not be dissolved unless a resolution in favour of dissolution of the Trust is passed by a majority of not less than 75%of the members present and entitled to vote at a Special Extraordinary General Meeting called for the purpose. A notice specifying the intention to pursue such a resolution must be given 30 clear days preceding the date proposed for the Special Extraordinary General Meeting.

17.3 Upon dissolution, the Board of Trustees shall determine the modes of disposition of the assets of the Trust provided that in so deciding they shall have regard to its objectives.

18.0 Liability of Members of Board of Trustees

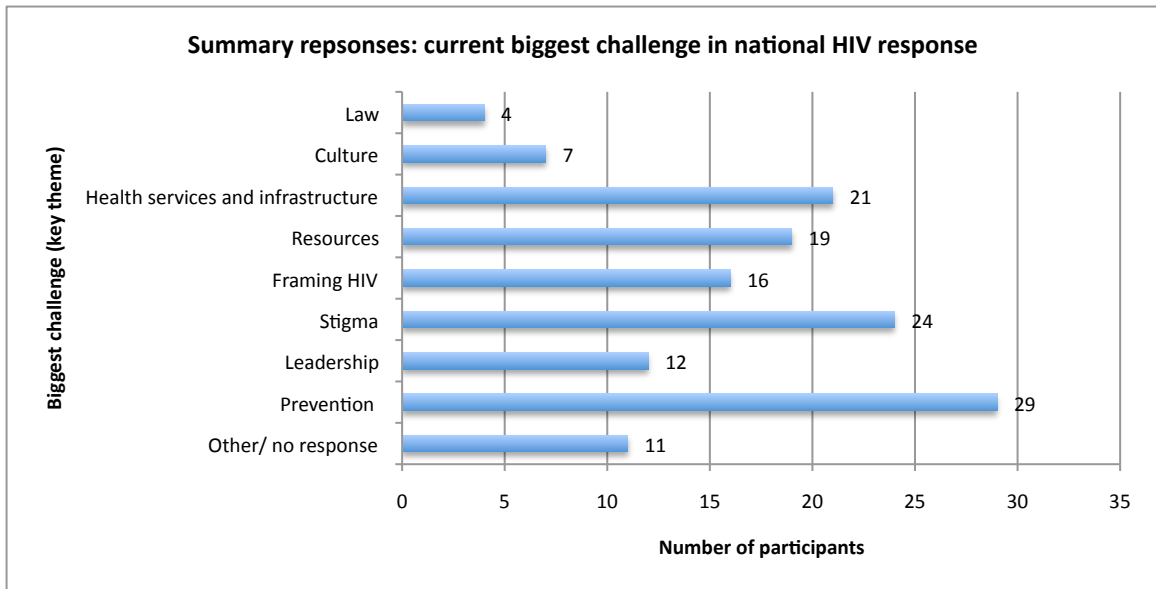
The Board of Trustees shall not be personally liable for any act or in the exercise, in good faith, or within the legitimate functions of the Trust.

Lucy Stackpool-Moore

Annex A List of Trustees

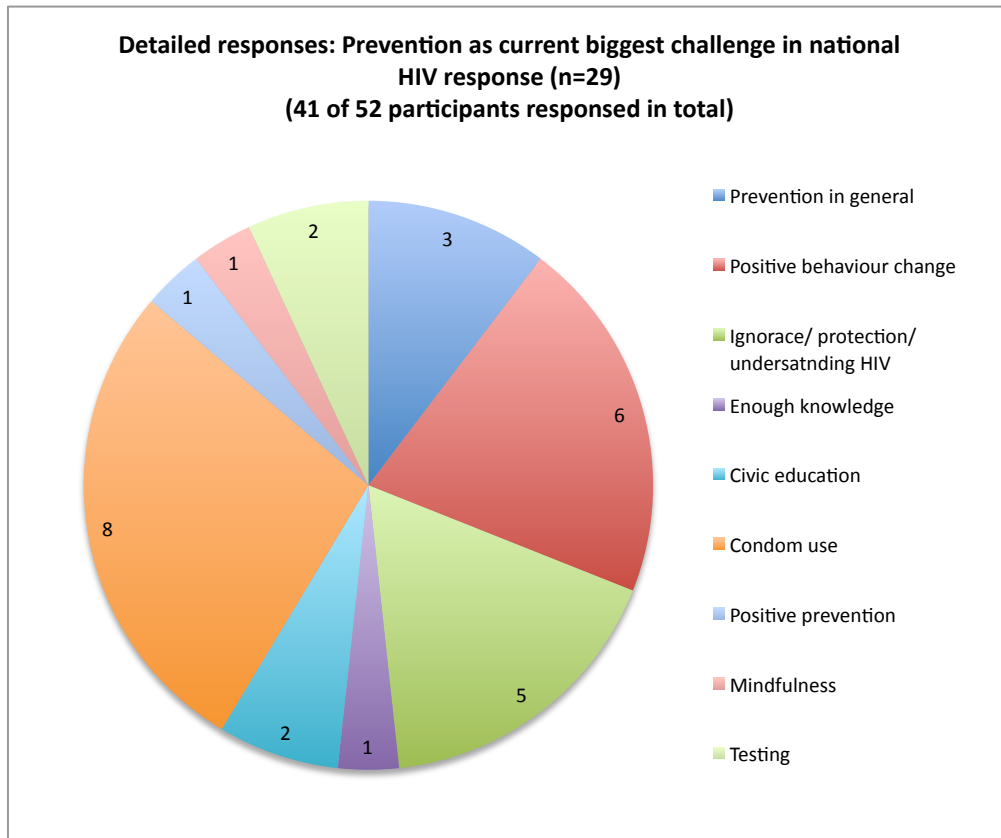
David Kamkwamba [DK] (Southern Region, Blantyre)
George Kampango [GK] (central Region, Lilongwe)
Ruth Kundecha [RK] (Central Region, Dedza)
Milliam Simkonda Kumwenda [MS] (Nortern Region, Mzuzu)
Lucy Stackpool-Moore [LSM] (international)
Gift Trapence [GT] (Central Region, Lilongwe)

Annex 4|1| Summary responses: current biggest challenge in national HIV response (n=41)



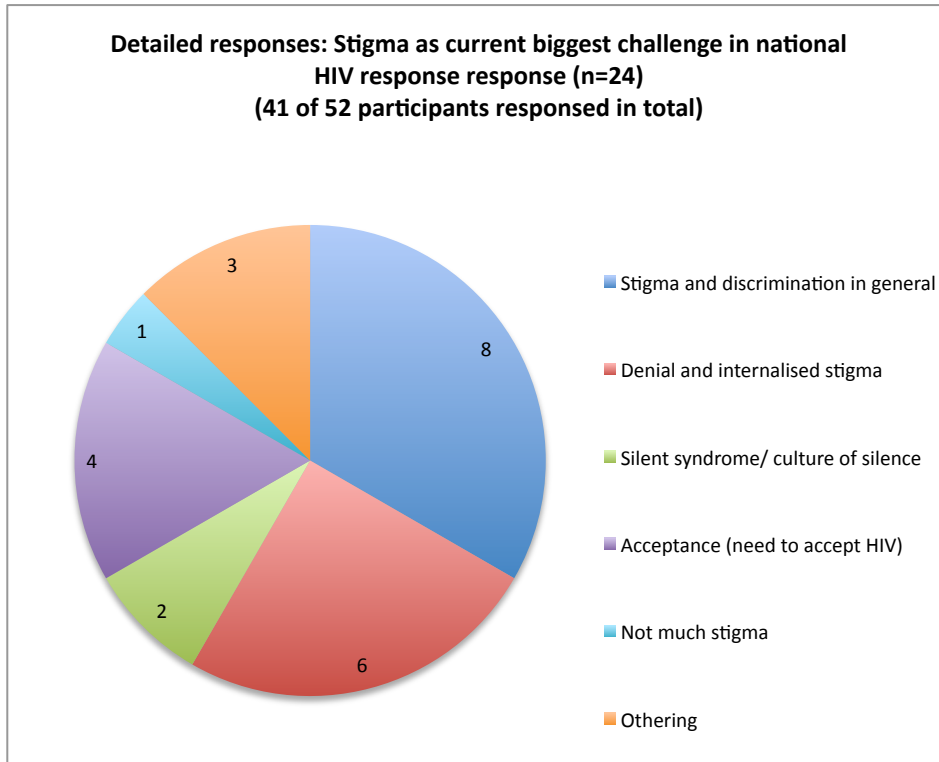
41 of the 52 participants’ responses were coded and grouped according to key themes. 11 participants did not respond or were unclear and grouped as “other”. Each theme identified by participants was coded individually, and participants could have more than one response.

Annex 4|2| Breakdown of detailed responses re HIV prevention as the biggest challenge in the national response to HIV



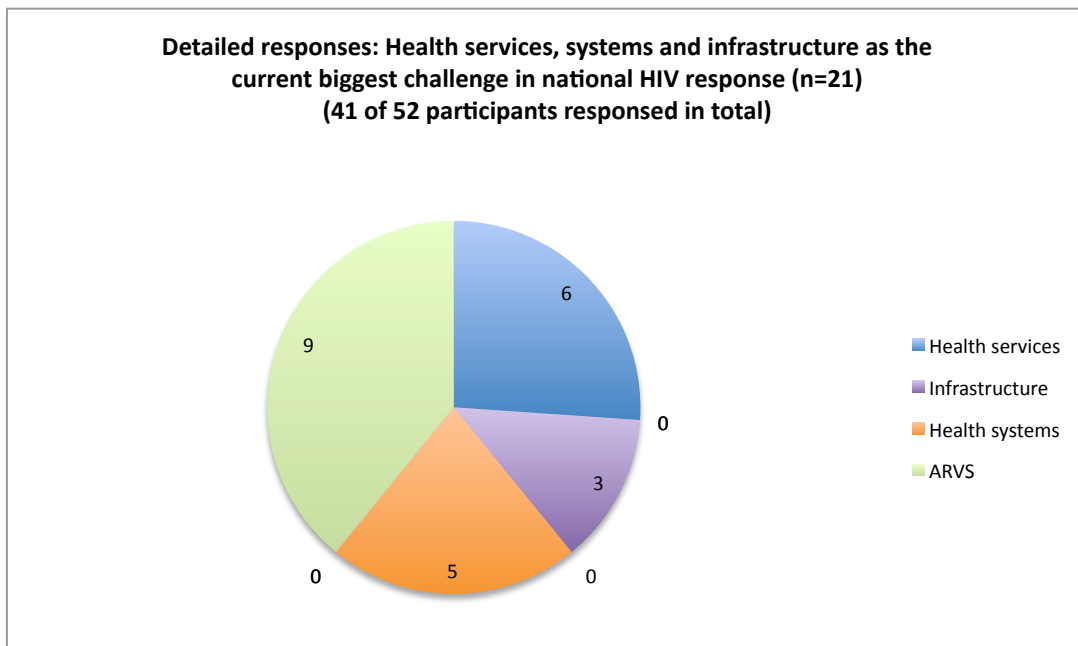
Annex 4|3

Breakdown of sub-categories within responses identifying stigma in relation to the national response to HIV

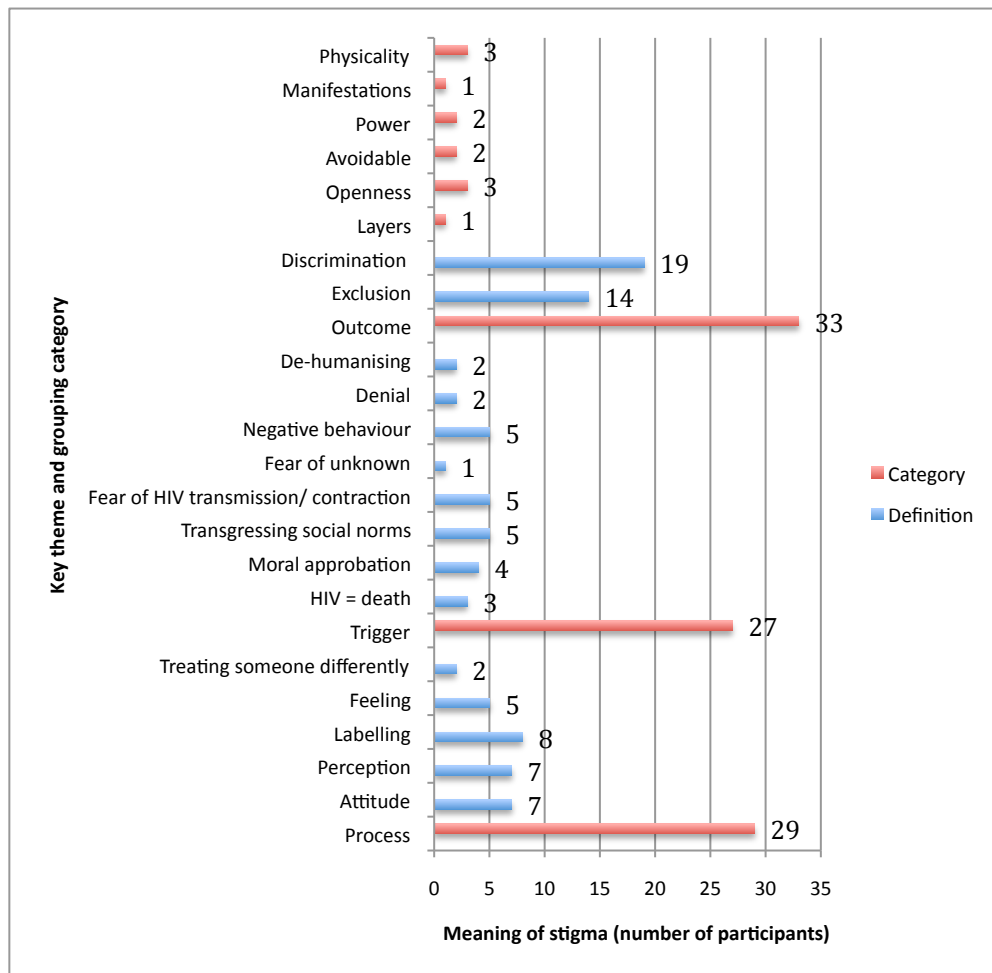


Annex 4|4

Breakdown of sub-categories within responses identifying health services and infrastructure in relation to the national response to HIV

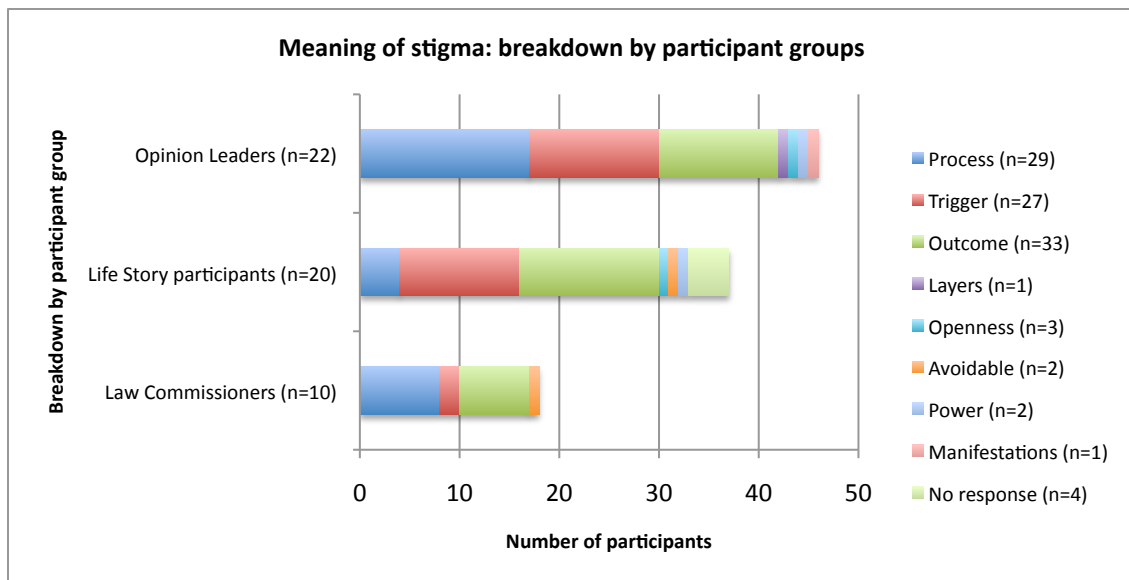


Annex 6|1| Notions: Defining stigma



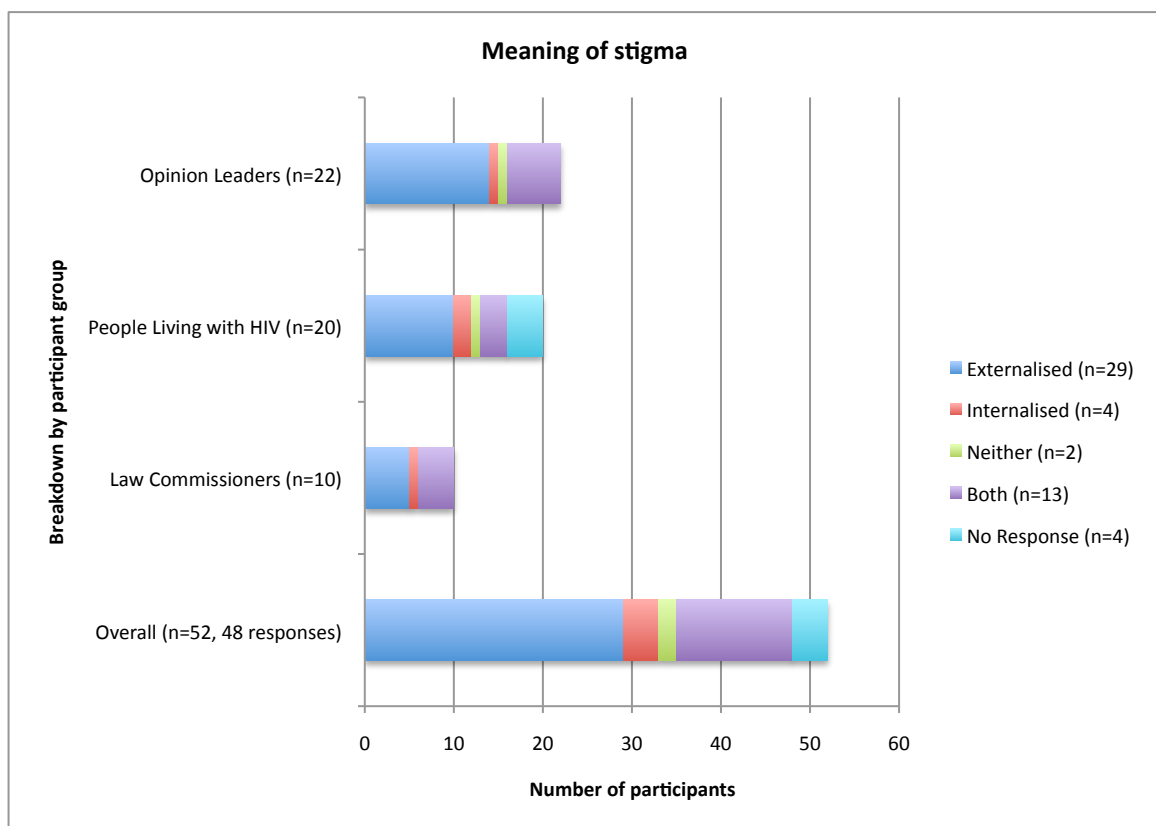
48 of the 52 participants responded to this question. Each response was coded uniquely (i.e. a participant could identify more than one solution for overcoming stigma). This graph shows the breakdown of themes within the definitions described, and the categorization used to group similar ideas together.

Annex 6 | 2 **Notions: Defining stigma by participant group**

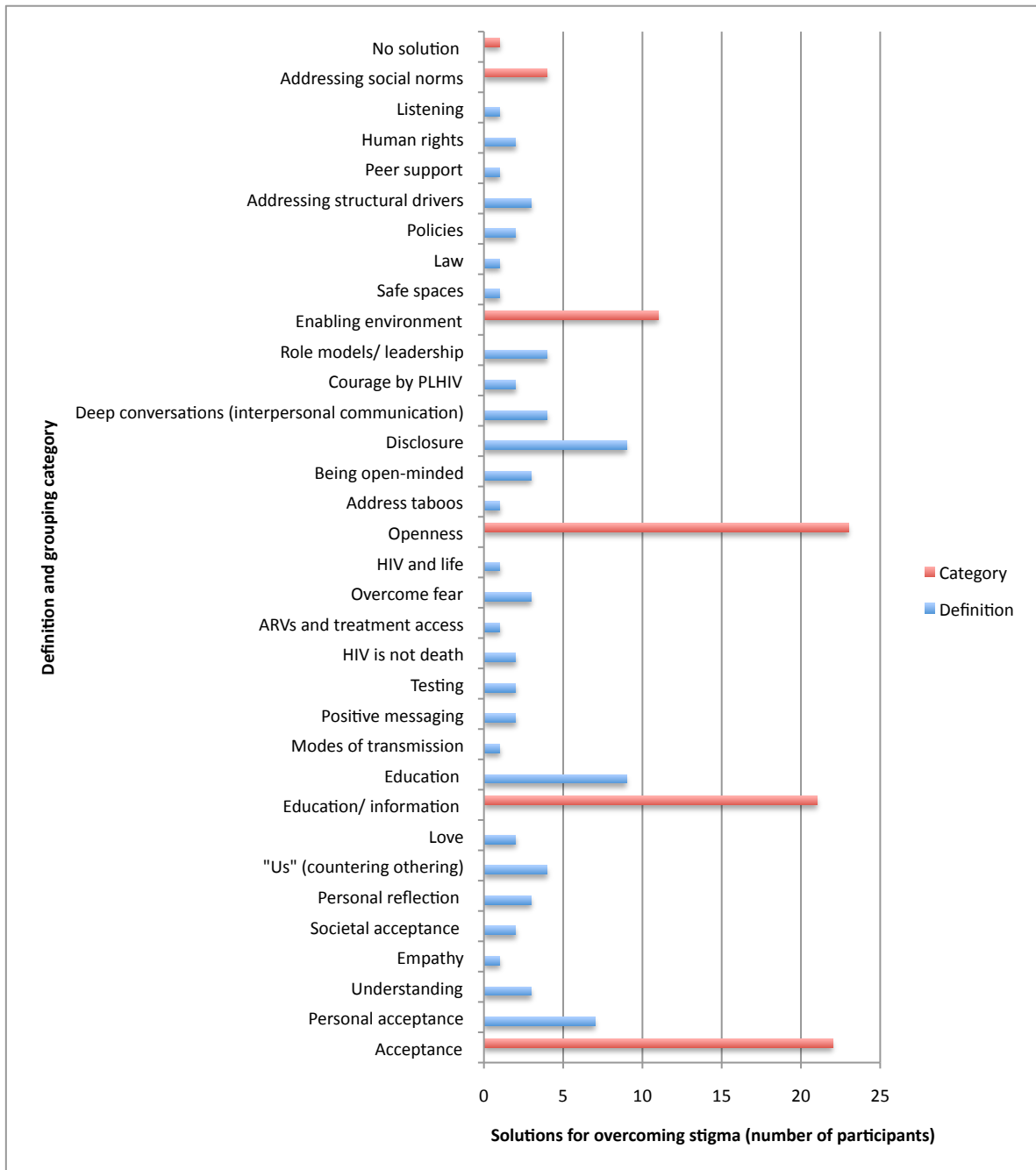


48 of the 52 participants responded to this question. Each response was coded uniquely (i.e. a participant could identify more than one solution for overcoming stigma). Breakdown This graph shows the breakdown and differences between participant groups.

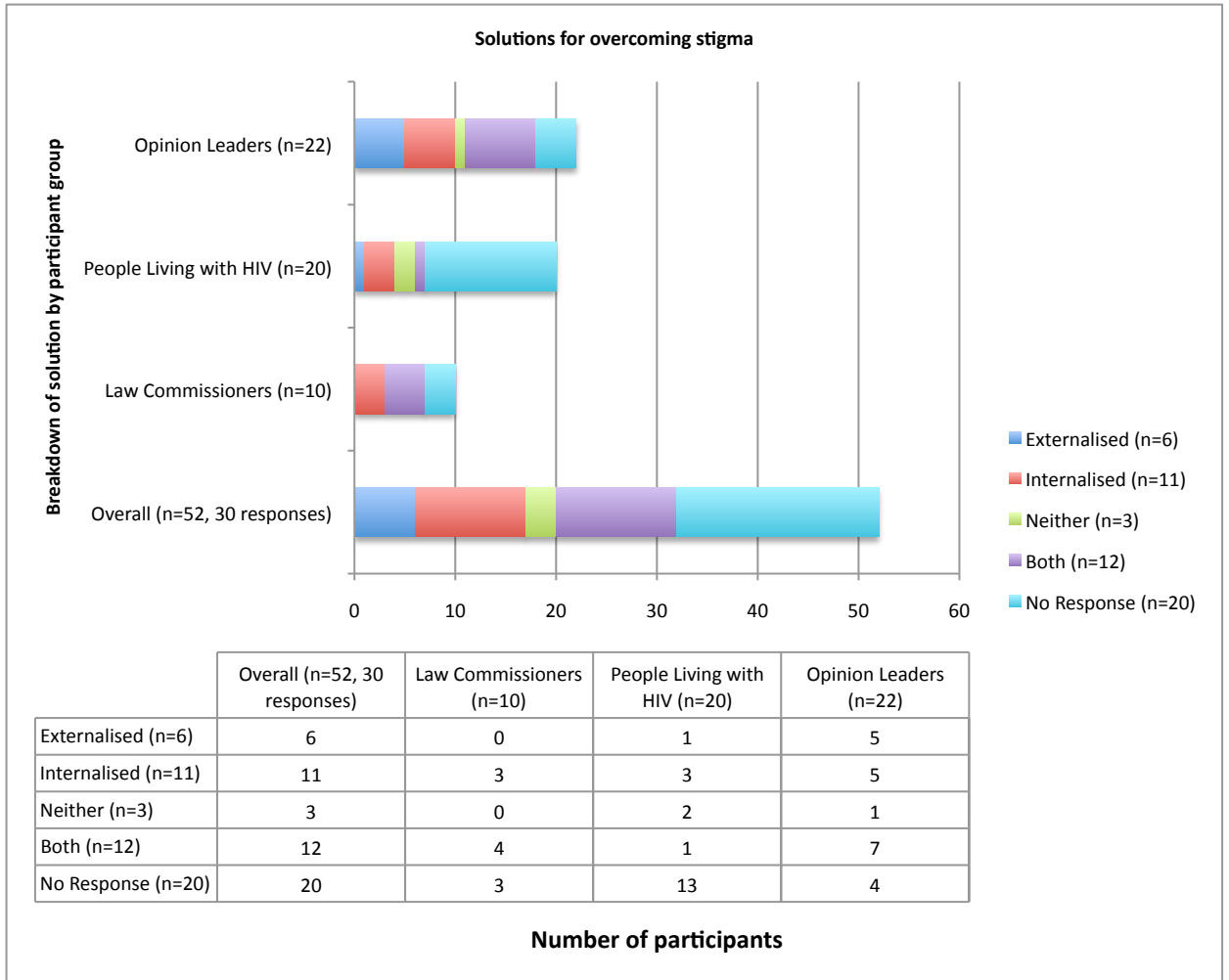
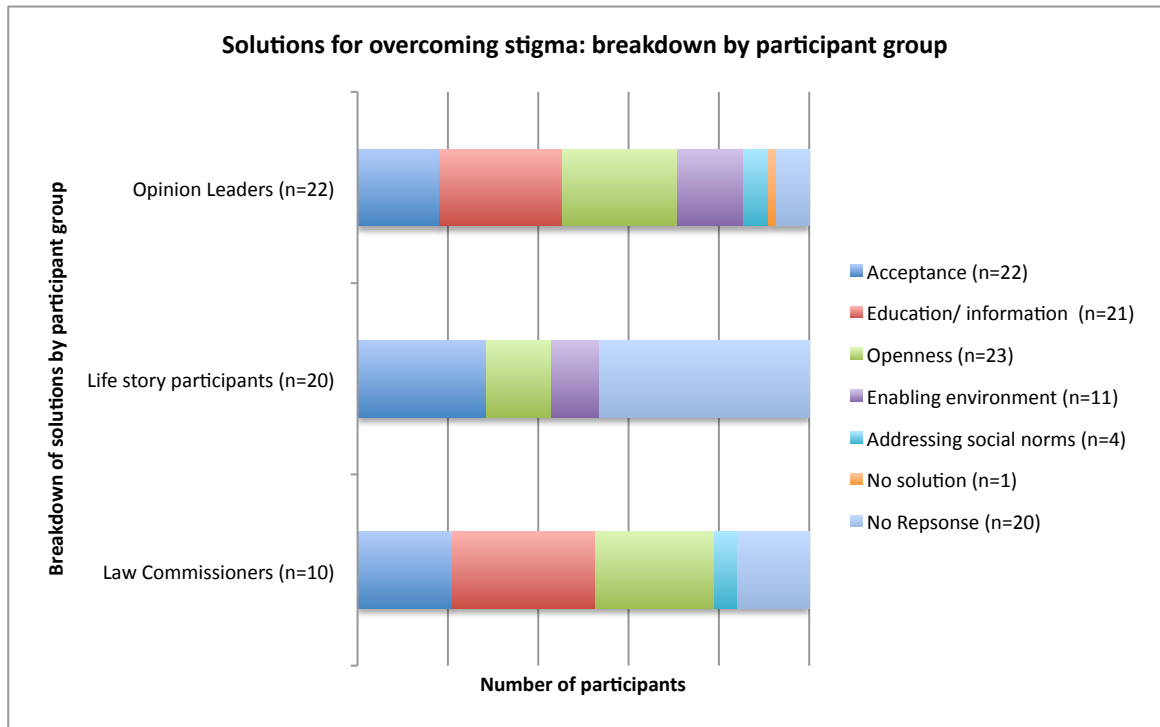
Annex 6 | 3 **Notions: Direction of action in defining stigma**



48 of the 52 participants defined stigma in their interviews. Each response was analyzed and coded only once to identify the direction of action as external, internal, neither or both.

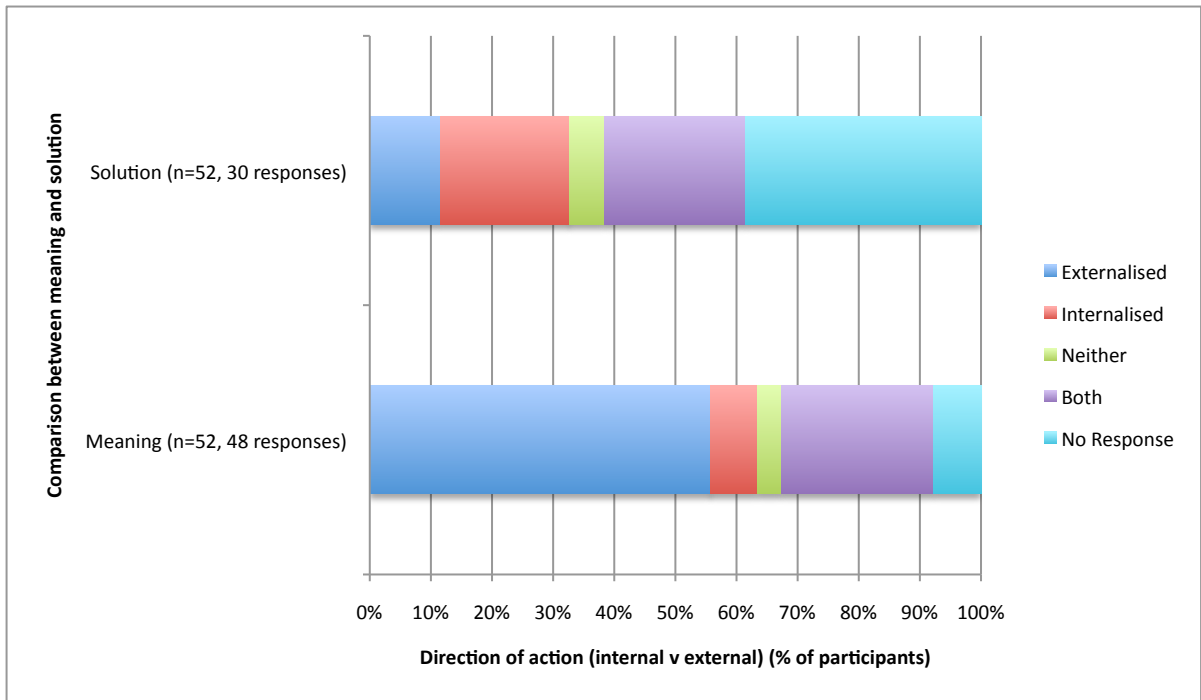


30 of the 52 participants responded to this question. Each response was coded uniquely (i.e. a participant could identify more than one solution for overcoming stigma). This graph shows the breakdown of themes within the definitions described, and the categorization used to group similar ideas together.

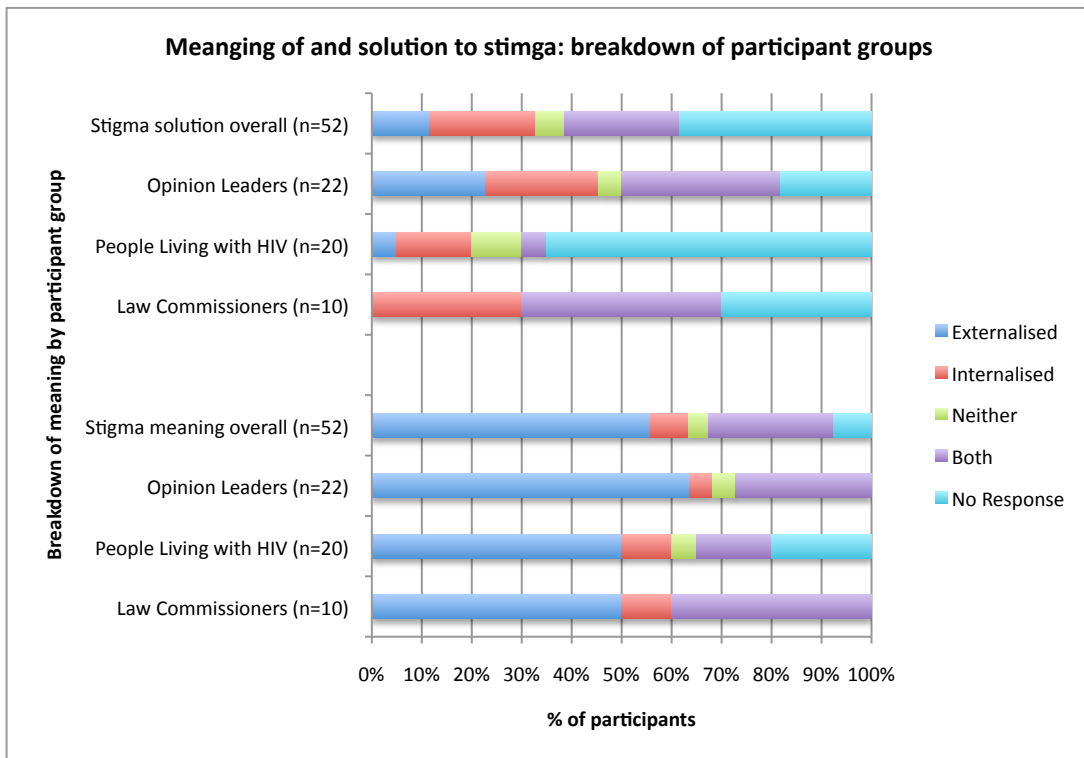


	Overall (n=52, 30 responses)	Law Commissioners (n=10)	People Living with HIV (n=20)	Opinion Leaders (n=22)
Externalised (n=6)	6	0	1	5
Internalised (n=11)	11	3	3	5
Neither (n=3)	3	0	2	1
Both (n=12)	12	4	1	7
No Response (n=20)	20	3	13	4

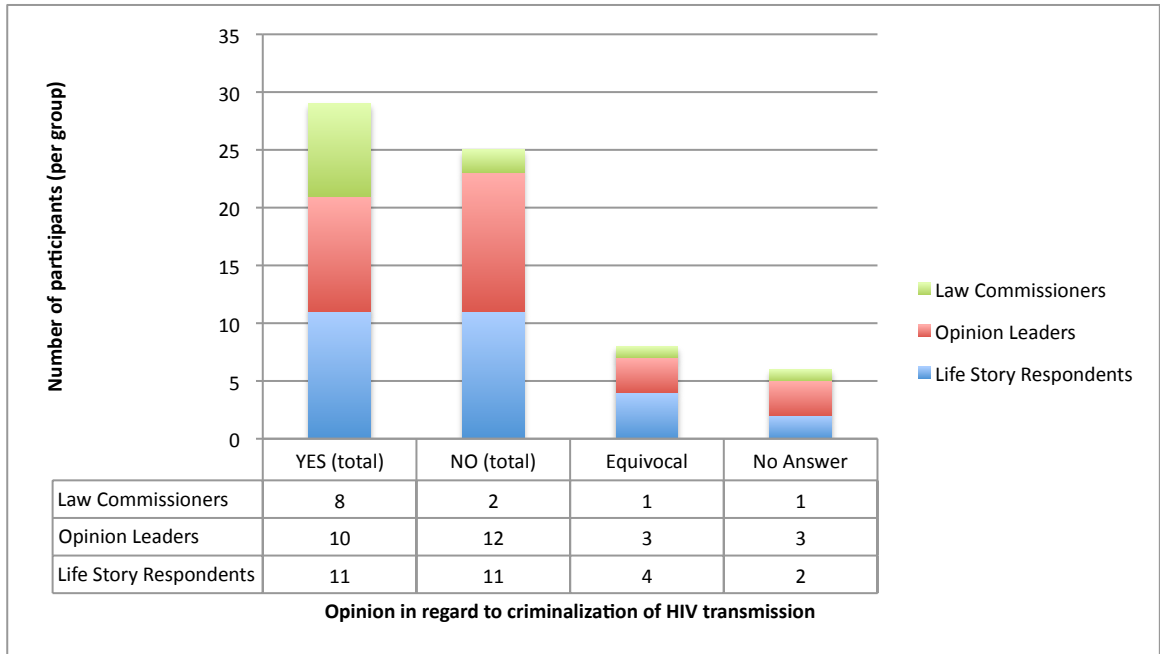
Annex 6|7| Nexus: Direction of action



Annex 6|8| Nexus: Meaning and solution direction of action

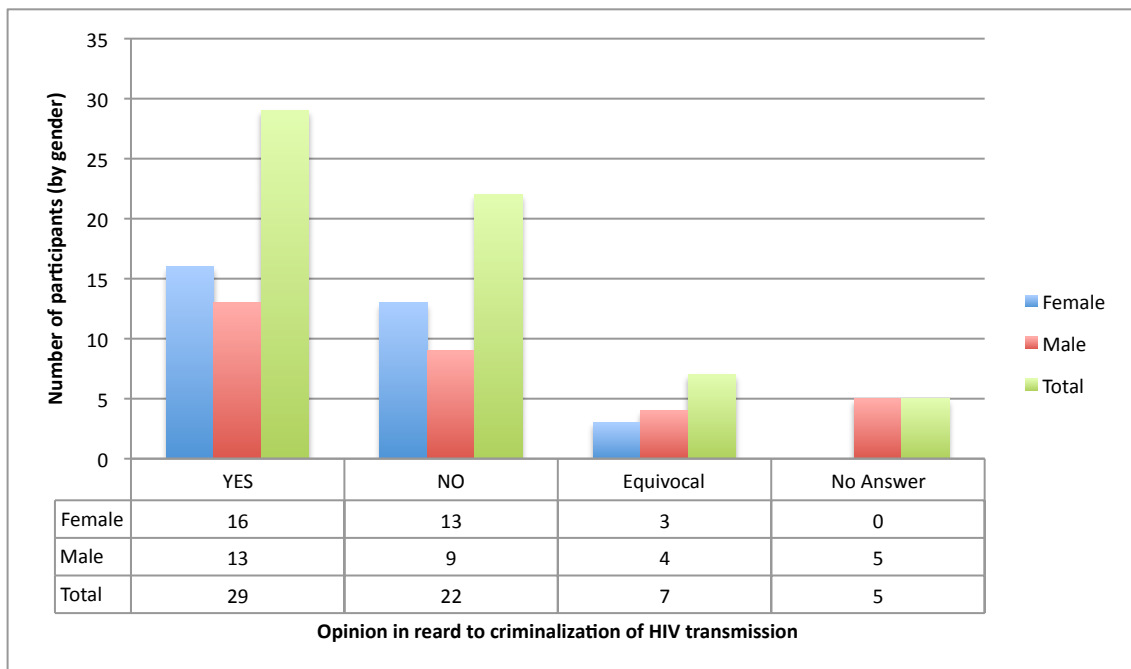


Annex 7|1 Participant group responses criminalization



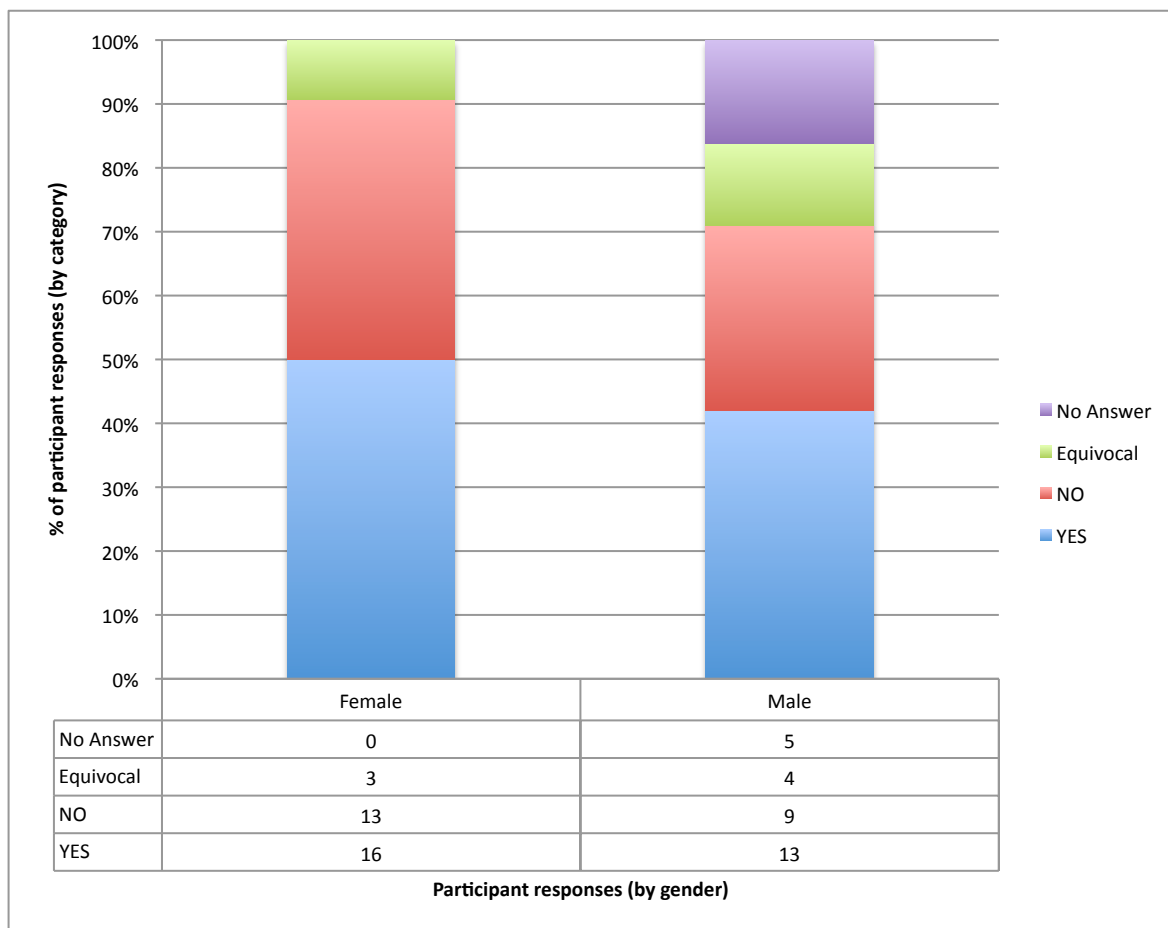
Summary of participant responses regarding whether HIV transmission should be a crime. [NB total number for “yes” and “no” includes participants who indicated both perspectives]

Annex 7|2 Gender breakdown criminalization opinions



Gender breakdown of overall responses relating to participants opinion as to whether HIV transmission should be a crime. [NB total number for “yes” and “no” includes participants who indicated both perspectives]

Annex 7|3 Gender breakdown criminalization



Gender breakdown of total responses regarding whether HIV transmission should be a crime. [NB total number for “yes” and “no” includes participants who indicated both perspectives; total Male = 31; Female = 21]

ⁱ The ethics for the research was founded on the guidelines of the British Oral History Society and from the protocol for informed consent and confidentiality outlined in the guidelines for *The People Living with HIV Stigma Index*. Ethical approval for my research was gained from the Committee for Ethical Research at the Royal College of Medicine, where this life story case study research was included as one of the contributing sources of data for case studies to enrich the findings from *The People Living with HIV Stigma Index* (reference P.08/10/974) granted by the College of Medicine Research and Ethics Committee (COMREC), 25 October 2010.

ⁱⁱ Special thanks also to all the participants who gave their time for the research, and to Kevin Osborne (IPPF), Mathias Chatulukwa (Family Planning Association of Malawi), Safari Mbewe (MANET+), Patrick Brenny (UNAIDS) and Dr Frances Cleaver (University of Bradford).

ⁱⁱⁱ News coverage of the Annual AIDS Conference on the website of the National AIDS Commission in Malawi: <http://www.aidsmalawi.org.mw/index.php/8-news/13-no-more-stigma-and-discrimination-says-president-joyce-banda> accessed 21 October 2012.

GAZETTE EXTRAORDINARY

**The Malawi Gazette Supplement, dated 31st December, 2008, containing
Report of the Law Commission (No. 2D)**

LAW COMMISSION REPORT NO. 20

CONSTITUTION OF MALAWI

REPORT OF THE LAW COMMISSION ON THE DEVELOPMENT
OF HIV AND AIDS LEGISLATION

The Report of the Law Commission on the Development of HIV and AIDS Legislation is hereby published as Law Commission Report No. 20, and shall be laid in Parliament, pursuant to section 135 (*d*) of the Constitution.

Dated this 23rd day of December, 2008.

FILE NO. LC/01/52A

H. D. Phoya
*Minister of Justice and
Constitutional Affairs*

**REPORT OF THE LAW COMMISSION ON THE DEVELOPMENT
OF HIV AND AIDS LEGISLATION**

TO: THE HONOURABLE HENRY D. PHOYA M.P., MINISTER OF JUSTICE
CONSTITUTIONAL AFFAIRS

This is the Report of the Law Commission which was appointed under section 133 of the Constitution to develop legislation on HIV and AIDS in Malawi. The report is on the development of HIV and AIDS legislation.

The Commission hereby submits the Report pursuant to section 135 (d) of the Constitution and commends the recommendations contained in this Report to the Government, Parliament and people of Malawi.

MEMBERS

REVEREND JOSEPH MPINGANJIRA

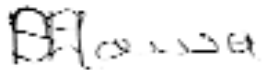
Chairperson,
Secretary General,
Episcopal Conference of Malawi



.....

DR. MRS. MARY SHAWA

Deputy Chairperson,
Principal Secretary,
Department of Nutrition, HIV and
AIDS in the Office of the President and
Cabinet



.....

MRS. JANET LAURA BANDA

Chief Law Reform Officer,
Law Commission



.....

MS ANDRINA FRANCES MCHIELA

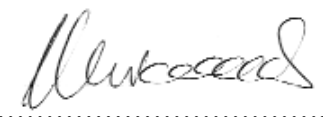
*Former Principal Secretary,
Ministry of Women and Child
Development*



.....

DR. BISWICK MWALE

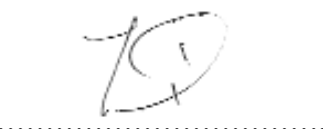
*Executive Director,
National AIDS Commission*



.....

PROF. NDALAMA GEORGE LIOMBA

*Chief Executive Officer,
Malawi Blood Transfusion
Service*



.....

MRS. FIONA KALEMBA

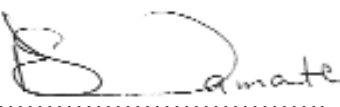
*Assistant Chief
Parliamentary Draftsperson,
Ministry of Justice and
Constitutional Affairs*



.....

DR. DOROTHY NAMATE

*Former Director of Health and
Technical Services,
Ministry of Health*



.....

MRS. AMANDA RUTH MANJOLO

*Executive Director,
National Association for People
Living with HIV and AIDS*



.....

DR. GRACE MARGARET E. MALINDI

*Deputy Director ,
Agriculture, Gender Roles
Extension Support Services,
Ministry of Agriculture*



MS EDITH CHIPO KANJO

*Senior Lecture in
Computer Science
Chancellor College*



MS. DINAH ESNATH ACHIWA NTODWA

Retired Civil Servant



Dated: December, 2008

Programme Officers

The programme officers for this programme were Mr. William Yakuwawa Msiska, LL. B with Honours (Malawi); and Mr. Chizaso Eric Nyirongo, LL.B with Honours (Malawi), LL. M (Oslo). During the course of the Programme, Mrs. Janet Banda went for further studies and was replaced by Mr. A. Mbang'ombe, LL. B (Hons) (Malawi), LL.M (Warwick).

Acknowledgements

Funding for this programme was provided by Government of Malawi and was administered by the National AIDS Commission.

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INTRODUCTION

General Background

The condition that is presently known as Acquired Immune Deficiency Syndrome (AIDS) is a phenomenon that is closely associated with the 1980s. Globally, scientists first isolated a case of what is presently known as AIDS as early as 1959.¹ As more and more cases of AIDS were being discovered, the disease was slowly becoming closely associated with homosexuals. By 1978, homosexuals in the United States of America and Sweden began showing signs of AIDS as it is known today. The first link of AIDS to blood was made in 1982 after a reported number of deaths in the United States of America alone had reached 853.² It was only in 1983 that *Institut Pasteur* of France made the claim that it had discovered the virus responsible for AIDS, the Human Immunodeficiency Virus (HIV).³

The first case of HIV infection was reported in Malawi in 1985.⁴ The first cases of blood screening took place in Blantyre in December, 1985 and in Lilongwe early 1986. Towards the end of 1985, Government established a Technical Committee to advise on how to respond to the new disease. The National AIDS Control Programme (NACP) was set up in 1989 under the Ministry of Health. The approach of the NACP was largely biomedical and this led to a number of governance and structural problems. In any event, the NACP lacked sufficient authority as a programme to respond quickly and decisively to the fast growing epidemic.

As the 20th century drew to a close, the global population of people living with HIV and AIDS had soared to a staggering 33.6 million people.⁵ By 2005, the number of people living with HIV had reached 40.3 million, with new infections making up a total of 4.9 million.⁶ Out of these statistical figures, 25.8 million individuals were living in Sub-Saharan Africa.⁷

At the UN General Assembly in June, 2001, the Heads of Governments agreed that strong leadership at all levels of society is essential for an effective response to the epidemic; leadership by Governments in combating HIV and AIDS is essential and their efforts should be complemented by the full and active participation of civil society, the business community and the private sector; and that leadership involves personal commitment and concrete actions.⁸ Following

¹See <http://www.aegis.com/topics/timeline/> (visited on 1st July, 2007)

²*ibid*

³*ibid*

⁴In neighbouring Tanzania, the first case of what is known as AIDS today was first discovered around the Lake Victoria region in 1983.

⁵UNAIDS/IPU, Handbook for Legislators on HIV and AIDS, Law and Human Rights: Action to Combat HIV and AIDS in View of its devastating Human, Economic and Social Impact, 1999, Geneva, Switzerland.

⁶UNAIDS, AIDS Epidemic Update-Special Report on HIV Prevention: December 2005

⁷*ibid.*

⁸See Global Crisis-Global Action, Declaration of Commitment at <http://www.un.org/ga/aids/coverage/FinalDeclarationHIVAIDS.html> (visited on 1 February, 2008)

the recommendations of UN General Assembly, the NACP was replaced by a new institution, the National AIDS Commission (NAC) in July, 2001, which was constituted as a public trust. An eighteen-member Board of Trustees was appointed. The initial plans to establish the institution by an Act of Parliament were shelved as Government feared there would be delay if Parliament was to be involved.

Until 2002, NAC operated under the Ministry of Health and reported to the Cabinet Committee on HIV and AIDS and Health. In August of that year, the reporting structure was changed and NAC, through the Office of the President and Cabinet, reported to the Minister responsible for HIV and AIDS who was the President himself. The change in the reporting structure of NAC to the Office of the President and Cabinet was done with a view to bringing the highest political office to commit fully to fighting the epidemic and to ensure Government oversight activities at the highest political level. This change brought NAC under the direct control of the President. This reporting structure was executed through the Minister of State responsible for Presidential Affairs.

In April, 2003, a Ministry exclusively responsible for HIV and AIDS was established. The Chairperson of NAC, then, reported directly to the Minister. After the General Elections in May, 2004, the Ministry responsible for HIV and AIDS was abolished and in the same year, the Department of Nutrition, HIV and AIDS was established under the Office of the President and Cabinet. Government realized that issues of HIV and AIDS cannot be separated from nutrition for a developing country such as Malawi. In line with principles of national policy enshrined in the Constitution, it was considered that embracing nutrition as an accompaniment of the fight against the spread of HIV would go a long way in prolonging life and improving survival chances for the infected.

The Department was established with a view to providing policy direction and guidance, overseeing and facilitating mainstreaming and the creation of operational structures with respect to nutrition and HIV and AIDS.⁹ The Department is also responsible for the facilitation of the enactment and enforcement of legislation and networking on issues of nutrition and HIV and AIDS.¹⁰ The objectives of the Department are to formulate and review nutrition, HIV and AIDS policies and to implement strategies; to provide guidance and support for the implementation of government policies on nutrition, HIV and AIDS; and to monitor and evaluate the implementation of Government policies on nutrition and HIV and AIDS.¹¹

⁹The Department of Nutrition, HIV and AIDS has not yet finalized the preparation of the *Nutrition, HIV and AIDS Business Strategy*. The note refers to the draft form which has been approved by Cabinet.

¹⁰*ibid*

¹¹*ibid*

Basis and Issues for Reform

In August, 2006, the Law Commission received two submissions: one from the Department of Nutrition, HIV and AIDS and the other from the National Aids Commission (NAC). The submission from the Department urged for the development of a comprehensive legislative framework to govern issues related to HIV and AIDS. The proposed legislation was suggested with a view to articulating and realizing the principles contained in the National HIV and AIDS Policy which was adopted by Government in October, 2003. The submission from NAC on the other hand focused on the creation of a legislative institutional framework to allow for the proper and effective functioning of NAC. NAC considers the present institutional arrangement inadequate for its proper functioning considering the magnitude of its responsibility. There was also doubt on the permanence of the institution as a public trust. Both submissions acknowledged that HIV infection in Malawi has risen rapidly necessitating the adoption of a legislative framework to protect individuals infected and affected by the HIV and AIDS epidemic in view of the current constitutional order which is human rights based.

Pursuant to these submissions, in November 2006, the Law Commissioner in consultation with the Judicial Service Commission appointed a twelve member special Law Commission for the development of legislation on HIV and AIDS in accordance with section 133 (b) of the Constitution. The main task of the special Law Commission was to develop legislation on HIV and AIDS. The membership of the special Law Commission comprised representatives from the public sector, the faith community, academia, civil society, people living with HIV and AIDS and ordinary citizens. The special Law Commission commenced its work in February 2007.

The first task of the Commission was to determine whether to review all statutes that have an impact on HIV and AIDS in order to address existing short falls in those pieces of legislation or whether indeed it was necessary to develop a new piece of legislation on HIV and AIDS. Secondly, the Commission also considered whether, in the event that new legislation has to be developed, it should combine or separate issues of institutional framework with or from issues of prevention and management of HIV and AIDS respectively.

In deliberating these issues, the Commission opted to develop a new piece of legislation on HIV and AIDS principally because the Commission considered the issue of HIV and AIDS as a cross-cutting multi-sectoral issue and as such inappropriate to be tackled under the existing pieces of legislation. Secondly, the Commission considered that the proposed law on HIV and AIDS should combine issues of prevention and management of HIV and AIDS and issues of institutional framework for managing and coordinating the response to HIV and AIDS since they go hand in hand.

The Different Facets of HIV And AIDS

(i) HIV and AIDS as a Bio-medical Issue

The initial approach to the HIV and AIDS phenomenon was bio-medical and public health. As time went by, it slowly progressed to being recognized as a multi-dimensional issue. As a bio-medical and public health issue, HIV and AIDS is understood primarily as a disease. As a disease, it concerns the physical health of an individual as a result of the invasion of a virus into his or her biological environment for which treatment is needed. AIDS is loosely understood as a disease notwithstanding the fact that technically and by its very name, Acquired Immuno-Deficiency Syndrome, it is a condition.

The virus that causes AIDS, the HIV, destroys the immunity of an individual thereby giving rise to opportunistic infections and other diseases which easily attack the body since the level of immunity in the body is reduced. In the absence of a known cure or vaccine for HIV infection, HIV and AIDS remains largely a bio-medical and public health concern especially with the emergence of anti-retroviral drugs as a remedy for individuals infected with HIV or those who are showing signs of AIDS. Although the anti-retroviral therapy does not cure AIDS, it considerably slows down the progression of the virus in the body thereby allowing individuals who are infected to live longer, healthier and better lives.

(ii) HIV and AIDS as an Economic Issue

HIV and AIDS is also an economic issue. In Malawi, the epidemic has killed many economically productive citizens. These are people on whom vast amounts of financial and other resources have been invested (by Government and the private sector) in terms of, among other things, education and training, health services and social and cultural development. As such, loss of life to HIV and AIDS is a loss of all that investment made on each and every individual and their unrealized potential. This, then, primarily places an obligation on Government and the private sector to replace the human resources lost in order to continue functioning properly. This also means that Government and the private sector lose considerable resources in continued education and training, provision of health and social services without gain. As such, economic prosperity becomes a pipe dream.

Individuals who are infected and affected with the HIV and AIDS epidemic are, in most cases, people who have social and financial responsibilities over their households. These individuals are parents, siblings and children on whom various relatives and family members and friends rely on for support of various kinds. In many cases, such individuals are heads of households and sole breadwinners whose death often leaves the survivors destitute. Death of such individuals often leads to an exponential increase of orphans who remain a financial and economic liability as they still have to be cared for by other people or the State. Channeling meager State resources to care and provide for the needs of orphans places a very huge cost on the State and other stakeholders.

HIV and AIDS is also a condition that is heavily characterized by long illness that renders the patient unproductive economically but requires financial and medical support. An AIDS patient like any other patient needs a good diet, treatment and adequate health care whether or not they will survive the sickness. Caring for a patient may also render the care giver economically unproductive due to the length of the sickness. This creates such a vicious cycle since sickness of one individual may and usually adversely affects the whole family. The situation becomes critical if, as indicated earlier, the patient is the sole breadwinner of the family.

(iii) HIV and AIDS as a Social Issue

HIV and AIDS is also a social issue. The most common method of transmission of HIV is through sexual contact. As a result, it is heavily associated with sexual immorality. When a person develops AIDS, society stigmatizes the individual and tends to shun the patient who is often viewed as paying for their immorality. However, this attitude tends to ignore the truth about HIV and AIDS. A person may contract HIV through the immorality of another person, for instance, in marriage where one spouse is promiscuous and the other is a passive and innocent recipient of the infection. There are also other methods of transmission of HIV infection which are not related to sexual immorality at all. These include parent to child transmission during pregnancy, child birth and breast feeding. HIV infection may also be contracted through blood transfusion, tissue transplants and various forms of sexual assaults, such as rape among other methods.

Another social aspect of HIV and AIDS is that it has redefined relationships in society as parents die in overwhelming numbers leaving the obligation to raise children on grandparents or between siblings. This, notwithstanding, stigmatization of people infected with HIV or suffering from AIDS remains a serious social problem.

The effort to prevent the spread of HIV infection and deal with people suffering from AIDS remains constrained due to numerous and widespread misconceptions and misunderstandings of matters concerning HIV and AIDS. Lack of a known cure or vaccine has created lucrative opportunities for various individuals who have wasted no opportunity to mislead the public that they have the ability to cure AIDS. This has been the case mostly for traditional healers. Cases of religious institutions and leaders making similar claims are also on the rise.

Terms of Reference

The special Law Commission developed the following Terms of Reference to guide its work—

- (a) to review laws of Malawi that have an impact on the HIV and AIDS pandemic and develop a law on HIV and AIDS, having regard to—
 - (i) the provisions of the Constitution and any other written laws that have an impact on the HIV and AIDS pandemic;
 - (ii) the National HIV and AIDS Policy and other national policy instruments such as, but not limited to, the Malawi Growth and Development Strategy and the National and International Millennium Development Goals;
 - (iii) Malawi's obligation under international and regional conventions, treaties and protocols on HIV and AIDS;
- (b) to consider and make recommendations on—
 - (i) the development of legislation on HIV and AIDS including effective implementation and enforcement mechanisms;
 - (ii) creation of an institutional legal framework for regulation and co-ordination of matters pertaining to HIV and AIDS;
 - (iii) any additional laws to effect change to unwritten laws of Malawi, including customary law;
 - (iv) any changes to be made to harmonize statutory and customary laws;
 - (v) any non-legislative approach so as to remove any unjustifiable discrimination of people suffering from HIV and AIDS with a view to ensuring the mitigation of the impact of the HIV and AIDS pandemic;
- (c) to consult widely amongst the Malawian community and with relevant bodies;
- (d) to conduct comparative studies at national, regional and international levels, including, where necessary, study visits;
- (e) to examine international instruments, such as—
 - (i) the Universal Declaration of Human Rights;
 - (ii) the International Covenant on Civil and Political Rights;
 - (iii) the International Covenant on Economic, Social and Cultural Rights;
 - (iv) the Convention on the Elimination of All Forms of Discrimination Against Women;
 - (v) the Convention on the Rights of the Child;

- (vi) the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women;
 - (vii) the Southern Africa Development Community Declaration on HIV and AIDS;
 - (viii) the Abuja Declaration on HIV and AIDS, Tuberculosis and Other Related Infectious Diseases;
 - (ix) the Tunis Declaration on HIV and AIDS and the Child in Africa; and
 - (x) the United Nations General Assembly Special Session Declaration of Commitment on HIV and AIDS,
in light of the HIV and AIDS pandemic;
- (f) to review local instruments in recognition of work already undertaken, having regard to all relevant documents and reports, including—
- (i) the Constitution of the Republic of Malawi and other written laws;
 - (ii) the National HIV and AIDS Policy and other relevant policy documents; and
 - (iii) reports of the Law Commission including Reports on the Criminal Justice Law Reform and Reports on the Review of Gender-related Laws;
- (g) to consider any relevant law of any other country, particularly, within the Southern Africa Development Community;
- (h) to consider any relevant customary laws and practices particularly those that have an impact on HIV and AIDS;
- (i) to consult stakeholders at regional and national workshops in order to solicit views on the findings and recommendations of the Commission; and
- (j) to make recommendations on any other matters relating to HIV and AIDS.

Work Methodology

The Commission adopted the following methodology in the development of the legislation on HIV and AIDS—

- (a) invitation of submissions from members of the general public through notices in newspapers and in the *Gazette*, and several written submissions were received;
- (b) holding Commission meetings. During these meetings, the Commission examined the relevant laws on HIV and AIDS in light of the Constitution, international law and comparable foreign municipal law;
- (c) the Commission conducted study visits outside Malawi in order to obtain a comparative perspective from other jurisdictions;
- (d) the Commission held several consultative meetings with stakeholders and

then three regional workshops in the three administrative regions of Malawi. The Commission presented its findings and recommendations to a National Consultative Workshop at the end of the review exercise for further feedback. The participants at the Workshop were drawn from the public service; academia; faith organizations; traditional leadership, especially Chiefs; private sector; and the general public;

- (e) the Commission reconvened to consider the feedback from the various consultative fora. All submissions, comments and criticisms were considered and debated and in large measure have been incorporated in this Report.

Overview of the Law

(i) The Constitution

The Commission deliberated at length on how the Constitution has dealt with matters of prevention and management of HIV and AIDS. The Commission observed that under the Constitution, the State is obliged to provide “adequate health care, commensurate with the needs of Malawian society and international standards of health care” (*emphasis added*).¹² The State is further obliged to “achieve adequate nutrition for all in order to promote good health and self sufficiency”.¹³

The Commission also noted that under Chapter IV of the Constitution, there are various rights that relate to HIV and AIDS. For example, section 19 provides for the dignity of all persons while section 20 prohibits discrimination in any form and on any ground including on the ground of status. The Commission noted that there is rampant discrimination and stigmatization against individuals on account of perceived or actual infection with HIV and AIDS. The Commission also observed that section 21 provides for the right to privacy; section 22 provides for rights and freedoms connected with family and marriage; section 23 provides for rights of children; section 24 for rights of women; section 25 for the right to education; section 26 for the right to culture of choice; section 29 for the right to an economic activity; and section 31 for labour rights.

The Commission thus concluded that the rights cited above, among others, are critical to ensuring the promotion of a rights based approach in relation to prevention and management of HIV and AIDS. The Commission took note of the existing constitutional framework and resolved that it shall form the basis of the specific provisions in the proposed law.

(ii) Legislation

The first statute to be considered by the Commission was the Public Health Act as the principle statute on public health issues. The Commission

¹²Section 13 (c) of the Constitution

¹³Section 13 (b) of the Constitution

noted that in its long title, the Public Health Act is intended to “amend and consolidate the law regarding the preservation of public health”. The statute also defines an infectious disease as “any disease that can be communicated directly or indirectly by any person suffering therefrom to any other person”.¹⁴ Other aspects of the Public Health Act relevant to the prevention and management of HIV and AIDS include parts that deal with infectious diseases,¹⁵ prevention and suppression of infectious diseases,¹⁶ epidemic and formidable diseases,¹⁷ prevention of introduction of infectious diseases,¹⁸ and venereal diseases¹⁹.

The Commission observed that addressing issues of HIV and AIDS under the Public Health Act may present a number of challenges. Firstly, the diseases listed under this Act do not share the characteristics of HIV and AIDS. Almost all of the diseases listed under the Public Health Act are diseases that are either curable or have vaccines.²⁰

The modes of transmission of the diseases listed as formidable epidemic or endemic diseases are also different from the modes of transmission for HIV and AIDS.²¹ The mechanisms for prevention and management of the diseases listed under the Act including disinfection of premises, destruction of articles, removal of persons, removal and burial of infected bodies and quarantine or isolation of patients would not apply to HIV and AIDS.²²

The other challenge related to the Public Health Act as a preventive and management tool for HIV and AIDS is that it takes an exclusively bio-medical approach. The Government of Malawi through the National HIV and AIDS Policy has recognized HIV and AIDS as a cross-cutting multi-sectoral issue of which the bio-medical component is only a part. The Commission considered that the issues concerning the economic, social, cultural and political dimensions of HIV would not be best addressed under a law that relates exclusively to the preservation of public health.

On the other hand the Commission noted that infecting another person with a venereal disease is an offence²³. The Public Health Act in section 53 outlines venereal diseases which among others include primary and secondary syphilis, acute and chronic gonorrhoea and soft chancre. A venereal disease is the one which is transmitted through sexual activity. The Commission observed that HIV and AIDS is not included as a disease capable of transmission through sexual activity. The Commission therefore resolved that offences related to HIV and

¹⁴Section 2

¹⁵Part III of the Public Health Act, Cap 34:01

¹⁶Part IV of the Public Health Act, Cap 34:01

¹⁷Part V of the Public Health Act, Cap 34:01

¹⁸Part VI of the Public Health Act, Cap 34:01

¹⁹Part VII of the Public Health Act, Cap 34:01

²⁰Section 11 of the Public Health Act has listed a number of infectious diseases as notifiable diseases. This extensive list refers to many diseases that either have vaccine or cures

²¹See section 30 for a comprehensive list of formidable epidemic or endemic diseases

²²See Parts IV, V and VI of the Public Health Act

²³Section 57 of Public Health Act

AIDS would be best dealt with under a law that specifically targets HIV and AIDS issues under a unified scheme.

The Commission also observed that the Public Health Act was enacted under a constitutional order which did not provide for human rights and freedoms extensively. The Commission noted that the scheme contained in the Act for purposes of preserving public health does not balance or protect the rights and interests of the infected and affected persons which are guaranteed under the new constitutional order. For instance, the Public Health Act provides for isolation and compulsory medical examination of persons suffering or suspected to be suffering from infectious diseases as modes of prevention of infection of formidable epidemic or endemic diseases.²⁴ Due to the peculiar and unique nature of HIV and AIDS, these modes of prevention seem to violate some human rights provisions enshrined by the Constitution.

The other statute considered was the Penal Code and it was looked at in the context of criminal sexual activity leading to infection with HIV and AIDS. The Commission observed that there are no specific provisions related to HIV and AIDS in the Penal Code which is the principal legislation regulating criminal matters in Malawi. although section 192 of the Penal Code provides for an offence where a person unlawfully or negligently poses a risk of spreading the infection of any disease dangerous to life.

The Pharmacy, Medicines and Poisons Act, was also considered inappropriate for the prevention and management of HIV and AIDS in that it regulates the pharmacy profession, and several matters relating to medicine and poisons. The Commission noted that there is a relevant aspect of this statute related to regulation of medicinal products in light of the availability of anti-retroviral therapy and traditional herbs that are claimed to cure HIV infection. The Commission noted that the scheme under this statute is to regulate individuals who are registered or operate under the Act rather than catch a variety of individuals who deal in medicinal products. The Commission thus concluded that this statute is not sufficient to deal with matters related to HIV and AIDS.

The Commission also applied the same reasoning when it considered the Employment Act. The Commission was of the view that the main objective of the Employment Act is to regulate matters of employment. Matters of HIV and AIDS are incidental to employment but do not form the main subject of the employment relationship.

Draft Legislation

As required by section 7 (1) (g) of the Law Commission Act (Cap. 3:09), the Commission has prepared draft legislation incorporating all recommendations of

²⁴See sections 31 (m) and 40.

the Commission. These include a draft Bill of the proposed “**HIV and AIDS (Prevention and Management) Act**”. The draft Bill is attached as part of this Report.

Synopsis of Draft Legislation

The Draft Bill proposed by the special Law Commission seeks to introduce a comprehensive law to regulate the prevention and management of the HIV and AIDS epidemic in Malawi. Further, the Bill seeks to provide for the institutional framework for effective regulation of the prevention and management efforts including the establishment, powers and functions of the National AIDS Commission. The Bill takes a multi-dimensional approach by combining public health, human rights and criminal law issues. The Bill, further, seeks to balance rights and obligations of people infected and affected by HIV and AIDS on the one hand and obligations of the State to protect the public at large from the epidemic.

The Bill is quite extensive in that it covers areas such as gender and human rights which are in their own right, cross-cutting issues. Human rights issues addressed relate to privacy and confidentiality; discrimination and equality; right to property; marriage and family life; and access to legal remedies. The Bill also addresses other critical areas such as regulation of information on HIV and AIDS; the role of education in the fight against HIV and AIDS; modes of HIV testing and the regulation of social and cultural practices that are perceived to propagate the spread of HIV infection.

The Bill also tackles thorny issues surrounding criminalization of deliberate infection of another with HIV, HIV screening for employees including domestic workers and the prohibition of polygamy in light of its perceived role in propagating HIV infection.

Structure of the Report

The first part of this Report is the narrative which contains specific findings and recommendations made by the Commission. All recommendations for enactment made by the Commission are indicated **in bold**. The second part of the Report is the Draft Bill which incorporates the recommendations of the Commission.

Scope of the Proposed Legislation

In light of the normative framework embodied in various policy and legal instruments in Malawi on matters of HIV and AIDS, the Commission identified the following areas to form the core of the proposed law—

- (a) institutional framework;
- (b) gender;

- (c) human rights—
 - (i) discrimination and equality;
 - (ii) privacy and confidentiality;
 - (iii) marriage and family life;
 - (iv) property; and
 - (v) access to judicial remedies;
- (d) information;
- (e) employment;
- (f) education;
- (g) public health; and
- (h) criminal law.

SPECIFIC FINDINGS AND RECOMMENDATIONS**1. INSTITUTIONAL FRAMEWORK***(a) Existing Framework*

The Commission observed that Government has set up a number of institutions that are responsible for coordinating the fight against HIV and AIDS. At the highest level of these institutions is the Department of Nutrition, HIV and AIDS in the Office of the President and Cabinet which is responsible for policy formulation. The Department is also responsible for oversight to the national response to HIV and AIDS in Malawi including oversight over NAC; facilitating and supervising HIV and AIDS mainstreaming, creation of operational structures, production, enactment and enforcement of HIV and AIDS legislation, networking and providing high level advocacy on issues of HIV and AIDS. The Department is complemented by NAC, a public trust which co-ordinates and facilitates the national response to HIV and AIDS. The Ministry of Health continues to maintain a unit responsible for HIV and AIDS which runs in place of the defunct NACP. It is now called the HIV and AIDS Unit. Every ministry also has an HIV and AIDS Focal Point which coordinates the implementation of HIV and AIDS activities within the ministry. The Ministries develop their own programmes pursuant to Government policy.

The issues before the Commission regarding institutional framework on HIV and AIDS were two-fold: First, to clearly spell out the roles of the Department and NAC in the fight against HIV and AIDS including reporting arrangements and second, to establish NAC as a State institution as opposed to a public trust.

In terms of the first issue, the Commission considered that the Department as the key organ of Government, should maintain its role of formulating policy relating to HIV and AIDS and its supervision and oversight mandate of the national response to HIV and AIDS. The Commission noted with approval the placement of the Department within the Office of the President and Cabinet for the proper and effective implementation of its mandate through the Minister responsible for HIV and AIDS.

Further, the Commission recommends that NAC should maintain its mandate of co-ordinating and facilitating the national response to HIV and AIDS and to that end the objectives of NAC as provided in its Trust Deed should be streamlined to achieve this mandate. The Commission has proposed provisions on the mandate of NAC at an appropriate Part of the Report.

On the issue of reporting arrangements, the Commission recommends that, in line with Government practice for state institutions, the Chairperson of NAC should report to the Minister responsible for HIV and AIDS. The Commission further observed that membership of the Principal Secretary responsible for HIV and AIDS on the Commission shall facilitate liaison between the two organs in their respective roles.

The Commission therefore recommends adoption of the following provisions on responsibilities of the Minister—

Responsibilities of the Minister

- ... The Minister shall be responsible for—**
- (a) the formulation of national policies on HIV and AIDS and providing high level advocacy on issues of HIV and AIDS;**
 - (b) taking the lead in the national response to HIV and AIDS and the development of the National Action Framework to provide guidance to the national response to HIV and AIDS;**
 - (c) monitoring and evaluating the national response to HIV and AIDS and the supervision of sectoral policies relating to HIV and AIDS;**
 - (d) the oversight of the finances and activities of the Commission;**
 - (e) facilitating mainstreaming of HIV and AIDS in all sectors of society; and**
 - (f) the proper administration of this Act.**

In deliberating on the second issue regarding the status of NAC, the Commission conceded that the current arrangement does not afford the institution permanence as it can easily be dissolved by resolution of the Board of Trustees. The Commission considered the present institutional arrangement most undesirable in light of the magnanimity of the HIV and AIDS scourge. The Commission observed that establishing NAC under statute would secure its existence and permanence as it may only be dissolved by repeal of a statute establishing it. The Commission also considered that creating NAC under statute would enhance Government's commitment since its existence would be strengthened within the Government structures and would ensure better coordination and liaison between NAC and other departments of Government, including the Department of Nutrition, HIV and AIDS.

Comparative studies carried out by the Commission show that, in some jurisdictions, bodies similar to NAC are established by statute as is the case in Tanzania and Ghana ²⁵. The Commission therefore concluded that for the proper coordination of the national HIV and AIDS response, NAC should be established by statute and so recommends.

The Commission also considered whether NAC should be established as a body corporate or state institution. The Commission observed that a body

²⁵See the Tanzania Commission for AIDS Act, 2001 and the Ghana AIDS Commission, 2002

corporate is a semi-autonomous institution with various rights and obligations, including the right to sue and be sued in its own capacity and has perpetual succession. Further, a body corporate is capable of acquiring, holding and disposing of real and personal property and also that it does or performs all such acts and things as bodies corporate may, by law, do or perform. On the other hand, a state institution is an extension of an organ of government. State institutions can be semi-autonomous and independent but are usually endowed with the authority and protection conferred upon the State machinery. As such, it cannot sue or be sued in its own capacity but still enjoys various powers in its own right including the power to receive and allocate donations of funds. A state institution therefore speaks with full authority of Government over matters that it has been charged with. Examples of state institutions established by the Constitution and legislation include the Law Commission, the Human Rights Commission, the Anti-Corruption Bureau and the Office of the Ombudsman.²⁶

The Commission recognized that establishing NAC as a state institution would confirm Government's resolve and commitment to effectively spearhead the national response. The Commission thus recommends that NAC be established under statute as a state institution.

In further discussion on the institutional arrangements of NAC, the Commission observed that NAC is headed by a Board of Trustees comprising of not less than ten members who serve for a period of three years. Further, the Commission was aware that membership of the Board is largely based on stakeholder representation rather than merit and that this has, to some extent compromised the competence of the institution. In discussing the size of the Board, the Commission was of the view that it is too large to facilitate broad consensus on issues. The open-ended size also means that too many representatives may be appointed without merit to the detriment of the proper functioning of the institution since this may have a bearing on the administrative costs of the institution. The Commission therefore recommends that the total number of approved Commissioners of NAC including ex-officio members should be reduced to seven. The Commission further recommends that members other than ex-officio members, should be appointed by the Minister on merit based on expertise to serve for a renewable term of three years and that these appointments should reflect the multi-sectoral approach to the national response. In terms of representation from key Ministries, the Commission suggested Principal Secretaries responsible for Health, Women and Children, Local Government and the Department of HIV and AIDS.

The Commission further recommends that the Chairperson of the Board should be elected from amongst the non-ex officio members.

Furthermore, in order to ensure adequate representation from stakeholders, the Commission recommends that stakeholders representing the following categories of sectors should be nominated as members of Committees of the

Commission: people living with HIV and AIDS, civil society, traditional leadership²⁷, and faith based organizations²⁸, and health services.

The other issue that engaged the Commission in discussing the institutional arrangements of NAC was that of management and administration. The Commission observed that, at present, NAC is headed by the Executive Director who is appointed by the Board of Trustees in consultation with Government on such terms and conditions as are befitting the position. The Executive Director leads the management and staff of NAC in the performance of duties.

First, the Commission consulted and debated on the appropriateness of the title of the head of NAC in view of the recommendation to change the legal status of the institution. The Commission resolved to maintain the title of “Executive Director” in line with Government practice for this particular institution.

However, the Commission observed that there is no appointment procedure for the administrative head of NAC and considered this gap may be perceived as a violation of principles of transparency and accountability. The Commission thus, recommends that appointment procedures should be adopted for transparency and accountability and that the approach of placing advertisements in the local papers should be used to identify eligible candidates, through interviews. Further, the Commission recommends that after the interview process, the Commission should recommend the most suitable candidate to the Minister for appointment.

The Commission also noted that the current arrangement does not provide for tenure of office of the Executive Director. The Commission considered that this arrangement deprives the head of NAC of job security as he or she can be removed at any time and without good cause or due process. In that regard, the Commission recommends that tenure of office for the Executive Director should be three years with a possibility of renewal. Furthermore, the law should also provide grounds for removal of the Executive Director on the recommendation of the Commission.

Further to matters of administration of NAC, the Commission deliberated on the issue of how NAC would be financed. The Commission considered that as a State institution, NAC would be able to get funds as appropriated by Parliament and that NAC should also be empowered to receive donations of funds and material support from matters of other sources.

The Commission therefore recommends adoption of the following provisions regarding establishment, composition, powers, functions, administration and financial arrangements, of the National Aids Commission–

Establishment of National Aids Commission **There is hereby established a body to be known as the National Aids Commission (in this Act referred to as the “Commission”).**

²⁶With the exception of the Anti-Corruption Bureau, the other institutions are primarily established under the Constitution

²⁷Since traditional leadership is very strong in Malawi and these leaders are recognized as custodians of culture

²⁸In recognition of the role faith based organizations have played in combating the HIV and AIDS epidemic

(2) The Commission shall be an independent State institution under the Office of the President and Cabinet or any other Ministry as the President may direct.

Functions and
duties of the
Commission

. . . The functions and duties of the Commission shall be—

- (a) to manage and co-ordinate the implementation of Government policies on HIV and AIDS;**
- (b) to co-ordinate and facilitate the national response to HIV and AIDS;**
- (c) to develop and maintain an up-to-date information system and establish suitable mechanisms of disseminating and utilizing such information;**
- (d) in liaison with the Secretary responsible for HIV and AIDS, to monitor and evaluate progress and impact of HIV and AIDS prevention, care and mitigation programmes;**
- (e) to mobilize, disburse, monitor and ensure equitable distribution of resources;**
- (f) to promote research, information sharing and documentation on HIV and AIDS prevention and control;**
- (g) to liaise with relevant Ministries as appropriate on all matters relating to HIV and AIDS to ensure that there are no barriers to information on HIV and AIDS;**
- (h) to ensure, through advocacy, that all political, community and traditional leaders play a strong, sustained and visible role in the prevention of HIV and AIDS;**
- (i) to screen and certify that the information on HIV and AIDS produced by any person is correct before dissemination;**
- (j) to develop and maintain profiles for HIV and AIDS;**
- (k) to provide technical support to Government in the formulation and review of HIV and AIDS policies;**
- (l) to provide technical guidance and support on HIV and AIDS to stakeholders;**
- (m) to provide capacity building assistance to implementing institutions involved in the**

national response to HIV and AIDS on behalf of Government; and

- (n) to compile and submit monthly, quarterly and annual reports to the Minister on the implementation of the national response on HIV and AIDS.

Powers of the Commission

. . . The Commission shall have powers to—

- (a) sponsor, support or organize conferences, seminars, workshops and meetings on any matter under its consideration or generally for the promotion of its functions and objects;
- (b) receive and allocate donations of funds, materials and technical assistance for the furtherance of its work and ensure the effective utilization of those funds;
- (c) engage persons having suitable qualifications and experience as consultants to the Commission;
- (d) determine its own procedures for carrying out consultancies for the general conduct of its work;
- (e) establish such number of its own Committees as it considers necessary for the performance of its functions and assign to such Committees any of its functions without prejudice to the power of the Commission itself to perform those functions;
- (f) co-opt any person to attend any of its meetings but that person shall not vote on any matter for decision by the Commission; and
- (g) do and perform all such things or acts as are necessary or expedient for the implementation of its programmes and the exercise of its functions, duties and powers.

Composition of the Commission

. . . (1) Membership of the Commission shall not exceed eleven people and shall consists of—

- (a) one person, appointed by the Minister, who is professionally qualified in the medical sciences or a relevant social scientific field;
- (b) one person, appointed by the Minister, who is a member of civil society and directly involved in issues of HIV and AIDS;

- (c) one person, appointed by the Minister, who is professionally qualified and practicing accountant;
- (d) the Principal Secretary for HIV and AIDS;
- (e) the Principal Secretary for Health;
- (f) the Principal Secretary for Women and Children; and
- (g) the Principal Secretary for Local Government and Rural Development.

(2) The members other than the *ex-officio* members shall be appointed by the Minister following the placement of advertisements in at least two local papers of daily circulation.

(3) An *ex-officio* member of the Commission or any person employed in the public service shall not be eligible to be elected Chairperson of the Commission but shall have the right to vote on any matter at the meetings of the Commission.

(4) Members of the Commission shall not, by virtue of their appointment to the Commission, be deemed to be officers in the public service.

(5) The names of all members of the Commission, as first constituted and every change in the membership thereof shall be published in the *Gazette*.

Tenure of
office

. . . (1) A member of the Commission, other than an *ex-officio* member, shall hold office for a period of three years from the date of his appointment and be eligible for re-appointment at the expiry of that period.

(2) When making appointment after the expiry of the three years, the Minister shall have regard to the need to maintain a reasonable degree of continuity on the membership of the Commission, so that at least half of the appointed members shall be re-appointed for the next term of office.

(3) A vacancy in the office of an appointed member shall occur if the member—

- (a) dies;
- (b) is adjudged bankrupt;
- (c) is sentenced for an offence against any written law to any term of imprisonment;

(d) is absent, without the permission of the Commission, from three successive meetings of the Commission of which he has had notice;

(e) becomes incapacitated by reason of physical or mental disability; and

(f) resigns in accordance with subsection (4).

(4) An appointed member may at any time resign his office by giving one month written notice to the Minister.

(5) A vacancy on the membership of the Commission shall be filled by the appointment of a new member by the Minister.

(6) A person appointed to fill the vacancy shall serve for the remainder of the term of office but no person shall be so appointed where the remainder of the term of office is a period of less than six months.

Chairperson

. . . (1) There shall be a Chairperson of the Commission who shall be elected by the Commission from among the appointed members at the first meeting of the Commission.

(2) Subject to subsection (3), the Chairperson shall hold office as such until the expiry of his term of office as member of the Commission.

(3) The Chairperson may be removed from office by the Commission upon the unanimous decision of the rest of the members of the Commission for—

(a) misconduct;

(b) incapacity; or

(c) any other good cause.

Commission
may establish
Committees

. . . (1) For the better carrying into effect of the provisions of this Act, the Commission may establish such number of committees as the Commission shall deem appropriate, to perform such functions and responsibilities as the Commission shall determine subject to the directions of the Commission.

(2) The Commission shall appoint a Chairperson for each committee from amongst the members of the Commission.

(3) The provisions of this Act relating to the meetings of the Commission shall apply *mutatis mutandis* to the meetings of the committees.

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- Commission may co-opt** ... The Commission may, in its discretion, at any time and for any length of period, co-opt any person on account of his special knowledge or expertise to attend any deliberations of the Commission, but such person shall not be entitled to vote on any matter at any meeting of the Commission.
- Meetings of the Commission** ...**(1)** The Commission shall meet as often as its business requires and in any event not less than once in every three months.
- (2)** Meetings of the Commission shall be held at such places and times as the Commission shall determine.
- (3)** Ordinary meetings of the Commission shall be convened by at least fourteen days written notice to the members by the Chairperson, and the Chairperson may, at his discretion, and shall at the written request of more than four members of the Commission and within seven days of such request, call for an extraordinary meeting of the Commission to be summoned at such place and time as he may appoint.
- (4)** A quorum for any meeting of the Commission shall be formed by the presence of more than half of the members of the Commission or committee.
- (5)** In the absence of the Chairperson, the members present and forming a quorum shall elect one of their number to preside over the meetings of the Commission, and the member so elected shall exercise all the powers, duties and functions of the Chairperson.
- (6)** Subject to the provisions of this Act, the Commission may make standing orders for regulation of its proceedings and business or the proceedings and business of any of its committees and may vary, suspend or revoke any such standing orders.
- (7)** The Commission, and every committee of the Commission, shall cause minutes of its meetings to be recorded and kept.
- Disclosure of interest** ... If a member of the Commission acquires any pecuniary interest, direct or indirect, in any contract, proposed contract or the other matter and is present at a meeting of the Commission at which the contract, proposed contract or the other matter is the subject of consideration by the Commission, he shall at the meeting, as soon as practicable

- after the commencement of the meeting, disclose the fact to the Commission, and shall not take part in the consideration or discussion of or vote on any question with respect to, the contract, proposed contract or the other matter.
- Remuneration** ... Members of the Commission shall be paid such remuneration for membership and such allowances when discharging their duties as may be determined by the Minister responsible for Finance.
- Reporting** ... The Commission shall report to the Minister and keep the Minister fully informed on matters concerning the general conduct of the affairs of the Commission.
- Executive Director** . . . (1) There shall be the office of the Executive Director of the Commission which shall be a public office.
- (2) The Executive Director shall be appointed by the Minister on the recommendation of the Commission on such terms and conditions as Parliament shall determine.
- (3) The office of the Executive Director shall be held by a person who has had experience and shown capacity in a profession or in activities devoted or relevant to matters of HIV and AIDS.
- (4) The Executive Director shall hold office for a period of three years subject to renewal on satisfactory service.
- Procedure for appointment of Executive Director** . . . (1) The procedure for appointing an Executive Director shall involve first the issuing of a public advertisement inviting applications for the post of Executive Director, and shall be signed by the Chairperson of the Commission.
- (2) The advertisement under subsection (1) shall invite applications in writing within thirty days of the date of the advertisement and the advertisement shall require applicants to submit a curriculum vitae.
- (3) The Commission shall assess the applications received pursuant to subsection (2), and—
- (a) may seek other or further information pertaining to an applicant, from the applicant or any other person or source;
 - (b) shall interview each eligible short listed applicant; and
 - (c) shall recommend to the Minister the most eligible candidate for appointment as Executive Director.

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- Duties of the Executive Director** . . . Subject to the general and special directions of the Commission, the Executive Director shall be responsible for the day to day management of the Commission and administrative control of other members of staff of the Commission and, in that regard shall be answerable and accountable to the Commission.
- Removal of Executive Director** . . . The Executive Director may be removed from office on the following grounds—
- (a) misconduct;
 - (b) incompetence;
 - (c) incapacitation by physical or mental illness; and
 - (d) otherwise inability or unfitness to discharge the duties of the Executive Director.
- Other staff** . . . (1) There shall be employed in the service of the Commission, subordinate to the Executive Director, such other management, professional, research, technical, administrative and other support staff as the Commission shall consider necessary for the exercise of its powers and the performance of its duties and functions, who shall be officers in the public service.
- (2) The staff of the Commission under subsection (1) shall be appointed by the Commission on such terms and conditions as Parliament shall determine:
- Provided that the Commission may by directions in writing, delegate to the Executive Director, the appointment of its staff in such junior ranks as it shall specify and the Executive Director shall report to the Commission every appointment made pursuant to this subsection.
- Attendance of meetings by staff** . . . (1) The Executive Director, or any other officer of the Commission as the Executive Director shall designate with the approval of the Commission shall attend meetings of the Commission or any committee of the Commission to record the minutes of the meetings and take part in the deliberations thereof subject to the directions of the Commission or committee but shall not be entitled to vote.
- (2) Where in any meeting the deliberations of the Commission or of a committee of the Commission concerns the Executive Director or any officer of the Commission designated to attend the meeting, the Commission or the committee, as the case may be, may exclude the Executive Director or such officer from the meeting.
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Funding of the
Commission

- . . . (1) The funds of the Commission shall consist of—
- (a) such sums as shall be appropriated by Parliament for the purposes of the Commission;
 - (b) such donation of funds, materials and any other form of assistance for the purposes of its functions, powers and duties;
 - (c) such sums of funds as are derived from the sale of any property by or on behalf of the Commission; and
 - (d) other lawful source of funding.

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No. 7 of 2003
No. 8 of 2003

- (2) The Commission shall at all times comply with the provisions of the Public Audit Act, the Public Finance Management Act and the Public Procurement Act.

Books and
other records
of accounts,
audit and
reports of the
Commission

- . . . (1) The Commission shall cause to be kept proper books and other records of accounts in respect of receipts and audit expenditures of the Commission in accordance with acceptable principles of accounting.

- (2) The accounts of the Commission shall be audited annually by the Auditor General or by independent professional auditors appointed by the Commission in consultation with the Auditor General, and the expenses of the audit shall be paid out of the funds of the Commission.

- (3) The Commission shall as soon as practicable, but not later than six months after the end of the financial year, submit to the National Assembly an annual report on all financial transactions of the Commission and on the work, activities and operations of the Commission.

- (4) The report referred to in subsection (3) shall include a balance sheet and an income and expenditure account, shall be laid before the National Assembly in accordance with the provision of Public Audit Act.

2. GENDER

(a) General

The Commission observed that the prevention and management of HIV and AIDS requires the full participation of all citizens regardless of their sex. The Commission noted that the subordinate status of women and girls in Malawi impairs their ability to access information on HIV and AIDS, promotes discrimination in all spheres of life, thereby disproportionately increasing their susceptibility to HIV infection. It was observed that women and girls are often

unable to negotiate safe sex due to social or legal requirements and mostly due to economic dependency. The Malawi Strategic Gender Country Assessment (2003) declares that 'HIV and AIDS is probably the single most critical threat to the welfare of the girl child and young women in Malawi'.²⁹ Cases of sexual and general violence, either on their own or as a result of traditional or cultural practice, promote risk of HIV infection as well as physical, psychological or social harm to women.

The Commission observed that the Constitution prohibits discrimination on the basis of sex³⁰, gender and marital status³¹. It was further observed that gender equality is a principle of national policy and requires the full participation of women in all spheres of society. At the international level, Malawi is committed, under the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) to condemning discrimination against women in all its forms and has an obligation to, by all appropriate means and without delay, pursue a policy of eliminating discrimination against women by, among other things, adopting legislation that prohibits discrimination against women.

Further, in 2000, Heads of State of UN member states adopted the Millennium Declaration and Development Goals. The sixth goal is to combat HIV and AIDS, malaria and other diseases with specific attention towards halting and beginning to reverse the spread of HIV and AIDS. The Millennium Declaration also considers that the promotion of gender equality and the empowerment of women as one of the most effective ways of combating poverty, hunger and disease. In June 2001, the Heads of State of UN member states also came up with, by far, the most comprehensive effort to address the HIV and AIDS epidemic, the "Declaration of Commitment", through which they adopted a number of policy and programmatic resolutions and recommendations regarding the fight against HIV and AIDS. Notably, the Declaration of Commitment acknowledged that gender equality and the empowerment of women are fundamental elements in the reduction of the vulnerability of women and girls to HIV and AIDS.³²

The Commission noted that the HIV and AIDS epidemic impacts on women from two dimensions: as affected parties and as infected parties. The Commission was informed that heterosexual contact accounts for ninety per cent of HIV infections and that in the fifteen to twenty-four years age group, new infections among women are four to six times higher than for men of the same age group. As of 1998, the Commission learnt that forty six per cent of adult infection occurred amongst the youth but women accounted for sixty per cent of those infections.

(b) Impact on Women

²⁹Ngwira, N. Kamchedzera, G. and Semu, L., *Malawi Strategic Gender Country Assesment*, Vol. 1: Main Report, World Bank and UNDP. June, 2003, p. 28

³⁰Section 20 (1) of the Constitution

³¹Section 24 (1) of the Constitution

³²Article 14

The Commission observed that HIV and AIDS affects men and women differently. During consultations, the Commission learnt that HIV and AIDS has a more adverse impact on women.

First, the Commission observed that women, including girls, as care givers, bear the heavier burden of looking after infected family members, siblings and parents within the household. Further, women still have to share their labour time between provision of caring services for the sick and domestic chores while ensuring that they engage in cultivation of food crops.³³ National statistics indicate that more women engage in subsistence farming to a much larger extent than men.³⁴

A recent survey, showed that forty three per cent of women in Malawi spend more than five hours a day caring for sick household members. The survey further showed that rural people were more likely to bear the burden of illness than urban folk. This inevitably interferes with their capacity to earn a living as more time is committed to caring for patients thereby making them less economically independent. In the event of death, women still spend a considerable amount of time caring for orphans and in many cases, girls are more likely to undertake such household chores than boys.³⁵ The Malawi Strategic Gender Country Assessment proposes that community based care programmes for the chronically sick should be promoted in order to reduce the burden borne by women.³⁶ The Assessment also posits that such programmes should be created within a legal framework.

Second, the Commission learnt that in terms of infections, statistics indicate that women are heavily affected by the HIV and AIDS epidemic. Further, an infected woman is liable to suffer an accelerated illness due to lack of care from a male partner or spouse. According to the Demographic and Health Survey, 2004 (DHS), HIV prevalence between adults of fifteen to forty nine years is higher among women in both urban and rural areas. The DHS further posits that women get infected earlier than men and that women who are separated, divorced or widowed have a significantly higher rate of infection compared to men with the same marital status. The current prevalence rate of HIV infection in Malawi stands at fourteen per centum.

The National HIV and AIDS Policy states that maternal mortality in Malawi doubled between 1992 and 2004 due to, among other things, the HIV and AIDS epidemic. The Policy further provides that women are socially, culturally, economically and legally vulnerable to HIV and AIDS. Due to social and cultural pressures, the Commission learnt, women are entrenched with values that

³³Lisa Arrehag, et. al., p. 67

³⁴Women are at 94 per cent while men are at 76.8 per cent (NSO, 1988)

³⁵Government of Malawi and World Bank (2006), Intergratd Household Survey

³⁶See page 28.

prepare them for lifetime subservience to men. Sexual abuse towards women is usually socially and culturally accepted and stereotypes that perpetuate this are promoted in society. The Commission observed that women usually have lower levels of education as attendance at school is limited by cultural and domestic obligations. Their knowledge of rights to which they are entitled is limited and in cases where these are known, enforcement is difficult, for fear of being ostracized from society and other negative consequences. Hence, women tend to be at higher risk of contracting the HIV than men.

In light of the foregoing, the Commission recommends that Government should embark on a deliberate effort to sensitize women on their rights in relation to HIV and AIDS. The Commission also further recommends the enactment of provisions that eliminate discrimination of women purely on the basis of their sex and gender in order to reduce the impact of HIV and AIDS on women. The Commission has recommended provisions in this regard at an appropriate part of the Report.

(c) Cultural Practices

The Commission observed that the vulnerability of women and girls to HIV and AIDS is aggravated by certain cultural and religious practices. The Commission further observed that such practices not only violate the dignity of females but are usually practised without the express consent of women and befall females mainly on the basis of their sex or marital status. The Commission observed that while the right to participate in a culture of choice is protected under the Constitution, in most cases, women participate in cultural practices without giving free consent due to high dependency on men as wives, mistresses and children. The Commission noted that beyond exacerbating the spread of HIV and AIDS, these harmful practices violate women's rights and also denigrate women as such. To this end, the Commission concluded that these practices were discriminatory against women.

Some of the customs and practices in question include widow inheritance, widow cleansing, sexual relations associated with initiation or rites of passage and swapping of spouses, among many others. Most of the cultural practices revolve around sexuality and sexual intercourse as an integral part. Noting sexual contact as one of the most common forms of transmission, the International Conference on Population and Development (ICPD) Programme of Action, with respect to reproductive rights and reproductive health, sets out key recommendations for addressing the spread of HIV and sexually transmitted infection.³⁷ The Commission also noted the State's obligation to take all appropriate measures in all fields, including introduction of legislation, in particular relating

³⁷See Article C of Chapter 7

to culture, for purposes of guaranteeing the exercise and enjoyment of human rights and fundamental freedoms on the basis of equality with men.³⁸ The Protocol also urges State parties to prohibit and condemn all forms of harmful practices which negatively affect the rights of women and which are contrary to recognized human rights standards.³⁹ With respect to sexual and reproductive rights, the Protocol urges State parties to observe a number of rights of women in connection with HIV and AIDS including the right to self protection and protection from sexually transmitted infections including HIV and AIDS; and the right to be informed of the health status of her partner, particularly if he is infected with HIV and AIDS.⁴⁰

The Commission observed that during consultations, the participants were generally in agreement with the prohibition of the cultural practices that are perceived to spread HIV infection. However, the participants were strongly divided on the issue of polygamy. At regional level, it was agreed that polygamy should not be prohibited but should be regulated by requiring the parties to undergo testing for HIV infection. The Commission thus recommends accordingly.

With respect to urban activities that are perceived to propagate the spread of HIV and AIDS, the Commission observed that most of these activities cannot be categorized as cultural. These activities include proliferation of pornography, obscene television and radio programmes and operation of hospitality places such as rest houses, for immoral purposes. The Commission took cognizance of the existence of laws that are applicable in such scenarios such as the Censorship and Control of Entertainment Act⁴¹, to regulate pornography; the Tourism and Hotels Act⁴², to regulate hospitality places; and the Communications Act⁴³, to regulate broadcasting media houses. The Commission argued that while the activities that are regulated under these laws may not be comprehensively and effectively be tackled under legislation, Government should seriously consider adopting behaviour change interventions to curb the proliferation of the practices that pose a threat of spreading HIV infection.

Pursuant to section 24 of the Constitution that requires the State to pass legislation to eliminate customs and practices that discriminate against women and the National HIV and AIDS Policy which reiterates the call for outlawing of customs and practices that perpetrate the risk of infection with HIV, the Commission recommends the adoption of the following Part:

³⁸See Article 3 of the CEDAW

³⁹Article 5.

⁴⁰Article 14 (1)

⁴¹Cap. 21:01

⁴²Cap. 50:01

⁴³Cap. 68:01

PART ...

HARMFUL PRACTICES

Harmful practices
First Schedule . . . (1) Any harmful practice listed in the First Schedule is hereby prohibited.

(2) Any person who contravenes subsection (1) shall be guilty of an offence and shall be liable to a fine of K100,000 and imprisonment for five years.

Subjecting another to a harmful cultural practice . . . Any person who subjects another person to a harmful cultural practice shall be guilty of an offence and shall be liable to to a fine of K100,000 and imprisonment for five years.

FIRST SCHEDULE

HARMFUL PRACTICES

1. *Chimwanamaye.*
2. *Fisi.*
3. *Hlazi.*
4. *Chijura mphinga.*
5. *Kuchotsa fumbi.*
6. *Chiharo.*
7. *Kuika mwana kumalo.*
8. *Kujura nthowa.*
9. *Kulowa kufa.*
10. *Kulowa ngozi.*
11. *Kupimbira.*
12. *Kupondera guwa.*
13. *Kusamala mlendo.*
14. *Kutsuka mwana.*
15. *Mbiligha.*
16. *Gwamula.*
17. *Bulangeti la mfumu.*
18. *Mwana akule.*⁴⁴

3. HIV AND AIDS AND HUMAN RIGHTS

(a) *General*

The Constitution of Malawi provides for, among other things, Principles of National Policy and a Bill of Rights. The Principles of National Policy place an obligation on the State to actively promote the welfare and development of Malawians but are directory in nature.⁴⁵ The Courts, however, are entitled to have recourse to them in interpreting and applying the Constitution or any other law or

⁴⁴In most areas, similar practices may be known by different names or have derivatives which may not be listed here. It is for this reason that the Minister has been empowered to amend the list as need arises

⁴⁵Section 13 of the Constitution

determining the validity of decisions made by the Executive branch of Government.⁴⁶

The Bill of Rights contains a list of human rights and freedoms which are enforceable before courts and tribunals, the Ombudsman, the Human Rights Commission and other organs of Government. While a number of these rights cannot be derogated, restricted or limited, restrictions or limitations may be imposed if they are prescribed by law, reasonable, recognized by international human rights standards and necessary in an open and democratic society.⁴⁷ The Constitution, however, prohibits any law that prescribes a restriction or limitation to negate the essential content of the right or freedom in question.⁴⁸

The Commission isolated a number of rights and freedoms from the Bill of Rights in the Constitution of the Republic of Malawi, which have a direct bearing on matters pertaining to HIV and AIDS. These rights include the right to the highest attainable standard of health,⁴⁹ the right to life,⁵⁰ the right to liberty and security of the person,⁵¹ the right to equality before the law and freedom from discrimination,⁵² the right to privacy,⁵³ the right to marry and found a family,⁵⁴ the right to education⁵⁵ and the right to participate in a culture of choice,⁵⁶ the right to property,⁵⁷ the right to economic activity and labour, the right to freedom of association,⁵⁸ the right to freedom of expression and opinion,⁵⁹ including the right to receive and impart opinions, among others.

The Commission further observed that HIV and AIDS permeates every aspect of human life such that human rights mechanisms are essential in the fight against the epidemic. The Commission observed that when an individual becomes infected with HIV, this leads to increased vulnerability to opportunistic infections leading to reduced household labour power, food production and household income and asset acquisition. This in turn, tends to affect attendance of children at school due to lack of resources and adoption of new responsibilities for them as care givers in circumstances where usually children are unable to cope properly. Alongside the new responsibilities brought by HIV and AIDS, exploitation of women and girls becomes rampant especially when they are forced into risky and promiscuous behaviour to make ends meet thereby facing greater risk of HIV infection. The natural consequence of this scenario is faster progression of AIDS and death.

⁴⁶*ibid*

⁴⁷See section 44 (2) of the Constitution

⁴⁸See section 44 (3) of the Constitution

⁴⁹Section 13 (c) of the Constitution

⁵⁰Section 16 of the Constitution

⁵¹Section 18 of the Constitution

⁵²Section 20 of the Constitution

⁵³Section 21 of the Constitution

⁵⁴Section 22 of the Constitution

⁵⁵Section 25 of the Constitution

⁵⁶Section 26 of the Constitution

⁵⁷Section 28 of the Constitution

⁵⁸Section 32 of the Constitution

⁵⁹Sections 34 and 35 of the Constitution

The *International Guidelines on HIV and AIDS and Human Rights*⁶⁰ provide a framework for a rights-based approach to HIV and AIDS. The Guidelines outline the human rights standards and how they apply in the context of HIV and AIDS by suggesting the introduction of legislative measures at municipal level. The Guidelines further suggest that in collaboration with and through the communities, States should promote a supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups.⁶¹

The Commission further observed that the rights applicable to Malawians are not only those provided for in the Constitution and statutes. Malawi has committed herself under several international instruments to respect, promote and fulfill a number of human rights obligations. Although Malawi remains a dualist State where international treaties to which she is party have no direct application unless it is so provided by an Act of Parliament,⁶² the Commission was aware that the Constitution requires Courts, in interpreting the provisions of the Constitution, to have regard to current norms of public international law and comparable foreign case law.

In view of the foregoing, the Commission concluded that for the effective implementation of any law on HIV and AIDS, the rights based approach should be adopted. The Commission therefore has adopted this approach in the development of the Bill attached to this Report.

(b) Discrimination and Equality

Discrimination of people infected and affected by HIV and AIDS ranks as the most notorious violation of human rights with respect to HIV and AIDS. Discrimination impedes full participation of people living with HIV and AIDS (PLHIV) in all spheres of Malawian life. Often, discrimination does not take into account the peculiar nature of HIV and AIDS especially with respect to the means of transmission and the fact that HIV infection does not necessarily render the infected person disabled to re-integrate and be useful in society.

Section 20 of the Constitution prohibits discrimination in general on the basis of, among other things, "other status". The Commission considered the adequacy of the words "other status" in encompassing HIV and AIDS as a ground on which discrimination is prohibited with a view to emphasizing the negative consequences of discrimination on People living with HIV and AIDS (PLHIV). The Commission observed that the United Nations through the Committee on Economic, Social and Cultural Rights as well as the Committee on the Rights of the Child have interpreted the term "other status" in the non-discrimination provisions in the relevant international human rights instruments which influenced the wording in section 20 of the Constitution, to include health status,

⁶⁰See www.ohchr.org/english/issues/hiv/guidelines.htm (visited on 1st November, 2007)

⁶¹See Guideline No. 8

⁶²See section 211 of the Constitution

including HIV and AIDS.⁶³ As such, for purposes of interpretation, “other status” as provided for in the Constitution shall be construed to include HIV and AIDS. The Commission was satisfied that on account of this interpretation, “other status” in the Constitution sufficiently includes HIV and AIDS as a ground on which discrimination is prohibited.⁶⁴

The Commission therefore concluded that section 20 underpins the basis for the development of a separate law on HIV and AIDS to promote the enjoyment and protection of the rights of people infected or affected with the HIV and AIDS epidemic. The 2001 United Nations General Assembly Declaration of Commitment (UNGASS) also calls on State parties to eliminate discrimination against people living with HIV and AIDS as well as members of vulnerable groups.

The most common form⁶⁵ of dealing with discrimination is the introduction of legislative measures which prohibit discrimination or sometimes, unfair discrimination, made on listed grounds. Such legislation usually proposes either civil or criminal consequences for cases of discrimination. However, in order to ensure that the proposed law effectively protects persons living with HIV and AIDS against any form of discrimination, the Commission recommends that the law should specifically spell out the rights of people living with HIV and AIDS over and above the traditional rights. The Commission further recommends that the proposed law should specifically criminalize discrimination on grounds of positive sero-status including perceived positive sero-status and AIDS.

The Commission also considered that in some instances, persons affected with HIV and AIDS are discriminated against and hence need protection. The Commission therefore recommends that provisions to protect such persons and criminalizing this form of discrimination should be introduced in the proposed law.

The Commission hence recommends adoption of the following Part—

PART ...

PROHIBITION OF DISCRIMINATION

Prohibition of discrimination on basis of HIV and AIDS . . . (1) Any form of discrimination on the basis that another person is infected with HIV or is suffering from AIDS or is perceived to be infected with HIV or perceived to be suffering from AIDS is hereby prohibited.

⁶³See the Committee on Economic, Social and Cultural Rights, *General Comment No. 14 (2000) on Article 12 of the International Covenant on Economic, and Social and Cultural Rights*, E/C. 12/200/4, paragraphs 18-18 and the Committee on the rights of the Child *General Comment No. 3 (2003) on ‘HIV/AIDS and the rights of the Child’* “CRC/GC/2003/3, paragraph 9. The Commission on Human Rights has also interpreted the term “other status” to include health status: see CHR Resolution on the protection of human rights in the context of HIV/AIDS, above footnote 6 preambular paragraph 16.

⁶⁴The Special Law Commission on the Review of the Constitution was equally convinced on this interpretation.

⁶⁵Anti-discrimination legislation has been introduced in Australia, Canada, Hong Kong, New Zealand, South Africa, the United States of America, France, The United Kingdom, among other Countries.

(2) Any person who contravenes subsection (1) shall be guilty of an offence and shall be liable to—

(a) in the case of an individual, a fine of K100,000 and imprisonment for five years; or

(b) in the case of a body corporate, organization or association, a fine of K500,000.

Right of persons infected with HIV or suffering from AIDS

. . . Any person who is infected with HIV or is suffering from AIDS, shall have the right to—

(a) dignity of his person, integrity, life and health;

(b) practice a profession of choice;

(c) compensation associated with the restriction of his enjoyment of rights; and

(d) free medication, at the expense of the State at any State medical institution, necessary for the treatment of any HIV related disease listed in the Second Schedule.

Second Schedule

Right of persons affected with HIV and AIDS

. . . (1) Any person associated with another person who is infected with HIV or is suffering from AIDS has the right to—

(a) dignity, physical integrity, life and health; and

(b) compensation associated with the restriction of the enjoyment of his rights.

(2) Any person who contravenes subsection (1) shall be guilty of an offence and shall be liable to—

(a) in the case of an individual, a fine of K100,000 and imprisonment for five years; or

(b) in the case of a body corporate, a fine of K500,000.

SECOND SCHEDULE

HIV RELATED DISEASES

(a) kaposi's sarcoma;

(b) chronic or recurrent diarrhoea;

(c) oral and oesophageal candidiasis (thrush);

(d) herpes zoster;

(e) high grade B cell malignant lymphoma;

- (f) cryptococcal and other fungal meningitis;**
- (g) pneumocystis carinii pneumonia; and**
- (h) pulmonary or disseminated tuberculosis.**

(c) Privacy and Confidentiality

The Commission observed that the right to privacy is enshrined in the Constitution under section 21. In the context of HIV and AIDS, this right entails that there exists a duty not to disclose information about the HIV status of another person. In medical practice, disclosure of a patient's bio-data including sero-status is deemed unethical. This duty transcends beyond the health service provider and equally applies to all individuals who work with the health service provider. The Commission noted that generally any form of disclosure of information regarding the health status of an individual is unethical and a violation of the right to privacy.

Local and regional consultations, including study visits, suggested two opposing views on the right to privacy and confidentiality in the context of HIV and AIDS. Interestingly, at meetings in Blantyre and Mzuzu, PLHIV were not in support of promoting this right in the context of HIV and AIDS for two reasons. First, it was submitted that too much emphasis on this right might be perceived to promote stigma and discrimination hence reducing further chances of the world treating AIDS as an ordinary disease. Second, it was submitted that for the effective fighting of the epidemic, Government should adopt a strategy that restricts the enjoyment of this right for purposes of containing new infections⁶⁶.

Contrary to this view, consultations with other groups of stakeholders in Malawi, indicated that the right to privacy and confidentiality of people living with HIV and AIDS should be protected. It was considered that protection of this right should help reduce instances of discrimination since it is usually when it is known that a person is infected with HIV that stigma and discrimination are perpetrated.

In debating this issue, the Commission observed that as a general rule, any person is entitled to privacy and confidentiality. The Commission thus considered that it is important to protect the right to privacy and confidentiality of persons infected with HIV despite divided opinion from stakeholders. The Commission was of the view that issues of discrimination could best be handled in two ways. One way is to legislate the protection of the right to privacy and confidentiality with penal consequences to violation of the right; and another way is to through civic education programmes regarding the nature of HIV and AIDS so that people are made aware of the negative consequences of negative publicity of

⁶⁶Similar sentiments were expressed by PLHIV in Tanzania.

reckless disclosure of other people's sero-status. The Commission was aware that the potential for discrimination as opposed to acceptance on knowing the sero-status of an individual in Malawi is high in both public and private institutions.

The Commission noted that in order to secure the privacy and confidentiality of individuals infected or affected by HIV and AIDS, there is need for enactment of comprehensive provisions that specifically regulate this issue. The Commission observed that in some countries medical data is specifically regulated, and there exists a co-ordinated enforcement mechanism with full powers granted to receive and investigate complaints and award compensation where conciliation fails.⁶⁷ Such laws cover both the private and public sectors due to a variety of records that contain HIV related information. Most privacy and confidentiality laws include issues of when and how personal information, including HIV status, is collected; the type of security measures required to protect personal data, whether the information is computerized or not; access to personal records;⁶⁸ use of information for medical or social research; the purpose for which information is collected, used and disclosed including exceptions which include informed consent, special legal requirement or court order⁶⁹ and partner or guardian notification.

The Commission took note of the fact that publication of a person's identity and HIV status may violate the right to privacy.⁷⁰ The Commission also noted that one forum where the identity and HIV status of an individual may be disclosed to the public is during legal proceedings. The Commission further observed that normally legal proceedings are public hearings and all manners of people including the press are free to attend trials. Realizing the potential exposure of an individual's identity which is likely to negatively affect an individual, the Commission further recommends that during legal proceedings, courts should be empowered to issue privacy or confidentiality orders protecting identity in cases where the HIV status of an individual is likely to be raised.

The Commission was aware that disclosure of an individual's sero-status becomes more critical with respect to stigma and discrimination. Many individuals opt not to know their sero-status or where they are informed of their status, they opt not to disclose their sero-status on account of fear of stigma and discrimination. Failure to disclose occurs in the domestic setting where spouses, parents, children and relatives are kept in the dark and in the wider sphere where employers, social and economic partners and the general public are excluded. The

⁶⁷The Commission learnt that in Canada, the Privacy Commissioner issued a Report in 1989 with guidelines on the strict regulation of collection, storage and use of HIV related information. Similar guidelines were issued in Australia in 1992 and were legislatively implemented through the Tasmanian HIV and AIDS Preventive Measures Act of 1993. In Netherlands, the Penal Code provides for proceedings which may be taken even on behalf of a deceased person on the basis of breach of professional secrecy.

⁶⁸The Commission learnt that this aspect may be unpacked to provide for access in order to ensure accuracy, relevance, completeness and currency of information.

⁶⁹In case of Criminal proceedings on HIV transmission.

⁷⁰In *Z. v. Finland*, the European Court of Human Rights, found that the publication of a person's identity and HIV status can violate the right to respect for private and family life. In Japan, in a libel suit brought by parents of a woman who had died of AIDS, the court awarded damages in favour of the claimants where the media had identified the deceased woman with photos and claimed that she had worked as a prostitute.

absence of a known cure for HIV and AIDS creates a heightened level of anxiety and fear since once an individual is infected, there is no way of reversing the status.

Also on account of stigma and discrimination, there is higher sensitivity with respect to information on HIV infection than over other medical data. HIV-related information includes health records, personnel records, court and police records, counseling records and applications for social benefits. HIV-related data has been defined as including information that identifies an individual or raises suspicion that an individual is or may be infected with HIV, or has AIDS or any AIDS-related condition; has undergone an HIV test; is or has received therapy that the person may have HIV or AIDS; has been asked or advised to have an HIV test, or received counseling about testing; has engaged in behaviour that could put the person at risk of contracting HIV; or is or was an associate of another person with HIV or AIDS.⁷¹

The Commission however observed that there are circumstances where the right to privacy has to be balanced against other interests. A person may waive this right by allowing another person to disclose his or her status or by making personal disclosure. The Commission observed that due to the peculiar nature of HIV and AIDS, especially due to rampant stigma and discrimination, individuals should be encouraged to disclose their sero-status after undergoing testing for HIV infection. Where an individual opts to disclose or consents to his or her status being disclosed, no right is violated.

The Commission also deliberated on what circumstances would arise that would justify the need to disclose another person's sero-status when there is no consent to disclose. The Commission discussed a number of scenarios.

The first instance related to cases where an individual knows his or her positive sero-status but deliberately refuses to disclose to a known sexual partner or a person likely to be infected by him or her. The Commission considered whether health service providers should be empowered to inform people at risk of infection when they know that an individual who is infected with HIV fails to disclose to the sexual partner(s) despite attempts to persuade, support and encourage the HIV positive individual to make such disclosure have been exhausted.

During consultations, the majority of the stakeholders were of the view that health service providers should be empowered to disclose the sero-status of a person under their care to people who are at risk of infection in order to minimize cases of reckless infections. The Commission also learnt that in other countries such as Singapore medical personnel are empowered to disclose HIV status to a spouse or other sexual contacts of an infected person where it is believed that there is reasonable and significant risk of infection to a spouse or sexual contact.

⁷¹UNAIDS, Handbook for Legislators on HIV and AIDS, Law and Human Rights: Action to Combat HIV and AIDS in View of its Devastating Human, Economic and Social Impact, 1999, Geneva, Switzerland (hereinafter "Handbook for Legislators")

The Commission therefore conceded the importance of disclosure of HIV and AIDS related information by health service providers in regulated instances as an effective strategy for preventing new infections and recommends that health service providers, including all personnel responsible for HIV testing, should be empowered to disclose the information by way of notification to all individuals who may be at risk of infection by the infected person. The Commission further recommends that before disclosure is made, the infected person should be counseled and be encouraged to disclose his or her sero-status on his or her own volition and that only where this has not been done should medical personnel disclose the information to those who may be at risk of infection with HIV through the infected person.

The second instance relates to disclosure of the sero-status of minors where they are found to be infected with HIV. In the first place, the Commission observed that where a minor is found to be HIV positive, parents or guardians should be immediately informed by medical personnel. It was noted that unless parents and guardians are informed, they will not be able to provide the best care to the infected minor. The issue at hand, however, was what would be the appropriate age of majority beyond which disclosure to parents or guardians would tantamount to privacy. The Commission deliberated at length on this issue and concluded that, for purpose of disclosure of the sero-status of a child under the proposed law, a child should be defined as anyone who is below the age of sixteen years. Where a person who is below sixteen years is tested for HIV infection, the health service providers conducting the test should be empowered to disclose to the parent or guardian of the minor in question.

The third instance relates to court proceedings and the Commission noted that there may be situations where a person's sero-status would be material for a fair and just disposal of a case. The Commission recommends that in such situations, the court may order disclosure of a person's sero-status but in a manner that balances the interests of justice and the interests of the infected person.

The Commission further observed that in the event that an individual is being referred to another health establishment or personnel, disclosure of that individual's sero-status to that establishment or personnel shall not be deemed to be unlawful disclosure. The Commission considered that this kind of disclosure is done in the interest of the patient.

Finally, the Commission considered whether disclosure should be allowed for statistical purposes. The Commission learnt that, for statistical purposes, research is usually unlinked to the individual who is tested and he or she remains anonymous except for data that is necessary for such purposes like age, sex and similar statistical information. The Commission therefore recommends the retention of this position.

The Commission further recommends that beyond legislative interventions, professional bodies that handle HIV related information should internally

discipline breaches of confidentiality or unreasonable invasion of privacy as professional misconduct under existing codes of conduct applicable to that profession.

To this end, the Commission recommends adoption of the following Part—

PART ...

DISCLOSURE OF HIV AND AIDS INFORMATION

Right to privacy and confidentiality regarding HIV Status . . . (1) A person who is infected with HIV has the right to privacy and confidentiality with regard to information concerning his state of health.

(2) It shall be the duty of every health service provider to strictly observe confidentiality in handling all medical information concerning a person infected with HIV.

Disclosure by health service . . . (1) A health service provider may disclose information relating to any person's HIV status where he reasonably believes that it is medically appropriate to—

(a) any person he reasonably believes has been or will be exposed to the risk of infection in the course of his duties or emergency services; or

(b) the spouse or sexual partner of the infected person.

(2) A health service provider shall not disclose any information under subsection (1) (b) unless he—

(a) has first counseled the infected person regarding the need to notify the spouse or the sexual partner and he reasonably believes that the infected person will not inform the spouse or the sexual partner; and

(b) has informed the infected person of his intent to make such disclosure to the spouse or the sexual partner.

(3) For the purposes of subsection (1) (a), “emergency service” means the Police Service, the Defence Force, the Fire Brigade or any other emergency response provider including a volunteer.

Disclosure of HIV status in other circumstances . . . (1) In addition to the provision under section ..., it is lawful to disclose the HIV status of any person under the following conditions—

- (a) where consent of the person infected with HIV is obtained;
- (b) where disclosure is made to a parent or legal guardian of a minor;
- (c) where such information is demanded by an individual's legal representative;
- (d) where a competent court of law orders that disclosure shall be made; and
- (e) for statistical and epidemiological purposes but such disclosure must not lead to the identity whether directly or by implication, of the infected person.

(2) For purposes of subsection (1),

- (a) "a minor" is any person who is below the age of sixteen years;
- (b) "consent" includes—
 - (i) where the infected person is dead, the written consent of the spouse, personal representative, administrator or executor; and
 - (ii) where the infected person is a minor, or is otherwise unable to give consent, the written consent of a parent, legal guardian; or where necessary, an immediate family member or health service provider.

Unlawful disclosure

. . . Any person who discloses the HIV status of another person otherwise than as provided for under this Act shall be guilty of an offence and shall be liable to—

- (a) in the case of an individual, a fine of K100,000 and imprisonment for five years; or
- (b) in the case of a body corporate, organization or association, a fine of K1,000,000.

(d) *Marriage and Family Life*

The Constitution recognizes the family as the natural and fundamental group unit of society entitled to protection by society and the State.⁷² The family is a forum for provision of security of the person, attainment of basic moral and social values that are passed on from generation to generation; procreation and acquisition or creation of wealth. Families are constituted depending on religious, moral, social, cultural and legal obligations that necessitate the compliance of certain norms if they are to be recognized as such. In many instances, such norms regulate entry, subsistence and exit from marriage. Owing to the sanctity that is accorded to the institution of marriage, there are rules that regulate each aspect of this institution. As such, marriages may be monogamous, polygamous or potentially polygamous; or they may be religious or secular; they may also be traditional or cultural based or outside cultural practice.

With respect to issues of HIV and AIDS, the Commission learnt during consultations that age of marriage is critical in determining vulnerability, especially of women, to HIV infection. The stakeholders observed that early marriages are rampant in Malawi and in the absence of legislation, girls shall continue to bear the responsibility of family life at the expense of attaining education and economic independence. The Commission learnt that early marriages condemn girls and women to life-long subservience to men and that low education levels limit their access to better employment and access to financial resources. It was also learnt that on account of age and lack of education leading to unbalanced power relations with males, girls often lack the power to negotiate for safe sex. It was therefore submitted that the introduction of a minimum age for all types of marriages may assist in the reduction of the spread of HIV especially among women. To that end, the Commission noted with approval the recommendation made by its sister Commission on the Review of Laws on Marriage and Divorce⁷³ to raise the age of marriage to eighteen.

The Commission also considered the case of polygamy. The Commission noted the recommendations of its sister Commission on the Review of the Laws on Marriage and Divorce which recommends the outlawing of polygamy as a form of marriage. The Commission considered the arguments raised in favour of and against the institution of polygamy both from a gender perspective and from the perspective of HIV and AIDS. The Commission noted that while some argue that polygamy increases the risk of HIV infection, others argue that the risk of HIV infection is reduced significantly on account of polygamy since the partners keep within the polygamous unit. The Commission observed that there is no data to justify either position and that in the event that the proposal made by the special Law Commission on the Review of the Laws on Marriage and Divorce to outlaw polygamy is rejected, then the law on HIV and AIDS should provide a compromise and require mandatory HIV test for the parties to the prospective polygamous union. In the view of the Commission, this would help parties to the anticipated polygamous unit to make informed choices and at the same time curb the spread of infections between spouses.

⁷²Section 22(1) of the Constitution

⁷³Law Commission Report No. 16

The other matter considered in discussing family relations was the contentious issue of whether PLHIV should be prohibited by law from having children. The Commission learnt that PLHIVs are advocating for the right to have children within the marriage setting regardless of their sero-status. The Commission further learnt that in light of anti-retroviral treatment and remedial drugs to prevent transmission of infection from mother to child, it is unjustified that PLHIVs should be restrained from having children. With the gradual movement from an era when there was completely no remedy for HIV infection to the present era when progression of HIV infection can be controlled, most PLHIVs feel that the problem of transmission of HIV from mother to infant is a problem for science and not the law.

In other countries within the region such as Tanzania, the Commission learnt that the Government is struggling to balance the duty of the state to protect the right of PLHIVs as individuals to have children and the duty of the state to prevent transmission of infection to unborn children. It is considered that having a child when you are aware of your positive HIV status would tantamount to deliberate or willful infection with HIV. Tanzania is therefore in the process of developing a law barring persons infected with HIV from having children as this would amount to willful infection. It is not clear whether this offence may be proven only when the child has tested HIV positive.

When this issue was presented to stakeholders during consultations at regional and national workshops in Malawi, the prevalent view was that criminalization of child-bearing by people living with HIV and AIDS would be a violation of the constitutional right to found a family. Views also emerged from stakeholders that in light of the likely infection of the unborn child, mass education of the public on consequences of bearing children when people know that they are infected should be implemented in order to protect the unborn child. The stakeholders also noted that programmes such as Prevention of Mother to Child Transmission (PMTCT) should be re-enforced with awareness programmes.

In debating the matter further, the Commission conceded that the right to found a family cannot supersede the importance of ensuring a healthy future generation of Malawi. Notwithstanding this concession, the Commission considered that barring PLHIVs from having biological children would violate the Constitution which prohibits limitations that amount to negation of a right.⁷⁴ The Commission was thus convinced that rather than barring PLHIVs from having biological children, the solution lies in imposing obligatory testing for pregnant women to protect the unborn child through anti-retroviral drugs. It was also observed by the Commission that imposition of obligatory testing for HIV infection for pregnant mothers should be done alongside parallel initiatives where women would be encouraged to go for voluntary testing and counseling. This has been provided for at an appropriate part of this Report.

⁷⁴Section 22 (3) of the Constitution provides that all men and women have a right to marry and found a family.

(e) *Property*

Issues of property and HIV and AIDS arise especially with growing cases of exclusion of PLHIVs from accessing property and also with respect to inheritance. Examples were given of cases in the rural areas where Chiefs who are the custodians of customary land prefer to give land to people who are perceived to be healthy. The Commission learnt that there are cases where property may be distributed when the owner is suffering from AIDS but alive. Property dispossession is aggravated by poverty in a country where 65 per cent live below the poverty line.⁷⁵

The Commission noted that women are the worst victims with respect to property rights. The Commission observed that there still exist laws that prevent women from acquiring property on their own notwithstanding the current constitutional order. The Commission further observed that there is significant dispossession of property from widows than widowers with dispossession occurring to women in 40 per cent of the cases compared to 20 per cent for men.⁷⁶ In the event of actual dispossession, women are likely to lose 74 per cent of the items while men are likely to lose up to 53 per cent of their property.⁷⁷ The current statute regulating inheritance in Malawi, the Wills and Inheritance Act⁷⁸, does not provide for a uniform inheritance system but a proportional method based on the type of marriage. In case of matrilineal marriages, a surviving wife and children share 40 per cent of the property while the remainder goes to customary heirs. In patrilineal marriages, the proportions are on an equal basis between the surviving wife and children and the customary heirs. In both marriages, the wife and children are entitled to all household property.

The Commission observed that property dispossession arises due to a combination of factors including multiplicity of heirs due to unclear guidelines as to who would benefit, opportunism coupled with greed, ignorance on writing wills and unfair cultural practices. Notwithstanding the criminalization of property grabbing under inheritance laws,⁷⁹ the practice remains prevalent in Malawi and has been aggravated by the HIV and AIDS epidemic due to the increase in the number of deaths.

The Commission was aware of the recommendations of its sister Commission on the Review of the Wills and Inheritance Act contained in the Law Commission Report No. 12 with respect to victimization of widows. The Commission learnt that its sister Commission recommended the variation of customary law relating to inheritance by providing that no person can claim under any law, customary or written, property to which a deceased person was entitled at the time of his or her death;⁸⁰ and devolution of property to surviving members

⁷⁵Malawi Strategic Gender Country Assessment, Vol. 1: Main Report, p. 35

⁷⁶ibid.

⁷⁷ibid.

⁷⁸Cap. 10:02.

⁷⁹Section 84A, Wills and Inheritance Act

⁸⁰See section 4 of the Deceased Estates (Wills, Inheritance and Protection) Bill

of the immediate family of the deceased in case of intestacy and dependants of the intestate.⁸¹ Both members of the immediate family and the dependants have been defined under that proposed law. The Commission therefore endorsed the recommendations contained in Law Commission Report No. 12, which are yet to be passed into law, with respect to property rights and protection of widows and children.

(f) Access to Judicial Remedies

The Commission picked up the issue of access to judicial remedies for PLHIV from its study visit to Tanzania. The Commission learnt that protracted litigation especially with respect to issues of deceased estates victimizes PLHIV, their survivors especially women. It was also learnt that protraction of litigation creates untold hardship for the family that survived the deceased since access to property including cash may be restricted until the resolution of the court matter.

The Commission noted that this matter did not arise during consultations at district and regional levels but observed that in light of the right to access justice and legal remedies entrenched in the Constitution, the matter should be considered. The Commission noted that under the Constitution, every person has a right to access the courts for final settlement of legal disputes and the right to an effective remedy in case his or her rights are violated. The Commission considered that an effective remedy ought to include a timely disposal of legal disputes so that individuals who seek redress from the courts are able to enjoy the fruits of litigation. The Commission learnt from the Tanzanian experience that legal technicalities have always been abused by litigants to the detriment of those duly entitled to benefit from the legal system. The Commission noted that protraction of legal proceedings with the anticipation that a contending beneficiary might die on account of HIV and AIDS status should not be condoned in the legal system in Malawi.

The Commission therefore recommends that the Judiciary should be encouraged to expedite cases involving violation of rights of PLHIVs.

4. PUBLIC HEALTH

(a) General

The Commission noted that from 1985 when the first case of HIV infection was diagnosed in Malawi up until 2000, HIV and AIDS was mainly treated as a public health concern. As such, Government interventions were mainly bio-medical and as such it was only the Ministry of Health that was responsible for undertaking a response to the epidemic. Although, HIV and AIDS is now recognized as a multi-sectoral issue, it still remains largely a public health issue. The Commission noted that there are several issues that arise under public health

⁸¹See section 17 of the Deceased Estates (Wills, Inheritance and Protection) Bill

and these include HIV testing; notifiability of HIV infection; provision and access to anti-retroviral treatment; prevention of transmission; care and treatment; the role and obligation of health and medical personnel; rights and obligations of patients, and issues of blood transfusion and tissue transplant.

(b) Testing for HIV Infection

The Commission observed that testing for HIV infection has, as a matter of practice, been accompanied with counseling of the individuals undergoing testing. Counseling has also, as a matter of practice, been conducted prior to and after the testing has been done. The Commission however noted that HIV testing is undertaken without clarity on the rights and obligations of the individual testing another person and the individual undergoing the testing. The Commission was aware that the process of testing for HIV infection poses a risk of infection to the individual conducting the testing and to the individual being tested, and hence require proper guidelines in order to secure protection for both parties. The Commission therefore recommends the promulgation of guidelines to ensure that the rights of both the health or medical personnel and the rights of the person undergoing the test are protected.

The Commission also observed that there is no legislative framework for the protection of patients at health facilities. It was observed that there are cases where individuals accessing health facilities may be at risk of infection due to negligence or carelessness of health personnel, for instance, where a health worker fails to wear protective gear when handling multiple patients or when there is use of unsterilized syringes or other equipment. The Commission learnt that in Tanzania, there is a proposal to criminalize negligent or careless conduct of health workers in the event of consequent HIV infection to patients. The offence to be charged is that of willful infection of another. The Commission considered this a fair approach and an incentive for health or medical personnel to exercise caution when dealing with patients and, thus, recommends a similar offence in the proposed law. The provision for the offence has been incorporated under the Part on Control of HIV and AIDS infection.

The Commission further observed that there is need for health service providers to respect the dignity of individuals undergoing HIV testing by according them humane and dignified treatment with respect to testing. The Commission observed, during consultations, that disclosure of results of HIV testing may adversely impact on the individual undergoing testing thereby leading to likely psychological trauma with devastating effects. The effect may be suicide, low self-esteem, accelerated depreciation of health due to anxiety and depression. The Commission recommends that Government should undertake the responsibility of providing proper training to personnel that is charged with HIV testing and that only those individuals who have received appropriate training and are accredited as such should be allowed to conduct testing for HIV infection under the law.

(c) *Modes of Testing*

The Commission observed that there are four modes of HIV testing: Voluntary Testing and Counseling (VCT), Routine Testing, Diagnostic Testing and Obligatory Testing.

(i) *Voluntary Counseling And Testing*

The Commission observed that in VCT, the individual presents himself or herself to a service provider and requests for an HIV test. The individual goes through pre-test and post-test counseling. This is the most common form of HIV testing and is characterized by consent of the individual undergoing testing. The Commission acknowledged this form of HIV testing and recommends that it should be recognized by law.

The Commission considered whether there should be an age limit on who may access VCT. The National HIV and AIDS policy proposes thirteen years as an appropriate age to access VCT without parental or guardian consent. In deliberating this issue, the Commission was confronted with two challenges. First, if the age is low, the question of mental maturity arises when it comes to handling test results in the event that a person is found to be HIV positive. Second, if the age for accessing VCT is high, cases of sexual abuse at the instance of parents, guardians or relatives would make it difficult for minors to access VCT. Likewise, if there is insistence that parental or guardian company is necessary for accessing VCT, the position of abused minors may be compromised. The Commission also considered that since children start learning about HIV and AIDS at an early stage in school, there is no harm in prescribing a lower age at which VCT may be accessed.

During consultations, several ages were proposed between 10 and 18 years. At the regional workshops, it was proposed that 13 years would be an appropriate age at which an individual may access VCT without requiring consent from a parent or guardian. Justification for this age was that at the age of 13, an individual has a considerable degree of mental maturity to handle the results of an HIV test whatever the outcome may be. It was suggested that at this age, which was traditionally believed to fall within the age of sexual debut, an individual may consider taking preventive measures in order to guard against infection. In light of the consultations and the direction given by the Policy, the Commission recommends the age of thirteen years as the minimum age for accessing VCT without parental consent.

(ii) *Routine Testing*

With respect to Routine Testing, the Commission learnt that this type of testing is offered in the course of other medical process or activity as a matter of routine and it does not require the consent of the patient. The Commission observed that Routine Testing fulfills a number of essential health needs, which include tracking HIV and AIDS, and learning about the progression of the epidemic and ensuring the safety of blood and tissue samples. It is also the form

of testing that is usually offered to pregnant women for purposes of protecting the life and health of the unborn child and the mother. The Commission learnt that Prevention of Mother To Child Transmission (PMTCT) is grounded on the understanding that knowledge of HIV status for pregnant women is critical in managing and preventing transmission to the unborn child. The Commission further learnt that the Defence Force, the Police, the Prisons and Immigration Departments also carry out Routine Testing as a periodical medical assessment for purposes of determining fitness to serve. The Commission recommends that this form of testing should continue and should be specifically provided for under the new law.

(iii) Diagnostic Testing

In Diagnostic Testing, a patient presents himself or herself for general medical examination and he or she is tested for HIV infection as part of diagnosis. Diagnostic testing also takes place in cases where the patient by reason of incapacity is unable to give consent to test for HIV. The patient has liberty to refuse the diagnostic test. The Commission considered that in light of the obligation of Government to manage the national response to HIV and AIDS, the proposed law should empower health service providers to carry out Diagnostic Testing. However, this testing should only be carried out where HIV and AIDS is suspected. The Commission also recommends that where the patient is conscious, pre-testing and post- testing counseling shall be mandatory.

(iv) Obligatory Testing

There are two types of obligatory testing: mandatory and compulsory. Mandatory testing is a precondition for obtaining a service or benefit. Compulsory testing is where a person has no choice in being tested and is required to provide a blood or other bodily fluid sample. Under mandatory testing, the law empowers the health service provider to conduct a test for HIV infection without seeking consent of the individual undergoing testing. The Commission considered a number of scenarios where it would be appropriate for the law to provide for either mode of Obligatory Testing.

The Commission noted that some participants proposed during consultations that obligatory testing for HIV infection should be adopted since the other forms of testing have failed to reduce the impact of the epidemic. The Commission learnt from the proponents of this view that compulsory testing should be universal and regular. The Commission considered this proposal and concluded that universal compulsory testing does not serve any public health objective as there are many variables in society that would render the effort unsuccessful. The Commission also considered that this approach would demand vast amounts of resources since some individuals who may test negative at any given time may be within their window period and would require further testing. The Commission also observed that compulsory testing may jeopardize the other public health initiatives and efforts being undertaken in the fight against the epidemic.

Further, compulsory testing raises a number of human rights issues with respect to enforcement of the scheme where an individual refuses to undergo testing. In Singapore, where an individual has refused to submit to an HIV test required by the Director of Health, he or she may be removed to a hospital or a detention centre under isolation until he or she has been tested. The Commission considered issues of capacity for enforcement of compulsory testing in cases where a considerable number of people refuse to submit to testing and they have to face criminal sanctions.

The Commission also observed that other than in Cuba where universal compulsory HIV testing was tried, there is no country in the world where universal compulsory testing has been adopted. In light of the foregoing, the Commission recommends that universal compulsory testing should not be adopted. The Commission however recommends that compulsory testing should be adopted in specified cases.

The first case identified as appropriate for compulsory testing is that of pregnant women. The Commission considered that if Government were to demonstrate its commitment to protecting the life and health of the unborn child, then it would be appropriate that the current Routine Offer of HIV testing to pregnant women should be made compulsory. The Commission, was aware that the routine test offered in health centers for pregnant women has led to negative social and economic consequences for many women where marriages end in divorce. The Commission however considered this negative consequence as a lesser evil compared to transmission of the virus to the unborn child.

In debating this issue further, the Commission learnt that although it has been acknowledged that there is likelihood of mother to child transmission during pregnancy, there are emerging cases of children being born HIV positive while the mothers are not infected. This has led experts to conclude that it is in fact proper to talk of parent to child infection and not mother to child infection only. In the light of this empirical evidence, the Commission saw the need to extend the requirement for mandatory testing to sexual partners of pregnant women. The Commission therefore recommends compulsory testing for both pregnant women and their sexual partners.

The second case considered by the Commission for compulsory testing for HIV infection was that of commercial sex workers. The Commission observed that there is a general understanding that prostitution is prohibited in Malawi and as such, to subject commercial sex workers to compulsory testing may be perceived as a means of legalizing prostitution. The closest offence to prostitution under the Penal Code is that of living on the proceeds of prostitution.⁸² The

⁸²Section 145 of the Penal Code. This provision is restricted to male offenders only. In its review of the Penal Code, the special Law Commission that undertook the task did not recommend changes to this provision other than deletion of the nature of the punishment.

Commission took cognizance of the recommendations of its sister Commission in the Report on the Review of the Penal Code that HIV infection was aggravated by prostitution and that the sentence for the offence of keeping brothels should be elevated to seven years.⁸³

The Commission observed that there is a trend at global level to decriminalize sex work where no victimization is involved, for instance, where no issues of trafficking or exploitation of the sex worker is involved.⁸⁴ The Commission learnt that most prostitution laws are founded on nineteenth century notions of morality that failed then as they do now in suppressing a demand driven profession. The Commission further learnt that there is a notion that public health objectives with respect to the role of sex workers in the fight against HIV and AIDS may be achieved by treating sex work as a personal service industry that is neither condemned nor condoned.⁸⁵

The Commission also observed that prostitution in Malawi is not institutionalized, as it is the case in other countries where prostitutes are found in regulated brothels. The Commission learnt when it visited Singapore that commercial sex workers are registered and routine testing is available almost on a compulsory basis. When HIV is diagnosed, the licence to practice is revoked and the brothel management is informed. However, there is a challenge for State authorities in testing freelance prostitutes who do not operate under brothels.

The Commission considered that sex work is a reality in Malawi and that there are a number of civil society organizations that interact with sex workers formally. The National AIDS Commission has knowledge of formal and informal groupings of sex workers that interact with the civil society in efforts to identify alternatives for prostitutes who are usually forced into the practice out of poverty and destitution. The Commission therefore concluded that although most commercial sex workers in Malawi do not operate in brothels, they should be subjected to compulsory testing.

Thirdly, the Commission considered whether compulsory testing should be undertaken with respect to issues of blood transfusion and tissue transplant cases. The *International Guidelines on HIV/AIDS and Human Rights* recognizes the need for public health legislation to provide for the safety of blood, tissue and organ supplies. Safety has been understood to mean that blood, tissue and organ samples are free from HIV and other blood transmitted pathogens in order that the right to health is realized. The Commission learnt that the risk of infection through transfusion of contaminated blood is over 90 per cent. As of 1997, UNAIDS indicated that up to four million blood donations are not tested for HIV and other infections.⁸⁶ HIV infection through blood transfusion or tissue transplant may be avoided by proper screening of blood and declaration by the donor of conduct likely to have put him or her at risk.

⁸³Law Commission Report No. 3, page 39

⁸⁴The Netherlands decriminalised prostitution in 1996.

⁸⁵See Bindman J. *Redefining Prostitution as Sex Work on the International Agenda*, Anti-Slavery International, London, 1997.

⁸⁶See Handbook for Legislators, p.47

The Commission recognized the need for stringent measures for ensuring safety of such products in hospitals, blood banks, tissue or organ suppliers, health care professionals, employees and donors by ensuring that only codified procedures have been complied with. The Commission also recognized that issues of compensation might arise where there is evidence of negligence, willful misconduct and false declarations. The Commission considered that liability may be limited on account of policy considerations such as the necessity to save lives; and where the infection could not be detected during the window period.

The Commission considered that for purposes of overcoming the “window period” issue which presents a risk of transfusion or transplant of infected blood and tissue respectively, the common method of testing for HIV, the anti-body test should be replaced by the anti-gene test which identifies HIV infection within a considerably shorter period of time. The Commission recommends that this method of testing should be made compulsory for all cases of blood, tissue and organ donations in order to protect the recipient.

The Commission further recommends that blood, tissue or organ donors should be required to sign a declaration form soliciting specific information to be provided in the law in order to minimize cases of careless infection.

Finally the Commission considered sex offenders as the last category for compulsory testing. The Commission observed that the sexual offenders, by the very nature of their crimes, put others at the risk of HIV infection. While not all cases of sexual assault lead to HIV infection, they give rise to a risk of infection regardless of the fact that complete intercourse has not taken place. Sexual activity for purposes of risk of HIV infection includes oral-genital contact, genital-genital contact, oral-anal contact and anal-genital contact between people of the same or opposite sex. The Commission took notice of the rising levels of sexual offences from media reports which in most cases constitute cases of violence against women and considered that this trend undermines efforts to contain the spread of HIV infection.

The Commission thus recommends that all suspects of sexual offences have to undergo compulsory testing for HIV infection. On whether the window period may slow down the pace of the criminal proceedings, thereby violating the right to speedy trial, the Commission concluded that in order to accommodate the right to fair and speedy trial, the anti-gene test rather than the antibody test for HIV infection should be employed for sex offenders.

(d) HIV and AIDS as a Notifiable Disease

The Commission noted that the Public Health Act has under Part III listed a number of diseases as notifiable diseases. HIV infection or AIDS is not among the notifiable diseases. If a disease is declared notifiable, in case of an occurrence of even a single incident of the disease, emergency response machinery is activated in order to arrest the spread of the disease. For notifiable diseases, there is also an obligation placed on a number of authorities to report the incidences of the disease to the District Health Officer in that district.

The Commission learnt that in Singapore, HIV and AIDS is a notifiable disease in order to allow for public health surveillance. As such, every diagnosis including reasonable suspicion or belief of HIV infection has to be reported to the Director of Health. The notification is name based in order to allow for tracing of sexual contacts of infected individuals.

With respect to HIV infection, the Commission considered that HIV and AIDS is a unique condition for which the scheme under the Public Health Act may not be applicable. The Commission observed that the measures under the Public Health Act apply to a different type of diseases, such as cholera, tuberculosis and bilharzia. For instance, while tuberculosis may be transmitted through air thereby requiring quarantine of the infected person, the mere presence of an HIV positive person does not imply risk of infection to warrant isolation. The imposition of such measures to people who are HIV positive is not compatible with the current constitutional order which is rights based.

The Commission was aware that there is need for a unified response to HIV and AIDS and the understanding that it is a public health problem that requires public health interventions. The Commission noted that it is critical to the fight against the epidemic that there should be a duty placed on health service providers within any district to report cases of HIV infection (and not AIDS) to the District Health Officer. The Commission considered such notification critical and relevant to the strategies that Government takes in budgeting and resource allocation in the fight against HIV and AIDS. The Commission therefore recommends that HIV infection should be notifiable and that the notification should be anonymous as a surveillance effort for purposes of developing statistical data.

The Commission thus recommends the adoption of the following provisions—

PART ...

PUBLIC HEALTH

- Modes of HIV Testing** . . . (1) **The modes of HIV testing shall include—**
- (a) voluntary counseling and testing;**
 - (b) routine testing;**
 - (c) diagnostic testing;**
 - (d) compulsory testing; and**
 - (e) any other mode of HIV testing that the Minister may prescribe.**
- Age of accessing VCT without parental guardian consent** . . . **Any person aged thirteen years and above may access VCT without the consent of a parent or a legal guardian.**
- Consent to HIV testing** . . . **A person shall not undertake HIV testing in respect of another person except—**

- (a) with the consent of that other person;
- (b) if, in the opinion of a health service provider who wishes to undertake the HIV test, the other person has a disability by reason of which he appears incapable of giving consent, with the consent of—
 - (i) a legal guardian of that person;
 - (ii) a partner or spouse of that person; or
 - (iii) an immediate family member;
- (c) where a person is required to undergo HIV testing under the provisions of this Act or any other written law.

Testing of
donated tissues . . . (1) Any person who offers to donate any tissue shall, immediately before such donation, undergo HIV testing.

(2) A health service provider shall not accept a donation of any tissue unless the donor has undergone HIV testing pursuant to subsection (1) and the result is HIV negative.

. . . (3) Notwithstanding subsections (1) and (2), the proposed recipient of the donated tissue or his immediate family members shall have the right to demand a second HIV testing on the donated tissue.

Testing of
donated blood . . . (1) Donated blood shall as soon as practicable after donation, be subjected to HIV testing.

(2) Any blood tested under subsection (1) which is found to be HIV positive shall be disposed of in accordance with the prescribed guidelines on the disposal of medical waste as soon as practicable after such result is obtained.

Consent to be
deemed . . . Consent to undergo HIV testing shall be deemed to have been given in the following circumstances—

- (a) where a person offers to donate any tissue;
- (b) where a person offers to donate blood;
- (c) in situations where it is prudent for a health service provider responsible for the treatment of a person to undertake HIV testing in respect of that person and—
 - (i) the person is unconscious and unable to give consent; and
 - (ii) the health service provider reasonably believes that such a test is clinically necessary or desirable in the interest of that person.

Prohibition of
compulsory
testing

. . . (1) Compulsory testing for HIV infection is hereby prohibited.

(2) Notwithstanding subsection (1), compulsory testing for HIV infection shall be permissible in the following instances—

- (a) under an order of the court, for any person who is charged with a sexual offence;
- (b) for commercial sex workers;
- (c) for persons intending to enter into polygamous unions;
- (d) for pregnant women and their sexual partners or spouses; and
- (e) for donors of blood and tissues.

(3) Any person who contravenes the provisions of subsection (1) shall be guilty of an offence and shall be liable to—

- (a) in the case of an individual, a fine of K100,000 and imprisonment for five years; or
- (b) in the case of a body corporate, organization or association, a fine of K1,000,000.

(4) In addition to the penalties imposed under subsection (3), a court may, upon conviction, order—

- (a) in the case of a body corporate, organization or association, the revocation of any business permit or licence; or
- (b) in the case of an individual, the revocation of a licence to practice the person's profession.

Pre-test and
post-test
counselling

. . . (1) Any health service provider who carries out an HIV test on any person shall be required to provide and conduct free pre-test and post-test counseling to such person.

(2) Notwithstanding subsection (1), any person who carries out HIV testing on any person for purposes of blood transfusion or body tissue extraction shall not be required to conduct pre-test and post-test counseling.

Duty to report
HIV infection

. . . Any health service provider who carries out HIV testing has a duty to give monthly reports of the number of HIV tests conducted and the incidence of HIV infection to the District Health Officer, for statistical and epidemiological purposes only.

Prohibition of
discrimination
in health
institutions

... (1) A person shall not be denied access to health care services in any health establishment or be charged a higher fee for any such services, on the grounds of the person's actual or perceived HIV status.

(2) A person who contravenes subsection (1) shall be guilty of an offence and shall be liable—

(a) in the case of an individual, to a fine of K100,000 and imprisonment for five years; or

(b) in the case of a body corporate, organization or association, to a fine of K1,000,000.

(3) Notwithstanding the provisions of subsection (2), a court may, in addition to any penalty imposed on a person convicted, order—

(a) in the case of an individual, revocation of a licence to practice the person's profession; or

(b) in the case of a body corporate, organization or association, revocation of the business permit or licence.

5. INFORMATION AND HIV AND AIDS

(a) *General*

The Commission observed that general awareness of HIV and AIDS in Malawi is virtually universal.⁸⁷ A considerable percentage of individuals is aware of preventive methods such as condom use, limitation of sexual partners and the fact that a healthy looking individual could have HIV.⁸⁸ The Commission further observed that in spite of this, there is lack of comprehensive knowledge of HIV and AIDS leading to various beliefs and myths about AIDS, knowledge of prevention and transmission of HIV and AIDS.

Literature on knowledge and behaviour in Malawi indicates that there are large gaps on general information on HIV and AIDS, especially with respect to origins and means of transmission. The study further indicates that due to low levels of illiteracy,⁸⁹ oral means of communication are more effective in disseminating information about HIV and AIDS than literature or the print media. The radio, community meetings by health personnel rank high among the methods of disseminating information. Men have a higher exposure to mass media than women.⁹⁰

(b) *Regulation of Information*

Information on HIV and AIDS includes information on modes of transmission, care and treatment of HIV and AIDS patients, modes of testing, means of prevention, curriculum of training materials for stakeholders, and vaccinations and cure. The Commission observed that there is a pressing need to regulate the dissemination of information on various aspects of HIV and AIDS. The main purpose of regulating information is to ensure that myths, religious overtones, conflicting information and traditional beliefs and practices do not compromise the legitimate efforts undertaken by Government to fight HIV and AIDS.

The Commission also observed that there are many institutions in both the public and private sectors and among civil society organizations that work on matters of HIV and AIDS. Naturally, these institutions reach out to the general public and disseminate information on HIV and AIDS. Such institutions use various forms of communication including public meetings, and electronic and print media.

The Commission observed that there is no authority responsible for co-ordinating the nature and content of the information disseminated by various stakeholders. Further, the Commission was aware that there is inadequate capacity of experts in Malawi to regulate issues of development and publication

⁸⁷Lisa Arrehag, et. al., *The Impact of HIV/AIDS on Livelihoods, Poverty and the Economy of Malawi*, Sida Studies No. 18, Edita: 2006

⁸⁸ibid.

⁸⁹The National Statistical Office reported in 2000 that 84 per cent of males and 92 per cent of females had no formal educational qualifications. See World Bank and Government of Malawi (2004) *Malawi Strategic Country Gender Assessment*. Lilongwe: UNDP-Malawi, p.49

⁹⁰The figures indicate 67 per cent for women and 85 per cent for men.

of information on HIV and AIDS. The Commission also observed that there are no procedures regulating the generation of information on HIV and AIDS and there is lack of capacity for the delivery of the information generated. This has led to multiplicity of sources of information on HIV and AIDS which is sometimes inaccurate, alarming and harmful to the public.

The Commission observed that access to information held by the State is guaranteed as a human right in the Constitution in so far as such information is necessary for the exercise of one's rights.⁹¹ The National HIV and AIDS Policy has noted this gap and posits that targeted information delivered within a culturally sensitive context can help to increase awareness and knowledge and to overcome issues of stigma and discrimination, myths, beliefs and prejudices associated with HIV and AIDS.⁹² The Commission also observed that current arrangements empower NAC to provide information to stakeholders and publish any technical or other information and communication that it deems necessary or expedient for the coordination of the HIV and AIDS response.⁹³

The Commission learnt that in Tanzania, issues of regulation of information on HIV and AIDS which includes the mandate to accredit information before being disseminated to the public are handled by Tanzania Commission on AIDS which is the overall coordinating body of all matters on HIV and AIDS in Government. The Tanzania Communications Regulatory Authority (TACRA) regulates broadcasting houses and the media in general but also has powers to intervene where information on HIV and AIDS is not compliant with the Strategy on Information. The Commission learnt that, in Singapore, information on HIV and AIDS is regulated by the Health Promotion Board which is a separate institution established under statute. The Health Promotion Board was previously under the Ministry of Health and it runs programmes on HIV and AIDS.

The Commission considered the importance of empowering an authority under the proposal legislation to accredit any piece of information on HIV and AIDS before it is released to the public. The Commission was aware that the task could also be discharged by experts or a group of experts in the field of HIV and AIDS, language, information and communication, culture and religion, psychology, sociology, among other disciplines. The Commission, however concluded that the mandate of NAC to coordinate, develop and disseminate information on HIV and AIDS would suffice in enabling it discharge this function. The Commission therefore recommends that NAC should be empowered to regulate information on HIV and AIDS.

(c) Misleading Information

The Commission noted that in the absence of a known cure for HIV and AIDS, information may and has been abused to promote messages that are detrimental to the fight against the epidemic. In that context, the Commission

⁹¹Section 37 of the Constitution

⁹²See page 10.

⁹³Sub-articles (7) and (8) of Article 20 of the Constitution of the National AIDS Commission Trust

noted that there is a tendency among some traditional healers, to exaggerate the extent of their ability by alleging that they can cure HIV infection. The Commission further noted that there have been a number of instances where some traditional healers have sensationally claimed to have discovered a cure for HIV and AIDS, and, HIV and AIDS patients flocked to such traditional healers for the cure. The Commission considered that the role of traditional healers has to be placed in context since there are a number of traditional remedies offered by traditional healers that assist various ailments associated with HIV and AIDS. The Commission also recognized that it is important that this role should be considered in line with the international approach by the World Health Organization and other UN Agencies that promotes recognition and sharing of experiences between conventional and traditional practitioners in the fight against HIV and AIDS. The Commission noted that in the absence of scientific or other proof that the traditional medicine actually cures HIV infection or AIDS, it is unacceptable to proclaim through the mass media, to the public that there is a cure.

In deliberating the matter further, the Commission observed that under the Pharmacy, Medicines and Poisons Act⁹⁴, promotion of sales of medicinal products is regulated. Under the said Act, the Minister is empowered to prohibit the issue of advertisements likely to lead to use of medicinal products of a particular description. A medicinal product under that Act is defined as any substance or article which manufactured, sold, supplied, imported or exported for use wholly or mainly to be used by being administered to a human being or an animal for a medicinal purpose. A medicinal purpose includes treating or preventing disease.⁹⁵ The Commission observed that the provisions of the Pharmacy, Medicines and Poisons Act may not apply to sufficiently restrict the advertisement of traditional medicine proclaimed to cure HIV infection or AIDS since the purport of the said Act is restricted to medicine of a different kind. The Commission therefore recommends that the proposed law should clearly indicate the prohibition of advertisement of traditional medicine as a cure for HIV and AIDS by borrowing the scheme under the Pharmacy, Medicines and Poisons Act.

The Commission also observed that there are spiritual and religious healers that advise against the use of anti-retroviral therapy provided by the State, on account of their power to use divine means to cure HIV infection and AIDS. The Commission observed that it is misleading, for any practitioner, whether spiritual or religious, to advocate against use of any medication and proclaim themselves as sole healing agents for HIV and AIDS. The Commission concluded that taking into account the levels of despair for a cure in persons infected with HIV and AIDS, and further taking into account that there are known cases where traditional, spiritual or religious healing has not cured HIV and AIDS, any person who proclaims to the public that he or she has a cure for HIV and AIDS shall be deemed to have offered misleading information to the public and thereby shall be deemed to have committed a criminal offence.

⁹⁴Cap. 35:01

⁹⁵See section 2 of the Pharmacy, Medicines and Poisons Act, Cap. 35:01

To this end, the Commission recommends the adoption of the following Part—

PART ...

INFORMATION

- Access to HIV and AIDS information** . . . (1) A person has the right to access information in connexion with HIV and AIDS held by the State or any organ of the State, if the information is necessary for the exercise of his rights.
- Duty of persons in charge of information** . . . (2) A person who is in charge of information on HIV and AIDS has a duty to ensure that the information is relevant to the exercise of the rights of a person requesting such information.
- Powers in relation to HIV and AIDS information** . . . The Commission shall, in addition to the powers conferred on it by this Act, have the power to develop, co-ordinate and disseminate information on HIV and AIDS.
- Accrediting authority** . . . (1) The Commission shall be the accrediting authority of information on HIV and AIDS disseminated to the public.
- (2) Any information on HIV and AIDS developed by any person other than the Commission, shall be screened and verified by the Commission to establish its accuracy before dissemination.
- (3) A person in charge of information on HIV and AIDS has a duty to ensure that the information—
- (a) is accurate; and
 - (b) is accredited by the Commission.
- Publication of misleading information** . . . Any person who gives or publishes false or inaccurate information concerning HIV and AIDS to any person or the public shall be guilty of an offence and shall be liable to—
- (a) in the case of an individual, to a fine of K100,000 and imprisonment for five years; or
 - (b) in the case of a body corporate, organization or association, to a fine of K1,000,000.
- Publication of unaccredited information** . . . Any person who gives or publishes information on HIV and AIDS which is not accredited by the Commission to any person or the public shall be guilty of an offence and shall be liable to—
- (a) in the case of an individual, a fine of K100,000 and imprisonment for three years; or
 - (b) in the case of a body corporate, organization or association, a fine of K1,000,000.

6. EMPLOYMENT

(a) General

The Commission noted that the employment sector, both private and public, has been severely affected by the HIV and AIDS epidemic in that there is a steady decline in the levels of human resources in whom heavy financial and material investment has been made. The Commission also observed that the areas of concern under employment include issues of discrimination of infected employees in the workplace, HIV screening for employment, lack of appropriate prevention measures for occupational health and safety including lack of adequate compensation for employees who are infected in course of employment and lack of clarity of employers' obligations in daily work practices. The Employment Act is the principle legislation regulating the relationship between employees and employers. Other statutes on the same issue include the Labour Relations Act,⁹⁶ the Workman's Compensation Act⁹⁷ and the Occupational Safety, Health and Welfare Act⁹⁸.

The Commission observed that it is possible for employees infected with HIV and AIDS to lead reasonably long and productive lives, especially with recent interventions like anti-retroviral therapy. As such, the Commission considered attempts to exclude individuals from employment on account of HIV infection as unfair and a breach of fundamental rights including the right to pursue an economic activity. The Commission further observed that exclusion of individuals who are still productive in turn creates social-economic problems as these individuals still bear social responsibilities as bread-earners in their respective families and remain in active pursuit of alternative employment or may turn to crime and still remain a social burden.

(b) Prohibition of Discrimination in Employment

The Commission considered whether the Employment Act sufficiently prohibits discrimination on the ground of HIV and AIDS status. The Act prohibits discrimination on the ground of "marital or other status or family responsibility" under section 5 and the debate was whether this phrase can be construed as sufficient to include HIV and AIDS status. The Commission referred to the interpretation offered by the United Nations that "other status" in the non-discrimination clause should be construed as including HIV and AIDS⁹⁹ and considered that the wording of the Employment Act is slightly different. The Commission was of the opinion that according to the wording of the Employment Act, it appears that the status in question relates to marriage, sexual partnership and family rather than status in terms of health, which would include HIV and AIDS. The Commission thus recommends that the law on HIV and AIDS should specifically prohibit discrimination in employment on the basis of infection or

⁹⁶Cap. 54:01

⁹⁷Cap. 55:03

⁹⁸Cap. 55:07

⁹⁹See footnote 63

perceived infection with HIV or suffering from AIDS. Further, the Commission recommends that section 5 (1) of the Employment Act should be amended to delete the phrase “birth, marital or other status or family responsibilities” to be replaced with the phrase “**marital or family responsibilities, birth or other status**” to encompass HIV and AIDS.

The Commission reiterates that women usually bear the brunt of caring for the sick and those infected with HIV. The Commission noted that this continues to be the case even when the women are in employment. The Commission considered that it would be necessary to protect the care-giver who usually turns out to be a woman, in formal employment where there is need to care for a patient of HIV and AIDS away from work. The Commission was of the view that knowing that HIV and AIDS has reached epidemic proportions, this privilege cannot be extended to care provided for each and every person and that there is need to limit the category of individuals to whom it would apply. The Commission considered that this privilege should be limited to care of a spouse and children who are under the custody of the employee and are under eighteen years of age.

(c) *HIV Screening for Employment*

The Commission noted that there are instances where HIV screening takes place at recruitment, for promotion purposes or has been used as a reason for transferring the employee to another duty station. HIV screening has also been conducted for purposes of considering training and career advancement opportunities where it has been used as a ground for preventing an employee from attaining further training and career advancement education. The Commission felt that this is an issue of human rights and has to be treated as such. The Commission further observed that some employers require disclosure of HIV test results from employees. The Commission observed that a person is entitled to privacy and confidentiality, which is a right that is enshrined by law. The Commission further observed that an employer generally does not fall within the category of individuals or institutions that would be entitled as a matter of law to such information as one’s bio-data in the absence of enabling legislation or other valid reason.

The Commission learnt that a number of states in the United States of America and in Australia have prohibited HIV screening of employees.¹⁰⁰ Furthermore, in Singapore, where no specific non-discrimination laws exist, the Singapore National Employers’ Federation developed guidelines on HIV and AIDS in the workplace. The Guidelines basically stipulate that HIV positive employees should not lose their jobs solely on the basis of HIV status unless they are unable to work; there should be reasonable accommodation or offer of alternative employment; employees should not be compelled to disclose result of HIV tests unless contractually obliged so to do; and employers are under obligation to maintain confidentiality of any HIV related information of their

¹⁰⁰California, Florida, Illinois, Texas, Massachusetts, Wisconsin in the US and Tasmania in Australia

employees. The Commission therefore recommends that HIV screening in employment as the basis for recruitment, promotion, transfer to another duty station, or as a condition precedent to an award of an opportunity for training or other career development opportunities should generally be prohibited. The Commission observed that HIV screening in employment is discriminatory and instead of assisting employees and prospective employees to receive better health care on employment, it is usually abused to the detriment of the employee or prospective employee. The Commission however acknowledged that there may be exceptions to this general rule.

The first exception considered by the Commission was that of domestic workers. The Commission debated whether domestic workers should be subjected to pre-recruitment HIV screening. The Commission observed that domestic servants belong to a peculiar category of employees who share a very intimate and often informal relationship with the employer. The Commission observed that this kind of relationship also gives rise to opportunities of infection to any member of the household especially young children. The Commission also noted that cases of sexual abuse of very young children by domestic employees have been on the increase according to media reports in Malawi. In considering this matter, the Commission weighed the rights of the employee to engage in an economic activity and to fair labour practices as enshrined under the Constitution against the rights of the employer in selecting a domestic employee of choice and the right to protect his family and himself or herself. The Commission felt that it would be in the interest of the employer to make an informed choice regarding the sero-status of the person he or she allows into his or her household. In conclusion, the Commission recommends that the employer in the domestic environment should be legally empowered to opt to demand a test for HIV infection in order to minimize exposure within the family setting in recognition of the right of the family to protection by society and the State.¹⁰¹

The second category considered by the Commission as warranting to be excluded from the general rule was that of “occupations requiring fitness to serve”. The Commission observed that there are some institutions that normally conduct various medical tests to employees prior to recruitment in order to ascertain the employee’s fitness to serve. These tests now include an HIV test. These institutions include the Defence Force, the Police Service, the Immigration Department and the Prison Service. The Commission observed that these routine pre-employment tests are intended not to stand as a condition for employment but rather as a way of assessing fitness to serve in these departments. The Commission further observed that the National HIV and AIDS Policy has made provision for these categories of service as exceptions. The Commission considered the exceptions reasonable and providing an opportunity to both the employer and the employee in circumstances that would benefit both parties in terms of deployment.

¹⁰¹Section 22 (1) of the Constitution

(d) *Adoption of HIV and AIDS Workplace Policy*

The Commission observed that since HIV infection has reached epidemic proportions, it is prudent and necessary for employers to adopt a work place policy with respect to HIV and AIDS. The Commission further observed that in light of the stigma, discrimination and prejudice at the workplace in relation to HIV positive employees, a work place policy would be a proper tool for protecting the rights of the employees. The Commission further considered that the workplace policy is the appropriate tool for clarifying the employers' obligation in daily work practices. For instance, issues involving obligations regarding confidentiality of personal and medical information of an employee, including HIV status, provision of general information and educational programmes including provision of condoms, relevant counseling to employees, adoption of programmes for sources of income support when the employee is no longer able to work may be covered in the workplace policy. The Commission thus recommends that Government should take active steps in encouraging employers to adopt HIV and AIDS Workplace policies.

(e) *HIV and AIDS as an Occupational Hazard for Service Providers*

The Commission noted that under the Workers Compensation Act, workers who contract diseases in the course of employment are eligible to claim compensation from the employer. However, under the scheduled diseases, HIV and AIDS is not included. As such the Commission concluded there is need to have a provision under the proposed law that an employee including health personnel infected with HIV and AIDS as a result of their employment should be compensated and recommends accordingly.

Further the Commission recommends that the Second Schedule to the Workers' Compensation Act be amended to include infection with HIV and AIDS.

The Commission also suggested that a list of the professions which are at risk of infection with HIV and AIDS should be provided for under the new legislation. The Commission proposed the following professions, to be covered, medical personnel including doctors, nurses, surgeons and clinical officers, police, fire-brigade and any person attending to an emergency at work.

Related to the above issue is the question of whether patients should be given the right to demand that the health service provider disclose his or her sero-status. When deliberating the issue, the Commission considered that giving such a right to the patient would be subject to abuse. On the other hand requiring the health care provider to disclose his or her sero-status freely would be stressful to both the patient and the health care provider especially if the health service provider is infected with HIV. As a result, consensus was reached that an obligation be placed on the health institution or employer to subject employees to routine testing and in the event that an employee is tested positive the employee should be reassigned to other duties where there is no risk to patients.

In light of the foregoing, the Commission recommends adoption of the following Part—

PART ...

EMPLOYMENT

- Prohibition of pre-recruitment testing** . . . **An employer shall not require any person to undergo HIV testing as a pre-condition for recruitment:**
Provided that pre-employment HIV testing may be permissible for—
- (a) purposes of assessing fitness to serve in—**
- (i) the Defence Force;**
(ii) the Police Service;
(iii) the Prison Service;
(iv) the Immigration Department; and
- (b) purposes of assessing the health status of a domestic worker.**
- Prohibition of termination of employment on grounds of HIV or AIDS** . . . **(1) An employer shall not terminate the employment of an employee only on the ground that the employee is HIV positive or is perceived to be HIV positive.**
(2) A person who contravenes this section shall be guilty of an offence and shall be liable to—
- (a) in the case of an individual, a fine of K100,000 and imprisonment for five years; or**
(b) in the case of a body corporate, organization or association, to a fine of K1,000,000.
- Promotion transfer and training** . . . **(1) An employee shall not be discriminated against or be subjected to unfair treatment on the ground that he is HIV positive or is suffering from AIDS.**
(2) A person who contravenes this section shall be guilty of an offence and shall be liable to—
- (a) in the case of an individual, a fine of K100,000 and imprisonment for five years; or**
(b) in the case of a body corporate, organization or association, a fine of K1,000,000.
- Procuring another to conduct HIV test for recruitment, etc.** . . . **A person who procures another person to conduct HIV testing as a condition for recruitment, training, promotion, termination of employment or other matters arising out of an employment relationship shall be guilty of an offence and shall be liable—**

- (a) in the case of an individual, to a fine of K50,000 and to imprisonment for three years; or
- (b) in the case of a body corporate, organization or association, a fine of K500,000.
- Aiding, abetting or concealing act of subjecting another to HIV test for recruitment etc.** . . . A person who aids, abets or assists another person to conduct HIV testing as a condition for recruitment, training, promotion, termination of employment or other matters arising out of an employment relationship shall be guilty of an offence and shall be liable to—
- (a) in the case of an individual, a fine of K100,000 and to imprisonment for three years; or
- (b) in the case of a body corporate, organization or association, a fine of K500,000.
- Compassionate leave for parents and spouse** . . . (1) An employee whose child or spouse is suffering from AIDS shall have the right to provide care for the child or spouse outside employment for a maximum of four weeks on full pay and to a subsequent four weeks on half pay.
- (2) An employee who is temporarily incapacitated from work under subsection (1) shall be deemed to be in continuous service for purposes of promotion, increments in personal emoluments, leave and any other employment benefits.
- Employer responsible for minimizing risk infection at workplace** . . . Where a person is employed in an occupation or is required to provide services where there may be a risk of transmitting or acquiring HIV, the employer shall provide appropriate training, protective equipment and clear and accurate information and guidelines on minimizing the risk of the spread of HIV.
- Work policy** . . . (1) The State shall take active measures to ensure that employers have adopted and are implementing an HIV and AIDS policy at the workplace.
- (2) The design and content of the workplace policy shall be in accordance with the policy guidelines issued by Government.
- Compensation** . . . (1) An employee who is been infected with HIV in the course of employment shall have the right to claim compensation in accordance with the Workers' Compensation Act.
- Cap. 55:03** (2) An employee who is infected with HIV in the course of his employment is entitled to higher compensation if he is able to show that his infection is due to non compliance of section 34 by the employer or is otherwise due to negligence of the employer.

7. EDUCATION

(a) *General*

The Commission observed that higher levels of education are positively associated with comprehensive knowledge on HIV and AIDS.¹⁰² Education therefore has been recognized not only as a primary agent in creating sustainable economic development but also an agent for combating the epidemic.

It has been observed that the demand for education is affected by the adverse impact on household income which declines and affects the budget allocated to school needs. Education also poorly competes with the demand for care services and labour in the households affected with HIV and AIDS. As such, one of the most likely impacts of HIV infection is the withdrawal of children from school. The Commission observed that data on the impact of HIV and AIDS in the educational sector is usually limited to students and teachers when the same impact has been felt in management of the educational sector. In a study on the effect of the epidemic on the Ministry of Education headquarters, divisional officers and district education offices, it was found that there are similar increasing levels of attrition in these institutions as among teachers and death accounted for 40 per cent attrition between 1999 and 2004.

The Commission noted that the Malawi Growth and Development Strategy (MGDS) underscores Government's commitment to the attainment of education. The MGDS proclaims education as a means to attaining prosperity and a catalyst for attaining socio-economic development, industrial growth and an instrument for empowering the poor, the weak and the voiceless. The MGDS aims at increasing enrolment to 95 per cent and reduction of the dropout rate to 5 per cent.

The Commission observed further that most HIV and AIDS programmes aim at promoting prevention from HIV infection and as such, people need to be educated about the virus and the disease while clearing myths, beliefs and misconceptions. The Commission at the outset noted the increasing role of the informal and indigenous educational sector in Malawian society. The Commission noted that both formal and indigenous education presents a forum for disseminating information on HIV and AIDS including the teaching of prevention and management strategies. The Commission however noted that education and training institutions may be used as a forum for promoting stigma and discrimination.

The Commission was aware that issues of HIV and AIDS are already being taught at primary, secondary and tertiary levels of education in Malawi and abroad even in the absence of legislation. The Commission learnt that in Tanzania, although legislation on HIV and AIDS has not been passed yet, literature for individual grades is already in use in primary and secondary schools. The Commission was aware that development of curriculum content is regulated by the Ministry responsible for Education through the Malawi Institute of Education.

It was however considered that the law on HIV and AIDS should include mechanisms to regulate content of curriculum on HIV and AIDS. The Commission observed that prevailing social, moral and cultural values may require the classification of educational materials into restricted or unrestricted category especially with a view to protection of children from inappropriate sexual content. While it is acknowledged that the Malawi Institute of Education is responsible for curriculum development, the Commission recommends that key stakeholders should be included in the process of developing curricula on HIV and AIDS to ensure that the audience is not unnecessarily offended or alienated by the material. Further, the Commission conceded that the material on HIV and AIDS has to take into account age, mental maturity, social responsibility and religious belief of the end-user.

(b) Role of Non-formal and Indigenous Education

The Commission also noted the profound impact of non-formal and indigenous education on the lives of many citizens. The non-formal and indigenous education sector includes religious education and traditional education including initiation instruction. The Commission observed that in many cases, non-formal education is very authoritative but usually lacks adequate and accurate information on HIV and AIDS. The Commission conceded the need to build capacity of such institutions through training on matters of HIV and AIDS to ensure that indigenous education instructors receive adequate, accurate and appropriate information. Further, the Commission, encourages Government that as a matter of policy, to put in place initiatives that would encourage non-formal and indigenous education to incorporate accredited HIV and AIDS information in their curriculum.

(c) Discrimination in Schools and Training Institutions

The Commission also considered that education or training institutions including schools may also provide an opportunity for individuals to promote discrimination against people who are infected with HIV or are suffering from AIDS. The Commission learnt that there are many circumstances under which individuals infected or affected with HIV and AIDS face discrimination in educational institutions. The Commission was also aware that the common discrimination forums in educational and training institutions include barriers on entry, awarding of scholarships, limitation of choice of courses and profession, participation in activities of choice and general teasing and bullying on account of actual or perceived HIV status. The Commission observed that where such malpractices take place, failure to take action to protect students or trainees that are either teased or bullied imports a certain level of culpability on the authorities of the institution in question which ought to be punishable by law.

The Commission also learnt that people infected with HIV or suffering from AIDS are likely and are actually excluded from participating in courses and

¹⁰²Lisa Arrehag, et. al., p. 154

activities of their choice. The Commission observed that this is discriminatory although it may be justifiable in cases where such exclusion is made on account of reducing the risk of infection to others. The Commission considered the case of some contact sporting activities, which take place in education and training facilities where likelihood of putting other students at risk arises. However, the Commission concluded that this is a matter best dealt with administratively on a case by case basis by each institution and that no general rule can be imposed.

The Commission therefore recommends adoption of the following Part—

PART ...

EDUCATION

Prohibition of HIV testing for educational purposes . . . (1) A person shall not be required to undergo HIV testing as a condition for—

- (a) entry into an education or training institution;**
- (b) an award of a scholarship, grant, bursary, benefit or other scholarly endowment; or**
- (c) remaining as a student or trainee in any education or training institution.**

(2) A person who contravenes subsection (1) shall be guilty of an offence and shall be liable to—

- (a) in the case of an individual, a fine of K100,000 and imprisonment for five years; or**
- (b) in the case of a body corporate, organization or association, a fine of K1,000,000.**

Prohibition of discrimination in education or training institutions . . . (1) An education or training institution shall not, where there is no risk of infection of others with HIV—

- (a) refuse a person admission into the institution;**
- (b) expel a person from the institution;**
- (c) segregate a person;**
- (d) refuse a person participation in an event or activity; or**
- (e) deny any benefits or services to a person,**

only on the grounds that the person is HIV positive or is perceived to be HIV positive.

(2) Any person who contravenes subsection (1) shall be guilty of an offence and shall be liable to—

- (a) in the case of an individual, a fine of K100,000 and imprisonment for five years; or**
- (b) in the case of a body corporate, organization or association, a fine of K1,000,000.**

(3) Notwithstanding the provisions of subsection (2), a court may, in addition to any penalty imposed on a person convicted, order—

(a) in the case of an individual, revocation of the licence to practice his profession; or

(b) in the case of a private education or training institution, revocation of the business permit, licence or certificate.

HIV and AIDS
materials in
school
curriculum

(1) The Minister shall, in consultation with the Minister responsible for Education, the Commission and other relevant authorities on HIV and AIDS, ensure that materials on HIV and AIDS are developed and integrated into the school curriculum for all education and training facilities at all levels.

(2) The Minister shall ensure that the materials on HIV and AIDS developed and integrated into the school curriculum are—

(a) appropriate for the level of education it is intended having regard to the following factors—

(i) age of pupils, students or trainees;

(ii) level of mental maturity; and

(iii) the objective of the materials used;

(b) free from all forms of stigmatization against persons living with HIV and AIDS;

(c) not sexually explicit;

(d) developed in consultation with associations representing parents and teachers, education officials and interest groups.

Teachers and
instructors to
be trained on
issues of HIV
and AIDS

... Teachers and instructors shall be trained on issues of HIV and AIDS before commencing teaching or instruction on any subject related to HIV and AIDS.

HIV and AIDS
information in
non formal
education
systems

... The Minister shall ensure that official information on modes of transmission and ways of preventing HIV infection is progressively integrated in non-formal or indigenous learning systems.

8. CRIMINAL LAW

(a) General

The Commission observed that although various parts of this Report have dealt with the criminal law aspect of HIV and AIDS, there are certain issues that require special attention under this topic. These issues include transmission or exposure offences, sexual offenders and embezzlement of funds related to HIV and AIDS activities.

(b) Transmission and Exposure Offences

The first issue regarding criminal law that the Commission considered was that of deliberate infection of another person with HIV. The Commission considered that the offence of deliberate infection with HIV takes several forms and isolated two common forms. First, is where the infected person withhold information about his sero-status where he knows or suspects that he or she is HIV positive and does not use protective measures. The second form is where such person informs the other party about his status but fails to use protective measures to prevent infecting the other party. The former scenario is easier since there is no informed consent while the latter entails informed consent on the other party who is exposed to the risk of HIV infection.

The Commission conducted consultations on this matter and learnt that there was overwhelming support for introducing criminal sanctions for cases of deliberate infection. The Commission noted that while stakeholders appreciated that the bulk of infections may arise at a time when the parties are ignorant of their status, the law should take a proactive stance and regulate cases where infection was known or suspected. The Commission learnt that this aspect of criminal law has also sparked heated debate in Tanzania especially with respect to PLHIVs who observed that introduction of the offence of deliberately transmitting HIV is likely to be abused especially in the absence of scientific proof of who, between the parties, might have contracted the virus earlier and infected the other.

Most female PLHIVs also indicated that notwithstanding their public disclosure of their sero-status, there are many men who still pester them for sexual relations. This fact was also confirmed at district consultations in Lilongwe and Mzuzu. Women PLHIV also lamented that due to their marginalized status and limited financial resources, it is possible that such persistence puts them at constant risk of further infection.

The Commission observed that it is an offence under section 192 of the Penal Code when any person unlawfully or negligently poses the risk of spreading the infection of any disease dangerous to life. The Commission further noted with approval the recommendation made by its sister Commission on the Review of

the Penal Code¹⁰³ to enhance the penalty for this offence to fourteen years in light of the prevalence of HIV and AIDS. Nevertheless, the Commission considered that the peculiar nature of HIV and AIDS, requires a specific penal provision and recommends accordingly.

The Commission considered that in cases where a person knows that he or she is infected with HIV or is suffering from AIDS, or ought to know his sero-status, and that person sleeps with another without informing that other of his sero status or his suspicion of infection, such person should be penalized as this may amount to deliberate infection. In other jurisdictions such as the United Kingdom, such conduct amounts to the offence of inflicting grievous bodily harm under the Offences Against the Person Act.¹⁰⁴

The Commission was aware of the evidential problems that may arise in connection with all transmission offences and felt that the proposed law should address these issues. The Commission proposed that issues of foreseeability of criminality of the act that constitutes an offence, such as intent and causation; that the conduct of the offender did actually lead to infection with the virus; and consent should be dealt with in considering these offences. The Commission further proposed that the proposed law should be limited to issues of deliberate or intentional acts and recklessness where the measure of recklessness is the likelihood by the offender of foreseeing the consequence of his or her conduct, but nevertheless taking the risk of bringing it about. The Commission further noted that its sister Commission on the Review of the Penal Code proposed negligence and recklessness as the necessary *mens rea*.

The Commission also noted that there is need for clarity in terms of what conduct poses the risk of infection to others. The definition of what constitutes conduct likely to infect another should be clarified as well as the acknowledgement that there could be defences available for such offences. For instance, informed consent or marriage, according to some jurisdictions, has been acknowledged as a defence. The Commission noted that the defence of informed consent acknowledges the privacy and autonomy of individuals being able to choose to engage in sexual activities without fear of reprisals from the State. The Commission noted that to decline consent as a defence might undermine public health efforts on counseling, testing, treatment and support. The Commission observed that to impose marriage as a defence might put women at a greater risk of failing to negotiate for safe sex generally and use of protective measures. The Commission therefore recommends that only informed consent as opposed to marriage should be recognized as a defence.

Where the issue under prosecution relates to exposure to infection, the Commission considered that use of preventive measures such as condoms should be able to suffice as a defence. The Commission was however aware that condoms are not 100 percent secure but conceded that they provide the best protection from the risk of infection. The Commission thus urged Government to

continue encouraging people to use condoms during sexual intercourse.

The Commission also noted that the enterprise of operating barber shops also increases the risk of exposure to HIV infection. The Commission noted that in this enterprise, there is a risk of injury to the skin thereby exposing the machine in use to come into contact with body fluids including blood. In the event that such contact is made with infected blood, the Commission noted that the public is exposed to HIV infection especially where no pre-caution is taken to clean and sterilize the instruments effectively. The Commission learnt that it is possible for barbers to sterilize their equipment before applying them to another customer. The Commission concluded that in case a barber does not exercise his duty to ensure that risk of exposure to HIV infection is removed, criminal sanctions should ensue.

The Commission therefore recommends the adoption of the following Part–

PART ...

CONTROL OF HIV INFECTION

- | | |
|--|---|
| Person with HIV or AIDS to undergo counselling | . . . Any person diagnosed as having HIV infection or AIDS shall be required to— |
| | (a) undergo counseling by a healthy service provider; |
| | (b) comply with such precautions and safety measures as may be prescribed. |
| Acts likely to spread HIV infection | . . . (1) A person who knows that he is HIV positive shall not do an act or omit to do an act which is likely to transmit or spread HIV infection to another person unless, before the act or omission takes place, the other person— |
| | (a) has been informed of the risk of contracting HIV infection from him or her; and |
| | (b) has voluntarily agreed to accept that risk. |
| | (2) Any person who contravenes this section shall be guilty of an offence and shall be liable to imprisonment for five years. |
| Deliberate infection with HIV | . . . Any person who deliberately infects another person with HIV shall be guilty of an offence and shall be liable to imprisonment for fourteen years. |

¹⁰³Law Commission Report No. 2

¹⁰⁴In the case of *R.v. Konzani* [2005] EWCA Crim 706, an appellant who knew his positive HIV status and slept with several women without informing them of his HIV status was convicted of inflicting grievous bodily harm to the women contrary to s.20 of the Offences Against the Person Act in the absence of a particular law on HIV and AIDS. The Court considered that his omission to inform the women of his status amounted to deliberate infection.

Negligent
and reckless
infection
with HIV

. . . (1) Any person who recklessly or negligently infects another person with HIV shall be guilty of an offence and shall be liable to imprisonment for ten years.

(2) Where the offence under subsection (1) arises out of exposure to infection in the course of employment, then lack of provision of preventive measures by the employer shall be a defence.

(c) Accountability for HIV and AIDS Related Funds

The Commission also noted the issue of embezzlement of funds intended for HIV and AIDS related activities. The Commission observed that there have been reports of bogus institutions being able to access funds intended for PLHIV, institutions that pose as undertaking work in HIV related areas such as orphan care, PLHIV support groups and similar activities but not delivering on their undertaking. The Commission noted that this conduct has become so rampant that there is need for the proposed law to intervene by requiring all individuals who receive donations in cash or in kind to account for the resources they receive to a regulatory body.

The Commission considered that such activities fall within the realm of general criminal law under which various offences under the Penal Code would suffice. The Commission noted that most activities surrounding embezzlement of HIV and AIDS related funds would be taken care by various provisions under the Penal Code. There is a regime of provisions under Chapter XXVI, under which offences of theft, stealing by persons in public service, negligence by public officer in preserving money or other public property, stealing by clerks and servants, stealing by directors or officers of companies and stealing by agents fall. Chapter XXVI of the Penal Code also defines things capable of being stolen, defines what constitutes theft, refers to funds held under directions, money received for another person. The Commission further noted that under Chapter XXXI of the Penal Code, another regime of offences under the heading False Pretences also has a bearing on matters arising under the present topic. Offences such as obtaining (of goods) by false pretences and obtaining credit by false pretences are further supplemented by offences under Chapter XXXII, where offences such as receiving stolen property, receiving property unlawfully obtained, being in possession of property suspected of being stolen and receiving or bringing in property dishonestly acquired outside Malawi are provided for.

The Commission therefore recommends that the provisions of the Penal Code should be invoked when matters relating to embezzlement of HIV and AIDS related funds arise.

9. CONSEQUENTIAL PROVISIONS

The Commission agreed on the scheme of the legislation as outlined above. In order to make the proposed law operational, the Commission recommends the adoption of the following consequential provisions—

(a) Long title

The Commission recommends the following long title to the proposed law—

An Act to make provision for the prevention and management of HIV and AIDS; to provide for the rights and obligations of people infected and affected by HIV and AIDS; to provide for the establishment of the National AIDS Commission; and to provide for connected and ancillary matters.

(b) Short title

The Commission considered several titles for the proposed Act and recommends that the short title should read as follows—

Short title . . . **This Act may be cited as the HIV and AIDS (Prevention and Management) Act.**

(c) Application

The Commission was of the view that this law shall be of general application in Malawi and as such, there is no need for a special provision to this effect.

(d) Commencement of the Act

The Commission further recommends that the Act should come into operation on a date to be appointed by the Minister. The Commission recommends the adoption of the following provision—

Commence- . . . **This Act shall come into operation on such date as the ment Minister shall appoint by notice in the *Gazette*.**

(e) Power to make regulations

The Commission observed that under the Laws of Malawi, it is common practice that the Minister is empowered to make rules and regulations over various matters arising under the piece of legislation in question. The Commission therefore recommends the following provision—

Regulations . . . **The Minister may, by notice in the *Gazette*, make regulations for the better carrying out of the provisions of this Act.**

(f) Definitions

The Commission recommends that the following terms and words that have been used in the proposed Act should be defined under the provisions on definitions as follows—

Interpretation	<p>In this Act, unless the context otherwise requires—</p> <p>“AIDS” means Acquire Immune Deficiency Syndrome;</p> <p>“Chairperson” means the Chairperson of the Commission and includes any person acting in that capacity;</p> <p>“child” means any person below the age of eighteen years;</p> <p>“Commission” means the National AIDS Commission established under section ... of this Act;</p> <p>“compulsory HIV testing” means testing imposed upon a person characterized by the lack of consent;</p> <p>“diagnostic testing” means a testing done on an individual who shows signs and symptoms that are consistent with HIV related diseases or AIDS to aid clinical diagnosis and management;</p> <p>“discrimination” means any prejudicial act of making distinctions or showing partiality in the granting of privileges or benefits to any person on the basis of actual, perceived or suspected HIV status;</p> <p>“Executive Director” means the Executive Director of the National AIDS Commission appointed pursuant to section ...;</p> <p>“harmful practice” means any social, religious or cultural practice that puts a person at risk of HIV infection;</p> <p>“health service provider” means—</p>
Cap. 36:07	<p>(a) a medical practitioner, dentist, paramedical and allied health professional registered under the Medical Practitioners and Dentists Act;</p>
Cap. 36:02	<p>(b) a nurse or midwife registered in any category of nurses and midwives registered under the Nurses and Midwives Act;</p>

(c) a pharmacist, pharmacy technologist or pharmacy assistant registered under the Pharmacy, Medicines and Poisons Act;

“HIV” means Human Immunodeficiency Virus;

“HIV positive” refers to the presence of HIV infection as documented by the presence of HIV or HIV antibodies in body tissue or fluid being tested;

“HIV prevention” refers to measures aimed at protecting non-infected persons from contracting HIV;

“HIV testing” means any laboratory procedure done on an individual to determine the presence of HIV infection;

“immediate family member” includes a spouse, mother, father, grandmother, grandfather, brother, sister, child, grandchild, aunt, uncle, niece and nephew;

“Minister” means the Minister responsible for matters of HIV and AIDS;

“post-test counseling” refers to the process of providing risk-reduction information and emotional support to a person who submits to HIV testing at the time the result is released;

“pre-test counseling” means the process of providing an individual information on the biomedical aspects of HIV and AIDS and emotional support to any psychological implications of undergoing HIV testing and the test result before he or she is subjected to a test;

“routine testing” means a test offered by a health service provider to an individual and the individual offered has the right to refuse such test;

“tissue” includes an organ or part of a human body, semen, breast milk and any other substance or secretion, other than blood, extracted from the human body or from a part of the human body;

“voluntary testing and counseling” means testing done on an individual who willingly submits to such a test.

(g) *Schedules*

The Commission recommends the adoption of the following schedules under the Act:

- (i) **The First Schedule—this shall cover Harmful Practices; and**
- (ii) **The Second Schedule—this shall cover HIV Related Diseases.**

The Commission further recommends the adoption of a provision that empowers the Minister to amend any schedule under the Act—

. . . The Minister may, by notice in the *Gazette*, amend any schedule to this Act.

APPENDICES

APPENDIX A

HIV AND AIDS (PREVENTION AND
MANAGEMENT) BILL 20....

HIV AND AIDS (PREVENTION AND MANAGEMENT)
BILL, 20...

ARRANGEMENT OF SECTIONS

SECTION

PART I—PRELIMINARY

1. Short title and commencement
2. Interpretation

PART II—RESPONSIBILITY FOR PREVENTION AND MANAGEMENT OF
HIV AND AIDS

3. Responsibilities of Minister

PART III—HARMFUL PRACTICES

4. Prohibition of harmful cultural practices
5. Subjecting another to a harmful cultural practice

PART IV—PROHIBITION OF DISCRIMINATION

6. Prohibition of discrimination on the basis of HIV and AIDS
7. Rights of persons infected with HIV or suffering from AIDS
8. Rights of persons affected with HIV and AIDS

PART V—DISCLOSURE

9. Privacy and medical confidentiality regarding HIV status
10. Disclosure by health service provider
11. Unlawful disclosure of HIV status of another person

PART VI—PUBLIC HEALTH

12. Modes of HIV testing
13. Age of accessing voluntary testing without parental or guardian consent
14. Consent to HIV testing
15. Testing of donated body tissues
16. Testing of donated blood
17. Consent to be deemed
18. Prohibition of mandatory testing
19. Pre-test and post-test counseling
20. Duty to report HIV infection
21. Prohibition of discrimination in health institutions

PART VII—INFORMATION

22. Access to information
23. Powers related to information
24. Accrediting authority
25. Duty of person in charge of information
26. Publication of misleading information
27. Publication of unaccredited information

PART VIII—EMPLOYMENT

28. Prohibition of pre-employment testing
29. Prohibition of termination of employment on grounds of HIV and AIDS
30. Promotion, transfer and training
31. Procuring another to conduct HIV testing for recruitment etc
32. Aiding, abetting or assisting to conduct HIV testing for recruitment etc
33. Compassionate leave for parents and spouses
34. Workplace policy
35. Employer responsible for minimizing risk of infection at work place
36. Compensation

PART IX—EDUCATION

37. Prohibition of HIV testing for educational purposes
38. Prohibition of discrimination in education or training institutions
39. HIV and AIDS materials in school curriculum
40. Teachers and instructors to be trained on issues of HIV and AIDS
41. HIV and AIDS information in non-formal education

PART X—CONTROL OF HIV INFECTION

42. Person with HIV or AIDS to undergo counseling
43. Acts likely to spread HIV infection
44. Deliberate infection with HIV
45. Negligent and reckless infection with HIV

Part XI—ESTABLISHMENT OF NATIONAL AIDS COMMISSION

46. National AIDS Commission
47. Functions and duties
48. Powers of the Commission
49. Composition of the Commission
50. Tenure of office
51. Chairperson
52. Committees
53. Commission may co-opt
54. Meetings of the Commission
55. Disclosure of interest
56. Remuneration
57. Reporting

PART XII—ADMINISTRATION OF NATIONAL AIDS COMMISSION

58. Executive Director
59. Procedure for appointment of Executive Director
60. Duties of Executive Director
61. Removal of Executive Director
62. Other Staff
63. Attendance of meetings by staff

PART XIII—FINANCIAL PROVISIONS

64. Funding of the Commission
65. Books and other records of accounts, audit and reports of the Commission

PART XIV—MISCELLANEOUS

66. Regulations
67. Amendment to schedules

SCHEDULES

A B I L L

entitled

An Act to make provision for the prevention and management of HIV and AIDS; to provide for the rights and obligations of persons infected and affected by HIV and AIDS; to provide for the establishment of the National AIDS Commission; and to provide for matters incidental thereto or connected therewith.

ENACTED by the Parliament of Malawi as follows—

PART I—PRELIMINARY

1.—(1) This Act may be cited as the HIV and AIDS (Prevention and Management) Act.

Short title
and
commence-
ment

(2) This Act shall come into force on such date as the Minister may appoint by notice published in the gazette.

In this Act, unless the context otherwise requires—

Interpreta-
tion

“AIDS” means Acquire Immune Deficiency Syndrome;
“Chairperson” means the Chairperson of the Commission and includes any person acting in that capacity;

“child” means any person below the age of eighteen years;

“Commission” means the National AIDS Commission established under section 47 of this Act;

“compulsory HIV testing” means HIV testing imposed upon a person characterized by the lack of consent;

“diagnostic testing” means HIV testing done on an individual who shows signs and symptoms that are consistent with HIV related diseases or AIDS to aid clinical diagnosis and management;

“discrimination” means any prejudicial act of making distinctions or showing partiality in the granting of privileges or benefits to any person on the basis of actual, perceived or suspected HIV status;

“Executive Director” means the Executive Director of the National AIDS Commission appointed pursuant to section 59;

“harmful practice” means any social, religious or cultural practice that puts a person at risk of HIV infection;

“health service provider” means—

Cap. 36:01 (a) a medical practitioner, dentist, paramedical and allied health professional registered under the Medical Practitioners and Dentists Act;

Cap. 36:02 (b) a nurse or midwife registered in any category of nurses and midwives registered under the Nurses and Midwives Act;

Cap. 35:01 (c) a pharmacist, pharmacy technologist or pharmacy assistant registered under the Pharmacy, Medicines and Poisons Act;

“HIV” means Human Immunodeficiency Virus, the virus which causes AIDS;

“HIV positive” refers to the presence of HIV infection as documented by the presence of HIV or HIV antibodies in the sample being tested;

“HIV prevention” refers to measures aimed at protecting non-infected persons from contracting HIV;

“HIV testing” means any laboratory procedure done on an individual to determine the presence of HIV infection;

“immediate family member” includes a spouse, mother, father, grandmother, grandfather, brother, sister, child, grandchild, aunt, uncle, niece and nephew;

“Minister” means the Minister responsible for matters of HIV and AIDS;

“post-test counseling” refers to the process of providing risk-reduction information and emotional support to a person who submits to HIV testing at the time the result is released;

“pre-test counseling” means the process of providing an individual information on the biomedical aspects of HIV and AIDS and emotional support to any psychological implications of undergoing HIV testing and the test result before he or she is subjected to a test;

“routine testing” means a test offered by a health service provider to an individual and the individual offered has the right to refuse such test;

“tissue” includes an organ or part of a human body, semen, breast milk and any other substance or secretion, other than blood, extracted from the human body or from a part of the human body;

“voluntary HIV testing” means testing done on an individual who willingly submits to such a test.

PART II—RESPONSIBILITY FOR PREVENTION AND MANAGEMENT OF HIV AND AIDS

3. The Minister shall be responsible for—

Responsibilities of Minister

(a) the formulation of national policies on HIV and AIDS and providing high level advocacy on issues of HIV and AIDS;

(b) taking the lead in the national response to HIV and AIDS and the development of the National Action Framework to provide guidance to the national response to HIV and AIDS;

(c) monitoring and evaluating the national response to HIV and AIDS and the supervision of sectoral policies relating to HIV and AIDS;

(d) the oversight of the finances and activities of the Commission;

(e) facilitating mainstreaming of HIV and AIDS in all sectors of society; and

(f) the proper administration of this Act.

PART III—HARMFUL PRACTICES

4.—(1) Any harmful practice listed in the First Schedule is hereby prohibited.

Prohibition of harmful practices
First Schedule

(2) Any person who contravenes subsection (1) shall be guilty of an offence and shall be liable to a fine of K100,000 and imprisonment for five years.

5. Any person who subjects another person to a harmful cultural practice shall be guilty of an offence and shall be liable to a fine of K100,000 and imprisonment for five years.

Subjecting another to a harmful cultural Practice

PART IV—PROHIBITION OF DISCRIMINATION

6.—(1) Any form of discrimination on the basis that another person is infected with HIV or is suffering from AIDS or is perceived to be infected with HIV or perceived to be suffering from AIDS is hereby prohibited.

Prohibition discrimination on basis of HIV and AIDS

(2) A person who contravenes subsection (1) shall be guilty of an offence and shall be liable to—

- (a) in the case of an individual, a fine of K100,000 and imprisonment for five years; or
- (b) in the case of a body corporate, organization or association, a fine of K500,000.
- Rights of persons infected with HIV or suffering from AIDS
- 7.**—(1) A person who is infected with HIV or is suffering from AIDS, shall have the right to—
- (a) dignity of his person, physical integrity, life and health;
- (b) practice a profession of choice;
- (c) compensation associated with the restriction of his enjoyment of rights; and
- (d) free medication, at the expense of the State at any State medical institution, necessary for the treatment of any HIV related disease listed in the Second Schedule.
- Second Schedule*
- Rights of persons affected with HIV and AIDS
- 8.**—(1) A person associated with another person who is infected with HIV or is suffering from AIDS has the right to—
- (c) dignity, physical integrity, life and health; and
- (d) compensation associated with the restriction of the enjoyment of his rights.
- (2) A person who contravenes subsection (1) shall be guilty of an offence and shall be liable to—
- (a) in the case of an individual, a fine of K100,000 and imprisonment for five years; or
- (b) in the case of a body corporate, organization or association, a fine of K500,000.

PART V—DISCLOSURE OF HIV AND AIDS INFORMATION

- Right to privacy and confidentiality regarding HIV Status
- 9.**—(1) A person who is infected with HIV has the right to right to privacy and confidentiality with regard to information concerning his state of health.
- (2) It shall be the duty of every health service provider to strictly observe confidentiality in handling all medical information concerning a person infected with HIV.
- Disclosure by health service provider
- 10.**—(1) A health service provider may disclose information relating to any person's HIV status where he reasonably believes that it is medically appropriate to—

(a) any person he reasonably believes has been or will be exposed to the risk of infection in the course of his duties or emergency services; or

(b) the spouse or the sexual partner of the infected person.

(2) A health service provider shall not disclose any information under subsection (1) (b) unless he—

(a) has first counseled the infected person regarding the need to notify the spouse or the sexual partner and he reasonably believes that the infected person will not inform the spouse or the sexual partner; and

(b) has informed the infected person of his intent to make such disclosure to the spouse or the sexual partner.

(3) For the purposes of subsection (1) (a), “emergency service” means the Police Service, the Defence Force, the Fire Brigade or any other emergency response provider including a volunteer.

11.—(1) In addition to the provision under section 10, it is lawful to disclose the HIV status of any person under the following conditions—

Disclosure of
HIV status on
other
circumstances

(a) where consent of the person infected with HIV is obtained;

(b) where disclosure is made to a parent or legal guardian of a minor;

(c) where such information is demanded by an individual’s legal representative;

(d) where a competent court of law orders that disclosure shall be made; and

(e) for statistical and epidemiological purposes but such disclosure does not lead to the identity whether directly or by implication, of the infected person.

(2) For purposes of subsection (1),

(a) “a minor” is any person who is below the age of sixteen years;

(b) “consent” includes—

(i) where the infected person is dead, the written consent of the spouse, personal representative, administrator or executor;

(ii) where the infected person is a minor, or is otherwise unable to give the consent, the written consent of a parent, legal guardian or where necessary, an immediate family member or health service provider.

Unlawful disclosure

12. Any person who discloses the HIV status of another person otherwise than as provided for under this Act shall be guilty of an offence and shall be liable to—

(a) in the case of an individual, a fine of K100,000 and imprisonment for five years; or

(b) in the case of a body corporate, organization or association, to a fine of K1,000,000.

PART VI—PUBLIC HEALTH

Modes of HIV testing

13. The modes of HIV testing shall include—

(a) voluntary counseling and testing (VCT);

(b) routine testing;

(c) diagnostic testing;

(d) compulsory testing; and

(e) any other mode of HIV testing that the Minister may prescribe.

Age for accessing VCT without parental or guardian consent

14. A person who is aged thirteen years and above may access VCT without the consent of a parent or a legal guardian.

Consent to HIV testing

15. A person shall not undertake HIV testing in respect of another person except—

(a) with the consent of that other person;

(b) if, in the opinion of a health service provider who wishes to undertake the HIV test, the other person has a disability by reason of which he appears incapable of giving consent, with the consent of—

(i) a legal guardian of that person;

(ii) a partner or spouse of that person; or

(iii) an immediate family member; or

(c) where a person is required to undergo HIV testing under the provisions of this Act or any other written law.

Testing of donated body tissues

16. (1) A person who offers to donate any tissue shall, immediately before such donation, undergo HIV testing.

(2) A health service provider shall not accept a donation of any tissue unless the donor has undergone HIV testing pursuant to subsection (1) and the result is HIV negative.

(3) Notwithstanding subsections (1) and (2), the proposed recipient of the donated tissue or his immediate family member shall have the right to demand a second HIV testing on the donated tissue.

17.—(1) Donated blood shall as soon as practicable after donation, be subjected to HIV testing. Testing of donated blood

(2) Any blood tested under subsection (1) which is found to be HIV positive shall be disposed of in accordance with the prescribed guidelines on the disposal of medical waste as soon as practicable after such result is obtained.

18. Consent to undergo HIV testing shall be deemed to have been given in the following circumstances— Consent to be deemed

(a) where a person offers to donate any tissue;

(b) where a person offers to donate blood; or

(c) in situations where it is prudent for a health service provider responsible for the treatment of a person to undertake HIV testing in respect of that person and—

(i) the person is unconscious and unable to give consent; and

(ii) the health service provider reasonably believes that such a test is clinically necessary or desirable in the interest of that person.

19.—(1) Compulsory testing for HIV infection is hereby prohibited. Prohibition of compulsory testing

(2) Notwithstanding subsection (1), compulsory testing for HIV infection shall be permissible in the following instances—

(a) under an order of the court, for any person who is charged with a sexual offence;

(b) for commercial sex workers;

(c) for persons intending to enter into polygamous unions;

(d) for pregnant women and their sexual partners or spouses; and

(e) for donors of blood and tissue.

(3) A person who contravenes the provisions of subsection (1) shall be guilty of an offence and shall be liable to—

(a) in the case of an individual, a fine of K100,000 and imprisonment for five years; or

(b) in the case of a body corporate, organization or association, to a fine of K1,000,000.

(4) In addition to the penalties imposed under subsection (3), a court may, upon conviction, order—

(a) in the case of a body corporate, organization or association, the revocation of any business permit or licence; or

(b) in the case of an individual, the revocation of a licence to practice the person's profession.

Pre-test and
post-test
counselling

20.—(1) A health service provider who carries out an HIV test on any person shall be required to provide and conduct free pre-test and post-test counseling to such person.

(2) Notwithstanding subsection (1), any person who carries out HIV testing on any person for purposes of blood transfusion or body tissue extraction shall not be required to conduct pre-test and post-test counseling.

Duty to report
HIV infection

21. A health service provider who carries out HIV testing has a duty to give monthly reports of the number of HIV tests conducted and the incidence of HIV infection to the District Health Officer, for statistical and epidemiological purposes only.

Prohibition of
discrimination
in health
institutions

22.—(1) A person shall not be denied access to health care services in any health establishment or be charged a higher fee for any such services, on the grounds of the person's actual or perceived HIV status.

(2) Any person who contravenes subsection (1) shall be guilty of an offence and shall be liable—

(a) in the case of an individual, to a fine of K100,000 and imprisonment for five years; or

(b) in the case of a body corporate, organization or association, to a fine of K1,000,000.

(3) Notwithstanding the provisions of subsection (2), a court may, in addition to any penalty imposed on a person convicted, order—

(a) in the case of an individual, revocation of a licence to practice the person's profession; or

(b) in the case of a legal person, revocation of the business permit or licence in respect thereof.

PART VII—INFORMATION

Access to HIV
and AIDS
information

23.—(1) A person has the right to access information in connexion with HIV and AIDS held by the State or any organ of the State, if the information is necessary for the exercise of his rights.

- (2) A person who is in charge of information on HIV and AIDS has a duty to ensure that the information is relevant to the exercise of the rights of a person requesting such information. Duty of person in charge of information
- 24.** The Commission shall, in addition to the powers conferred on it by this Act, have the power to develop, co-ordinate and disseminate information on HIV and AIDS. Powers in relation to HIV and AIDS information
- 25.** (1) The Commission shall be the accrediting authority on information on HIV and AIDS disseminated to the public. Accrediting authority
- (2) Any information on HIV and AIDS developed by any person other than the Commission, shall be screened and verified by the Commission to establish its accuracy before dissemination.
- (3) A person in charge of information on HIV and AIDS has a duty to ensure that the information—
- (a) is accurate; and
- (b) is accredited by the Commission.
- 26.** A person who gives or publishes false or inaccurate information concerning HIV and AIDS to any person or the public shall be guilty of an offence and shall be liable to— Publication of misleading information
- (a) in the case of an individual, a fine of K100,000 and imprisonment for five years; or
- (b) in the case of a body corporate, organization or association, a fine of K1,000,000.
- 27.** A person who gives or publishes information on HIV and AIDS which is not accredited by the Commission to any person or the public shall be guilty of an offence and shall be liable to— Publication of unaccredited information
- (a) in the case of an individual, a fine of K100,000 and imprisonment for five years; or
- (b) in the case of a body corporate, organization or association, a fine of K1,000,000.
- PART VIII—EMPLOYMENT**
- 28.** An employer shall not require any person to undergo HIV testing as a pre-condition for recruitment: Prohibition of pre-recruitment testing
- Provided that pre-employment HIV testing may be permissible for—
- (a) purposes of assessing fitness to serve in—

- (i) the Defence Force;
- (ii) the Police Service;
- (iii) the Prison Service; and
- (iv) the Immigration Department; or

(b) purposes of assessing the health status of a domestic worker.

Prohibition of termination of employment on grounds of HIV or AIDS

29. (1) An employer shall not terminate the employment of an employee only on the ground that the employee is HIV positive or is perceived to be HIV positive.

(2) A person who contravenes this section shall be guilty of an offence and shall be liable to—

(a) in the case of an individual, a fine of K100,000 and imprisonment for five (5) years; or

(b) in the case of a body corporate, organization or association, to a fine of K1,000,000.

Promotion, transfer and training

30.—(1) An employee shall not be discriminated against or be subjected to unfair treatment on the ground that he is HIV positive or is suffering from AIDS.

(2) A person who contravenes this section shall be guilty of an offence and shall be liable to—

(a) in the case of an individual, a fine of K100,000 and imprisonment for five (5) years; or

(b) in the case of a body corporate, organization or association, a fine of K1,000,000.

Procuring another to conduct HIV test for recruitment, etc

31. A person who procures another person to conduct HIV testing as a condition for recruitment, training, promotion, termination of employment or other matters arising out of an employment relationship shall be guilty of an offence and shall be liable to—

(a) in the case of an individual, a fine of K50,000 and to imprisonment for three (3) years; or

(b) in the case of a body corporate, organization or association, a fine of K500,000.

Aiding, abetting or concealing act of subjecting another to HIV test for recruitment,

32. A person who aids, abets or assists another person to conduct HIV testing as a condition for recruitment, training, promotion, termination of employment or other matters arising out of an employment relationship shall be guilty of an offence and shall be liable to —

(a) in the case of an individual, a fine of K100,000 and to imprisonment for five (5) years; or

(b) in the case of a body corporate, organization or association, to a fine of K500,000.

33.—(1) An employee whose child or spouse is suffering from AIDS shall have the right to provide care for the child or spouse outside employment for a maximum of four weeks on full pay and to a subsequent four weeks on half pay.

Compassionate leave for parents and spouses

(2) An employee who is temporarily incapacitated from work under subsection (1) shall be deemed to be in continuous service for purposes of promotion, increments in personal emoluments, leave and any other employment benefits.

34. Where a person is employed in an occupation or is required to provide services where there may be a risk of transmitting or acquiring HIV, the employer shall provide appropriate training, protective equipment and clear and accurate information and guidelines on minimizing the risk of the spread of HIV.

Employer responsible for minimizing risk of infection at workplace

35.—(1) The State shall take active measures to ensure that employers have adopted and are implementing an HIV and AIDS policy at the workplace.

Workplace policy

(2) The design and content of the workplace policy shall be in accordance with the policy guidelines issued by Government.

36.—(1) An employee who is been infected with HIV in the course of employment shall have the right to claim compensation in accordance with the Workers' Compensation Act.

Compensation
Cap. 55:03

(2) An employee who is infected with HIV in the course of his employment is entitled to higher compensation if he is able to show that his infection is due to non compliance of section 34 by the employer or is otherwise due to negligence of the employer.

PART IX—EDUCATION

37.—(1) A person shall not be required to undergo HIV testing as a condition for—

(a) entry into an education or training institution;

(b) an award of a scholarship, grant, bursary, benefit or other scholarly endowment; or

(c) remaining as a student or trainee in any education or training institution.

Prohibition of HIV testing for educational purposes

(2) A person who contravenes subsection (1) shall be guilty of an offence and shall be liable to—

(a) in the case of an individual, a fine of K100,000 and imprisonment for five years; or

(b) in the case of a body corporate, organization or association, a fine of K1,000,000.

Prohibition of discrimination in education and training institutions

38.—(1) An education or training institution shall not, where there is no risk of infection of others with HIV—

(a) refuse a person admission into the institution;

(b) expel a person from the institution;

(c) segregate a person;

(d) refuse a person participation in an event or activity; or

(e) deny any benefits or services to a person,

only on the grounds that the person is HIV positive or is perceived to be HIV positive.

(2) A person who contravenes subsection (1) shall be guilty of an offence and shall be liable to—

(a) in the case of an individual, a fine of K100,000 and imprisonment for five years; or

(b) in the case of a body corporate, organization or association, organization or association, a fine of K1,000,000.

(4) Notwithstanding the provisions of subsection (2), a court may, in addition to any penalty imposed on a person convicted, order—

(a) in the case of an individual, revocation of the licence to practice his profession; or

(b) in the case of a private education or training institution, revocation of the business permit, licence or certificate.

HIV and AIDS materials in school curriculum

39.—(1) The Minister shall, in consultation with the Minister responsible for Education, the Commission and other relevant authorities on HIV and AIDS, ensure that materials on HIV and AIDS are developed and integrated into the school curriculum for all education and training facilities at all levels.

(2) Pursuant to subsection (1), the Minister shall ensure that the materials on HIV and AIDS developed and integrated into the school curriculum are—

(a) appropriate for the level of education it is intended having regard to the following factors—

- (i) age of pupils, students or trainees;
 - (ii) level of mental maturity; and
 - (iii) the objective of the materials used;
- (b) free from all forms of stigmatization against persons living with HIV and AIDS;
- (c) not sexually explicit;
- (d) developed in consultation with associations representing parents and teachers, education officials and interest groups.

40. Teachers and instructors shall be trained on issues of HIV and AIDS before commencing teaching or instruction on any subject related to HIV and AIDS.

Teachers and instructors to be trained on issues of HIV and AIDS

41. The Minister shall ensure that official information on modes of transmission and ways of preventing HIV infection is progressively integrated in non-formal or indigenous learning systems.

HIV and AIDS information in non formal education systems

PART X—CONTROL OF HIV INFECTION

42. A person diagnosed as having HIV infection or AIDS shall be required to—

Person with HIV or AIDS to undergo counselling

- (a) undergo counseling by a health service provider; and
- (b) comply with such precautions and safety measures as may be prescribed.

43.—(1) A person who knows that he is HIV positive shall not do an act or omit to do an act which is likely to transmit or spread HIV infection to another person unless, before the act or omission takes place, the other person—

Acts likely to spread HIV infection

(a) has been informed of the risk of contracting HIV from him or her; and

(b) has voluntarily agreed to accept that risk.

(2) Any person who contravenes this section shall be guilty of an offence and shall be liable to to imprisonment for five years.

(3) In this section, a person shall be deemed to be HIV positive if HIV testing was carried out on him and the results indicate that he is HIV positive.

44. A person who deliberately infects another person with HIV shall be guilty of an offence and shall be liable to to imprisonment for fourteen years.

Deliberate infection with HIV

Negligent and reckless infection with HIV

45.—(1) A person who recklessly or negligently infects another person with HIV shall be guilty of an offence and shall be liable to imprisonment for ten years.

(2) Where the offence under subsection (1) arises out of exposure to infection in the course of employment, then lack of provision of preventive measures by the employer shall be a defence.

PART XI—ESTABLISHMENT OF NATIONAL AIDS COMMISSION

Establishment of National AIDS Commission

46.—(1) There is hereby established a body to be known as the National AIDS Commission (in this Act referred to as the “Commission”).

(2) The Commission shall be an independent State institution under the Office of the President and Cabinet or any other Ministry as the President may direct.

Functions and duties

47.—(1) The functions and duties of the Commission shall be—

(a) to manage and co-ordinate the implementation of Government policies on HIV and AIDS;

(b) to co-ordinate and facilitate the national response to HIV and AIDS;

(c) to develop and maintain an up-to-date information system and establish suitable mechanisms of disseminating and utilizing such information;

(d) in liaison with the Secretary responsible for HIV and AIDS, to monitor and evaluate progress and impact of HIV and AIDS prevention, care and mitigation programmes;

(e) to mobilize, disburse, monitor and ensure equitable distribution of resources;

(f) to promote research, information sharing and documentation on HIV and AIDS prevention and control;

(g) to liaise with relevant Ministries as appropriate on all matters relating to HIV and AIDS to ensure that there are no barriers to information on HIV and AIDS;

(h) to ensure, through advocacy, that all political, community and traditional leaders play a strong, sustained and visible role in the prevention of HIV and AIDS;

(h) to screen and certify that the information on HIV and AIDS produced by any person is correct before dissemination;

(i) to develop and maintain profiles for HIV and AIDS;

(j) to provide technical support to Government in the formulation and review of HIV and AIDS policies;

(k) to provide technical guidance and support on HIV and AIDS to stakeholders;

(l) to provide capacity building assistance to implementing institutions involved in the national response to HIV and AIDS on behalf of Government; and

(m) to compile and submit monthly, quarterly and annual reports to the Minister on the implementation of the national response on HIV and AIDS.

48. The Commission shall have powers to—

Powers of the
Commission

(a) sponsor, support or organize conferences, seminars, workshops and meetings on any matter under its consideration or generally for the promotion of its functions and objects;

(b) receive and allocate donations of funds, materials and technical assistance for the furtherance of its work and ensure the effective utilization of those funds;

(c) engage persons having suitable qualifications and experience as consultants to the Commission;

(d) determine its own procedures for carrying out consultancies for the general conduct of its work;

(e) establish such number of its own Committees as it considers necessary for the performance of its functions and assign to such Committees any of its functions without prejudice to the power of the Commission itself to perform those functions;

(f) co-opt any person to attend any of its meetings but that person shall not vote on any matter for decision by the Commission; and

(g) do and perform all such things or acts as are necessary or expedient for the implementation of its programmes and the exercise of its functions, duties and powers.

49.—(1) Membership of the Commission shall not exceed eleven people and shall consist of—

Composition

(a) one person, appointed by the Minister, who is professionally qualified in the medical sciences or a relevant social scientific field;

(b) one person, appointed by the Minister, who is a member of civil society and directly involved in issues of HIV and AIDS;

(c) one person, appointed by the Minister, who is a professionally qualified and practicing accountant;

(d) the Principal Secretary for HIV and AIDS;

(e) the Principal Secretary for Health;

(f) the Principal Secretary for Women and Children; and

(g) the Principal Secretary for Local Government and Rural Development.

(2) The members other than the members *ex-officio* shall be appointed by the Minister following the placement of advertisements in at least two local papers of daily circulation.

(3) An *ex-officio* member of the Commission or any person employed in the public service shall not be eligible to be elected Chairperson of the Commission but shall have the right to vote on any matter at the meetings of the Commission.

(4) Members of the Commission shall not, by virtue of their appointment to the Commission, be deemed to be officers in the public service.

(5) The names of all members of the Commission, as first constituted and every change in the membership thereof shall be published in the *Gazette*.

50.—(1) A member of the Commission, other than an *ex-officio* member, shall hold office for a period of three years from the date of his appointment and be eligible for re-appointment at the expiry of that period. Tenure of office

(2) When making appointment after the expiry of the three years, the Minister shall have regard to the need to maintain a reasonable degree of continuity on the membership of the Commission, so that at least half of the appointed members shall be re-appointed for the next term of office.

(3) A vacancy in the office of an appointed member shall occur if the member—

(a) dies;

(b) is adjudged bankrupt;

(c) is sentenced for an offence against any written law to any term of imprisonment;

(d) is absent, without the permission of the Commission, from three successive meetings of the Commission of which he has had notice;

(e) becomes incapacitated by reason of physical or mental disability; or

(f) resigns in accordance with subsection (4).

(4) An appointed member may at any time resign his office by giving one month written notice to the Minister.

(5) A vacancy on the membership of the Commission shall be filled by the appointment of a new member by the Minister.

(6) A person appointed to fill the vacancy shall serve for the remainder of the term of office but no person shall be so appointed where the remainder of the term of office is a period of less than six months.

Chairperson

51.—(1) There shall be a Chairperson of the Commission who shall be elected by the Commission from among the appointed members at the first meeting of the Commission.

(2) Subject to subsection (3), the Chairperson shall hold office as such until the expiry of his term of office as member of the Commission.

(3) The Chairperson may be removed from office by the Commission upon the unanimous decision of the rest of the members of the Commission for—

(a) misconduct;

(b) incapacity; or

(c) any other good cause.

Commission
may establish
Committees

52.—(1) For the better carrying into effect of the provisions of this Act, the Commission may establish such number of committees as the Commission shall deem appropriate, to perform such functions and responsibilities as the Commission shall determine subject to the directions of the Commission.

(2) The Commission shall appoint a Chairperson for each committee from amongst the members of the Commission.

(3) The provisions of this Act relating to the meetings of the Commission shall apply *mutatis mutandis* to the meetings of the committees.

Commission
may co-opt

53. The Commission may, in its discretion, at any time and for any length of period, co-opt any person on account of his special knowledge or expertise to attend any deliberations of the Commission, but such person shall not be entitled to vote on any matter at any meeting of the Commission.

Meetings of
the
Commission

54.—(1) The Commission shall meet as often as its business requires and in any event not less than once in every three months.

(2) Meetings of the Commission shall be held at such places and times as the Commission shall determine.

(3) Ordinary meetings of the Commission shall be convened by at least fourteen days written notice to the members by the Chairperson, and the Chairperson may, at his discretion, and shall at the written request of more than four members of the Commission and within seven days of such request, call for an extraordinary meeting of the Commission to be summoned at such place and time as he may appoint.

(4) A quorum for any meeting of the Commission shall be formed by the presence of more than half of the members of the Commission or committee.

(5) In the absence of the Chairperson, the members present and forming a quorum shall elect one of their number to preside over the meetings of the Commission, and the member so elected shall exercise all the powers, duties and functions of the Chairperson.

(6) Subject to the provisions of this Act, the Commission may make standing orders for regulation of its proceedings and business or the proceedings and business of any of its committees and may vary, suspend or revoke any such standing orders.

(7) The Commission, and every committee of the Commission, shall cause minutes of its meetings to be recorded and kept.

Disclosure of
interest

55. If a member of the Commission acquires any pecuniary interest, direct or indirect, in any contract, proposed contract or other matter and is present at a meeting of the Commission at which the contract, proposed contract or the other matter is the subject of consideration by the Commission, he shall at the meeting, as soon as practicable after the commencement of the meeting, disclose the fact to the Commission, and shall not take part in the consideration or discussion of or vote on any question with respect to, the contract, proposed contract or the other matter.

Remuneration

56. Members of the Commission shall be paid such remuneration for membership and such allowances when discharging their duties as may be determined by the Minister responsible for Finance.

57. The Commission shall report to the Minister and keep the Minister fully informed on matters concerning the general conduct of the affairs of the Commission. Reporting

PART XII—ADMINISTRATION OF THE NATIONAL AIDS COMMISSION

58.—(1) There shall be the office of the Executive Director of the Commission which shall be a public office. Executive Director

(2) The Executive Director shall be appointed by the Minister on the recommendation of the Commission on such terms and conditions as Parliament shall determine.

(3) The office of the Executive Director shall be held by a person who has had experience and shown capacity in a profession or in activities devoted or relevant to matters of HIV and AIDS.

(4) The Executive Director shall hold office for a period of three years subject to renewal on satisfactory service.

59.—(1) The procedure for appointing an Executive Director shall involve first the issuing of a public advertisement inviting applications for the post of Executive Director, and shall be signed by the Chairperson of the Commission. Procedure for appointment of Executive Director

(2) The advertisement under subsection (1) shall invite applications in writing within thirty days of the date of the advertisement and the advertisement shall require applicants to submit a curriculum vitae.

(3) The Commission shall assess the applications received pursuant to subsection (2), and—

(a) may seek other or further information pertaining to an applicant, from the applicant or any other person or source;

(b) shall interview each eligible short listed applicant; and

(c) shall recommend to the Minister the most eligible candidate for appointment as Executive Director.

60. Subject to the general and special directions of the Commission, the Executive Director shall be responsible for the day to day management of the Commission and administrative control of other members of staff of the Commission and, in that regard shall be answerable and accountable to the Commission. Duties of the Executive Director

61. The Executive Director may be removed from office on the following grounds— Removal of Executive Director

(a) misconduct;

(b) incompetence;

(c) incapacity by reason of physical or mental illness; and

(d) inability or unfitness to discharge the duties of the Executive Director.

Other staff

62.—(1) There shall be employed in the service of the Commission, subordinate to the Executive Director, such other management, professional, research, technical, administrative and other support staff as the Commission shall consider necessary for the exercise of its powers and the performance of its duties and functions, who shall be officers in the public service.

(2) The staff of the Commission under subsection (1) shall be appointed by the Commission on such terms and conditions as Parliament shall determine:

Provided that the Commission may by directions in writing delegate to the Executive Director, the appointment of its staff in such junior ranks as it shall specify and the Executive Director shall report to the Commission every appointment made pursuant to this subsection.

Attendance of meetings by staff

63.—(1) The Executive Director, or any other officer of the Commission as the Executive Director shall designate with the approval of the Commission shall attend meetings of the Commission or any committee of the Commission to record the minutes of the meetings and take part in the deliberations thereof subject to the directions of the Commission or committee but shall not be entitled to vote.

(2) Where in any meeting the deliberations of the Commission or of a committee of the Commission concerns the Executive Director or any officer of the Commission designated to attend the meeting, the Commission or the committee, as the case may be, may exclude the Executive Director or such officer from the meeting.

PART XIII—FINANCIAL PROVISION

Funding of the Commission

64. The funds of the Commission shall consist of—

(a) such sums as shall be appropriated by Parliament for the purposes of the Commission;

(b) such donation of funds, materials and any other form of assistance for the purposes of its functions, powers and duties;

(c) such sums of funds as are derived from the sale of any property by or on behalf of the Commission; and

(d) other lawful source of funding.

(2) The Commission shall at all times comply with the provisions of the Public Audit Act, the Public Finance Management Act and the Public Procurement Act.

No. 6 of 2003
No. 7 of 2003
No. 8 of 2003

65.—(1) The Commission shall cause to be kept proper books and other records of accounts in respect of receipts and audit expenditures of the Commission in accordance with acceptable principles of accounting.

Books and other records of accounts, audit and reports of the Commission

(2) The accounts of the Commission shall be audited annually by the Auditor General or by independent professional auditors appointed by the Commission in consultation with the Auditor General, and the expenses of the audit shall be paid out of the funds of the Commission.

(3) The Commission shall as soon as practicable, but not later than six months after the end of the financial year, submit to the National Assembly an annual report on all financial transactions of the Commission and on the work, activities and operations of the Commission.

(4) The report referred to in subsection (3) shall include a balance sheet and an income and expenditure account, shall be laid before the National Assembly in accordance with the provision of Public Audit Act.

No. 6 of 2003

PART XIV—MISCELLANEOUS

66. The Minister may, by notice in the *Gazette*, make regulations for the better carrying out of the provisions of this Act.

Regulations

67. The Minister may, by notice in the *Gazette*, amend any schedule to this Act.

Amendment to schedules

FIRST SCHEDULE
HARMFUL PRACTICES

s. 5

1. *Chimwanamaye*
2. *Fisi*
3. *Hlazi*
4. *Chijura mphinga*
5. *Kuchotsa fumbi*
6. *Chiharo*
7. *Kuika mwana kumalo*
8. *Kujura nthowa*
9. *Kulowa kufa*
10. *Kulowa ku ngozi*
11. *Kupimbira*
12. *Kupondera guwa*
13. *Kusamala mlendo*
14. *Kutsuka mwana*
15. *Mbirigha*
16. *Gwamula*
17. *Mwana akule*
18. *Bulangete la mfumu.*

SECOND SCHEDULE

s. 8

HIV RELATED DISEASES

1. Kaposi's sarcoma
2. Chronic and recurrent diarrhoea
3. Oral and oesophageal candidiasis
4. Herpes zoster
5. High Grade B cell malignant lymphoma
6. Cryptococcal and other fungal meningitis
7. Pneumocystis carini pneumonia
8. Pulmonary or disseminated tuberculosis

APPENDIX B

EMPLOYMENT (AMMENDMENT)
ACT 2008

A B I L L

entitled

An Act to amend the Employment Act.

ENACTED by the Parliament of Malawi as follows—

1. This Act may be cited as the Employment (Amendment) Act, Citation
2008.

2. The Employment Act (hereinafter referred to as the “principal Act”) is amended in section 5 subsection (1) by deleting the words “birth, marital or other status or family responsibilities” and substituting therefor the words “marital or family responsibilities, birth or other status”.

OBJECTS AND REASONS

The object of this Bill is to give effect to the recommendation made by the Law Commission in the Report on the development of the HIV (Prevention and Management) Act which makes provision for the introduction of an additional ground upon which discrimination is prohibited under the Employment Act.

Attorney General