An ethnography of HIV/AIDS care transformation in Zambia

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An Ethnography of HIV/AIDS Care Transformation in Zambia

by
Joseph Simbaya

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DEDICATION

I dedicate this dissertation to my dear wife and children. To my wife Mary for your unwavering support and trust in me. I went through this difficult road with you. You carried the burden more than I did. You were my wonderful counsellor who gave me inspiration and strength to go on even when I was almost tiring out and giving up. My children for your obedience, understanding and support. This is for you. May it inspire you to greater heights in your careers. Nothing is impossible when you put your mind and effort to it. Always remember this!

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I thank all of you for your unwavering support and wish you all the best in your endeavours.

CONTENTS

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LIST OF ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ARV	Antiretroviral drug
ART	Antiretroviral Therapy
CBO	Community-based Organization
CDC	Centers for Disease Control
CIDRZ	Center for Infectious Disease Research in Zambia
FPWAZ	Family Planning Welfare Association of Zambia
GF	Global Fund
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
INESOR	Institute of Economic and Social Research
MAP	Multicountry AIDS Programme
MOH	Ministry of Health
NAC	National HIV/AIDS/STI/TB Council
NASF	National AIDS Strategic Framework
NGO	Nongovernmental Organization
NZP+	Network of Zambian People Living with HIV
PEPFAR	President's Emergency Fund for AIDS Relief
PITC	Provider-initiated Testing and Counselling
PLHIV	People (or Person) Living with HIV
PMTCT	Prevention of Mother-to-Child Transmission of HIV
SIDA	Swedish International Development Agency
STI	Sexually Transmitted Infection
UNAIDS	United Nations Joint Programme on HIV/AIDS
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
UNDP	United Nations Development Programme
USAID	United States Agency for International Development
US	United States
VCT	Voluntary Counselling and Testing
WHO	World Health Organization
ZPCT	Zambian Prevention Care and Treatment

Part I

The Research

Part I introduces the research and highlights the theoretical lens used to tell and reflect on the ethnographic story. This part concludes with methods employed in the collection and analysis of data.

CHAPTER 1
Introduction

> It is difficult to tell. I would say that our partners have the knowledge from implementing similar programmes in other countries. For example the WHO gives us guidance about what ARV [antiretroviral drug] regimens to give to whom. We cannot rule out their research and experience from other countries, including African, on how these ARVs work and how different people react to them. … That is not to say that we are dormant and just take what they give us. For example, when we realised that a certain type of ARVs had too many side effects, we stopped administering it, even though we had a lot of it in our medical stores. Also when we proposed that we test all exposed children for HIV, regardless of consent from their parents, it was regarded as against human rights, but we did it anyway and now people can see the benefits. In short, it's mixed. When you are given money, the funders have a right to tell you what to do with the money. At the same time, they usually fund our government priorities. They cannot fund gay programmes when we as government do not recognise gay people as acceptable in our society. So to answer your question, we tell them what to do and they tell us what to do, and through dialogue we agree.
>
> – Home-based care coordinator in charge of HIV counselling, Ministry of Health, 2011

When I set out to study HIV/AIDS care and support practices in 2010 and how they had evolved since the emergence of AIDS in Zambia, I went into the 'field' with the assumption that guidelines and practices had come to be predominantly shaped by international nongovernmental organizations (NGOs) and development agencies. While I entertained the thought that some HIV/AIDS care guidelines and practices were shaped by the interaction of local, national and international actors, it seemed evident from my ongoing involvement with HIV/AIDS work as a consultant and researcher that international organizations handed down policies and practices to local organizations who were expected to implement them with little question – this included the Zambian government in my mind. Thus, my study was framed by this assumption: existing systems of HIV/AIDS care and support had evolved and been influenced by external powers. This view of the relationship between external and local actors was informed by two things: first, a significant proportion of funding for HIV/AIDS, tuberculosis and malaria interventions came from other governments and international NGOs. Second, from my previous research and experience working on HIV and growing up in a country highly affected by the disease, it seemed that most policies and programmes related to prevention, treatment, care and support for people with HIV were dictated by donors who asked aid recipients to 'take ownership' of ideas developed in Washington, DC and Geneva with little questioning or revision.

I chose to focus on HIV counselling as a lens through which I could study the interactions among different actors. HIV interventions consist of prevention, treatment, care and support. Most HIV/AIDS interventions provide more than one of the three components. Prevention often consists of raising awareness about the modes of HIV transmission, testing and treatment. Counselling before and after testing for HIV takes a central place in prevention. As currently designed, counselling plays a pivotal role in HIV treatment. Due to the life-long nature of HIV treatment, public health specialists prescribe pre-treatment counselling as a first step to ensure adherence to treatment. Like antibiotic drugs, antiretroviral therapy (ART) can stop being effective if a person skips doses or stops altogether. To avoid drug resistance, counselling has also been incorporated in treatment in the form of adherence counselling. This form of counselling is a central feature of HIV treatment and is offered each time a person on HIV treatment goes back to the facility to refill their drug ampoules. Beyond treatment, people with HIV still need counselling as part of ongoing care. Even when people are 'living healthy' on treatment, they may experience traumatic episodes that call for counselling, and as they rebuild their lives and return to 'normal life', the need to marry and have children resurfaces for some, which also calls for specialised forms of counselling. Thus HIV counselling becomes a shared aim for most organizations involved in HIV/AIDS care.

HIV/AIDS counselling started as trauma counselling in the 1980s, mainly as part of palliative care. When HIV testing became available and accessible, the practice evolved. It became part of the HIV-testing package and was formalized into pre- and post-test counselling. It still took the form of traumatic stress management (Silverman 1997), but also included preparedness for HIV testing and receiving test results. In the HIV-treatment era, counselling permeates all spheres of life for people with HIV. Thus HIV counselling is a good ethnographic lens to understand transformations in HIV/AIDS care practices.

Influence of International Donors; Conception of Assumptions

With the arrival of global HIV treatment initiatives in Africa, Zambia saw a rapid increase in donor support.[1] Zambia has received funding for health interventions from international organizations since its birth in 1964. In 1980, for example, the country received US$3.8 million from the United Nations Population Fund (UNFPA) to set up a family health unit at the Ministry of Health (MOH). Earlier, in 1972, Zambia had received support to establish the Family Planning Welfare Association of Zambia (FPWAZ) from the International Planned Parenthood Federation (IPPF). In 1993, USAID started to provide substantial support for health services both through government and NGOs. Other organizations that provided international funding included the World Bank, Overseas Development Assistance–UK (ODA) and the Swedish International Development Agency (SIDA) (Kalumba 1994). Thus from very early on, international aid to both the government and Zambian NGOs has played a critical role in providing health services in Zambia.

When HIV/AIDS came to the centre stage of the health scene, more funding followed. Although funding for AIDS control started flowing to Zambia for prevention, prior to the availability of HIV treatment, international funding has increased in the treatment era. For example, between 2002 and 2004, the Global Fund to Fight AIDS, Tuberculosis and Malaria (GF) promised Zambia close to US$224 million. In 2003 alone, GF and the World Bank's Multi-country AIDS Programme (MAP) gave Zambia US$132 million for AIDS control. In 2004, Zambia also began receiving funds from the

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[1] According to Ndubani et al. (2007), it is not possible to report how much money earmarked for HIV was coming into Zambia prior to the expansion of treatment programmes ('scale-up') because there was no central body tracking it.

US President's Emergency Plan for AIDS Relief (PEPFAR) – US$59 million in 2004, US$47.7 million in 2005 and over US$100 million in 2006 (Ndubani et al. 2009; Ndubani et al. 2007).

In 2005, total funding from GF and PEPFAR alone was US$362 million. In 2006 and 2007 PEPFAR provided US$147 million and US$216 million respectively (Ndubani et al. 2009). In addition to direct funding from these global initiatives, some implementing organizations, known as 'implementing partners' or the government's 'cooperating partners' also receive funds mainly from the United States government either through CDC or USAID to implement AIDS control programmes. Other international NGOs, bilateral organizations and multilateral organizations all fund HIV/AIDS interventions in Zambia.

In Zambia, the huge influx of funds for AIDS control was also accompanied by technical assistance and restrictions. For example, only facilities that had a trained HIV/AIDS doctor or clinical officer were allowed to provide HIV treatment. Organizations that were primary recipients of international funding, such as the Center for Infectious Disease Research in Zambia (CIDRZ), provided doctors and pioneered the training of Zambian treatment providers.

In Lusaka, as in several provinces in the southern half of Zambia, CIDRZ became the main provider of HIV treatment between 2004 and 2013. A recipient of PEPFAR funds, this research-based organization affiliated with the University of Alabama at Birmingham dominated the field of HIV-treatment provision to a degree rarely seen in Africa. Since the organization's incorporation in Zambia in 2001, it has completed more than thirty-five projects and by 2012 had forty more underway. At the time of my research between 2010 and 2012, CIDRZ employed 650 people and provided treatment in partnership with the Zambian Ministry of Health at 321 public health facilities in Zambia, representing about a quarter (24 per cent) of all public facilities in Zambia. Based in Lusaka, the seat of the national government, CIDRZ helped to define standards of care for treatment at the national level through the provision of treatment and the training of HIV treatment providers.[2]

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[2] This and the previous paragraph are replicated here from Chapter 5 (published article) as

Within the southern region of the country, CIDRZ was not the only organization providing HIV/AIDS prevention, treatment and care services. In a three-year project that began in 2004, which was co-funded by USAID and the European Union, the International HIV Alliance worked with NZP+, the Catholic Dioceses of Lusaka and Ndola and the Traditional Health Practitioners Association of Zambia (THPAZ) to pioneer a programme that employed people living with HIV as counsellors. They argued that using HIV-positive counsellors who looked healthy made it easier to convince people to start and continue taking antiretroviral drugs (ART), and gave hope to those testing positive. Zambian public health officials lauded the project, which was viewed as an unusual example of a successful partnership between international donors and advocacy groups and Zambian institutions and activists. Lusaka's District Health Management Team (DHMT) director hailed the use of HIV-positive counsellors as 'the missing link' in all existing HIV/AIDS programmes. I worked as the research manager for this project, which aimed to provide treatment to two hundred people and documented success stories of how communities were mobilized to participate in HIV treatment using people with HIV as community mobilizers and treatment supporters between 2004 and 2008. I observed during my time with this project that international organizations had a dominating influence on emerging HIV/AIDS care policies, guidelines and practices.

The project came to the scene at a time when treatment was not yet freely accessible in public health facilities. Only one pilot HIV-treatment programme had been implemented at Ndola Central Hospital on the Copperbelt and University Teaching Hospital in Lusaka. All clinicians and nurses involved in administering ART at clinics that were implementing the project were trained by CIDRZ and its partners. Since HIV treatment had not been expanded to other hospitals and clinics, the project determined how people with HIV were to be mobilized from the community for testing and subsequent enrolment for treatment, and how they were to be attended to at the clinic. There were no guidelines yet for providing HIV treatment from the government. The situation remained the same for many years.

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they demonstrate a central idea about the interaction of the different actors prior to and during the time of my research. It forms the starting point for the dissertation.

By the time I was developing ideas for my PhD research, I had been involved in HIV/AIDS research in Zambia for about eleven years. Looking back, my involvement in two studies conducted between 2008 and 2009 also shaped my views about the influence of international donors more than others. The first was based on a project funded by the Open Society Institute, which supported researchers from the London School of Hygiene and Tropical Medicine and the Royal College of Surgeons in Ireland to study the effects of global health initiatives (PEPFAR, GF and World Bank), aka 'GHIs', on the national health systems of a number of sub-Saharan countries (Ndubani et al. 2009; Brugha et al. 2010; Walsh et al. 2010; Brugha et al. 2010). In Zambia, I worked as one of the local investigators. The study was done in three districts: Lusaka District in Lusaka Province, and Kabwe and Mumbwa Districts in Central Province. One of the objectives of the study was to assess the extent to which global health initiatives contributed to the scale-up of HIV services. I led the team in the three districts to collect data on the services that had been provided between 2004 and 2007.

What struck me most during this study was the difficulty of accessing data on health services, which were under the custody of CIDRZ in Lusaka, and under Zambia Prevention, Care and Treatment (ZPCT) in Kabwe and Mumbwa. Zambia has a national health management information system. This system enables the collection of data at all health facilities in the country using registers and other paper-based tools, which are taken monthly to the district health office. At each district office, data are entered electronically and then transmitted to Lusaka where the Ministry of Health headquarters sit. When the global health initiatives came in to provide HIV/AIDS services, they introduced a parallel system and argued that the existing system did not capture all the indicators that they were required to report. CIDRZ began employing data-entry clerks at each facility, and data were electronically transmitted to CIDRZ for analysis and could only be accessed by the Ministry of Health upon request. This presented a great challenge for my research team. We could not easily access data on health services from CIDRZ; only after repeatedly following up with both CIDRZ and the district health office were we able to access the data. One official from Ministry of Health said: 'It's not you alone. We also struggle to access data from our own health facilities. It's not fair. We are the custodians of our own health and we must be able to easily access data for planning and management'.

The second study that shaped my view of the interaction among local, national and international health actors in Zambia was a study that resulted in the publication: 'The Pipers Call the Tunes in Global Aid for AIDS: The Global Financial Architecture for HIV Funding as Seen by Local Stakeholders in Kenya, Malawi and Zambia (Edström et al. 2010). Finding both positive and negative experiences of working with global health initiatives, in this paper we suggested that such initiatives should engage with local stakeholders, government and each other to develop a joint 'code of practice' in order to create more coherent systems all the way down to the community level. Our data showed that existing practices were externally driven and that the whole funding architecture was imposed on local communities. These two studies shaped my assumption prior to my PhD research that international actors called the tune in the provision of HIV/AIDS care in Zambia. It seemed that although there could have been some resistance, resulting policies, guidelines and practices were shaped by international actors.

Friction or Imposition?

Going into the 'field' as an anthropologist and taking more than two years to observe HIV services being provided and the interactions of various organizations and actors in different projects and forums, I began to question this assumption. I found that HIV/AIDS care guidelines and practices have evolved in a disordered milieu, and realized that it is the 'friction' (Tsing 2005) in the interactions among diverse actors that defines care practices, rather than international organizations simply imposing procedures and guidelines from above. Not only does this friction shape what happens locally in Zambia, but I found that local concepts of care have contributed to shaping international guidelines; these have then been institutionalized and returned to the local context through global health initiatives and transnational organizations. It is thus difficult to pinpoint one force as the dominating influence, as transformation occurs as a result of the friction between two or more forces, with new forms emerging that may resemble one force more than the other(s).

Using counselling as a lens through which to study the transformation of HIV/AIDS care, I document an important history that helps us understand the present. The dissertation places understanding of current HIV/AIDS care and its imperatives in the historical processes leading to the present. It demonstrates how international guidelines, technologies, project goals, existing forms and concepts of HIV/AIDS care, and local agency have interacted to transform HIV/AIDS care practices. As a result of this friction, new social forms have emerged that position local actors as rational agents of change. This ethnography demonstrates that international donors and organizations have adopted and adapted some practices that were first developed in Zambia as much as local actors have adopted and adapted care practices from outside.

I propose that we understand the relationships among the different actors and forms of international knowledge and experience – and apparent local collusion with it – as a set of diverging interests and perspectives that exist at different moments in time, which give rise, through their interaction, to new forms and practices of HIV/AIDS care. I use Tsing's (2005) idea of 'friction' as an important metaphor for explaining the ways that global policies and practices touch down in national and local contexts, rubbing up against existing practices and ideas, and how the resulting friction shapes forms and practices of care.

The choice to complement ethnography with historical engagement is a conscious one. It allows me to do two things: first, a partial historical approach enables me to understand the shifts in counselling over time and the different actors at each space and time. This look at historical events is important to understand the transformation process. Second, ethnography adds to this by reinterpreting the existing practices and responses to recent calls to understand the evolution of the HIV/AIDS and existing responses from a historical perspective (Illife 2006; Seeley 2015). The combination of approaches also helps to understand how existing forms and guidelines shaped international guidelines and vice versa.

History has documented how the 'Global North' has not only determined the funding architecture for 'global' interventions, but also, along with funding, determined priority areas for intervention (Edström et al. 2010; Hanefeld 2010; Campbell et al. 2012). This was evident during my data collection. When evidence that male circumcision reduced the likelihood of getting infected with HIV was published, funding for male circumcision was soon set aside and funding agencies of the US government announced a round of funding for circumcision interventions. Terms such as 'voluntary medical male circumcision' were immediately introduced and local organizations incorporated this new intervention into their activities to access funding. As much as one cannot dispute the notions of global power and influence, one can neither dismiss the presence of local knowledge, agency and resilience. It is where the two converge that is of interest in this study: the interactions among different actors and how such interactions shape care practices.

Buse and colleagues (2005) provide a conceptual framework for the study of health policy. They argue that researchers should examine the context within which different actors, through various processes, interact to formulate guidelines and policies. The interplay among the various actors happens at the beneficiary (community), provider (facility) and administration (policy/national) levels. The model does not assume unity among actors at one level, but rather a power struggle to influence policy decisions. There are usually contestations and power micro-dynamics among actors within a level.

With regard to whose voice sings loudest when it comes to determining policies and practices for HIV/AIDS care and support, there were contested views from different key informants in my study. Most participants from international NGOs and bilateral organizations felt that the community of people with HIV/AIDS adequately participated in the processes. However, NZP+, the largest support organization of people with HIV in Zambia, felt that there were inadequate forums for the meaningful and effective participation of people with HIV and their communities in the policy-making process. One person from NZP+ at a focus group discussion in Lusaka said: 'I think it is the people at the higher-level meetings who determine how counselling is done. … In as much as they say they are going to the community to do consultative meetings, at the back of their minds already they have sat down and decided. … There is a need to see donors helping local organizations or communities to participate effectively'. Another person in the same discussion said:

> I think it is the people who have the money that make decisions, and we have seen that happening a lot in our country – so once money is given you have to adhere to certain rules and regulations that they would want you [to do]. Because, for them, they also have targets and they would indicate to us that they would want to meet those targets, so whether we like it or not we need to follow certain things. But even to our interests we will be able to

> say I think we did not do it in the right way. But because we want that money, we want to help people in a way, whatever way and however small, [so] we will follow what those people are telling us. So really I think it is more to do with people that have the muscle, the people that have the money … but we are hoping that it will be able to change. And there are some signs that things may change if you look at the Sixth National Development Plan, and how the government is trying to negotiate for some aspects of care. I think we have seen a positive situation where we have seen donors who have been able to adhere to what the community wants; now donors are buying into – whether it is the NASF[3] or whether it is the Sixth National Development Plan – and also donors buying into strategic plans to some extent, but not all of them, just some flexible ones. Others you have to follow because they are the ones that are giving you money.

Through workshops and knowledge-sharing avenues like technical working groups,[4] transnational actors create discourses that work to structure the activities of local-level actors. It is this production of meaning – although applied in specific socioeconomic, cultural and political historical contexts – that has partly shaped HIV/AIDS care and support practices (Pishchikova 2006; Buse et al. 2005). As Buse et al. (2005) note, such policy making is rarely a rational process; instead, it is iterative and affected by the interests of the actors involved (see also Alaszewski and Brown 2012, Behague et al 2009, Lee and Kirkpatrick 2006).

The Context

In response to the growing challenges associated with the HIV/AIDS epidemic – and pressure from the WHO and UNAIDS – Zambia adopted a multisectoral approach in the early 1990s, which resulted in different models of care and support being implemented by different sectors and actors (MOH & NAC 2008). This has been done through the involvement of multiple actors to provide a continuum of care for people affected by HIV/

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[3] National AIDS Strategic Framework

[4] Technical working groups are organized by the Ministry of Health, Ministry of Community Development, Mother and Child Health and National HIV/AIDS/STI/TB Council along different health thematic areas and draw their membership from the government and NGOs implementing related activities.

AIDS, including governmental bodies and NGOs. NGOs also include community-based organizations (CBOs). In the multisectoral approach, various actors provide different models of care and support, which allows for comparison and experimentation.

National data illustrate a remarkable expansion in the delivery of HIV/AIDS services in Zambia since 2000. Voluntary Counselling and Testing (VCT) and Prevention of Mother-to-Child Transmission (PMTCT) programmes were piloted in 1999 and introduced in 2000. In 2002, the Zambian government introduced the provision of ART in public health institutions.[5] The country started to extend free HIV treatment in public facilities in 2004, twenty years after the first case of AIDS was officially reported by the state. The many years without treatment saw the skyrocketing of new HIV infections and related deaths, and the arrival of many externally funded interventions.

The number of centres providing ART increased from 156 in 2006 to 322 in 2007 (Ndubani et al. 2009). By 2007, 149,199 clients, accounting for 50.5 per cent of all those in need, were registered and receiving ART (NAC 2008). By 2012, the number of people receiving ART was about 480,925 countrywide, representing 79 per cent coverage (WHO/UNICEF/UNAIDS 2013).

Amidst such rapid scale-up are the inevitable challenges of finding and training sufficient human resources to provide comprehensive care and support for increasing numbers in need of care (Gordon 2008). Many scholars (Dame et al. 2006; Scheider et al. 2006; Lehmann et al. 2009; Wash et al. 2010) have demonstrated the gravity of having inadequate human resources to provide care and support to people living with HIV in resource-poor countries. These studies have called for the transformation of ART delivery models to meet the growing and diversifying needs for care and support, as well as to ease the burden of care on overstretched health workers.

The human resource challenges have resulted in task shifting, which made it possible to have different trajectories of counselling. Prior to the availability of HIV treatment in Zambia, counselling was mainly the preserve

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[5] This was before approval of its Round 1 grant from the Global Fund in 2003, and it adopted a policy to provide free ART services to eligible patients prior to the arrival of the funds.

of health staff (nurses, clinical officers and doctors), with limited assistance from trained lay counsellors and, in isolated instances, psychiatrists. As treatment became available, more people responded to interventions related to HIV testing and the initiation of treatment. This resulted in swelling numbers of people who needed different types of counselling. The volume of clients for VCT increased and so did the number of clients that were being put on treatment, who required adherence and eventually reproductive health counselling. International NGOs (CIDRZ and ZPCT) as the main ART providers engaged more and more lay counsellors for VCT, adherence and other types of counselling. As HIV/AIDS counselling was devolved from health staff to lay counsellors, it became possible to pay attention to the emerging counselling needs of people with HIV who had been on treatment for a long time, and whose counselling needs had evolved from dealing with the trauma of HIV diagnosis to other needs that included how to navigate sexual relationships while on treatment, and reproductive health and family planning. These counselling needs could only be met by a cadre of staff who had more time and training to attend to them.

Despite significant gains in prevention and treatment over the last decade, HIV/AIDS continues to be a global concern (WHO/UNAIDS/UNICEF 2011). The geographical distribution of the disease has been highly uneven. By 2010, sub-Saharan Africa had the highest number of HIV infections and AIDS-related deaths worldwide (WHO 2012). This is despite the high influx of funding, including HIV treatment, which started flowing to most African countries, including Zambia, from the West in the mid-2000s to contain the epidemic (Oomman et al. 2007; Ndubani 2009).

Zambia, like other countries in sub-Saharan Africa, has received enormous financial and technical resources to help prevent new HIV infections and provide care and support for people with HIV from its ‘cooperating partners’ in developed countries (Oomman et al. 2007; Ndubani 2009). Such a high level of resource infusion has introduced multiple actors and agencies to the Zambian HIV scene. This interaction of internal and external actors has and continues to shape the way HIV/AIDS services are provided. Local structures of care and support for people with HIV-related illnesses have been internationalized as different organizations have emerged to implement HIV/AIDS programmes in diverse Zambian settings over time. Although I use a historical lens to understand how HIV/AIDS care has evolved, my ethnography focuses on the funding agencies, international implementing agencies, local NGOs and people with HIV and their networks during the present HIV-treatment era. I examine the constellation of these actors and their interactions, and how such interactions shape care practices in HIV treatment.

The incurable nature of HIV has led to emotional and other stresses that come with terminal illnesses, requiring continuous care and support for people infected and affected.[6] While many acknowledge that people with terminal illnesses like HIV are in need of ongoing care and support (Mwewa et al. 2013), the specific needs of specific groups of people can only be understood in their context and time. Although HIV counselling is generally acknowledged as part of the continuum of care and support for people with HIV (WHO 2004), there are different counselling needs for different people at different times and in different environments and spaces. In this dissertation, I focus on how HIV/AIDS care and support, mainly through psychological counselling, has evolved, and how different national and local actors have played a role in this transformation.

HIV/AIDS Counselling in Zambia: A Brief History

Before there was treatment for HIV in Zambia, counselling was a prevention strategy aimed at raising awareness to avoid infection and providing psychosocial support to manage stress, including living hopefully despite impending death for those infected. Counselling was particularly important in so-called Voluntary Counselling and Testing (VCT) programmes, which were introduced in 1999 in Zambia. People needed to be prepared for learning that they were HIV positive at a time when treatment was not yet available. If they tested negative they needed to be told what to do to stay negative.

The provision of free HIV treatment at public facilities was first piloted at general hospitals in two sites, Lusaka and Ndola, in 2002. Expansion to the national level was not initiated until a presidential pronouncement in 2005. By 2004, a number of international agencies were already designing parallel interventions, in 'consultations' with government, to scale up access to HIV treatment, which without subsidy would be too expensive for the majority

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[6] People 'infected' are those people living with HIV (PLHIV) or AIDS while those 'affected' include PLHIV and those without HIV who have a friend or relative with HIV.

of Zambians. The International AIDS Alliance, with funds from the European Union and USAID in 2004, started implementing interventions at the community level to educate and mobilize people for treatment ('treatment literacy'), and at health facilities to provide support and referrals to people seeking testing and treatment, and to provide HIV medicines. The project was to provide treatment for two hundred people living with HIV. Slightly earlier, CIDRZ had started providing HIV counselling and treatment services in public health facilities with funds from the United States government.

Due to the large amount of funding from CIDRZ and their relationship with the Lusaka District Health Management Team at the time, CIDRZ was allowed to choose in which health facilities to work in the district. In fact, the implementation of activities by International AIDS Alliance and its partners could not begin in 2004, as they were not assigned a health facility where they could provide free treatment until one year later. They were told to wait for the construction of an HIV-treatment wing at one facility (N'gombe Clinic), which was not completed until three years later. As a result, they negotiated to start providing HIV treatment at the University of Zambia Clinic, a quasi-government clinic near N'gombe. This display of power by some agencies over others has partly shaped the landscape of HIV/AIDS services in Zambia.

Until 2004, HIV treatment was elusive in Zambia. The emphasis of counselling, particularly for PLHIV, was on providing therapeutic support to accept their situation and hopefully live longer due to acceptance and the adoption of certain prescribed behaviours. In the context of counselling sessions, more skill and time was usually required for counsellors to deal with a seemingly hopeless situation. Thus the pioneers of HIV/AIDS counselling in Zambia were psychiatrists and public health specialists. Most of these were long-term experts who had been working in Zambia in related areas, and some of them were affiliated with mission hospitals. As the National AIDS Council (NAC) acknowledges, community- and home-based care for the chronically ill, which later was extended to people with HIV/AIDS, evolved as a religious response in the late 1980s (NAC 2007; Iliffe 2006). When the first team of experts was constituted at the University Teaching Hospital, a number of people from the church were involved, including Father Kelly, a Catholic priest, who, together with others, later founded the Kara Counselling and Training Trust. This was the first NGO to provide HIV/AIDS counselling services in Zambia.

When HIV/AIDS counselling started in Zambia, the focus was the family, which was already the focus of most church activities, and also in line with existing social norms in Zambia that held the family as the primary institution for providing care during illness. Counselling focused on helping the individual and those affected to cope with an illness or situation, partly in the form of prescribing behaviours that were thought to help a person cope with a difficult situation. As a 76-year-old informant, and ethnomusicologist, put it:

> the meaning … of counselling is to make the sick person conform to something that is going to bring normalcy to what is wrong, but since he is not the only one who is there, counselling is always held in a group with other members, to show that the family is also obligated to see that this person adheres to this counselling. If the person that does not adhere to counselling, they say, 'they are foolish' [*ala fipuba*], they don't say 'he is a fool' [*ala cipuba*]. They say 'they are foolish', and this is where part of the difference comes in. Where now you only counsel one person and it is private counselling, that private person goes to live with people in the home but is the only one who has the information. How do you expect help from other people to be given to this person? Because you only dealt with one person, the knowledgeable person is the one who is sick, and he is so sick on the bed that he can't do anything for himself.

During the pre-HIV-testing era, the emphasis of counselling was to manage the crisis brought about by AIDS without reference to HIV or AIDS. When HIV testing technology became available, counselling evolved to incorporate an assessment of an individual's readiness to receive results, and to manage the crisis introduced by the knowledge of one's status. During the post-testing/pre-HIV-treatment era, the objective was to encourage HIV testing as a preventive measure against new infections, and to help those testing positive to come to terms with their newly known health status. With no possibility of treatment on the horizon, crisis management skills were required to stabilize those infected. For those not infected, the emphasis was on how to maintain a negative status. In both cases recipients of HIV counselling were responsibilized, through a set of instructions, to avoid spreading HIV infections.

When the rapid test for HIV became available and easily accessible in 2006, HIV counselling evolved alongside the new technology. Because counselling, testing and test results could be done within an hour, HIV counselling was divided into pre- and post-test counselling, usually guided by testing and prevention goals. However, since a cure for HIV remained unavailable, knowing one's status was, and still is, a private and voluntary matter. Thus, voluntary counselling and testing (VCT) programmes started to be used in reference to HIV testing. Because symptomatic HIV and AIDS patients resisted getting tested for HIV voluntarily, public health and medical specialists introduced 'provider-initiated counselling and testing' (PITC) initiatives in the HIV-treatment era to enable people with HIV to access treatment.

As treatment became available, HIV counselling was also used as an entry point and tool to support adherence to treatment. This was later supported by 'treatment as prevention' (TasP) initiatives, driven by HIV-prevention goals; these initiatives were based on the idea that if more people were tested, more could enrol in treatment, which would prevent further spread of HIV. Since treatment could lower the level of HIV in the body to undetectable levels and thus reduce chances of transmission, the goal of counselling to increase the number of people on treatment was still a prevention goal. This need to prevent new infections by putting more people on treatment early was compounded by the need to report adequate numbers to justify the high levels of funding received by funding and implementation agencies. Designers of HIV counselling during this stage of the epidemic in Zambia assumed that 'treatment availability' did part of the crisis-management counselling and thus, the necessary skill level of counsellors' was less advanced, and the time needed to provide counselling could be shortened. With the hope of postponing death and living longer, treatment availability slowly moved HIV counselling from a crisis management tool to a mobilization tool for further responsibilization, via adherence counselling.

This technological breakthrough in treatment has led to people living longer, healthier lives punctuated by occasional illness, and requiring diversified types of care and support. Availability of treatment, while creating a demand for HIV counselling and testing, has also led to the diversification of counselling into different trajectories, which in turn has led to adjustments in counselling protocols, and counsellor recruitment, training and qualifications. However, as people live longer, and relatively 'normal' lives, counselling needs have also become complex, creating a gap in care and support for PLHIV. As this study demonstrates, HIV/AIDS counselling has been transforming, but its different trajectories still manifest local values and concepts of care that were present in the community-driven responses that emerged before care and support for PLHIV became institutionalized in a variety of AIDS treatment and prevention programmes.

Zambia has faced a number of challenges in its efforts to combat and contain HIV/AIDS. Despite the state's and donors' commitment to fighting AIDS, human resource shortages in health care have made it difficult to provide support services such as counselling in sufficient quantities or of sufficient and appropriate quality to the increasing numbers of PLHIV in need of treatment, care and support (Hanefeld and Musheke 2009; Ndubani et al. 2009). More recently, this has been compounded by external funders' unwillingness to fund human resources for health, and their preference to focus on funding equipment and medicines (Walsh et al. 2010; Brugha et al. 2010). This approach has partly transformed counselling, causing it to orbit around prevention and treatment goals whose silently chanted slogan is 'test-treat-prevent'. In the treatment era, less emphasis is placed on the quality of interaction in the counselling room, and more on the number of people who receive counselling and adhere to subsequent HIV treatment.

Conceptualizing Counselling

There are many forms of HIV/AIDS counselling with varying uses and preferences among providers and recipients (McLeod 2012; de Paoli et al. 2002). The different forms and uses of counselling can only be understood when contextualized in time. Generally, HIV counselling has been transforming in both its forms and uses since it emerged in Zambia in 1987 (Simbaya and Moyer 2013; Iliffe 2006; Hall 1990).

Before HIV treatment became available, counselling services focused on the prevention of new infections and psychosocial support. Following an increased number of deaths related to AIDS in the late 1980s and 1990s, public health authorities realized the need to focus on 'the new disease' – HIV/AIDS – and develop counselling services for those infected. Counselling therefore needed more skill and time. Training of HIV/AIDS counsellors started in 1989 and by 1990, counsellors in provinces were trained to provide training to would-be HIV/AIDS counsellors. In 1996, the Zambia Counselling Council was established to provide oversight to and regulate counsellors, particularly those involved in HIV/AIDS counselling. Triggered by the international focus on preventing infections among newborns, as underwritten by the WHO, Zambia launched and established the Prevention of Mother-to-Child Transmission of HIV (PMTCT) programme in 1999.

In the new millennium many different counselling policies and guidelines emerged. In 2001, for example, CIDRZ, affiliated with the University of Alabama, started providing PMTCT services using their own counselling guidelines. WHO counselling guidelines came to be adapted by the Ministry of Health in 2007, following adaptation of general VCT guidelines in 2006. By 2012, most health facilities were using CIDRZ guidelines on adherence counselling (see Chapters 4 and 5). Child counselling guidelines, developed with the assistance of 'cooperating partners' were adopted in 2011 (NAC 2011). By the close of 2012, the Zambian Ministry of Health adapted the WHO guidelines for couples counselling.

The Research

This dissertation documents a history and transformation of HIV/AIDS care and support, mainly through counselling in Zambia. While some studies have documented the increasing role of and justification for lay counselling in Zambia and elsewhere (Walsh et al. 2010; Wools-Kaloustian et al. 2009; Cohen et al. 2009), this thesis adds to the debate by examining how the different actors and agencies involved in HIV/AIDS care have interacted to shape counselling policies and practices.

Drawing on a rich ethnography of HIV/AIDS counselling, including both 'official' counselling in institutional counselling rooms as well as 'informal' counselling as observed in interactions in and outside the clinic, I show that HIV/AIDS counselling has been transformed. While HIV/AIDS care practices have evolved around programme prevention and treatment goals, this dissertation makes it evident that it is the friction between actors that has shaped care practices. As such, while HIV/AIDS care and support in general and HIV/AIDS counselling in particular have been transformed, in the individual trajectories of counselling, the local concepts, values and elements of care are still present.

In this thesis, I approach counselling as both an existing and travelling technology that is used differently by different actors, and one that shifts over time depending on time and context. I present and analyse narratives of differently positioned people and show how meanings are co-created by providers and recipients of counselling and what the different trajectories of counselling mean to the different actors. Finally, I demonstrate how international actors have interacted with local actors, and how together they have shaped the shifts in HIV/AIDS care and support. These shifts are then related to changes in medical technology, (inter)national political will, and the epidemiological maturity of the disease.

Theoretical Concepts

This dissertation builds on existing theoretical concepts. As mentioned, the main theoretical concept that stitches the dissertation together is that of *friction* (Tsing 2005). I show how HIV/AIDS care practices are defined and mediated through the collision and negotiation of ideas resulting from the interaction of different actors. In those interactions, care practices are negotiated and new forms are created. I look at the full range of actors and their interactions at the community, provider and policy levels using a multilevel perspective.

Through a diachronic approach, I analyse how actors and contextual factors have influenced changes in practices of care and support for people with HIV/AIDS. The actors studied in this dissertation include people with HIV and their support groups and networks, relatives and friends of people with HIV (community members), HIV/AIDS counsellors, community care givers, community-based organizations (CBOs), and local and international NGOs. Other actors are clinical staff, national-level governmental institutions and officials, counselling-training institutions and external donors, and bilateral and multilateral organizations. These actors interact within a context, time and space, and, through processes of friction and negotiation, determine HIV/AIDS care practices.

The evolution of care and support practices for HIV/AIDS has also been shaped by other factors beyond human and institutional. I refer to these as ‘contextual factors’ that include the scope of the HIV/AIDS epidemic at a particular time (in terms of people infected and affected and in need of counselling services); financial resources available for the provision of services including medicines; available human resources to provide care and support; and other situational, cultural, structural and exogenous factors (Buse et al. 2005).

In addition to these contextual factors, technological innovations like the rapid HIV test and ARVs have significantly shaped care and support practices. When rapid testing, which enabled HIV test takers to receive results within minutes of having their blood drawn, became available counselling was transformed and reshaped around the antibody test. This resulted in pre- and post-test counselling. Pre-test counselling focused on providing HIV/AIDS information, preparing people for the test and assessing readiness for the test. Post-test counselling focused on assessing people's ability to receive results, especially HIV-positive results, before breaking the news.

Although changes and advancements in technology have been transforming HIV/AIDS counselling, counselling recipients and providers have also shaped the practice. As observed by other researchers, practices are adaptive systems shaped by the interaction of different agents (Rhydderch et al. 2004; Crabtree, 2001; Plsek et al., 2001). I view the transformation process in HIV/AIDS counselling as partly shaped by the ongoing interactions and negotiations among different actors in a space characterized by non-linear dynamic processes. Pragmatic responses by local agents are often overtaken or even influenced by external forces and context and vice versa.

In the Zambian situation, for example, international organizations introduced counselling models that challenged the already-existing pragmatic approaches to care that were perceived by communities to be locally and culturally appropriate. This led to transformation in care and support practices in line with international guidelines, but with traces of existing practices of care still present. In this adaptive landscape, co-evolution took place in which actors, both local and international, were not only adapting to the milieu, but through their agency were shaping the landscape (Miller 2005).

I analyse the discursive practices of involved organizational actors, tracing their different perspectives on issues, and attempt to define the premises around which these discourses are constructed and deployed (Vasconcelos 2007). As some researchers (Tovey and Adams 2001; Woodman 1989) note, there is often a tendency to look for areas of similarity between a practice's aims and those things that must be done to satisfy external agendas. On the other hand, local actors claim culturally appropriate approaches to care and support and exercise both support of and resistance to externally introduced forms of care and support. The complexity of care practices is best understood from these *multiple perspectives* (Stange et al. 2001). I therefore use a multilevel perspective in an attempt to gain a holistic understanding of how the HIV counselling agenda is set and to integrate the perspectives of actors at different levels into a coherent whole (van der Geest et al. 1990), in order to unravel the transformation of HIV/AIDS care and support practices in Zambia.

Zambia has not only liberalized its economy – it has also liberalized its health care, allowing for local and international NGOs to play important roles in the provision of care and support. While local pragmatic responses emerged in the early years of the epidemic, national and international NGOs as well as bi- and multilateral organizations have been transforming agents, as care and support practices accompany the funding received from outside to implement local care and support interventions for HIV/AIDS. These are sometimes met with resistance, as this work shows, resulting in existing local forms of care being present in new technology-led forms of care. Thus the local scene is decorated by a constellation of local and transnational organizations that shape the care and support landscape through constant frictions and negotiations.

Structure of the Dissertation

This dissertation is organized into four parts. Part I (The Research) consists of Chapter 1, which introduces the study's main focus and the theoretical concepts used, and Chapter 2, which presents an overview of the methods used to collect data. In Chapter 1, I explain my use of a multilevel perspective to understand the views and interactions of different actors. In the complex group of local, national and international actors, each actor shapes the others' care practices. I argue and demonstrate that pre-existing and resilient local forms of care interacted with guidelines from 'outside' to shape international guidelines, which were later institutionalized through transnational bodies. The friction between these actors and their concepts and practices results in the emergence of new forms and practices that are shaped by both the pragmatism and agency of local actors and the knowledge of international agencies.

Part II (Ethnography) is an ethnography of counselling within a clinical setting. Chapter 3 presents a 'thick description' of counselling at Chelston Clinic in Lusaka, describing the practices there and highlighting inequalities in accessing care in urban spaces. The chapter sets the tone for exploring the history of care practices in Zambia and discussing HIV/AIDS counselling in policy and practice.

Part III (History) details the Zambian history of care and support and shows how local and international actors interacted to shape HIV/AIDS care and support in general and HIV counselling in particular. In this section, I present a history of HIV/AIDS care giving, including counselling, and show how ARV medicines have not only changed the management and treatment of HIV and AIDS, but have also contributed to the transformation of care and support for people with the disease. The section demonstrates how friction among actors has transformed care giving for people with HIV/AIDS in Zambia. While key elements of care and support as prescribed by the World Health Organization are present, local concepts and values continue to suffuse care practices, demonstrating that it is friction between actors and concepts rather than external imposition that has shaped HIV/AIDS counselling.

Chapter 4 focuses on community-based forms of care giving that have emerged and evolved over time, and details their evolution and 'integration' into the health system in Zambia. This chapter examines how patients' needs and caregivers' roles have evolved in the last twenty-five years, evolving from hospital-based home care to community-based care, before transforming once again into hospital-based community care. It demonstrates that care giving has been shaped by both actors and technology, shifting the roles of caregivers from traditional physical and psychological care of bedridden patients in their homes to the monitoring of clients' adherence to HIV medicine regimens alongside overall changes in home-based care models. I argue that current forms of care, where hospital-based volunteers go out to the community to trace 'treatment defaulters', draw on pre-existing forms of care that were part of the early pragmatic responses to the HIV/AIDS epidemic.

Chapter 5 brings the focus to counselling, presenting a history of HIV-related counselling practices and how they have evolved since emerging in Zambia in 1987. Initially, the goal of HIV counselling was to provide psychological support to the dying and their families, but as knowledge about (and treatment for) HIV grew, counselling objectives expanded to include encouraging behaviour change, such as encouraging safer sexual practices and getting tested, disclosing HIV status, encouraging people to begin and continue ART, and shaping the sexual and reproductive choices of HIV positive people. The chapter highlights a number of key shifts in counselling practices in Zambia over the last twenty-five years, and discusses the relationship between those shifts and changes in medical technology, local resilience and agency, (inter)national political will, and the epidemiological maturity of the disease. Chapter 6 examines HIV/AIDS care and support practices in the HIV-treatment era and highlights further shifts in counselling practices and how different actors shaped those changes.

In Part IV (Friction in Counselling Policy and Practice) I discuss policy agenda setting and the difference between policy and practice. Drawing on the ethnographic material in Part III, Chapter 7 shows how both counsellors and their clients resist guidelines, and examines the contested terrain of disclosing HIV-positive status. This ethnography shows that while disclosing HIV status has long been seen as a tool for fighting stigma, non-disclosure is a way of protecting reputation and moral dignity, and should be understood as a practice of stigma management.

Chapter 8 examines models of community engagement and highlights the contestations in the HIV/AIDS policy landscape. It shows how local, national and international actors in this landscape of HIV/AIDS care interact to shape policies and guidelines, and demonstrates that this process is neither linear nor unidirectional. By highlighting the micro-dynamics of power, I draw attention to the workings of local agency and the resilience of existing forms and practices. I conclude in Chapter 9 by drawing together insights from the preceding chapters, and reflecting on the main issues and their implication for policy, practice and further research.

CHAPTER 2
Methodology

Intentions

Leaving Amsterdam in April 2010 to do my research in Zambia on the evolution of counselling, I was mainly concerned with how counselling was provided, who provided it, and how it was viewed and used by both providers and recipients. I was also particularly interested in how the practice was shaped by different actors, both from abroad and within. This interest stemmed from the earlier observations (Ndubani et al. 2009) that Zambia was becoming a site for the international convergence of AIDS funds. What was the history of HIV/AIDS care and support and how did it evolve? Could this inflow of funds for AIDS control have come with guidance on how to provide different services for people with HIV without regard to context? How was counselling shaped by the different providers and users and with what intentions?

I spent more than two years searching for answers to these questions. As I observed – my main research method – I came to realize that each scene existed within a multi-layered and interrelated context. So that I could contextualize my observations within a larger perspective, my fieldwork was extended to last more than two years from May 2010 to September 2012 (see Fetterman 2010).

Getting Started with the Research

Ethical conduct of ethnographic research does not begin and end with obtaining a document from an institutional review board or an ethics committee. I committed not only to the long and taxing effort of obtaining bureaucratic approval, but to following ethical standards throughout my research process, continuously reflecting on the ethical dilemmas that emerged in the field where I was examining care infrastructures surrounding a highly stigmatized disease.

Zambia has a two-tier approval system for anyone to carry out research in the country. For health facility-based research, additional approval from the district health office is required to access any public health facility. The first step is to get one's research ideas approved by one of the four research ethics committees. The challenges I encountered in getting permission to carry out my research opened my eyes to examine more closely the ways various organizations, both local and international, influence the policy process in Zambia. When a microbicide trial in Mazabuka, southern Zambia, conducted by the Microbicide Development Programme failed in 2010, it sparked a controversy that led to a ban of all research on human subjects by the Zambian Ministry of Justice. The justice ministry instructed the health ministry to suspend all human subjects research until a research bill was drafted, passed by parliament and enacted, to ensure proper oversight of researchers and participants.

Following the ban, larger research organizations, mainly international and transnational organizations, managed to get the ban lifted within months despite the lengthy roadmap envisioned by the state. This was achieved through conscientious and strategic use of relationships with the relevant branches of the state. Using the working groups of the Ministry of Health and National AIDS Council, government 'partners' were able to get the ban lifted. A lot was at stake: organizations like CIDRZ, Clinton Health Access Initiative (CHAI), Zambia Prevention, Care and Treatment organization (ZPCT) and others, all with funding from different sources, including CDC and USAID, had many studies being implemented. Not only were these organizations involved in funding HIV/AIDS interventions, they were also the main providers of ART in most of the health facilities, and a large component of their work involved research. During the ban, extraordinary meetings were convened among the leadership of these powerful research-oriented organizations and key members of government to chart a course to lift the ban, and indeed, the ban was lifted within months. Representatives of international organizations used forums in which they were already members, such as the technical working groups at the National AIDS Council and Ministry of Health, and other avenues to strategize to get the ban lifted. In addition to letters of appeal written to the Ministry of Health, meetings were held with the relevant officers within the ministry, including the director of public health and research directorate and the permanent secretary. All these efforts resulted in the lifting of the ban by the end of 2010.

By June 2013, the proposed research bill had not yet been enacted, yet research was continuing apace. The power of international organizations to come together and find a way to effect change through negotiation with the state was again observed toward the end of my fieldwork. The Centers for Disease Control and Prevention (CDC) had funded a study of what was called the 'most at-risk populations' (MARP), which included sex workers and men who have sex with men. According to Zambian law, both sex work and men having sex with men are forbidden. As such, the government has not only put a ban on such practices, but also on research on them. Driven by the desire to provide a holistic prevention package, international organizations involved in AIDS control target MARPs as they are assumed to contribute to HIV infections. But the Zambian ethics review boards would not approve or even review research protocols that related to men who have sex with men.

Sometime in 2012, I was requested by the Population Council, an international NGO in Zambia with headquarters in Washington DC, to lead a mapping study for men who have sex with men. The objective was to determine the existence and prevalence of men who have sex with men in Zambia using snow-balling sampling methods, in which each person interviewed recommends other people to contact. As the Zambian principal investigator, I put the protocol and documents together and applied for ethical review from the University of Zambia institutional review board (Humanities and Social Sciences Research Ethics Committee). Just looking at the title of the study, the committee refused to review the study and 'put a nail in the coffin', arguing that such practices as men having sex with men are illegal in Zambia and therefore could not even be studied. The committee members anonymously agreed not to even review the study.

Having met that same roadblock, the CDC and its partners, in a technical working group as part of the National AIDS Council, immediately initiated negotiations with the government to be allowed to conduct studies among men who have sex with men. By the time I finished my fieldwork in 2012, the government had not yet yielded to their requests. But in 2013, I learnt that the Population Council and the CDC had achieved some success, and had managed to convince the government to allow them to implement the studies.

From this encounter, I noted the proactivity of the government as a custodian of national health, able to ban all research with human subjects and all research on men who have sex with men, when they noticed a problem or thought a particular line of research was not in line with their government priorities or interests. On the other hand, as a collective, the group of different international organizations was able to exert their influence to get the bans lifted. Thus the friction between different actors, and how such friction defined what got to be done, was evident from very early on in my research.

When I applied for ethical review of my PhD research, there were four research ethics committees in the country, three of which were hosted by public institutions and one of which was private. Interestingly, the private ethics committee was owned and chaired by the head of the public biomedical ethics committee. Considering the sensitivity of the subject, my study sites and methods, I was concerned about the legitimacy of the private committee, particularly when applying for approval to conduct interviews and observations at public health facilities, including observation of counselling sessions. This influenced my decision to apply for review at the University of Zambia's Humanities and Social Sciences Research Ethics Committee.

Contrary to my fears that the committee would not allow me to observe counselling sessions, the issues raised in the first round of comments was mainly around access to the support groups for PLHIV. When I met with the chair of the committee to receive feedback and seek clarification on some of the issues raised by the committee in the letter they had sent to me, the Irish priest and lecturer of ethics who had been serving as the committee chair since the committee was established, sat with me in his office and explained: 'You see, the committee is concerned about you just intruding into the private space of PLHIV. "Who told you we are living with HIV?" they may ask. These issues are at the core of ethics in research. You have to make it clear, if you are going to access people living with HIV through their health providers, that is a different situation and you have to clearly state that'. The other concern, raised in the second review, was that the list of questions I intended to ask were too difficult for clients. This feedback came a month after I had applied and when I addressed the issues, it took another month to get approval.

The next step was to apply for authorization by the Ministry of Health through the Office of the Permanent Secretary, which I did the same day

I got ethical clearance. I received authorization to conduct the study after three weeks and after following up three times and going back and forth between the offices of the permanent secretary, the director of public health, and the research surveillance officer to determine the status and location of the authorization letter. I finally got the letter of authorization on the condition that the permanent secretary was given an annual update of the research progress and that findings would be shared with the office before publishing. This letter and the ethical approval letter were attached to my application to conduct research that was submitted to Lusaka and Chongwe District Health Offices.

Since I was using a multilevel approach, I decided to start with national-level interviews and the review of key documents to get a sense of the policies and guidelines that existed. At the national level, I visited policy makers at the Ministry of Health, the National AIDS Council, bilateral and multilateral organizations and donors, as well as activists and members of network organizations. I sought to gain insights into counselling guidelines and policies and how these were developed, and the agency of the different actors involved. As expected, I had to go several times to some of the international organizations to interview their officers. After almost a year of observations and interviews at the clinic where I conducted the ethnographic research, I followed up with national-level respondents to clarify issues and to comment on the disparate views that existed between policy makers and counsellors.

Accessing Study Locations and Participants

Studying counselling and its transformation in Zambia, one cannot avoid Lusaka, the capital, genesis and centre of HIV/AIDS interventions, and the place where most counselling was happening.

I started asking people for interviews and gathering their views in 2010. These included people who make laws and decisions that affect how things are done at the national level, both from Zambia and from other countries that were providing funding and services related to HIV and AIDS in Zambia. In addition to these, I talked to local, national and community-based organizations providing AIDS counselling and other care and support services for people with HIV. With government offices and officers, I was mainly concerned to learn about guidelines for HIV/AIDS care and support and how these were decided, and to capture the official strand of HIV counselling history in the country. The main government agencies were the Ministry of Health, the National AIDS Council and health training institutions. Multilateral, bilateral and international implementing agencies were also among key national-level informants. They discussed their perspectives on HIV counselling and its evolution, and their role in developing policies, guidelines and practices. To access national-level respondents, I built upon my existing network of people I knew and had worked with, then expanded to their networks through snowballing.

In addition to interviewing people from different organizations, I spent a lot of time at two clinics to observe how counselling was provided and talked to counsellors and the people they counselled. Although I spent some time at Mphanshya Mission Hospital, a rural health facility, I spent much more time at Chelston Clinic in Lusaka. This is a first-level referral clinic that refers difficult and complicated cases directly to the national University Teaching Hospital. At Chelston, I mainly observed three places: the VCT section, the youth-friendly corner and the ART clinic, which are the three areas in the clinic where a lot of counselling was expected. I also spent some time at the maternal and child health section.

Chelston Clinic has been our own family clinic since 2002 when my wife and I moved to stay in Chelston compound, a middle-income, medium-density residential area of Lusaka. Besides the private facilities, which we visit if a family member falls sick and we have some money to pay for care, Chelston Clinic has been our main clinic and therefore my experience with it extends beyond the fieldwork for this study. For the births of four of our five children, my wife has been tested for HIV at Chelston Clinic. I have regularly attended antenatal clinic sessions there with my wife, earning admiration by both nurses and expectant mothers as a model father. This earlier and ongoing interaction with the health facility has provided additional insights, particularly during my fieldwork as it helped me put my earlier observations into the larger research context.

Before I even approached the clinic as a researcher, my brother-in-law and friend had introduced me to the clinical officer in charge of ART at Chelston. In fact, my brother-in-law would often call upon him to skip the line and receive fast services, and would often ‘tip’ him whenever he was able. This clinical officer then introduced me to the nurse in charge of VCT, and so in some ways I was ready to start working even before I got the official 'go ahead' from the clinic's matron. When I arrived at the clinic, the sister in charge[7] looked at my letter from the District Health Office and then brought me to the nurse in charge of VCT, who later introduced me to other staff in the department. Most of these other staff were interns from different training institutions in HIV counselling, including Chainama College of Health Sciences. Within one hour of arriving at the clinic, I was already starting to blend in and start my observations. On my first day, I sat on the desk by the entrance to see how they welcomed and registered VCT seekers. Within one week, I was already helping to recruit VCT seekers and to participate in counselling sessions as an observer.

Initially I was introduced as a 'student of counselling' who was there to learn how counselling was provided. The nurse in charge of VCT often had coaching sessions on Mondays where patient–counsellor role-plays were performed. During one of these sessions I declared that in fact I was a doctoral student. The following Monday after I had declared who I really was, and what I was there to do, all the people doing role-plays, but one, were very nervous during their performance. One of them said, at the end of the session, 'It's not easy to do this in the presence of someone who has done counselling at the PhD level'. I realized I had not done my introduction well, and then took time to explain that I did not know anything about counselling, and that I was there to learn first-hand how it was provided. This released the tension from the situation, and everyone then was eager to have me to accompany them in their counselling sessions. I was soon overwhelmed and even felt burnt out not only by the continuous counselling sessions, but also by observing the challenging and distressing moments when VCT seekers were told of their HIV-positive status. This eventually was an emotional strain so after nine months I switched back to national-level interviews for a month to pose new questions to my respondents there, and to reassess the existing literature on guidelines and policies in light of my observations of counselling practices.

When I went back to the clinic after about two months, I scheduled my time between the three main sections of the clinic that offered counselling. At the VCT centre, I observed the entire process from the time a person who wanted or who was sent for testing arrived to the time they left, observing

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[7] The sister in charge is the manager, matron and supervisor of all staff at the clinic.

both the pre-and post-test counselling sessions. At the youth-friendly corner[8], I observed youth and even some older people who were counselled by young people on various concerns, but mainly related to sexually transmitted infections and the use of condoms. Some older people preferred the friendly approach they encountered there, and what they perceived as non-judgmental interactions with these young counsellors.

At the ART clinic, I sometimes observed people on the queues waiting to be attended to, but most of the time I sat in the adherence counselling room and observed the volunteers, all people with HIV, talk to people about why they needed to follow the treatment schedule and have enough food so that the medicines could continue working properly. They also asked people whether they or their children skipped their medicine and whether they were eating well.

My last days at Chelston Clinic were devoted to interviewing health care providers, including ART specialists, nurses and counsellors. The interviews helped me to fill the gaps in the observations and informal discussions I had with different providers. Following interviews at the health facilities, I attended HIV/AIDS workshops and HIV/AIDS working group meetings at the MOH.

Workshops and Working Group Meetings as Ethnographic Sites

I took time off from my ethnographic research in the clinic to observe workshops and working group meetings as a participant. My position as Research Fellow at the University of Zambia's Institute of Economic and Social Research gave me additional opportunities to engage in participant observation. While the institute conducts both basic and applied research, due to cuts to research funding from both international and local sources, we have tended to do more applied research, commissioned by local and international NGOs, than basic research. Although the institute responds to calls for proposals, faculty members are also often contacted with invitations to participate in research opportunities.

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[8] Youth-friendly corner is a room or section of the clinic providing sexual and reproductive health services for adolescents and boys and girls in their early 20s who often feel uncomfortable to access them from the mainstream services. The ministry of health encourages all clinics to have a youth friendly corner.

As part of this doctoral research, I decided to follow a national evaluation of the Prevention of Mother-to-Child Transmission (PMTCT) of HIV programme, which brought together most of the key stakeholders in HIV/AIDS care. My earlier work on the effects of global health initiatives on the national health system (Ndubani et al. 2009; Ndubani et al. 2007; Walsh et al. 2010; Brugha et al. 2010a; Brugha et al. 2010b) also sparked my interest in this study. In terms of HIV/AIDS services, Zambia is divided into two regions. The northern region is mainly funded by the US government through the United States Agency for International Development (USAID) and is implemented by a consortium led by Family Health International 360. The consortium is named Zambia Prevention, Care and Treatment (ZPCT), and by the time of my fieldwork the ZPCT was implementing a second five-year phase. The southern region is also mainly funded by the US government but channelled through the Centers for Disease Control and Prevention (CDC). The Center for Infectious Diseases Research in Zambia (CIDRZ) implements HIV/AIDS services in the southern region.

When USAID announced during a working group, which is usually held in the Ministry of Health's boardroom, that they had contracted Population Council (of Washington, DC) to carry out an evaluation of PMTCT services in the northern region, the members of the PMTCT working group, chaired by Dr Kankasa, noted that the CDC was also wanting to do a similar evaluation in the southern region. They further decided that one protocol should be developed for both regions and that research assistants should be trained together, and that the resulting data were to be owned by the Zambian government. The CDC decided to work through the National AIDS Council to identify a local consultant, and two of my colleagues at the Institute and I were identified and awarded contracts to implement the study in the southern region. Later, the Population Council contracted me as a national consultant to locally manage the study, as their principal investigators were based in Washington, DC. As the study brought together most of the key HIV/AIDS stakeholders, it allowed me to observe both formal interactions during PMTCT working group meetings and study planning and implementation meetings, and informal interactions related to the study. These two studies, one in the north and one in the south, extended my ethnography beyond the health facility.

Literature Review

An appreciable amount of time was devoted to reviewing archival material to gain insights into the history and evolution of care and support for PLHIV and to map the HIV policy landscape. I reviewed policies and guidelines guiding caregivers and counsellors, with particular attention to their origin, context and content. Both official publications and grey literature were reviewed to understand what had been documented in my study area.

Observations

Both participant and non-participant observations were employed as the main methodology for data collection. Although everything I encountered during my fieldwork comprised these observations, even what I saw when I took my children to the under-five clinic, I had two main ethnographic sites: the clinic and the workshops and meetings.

At the clinic I observed different trajectories of counselling, and I sat in on counselling sessions delivered by both experienced and intern counsellors. I observed pre- and post-test counselling sessions, couple-counselling sessions, sexually transmitted infections counselling among the youth, adherence counselling and PMTCT counselling. Working in different departments within the clinic gave me an ethnographic vantage point that allowed my research respondents to tell the story and argument of this dissertation through their day-to-day interactions. In order to partially eliminate the inherent influence of the researcher's presence, I spent more than a year observing counselling at the same facility, spending months at each location. This helped counsellors start to see me as part of the institution (Gobo 2008).

In order to observe interactions at workshops and meetings, I needed to be part of the delegations for such meetings. My participation in the two studies at my institute opened doors for me to take part in these meetings and workshops. While I was an active participant, I also exercised an ethnographic ear in order to contextualize the interactions among the different actors relevant to my PhD work.

Interviews and Focus Group Discussions

Interviews were conducted using a multilevel approach. At the national level, policy makers from the Ministry of Health, the National AIDS Council, bilateral and multilateral donor organizations, and activists and members of network organizations were interviewed to gain insights into counselling guidelines and policies and how these are developed and the agency of the different actors involved. At the provider level, ART providers, counsellors and support-group organizations and their members were interviewed to understand how counselling is provided in practice and to supplement and triangulate my observation data. At the HIV-counselling recipient level, PLHIV were interviewed, identified either through the clinic or support groups, to validate and triangulate national and provider level perspectives.

Student counsellors on attachment, peer counsellors from the youth-friendly corner and PLHIV from support groups were interviewed using focus group discussions. These discussions not only provided an opportunity for establishing consensus among study participants, but also helped participants to speak freely and relate their experiences to those of others.

Field Journals

At the end of each counselling session, I retreated to write out the interaction as close to verbatim as I could recall, so that I had a record as close to the actual conversation as possible. Since those seeking HIV counselling are often concerned about confidentiality, I chose not to record the counselling sessions as it would have infringed on the rights of the counselling seekers and possibly negatively affected the counselling services. In addition, listening carefully and writing out the conversation immediately thereafter gave me an opportunity to reflect on the counselling process; I sought to describe what the counselling meant to counsellors and the person receiving it, how each of them negotiated their understanding of what the process should have been, and my reaction to the process. I then presented the journal entry to the counsellor to ensure that nothing was missed or inaccurately recorded. In some cases, this was done before the counsellor started another interview. This was also made possible by an inadequate number of counselling rooms, which meant that counsellors often were waiting with their clients for a room to become available. However, due to the high number of clients on some days, some sessions' records were reviewed after the counsellors had been with other clients.

The Multilevel Perspective as an Analytic Method

Given my focus on the interactions among different actors and how each actor or groups of actors negotiate the meanings and definition of HIV care practices, I used a multilevel perspective to gain an understanding of how the HIV counselling agenda is set and to integrate the perspectives of actors at different levels into a coherent whole (van der Geest et al. 1990). Study of the multilevel perspectives gained through interviews and observation enabled me to understand how interactions in both the history and the present shaped the transformation. Analysing how HIV/AIDS care is conceived and implemented at different levels of social organization helped reveal how the different interests interacted, intersected and competed in shaping the meanings and expectations people attach to HIV/AIDS care. I analysed perspectives of differently positioned people at three levels:

- ***National Policy Level***

  At this level, my focus was on the interactions between national policy-making bodies such as the Ministry of Health and the National AIDS Council, and bilateral organizations, funding agencies and international NGOs. From my previous research at the Institute of Economic and Social Research (INESOR, formerly the Rhodes Institute and later the Institute for African Studies), where I am a Research Fellow, I noticed that international NGOs typically spearhead the formulation of guidelines and other protocols. I therefore set out to analyse the discourses and map how agendas were set at this level. I observed how national-level institutions namely Ministry of Health, the National AIDS Council, and their PMTCT of HIV Working Group interacted with international funding and implementing agencies as well as the United Nations system to shape HIV/AIDS care practices. It was thus imperative that I use a multilevel perspective to gain insights into the formulation, interpretation and implementation of HIV/AIDS care guidelines and practices. The key question here was ‘at this pivotal level of policy engagement, which actors exerted power in the policy making process?’ I chose to study these national-level actors because they represented both political (decision making) and financial power. I used interviews and observations to gain insights into the national policy-level interactions.

- ***Provider or Service Delivery Level***

  At this level I looked at interactions among providers: between NGOs (providing HIV treatment, care and support services) and government health care providers, and between ‘lay’ and ‘professional’ counsellors and other providers. I also interacted with different institutions providing training for counsellors. My focus was to understand how each of these actors influence and are socialized to adopt and adapt HIV/AIDS care practices, and how their preferences are patterned, mediated and institutionalized. This level of actors is a critical link between policy and practice as they interpret policies and guidelines and enact them in service provision. Therefore, the gap between policy and practice was also assessed at this level.

In addition to interviewing HIV/AIDS service providers and trainers of counsellors, I observed interactions at the clinic to understand how guidelines were interpreted and put to use by service providers. The relationship among different providers and the sometimes uncomfortable relationship between providers and clients in the counselling room was critical in understanding the gulf between policy and practice, the resistance to guidelines that were not considered to be resonant with existing forms and practices, and the role played by providers and their clients in the HIV/AIDS care transformation process.

- ***Beneficiary or Community Level***

  In an ideal situation, people with HIV, their families and communities would play an important role in establishing HIV/AIDS care practices. I interacted with 'beneficiaries' during my observations in counselling rooms and in interviews with network organizations for people with HIV. At this level I focused on the competing interests among people with HIV, their support groups and their network organizations. From my previous study on global health initiatives (PEPFAR, Global Fund and World Bank) and their effect on the health system, we found that some of these initiatives were directly funding NGOs without government coordination or oversight. I considered this scenario as likely to socialize people with HIV in particular ways. Thus, I was interested to understand how these direct interactions between external organizations and local communities of people with HIV shaped HIV/AIDS care perspectives at the local level.

This chapter has provided an overview of the methods I used to conduct the study, namely observation, interviews and focus groups, and documentary research. The methods employed were dictated by the data needed and the existing gaps in the data I had at any point of my fieldwork.

Part II

Ethnography

This part sets the tone for the main story of this dissertation. I provide a thick description of HIV counselling practices in the clinic's VCT, ART and Maternal and Child Health Departments, and focus on their counselling trajectories before turning to their historical evolution.

CHAPTER 3

HIV/AIDS Care through Counselling – A Clinic Ethnography

This ethnography examines the different actors and practices involved in HIV counselling in Zambia, and shows how through their interactions, negotiations and friction, some existing forms of care maintain their resilience while new forms emerge. I use counselling as a lens to zoom in on the institutions of care and understand how they transform. In this chapter I present vignettes from counselling at Chelston Clinic as observed during fieldwork in 2010 and 2011. The ethnography describes counselling in terms of who provides guidelines and training, who provides HIV counselling, what trajectories of HIV counselling exist, who the clients are, and how differently positioned actors exercise their agency in shaping HIV counselling practices. By describing counselling practices, I draw out the present HIV counselling objectives and identify the main agents and how they transform and shape HIV counselling in Zambia.

Working as a Research Assistant on a community profiling survey in 2000, in one of the peri-urban settlements of Lusaka, I administered a questionnaire that asked two questions on HIV counselling and testing: Had the respondent tested for HIV? If not, why not? When I asked one woman why she had not gotten tested, she related that one day she and her husband were supposed to do so as a couple, following an invitation by community workers affiliated with the Zambia Emory HIV Research Project.[9] She said that her husband took forever getting ready in the bedroom to go for a test. After she had waited for a reasonable amount of time, she decided to check

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[9] This is an HIV counselling and testing research centre for couples, established in Zambia in 1994 by Emory University of Georgia, USA.

on him and found he had gone out through the window. Back then this was a familiar picture for most couples as well as individuals. Learning that one had a positive HIV status in the absence of treatment was perceived by some as a death sentence. However, with increased awareness of HIV and the availability of treatment, and with testing being a prerequisite for access to HIV medicines, participation in VCT has increased in step with the expansion of counselling and testing services in the country. In many health centres, there are vertical (stand-alone) VCT and ART clinics. This chapter presents an ethnography of counselling as observed in the different trajectories of counselling, and how each is done in day-to-day practice at Chelston Clinic, a peri-urban referral health centre in Lusaka.

About three kilometres to the west of Chelston Clinic is Chainama College for Health Sciences, known for its contribution to the training of health practitioners. Most of the clinical officers and counsellors are trained at this college, including many midwives and nurses. Chainama College started training psychosocial counsellors in 1998 with an eight-week course that aimed to enable students to apply counselling skills specific to HIV. In 2001, an advanced certificate course was introduced to provide supervisory skills to would-be counsellors and this was followed by the introduction of a two-year diploma course in 2003. By 2012, the college had developed a framework for introducing a degree course in counselling.

These changes have partly been precipitated by the demand for HIV counselling in the era of ART. Each training course ends with institutional attachment for students to gain practical skills. Most counselling students at Chainama find themselves attached to Chelston Clinic to acquire practical experience, after which they go on to practice in different centres across the country. In this way, the experience counsellors get at Chelston Clinic goes beyond the clinic to shape the practice in different places. This inspired my choice of Chelston Clinic as an important centre for shaping counselling practices in Zambia as a whole.

At the VCT Corner

When I started living in Lusaka in 2003, my wife and I settled in Chelston, less than a kilometre away from the clinic and Chelston Clinic became our first-contact health facility. However, going there as a patient or guardian of a patient is very different from going there as a researcher. On Wednesday 29 January 2011, around 10:30 in the morning, I walked into the clinic with three letters in my hand: one from the Research and Ethics Committee, one from the Ministry of Health and one from the Lusaka District Health Management Team, all authorizing me to conduct research at Chelston Clinic. Within five minutes of my arrival and meeting with the sister in charge, the head nurse who manages the clinic, I was introduced to the nurse in charge of VCT, Ms Maida,[10] and the clinical officer in charge of ART, Mr Mukalakasye. I was amazed how powerful my letters were and how many doors they opened for me. I chose to start the research in the VCT department. I spent about ten minutes explaining what I was there to do: I was a PhD researcher there to learn about how counselling was provided, and that I preferred learning first-hand by observing all aspects of what was being done. After noticing that interns were not at easy in my presence, I emphasized that I was a layperson when it came to counselling and that I had no idea how it was done and needed to experience it and learn.

Maida took me to a group of young men and women sitting by a second entrance to the clinic, next to the outpatient department that leads to the maternity, VCT and ART wings. Right beside the door was a concrete bench, a table, some cards and a huge book used as a register. There was another bench on the other side of the door where I sat, after being introduced to the five young men and women, three of whom sat on the bench with a table while the other two sat on the opposite side. Soon, a young man in his late teens approached and shyly asked me, '*Bwanji boss, kodi nipano po pimisa?*' (How are you boss, is this the place for testing?).

The VCT reception area is not labelled. Because it is situated at this secondary entrance, it is difficult to know whether a person is there for VCT or passing by to go and access other services. This seemed to be the reason why counsellors were hesitant to welcome every person entering and waited for them to ask first. On occasion they would ask those who seemed to be lost. For this particular client, they waited as he looked around and eventually bowed to me, as I was sitting at the edge of the bench, to ask.

I quickly turned to the lady I was sitting next to, who I later came to know as Nanyinza, in her mid-twenties and single, and told her that there was a client. Nanyinza was one of the counsellors. She referred him to the table

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[10] Most names have been changed in order to ensure anonymity.

across from the bench, where his details were entered into the register and he was told to wait. For a while, I wondered why he was supposed to wait, but could not ask at this early stage of my interaction with the team. Within ten minutes, another client came and went directly to the table and I saw her details being entered into the same register. She too was told to wait for a while. As I looked at her sitting on the concrete bench that stretched all the way along the corridor to the pharmacy, I noticed that there were four others, including the young man who had spoken to me, all sitting there and evidently waiting for something. Soon it became apparent that the counselling rooms were all engaged. After a short while, three of the counselling rooms became vacant and the first three on the waiting bench were invited by different counsellors to start the process. Eventually the other two were invited and left for their counselling rooms.

Nanyinza and I remained at the front desk. Lunch time (13:00) was approaching. I then had a conversation with Nanyinza who told me that most of the counsellors there were from her school (Chainama) and had been there as interns to gain practical experience in HIV counselling. Once these interns come to the facility, they are closely supervised by the two permanent counsellors, including Ms Maida. Initially, each trainee is expected to observe as one of the two experienced counsellors conducts counselling sessions. After the sessions, the intern is given time to ask questions and seek clarifications before they are allowed to conduct their own counselling sessions, which are observed by the experienced counsellors. Due to the large number of people seeking VCT, interns observe one to two sessions on average before they start handling counselling sessions under observation of an experienced counsellor. After being observed by one of the experienced counsellors for about a week, the intern is then left on their own. Due to the large number of interns and the small number of experienced counsellors, Maida had also improvised role-play sessions to help train the interns. Every Monday, she had a meeting with all the interns and observed as they took turns to perform role-plays of a typical counselling session and gave advice, even pre-directing some of the sessions. When they have completed a four-week attachment to the clinic, interns go back to the college with their field reports, which constitute part of the assessment.

By the second week at the clinic, I noticed that on Wednesdays, there was always a large number of people, mostly men, around the clinic. One Wednesday, I asked Nanyinza what a group of people I had seen outside the clinic were doing. Out of curiosity I had counted them: they numbered eighty-seven, and were mostly young men in their early teens and some women who brought their children. Some were standing and others were sitting on lawns, benches, bricks, or whatever they could find. I was amazed at this big crowd, which was surrounding a caravan container located on the eastern side of the main clinic building. She explained that Wednesday was the only day Marie Stopes International conducted male circumcision as well as consultations at the clinic and most of the people I had seen were either there for circumcision or for consultation. Two months after my fieldwork, male circumcision was renamed 'voluntary medical male circumcision' (VMMC), and it quickly became popular as a HIV prevention tool.

The counsellors did not expect many clients as Wednesdays were not very busy days in terms of client inflow compared to Mondays and Tuesdays. Maida came and reminded counsellors that if a client came, whoever was taking the pre-and post-test sessions should not forget to bring me along as an observer and introduce me as a trainee. While she was still talking, a woman in her mid-thirties came in seeking VCT. Nanyinza took her details, made her sign a form and invited the lady to follow her. I also followed and within a minute we found ourselves in one of the two counselling rooms. As we walked to the counselling room, I was very anxious. I had never attended a counselling session as an observer, and I was not sure whether the woman who had come for counselling was going to accept my presence during the two counselling sessions. I was also concerned about ethical issues from two perspectives: intruding on the confidentiality of the woman and her counsellor, and being introduced as a trainee counsellor when I was not.

Although counselling was taking place in many rooms, the spaces were usually not specifically only for counselling. There were only two designated counselling rooms at the clinic, and an average inflow of between twenty and fifty VCT seekers per day. When we reached the room, Nanyinza directed both of us where to sit and introduced me as a trainee.

Nanyinza welcomed the client and made every effort to make her feel at home and stressed the issue of confidentiality, saying that 'what happens in the counselling room remains in the counselling room'. She told the client that whatever was shared would not be heard anywhere and no one other than the three of us would know anything related to the client's visit. She outlined the circumstances under which she was excused from keeping confidentiality, including if a client became suicidal after learning about their status. She also said confidentiality would be broken if we were asked by a court of law to disclose her status in, for example, a rape case. She then asked the client why she had come and what the main problem was. The client responded that she was troubled about the reckless behaviour of her husband and that she needed to be sure that he had not infected her with HIV. Nanyinza then asked whether she had had sex recently with anyone. The client answered by asking the counsellor whether it was possible for a married woman not to have had sex. She said she was sexually active with the husband, but not with anyone else. Nanyinza asked the client what she knew about HIV and AIDS. The client said she knew it was transmitted through sexual intercourse and it could kill. She also said that her husband was sleeping with other women and she was worried he was going to infect her and leave her soon. She added that she knew that contaminated blood through contact or transfusion could also transmit HIV, but was quick to emphasize heterosexual transmission by saying that usually men brought the virus to their wives. She asserted that she was the laughingstock among her neighbours, as they knew about her husband's promiscuous behaviour, and that she was deeply troubled and did not know what to do. Using her checklist, the counsellor asked whether she knew other ways of transmission and when the client could not add anything, the counsellor mentioned other ways of transmission, including vertical transmission from mother to child during pregnancy, delivery and breastfeeding.

The counsellor moved on to ask whether the client knew any ways through which HIV transmission could be prevented. The client outlined many ways and emphasizing faithfulness in sexual partnerships, but she did not mention PMTCT. After explaining about PMTCT, and ascertaining that the client now was adequately informed of all means of transmission and prevention, Nanyinza explained the type of result expected from an HIV test.[11] She said that they could be positive, meaning you have HIV in your body, negative meaning you do not have the virus, or indeterminate, meaning the clinic would not be able to tell you whether you have HIV. After explaining

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[11] The testing procedure recommended by MOH has three stages. The first-level test is the Abbot Determine test. If results are negative, they are reported as such and the testing procedure ends there. However, if the results are positive, a second-line test by Uni-Gold is performed to confirm. If the results are positive, they are reported as positive; if they are negative, then there is a tie and a third-line test, Bio-line, is performed as a tiebreaker. However at times, Bio-line was not available at the clinic.

about the meaning of the different results, the counsellor also talked about the 'window period', which she defined as the period between the time a person is infected and the time HIV is detectable in the body.

'Are you ready for the test?' Nanyinza asked the client. The client nervously respondent that she was ready, and then Nanyinza asked her a series of questions exploring what she could do if she found out that she was positive. After Nanyinza had exhausted her line of questioning, she asked the client whether she had any questions before inviting her to the 'lab' for drawing blood. Testing kits are kept in Maida's office, which acts as both the VCT laboratory and the main VCT room, where Maida assisted with drawing of blood and testing. We silently walked to the main VCT room next to the maternity ward, which was no longer operational as it was under renovation. Maida happily greeted the lady and offered her a seat. Then she looked as Nanyinza drew blood and told the lady to wait on the concrete bench outside the room.

From my readings on counselling, I recalled that Nanyinza was following the prescribed procedure for VCT pre-test counselling, which is to learn about the client's history and assess their HIV/AIDS knowledge, risk and exposure to HIV, and then their readiness to test and receive results (MOH & NAC 2006; WHO 2004; Silverman 1997). However, from the conversation in the counselling room above, even as a layperson, one notices that the woman needed to talk to someone about the husband's behaviour as much as she wanted to learn her sero-status. She needed solutions on how to deal with the situation in which she had found herself, with her 'unfaithful' husband. The counsellor was concerned mainly with her readiness to test. On the one hand, the counsellor was doing what she was trained to do, all in accordance with the objectives and procedures of VCT, but without attention to the real problem that the woman needed counselling for. One of the two main counselling concerns she had was not addressed. On the other hand, perhaps VCT is not the best forum for addressing such concerns. It is noteworthy though that many do not have any other option, or at least options that are known to them. And since her marital problem is related to HIV infection, it may be justified to address such concerns within the context of VCT. However, the skill level of counsellors and the existing goals of VCT programmes, driven by the goal of containing the HIV epidemic through prevention of new infections, do not allow such counselling needs to be met.

As the client waited on the bench, Nanyinza analysed her blood sample using Abbot Determine, an HIV antibody test. Antibody or antigen tests look for antibodies or antigens against HIV; they do not detect the virus itself. When HIV enters the body, it infects white blood cells known as T4 lymphocytes, or CD4 cells. The infected person's immune system responds by producing antibodies to fight the new HIV infection. In this rapid test, the presence of the antibodies is equated with the presence of HIV infection (MOH & NAC 2006). As we sat waiting for results, I was anxious about being present in a post-test counselling session that might have a positive result. I was partly worried about the confidentiality of counselling ethics. Guidelines talk about 'shared confidentiality' in the sense that when the counsellor becomes aware of the results or when the client is referred to other services such as ART and PMTCT, health providers share in the confidentiality. However, in my particular case, such shared confidentiality would extend to me. This made me uneasy and quiet throughout the testing process. I looked out for a single stripe on the rapid test kit, which would mean that the blood was non-reactive and hence there was no presence of HIV antibodies and, interpretively, no HIV. After waiting for fifteen minutes, we were ready for post-test counselling. Nanyinza invited the client to the next room, which had just become vacant. As we started, I noticed the restlessness of the client: she was nervous and it seemed she did not want another second to go by without knowing her results. Nanyinza smiled at her and she smiled back, but her worries betrayed her pretence and her artificial smile disappeared quickly.

Nanyinza started by asking the client whether she could remember what we had discussed in the pre-test counselling session and requested her to echo all that was discussed. The client went through most of the things we had discussed. Then she was asked whether she was ready to receive the results and what she would do in any of the test results cases. 'If I am positive, I will leave him,' she said. She said that if she was negative, then she would be very happy and very careful henceforth. She was then given the option of viewing her results on the paper for herself or having them read to her, and she said she preferred having them read out for her. When she was told that she was negative, she smiled and her face suddenly brightened after a very deep sigh that indicated she had been holding her breath. The counsellor then asked her what the results meant to her. She said nothing would change as she had lived a 'clean' life, but still expressed worry about her husband's behaviour. She said that she could only fully protect herself if she left him, but could not do so due to their children: she didn't know where to take them or how she could care for them. Nanyinza revisited the notion of the window period and advised the client to come back after three months for another test. She then advised her about positive living, which included not worrying excessively, exercising and eating a balanced diet, stressing that a balanced diet did not mean expensive foods like meat, but could be found in common backyard vegetables that were readily available. I then joined Nanyinza in thanking the client for coming, and we all bade farewell.

My first day at the VCT corner was a truly new experience. The power differentials were plainly evident. Nanyinza was in her mid-twenties and the client was in her mid-thirties. Coming to a clinic to seek 'expert' knowledge and a laboratory test already defined the power relationship between Nanyinza and the client. Nanyinza was not only being consulted as a counsellor, but as an HIV 'expert' who could tackle all the client's related issues, including how to go about her marital relationship despite the fact that Nanyinza had never experienced marriage and its problems. This 'expert' knowledge by Nanyinza was ratified by the place from which she was offering it. Practicing counselling in a medical environment gives the counsellor institutional power and authority that weakens the client's power. Nanyinza's drawing of blood and using sophisticated equipment to determine whether the client had HIV further widened the power gap between her and the client. The client was dealing with someone who could tell her news that could permanently change her life. The client's desire to tackle her marital problem was silenced by the HIV 'expert discourse', and while the pre-test counselling session seemed conversational, the post-test session was characterized by information giving and receiving. Most clients were too anxious to speak freely.

This became an everyday routine, but with cases of different levels of sophistication, ranging from refusing to go for treatment to refusing to disclose to spouses. In nearly all the cases, counsellors followed a prescribed path. During the pre-test session emphasis was on four main topics: 1) the client's personal history and risk of being or having been exposed to HIV; 2) the client's understanding of HIV/AIDS and previous experience in dealing with crisis situations; 3) the client's description of previous risk reduction steps attempted; and 4) the client's understanding of what the HIV test is and deciding if the client wants to take it.

These steps are inscribed in the national VCT guidelines (MOH & NAC 2006). Interestingly, few sessions I observed dealt with the third step above. Instead, knowledge about infection and prevention was discussed extensively, and in many cases, counsellors echoed back the correct knowledge the clients gave. Some attention was also given to what the client would do if they found out that they were HIV positive and possible ways of coping with a positive result, including notifying the significant other. The post-test session focused on reviewing the client's knowledge about HIV/AIDS and their readiness to receive results. In accordance with national guidelines, all HIV-negative clients were reminded about the window period and very forcefully invited for another test after three months. In some cases post-test counselling sessions explored a risk-reduction plan specific to the client's test results and personal life situation.

I noted that while guidelines regulate how counselling is offered and enable the provision of uniform counselling to clients, they statically did so even in dynamic situations. In interviews, which I conducted toward the end of my stay at the clinic, counsellors described their best session as one that made choices available for clients to explore alternative solutions to their problems. This 'book definition' (Silverman 1997; WHO 2004) of counselling is what they gave me whenever I asked them what a successful counselling session was. Initially, I tried asking them to tell me what good counselling was, which always produced the same book definition. However, even when I changed the question, and asked them to 'narrate' to me what their best and most successful session was, the general definition was marked by choices for clients. Interestingly, I noted that the most successful counselling sessions were those that ended with a client being convinced to take a particular set of actions. Failure to convince someone to test or 'accept' results was perceived as failure on part of the counsellor. On the other hand satisfaction for clients was found not only in having their questions answered, but in managing to get the counsellor to discuss their issues and providing plausible solutions. Often, a negative test result helped make a counselling session satisfactory.

After observing sessions and role-plays, I decided to volunteer as a client in a role-play session one Monday morning. The counsellor, a female intern in her last week, in fact on her last day of attachment at Chelston, shyly welcomed me to the room and directed me where to sit. She went through the procedural phases of a typical counselling session, and I thoughtfully responded to her questions and raised my concerns. Soon we moved into role-playing the post-test counselling and she told me my results were positive. When she asked me whether I understood what the results meant, I burst into a long uncontrollable laugh and thanked her for telling me. This unsettled her, and she did not know how to proceed. Her memorized procedure seemed to have failed her. After noticing that she had run out of ideas on how to proceed, I bade her farewell and thanked her for the good work they were doing as a clinic, and said that I wished to see her again but it might not be possible. She also thanked me for coming and bade me farewell. This new dimension I added to the session gave Maida an opportunity to explain how to handle such situations. That Monday session lasted about one hour longer than a typical practice session as a Pandora's Box of questions from the interns was opened.

On a Friday two weeks later, I accompanied Siwulapwa, a male counsellor, for a couples-counselling session. Siwulapwa had a diploma in counselling from Chainama College of Health Sciences and was planning to go for his degree in counselling at one of the local public universities. He had been working at the health centre for more than three years and was employed by the Ministry of Health. He greeted the couple in the usual format, and asked them whether they had been tested before as a couple or as individuals. The man answered, saying they had not, while the woman looked down. While the man was very anxious, the wife seemed relaxed and the procedure seemed familiar to her. During the pre-test counselling session, both answered questions asked by Siwulapwa. Whenever the man tried to dominate the session, Siwulapwa tactfully directed the question to the woman. Eventually the session came to an end and the couple was led to the laboratory to draw and test their blood.

After their blood was drawn, they were told to wait by the concrete bench as their blood samples were analysed. Inside the lab, I observed Siwulapwa carry out the tests. After a few minutes, I saw Siwulapwa in a face of wonderment as he gazed at the results. I asked him in a whisper what was the matter, and he told me the results were different. 'They are a discordant couple', he said. Siwulapwa then confirmed both results by doing confirmatory tests, before inviting the couple for a post-test counselling session.

During the post-test session, I was again nervous. I was wondering how the couple, especially the man, would react and whether the session would be successfully handled. I was consoled by the fact that Siwulapwa was experienced and had received training in couple counselling before from the Zambia Emory HIV Research Project, an HIV/AIDS research institution established in Zambia in 1994, whose main focus was couple HIV counselling. He had also boasted to me that he had handled difficult discordant couples before. The post-test session followed the usual format and started by reviewing their HIV/AIDS knowledge. Siwulapwa then asked them whether they were ready to receive their results, and the couple answered affirmatively. They were then asked how they would like to receive the results. Siwulapwa offered them three options: he could read the results aloud to them, he could give each of them their results separately, or he could swap their results and let them tell each other their results. The lady quickly opted for the third option to which the husband nervously agreed.

They both looked down as they read their results and brief moment of silence followed. The man asked his wife: 'What do my results say?' She nervously said, 'Negative. You are fine. What about mine?' The man wrinkled his face in wonder and looked at the paper he was holding in his hand again, then he grabbed the paper from the wife's hand to compare. 'How come?' he asked? 'Your paper shows you are positive'. 'Really?' the wife asked. Then she became silent, but it was not the kind of silence and confusion I had seen before with those who received similar results. I suspected that something was going on. Siwulapwa took time to explain discordance and how that was possible. He also explained how they could maintain their discordance and prevent the husband from becoming HIV positive. I could see that he had difficulties explaining these things. In cases where both partners are positive, it was often emphasized that it was not possible to know who brought the virus to the relationship, and that sticking together and supporting each other was recommended. However, in this particular case, it went without saying that the husband could not have infected the wife and remained negative. By implication, the wife had brought the virus to the family. This put the counsellor in a difficult position. Would he encourage the husband to take a risk and continue using a condom? Would he prescribe 'no sex' but urge them to stay married? I was looking forward to how these questions in my mind would be answered.

Siwulapwa turned to the man and took time to explain how much they needed to support each other. He explained that there are couples that had remained discordant without 'converting' a negative sero-status to positive. He advised:

> Do not think you are risking yourself and therefore must divorce. In any case that is when you need each other more now. Think about this; if you did not get the virus when you were not even aware that she had it, do you think you can easily get it now that you know? So just continue as husband and wife and do all the things you do together. In fact if you are both healthy, chances of getting the virus from her are very slim. There is also treatment for HIV now. We will refer her to the ART clinic here and they will take additional tests. When she is eligible, she will start treatment and will live a healthy and normal life like she has always been.

After this lecture, Siwulapwa asked the couple how they were going to ensure that they did not pass the virus to the husband and the unborn child, if they intended to have one. The man answered that they already had three children and did not intend to have more. He also said they would try to use condoms. The counsellor advised them to think about testing the children to know their status. He also encouraged them to keep testing for HIV every three months. There being nothing more to discuss, the couple bade farewell and left in what seemed to be a peaceful state of mind.

After they had left, Siwulapwa turned to me and said, 'You know, that lady has been here two times before and she knew she was positive. I think she did not just know how to tell her husband'. When I went back for a follow-up visit to the clinic in November 2012, I was told that Siwulapwa was on leave and had started his studies. I called him and asked him about the couple, and he said he was very happy the couple were still together and he felt he did a good job. He said that they had come back twice and requested for him to test them. He said they were still discordant and the woman was not yet eligible to start ART.

At the ART Clinic

Inside the ART clinic *Waiting to gain access* *Fresh air outside the ART clinic*

Figure 1: At the "White house" accessing ART services, 27th July 2011

After having been observing the VCT department for three months, I decided to take a break and see what was going on at the ART clinic. The ART clinic is hidden behind the main Out Patient Department building. To get to the ART clinic at Chelston, one needs to go through one of the two main entrances, and then past the dental department to the hidden building behind it named 'the white house', in a reference to its PEPFAR funding. The 'white house' was usually full and, due to its lack of ventilation, about half of the people sat outside waiting for their names to be called. Once called, they either go inside to have their 'vital statistics' taken – weight and other measurements – and see Mr Mukalakasye, or go to the pharmacy window to receive their medications. I walked through the entrance, negotiating my way through a crowd of people that nearly blocked the entrance to the clinic, as they impatiently waited for their names to be called. Making my way through, I passed through the unventilated corridor with rooms on both sides to Mukalakasye's room, but the door was closed and about ten to fifteen people were waiting to go in, with another five standing by the door. I found my way back out and sat with a group of men and women at the pillars near the entrance to the clinic.

As I sat there, a woman's name was called and a young man in his twenties went in. The three ladies I was sitting next to started talking about the young man and one of them, loudly, as if she wanted everyone to hear, said that whatever happened she would never use a fake name when getting ART. She had a 'black eye' and one of her friends asked her what had happened. She said she had been beaten by her boyfriend, who had just been with her for a couple of weeks and was paying for the house she was living in. She said all hell broke loose when she told him that he had a small penis like that of a baby: he beat her and then moved out. She said she did not know how she would pay rent when it was due. As we all intently listened to the story, one man in his late thirties sitting on my other side turned to me and smilingly asked, 'Can HIV end like this?' I did not know what to answer and as I smiled back and struggled to find words that would offend neither of the two, the man was called and he went to the window to collect his medicines.

This space seemed to be a different space to different people. Some, like in the example above, felt safe to interact and exchange views and opinions and encourage one another. For others, the space was horrific; it was a place they did not want to be seen in or their names to be heard. Some constantly looked down while others did not use their real names. The 'buddy system', in which a client has a close friend or relative help them navigate the system and sometimes collect medicines for them when they are not able to, made it easy for some to use fake names to increase 'confidentiality'. When free HIV treatment became available in 2005, many people's illness had advanced from HIV to AIDS and they were very sick, in some cases, bedridden. As such the buddy system was promoted, mainly by NGOs. People with HIV wanting to disguise their status used this opportunity to use fake names; even if there were people in the ART clinic who knew them and heard them respond when a different name was called, they could masquerade as someone's buddy when in fact they were getting services for themselves. This was also facilitated by the fact that the Zambian health care system does not require identification documents to access the services, except in exceptional circumstances of the few who are under insurance schemes. The only requirement is that clients provide the clinic with a name and address of residence, which are never verified.

After sitting for two hours, I decided to see Mukalakasye, who quickly introduced me to Olin, an expert client. She had been diagnosed with HIV and was on treatment, and was working as a treatment support volunteer for CIDRZ. She was chairing a CIDRZ-funded support group, and was one of the few support group members employed by CIDRZ to provide adherence support to those receiving treatment at the Chelston ART clinic. The clinic is open from Monday to Friday and from 08:00 to 13:00, though the many weeks I spent at the clinic, I never saw the clinic close on time. The earliest they managed to finish attending to clients was 15:00 and usually only on Fridays. Most PLHIV receiving treatment at the clinic come once a month to refill their drugs, have check-ups, and in some cases get their CD4 level tested. One of the things that struck me at the ART clinic was not only the high number of people, but the length of time people had to wait to receive services. Some would spend as many as five hours at the clinic before leaving the facility and this was mainly due to long queues of people. I took advantage of these long queues to listen to conversations and observe people's feelings and perceptions of the services, and paid particular attention to their reaction to the different trajectories of counselling and how they felt about them.

As Olin and I sat chatting about which part of the country my name comes from, Clifford, a man in his forties walked in with his son. I was introduced as working with Olin in the clinic and getting oriented to the work there, and therefore I needed to be present as they discussed. Olin turned to the thirteen-year-old boy and greeted him with a smile and asked how he was doing.

The father then hastily excused the boy and told him to wait outside. The boy went to sit on the bench in the corridor and the door was closed behind him. Olin went through what I came to know as the routine CIDRZ[12] adherence counselling procedure. She asked questions from a semi-structured questionnaire about the boy's health (whether he had fallen ill in the last month), his compliance in taking medicines, his appetite, and what type of foods he had been eating, and marked/circled each corresponding response on the questionnaire. After that she asked the man about whether he had now thought things through about telling the boy that he had HIV. This question led to a discussion that revealed the complicated nature of disclosure and was an obvious case of client resistance, which I came to understand as a form of agency that was present in most of the related cases during my fieldwork.

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[12] The Center for Infectious Disease Research in Zambia (CIDRZ) was one of the two main implementers of PEPFAR-funded ART programmes in Zambia.

The man had lost his wife to HIV-related complications when the child was very young and, due to the child's continuous illness, he took him for testing and the boy was diagnosed with HIV. The child started treatment in 2008, and by 2011 the child had not yet known his status, nor did he know that the medicine he was taking was for HIV, rather than anaemia, as he had been told. The father told Olin that he had not yet told his son. The counsellor aired her concerns that the child was going to school and was obviously learning about HIV and AIDS, and that those who have HIV take medicines every day for the rest of their lives. She argued that it was better for the child to know at that stage. The man firmly said his son was fine as he was, and that when the time was right he would tell him. He continued: 'I am worried about the psychological effect knowing his status might have on him. I want him to continue, knowing he is like any other child. I do not want him to isolate himself when he knows that he is positive'.

Olin argued that, whatever the reason, it was better for the child to know his status, especially now that he was thirteen years old. He countered, boastfully, that he had managed to keep his son healthy and on treatment without knowing since 2008. He was concerned that, since the mother died of AIDS-related complications, knowing his status might make the child worry, remembering his mother's death, and that would not help matters. He said he would determine the right time to disclose to the child and that, as a father, he knew what was good for his son. He related a case of one child who knew his status at an early age and was constantly worried, isolated himself and looked thin and unhealthy. The session was interrupted by a registry clerk who came to find out about the location of some files she could not find, and Olin left the room. The man turned to me and said:

> You see, my friend, I am the father and I know what is good for my son. The problem here is that whatever their donors tell them they want to push it to us. … As long as they are told that you have to do this and that … then they think that is good for us. I am an educated person. ... My wife died when the boy was very young, but I have managed all these years. He started treatment in 2008 and he is fine. My wife died of HIV and I know what knowing his status will mean to him. I can't tell him because he will start relating it to his mother's death and think he is dying all the time. I do not want that to happen.

When Olin returned, she did not have much to say and encouraged the man to continue doing his best to help the boy to eat and stick to his treatment schedule.

This dialogue left me thinking about the contested nature of disclosure. On the one hand, while it is assumed that disclosure makes it easier for a PLHIV to have support, especially in relation to treatment adherence, and may be part of a risk-reduction plan for the uninfected partner, this particular case is different. The counsellor's reasons are that the child needs to come to terms with his real situation early on in life and that it is the norm for someone to know their status. On the other hand the VCT guidelines (MOH & NAC 2006) stipulate that anyone below sixteen years of age is below the age of consent, and counsellors must use their discretion and take into consideration their perception of the child's ability to understand and comprehend the situation before telling them the [positive] HIV result.

In this case, when I went back to the health facility toward the close of 2012, Olin told me that the man and child had stopped coming to the facility and she did not know where they were accessing treatment. Because the counsellors would eventually force the man to disclose, he resisted by finding an alternative ART clinic from which to access medicines for his son.

One Monday morning, I went to the 'white house' and encountered Mr Silozi, whom I had known since 2001. I share a religious background with him and we had lived in the same neighbourhood from 2004 to 2009. In 2004 I joined an international NGO where he was working. So I shared three social worlds with him: religion, neighbourhood and workplace. I started noticing that his health was failing around 2008 when he would have frequent bouts of illness. I visited him a couple of times during one of his illness episodes. During my fieldwork, I noticed that his mother was accessing ART from Chelston Clinic, and I was aware that two of his siblings were on ARV medicines though not from Chelston.

This was the second case I had come across in which several family members were on HIV treatment. The other case was of Nakawala, a woman from the western part of Lusaka who was accessing her treatment from Chelston. She was a divorcee whose husband died from suspected AIDS-related complications after they had separated. Out of her five children, only one was not known to have HIV. Her first child was in her early forties and was on treatment, and her other daughter died of meningitis during my fieldwork. Like the mother, all of her children started treatment when they were very sick. What struck me about this family was that they were accessing treatment from different health centres. When I spoke to the mother about this, she told me that she would not go anywhere near her community, as it would affect her honour. She could not live with the idea that everyone around her knew her status. She said that even her closer relatives, including those who were at the bedside of her and her children when they were very sick, did not know. If they knew, it was something they kept to themselves. They never discussed it. She said she knew her children were on treatment, and she suspected they knew she was on treatment, but they had never discussed it.

When I found Mr Silozi at the ART clinic, he was complaining of fever and I could feel it in his quivering handshake. He was with his wife, who looked very healthy, and it seemed she was there only to escort her husband. I felt uneasy and very uncomfortable. As I struggled to find words to explain why I was there, Mr Silozi quickly said they were there looking for someone. He also said he was 'down with a bout of malaria'. They excused themselves and left. I later heard his name called, but he had already left. I never saw Mr Silozi again for the remainder of my fieldwork. After he left, I started reflecting on the challenges of encountering someone you know when you do not want them to know your HIV status. Early in 2007, Mr Silozi came to my home to use the Internet to do some research on HIV/AIDS. He said that there was a conference organized by a certain Edgar Ngoma and his US partner Boyd Graves where they were going to discuss a newly found cure[13] for AIDS. He said he had already registered for the one-day conference and before attending he wanted to know more about the cure. That evening, he spoke passionately about how a cure was already found and that Western pharmaceutical companies were just withholding it to recover their money spent on antiretroviral research. I was left wondering about the depth of

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[13] The alleged cure was Tetrasil. It was reported that following the one-day conference, some people with HIV abandoned their ARVs and started taking Tetrasil, which attracted the attention of both the state and HIV/AIDS activists. The Ministry of Health made an official statement that Tetrasil had not been proven by any scientific means to cure AIDS, but that it was a known pesticide, which was also used to disinfect swimming pools. Felix Mwanza, one of the HIV/AIDS activists and the leader of the Treatment Advocacy and Literacy Campaign, called on the government to ban Tetrasil, reporting that some people with HIV were abandoning their treatment regimens. This was followed by the state summoning Edgar Ngoma and his US counterpart to appear before a parliamentary committee. The case became silent soon thereafter.

his interest in AIDS medicines, given that his line of work was mechanical engineering. I was only able to connect the pieces together at the ART clinic when I heard his name called.

At the Maternal and Child Health Department

Figure 2: Accessing maternal and child health services, 3rd August, 2011

The Prevention of Mother-to-Child Transmission of HIV (PMTCT) programme is housed in the Maternal and Child Health Department. This was one of the difficult programmes to observe. Most maternal health providers at Chelston Clinic were women, and men were typically only involved in registry work. This made blending in somewhat difficult. Sessions usually started early. Pregnant women coming for the first time in their pregnancy needed to report as early as 07:00 in order to be attended to. The sessions often opened with collective health talks in the waiting room, in which women were bombarded with information on a variety of topics, ranging from cancer and HIV/AIDS to planning for their delivery.

After noticing that I always found the PMTCT sessions half-way finished I decided to go very early. By 07:30, I was already at the clinic. The PMTCT room has five rows of concrete benches, each about ten meters long, punctuated by two passages. On the right-hand side were located two computers, labelled 'CIRDZ', with two people entering women's details. On this particular day, a dark, slim and tall lady in her mid-forties suddenly stood in front of the crowd of women and greeted them. She requested the women to stop making noise and listen. Suddenly the room was quiet and she started talking about cervical cancer, how it affects women and why it was important that they all be screened. She said, 'It is better to know as this disease sits on the engine and if you have a defective one, won't the man run away? This disease sits on womanhood and it is very important that treatment is sought in time'. She concluded her talk by inviting women to come to her table, just in front of the room labelled 'Cancer Screening Room'. Then she sat down, and a young lady in her thirties went and sat on the chair next to the table, and the health worker began recording her details on a laptop before taking the young woman into the room.

Meanwhile, a counsellor from the VCT room walked into the PMTCT room and started talking to the women about HIV/AIDS, asking them questions about transmission and prevention. He spent some time explaining how a HIV-positive woman could prevent passing on the virus to the baby. After finishing his talk, which lasted about thirteen minutes, a nurse wearing a PMTCT apron with PEPFAR, UNICEF, MOH and other logos on it, started giving women papers with unique identifier numbers. Later, their names were added to these papers. After she had finished, they began inviting women to the lab by the numbers they had been assigned, going in ascending order. After blood samples were drawn, the women returned to the room to wait. One woman came to sit next to me after coming back from the lab. She was very outgoing and greeted me and asked whether I had come there with a wife. I told her that I was a student and was there to learn how maternal and child health services were provided. As we continued chatting about the clinic and the huge numbers of people coming there, and how early one must be to be attended to in time, almost all the women returned and were again waiting. Soon after, the nurse appeared and started calling the numbers, and their bearers followed her to a private room. After spending about two to five minutes in the room, the women came back to the benches and continued waiting. I looked at the women as they came back from the room. Each of them displayed different emotions. Some were excited and others were sad or confused. Soon, the lady I was sitting next to was called, and when she came back a while later, she could barely walk. She looked emotionally drained and confused. For a moment, I wondered what we would talk about as she returned to sit next to me. But for some reason, she sat on an empty bench next to the two computers. When I discreetly looked at her about ten minutes later, she was wiping tears off her face as she looked down.

After all the women had returned from receiving their results, the nurse came back and called out some numbers and said; 'If you did not hear your number, go to the next room, if you did, please, come with me'. About a quarter of the women followed her, including the lady I had talked to earlier. After about twenty minutes, the women returned and were directed to the other room to finish off their registration. Curious about what went on inside the rooms where women got their results and later where they went as a group, while the rest were released to do final registration formalities, the following week, I decided to accompany the nurse as she met with the women individually and as a group.

After the women's results were ready, the nurse started calling women individually to the room. The first woman entered and was asked to confirm her number and name. Then the nurse showed her a laminated paper with an illustration of what a results slip looked like and what a mark on each of the three spots (positive, negative indeterminate) meant. After the woman signalled by the up and down movement of her head that she clearly understood, she was given the results. The nurse encouraged her to continue 'keeping herself', and encouraged her to return after three months to test with her husband. After giving results to about thirteen women, the nurse remarked to me that it was a fantastic day, as there seemed to be few women who were HIV-positive on that day. Later a woman in her late twenties came in and the nurse followed the same procedure. When she was given a positive result, she did not appear surprised; it seemed she had already known her status. The nurse told her to return to the main room and wait for her, as she would come to talk to her and give her more information.

By the end of the morning, when all of the women had received their results, there were seven women whose results were HIV-positive and awaiting further instruction. The nurse called the numbers of those who were negative, and told them to go to the next room and complete their registration while the other seven were invited for further discussion with the nurse. It was a very silent moment for most of them. Even for those who seemed to have already known their status, a feeling of shame could be read on their faces, as they looked down and to the side. The nurse explained that their main concern as nurses was the unborn baby. She stressed that the desirable situation was to have a HIV-free baby, and that it was possible but only if they followed the instructions they were going to be given very closely, including delivering the baby at the health facility.

This ethnographic description of HIV counselling shows that, as currently practiced, HIV counselling has many trajectories, requiring different levels of counselling skill. In one clinic many trajectories of HIV counselling may co-exist, including but not limited to HIV testing (VCT), family planning, voluntary medical male circumcision, adherence, and PMTCT. Counselling is also adapted and applied in relation to disclosure, family planning, stigma, breast and cervical cancer and youth-friendly STI counselling. All these are used as facilitative and responsibilization tools with very specific prevention, crisis management and treatment objectives.

In the next chapter I give the historical background to these current practices and how they have evolved over time. Using HIV/AIDS care generally, and HIV/AIDS counselling specifically, I highlight how the institutions of HIV/AIDS care have evolved and what has been at the core of the evolution process.

Part III

The History

Part III of this dissertation provides a historical evolution of HIV/AIDS care. It starts in the early 1980s when the first AIDS case was officially reported by the state to the present time (2012 and beyond). I highlight the main care models during the pre-HIV treatment era, the VCT era and the ART era, with a focus on counselling as care for people with HIV/AIDS. I use this history to explain how HIV/AIDS care practices have evolved and transformed.

CHAPTER 4

Evolution of HIV/AIDS Care and Support in Zambia

Counselling as Compassionate Care in the Pre-ART Era

Care and support for people with chronic illness in Zambia has existed since time immemorial. This chapter examines the intersection of existing forms of care and support with HIV/AIDS care that emerged in the late 1980s. It provides a historical account of how HIV/AIDS care and support, particularly HIV/AIDS counselling, emerged and evolved prior to HIV medicines. Through parallel accounts of HIV/AIDS care and support in general and HIV counselling as a specific form of that care, the chapter shows how both evolved on the scene populated by international and local actors.

Different groups and networks of providers have emerged in the history of HIV/AIDS caregiving in Zambia. While early groups were organized around pragmatic need and a sense of community and Christian duty, these soon transformed in response to guidelines being promoted by emerging global discourses around HIV prevention, treatment and care. How have existing forms of care and support interacted with external forms to shape HIV and AIDS care and support practices in Zambia? Has the emergence and transformation of HIV/AIDS-related home-based care in Zambia been primarily driven by donors and other (inter)national actors? How have processes of institutionalization shaped the ways that home-based care has been defined and practiced over time? How has HIV/AIDS counselling evolved as a form of care and support? I attempt to answer these questions by examining the history of HIV/AIDS caregiving in general and HIV/AIDS counselling in particular and how these evolved prior to HIV treatment. Next, in Chapter 5, I focus on VCT and attempt to map its transformation before continuing in Chapter 6 to discuss how general forms of care evolved once

HIV medicines became freely accessible in 2004, through to the time of my research in 2012. Together, the these three chapters highlight a number of key shifts in counselling practices in Zambia over the last twenty-five years, demonstrating the relationship between those shifts and changes in medical technology, (inter)national political will, and the epidemiological maturity of the disease.[14]

I demonstrate that HIV-related counselling practices have evolved since first emerging in Zambia in 1987. Whereas, initially, the goal of HIV counselling was to provide psychological support to the dying and their families, as knowledge about HIV grew, counselling objectives expanded to include behaviour change; encouraging safer sexual practices; encouraging disclosure; convincing people to test; and shaping HIV-positive people's sexual and reproductive choices. Continued shifts in counselling have been shaped not only by treatment availability, but the interaction and friction of different local and international actors and concepts.

Although the first official case of AIDS was reported in 1984, most agree that HIV reached Zambia in the mid-1970s (Iliffe 2006; Hira et al. 1989; Colson 2010: Simpson and Bond 2014). State-sponsored antiretroviral treatment (ART) for HIV did not become available until twenty years later. During the 1980s and 1990s, HIV prevalence swelled, reaching a high of 20 per cent before dropping to 16.5 per cent in 2001 and 14.3 per cent in 2005 (WHO 2005). These shifts reflect the Zambian response to HIV in the pre-treatment era, which focused on prevention, but could also be attributed to attrition rates resulting from high mortality. While much prevention work was carried out through public health initiatives, a key component of prevention was counselling provided in the context of HIV diagnosis.

I position care related to HIV counselling as a 'travelling technology', imagined, developed and deployed to Africa by public health specialists and HIV health advocates based largely in North America and Western Europe, occasionally with input from African counterparts. This technology brought with it revolutionary ideas about patients, who were configured as having the right to information about health conditions and choice regarding prescribed treatments.

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[14] Part of the text in this and the next chapter has been published elsewhere (Simbaya and Moyer 2013).

Prior to HIV and the introduction of international guidelines, it would have been unusual for a patient with a terminal illness to receive counselling in a health facility. It might have been unthinkable even to inform the patient that the disease was terminal, a psychological burden better shouldered by loved ones. Because HIV counselling, from the outset, introduced radical ideas about the relationship between healthcare providers and patients and about patient rights and responsibilities, I consider it an especially important topic for study. By tracing its emergence and transformations over time in Zambia, we also learn much about the way care models emerge, transform and travel in the company of international aid.

HIV counselling as a national health policy in Zambia found its origins in the late 1980s at the main referral hospital, University Teaching Hospital (UTH) in Lusaka (Peltzer et al. 1989; Hira et al. 1990; Hira et al. 1989). Initial counselling services were set up mainly by psychiatrists and some public health specialists with a focus on crisis management. As the following quotes from two key informants demonstrate, earlier efforts to provide HIV care were pragmatic and led by existing related service providers.

> Personally I have been involved in counselling services since 1987. I graduated from Chainama College as a Clinical Officer specialized in Psychiatric ….. There was a problem of HIV and the mental health [department] had been asked to establish counselling services, and therefore there was need for volunteers to talk about a number of issues concerning AIDS, and so number of us volunteered in August 1987. … We were conducting course after course from province to province until we covered all the nine provinces. By 1990 we had covered all the nine provinces we had started in 1989 February and by the end of the year we had covered all provinces and thus the whole country. – National HIV/AIDS counselling trainer, MOH

> I have a medical background and when I just started as a nurse we saw that there was this new disease in the hospitals, in our wards, which we couldn't understand. Patients would be given medicine, discharged, and three days later they would be brought back. And it was so traumatizing being a new nurse in the late '90s because people would get sick and we did not know what to do with them. ... When I was working at UTH in the medical ward, what trau-

> matized me was that I had twelve deaths in my ward on one night, twelve people dead. And I tried my level best because I was a new graduate. So after that I talked to one of my colleagues and asked what are these people suffering from – because, by the way, in our nursing training really we did not learn about HIV/AIDS in detail, it was just a 'by the way' thing. So we were just beginning to understand it by experience, and it was very difficult even for people to be tested at that time. It used to take even more than one month; if you drew blood for a person to be tested it would take more than a month, and by the time the results came to the ward that person could have died or you might have discharged them. There was no home-based care and they could never come back, so they could have died. … When we received these results, if you had to tell somebody, it was very difficult for us as nurses to tell them. How was I to tell them that this disease that you have does not have any treatment, there is no cure, and there is no hope for you? It was like giving them a death sentence. So at that point I started thinking I needed to have skills on how to discuss [such diagnoses] with these people and disclose to them, and I did my first counselling trainings with Kara in my second year of nursing. – Nurse trained in the early 1990, now working as PMTCT specialist with NAC

As these narratives show, initially HIV counselling services focused on trauma management, largely because there was no treatment. This focus was eventually transformed when treatment became available and the international counselling guidelines began to shift.

However, HIV-related counselling was already being carried out at the time by various community- and faith-based organizations around the country, many of them in home-based settings and involving family members (Chaava 1990; Jordan and Haworth 1995). The initial focus of counselling was to help those diagnosed and their families cope with the psychological burden of a much-feared, highly stigmatised, debilitating and terminal disease with no available treatment. Counsellors also offered advice about providing care for patients at home and attempted to alleviate family-based stigma. With greater knowledge about HIV and its modes of transmission, which was already evident in the late 1980s (Colson 2010) counselling eventually became more concerned with prevention. As HIV-testing technologies developed in the 1990s, counselling came to be divided into pre- and post-test counselling.[15] When initiatives to scale-up ART access began around 2003–2004, the contexts and objectives of counselling shifted again. Treatment scale-up also meant the scaling-up of counselling for HIV testing and treatment adherence, as well as continued counselling for prevention of new infections, which increasingly focused on regulating the sexual and reproductive lives of the growing number of people living with HIV on treatment.

In this and the next chapter I present a history of HIV counselling from 1987 through early 2012. I attempt to present the official historical strand as it emerged and evolved in the context of state HIV care and treatment programmes, while acknowledging that much of the important early work in counselling was carried out by non-state actors. However, this is merely one of the histories, unfolding and overlapping with other parallel histories of counselling. Despite various international and national efforts to mainstream and centralize HIV responses within the public health care sector, HIV services have remained fragmented, with diverse actors providing diverse services in particular places for various periods of time. HIV counselling services are no different and, as such, it would be impossible to provide an exhaustive history. By focusing on the official national narrative, with attention to specific international, bilateral, nongovernmental, and faith-based initiatives that have shaped that narrative, I aim to demonstrate the range of actors contributing to the development of national public health policies and practices of HIV counselling in Zambia. I show that, although Zambian medical professionals and health care policy makers have been concerned with providing psychosocial care and support to people infected with HIV since the beginning of the epidemic, the form counselling has taken, especially since the mid-1990s, has been largely shaped by international testing and counselling guidelines, funding agency directives, project targets of implementing agencies, and objectives of research organizations. However, this does not mean that there was no friction as international guidelines touched down in Zambia. Different local actors exercised their agency, sometimes in subtle ways, resulting in the ongoing presence of local concepts of care in existing guidelines and practices.

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[15] I discuss this more in Chapter 5.

The first phase of HIV/AIDS in Zambia (from 1987 to 1992) saw the birth of hospital-based home care, which later evolved to home-based care. In the hospital-based home-care model, health staff, mainly at mission hospitals, worked with community members to provide care and support to people with AIDS in their homes. The patients' needs during this period included medicines, food, bodily care and emotional support, which partly shaped caregivers' roles. During this phase, we see gradual emergence and involvement of NGOs, mainly faith-based organizations, providing most aspects of care for HIV patients. The government did little to support their care effort. Family and community caregivers emerged as heroes who shouldered most of the care responsibilities in the homes under difficult conditions (Iliffe 2006). In terms of counselling, this period marked the beginnings of HIV counselling, when counselling practices were first formalized in health facilities.

The second period (1993 to 2002) marks the period when international guidelines for HIV testing and counselling were formalized by the WHO and the CDC and found their way to Africa. Voluntary Counselling and Testing (VCT), as it was now formally known, became the standard of care, and counselling offered pre- and post-test was seen as key to prevention. This period also saw the rise of Zambia's national activist network, NZP+, which played an important role in developing support groups, a key platform for psychosocial support. Support groups offered various trainings to their members on 'living positively', which reinforced what they were being told in health facilities. The treatment-literacy component of this training, however, also potentially put people living with HIV at odds with caregivers, encouraging patients to learn about their disease and treatment so they could demand better services. An emerging ideology strongly argued that trained people living with HIV made the best counsellors for those recently diagnosed, as they could offer advice based on personal experiences, while also offering physical proof that life with HIV was possible.

In terms of HIV/AIDS care and support in general, this second phase (1993 to 2002) was characterized by the formalization and professionalization of home-based care through trainings based on manuals endorsed by the Ministry of Health. These trainings targeted community home-based care providers who were already providing care and support through existing community-level home-based care programmes. As the period was marked by the steadily increasing prevalence of HIV and a growing number of acute AIDS cases, the health system continued to be faced with a shortage of in-patient beds and attention was given to home-based care. Although the state gradually became involved in offering trainings and some material support during this period, the Zambian government had yet to issue a regulatory framework for home-based care.

Palliative Care and the Beginning of HIV/AIDS Counselling (1987 to 1992)

This period witnessed a shift in the HIV/AIDS care model from hospital-based home care, when HIV/AIDS patients were provided with care and support services at their homes by hospital staff, to community-based home care. From 1984 when the first case of AIDS was officially reported in Zambia until free HIV treatment became available in 2004, the number of people infected continued to increase, with a large proportion becoming bedridden and requiring intensive end-of-life care. The already-overstretched public health system could not cope with the numbers of patients. As a result, most people with AIDS were sent back to their homes for care while a few were placed in a limited number of chronic care homes, most managed by the Catholic Dioceses of Zambia. Capitalizing on their existing community outreach church programmes, mission hospitals soon started providing care and support to AIDS patients at their homes fairly early in the epidemic.

The presence of HIV/AIDS in Zambia increased both the burden and demand for palliative care. The failing health system, due to economic downturns, led to innovative approaches to care and support for the increasing number of people dying from AIDS in the 1980s. Initially, the care of people with AIDS took place in families and communities. This alleviated not only the suffering of individuals, but also the burden of care on in-patient wards in health facilities. One of the examples of formalized home-based care was the hospital-based home-care model pioneered by Chikankata Mission Hospital under the Salvation Army in the southern part of Zambia in 1987 (Iliffe 2006).

The hospital-based home-care model, which started as an initiative to care for tuberculosis and leprosy patients, was extended to people with AIDS (Iliffe 2006). In this model, clinical staff worked alongside community volunteers to provide care and support to bedridden AIDS patients in their homes. These 'caregivers from below' (Iliffe 2006) initiated a response based on shared social values that was both pragmatic and innovative. The initiative was birthed out of an inability to provide sufficient number of hospital bed spaces for the growing number of AIDS patients. According to those I interviewed, this model was improvised after recognizing that the swelling numbers of people with AIDS could not be managed within the hospital setting given the limited number of beds. Moreover, most of the patients only reported to the hospital when they were very sick, and there was little to offer them biomedically since AIDS was untreatable at the time. This forced Chikankata Mission Hospital to develop its hospital-based homecare programme as a pragmatic response.

It was argued that this model of care, which allowed a mobile medical team to visit patients in their homes, would be cheaper, expand local knowledge, foster family life and allow patients to die in a familiar environment. In this model, clinical staff would discharge patients to their homes and follow up with them to provide treatment of opportunistic infections. They also aimed to mobilize families and communities to support patients. Volunteers from the community (often congregation members of the Salvation Army Church) were trained to provide basic nursing care in affected households. It has been argued that the model placed the burden of physical care mainly in the hands of women while men were expected to provide economic resources (Myslik et al. 1997).

The model was relatively easier to implement in urban areas due to fewer travel costs and staff time (Iliffe 2006). Given costs associated with travel and time in remote areas, travelling clinical health workers were supplemented, in some cases even replaced, by trained laypeople in the community. These non-medical caregivers bridged the gap between medical institutions and family caregivers. It was reported that the initiative reduced the cost by 90 per cent, while increasing contact time between support workers and people with AIDS and their families (World Bank 1997). It is this early involvement of religious organization in the provision of care and support for people with AIDS that laid a foundation for what has now come to be known as 'faith-based organizations' and their active participation in AIDS control initiatives such as Global Fund and PEPFAR (Burchardt et al. 2009).

Thus religious organizations pioneered the provision of care and support to people with AIDS in Zambia. Using professional ideas from mission-related health care services in the early years, and an existing pool of care volunteers mobilized through the church, these mission hospitals were able to provide physical and psychological care for AIDS patients in communities. Later, as the AIDS landscape changed and more funding became available for AIDS care, existing mission hospitals expanded their mission-related health care services in the form of NGOs, in line with institutional structures and demands of international development, mobilizing existing volunteers to provide care and support to people with HIV/AIDS (Burchardt et al. 2009).

From the mid-1990s onward, extensive networks of community members became actively involved in the provision of HIV care and support in Zambia. The influx of external funding aided programmes to expand their coverage and professionalize these programmes (Ndubani et al. 2009; Wringe et al. 2010).

The involvement of religious organizations in the provision of care and support for people with AIDS continued increasing in both form and scale such that by 1993, around twenty mission hospitals were providing hospital-based home care to AIDS patients. The formation of several community-based and nongovernmental organizations, which transferred and institutionalized HIV/AIDS care and support from the family and clinic to community-based institutions further followed. By 1996, there were more than one hundred community home-based care facilities in the country (Iliffe 2006).

Other community-based responses, including Bwafwano ('Helping one another') Community Home-based Care, established in 1996 in Lusaka, also started with supporting tuberculosis patients in their homes with the aim of assisting them with treatment adherence in 'directly observed therapy' (DOT). In urban settings, some patients did not have adequate family support. Community-based volunteers received training in caring for patients, helping with house cleaning, washing clothes, ensuring patients had eaten and had taken their pills, mobilizing family support and encouraging and assuring both the patient and family members. Many of the caregivers who worked as volunteers were elderly women, often widows with very limited livelihoods. As funding increased and knowledge became more available about the co-infection of tuberculosis and HIV, most of the community-based organizations involved in care and support for people with HIV/AIDS and tuberculosis expanded their programmes to include HIV-testing facilities and in some cases, like in the case of Bwafwano, these evolved into clinics, eventually offering HIV treatment. This marked the emergence of formal interaction between lay providers and medically trained staff in Zambia to bridge the gap between the clinic and the home/community in providing treatment, care and support for PLHIV, mainly due to the shortage of service providers and resources in the public health system (Burchardt 2009).

The needs of people with AIDS during the pre-HIV treatment period were broadly around physical, emotional, medical and spiritual care. It was a period of many uncertainties for people with HIV/AIDS, and worries about death lingered and weighed heavily on patients' minds. Counselling and encouragement were also among the key patient needs. There was a definite need for someone to 'be there for them'. These patient needs also shaped caregiver roles. For medical staff visiting patients in the community, their roles mainly included monitoring their health status and administering treatment for opportunistic infections while also mobilizing family and community support. For community-based volunteers, the roles included bathing patients, washing clothes and performing other household chores for them. They also reminded and assisted tuberculosis patients to take their medicines and engaged and encouraged family members to provide food and continuous psychosocial, physical and material support, while reaching out to the community for support and as a strategy to reduce the stigma that was so rife at the time.

The state had not yet considered the provision of health care and support to people in their homes as part of the formal health system and as such did not provide guidelines on how to provide such care. While there was recognition of the importance of community home-based care services, there were no formal regulatory guidelines, either created by the state or adapted from transnational health bodies like the WHO, to regulate the provision of home-based care services. The services were viewed by health authorities as the usual outreach services of the church. As a result, the form that care and support for people with HIV/AIDS took was modelled after 'traditional' family-care systems, providing encouragement and support through continuous interactions. The link between community volunteers as caregivers and clinical staff was merely to facilitate home nursing, emotional and material support at home. Caregivers were not expected to perform their roles at health facilities.

The absence of guidelines from donors and government facilitated the burgeoning of a model of care that was viewed as culturally appropriate and suitable for the communities where these interventions were taking place. Even though a few guidelines were in circulation during this time, faith-based organizations used the churches' model of visiting congregation members and encouraging them in their homes to provide care and support for people with HIV/AIDS. So this period was marked by care innovations driven by charity, a sense of Christian duty and pragmatism.

As a result, this early phase of the epidemic was marked by extended care in the sense of 'being there for the patient' and community volunteers provided that support. They were neither expert clients nor trained HIV/AIDS care providers. They simply offered themselves to 'help'. In the matter of counselling as care and support for example, this made it possible for them to pilot a novel model that was not focused on doctor-patient confidentiality but rather a kind of a community approach to 'shared confidentiality', a concept that would later be used in health facilities to refer to cases where an expecting mother who was HIV positive, for example, would have the knowledge of her status shared with several clinical staff who attended to her in a health facility setting.

Volunteers mainly from religious organizations provided care and support within what they thought were societal expectations, in some cases even resisting Western notions of care. In the case of HIV/AIDS counselling for example, WHO guidelines for confidentiality were resisted in favour of shared confidentiality. This pragmatic approach was informed by reality. As medical teams visited homes of bedridden AIDS patients, they were noticed by the community – maintaining confidentiality as it is known today would not have been possible. Noteworthy also is the fact that this model was pioneered in a rural setting, where if one person was continuously sick and bedridden as was the case with people with AIDS, most community members in the locality would visit the patient to offer encouragement and support.

Most community members, while assembled by the church, provided services 'voluntarily' out of the desire to care in line with their Christian values. The volunteer landscape was not yet characterized by incentives in the form of stipends now being provided by NGOs. The few international organizations that were active did not provide stipends to mobilize community members to volunteer their time in order to reach the desired targets with minimal cost, nor did they couch this in the sustainability discourse as is the case today. Yet these non-kinship non-monetized exchanges in the form of volunteerism worked well in rural settings like Chikankata, where volunteers had their own livelihoods, mainly from farming, and provided community care usually after attending to household chores and livelihood activities. In fact such non-monetized exchanges were always characteristic of rural communities (Williams and Colin 2005). What HIV/AIDS brought to practice was a transformation of such exchanges from between individuals to between the sick person and groups of volunteers, as different HIV/AIDS projects were conceived and worked with different groups of volunteers.

The local model of palliative care for people with AIDS emerged with a strong emphasis on family and community involvement. The model also involved clinicians and patients, who oftentimes were very sick and bedridden, and thus had limited agency. From early on care and support for people with AIDS in Zambia involved all the four of what have come to be known as the 'key elements of chronic care': community resources and policies, health system, informed and activated patient and a prepared and proactive practice team (WHO 2002). This novel approach laid a foundation for community support-group approaches to care for and support people with HIV/AIDS in Zambia. It also provided a platform that put religious organizations in good stead for accessing external resources for HIV/AIDS care.

The Beginnings of Counselling

Interviews with people involved in counselling during this period make it clear that people in Zambia worked hard to meet the rapidly growing psychosocial needs of people infected and affected by HIV in their communities, and that they were often pioneering modes of counselling on the ground that were at the time unheard of in Western countries, including family- and community-based counselling and shared confidentiality (WHO 1988; Chaava 1990; Nkowane 1993; Jordan and Haworth 1995). Clement Chela, the director general of the National AIDS Council during my fieldwork in 2011 and 2012, who provided counselling services through Chikankata Hospital in Mazabuka early on in the epidemic, explained:

> In terms of origins, counselling has always existed in African societies. It has always been part of life. Elders provided guidance based on their experience in life. Counselling was based on kin-

> ship relations. … We started providing counselling (for AIDS) in the early 1980s and what we provided was community counselling. This was the original concept and we linked it to home-based care. … We would … provide counselling to people in their homes using community members, whom we knew would continue the counselling. … We worked with the concept of shared confidentiality right from the start. … We did not think confidentiality was an issue so we broke with the Western model of counselling. We recognized very early that this emphasis on confidentiality and privacy … contributed to the stigmatization of people with HIV.

Around the time Zambian health care providers recognized the need for psychological support for people diagnosed with AIDS, a number of agencies, including the WHO and the CDC, defined and endorsed pre-test counselling, HIV testing, and post-test counselling as the main components of VCT. In 1986, the CDC published VCT guidelines for use in the United States that emphasized counselling and confidentiality. These US guidelines commonly accompanied US aid that was earmarked for HIV prevention and control in African countries despite different manifestations of the epidemic and cultural settings (Iliffe 2006). The guidelines were part of the context in which Zambian counselling services were instituted in 1987, though some of those interviewed stated they were not taken very seriously at that time in Zambia. In that year, at the behest of the National AIDS Task Force (now National AIDS Council), University Teaching Hospital (UTH) established the nation's first counselling services and training unit, which began its work with a training of trainers, using WHO staff and curriculum.

From the beginning, counselling in Zambia was shaped by input from individuals and institutions outside of Zambia, as well as long-term expatriates like the Irish-born Jesuit priest, Michael Kelly who lived and worked in Zambia for many years.[16] According to Pascal Kwapa, who was working for the Ministry of Health as a psychiatry clinical officer when he helped to develop the first training programme and guidelines in August 1987:

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[16] Father Kelly, who has a PhD in child and educational psychology (1974), also brought scientific clout to the table.

> Professor Allan Haworth[17] told us there was a problem with HIV and that mental health had been asked to establish counselling services. ... So a number of us volunteered. I think we were about eight from that meeting, and then there were four from UTH. … Personally I did not do formal counselling training; I was using mental health psychiatric knowledge and I was assisted by a Catholic nun named Sister Mored who provided me with counselling literature. ... By 1988 we had collected enough data to plan our training. I worked with Professor Haworth and Mr Chilimba, who had come from his studies in the UK – he had gone to do a public health diploma. I worked with them to plan the first training but we did not have a curriculum. We requested the WHO's help with the curriculum and technical assistance, so they provided Dr John Green as a consultant from England; he was coming from St Johns Ambulance/Norwegian Church AID in Kenya. Mr Alfred came from Zimbabwe and we had a local consultant by the name of Virginia O'Dell. She was an American nurse … and also locally we had Father Michael Kelly (from Kara Counselling) who was working with us on the training team.

In the absence of formal counselling guidelines, those providing psychosocial support in the early years were using what they had learned through informal networks, including church-based publications, and their own personal experience assisting people to cope. Although WHO experts coordinated the process, the experiences of those already providing counselling in Zambian also shaped the trainings and practices formally developed in 1987 and, as the quote from Chela suggests, even early on people were resisting what were considered Western notions of privacy and confidentiality.

Around the same time, Zambian health workers began providing home-based palliative care to infected people. Without treatment, many patients ended up in hospices or under the care of specific programmes; most, however, were cared for by family members in their homes. As indicated earlier, in 1987, a hospital-based home-care model, pioneered by the Salvation Army-run Chikankata Hospital to care for tuberculosis and leprosy patients, was extended to HIV (Chaava 1990; Iliffe 2006). Because there

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[17] Zambian-born UTH psychiatrist of British descent.

were insufficient hospital beds and health centres for the growing number of AIDS patients, home-based medical care (HBC) was conceived as a less expensive way to reach those in need while providing opportunities to expand local knowledge about HIV, foster family life and allow patients to die with dignity at home. An unintentional result of HBC initiatives was that the burden of caring fell increasingly and disproportionately to women. By the mid-1990s, one in five Zambian women were caring for someone with AIDS (Myslik et al. 1997). Counselling in the context of HBC helped those infected, but also provided advice and psychological support to family caretakers. The practice of shared confidentiality, which was so common in faith-based and community-based responses, allowed for this focus on family caretakers.

As stated earlier, this marked the emergence of formal interaction between lay providers and medically trained staff to bridge the gap between the clinic and the home in providing care and support to people with AIDS in Zambia. It also marked the turning over of counselling to community-based lay health workers. Counselling in these contexts mainly consisted of offering encouragement to the dying and their families, and teaching caregivers how to limit HIV exposure. There was an assumption by medics that laypeople could easily take on the task of providing counselling and psychosocial support to people with AIDS and their caretakers.

This system of providing AIDS care and support in Zambia transferred health care responsibilities from public medical facilities and families to NGOs and faith-based organizations (FBOs) for the first time. Christian morality was often invoked to motivate community members to volunteer their time to care for the sick and dying. To this day, such reasoning continues to permeate counselling services, including those offered in public health settings.

Following the documented successes of religious- and other community-based organizations in the implementation of home-based care programmes, the Ministry of Health (MOH) and its cooperating partners recognized the role of these organizations in HIV/AIDS care and support. As a result HBC manuals were adapted from guidelines published by the WHO and other organizations to provide training to HBC providers, most of whom were from civil society organizations. The HBC portfolio was created within the MOH structure, marking the institutionalization of the practice in the Zambian health system. This period saw massive production of training materials for HBC providers and trainings of HBC groups with MOH endorsement. Local HBC providers continued to receive external funding. Bwafwano, for example, received support both in the form of technical expertise and funding from organizations like Project Concern International (with funding mainly from USAID), the Danish International Development Agency, Cecily's Fund, TB Alert and others that enabled the organization to expand its HBC programmes (Simbaya 2002). Bwafwano Community Home-Based Care later changed its name to Bwafwano Integrated Service Organization. Beginning in 2004, Bwafwano added a laboratory, a maternal and child health clinic, and voluntary counselling and testing, PMTCT and ART programmes to their existing health services with direct funding from PEPFAR and other international organizations.

This period saw most of the evolution and 'formalization' of concepts related to HBC. Because treatment was still not accessible due to high costs,[18] the government and its partners focused on 'professionalizing' HBC through trainings. It was recognized as a critical complement to the formal health system and the aim was to train community members in pain management and as agents in direct observed therapy (DOT) for tuberculosis. While during the earlier phase (from the 1980s to the late 1990s), caregivers focused on providing care toward a dignified death (Wringe 2010), the goals of HBC shifted during this phase to the management of opportunistic infections. As tuberculosis increasingly became known as a HIV co-infection, its early detection and treatment also received priority, while ensuring that caregivers took measures to avoid infection as a result of extended contact with patients. This was particularly the case as caregivers' roles continued to focus on providing nursing care. As such, HBC kits were provided to organizations involved in delivering community care and support services in people's homes. Each kit contained gloves, bandages, painkillers, oral rehydration salts and other non-prescription medicines. Even though there were frequent cases of stockouts, these kits conferred on care givers some form of authority, even in some cases serving as an incentive.

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[18] Prior to the presidential pronouncement of free HIV treatment and laboratory tests, the average monthly cost of ARVs was K40,000 (about $US8) per month.

Government involvement during this phase was limited to endorsement and provision of trainings. There was no state regulatory framework and most HBC providers were affiliated with non-state actors. As a result the HIV/AIDS care landscape was characterized by a shift in the cost of providing HIV/AIDS care and support from the formal health system to individual volunteers who were not remunerated and in most cases were the neediest of the community: widows and grandparents. In addition, HBC volunteers in urban areas received trainings while those in remote areas, particularly where there were no mission hospitals, did not.

As HIV treatment during this period was available but inaccessible, the needs of people with HIV/AIDS were the same as in the 1980s: they required assistance with hygiene, food and emotional and psychological support. And the roles of community volunteers continued to revolve around meeting those needs. However, the demographics of these community volunteers shifted to comprise a high proportion of widows and elderly women, further increasing the care burden disproportionately on women (Myslik et al. 1997).

This period marked the formalization of non-state actors in the provision of HIV/AIDS care and support, and terms emerged to describe these various actors: 'community-based organizations' (CBOs), 'faith-based organizations' (FBOs) and 'non-governmental organizations' (NGOs). This second wave of care triggered the transformation of existing local organizations – a process of 'NGO/FBOization' – to enhance their democratization and accountability in order to facilitate access to resources from global and transnational actors. While these groups restructured to access funding from the international community, standardization and professionalization of these care organizations took place through trainings. In the absence of HIV treatment, efforts to maximize the well-being of people with HIV were channelled through a form of 'biopower' (Foucault 1978) as people with HIV/AIDS were prescribed certain behaviours that were considered healthy.

This phase of care giving was dominated by NGOs and saw a shift from hospital HBC to community HBC as a model of palliative care. These donor models of care emerged from existing local models, as they were mainly led by international organizations through a process of socialization of existing community-based organizations. Donor funding going directly to community-based organizations like Bwafwano began to shape palliative care along international guidelines with an emphasis on care and support norms as provided by WHO and transnational health bodies. Due to continued challenges faced by the public health system, a gap occurred between public health facilities and community-based palliative care organizations as the care model shifted from hospital home-based care to community home-based care mainly due to swelling costs of transport and time for mobile clinical staff. The situation was also significantly compounded by the disease burden due to increasing numbers of people with AIDS. NGOs and CBOs increasingly started providing clinical services in addition to existing mission hospitals and clinics and most of those, like Bwafwano, started proving HIV diagnostic services and voluntary counselling and testing to help fill the gap.

The new community partnerships of existing organizations and NGOs that evolved also began to include livelihood and social welfare assistance in addition to providing psychological support and health care. This was in line with international discourses of 'food as prescription' and a focus on restoring livelihoods for people with HIV/AIDS. This shift added an economic aspect to the existing social and health components of care being provided to people.

In this chapter, I have demonstrated that HIV/AIDS counselling as a form of care and support for people with HIV has evolved since emerging in Zambia in 1987. Starting as a community response to the swelling numbers in need of care and pioneered by faith-based organizations, care and support practices were soon taken up by many community-based organizations in the 1990s. In recognition of the vital role these organizations played, international NGOs and the state got involved in the provision of care through these organizations, which relied heavily on community volunteers. Wanting to standardize care and control the forms and practices of care in order to maximize HIV prevention, international NGOs pioneered trainings for caregivers, later with government support. These trainings intersected with existing forms of care to shape care and support practices prior to the arrival of HIV treatment. The same volunteers who emerged as compassionate carers were trained and equipped with non-prescription drugs and kits to provide care to their patients and clients. There is no doubt that resulting care and support forms were a hybridization of existing compassionate (end-of-life care) and pragmatic practices and new forms of care that emphasized prevention of infection. As there was no hope for HIV treatment and a HIV diagnosis meant imminent and impending death, the resulting forms of counselling focused on 'being there for the client' and psychological needs, which called for more skills on the part of counsellors.

This chapter has also demonstrated that the difficulties of identifying who influenced and shaped HIV/AIDS care practices is as difficult as disentangling the national from the global. The earlier years of the HIV/AIDS epidemic saw the pragmatic response of communities organized by the church. Christian values are foreign as much as a sense of community is indigenous to Zambian communities. Therefore the earlier care and support activities for people with HIV were shaped by both local and international values, by the friction between local pragmatic community responses and views from abroad including the Christian faith and its values. It is the intersection or friction of the two that shaped and defined care and support practices for people with HIV/AIDS in the pre-HIV treatment era.

As the next chapter shows, in the era of treatment, counselling practices further evolved within the prevention paradigm, but with expanded goals, to emphasize support for HIV treatment adherence, which led to the trivialization of clients' psychological care needs.

CHAPTER 5
Voluntary Counselling and Testing

The 1990s were the years of HIV prevention. With no affordable treatment and little hope for cure or vaccination, efforts focused on controlling the spread of HIV. A key component of prevention was HIV counselling and testing. The aims of counselling around testing included helping people accept their diagnosis, alleviating anxiety and depressive reactions, improving coping, and bringing hope and relief (Zulu 1990). In addition, counselling was meant to facilitate disclosure to involve family and friends, which was thought to increase the likelihood of people receiving care and support.

Voluntary Counselling and Testing in the Pre-ART Era

In the 1990s, as voluntary counselling and testing (VCT) became a standard component of HIV prevention programmes, so did the government practice of working hand-in-hand with NGOs and FBOs. In November 1992, the first HIV testing services outside government facilities in Zambia were set up by Kara Counselling and Training Trust ('Kara'), a NGO run by the same Michael Kelly who helped establish government-based counselling services at UTH five years earlier (Baggaley et al. 1998). Kara and the Society for Family Health were the main providers of counselling services outside government facilities. Kara was exceptional for many reasons, not least of which was their commitment to work with HIV-positive activists like Winstone Zulu and Clement Mfuzi, among the first to go public with their HIV status in the late 1980s. Throughout the 1990s and the first decade of the twenty-first century, Kara provided training to many Zambian HIV counsellors, while offering VCT and, eventually, ART services outside government facilities.

International VCT guidelines emphasized counselling, confidentiality and consent – 'the three Cs' – as cornerstones of good HIV-testing practices. This framework was developed in particular health care settings, in a context where those most likely to be infected were already members of stigmatized populations, a primary motive for promoting confidentiality in particular. Despite questions about whether such an approach made sense in countries where HIV infection was a threat to the general population (Sikkema and Bissett 1997; Doll and Kennedy 1994), the three Cs accompanied most HIV-testing programmes, if not always in practice, then at least in principle. In Zambia, however, many programmes, especially those operating in rural areas and at the community level, continued to practice forms of community and family counselling and resist moves toward individual confidentiality and consent in favour of shared confidentiality and consent.

It would be some years before ARVs became available in Zambia, but by the mid-1990s some effective pharmaceutical treatments were available, giving weight to public health HIV-testing initiatives. As the cost per VCT client declined following the availability and approval of rapid tests in the United States in 1996, testing began to be framed internationally as a cost-effective HIV-prevention strategy even though rapid tests were not available in Zambia until 2006 (Gersovitz 2010) and those testing needed to wait for more than two weeks to receive their results (Fylkesnes et al. 1999).

Throughout the 1990s prevention efforts in Zambia focused on discouraging infidelity, sex among young people (especially girls), and condom use. Although there were some national-level prevention campaigns, most work was done at the community and family levels where the reality of HIV was impossible to deny. In the late 1990s, when Uganda reported dramatic declines in the incidence of HIV, scientists, mainly from the United States, attributed it to a combination of practices, which were eventually distilled into the prevention strategy known as 'ABC': abstain, be faithful, and use condoms (Green 2003; Kinsman 2010). Although HIV incidence and prevalence rates dropped steadily throughout the 1990s in Zambia, Zambia never received the international attention that Uganda did (Fylkesnes et al. 2001). As in Uganda, the decline was eventually attributed to behaviour change, but how behaviour change came about in Zambia, a country that could not claim Uganda's openness or political will, was never fully explored or explained. Epstein's (2007) explanation for Ugandan success – community-based interventions and commitment – may also explain what happened in Zambia, where home-based care programmes and community-based lay volunteers providing direct and pragmatic counselling services were the standard.

As research led to new treatments and better understanding of HIV transmission, VCT evolved into a didactic, health education format, providing basic information on transmission routes and safer sex, with little attention to counselling quality or effectiveness in promoting individual responsibility (Valdiserri 1997; Epstein et al. 1998). CDC guidelines published in 1993 linked the standardizing of VCT to treatment goals and encouraged counsellors to use a personalized, client-centred approach to help clients negotiate a risk-reduction plan, but offered few practical suggestions on how to accomplish this. The degree to which a client-centred approach actually affected Zambian counselling practices in the 1990s is largely unknown because few studies in Zambia or elsewhere have examined provider-client interactions or the quality of counselling in practice (Silverman 1997; Sheon 1999). Those interviewed who provided counselling during this period, however, suggest that counselling continued to target families rather than individuals only.

Soon after highly effective antiretroviral therapies (ART) became available in Western countries in 1996, they also became available in Zambia, though access was limited to those who could afford to pay hefty monthly fees in Lusaka or Ndola. A small number of activists also traded public disclosure for access (see Nguyen 2010). Around this time, public health campaigns began encouraging people to get tested. Public testimonials of HIV-positive people were seen as key to promoting openness and public discussion.

HIV/AIDS Counselling in the Early Years of HIV Treatment (2004 to 2009)

With the coming of global treatment initiatives to Africa, Zambia saw a rapid increase in donor support. Between 2002 and 2004, Zambia was promised close to $US224 million from the Global Fund (Rounds 1 and 4) and $US42 million from the World Bank. In 2004, Zambia also began receiving funds from the US President's Emergency Plan for AIDS Relief (PEPFAR); amounts were $US59 million in 2004, $US47.7 million in 2005 and over $US100 million in 2006 (Ndubani et al. 2007; Ndubani et al. 2009). As noted earlier, according to Ndubani et al. (2007) there was no central body tracking these funds prior to treatment scale-up, and so we cannot know how much money earmarked for HIV was coming into Zambia before this time. Although a great deal of aid was made available for testing and treating, it is also difficult to estimate the amount that went to improving or expanding HIV counselling services because funds for counselling were often imbedded in prevention initiatives with no clear demarcation of resources, and because multiple actors provided counselling with funding from various sources.

With ART scale-up, which began in 2003, new modes of counselling were imported, including adherence counselling, the main objectives of which were to get people to take their medications as prescribed and engage in safer sexual practices, including 100 per cent condom use. In a three-year project co-funded by USAID and the European Union that began in 2004, the International HIV Alliance worked with NZP+, the Catholic Diocese, and the Traditional Health Practitioners Association of Zambia to pioneer the employment of people living with HIV as counsellors. They argued that using HIV-positive counsellors who looked healthy made it easier to promote uptake and adherence to ART, and gave hope to those testing positive. In effect, HIV-positive counsellors became walking advertisements for ART efficacy. Zambian public health officials lauded the project, which was an unusual example of a successful partnership between international donors and advocacy groups and Zambian institutions and activists. Lusaka's District Health Management Team director even hailed the use of HIV-positive counsellors as 'the missing link' when he was interviewed by a consultant conducting an evaluation of the project.

Using HIV-positive 'expert clients' as service providers in public health care settings is now widely accepted by both governments and NGOs. However, the majority of HIV-positive service providers remain classified as lay counsellors because they have not been certified through government-recognized training programmes. While some receive reasonable salaries while employed by a project, most work on a semi-volunteer basis, with minimal and sporadic pay. This means that most people providing counselling in Zambia have received (often multiple) trainings according to the specific objectives of externally funded projects that are implemented by a range of NGOs, while never being formally recognized as counsellors by the state.

In Lusaka, as in several provinces in the southern half of Zambia, the main provider of HIV treatment between 2004 and 2010 was the Center for Infectious Disease Research in Zambia (CIDRZ). As a primary recipient of PEPFAR funds, this research-based organization affiliated with the University of Alabama at Birmingham, dominated the field of HIV treatment provision to a degree rarely seen in Africa. Since their incorporation in Zambia in 2001, they have completed more than thirty-five research projects and have at least forty more ongoing; they employed 650 people and provided treatment in partnership with the Zambian Ministry of Health at 321 public health facilities in Zambia. Because they were based in Lusaka, the seat of the national government, CIDRZ helped to define standards of care for treatment at the national level, particularly in regards to encouraging adherence, which was accomplished through the establishment of health-facility based support groups and one-on-one adherence counselling delivered by trained HIV-positive peer educators.

According to NZP+ spokespeople who were involved in running community-based support groups, there were few support groups in health facilities prior to CIDRZ's dominance. When CIDRZ began providing treatment in targeted facilities in Lusaka, they also launched support groups and encouraged those testing positive to attend. These groups played an important role in advising those beginning ART treatment about adherence. According to some activists, CIDRZ support groups seemed to purposefully exclude the involvement of existing community-based support groups or HIV-positive activist groups in Lusaka, and were facilitated by CIDRZ-trained HIV-positive people. Those who enrolled in treatment in 2004 became the core of CIDRZ's HIV-positive semi-volunteer workforce, receiving the bulk of training and work opportunities offered to people living with HIV. Some treatment activists suggested that the CIDRZ model – providing adherence counselling by HIV-positive people trained from a public health rather than a rights-based perspective – broke with community-based models that emphasized empowering HIV-positive people to make informed health care choices.

In 2005, when free treatment for HIV first became available, 39,351 people were on treatment; only five years later in 2010, the number had increased nearly ten-fold to 344,407, with 72 per cent of those in need receiving ART (NAC 2010; WHO/ UNICEF/UNAIDS 2011). In 2003, 106 sites were providing VCT in Zambia; this number increased to 1,689 sites in 2010 (WHO/UNAIDS/UNICEF 2011). This rapid expansion of ART and VCT provision also saw an increase in the number of people testing. In 2006, 234,430 people were tested; a number that grew to 511,299 in 2008 before nearly doubling again to 1,050,137 just one year later. The proportion of pregnant women tested increased from 14 per cent in 2005 to 94 per cent in 2010 (Ibid.). While everyone tested should have received counselling, few have studied the form or quality of counselling offered in the context of such a rapid expansion.

As explained in the preceding chapters, prior to 2004 most HIV counselling and testing was embedded in community-based projects run by FBOs and NGOs, or in health facility-based projects funded by international donors, mainly PEPFAR. The pivotal year of 2005 marked the start of free ART at public facilities. Although many thought treatment availability would automatically result in people wanting to test, the numbers presenting for VCT were considered too low for many project goals, which required a certain level of enrolment to justify continued funding. Recent years have seen the emergence of new models of provider-initiated testing and counselling (PITC) services, including mobile testing; door-to-door testing; and testing campaigns in workplaces, high schools, colleges and universities, and at public events. These new forms are still met with resistance despite their perceived convenience due to reasons related to stigma, confidentiality and trust (Jürgensen et al. 2013). Prevention of Mother-to-Child Transmission (PMTCT) programmes, another form of PITC, have increasingly targeted fathers, sometimes requiring both parents to test before pregnant women are granted access to health services. VCT centres, like the USAID-funded New Start centres run by Population Services International, have worked to become ‘male friendly’ and now target couples. In most PITC initiatives, minimal attention is given to pre-test counselling, which is usually replaced by information-based health talks given to groups, usually by peer educators. Those testing HIV-positive are generally referred to treatment clinics for further evaluation and adherence counselling, while those testing negative normally receive no information or are advised on condoms.

In addition to shifting in the face of emerging PITC strategies, counselling has had to evolve as people with HIV live longer as a consequence of ART. Since ART is a life-long treatment, and adherence to the prescribed regimen is vitally important for viral suppression and preventing drug resistance, adherence counselling has become a regular part of the medicalized lives of people living with HIV. While adherence counselling has evolved to now include advice on dealing with long-term side effects of treatment and on nutrition, emphasis is also put on the sexual and reproductive behaviour of HIV-positive individuals and couples. Every adherence counselling session spends several minutes underlining the need to always use condoms to prevent (re)infection and to disclose one's status to sexual partners, as well as advising on reproductive matters, including when and how many children to have, and how to conceive and deliver safely. This attention to the sexual and reproductive lives of HIV positive people marks a shift from the content of counselling provided in the 1990s.

The first decade of the twenty-first century saw a rapid transformation in HIV care treatment and control efforts. Prevention, which had previously been linked primarily to behaviour change at the community level, increasingly came to be linked to biomedicine and the clinic. Testing and limited counselling were framed as the first critical step to treatment enrolment and limiting new infections. The numbers of people testing for the first time from 2004 to 2009 attest to the zeal and success of a wide range of 'test-to-treat initiatives' instituted by a diverse group of organizations in partnership with the Zambian government. The driving ideology of this period was one of crisis. As one high-placed CIDRZ official from the United States put it: "When we came here AIDS was an emergency, and PEPFAR was a response to an emergency. In an emergency you do not have time to follow existing systems and procedures, and we hope that eventually we will give back the power to government and harmonize the system".

VCT and ART Mainstreaming, Cost-Cutting and Reutilization (2010 and beyond)

Treatment is still being scaled up, but since many in need are already on treatment, the process has slowed. In 2010, funding for HIV interventions in Zambia was dramatically cut. Following evidence of corruption and misappropriation of funds, the Global Fund suspended more than $US300 million in health aid to Zambia in 2010; the governments of Sweden and the Netherlands, substantial donors in their own right, also froze their health aid. The end of 2009 also brought an end to many PEPFAR-funded projects. Concern with corruption in Zambia came at a time when the Global Fund was having trouble getting donors to honour existing pledges, let alone increase their financial commitments. At the 2011 International Conference on AIDS and STIs in Africa (ICASA) meetings in Addis Ababa, the Global Fund announced that it would delay its Round 9 funding while it continued to pressure donors for money. Although PEPFAR has maintained its commitments to Africa, US Secretary of State Hillary Clinton delivered a carefully crafted message at the 2012 International AIDS Meeting in Washington, DC, making it clear that the 'emergency' was over.

The Addis Ababa meeting was significant because it signalled on the international stage that the rules of the game were shifting. African countries were pressured to take on a greater financial responsibility in providing HIV care. Internationally funded projects and programmes that had established best practices were to be taken over by national healthcare programmes and mainstreamed. Amidst talk of cutting costs, global and local activists expressed concern about continued access to ARVs for those already on treatment; however, there was almost no mention of how to maintain the quality of services as salaries for project-embedded health workers were cut and funding for the thousands of semi-volunteer HIV-positive peer mentors, educators and counsellors who had become integral to service provision disappeared as well.

Recent concerns about those testing positive through PITC – and how to make sure they stay in treatment and are not 'lost to follow up' – has caused some to call for more attention to improving linkages and referral systems to ensure those who test positive make it to a treatment centre and those on treatment are supported to continue. Perhaps not surprisingly, many counsellors I interviewed suggested that these problems could be addressed by a return to individual-focused counselling in PITC contexts, and by not urging people to test before they are ready to accept the results. They point out that although HIV may no longer be a national crisis, it is still a personal crisis for each individual testing positive and, as such, adequate and quality HIV counselling services should be integrated into any testing initiative.

HIV Counselling Transformation: A Synthesis

Rarely in the field of HIV do we look at the ways the disease and the programmes co-develop and how the actors interact to transform the everyday practice of care giving. In this and the preceding two chapters, I have examined how HIV counselling as a care practice emerged and evolved in Zambia since 1987. I have shown that in the face of locally recognized need, HIV counselling was developed combining international expertise and materials with the experience of local health care practitioners and policy makers. Although counselling guidelines continue to be shaped by external actors located primarily in Washington, DC, and Geneva, policy makers and implementers on the ground continue to work hard to selectively domesticate these ‘foreign’ technologies.

Most agree that counselling changed radically as a result of treatment scale-up in Zambia. Just as counselling practices have changed, so too has the cast of characters providing services. Although the tasks of defining counselling guidelines and curricula are largely left to biomedical doctors and experts, those doing the counselling include nurses, trained counsellors, lay counsellors, and expert patients. By February 2012, the Ministry of Health’s Counselling Services and Training Unit had trained 13,844 HIV counsellors, 5,785 psychosocial counsellors, 81 home-based care providers, 461 child counsellors, 232 couple counsellors, and more than 360 lay counsellors. These have been deployed to all public and mission health facilities in all seventy-four districts of the country (MOH 2012a, MOH 2012b).

As knowledge about HIV has grown, and as treatment has become available, counsellors have had to adapt their practices. In the beginning the emphasis was on not infecting sexual partners. Doctors and counsellors routinely advised people with HIV to avoid sexual relationships, refrain from marriage and forgo having children. With evidence of declining HIV prevalence in Uganda, technocrats crafted a new ‘ABC’ response: abstain, be faithful, use condoms. With the scale-up of treatment and the emergence of test-to-treat programmes (along with evidence that most new infections were occurring in stable partnerships) came an emphasis on promoting monogamy, partner disclosure, couples counselling, and using condoms to prevent infection in cases of discordancy or re-infection among HIV-positive couples (Allen et al. 2007; Conkling et al. 2010; Kelley et al. 2011). As effective treatments allowed people to live longer with HIV, greater attention was given to the sexual and reproductive rights of people living with HIV (Moyer 2012).

The research has also shown that, in the treatment era, the objective is to identify HIV-positive individuals and get them on treatment, with little attention to counselling that helps people identify personal risk-taking behaviours or develop strategies for prevention. Current public health discourses on HIV counselling rarely acknowledge the need for psychological support for people diagnosed with what is still a highly stigmatized disease with no cure on the horizon that requires a lifetime of treatment and behaviour modification, and the need to develop social skills to navigate issues of disclosure, dating, marriage, sexual relations and reproduction.

I have demonstrated that, although HIV counselling in its current form is best understood as a social technology embedded in HIV prevention and treatment programmes that are funded largely by foreign donors, it has and continues to be shaped through practice by those offering counselling services on the ground. Although it is true that counselling, in the form of advice giving from elders, has most likely always existed in Zambia, counselling in the context of HIV and other health interventions has evolved. Whereas it was initially conducted by religious organizations as compassionate care, people are now counselled by relative strangers in health care settings. Just as it is impossible to say whether this 'foreign' technology was or is appropriate, it is equally impossible to imagine HIV care without it.

Overall, this chapter has demonstrated: 1) the shift toward testing to get people enrolled in treatment programmes helped to create an environment in which attention to the psychological health of the individual was diminished as group health talks replaced pre-test counselling in many health facilities; 2) support groups shifted from the community to the health facility, where they increasingly came to focus on advice giving and adherence rather than patient empowerment; 3) testing practices shifted from the clinic to the community and people's homes; 4) shared confidentiality replaced anonymous testing in health facilities; and 5) testing has become increasingly less voluntary, especially in opt-out and PMTCT settings. In provider-initiated counselling and testing and PMTCT programmes, all clients are tested or opt-out - meaning that HIV test is done routinely unless a client or patient explicitly refuses to take an HIV test. There is no doubt that more people were tested for HIV and put on treatment in this period, but questions remain regarding the consequences of decreased confidentiality and lower quality counselling (cf. Njeru et al. 2009; Jürgensen et al. 2012), not least of which are growing concerns about treatment defaulting and high rates of people who are 'lost to follow-up' among those testing positive.

CHAPTER 6
HIV/AIDS Care and Support in the HIV Treatment Era

This chapter documents transformations in HIV/AIDS care and support practices during the last decade (2004 to 2013) of HIV treatment in Zambia. It provides a history of how care and support particularly in the form of HIV/AIDS counselling has evolved in the era of HIV medicines. It sheds light on shifts in the needs of people with HIV and the roles of their caregivers, and how international actors, mainly NGOs, have interacted with local actors to transform care practices. I argue that the intersection and friction between existing forms and practices and global ones has shaped current practices. As shown in the previous chapters, the emergence of HIV/AIDS care and support practices started as pragmatic community responses. However, as the problem grew, with more and more people requiring care and support, other players, including the Ministry of Health and local and international NGOs, joined in the provision of care and support. When HIV treatment became available in 2004, even more players, both local and international, became involved in the provision of HIV treatment.

The 2004 to 2013 period, marked by the growing availability and rapid scale-up of antiretroviral treatment (ART) for HIV, has also been characterized by shifting patient needs as those on treatment regain their health. Home-based caregivers no longer focused on nursing bedridden patients. During this period, many have been retrained to provide treatment support, and to move from community-based care activities to health facilities where they receive additional training to support treatment adherence. Their expanded role means they provide less hand-on care and less psychological and spiritual counselling. Their focus now is on providing information about treatment and monitoring treatment adherence. When they do venture out to the community now, it is mainly to speak with people who have defaulted on their prescribed treatment. For HIV counsellors, their roles have continued to revolve around VCT. In line with expanded HIV awareness, prevention and treatment programmes, the number of clients seeking HIV testing – both to know their status or as an entry point to treatment access – has swelled. This has led to HIV counsellors spending most of their time preparing people for testing and learning results through abbreviated pre-and post-test counselling sessions. Their roles have also been further medicalized to include the tasks of finger pricking and blood testing in the laboratories.

These shifts in the roles of caregivers and counsellors have led to the trivialization of psychological care for people with HIV. While it is acknowledged that HIV medicines have dramatically changed the lives of people with HIV for the better in terms of their health, they still are faced with continued stigma as well as challenges that come with being HIV-positive and on treatment. They have to learn not only how to manage the side effects of HIV medicines, but also how to navigate their social lives on these medicines, including how to manage stigma. In addition, when clients present themselves for HIV counselling at health facilities, counselling around the test and its results are not always their main concern. Tied to knowing their HIV status are webs of social lives for which they need psychological care and support (also see Chapter 3).

The period of 2004 to 2013 saw the arrival of free ART to Zambia along with a rapid scale-up of HIV services countrywide. This period witnessed a massive increase in foreign aid, including technical advice, international guidelines, funding to buy medicines, and monitoring and evaluation mechanisms designed to feed into reports. As policies and interventions were initiated to increase testing in response to new WHO guidelines that emphasized opt-out and provider-initiated testing schemes, counselling came to be more of a convincing game, and success was judged on whether a client agreed to test or not. This research demonstrates that consent and confidentiality, the previous hallmarks of VCT, came to be less valued in this period. Simultaneously, the imperative to promote adherence led to the widespread development of support groups in health facilities in Zambia. The health workers who supervised these groups, together with facility-selected peer leaders, replaced talk of patient rights and responsibilities with an emphasis on patient compliance. HIV counselling also became more focused on regulating sexual and reproductive practices within HIV positive and sero-discordant couples (Allen et al. 2007).

If treatment came to Zambia with what seemed a surplus of international aid, the years since 2010 can be defined as a period of declining funding. As financial crises engulfed Western donors, they increased demands for financial accountability and cost cutting among aid recipients, including those providing HIV services. Simultaneously, Western donors have quietly declared that HIV is no longer a crisis in Africa, and that it is up to African governments themselves to 'mainstream' treatment programmes and routinize testing procedures, which minimize or even trivialize the role of counselling.

In this age of treatment, home-based caregivers have moved into health facilities directly supporting rapidly expanding treatment programmes. Yet they are expected to volunteer their time and services in spite of their evolving and expanding roles. At the time of writing, the Zambian government was at a crossroads. The state was faced with the enormous task of providing care and treatment to over half a million people. International funding for HIV/AIDS care and support was declining. Most of the counsellors working at health facilities, especially at ART clinics, were working under initiatives like the Center for Infectious Diseases Research in Zambia (CIDRZ) that were scaling down and closing up.

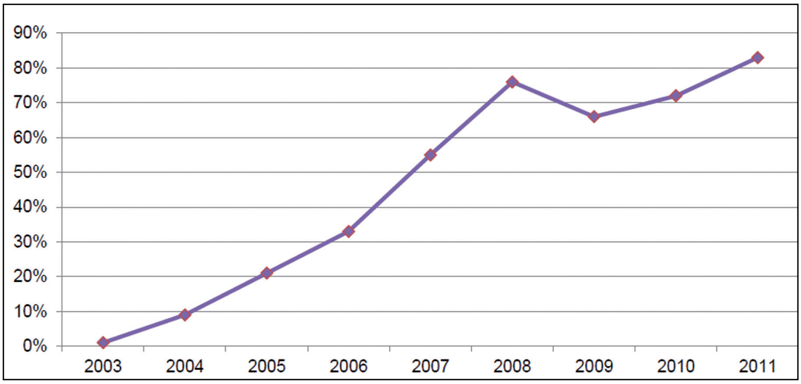
From Palliative to Chronic Care (2004 to 2009)

The 2004 to 2009 period can best be described as the period characterized by HIV treatment scale-up, institutionalization, clinicalization of care and medicalization of community caregivers. Although HIV treatment became available earlier, it was not widely accessible until 2005. On 16 January 2004, in a state-of-the-nation address to parliament, President Mwanawasa revealed that ten thousand people were receiving government-funded HIV treatment and that in 2005 one hundred thousand people would receive free ART. In August 2005 the president announced that HIV treatment, including all laboratory investigations, would be provided by public facilities without charge. Bilateral and other international support later followed. International NGOs, mainly with funding from the US government, appeared on the scene to provide treatment, care and support and to channel the funding to local organizations. The Zambia Prevention, Care and Treatment Programme (ZPCT) and CIDRZ, established in 2005 and 2006 respectively, were among the international projects providing treatment, care and support.

As a result of huge influx of international funding – mainly from global health initiatives like the US Presidential Emergency Plan for AIDS Relief (PEPFAR), Global Fund (GF), the World Bank Multi-country AIDS Programme (MAP) and other 'cooperating partners' – a steady scale-up of HIV/AIDS services occurred (Ndubani et al. 2009; Walsh et al. 2010; Oomman et al. 2007; Oomman et al. 2008). As one of the countries hardest hit by the epidemic in sub-Sahara Africa, Zambia has been among the countries that received high levels of funding for AIDS control from different donors. Data show a steady increase in both number and coverage of people receiving HIV medicines. Figure 3 demonstrates this scale-up and points to the need for an increase in the number of treatment, care and support providers.

The upsurge in the provision of treatment as well as coverage was mainly due to government's introduction of free treatment in 2004 and its subsequent expansion to include free provision of related services like laboratory investigations including CD4 and renal tests (UNGASS 2011).

Figure 3: Zambia ART coverage for the period 2003 to 2011
Source: WHO/UNAIDS 2011



The decline in ART coverage between 2008 and 2009 is as a result of a revision in eligibility criteria. One's qualification for beginning ART is determined by the viral load in the body and how much damage the virus has caused to the defence and immune system. The data used from 2003 to 2008 were based on eligibility criteria for a CD4 count of less than 200, while the data presented from 2009 onwards were based on eligibility criteria for a CD4 count of less than 350, as recommended by the recent ART guidelines by the WHO (2010).

The new criteria were based on evidence indicating that starting ART earlier in the course of a HIV infection greatly reduced morbidity and mortality among people with HIV and tuberculosis and reduced HIV and tuberculosis transmission. This has implications for care and support. As people enrol early on HIV treatment, their care needs are reshaped and require less nursing care since they are no longer bedridden. Therefore, psychosocial support and assistance to remain faithful to treatment regimens continue as the overarching needs as framed by public health efforts. As such, in the HIV-treatment era, focus is on treatment adherence with prevention perceived as care; the roles of caregivers revolve around monitoring treatment adherence, and less on providing psychological and emotional care. These notions of care are promoted by transnational actors of care (Dilger et al. 2012).

During the period depicted in figure 3, a global movement to mobilize resources and provide treatment catalysed national agendas to scale-up treatment by mobilizing both international and local resources. The WHO and UNAIDS (2011) described 2000 to 2010 as a decade of progress in the area of treatment, care and support for HIV and AIDS. Starting with a call for an end to treatment inequality between developed and developing countries during the XIII International AIDS Conference in South Africa in 2000, the decade also witnessed the 2001 United Nations General Assembly Special Session on HIV/AIDS (UNGASS) Declaration of Commitment on HIV/AIDS. In 2002 the Global Fund to Fight AIDS, Tuberculosis and Malaria was established to provide a flexible country-driven funding mechanism for AIDS control. PEPFAR launched a $US15 billion five-year bilateral AIDS programme in 2003, which was later renewed as a $US48 billion programme in 2008. On World AIDS Day in 2003, WHO/UNAIDS launched the ‘3 by 5’ initiative to have three million people on HIV treatment by the year 2005, a goal that was attained in 2007. In 2006 UN member states committed to universal access to HIV prevention, treatment, care and support for all in need by 2010, which resulted in major increases in AIDS financing from public and private sectors to scale-up ART provision. These shifts at the global level led to dramatic changes at the local level in Zambia as international actors worked with local organizations to implement the global agenda.

Therefore the introduction of ART in the early 2000s changed the functions of both health facilities and home-based care programmes dramatically. Health facilities introduced new services oriented around HIV treatment and the identification of eligible patients. Treatment programmes first appeared at top-tier health facilities, but as funding enabled and pushed further expansion, lower-level health facilities began accommodating a more vertical treatment programme for HIV, and home-based care programmes started functioning as referral mechanisms to treatment programmes. The availability of treatment encouraged a process whereby community home-based care programmes and health facilities engaged in more structured partnerships. The Zambian government developed a manual outlining 'minimum standards' for home-based care in 2005, together with key non-governmental players based on what existing community-based organizations were using and WHO guidelines (WHO 2002). Community-based organizations like Bwafwano in Lusaka were already using training manuals developed with the support of their partners, mainly international NGOs like Project Concern International. While health facilities took charge of the treatment component, home-based care programmes gradually transitioned to a supportive function for people with HIV who were doing well on ART but struggling to meet their basic livelihood needs. More recently, volunteers from home-based care programmes have been mobilized by both national and international organizations with funding from diverse sources, but mainly through international implementing agencies of the United States government to support treatment adherence.

With the 'Greater Involvement of People with AIDS' (GIPA) discourse, more community involvement, especially of those infected, was also promoted, reconstituting local care giving actors to include people with HIV as counsellors/expert clients who came in to promote 'positive living' among people with HIV as living testimonials (Nguyen 2010).

By 2009, increasing evidence that earlier ART initiation reduced HIV- and tuberculosis-related morbidity, mortality and transmission led to efforts to put people with HIV on treatment early as a prevention tool. This led to the updating of ART guidelines in 2010 to recommend earlier ART initiation

(WHO 2010a; WHO 2010b; MOH 2010). In the same year, UNAIDS/WHO launched 'Treatment 2.0', a framework for sustaining universal access to HIV treatment by optimizing drug regimens, providing access to point-of-care diagnostics, reducing costs, adapting delivery systems and mobilizing communities. Part of the strategy was to get community health workers and volunteers more involved in ART provision, which they envisaged should be devolved to the community. By the close of 2010, 6.6 million people worldwide were on HIV treatment. In 2011 a randomized, controlled clinical trial demonstrated the efficacy of ART to prevent sexual transmission of HIV in sero-discordant couples (Baeten et al. 2012). This led to a high-level meeting recommitting to universal access and revising global targets (Mwewa et al. 2013). All these global developments have meant shifts in care and support at the local level. International funding and technical guidelines focus on maintaining high levels of treatment adherence and preventing further infections, and give less attention to aspects of social and psychological care.

This tsunami of funding, for a health system with limited health infrastructure and human resources for health (Walsh et al. 2010), has resulted in the integration of community volunteers and expert clients in the medical care arena. Starting in 2004 with an intervention implemented by International HIV/AIDS Alliance and its partners, including the Network of Zambian People Living with HIV (NZP+), people living with HIV were recruited and trained to assist medical staff at health facilities with handling clients at VCT clinics, retrieving and cataloguing client files, counselling for HIV testing and helping newly diagnosed HIV-positive clients to navigate the services at HIV-treatment facilities. These efforts were thought to demonstrate that a person could have HIV and live normally and positively, while at the same time increasing uptake of counselling, treatment and care services.

This was the birth of 'living positively' or 'positive living' that has narrowly been equated to eating well and *caring for the self*, and maintaining a positive outlook on the future in spite of a virus-carrying body. Traced back to what Michel Foucault (Nguyen 2005, Martin et al 1988) called 'technologies of the self', these 'living positively' groups encouraged individuals to effect by their own means or with the help of others (such as adherence counsellors and other expert clients) a certain number of operations on their own bodies, souls, thoughts, conduct, and ways of being, so as to transform themselves in order to attain a certain state of happiness and perfection. Earlier versions of positive living in Zambia prescribed a life free from tobacco and alcohol use, abstinence from sex, and adherence to HIV medicines, and encouraged the eating of certain foods like carrots. Some of these could not be accessed by people with HIV, most of whom had lost the source of their livelihood due to long illness episodes prior to accessing treatment. These ideals were a result of global discourses aimed at promoting behaviours that were considered essential for better treatment outcomes. This form of biopower was easily accepted by ‘treatment citizens’ who were already benefiting from treatment, a tool already associated with the ingenuities of international and transnational actors (see Nguyen 2005).

The notions of self-care for people with HIV evolved differently in different settings. While condom use was emphasized in public health facilities, faith-based organizations providing treatment through mission hospitals emphasized abstinence, especially among those not married. Generally condoms were not mentioned as part of living positively in mission facilities. This did not prevent them from receiving funding. In fact the funding received from bilateral funders like PEPFAR increased.

The position of faith-based organizations was also strengthened by the structure and administration of the Global Fund to fight HIV/AIDS, TB and Malaria. From the start, Zambia had three principal recipients: Zambia National AIDS Network (ZNAN) for civil society organizations, Ministry of Finance for other ministries and Churches Health Association of Zambia (CHAZ) for faith-based organizations. This enabled faith-based organizations to provide a range of care and support services within the less prescriptive and flexible framework of the Global Fund. Following recent abuses of global funds as revealed in the national audit report of 2011/2012, faith-based organizations have remained in a strong position to access funding due to the reconstitution of the national administration of Global Funds recipients that has included CHAZ as the only non-government recipient.

After state-sponsored treatment had been available for some time, the needs of clients began to shift to restoring livelihoods, returning to ‘normal’ lives characterized by employment, and being viewed normal people whose bodies did not carry the virus. However, such hopes were connected to strict adherence to HIV drugs and as such adherence support continued to be considered as a critical need for people living with HIV. Motivated by maintaining high numbers of people on treatment for prevention of further infections, the funded positions for community workers gravitated toward providing treatment adherence support. International agencies like CIDRZ expanded the use of expert clients, an initiative first attempted in Zambia by the HIV/AIDS Alliance and its partners in 2004 (Simbaya et al. 2005, Simbaya et al 2008a). Every health facility providing HIV treatment mobilized support groups, from which individuals were selected and 'employed' as counsellors and treatment supporters at the health facility. Funding was set aside by donors and cooperating partners to provide training for these people as community health workers based at health facilities. Their roles mainly involved providing information and education, counselling and adherence support to clinic patrons, mainly those infected with HIV.

As most community-based organizations that had been involved in the provision of home-based care as established in the 1990s evolved to start providing ART, their roles also changed. Community caregivers became more engaged in provision of treatment adherence counselling and support (Wringe et al. 2010; Cataldo 2008; Kielmann et al. 2010), moving them from the community to health facilities as experts alongside clinicians, nurses and expert clients. During this era, the demographics of caregivers changed dramatically as more young people with HIV joined the ranks of caregiver through their support groups. Clinic staff shifted from conducting outreach to communities for the treatment of opportunistic infections, and for the provision and mobilization of care and support for patients, to the institutionalization of community volunteers at health facilities to provide adherence support. This transformed care and support from 'being there for the client' to 'monitoring treatment compliance' and thus medicalized the roles of community caregivers. The transformation of roles from caregiving to compliance monitoring has been shaped by existing global guideline and funding as well as initiatives such as the WHO/UNAIDS initiative Treatment 2.0 (WHO 2011). Driven by the need to provide treatment cheaply and sustainably in the midst of health staff crisis (Walsh et al. 2010), UNAIDS proposed an agenda in 2012 to move HIV treatment closer to the family by involving community caregivers in the provision of HIV treatment.

As informants from the MOH and WHO put it, the role of community caregivers has gravitated toward treatment support as promoted by both the MOH and its cooperating partners. In my interviews with them, the ART coordinator at the MOH national headquarters and the officer in charge of

ART at the WHO, both key players in the HIV/AIDS treatment and care landscape, describe community caregivers as having a critical role to play:

> It's foregone that they [community caregivers] play a critical role. ... For these sites that are partner supported they have more resources, their volunteers may have a little bit more money in their pockets than volunteers elsewhere. So volunteers help with triaging, keeping records, tracking patients out in the community, linking patients to different services, offering peer support or possibly participating in health education talks, emotional support and all that, so without that cadre there, the programme starts to fall to pieces. In government clinics, even though volunteers are not getting remuneration or anything, they are doing the same things as in partner-supported facilities like patient registration, patient flow in the clinic, helping patients get to the right provider at the right time, weighing patients, helping the patients count through their pills, offering adherence counselling, and if patients are missing clinic visits, they go out into the community and track the patients and bring them back into care. – ART coordinator, MOH

> They have a critical role to play to support the whole process. They will need to talk about health education with the client, touching on critical issues like adherence, following up patients in the communities, those who don't come for follow-ups. – ART officer, WHO.

The current emphasis on adherence support and health education means that 'community support' most often takes place in health facilities with limited community visitation. Most home visits are devoted to tracking down HIV treatment defaulters at the behest of the healthy facility and its donors.

In addition, most caregivers are linked to HIV/AIDS programmes. In the last two decades HIV/AIDS has received more funding than any other disease. This has contributed to more community volunteers being associated with HIV programmes than with any other illness. As such, the majority of community caregivers are HIV/AIDS counsellors, adherence supporters and/or treatment defaulter tracers.

As observed from my interactions with caregivers and their clients, the changing roles of caregivers that have placed them as 'experts' who monitor their clients' compliance with treatment has conferred a different form of authority on them that has redefined their relationship with their clients. As shown by other studies (Cataldo et al. 2010) this authority has altered the nature of caregiving relationships and is not always welcomed by either clients or caregivers. Clients contest the new medicalized roles as they perceive a bureaucratic, uncaring and prescriptive health system coming into their home. Caregivers too express dissatisfaction that their newfound accountability to the system places them at cross-purposes. On the one hand, they are expected to fill the care gap by providing support to clients in their communities, a kind of care that is not possible to provide at a health facility due to large numbers of clients, and on the other hand they must masquerade as clinical staff even though this new occupation is not formally recognized through remuneration (Cataldo et al. 2010). The current move in 2012 by the state to recruit and train 'community health assistants' who would eventually be on the government payroll, parallel to existing volunteer community workers, has added to their frustrations. Such community health assistants are expected to manage health posts[19], reach out to communities with health education and coordinate community caregivers.

The 2003 to 2009 period in HIV/AIDS caregiving witnessed the active involvement of the MOH in the regulation of community caregiving through guidelines and trainings. This MOH/donor model saw a return to the initial hospital-based community home-care initiatives with caregivers mobilized by different groups affiliated with health centres, who mainly provided adherence counselling and defaulter tracing in the communities. While these transformations take place, the clinical, economic, and social components of care – and the patient, family, community partners and health services – all continue to be present. With the return to the initial local model that was present during palliative care, in which clinical staff and community volunteers provide hospital-based community home care, it can be argued that while care and support for HIV/AIDS has been transformed, local concepts and values for care and support still suffuse community home-based care

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[19] Health posts are the lowest level of the primary health care structure and often manned by a classified daily employee. These are community health workers who receive two weeks of training, mainly in first aid, and are supposed to refer cases to the nearest clinic for diagnosis and treatment.

and chronic care. The emergence of chronic care in Zambia has particular characteristics that include local concepts and values of care and support that were the foundation of early responses to HIV, negotiated through friction over the years.

The Era of Mainstreaming, Cost-Cutting and Reutilization (2010 to 2013)

With countless organizations dotting the HIV/AIDS landscape in Zambia, community caregivers now have many affiliations. It is not uncommon for community volunteers to work with more than one organization. Those involved in health services often work with local health facilities. Most organizations 'employing' caregivers provide incentives that keep them volunteering their time and services to support project activities, but also keep them moving from one organization to another in search for greener pastures. Others associate with more than one organization, being careful not to wear the wrong organization's T-shirt when they have meetings. While there is recognition of the critical role they play, caregivers, most of whom are elderly women and widows and some people living with HIV, do not have a spot in the formal health system and thus do not receive compensation for their valued services. Questions remain as to what will happen to this cadre of workers when these projects phase out, for it is clear that they cannot be absorbed by the public health system. At the end of my fieldwork in 2012, CIDRZ was no longer providing financial resources to most of the support groups they initiated as their funding was coming to an end. This raised a lot of anxiety and discussion about the gap that would be left in treatment support at health facilities.

When asked about the future of community care and support in Zambia, MOH officials, including home-based care and ART coordinators, said that they intended to fill this gap with community health assistants (CHAs). From the definition of their roles, it appeared that the community aspect ended with the title. In fact, all agreed that these would not replace community caregivers, but would instead mediate between community caregivers (a cadre that does not exist on the official organizational chart of health care actors) and health facilities. CHAs will be expected to manage health posts and link health services and communities (MOH 2009a, MOH 2009b). The government has already started training this cadre of health workers, and the minimum requirement is a Grade 12 certificate. The very fact that they are to be placed at health posts means that they are simply a reinforcement of the existing clinic staff and not a formalization of community care and support. Secondly, caregivers' aptitude and readiness for care does not need or depend on an academic qualification. In fact when these new graduates are recruited and deployed to their assignments, their main role will be to refer complicated cases onward to health centres. Just after my fieldwork ended in 2012, the first group of CHAs graduated and were deployed to their stations. Interestingly, this initiative is donor driven and funding for both their training and their stipends when deployed are provided by the Department For International Development through the Clinton Health Access Initiative. These assistants are to receive a year-long training and monthly monetary stipends, and will be accredited by the Health Professionals Council of Zambia. It is envisaged that the primary functions of the CHAs will be to promote preventive health initiatives at the community level. Rather than curative or care function, they will focus on preventing malaria, respiratory illnesses, diarrheal diseases, tuberculosis, and HIV/AIDS, and promoting maternal and child health.

Clearly then, the community care and support gap is perpetuated by both government and its partners as they continue to medicalize the roles of caregivers and play down psychological support. Caregivers have their time, lived experience and life to offer as support for people with HIV. With high levels of unemployment in Zambia, pegging entry requirements for caregiving at Grade 12 only provides employment opportunities for younger unemployed youths and does nothing to integrate HIV/AIDS community care and support into the public health system.

As one examines the HIV/AIDS care and support landscape in the treatment era, when HIV treatment is also used for the prevention of further infections, the frictions between community caregivers and people living with HIV on the one hand, and donors and government on the other, is clearly evident. Should care and support for the already infected be prioritized in national interventions? Or should HIV treatment be prioritized in order to prevent new infections? This chapter has demonstrated that the answer to these questions depends on the actor. It has also shown that actors' needs and interests shift over time and through friction with other actors' interests, care practices are shaped.

In this and the previous two chapters, I have tried to provide one of the many histories of the emergence and evolution of HIV/AIDS care and support in

Zambia. I have demonstrated that the HIV/AIDS landscape has been dominated by international actors as much as it has been shaped by local actors. The two have interacted in an economic and technological space initially characterized by the absence of a state-led care system. The resulting care and support practices have been shaped by the friction among actors as each has advanced their interests and resisted what they considered 'inappropriate' practices. This section of the dissertation has shown that while HIV/AIDS care and support has evolved through various forms (from hospital-based home care to community-based home care and back to hospital-based community care) as actors exercised their agency in specific times and spaces, from 'being there for the patient' to monitoring treatment adherence, existing local values and concepts of care are still present. It has shown that current standards of care, as prescribed by transnational health bodies, were already present and being practiced before they were introduced to the country by international actors; that they were transformed through friction to what they are now; and that they continue to transform.

Part IV

Friction in Counselling Policy and Practice

Part 4 highlights the shifts in HIV/AIDS policy and practice as the epidemic matured from the pre-HIV test era through the pre-HIV treatment era to the treatment era and beyond. It demonstrates the relationship between those shifts and the agency of different actors, technology and the stage of the epidemic, and shows how friction between these actors has shaped HIV/AIDS care transformation in Zambia.

CHAPTER 7

Contesting Disclosure in Stigma Management

According to the Bemba[20] tradition, serious illnesses were a family affair. This was also true of many other ethnic groups in Zambia. When someone consulted a traditional healer, information and counselling were given to the family of the ill. As the narrative in chapter 1 shows, this approach to counselling was premised on the notion that an ill person was already overburdened by the illness and needed to have the load shared by family members. As Jansen (1978) describes it, this form of therapy management was the common type of family-based care for people who are ill. As family members shared in the counselling, which often took the form of information and advice giving by an older person or someone with special knowledge of medicine, responsibility to ensure that the ill person adhered to instructions were also shared. However, when HIV/AIDS became common in the late 1980s and 1990s, secrecy, privacy and individualism in dealing with the disease also became common.

As knowledge about HIV/AIDS increased, and following the Western rights-based approaches to dealing with people with HIV (Hardon 2012) that accompanied aid to fight and contain the epidemic, notions of privacy and confidentiality became common in Zambia. In addition, HIV prevention interventions promoted support groups for people testing HIV-positive. So HIV interventions came with new forms of counselling that encouraged a particular form of disclosure, especially to the family.[21] This often entailed that a person with HIV could disclose only to those with whom they were comfortable, who might not even be an immediate family member.

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[20] Bemba is a tribal grouping found mainly in the Northern, Muchinga and Luapula provinces of Zambia.

[21] ‘Family’ here refers to parents, siblings, children and other members, and not the spouse.

From early on, HIV/AIDS interventions encouraged disclosure as a way for HIV-positive people to gain support. It was believed that testimonies of disclosure would put a face to the epidemic, thus reducing stigma. When treatment became freely available in Zambia, like other countries in the early 2000s, disclosure was further promoted to increase adherence to ART. As most people then learnt about their HIV status when they were very sick, it was thought that adherence to treatment would only be possible if someone close to them was aware about their status and treatment requirements. Despite all these efforts by programmes to promote and facilitate disclosure however, it is not often practiced by people with HIV and those on HIV treatment. This shows that disclosure remains a contested issue among people with HIV, and may also bring anxiety to those to whom they disclose.

Numerous studies carried out in African countries since HIV treatment scale-up have demonstrated that silence and secrecy continue to surround HIV despite predictions by public health experts that HIV treatment would make disclosure easy (Bond 2010). Contrary to public health expectations, HIV stigma remains a significant factor, limiting disclosure even among informed patients. Although different aspects of HIV disclosure have been carefully studied and thoroughly reported (Lugalla et al. 2012; Moyer 2012; Moyer et al. 2013; Burchardt 2013; Bott et al. 2013; Hardon et al. 2013; Kyaddondo 2013; Tiendrebeogo et al. 2013; Ky-Zerbo et al. 2013; Sow 2013; Chaudoir et al. 2011; Gillard and Roark 2013; Desclaux et al. 2013; Linda 2013), the subject forms a key part and central focus of this dissertation. This chapter demonstrates that disclosure shifts over time and is contextual.

I argue that although disclosure is promoted as a norm in public health messages, it is contested. The resulting friction between the disclosure imperative and non-disclosure has led to selective disclosure and non-disclosure as forms of stigma management. The chapter adds to the body of studies on HIV disclosure by historicizing the contested domain of HIV disclosure in Zambia, providing a brief account of HIV disclosure and the rationale for disclosure at each moment in the HIV/AIDS epidemic in Zambia. It argues that the public health discourse on disclosure emerged in the context of and evolved around different technologies, aid and interventions. I show how existing forms of disclosure in Zambia interacted and intersected with external forms to create an ambivalent space where disclosure, particularly in the era of treatment, began to be questioned as people with HIV/AIDS have moved from fighting stigma to stigma management. Ethnographic material shows how people manage stigma through non-disclosure as they navigate their socio-medical worlds in their day-to-day experiences. Instead of being led by the assumption that when people talk openly about their status, they will be accepted without any stigma or form of discrimination, most people on HIV treatment choose to manage stigma through non-disclosure.

Disclosure as Activism and the Fight for Treatment

Winstone Zulu was the first person to disclose his HIV status publicly in Zambia. After testing for HIV as a requirement for a scholarship to pursue studies in Russia in 1989, Zulu found out that he had HIV and started writing poems about HIV/AIDS. In 1990, he publicly came out as living with HIV amidst high levels of stigma and discrimination for people with HIV/AIDS. This act of activism immediately captured the attention of then President Kaunda, who immediately honoured him by giving a special luncheon at the State House with Zulu as the guest of honour. Earlier, at a press conference on 4 October 1987, Kaunda had said that his son who died in 1986 had died of AIDS and he appealed to the international community to treat AIDS as a 'world problem'. Kaunda stated, 'It does not need my son's death to appeal to the international community to treat the question of AIDS as a world problem' (*The Register Guard*, 5 October 1987). He again spoke publicly about the AIDS-related death of his son at an International AIDS conference of 1988 in Vancouver (Bond 2010). The problem of AIDS, he insisted, was to be viewed as a problem that affected everyone and as such it begged the help of all. He implored the international community to fund AIDS interventions to halt the scourge. While Zulu's activist stance inspired many people with HIV/AIDS to come out in the open, it was received with mixed feelings by the public. Some felt it was unbelievable that someone would disclose their status, others called it a daring act, and still others asserted that he was faking his HIV status to get international attention and financial rewards. These reactions were echoed across Africa as people with HIV began to publicly disclose their sero-status (see Nguyen 2005).

Early acts of disclosure, like that of Zulu and a few others, were encouraged by organizations like Kara Counselling and Training Trust. As discussed in Chapter 5, Kara, under the leadership of American Jesuit priest Father Kelly, was one of local pioneers to champion the fight against HIV in Zambia. During the 1990s and early 2000s, more people 'came out' as living with HIV. Although the few who came out earlier like Zulu were indeed rewarded, as they gained privileged interactions with the outside world that allowed them to access treatment, many did it as an act of solidarity to let the government and its international partners know that they existed and needed treatment. The president added on to their voice. This was patterned after earlier acts of activism among gay people in America (Nguyen 2010; Hardon 2012). One of my informants, who later worked closely with Zulu and who herself 'came out' publicly in the early 2000s, also related how many people accused her of 'lying for money' because she looked healthy. She only started on treatment about ten years after she learned she was HIV positive, and about five years after treatment became freely available through the public health facilities in 2004.

As Chapters 4 and 5 show, access to free HIV treatment did not happen until 2004. The twenty years after the first official case of AIDS in 1984 saw many people in need of palliative care. With so many knowledge gaps about transmission of HIV, confirmed AIDS patients were encouraged to disclose their status to their carers. This was necessary to secure physical support from close family members and prepare them for perpetual care and support (Hardon et al. 2013). While family members provided support in difficult times, such as during illness, AIDS patients needed continuous care without the possibility of recovery. Letting some family members know would have secured the sympathy and empathy needed to sustain care over the long term. It was also necessary to allow family members to protect themselves against HIV infection. In reality though, during the 1990s, very few people even knew their status, as HIV testing was rare. Individual patients and their carers only suspected that it was HIV/AIDS. For those who were married and knew their status, they were encouraged to disclose to their spouses to protect them from infection if they were not already infected.

'Coming out' in the early years of the epidemic in Zambia (1990s) was thus linked to activism and the fight for treatment access. The practice was also guided by existing notions that linked disclosure to 'healing', based on the idea that coming to terms with one's illness and accepting it – demonstrated by talking about it openly – had positive health outcomes for the individual (Hardon et al. 2013). In addition, it was assumed that if people talked openly about HIV/AIDS, particularly their status, it would put a face on the epidemic and stigma would lessen (Nguyen 2010). Thus this was also viewed as a step in the fight against stigma and discrimination against people with HIV/AIDS. While international NGOs advocated that 'coming out' was an important step in fighting stigma, those publicly disclosing their status during the pre-treatment phase did not have a big push from international NGOs, as would become the case during the early years of treatment (mid 2000s). It was, therefore, rather heroic to disclose then as very few people had done so due to high levels of stigma. When the Network of Zambian People Living with HIV (NZP+) was established in 1996, most of those who had disclosed or were in the process of disclosing joined the organization, mainly to support each other as well as to pursue prospects for employment. By 2003, NZP+ had a membership of well over one million people.

Contested Disclosure Arena: Disclosure as Livelihood?

While early acts of disclosure were fuelled by a sense of activism and solidarity, the later disclosures soon started to be viewed as a quest for support and securing of livelihood. The reasons for this were twofold: first, some felt that no person in their right frame of mind would go to the public to discuss their private affairs, especially when linked to 'unacceptable behaviour'. This was mainly due to the existing notions at the time that HIV was a disease for promiscuous people. Second, most of those who disclosed were eventually employed as HIV testing and treatment advocates for NGOs, or at least operated as such in a volunteer capacity (Nguyen 2010). Organizations like International HIV/AIDS Alliance employed people with HIV as community mobilizers for testing and treatment and as health facility-based HIV-treatment supporters. This contributed to many more people disclosing and was fuelled by slogans like 'Nothing about us without us', fashioned by NZP+ to propagate and ratify global notions of the 'greater involvement of people with AIDS' (GIPA).

Disclosure as Prevention in VCT

Throughout my observations of VCT and ART adherence sessions at Chelston clinic, I was intrigued by the passion with which some counsellors persuaded people with HIV to disclose to their spouses. Although information about discordance was often discussed during pre- and post-test counselling sessions, it was only emphasized during post-test sessions for those who tested negative for HIV, in order to relay the message to spouses who had not tested. As one VCT counsellor explained to a man getting tested at Chelston clinic:

> These are your results and not your wife's. Remember what I told you at the start, that there is discordance and we have witnessed an

> increase in discordant couples in the last few years. So encourage her to test also. If you can, come together here again. If not now, keep talking to her and maybe when you come again after three months, she can accompany you. Remember the window period, it is very important to test again. Otherwise, congratulations!

For those testing positive, the counsellors emphasized that the person's spouse needed to be told. In fact during my fieldwork, there were informal debates in newspapers about prosecuting those who 'wilfully' infected others by not disclosing their known status. This disclosure imperative mainly had the objective of preventing infection of the 'innocent' spouse and the unborn baby in case a couple decided to have a child without the woman knowing that the spouse had HIV.

This disclosure discourse was shaped partly by the surrounding informal discourses, and partly by disclosure required for support, but mainly by morality discourses. In the counselling room, the morality imperative was the leading reason. As one male counsellor advised a husband:

> Don't you think she has a right to know? How can you live with that? And day after day you live together, eat together and sleep together and yet you are living a lie. You know, if both of you know your status, it will be easy to prevent her from getting HIV if she does not have it. … In fact it will be easy to negotiate for a condom when she wants it 'live' (*penetrative sex without a condom*). Your conscience will be clear and you will be healthy, free from worries.

It was often argued that the spouse had a right to know and a right to protect themselves from infection. Their knowledge, it was suggested, would enable them to protect themselves. Thus prevention of infection of the spouse was the main goal of disclosure in VCT settings. Counsellors often said that even if both partners were HIV-positive, they needed to prevent each other from getting different 'types' of HIV.

Disclosure as a Treatment Support

As HIV interventions and treatment expanded in 2004, those who were willing to publicly disclose their HIV status were able to be employed in treatment and care programmes based almost solely on their sero-status. They were to be model clients who would not only give a face to the epidemic, but also demonstrate that people could stay healthy on treatment if they followed certain prescribed behaviours, described as 'living positively'. Whenever needed, they could also use their testimonials to help newly diagnosed clients to come to terms with and accept their HIV status. Their involvement was also in rhythm with the 'greater involvement of people with HIV/AIDS' (GIPA) principle, in addition to providing cheap labour since they often worked as volunteers who only got a stipend when it was available.

In order to support adherence to HIV treatment, international NGOs that pioneered the provision of ART and the government used the 'buddy system' developed by Medicines Sans Frontieres (MSF) (Hardon 2012). In this system, a person with HIV identified someone, usually a close family member, disclosed their status to them and then went with them to access HIV treatment. Given worries about poor adherence and its effects, in order to access treatment during the earlier year of HIV treatment in Zambia (mid 2000s), it became mandatory for an HIV-positive person to disclose to someone who would accompany them to receive treatment, their 'treatment buddy'. This became an important system at the start of ART availability, but later on it lost its importance as it was replaced by other support systems, like ART support groups, where ART patients came together and discussed their experiences, as well as the use of expert clients.

When projects like the Antiretroviral Community Education and Referral (ACER) project (described further in Chapter 8) started providing HIV treatment in 2004, the focus of disclosure was to support adherence to treatment, patterned after the MSF buddy model. As most people were very sick and bedridden when they started treatment, a treatment buddy was expected to help them navigate the new life on medicines. 'Clients', as people on treatment were called, were persuaded by project staff (including nurses) to identify someone to whom to disclose their HIV status, someone who could support them on treatment. In fact it was an informal requirement that a client present a buddy at the health facility even just to receive the information and instructions, even though it was not part of the guidelines. The buddy could then come alone to collect refills in case the client was unable to do so. The treatment buddy was also tasked with supporting the person on treatment with physical chores as well as nutritional support. At the time, food was also being prescribed as part of treatment, as most people had been devastated in the absence of treatment and their bodies could not easily respond to treatment without adequate nutrition. As such the ACER project partnered with the Catholic Dioceses of Lusaka and Ndola to link clients to home-based care programmes. As most people had been sick for some time prior to treatment, they were visible as people living with HIV/AIDS. But even within families, this disclosure was indirect and unvoiced.

The concept of a treatment buddy was partly shaped by the assumption that Africans could not adhere to lifelong treatment. It came in handy as most people during the early years of HIV treatment in Africa accessed ARVs when they were already very sick, frail and in some cases either not ambulant or needed help walking the often long distance to the clinic. Interestingly, for most diseases adherence was encouraged through existing forms of family support. What changed with HIV/AIDS was the stigma attached to it. The acquisition of HIV, which was highly moralized and linked to sexual promiscuity and imminent death made it difficult to talk about it openly within the family and beyond. Although in the West this moral discourse was initially linked to what was considered the perverse behaviour of men having sex with men, in the African AIDS epidemic, it was moralized because a person who acquired HIV was considered to have had illegitimate sex. Even when allegations of witchcraft were used to mask sexual contact as route of acquisition of the virus, it did not do much to reduce the stigma. This is because the stigma was not only associated with the route of transmission, but also with the dying body, which often was frail and dysfunctional, vomiting and soiling clothes, actions often associated with HIV opportunistic infections (Moyer 2012; de Klerk 2011; cf. Livingstone 2012).

In the midst of high levels of stigma even within the nuclear family, the buddy system interacted, revived and reshaped existing extended family support for illness to a more personalized type of support in which a person could only disclose to a person they felt most comfortable with. This appealed to people with HIV as stigma was experienced even in the family, and this instruction to disclose to a buddy was therefore welcomed. For caring family members, knowing the cause of suffering was always considered important. Thus, existing forms of family disclosure and the value on caring for people with serious illness interacted with a biomedical model of disclosure and shaped treatment support and adherence. While medicines were acquired in the clinic, adherence needed to happen in the community and the treatment programmes pragmatically emphasized this support system.

Participating in this form of disclosure also seemed the only way to access the treatment that was so needed, as still is, for people with HIV. As mentioned, most people accessing treatment during the early years were very sick and needed help managing the complex regimens. As treatment enabled people to regain their health, making physical symptoms hibernate, their agency was also renewed, which allowed them to resist disclosure as a new form of stigma management (as discussed below). Since people with HIV may well show no signs of illness and can do almost anything that people without HIV can, they no longer need to be defined by the virus, but instead accorded the same dignity, honour and consideration given to people without the virus. This normalization could only come about if those with HIV abandoned the sick role and went on with their lives without regard to their sero-status. An act of disclosure works against this notion as it constantly associates the person with the virus, so much so that people do not think of the person independent of the virus, but define them by it. Even usual displays of affection such as hugging are likely to be viewed not as simple gestures, but as demonstrations that the HIV-positive person is not stigmatized.

Treatment Citizenship: Support Groups as Disclosure

NZP+ was the only support organization for people with HIV prior to the arrival of free treatment. It was established in 1996 as a group of people living with HIV/AIDS to support and represent themselves and their peers. NZP+ did not evolve to become an activist organization for two main reasons: first, their agenda was to provide a safe space for people with HIV to interact and through their solidarity fight stigma. Secondly, as the government and international NGOs implemented HIV programmes, they worked with NZP+ as partners in such programmes or as participants in different policy forums. Eventually, in the early 2000s, their focus turned to lobbying for free access to treatment. Just after treatment became freely available, the Treatment Advocacy and Literacy Campaign (TALC), another advocacy organization, was formed in 2005 with similar objectives. TALC aimed to lobby for equitable and affordable treatment care and support for people with HIV, while also promoting treatment literacy. These two groups work through their district chapters to coordinate with their support groups, which have for a long time been used as a forum for sharing and disseminating HIV/AIDS-related information.

Pioneers of ART provision in Zambia, including CIDRZ and the ACER project, supported the formation of support groups mainly to mobilize people for and support them in treatment. The other aim was to nurture a pool of model clients who would be used to help with adherence and general treatment support for other clients. Support groups would also help people regain their lost self-esteem and come to terms with their sero-status. By presenting oneself to a group, a person discloses not only to the group, but publicly, and they associate themselves with a group that may be visible in their community. Although research shows that such groups support careful and pragmatic disclosure (Moyer 2012), some group members disclose and live with HIV more openly than others. Even those disclosing publicly may develop some discomfort with it over the years. After openly living with HIV for about seventeen years, Winstone Zulu continued to disclose his status at public meetings, but probably not with the same level of zeal and enthusiasm as he did at first. When he gave a speech on 9 June 2008, at the Global Leaders Forum in New York, he started by disclosing his status, but rather hesitantly: 'Let me just make a little fool of myself. I don't normally do this. But I am tempted to do this. When I was tested for HIV seventeen years ago, I was told…'. As Moyer (2012) demonstrates, when disclosure is viewed as a norm, people disclose more when they first discover their HIV status and eventually stop disclosing, or at least disclose more discreetly and strategically as they come to terms with the reality that there is more at stake in disclosing.

Non-disclosure as Stigma Management

Before I met Mr Silozi[22] at the Chelston ART clinic, I had a naive idea that since treatment had been around for some time and those accessing were looking healthy, people with HIV did not care about being known as such. The fact that Mr Silozi quickly told me he was only there to look for someone, and then left, made me contemplate the possibility that he had already thought about or even rehearsed the situation. After he left, when his name was called, I realized that disclosure was not as easy as it was preached by public health interventions. I remained for almost six months doing my observations and interviews at the clinic and never saw Mr Silozi at the clinic again. Later, when I went to his home to have my car fixed, we did not talk about the day we encountered each other at the ART clinic. In an infor-

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[22] See Chapter 3.

mal interaction with Mukalakasye over lunch, I discreetly asked him about whether he was aware that Mr Silozi was accessing treatment at his clinic and he said he was, but that Mr Silozi had called him to let him know that he had changed residence and was thus accessing treatment at the University of Zambia clinic, which was nearer to his new residence.

I felt so uncomfortable after confirming what had actually happened behind the scenes. I spent a week without visiting the clinic, reflecting on how I had infringed upon the space. This experience also made me zoom in more on the issue of disclosure in the different spaces. As I paid more attention to what was going on at the ART clinic registry, I realized that pseudonyms were often used to collect drug refills. The buddy system was strategically used by people on treatment to disguise themselves with fake names when accessing medicines. For example, I encountered Tonny, who I had known since 2002, at the ART clinic. After chatting for a while the name 'Ngoma' was called, and Tonny stood up and went in to see the doctor. When I saw him after, Tonny asked me what I was doing at the ART clinic, and I explained to him about my study. He looked down and, with a sigh, told me he had been taking ARVs for two years. He asked, 'You remember when I was very sick and you gave me a lift to town and offered me a Coca Cola and I refused and asked for money instead? That is when I started treatment. But so far, so good'. I then offered to take him for a drink at the nearest Kantemba (makeshift store) when he was done, and he signalled to me after collecting his prescription refill.

I offered to take him for a drink partly to learn more about his experience with treatment and disclosure, but mainly because I did not know what to say after he told me his status. The little space as we walked would allow me to think about how I was going to talk to a person who was not only HIV positive, but also a former neighbour. My family lived in the same neighbourhood as Tonny before he moved to another township within Lusaka. When Tonny told me he had HIV, the feeling that I now shared a heavy responsibility to keep his secret was overwhelming. Our relationship would now be partly determined by his HIV status; the dynamics of the relationship would become that of a normal and able person who was to help a vulnerable one. His position was to be pitied even though he was now healthy. The responsibility was not only overwhelming, but also difficult to navigate. Apart from the many people I knew who have HIV, with whom I interacted in a work setting, Tonny was the first one who was a neighbour and who entrusted me with the secret. He made me realize that disclosure was as difficult for the person disclosing as it was for those to whom it was disclosed.

Tonny started treatment after he had already moved to the new place, but decided to come back to Chelston clinic. As we sat and enjoyed our drink, I thanked him for telling me, doing so almost silently, even though there was no one else nearby. We sat on a bench under a tree that provided us refreshing shade. He told me that he did not just tell anyone, but that he trusted me as a friend. He related how I had helped him with money in the past, something that I had forgotten about, and how he still missed me for what he called my 'kind heart'. He said using a different name at the clinic provided double protection to his honour and reputation (see Illife 2006). He mused, 'What if people at the church knew that I had HIV? They obviously would not understand when and how I got it'. I offered to drive him to his home and we had a long chat in the car about how he felt about disclosure. One thing was clear for him; there needed to be a very good reason to disclose.

Many people on treatment, like Nakawala whose story was briefly mentioned in Chapter 3, do not want to be known as such by their community. They also do not see the need to disclose to their family members. In the case of Nakawala, she learnt about the status of her children when she had to care for them. Fred, her second-to-last son, was very ill during my fieldwork and I visited them several times at the University Teaching Hospital. Because he was so sick and almost unconscious, the doctor explained to Nakawala about his HIV status and the medicines he had prescribed and encouraged her to ensure that he took his medicines on time. When Fred recuperated, Nakawala told me that the nurse spent some time talking to Fred and she suspected that the nurse had advised him on how to continue with treatment. Nakawala told me that the only direct discussion that she and Fred had about his HIV status was when she told him that 'the doctor said he had to continue taking the medicine so he needed to go to a nearby clinic to get some more'.

As Nakawala said, maintaining honour is one reason she did not want her community to be aware that she had HIV. Even within the family, disclosure usually does not purposely happen, even in cases of serious HIV-related illnesses. As people regain health, they also want to be seen as 'normal', like everyone else. They do not want to be defined by the virus they carry in their bodies, sometimes in very low and undetectable quantities. So in subtle ways they resist anything that could result in their being known as HIV-positive and thereby losing honour (Moyer 2012). I am happy to report that I encountered Fred almost a year later when I visited Nakawala and he was in good health.

Another example of resisting disclosure is the case of Clifford (also mentioned in Chapter 3). Clifford expressed an unwillingness to disclose his son's status to his thirteen-year-old son because he said he felt his son was still too young to know. Clifford's case demonstrates his resistance to a system of care and support that he considers an imposition from the West, and exemplifies the kind of discomfort that people experience when they must be a bearer of bad news. Clifford felt very uncomfortable about telling his son, and as pressure to disclose mounted, he decided to change the treatment access point for his son, probably in the hope that he might be less pressured to tell his son there.

Although some studies relate failure to disclose to stigma, often linked to illness and disease, disclosure is still contested in an era where most people with HIV have no visible illness symptoms. One of the earlier rationales for disclosure was that when people know your status, they would give you support. In the time of treatment and with the recent revision in guidelines that make people start treatment early (WHO 2010, 2013), such kind of support is no longer required. The disclosure imperative paradigm placed the patient in a position to be constantly pitied and helped. The person disclosing was thought to be placing an endless burden onto someone else, a duty not to betray the heavy trust and to provide continuous support. For the person disclosing, not only were they delegating responsibility for caring for the self, but also trading their honour. As such it made both the person disclosing and the one to whom disclosure is made uncomfortable.

While frictions between the disclosure imperative and practices of non-disclosure have been present through the history of the epidemic from the pre-treatment era to the arrival of treatment access, they are even more present in the current early treatment programmes. Following the recent revisions in guidelines that enable people with HIV to access treatment even when the CD4 count is still high and they are still without illness (WHO 2013), the disclosure imperative has shifted from treatment adherence back to prevention. Moreover, with treatment freely available and people with HIV looking healthy, the imperative to disclose has diminished. This situation has brought challenges for counsellors who have been trained to promote disclosure. During the early years of treatment, most people were very sick and the justification for disclosure was that they needed support to be well. Thus prevention and treatment adherence goals were linked to the support and welfare of people living with HIV. In the treatment-as-prevention era of today, when people may start treatment early, justification for disclosure is difficult and often counsellors do not know how to effectively explain why someone should disclose. The imperative to disclose is further confusing today as the kind of support required to adhere to treatment has changed, as treatment literacy has not only increased (ZDHS 2007; Simbaya et al. 2008b), but many people start treatment before any serious illness and can care for themselves.

As people with HIV navigate their social worlds, they learn ways of managing stigma. This entails knowing to whom, why, when and how to disclose. As Hardon and others (2013) argue, disclosure is embedded in social relationships and people disclose only to the people they chose and in particular social spaces. Studies have shown that those associated with support groups disclose less (Moyer 2012, Moyer et al. 2013). Some people learn how to decipher public health information in a safe space of fellow HIV-positive people. This study adds, however, that non-disclosure is an emerging form of stigma management.

With most people with HIV looking healthy, about nine years after HIV treatment became free and accessible, stigma still persists in Zambia. This raises doubts about the assumption that treatment or even disclosure would lead to less stigma. As the data show, people use stigma management strategies that involve non-disclosure or very selective disclosure to a significant few (Bond 2010; Colson 2010). The situation can best be described as a continuing friction between the disclosure imperative and local solidarity and moral integrity.

This chapter has demonstrated how the objectives of disclosure have shifted over time, alongside disclosure itself. In the pre-treatment era, the disclosure imperative aimed to strengthen social and other networks so that the sick might have support to access food and other supplies, and also enable prevention of HIV infection among those caring for them. Disclosure has shifted and been shaped by technology in a contested space. In the early years of treatment, the disclosure imperative pendulum swung toward treatment adherence while still supporting prevention goals. As treatment was scaled up and people with HIV became ambulant and ‘healthy’ the question ‘What is the point?’ became inevitable (Moyer 2012). In current programmes that emphasize treatment as prevention, the disclosure imperative pendulum has swung back toward prevention goals as knowledge of HIV has increased and the type of support needed has shifted.

Whether stigma is perceived or experienced, most people choose not to disclose as a way of managing stigma. This study demonstrates the difficulty of pinpointing one group of actors as calling the tune in HIV/AIDS care interventions and shows that local concepts feed into international guidelines, which are later handed down and formally institutionalized. However, the application of guidelines is often selective, creating a gulf between policy and practice.

CHAPTER 8
Contesting Models of Community Engagement in HIV/AIDS Programmes

In this chapter I look at the way in which HIV/AIDS care and support guidelines were shaped in the relationship between international donors, policy organizations and the Zambian national government. The key question that guided the gathering of the data for this chapter was: How do these differently positioned players shape the policy landscape and, consequently, with a focus on the role of communities and more specifically people living with and affected by HIV, how are HIV/AIDS care and support services provided? While this chapter does not aim to provide a comprehensive examination of all HIV/AIDS policies, it attempts to describe the policy-making arenas and policy-shaping engagements in which different actors interact to shape care and support practices. After providing a brief history and evolution of care guidelines and policies, I offer a case study on the provision of HIV/AIDS services in the early 2000s, paying close attention to the ways that differently positioned actors from global, national and local contexts (myself included) interacted to shape various aspects of ART scale-up in Lusaka.

Care and Support Policies in a Historical Perspective

Our understanding of the current HIV/AIDS policies and guidelines in Zambia can be enhanced by reflecting on the historical development in care and support guidelines that provided a framework at different moments in the history of the epidemic. Although some policies were not fully implemented due to political and/or financial reasons, care and support programmes were neither hampered by nor dependent on the implementation of these policies. For example, the national HIV/AIDS policy remained in draft form for more than three years, yet HIV/AIDS programmes proliferated during the same period. An examination of these policy developments is important, however, because they situate care and support in time and space, demonstrating the contexts in which care evolved. How did Zambia end up with the current situation of a weak and fragmented policy and regulatory framework for providing HIV/AIDS care and support? What could explain the existing gap between policy and practice in caring for people with HIV/AIDS, and what pre-conditions led to the current non-government-led HIV/AIDS care and support practices?

From the 1970s to date, Zambia has undergone policy and structural reform processes that partly account for the history and evolution of caregiving in Zambia. The Alma-Ata Declaration[23] of 1978 provided the drive and direction for the Zambian government to make primary health care the key channel for the delivery of health services. The Alma-Ata Declaration is considered a major milestone of the twentieth century in the field of public health, as it identified primary health care as the key to the attainment of the goal of 'health for all'. Before international instruments like the Alma-Ata Declaration, community participation had already been recognized and was playing a key role in the Zambian health system. This is demonstrated by the fact that almost one in three rural facilities were developed on a 'self-help basis' (Mwewa et al. 2013). The construction of these health facilities was community driven, with little or no external support from either national or international sources. In most cases, this meant community members mobilizing and using local materials to build the structures. Such practice made sense in a Zambian cultural context where families (nuclear and extended) and communities routinely support people in times of crisis, including illness.

Policies during the late 1970s and early 1980s also included elements of free medical services (Kalumba et al. 1994; Malama 1994). In response to management challenges in the health system, and pressure to restructure the delivery of health services in line with structural adjustment programmes (SAP), reform processes were provided for under the Medical Services Act of 1985, including the creation of semi-autonomous hospital management boards for all major hospitals.

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[23] Additional information on the Alma-Ata Declaration is available at www.who.int/social_determinants/tools/multimedia/alma_ata/en/index.html.

In 1991 the Ministry of Health began to promote community involvement, which was framed as way to bring essential health care as close to the family as possible. Neighbourhood health committees (NHCs) were created (in 1994) to link clinics and communities and increase access to basic health services. Through this process, a national community mobilization curriculum was developed and a training of trainers and roll-out methodology was adopted. These were intended to increase the effectiveness of the more than one hundred thousand NHC members countrywide, with a specific focus on teaching NHCs health promotion and community mobilization skills (Mwewa et al 2006).

Although the Kaunda[24] government had long had a socialist manifesto that promoted community involvement, interestingly, this move toward increased community involvement was renewed in 1991 during a period of structural adjustment. The World Bank-funded Social Recovery Project increased community targeting and involvement as way of reversing the effects of structural adjustment programmes and assisting the rural poor. This effort was then renewed as the Zambia Social Investment Fund in 2000. The rationale for the World Bank's involvement was captured in this statement that stressed the reasons for community involvement:

> The Bank will bring its experience of social funds in more than 30 countries, as well as expertise in supporting decentralization processes, strengthening poverty monitoring and analysis systems, and using community-based development as a strategy to contribute to poverty alleviation and creation of a system of efficient local governments. (World Bank 2000)

Community involvement was necessary as these projects stipulated that any infrastructure built in communities must have a twenty five per cent contribution, either financially or materially, from the benefiting communities. This approach interacted with existing community participatory approaches to shape community involvement in health care, which climaxed in the creation of neighbourhood health committees.

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[24] Kenneth Kaunda was the first president of Zambia for twenty-seven years from 1964 to 1991.

In March 1996, a new National Health Services Act came into operation that established the Central Board of Health. The Central Board of Health was designed to monitor, integrate and coordinate the programmes of the health management boards, whereas the Ministry of Health was the main policy-making and regulatory body (Mwewa et al. 2013; Bossert et al. 2000). The health delivery system was reorganized into four levels, with the Ministry of Health at the apex and the health centres/health posts at the lowest level. The reform programme also provided for local resource mobilization and the creation of a number of structures for popular participation, including area health boards and health centre advisory committees (Masiye et al. 2008; Bossert 2000; Kalumba et al. 1994). Alongside actors in the state health care provision structures were non-state actors, mainly organized through community home-based groups as caregivers.

My interviews with HIV care and support policy makers, implementers and recipients support the claims of existing studies that community home-based care is viewed as an integral part of Zambia's public health system. Non-state actors, including religious organizations, provided the initial innovative community-level responses to HIV, but increasingly the government has engaged in the coordination and regulation of such services through the Ministry of Health, National AIDS Council and the development of various operational frameworks. However, NGO-led programmes have continued to evolve independently due to resource constraints, changes in clients' needs, increased demands for services, introduction and scale-up of ART and the direct engagement with communities by NGOs. Although community caregivers were already an integral extension of the public health system prior to the introduction of ART, treatment scale-up has increased and expanded their roles and promoted the clinicalized and medicalized care roles at the expense of psychological and other social care needs (Cataldo et al. 2010).

Between 1988 and 1990, the Catholic Church and the Salvation Army established large community home-based care programmes. By 1993, more than twenty mission hospitals were providing such services to people living with HIV.[25] While religious-based organizations have long provided care

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[25] In 1993, the Ministry of Health oversaw 43 hospitals and 796 other government health facilities, while there were 29 mission hospitals and 69 other mission health facilities, and 11 private hospitals and 139 other private health facilities (Berman 1995).

and support to people inflicted by illness, particularly the rural poor, state regulation of these did not begin until the mid-2000s. Although the state had, by default, always been involved in regulating health care as custodians of its citizens' health, such regulation of home based care began to be formalized in 2005 through the creation of the Home-Based Care Forum.

The forum was established by key community home-based care organizations and other stakeholders, with a primary responsibility to address the lack of guidelines and standards in home-based care. In 2007, several stakeholders, including the National AIDS Council and the forum, developed through a series of 'consultative' processes a set of guidelines entitled the 'Zambia National Minimum Standards for Community and Home-Based Care Organizations'.

Following these guidelines, eight modules comprising 'the National Community and Home-Based Care Training Package' were developed for the comprehensive training of community caregivers. The guidelines provide a framework for accrediting the operations of community home-based care organizations, which is based on meeting the 2007 National Minimum Standards (MOH & NAC 2007). The associated comprehensive training guide provides for both qualitative and quantitative monitoring of such programming by the National AIDS Council and the Ministry of Health. The extent to which monitoring is done depends largely on resource availability.

The current policy environment is shaped by various sector-specific and national-level policies, usually as conceived by global and transnational health bodies and agencies. Since 1992, Zambia has been implementing wide-ranging health-sector reforms aimed at attaining equity of access to cost-effective quality health services, as close to the family as possible. The Sixth National Development Plan (SNDP) provides the overall national framework for all government social and development efforts. The health chapter in the plan lists four key priorities in the area of HIV. These priorities are also reflected in the current National AIDS Strategic Framework for 2011–2015. Among the priorities listed in both the national development plan and the strategic framework is a focus on accelerating universal access to ART and care and support for people living with HIV, as well as their caregivers and families. Community care and support is recognized within the strategic framework as an integral component of the continuum of care, particularly in the context of ART. However, such community care is often tied to treatment support. In fact all policy documents always mention the terms 'treatment', 'care' and 'support' together, linking care and support to HIV medicine availability and the support to take them.

The Joint Mid-term Review of the National AIDS Strategic Framework (2006–2010) indicates that the introduction of the 2007 minimum standards contributed to an improvement in the quality of care provided to clients (NAC 2009). However, the national HIV policy does not provide specific definitions of the types and roles of 'community volunteers' who provide such care. The term 'caregiver' is not explicitly used in the text despite the recognition that community-based volunteers and support from faith-based organizations and religious health facilities form the backbone of care and support programmes. Moreover, the absence of a regulatory framework for incentives given to community caregivers has hampered the effective management of community caregivers in Zambia, including in providing guidance to faith-based organizations and other NGOs on how to better support community caregivers, most of whom are volunteers and are not compensated for their work.

Due to a proliferation of NGOs, including what have been referred to as 'pocket' or 'briefcase' NGOs, the state has moved in to regulate their formation by pegging registration prerequisites slightly higher. In 2009, Parliament passed the NGO Act, intended to address and clarify the registration of NGOs, including community-based organizations.[26] The full implications of the law for civil society are still unclear as it has not yet been fully implemented by the government.

This brief historical description leaves us with the clear impression that care and support policies and guidelines have not been coherent, and that whatever existed in form of guidelines was fragmented and not effectively implemented. This has consequently led to a fragmented care and support terrain that has depended mainly on community-based organizations and other NGOs mainly driven by international organizations in both scope and funding for their activities.

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[26] In Zambia, for any pronouncement to become law, it has to be debated and passed by Parliament.

The link between policy and practice is not always clear-cut. Often there is a lag between policy and its implementation. While the extent to which the policies and guidelines influenced practices cannot be ascertained, it can be argued that the policy environment, including both local and international actors during the different periods of the epidemic, influenced the evolution of care and support for people with HIV/AIDS. The weak and fragmented policy framework for care programmes and the influx of financial resources provided a fertile ground for piloting and implementing varied approaches of care and support for HIV/AIDS by different international and local actors at different times and spaces.

Globalization of the Local and Localization of the Global

In 2003, just before state-sponsored HIV treatment became available, the International HIV/AIDS Alliance (United Kingdom) and the Population Council (Washington, DC) jointly developed a proposal and received funding from the US government and the European Union to implement and document an intervention that aimed to test the effect of community education and referral on communities' knowledge about ART and how to access it. The project also aimed to build the capacity of people with HIV to contribute to preventive behaviour, ART adherence and health maintenance, and to measure levels of adherence among people with HIV on treatment. The project would provide ART to two hundred people in Zambia and test a model for supporting adherence to treatment using people with HIV as treatment supporters. As discussed in Chapter 6, ideas about a person's right to absolute confidentiality were shifting, and this project introduced a 'buddy' system to support adherence to treatment in 2004. People testing positive for HIV were encouraged (and in some cases, required) to disclose to a close friend or relative who was expected to come along with them to the health facility as a buddy or treatment supporter. It was assumed that this buddy would remind the person with HIV to take their medicines consistently and on time. This 'expert client' and 'treatment buddy' model soon accompanied HIV treatment as more sites were opened to provide ART. This was influenced by Medicines Sans Frontieres' earlier approaches to providing treatment (Hardon 2012).

The project involved several partners, including traditional healers, the Network of Zambian People Living with HIV (NZP+) and the home-based care groups coordinated by the Catholic Diocese. The partnership was strategic: most people who needed HIV treatment were bedridden due to long bouts of sickness. The home-based care groups would provide a strong community component, including home visitations and food packages that were an integral part of treatment as most people with HIV/AIDS then were not ambulant and had lost their means of livelihood. People with HIV who were part of NZP+ were already open about their status and would prove invaluable in mobilizing others for treatment, supporting them at the health facilities and occasionally displaying themselves as 'models' of 'living positively'. Traditional healers would refer their clients with visible symptoms of HIV to the biomedical system to access HIV treatment. The project provided a referral book to all partners, which they would use to document referrals made between traditional healers and health facilities, between health facilities and home-based care and between home based care and traditional healers. Although traditional healers talked romantically during workshops about how they had told their clients that there was no known cure for HIV and that the solution was ART from health facilities, such referrals were never traced to the public health facilities.

The Institute of Economic and Social Research at the University of Zambia was involved as a research partner, but drawing principal investigators from different organizations, including the Population Council, the International AIDS Alliance and the Ministry of Health. I was employed on the project as Research Manager to coordinate the Operations Research housed at the institute. As a non-faculty member at the time, my main responsibility was to plan and implement all research activities and to liaise with the intervention group at International AIDS Alliance.

The project's activities, which were originally intended to begin in May 2004 in Lusaka, only did so about seven months later in November. The main reason for the delay was that the Center for Infectious Diseases Research in Zambia (CIDRZ), which had more funding from the US government to provide HIV treatment in Zambia, was working with all the health facilities able to provide treatment at that time.[27] It was common knowledge in Lusaka that this had come about largely because the director of the Lusaka District Health Management Team had ties to CIDRZ and had given them

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[27] Prior to state-sponsored free ART treatment in Zambia, provision of ART was gradually rolled out as more clinical staff were trained in ARV management, provided through a verticalized system with stand-alone VCT and ART clinics. Thus clinics without trained staff could not provide ART.

priority. He was a medical doctor who had been trained in public health at the University of Alabama at Birmingham (the research institution behind CIDRZ) and was also serving on CIDRZ's first board of directors. Given the amount of funding the CIDRZ programme was offering for HIV treatment and the good relationship between them and the Ministry of Health, which had been established via their ties to the Lusaka District Health Management Team, CIDRZ started providing treatment in most of the health facilities able to provide ARVs in Lusaka.

The International HIV/AIDS Alliance and its partners had to wait for additional facilities to be ready to provide HIV treatment services. To be eligible to provide ART, health facilities needed physical space (preferably with adequate privacy) and at least one clinical officer trained to prescribe ART. With more funds to support both infrastructure expansion and training of health staff, CIDRZ had more capacity to decide which facilities they worked in. When N'gombe clinic (one of Lusaka's peri-urban health centres) was chosen as a site for the International HIV/AIDS Alliance, it still awaited the construction of an ART block and the training of ART providers. The project only had funds to provide treatment and other intervention activities. About seven months later, the N'gombe clinic was still not ready to provide treatment, while CIDRZ expanded the number of their health facilities. The International HIV/AIDS Alliance project had to re-strategize and negotiated with the University of Zambia to provide treatment at the university clinic, where they were allowed access toward the end of 2004.

By the time the N'gombe health facility was 'ready', Zambian president Levy Mwanawaza had declared free access to HIV treatment. When treatment began to be rolled out, the expert client and treatment buddy model described above pioneered by these international NGOs was scaled-up as CIDRZ continued to provide treatment in most health facilities. In 2005, Zambia Prevention, Care and Treatment Support (ZPCT), an HIV/AIDS implementing organisation under Family Health International (FHI360), joined CIDRZ in the provision of treatment, using the same model and extending it to include more 'lay' HIV/AIDS counsellors. Eventually, CIDRZ, with funding from the CDC and ZPCT (via USAID) divided the country into two parts, with CIDRZ taking the southern region and ZPCT providing treatment in the northern region. Both teams worked with the Ministry of Health and possessed both the technical know-how and the technological equipment required for diagnostic tests of the different aspects related to HIV treatment. The reporting chain of command for both was that they collected data from their partners and reported to their national organizations through district and provincial structures. Every six months, a report was sent to the United States Office of the Global AIDS Coordinator, a body that has global, transnational, national and sub-national structures that work with local actors to implement HIV/AIDS services.

Project goals guided the official national response to the epidemic, particularly during the treatment scale-up era. Existing responses to the epidemic by the Ministry of Health and the National Aids Council, as well as by some local NGOs, were shaped by international actors as these entered the health facilities, not only with equipment and medicines, but also the technical expertise of how to care for people with HIV/AIDS. For example, there was change from existing notions of shared care responsibilities at the community and the family levels, to a buddy system where people with HIV only needed to share their status with one other person of their choice and not necessarily turn to their family to support them. The nature of care and support was not only limited to adherence, but also medicalized. As observed in the working group meetings, these international norms also came to dominate the policy think tanks of the ministry of health through the participation and agency of international actors in working group meetings.

This case also demonstrates the existence of power struggles between international players. Because CIDRZ had more resources to provide treatment care and support to more people, due to their existing relations with the district health office, they had more bargaining power to influence government decisions. However, this power was facilitated by the director of the Lusaka District Health Management Team, a local government official. On the other hand, the International HIV/AIDS Alliance project, also an international partner, was without a matching level of resources and could not move things in their favour. They too had strategized and included Dr Velepi Mtonga, then the director of Technical Support Services at the Ministry of Health, as one of the principal investigators on the project. But this did not facilitate their efforts because during this start-up phase Dr Mtonga had left the country in order to study in the United States. The project had repeated meetings with the permanent secretary at the Ministry of Health, but these did not yield much in the way of results.

Third, the initial pragmatic response to the epidemic (as shown in Chapter 4) emphasized family and community involvement, elements of which are still present in care and support programmes. However, this approach was prevented from emerging organically in response to locally identified needs when international NGOs provided funding to implement health-facility-based models that emphasized the buddy system, rather than family networks, to support treatment. This shift also marked a transition from the psychological care and support model that had dominated previous pragmatic responses toward a biomedical model that focused more on support for treatment adherence. Thus the international programmes that brought HIV treatment to Zambia also brought with them a shift toward a predominantly biomedical understanding of HIV at both policy and practical levels. This view supersedes longstanding framings of HIV as a disease shaped by social life. The Zambian model of caring for people with HIV, which emerged prior to treatment and which placed a strong emphasis on family and community involvement, has become overshadowed by a biomedical model of care in the age of treatment.

This case of interaction between international and local organizations reveals how they are in a continuous process of interaction, shaping and reshaping each other. One cannot locate a single point of power; power is spread among the actors and throughout the hierarchy as international NGOs fund and work with or through local community-based organizations.

This kind of influence from international organizations in local and national contexts has a long history of shaping policy engagements, particularly in countries like Zambia, which heavily depend on international aid. While this chapter does not provide an analysis of policies related to HIV/AIDS care and support, it has shown how such policies are made and how different actors demonstrate their agency. It has highlighted the role played by international organizations in shaping HIV/AIDS care and support policies and practices while demonstrating the micro-dynamics of power within the various interactions among the international and the local and how the intersection has shaped HIV/AIDS care policies and practices.

This chapter has demonstrated that policy-shaping engagements are multidimensional, multidirectional and dialectic. There is often a friction of the local and global concepts just as there is between local and international actors, both of which shape the formulation of policy. While I have argued that international actors have dominating effects on care practices in Zambia, it goes without saying that local actors as individuals and as a collective are not docile and passive recipients of change. In many cases, local ideals influence international and national guidelines while these are later institutionalized as guidelines and policies through a dialectical process. As Foucault argued, where there is power, resistance is evoked and actors develop ways of resisting practices that challenge their perceived norms (Foucault 1978; Lupton 1997). This was evident in the counselling room as counsellors chose to resist certain aspects of counselling guidelines and replaced them with shared societal norms, as we saw in Chapter 3. Therefore counselling as a practice has evolved and been transformed by the interaction of actors at many levels (donors, policy makers, care providers, people living with HIV and communities) and linkages and interactions within and across the levels (van der Geest et al. 1990).

Part V
Conclusion

This part attempts to draw conclusions from the data and shows the challenges of drawing conclusions using a multilevel perspective. It summarizes the research results and makes suggestions for HIV/AIDS care policy, practice and further research.

CHAPTER 9
Conclusions and Reflections

Throughout this book, I have shown the difficulties anthropologists face in their attempts to draw conclusions. What transformed counselling? This question was more difficult to answer at the end of my writing than when I began my research. As I have shown, drawing a conclusion from a multilevel analysis is a daunting task. It is difficult because all the perspectives from the various levels contain some empirical truth, making it is hard to discern which perspective to weigh more than the other. The ambivalent niche where multiple perspectives converge is more of a constellation of different views than a conclusion. For this reason I do not provide a conclusion per se, rather I provide a set of reflections that can be interpreted by the reader.

I started by demonstrating that different concepts and frameworks are only relevant at a particular time and place. As most people returned to 'healthy' and working lives, the idea of defining themselves as a group of citizens that claims rights and responsibilities based on their HIV status became less important. The objective of activism and support groups slowly faded as treatment was assured. Most people now start their treatment early and do not have to experience serious illness before commencing treatment. The dissertation depicts a constantly shifting HIV/AIDS care scene characterized by technological advancements, international project goals and local concepts and perspectives of care interacting at different times and spaces to define and shape practices.

How did transformation occur and what shaped HIV/AIDS care practice? Friction. Ethnographic vignettes in this dissertation have shown different interactions and how they shape HIV care practices. These interactions are never uniform and predictable. One group of actors may be successful at influencing and defining the agenda in one situation and quite unsuccessful in another. Each project has goals, which sometimes are in line with national goals, and sometimes are in line with international funding opportunities and not Zambian priorities. In the health sector, several committees and working groups have been formed to bring together all stakeholders working in a particular area, like HIV/AIDS. These groups usually meet to discuss and decide on policy and practices related to their areas of intervention. During these meetings, different interests are presented and debated and decided on. I have referred to the collision of the interests and goals advanced by the different actors in HIV/AIDS care as 'friction'. Since different views and ideas are eventually resolved and decisions made, I argue that it is the friction between the different interests advanced by different actors at a particular time and space that transforms and produces care practices.

Also noteworthy is the facilitative role that technology plays in fuelling transformation. When new medical technologies have been introduced, external actors have been more successful in defining policies and practices. For example, when HIV testing became available in Zambia, it came as a package of prescribed biomedical and social components of testing and counselling. The counselling component was shaped more by the biomedical component than the social, as pre- and post-test counselling was defined by and around testing technology. When access to ART began to increase in 2004, earlier external actors of HIV/AIDS care with experience implementing similar programmes in other countries, such as the International HIV/AIDS Alliance, were instrumental in defining and shaping HIV/AIDS care practices. They pioneered the 'buddy' treatment support system as well as the use of laypeople at ART clinics as treatment supporters. Motivated by the low turnout for counselling and testing, the organization recruited, trained and deployed community mobilizers. Later, these came back in the form of adherence counsellors and treatment defaulter tracers. When such new concepts are introduced, those that resonate with existing ones are not resisted, but the interactions between different actors that institutionalize care concepts are not without disagreements.

Instead of theorizing HIV/AIDS forms and practices as an imposition from outside, I have argued that it is friction that produces care forms and practices. I use friction as a metaphor to describe divergent and usually conflicting interactions among HIV/AIDS actors that produce care practices. Existing national forums facilitate the presentation of agendas, discussions and adoption of practices. These interactions are never without differences of opinion, and the resulting resolutions are similar to what is called 'collective bargaining' in the labour market. All views contribute to the outcome. It is difficult to isolate one factor or actor as a dominating influence on the transformation. Technology, global public health goals, local and international actors all come together as actors in HIV/AIDS care. Knowledge and technology converge as the friction between the different actors shapes care practice. I have shown how local concepts of care made their way to the international scene and how they bounced back, sometimes received without question and institutionalized, but other times contested. In either case, resulting forms of care practices are a negotiated product of friction between and among different actors. This dialectical process of the fertilization of ideas to create stable forms is clearly distinguished and departs from prevailing views that suggest an imposition of ideas from outside as shaping HIV/AIDS practices in sub-Saharan Africa.

This study shows that although HIV/AIDS care has been transformed, local concepts and notions of care are still present. The Chikankata case demonstrates how earlier years of the epidemic were informed by pragmatism and Christian duty to provide a package of care that, in the absence of treatment, brought together existing local forms and concepts of care with Christian concepts. Existing concepts of 'family' counselling where an individual received counselling and information in the presence of at least one family member, was used in the earlier work of the Chikankata mission hospital as they visited and provided services to people with HIV/AIDS in their homes. As such the existing concepts of care where serious illnesses were disclosed to the family to ensure compliance with sometimes complex, traditional regimens and information given came to be used when providing HIV/AIDS services during the earlier years when the hospital-based community home-care approach was used. These forms later came to be formalized through, and partly replaced by, the 'buddy' system and couples counselling. Concepts like 'shared confidentiality' also reflect the original 'family' counselling model in the pre-treatment era, during the 1980s. Hospital-based community home-care has re-emerged in its current form, where health facilities organize groups of volunteers to support treatment adherence and trace defaulters in communities, sometimes even conducting home-based VCT (Mutale et al. 2010). These volunteers are recruited by and based at health facilities and are sent to the community to trace people with HIV who initiated treatment and have been lost to follow-up. Thus the evolution of HIV/AIDS care has been constantly punctuated by frictions among different actors with regard to models of community engagement, resulting in hybrid models where both local and transnational concepts are present.

Existing knowledge, the stage of the HIV/AIDS epidemic, new technologies, economic circumstances, and local and international organizations form a group of actors at every moment in the history of the epidemic. I have sought to demonstrate how the interaction of a group of HIV/AIDS care actors results in care practices. I show that it is difficult to distinguish between the local and the global as the local is always present in the global and vice versa. It is also not possible to distinguish between different groups of HIV/AIDS care at any particular moment. Different working groups bring actors together – local and international care providers, government and non-governmental organizations, local community-based organizations and international non-governmental organizations, academic and non-academic institutions and counselling providers – all work together in different constellations to define care practices.

This study also suggests that transformation can best be studied through a historical lens, demonstrating the value of combining history and ethnography to understand the present. This engagement with history shows how different actors found themselves in the group of HIV/AIDS care actors and through their interactions with other actors, in a milieu fashioned by existing medical technology, defined care practices. The hospital ethnography shows what is happening in the area of counselling as a form of HIV/AIDS care and demonstrates that there is a difference between policy and practice, highlighting both the pragmatism of both counsellors and their clients as they selectively apply national, global, and project guidelines.

It is also evident from the ethnography that shifting project goals have shaped forms of counselling as seen in the different trajectories. HIV/AIDS counselling as a practice has evolved since it was first practiced in the 1980s. It shifted alongside the epidemic and intervention goals, initially from care, to prevention, to treatment goals. These shifts have shaped the form and trajectory that HIV/AIDS counselling has taken. Thus, HIV/AIDS counselling has been shifting over time alongside the different goals and priorities of the HIV/AIDS care actors.

In Chapter 5, I demonstrated how technology shaped counselling as treatment became available, further shifting counselling goals to support people to stick to their schedule of taking medicines. As overall HIV/AIDS care shifted, counselling goals also shifted. As treatment became available, counselling as psychosocial support began to decline and became replaced with ritualistic forms of 'inform and test', as pre- and post-HIV test counselling is often done, and treatment compliance monitoring through adherence 'counselling'. During the pre-HIV treatment era and after, choice, counselling and confidentiality (the three Cs) became emphasized as voluntary counselling and testing programmes scaled up their interventions with both prevention and treatment goals. However, as the ethnography shows, voluntary counselling became less prevalent in the HIV-treatment era, as 'provider-initiated testing and counselling' and PMTCT of HIV initiatives, respectively, took root in HIV/AIDS care settings. This raises the question: Are these forms of counselling appropriate?

Tracing the origins of HIV/AIDS disclosure in Zambia and following it through the grey literature over the years adds to the argument that existing local forms and concepts in HIV/AIDS care informed the international discourse and norms on disclosure. I have shown how earlier acts of self-disclosure were considered activist and heroic, and not as influenced from outside. NGOs later came to engage with these confessional technologies with different goals: to aid in the counselling and acceptance process and to promote positive living and adherence to treatment. Later acts of disclosure were 'calculated' and selective and in many cases non-disclosure was preferred as a way to manage stigma. The dissertation has shown how the ever-changing goals for disclosure as part of HIV/AIDS care have shifted alongside disclosure itself, a relationship that has been facilitated by treatment availability. It has demonstrated the friction between the disclosure imperative and non-disclosure as a form of stigma management. On the one hand providers are socialized to promote disclosure as a way for HIV-positive people to gain support in their treatment (thus boosting adherence and fighting stigma), while on the other hand both providers and people with HIV subtly resist classic forms of disclosure as promoted by HIV/AIDS care programmes. People with HIV particularly resist the disclosure imperative and use non-disclosure to manage stigma, especially in the HIV-treatment era where most people living with HIV start treatment early without clear signs of AIDS illness.

The policy landscape is a cluttered milieu. No one actor or group of actors dominates the scene, but each negotiates their agenda to collectively define practice. Actors interact in a specific place and time to produce forms of care and practice, and this ethnographic research shows that obvious fissures exist between policy and practice. This has been demonstrated by the resistance observed in the counselling room.

Both policy and practice result from frictions among HIV/AIDS care actors. For example when one of the pioneers of PMTCT research and paediatric HIV treatment, Dr Chipepo Kankasa, proposed testing all HIV-exposed children (born to HIV-positive mothers), she was met with resistance. Both local and international actors felt it was against the rights of both the mother and the child, unless the mother consented to the HIV test. Discussions of the issue went on for some time before her proposal became policy. At the time of my research, all children born to HIV-positive women were being tested routinely as they were brought for vaccinations using DNA polymerase chain reaction (DNA-PCR) test before the age of one year, and using a rapid test after one year. Since 2011, Dr Kankasa heads the centre of excellence for paediatric HIV/AIDS at the University Teaching Hospital, which is mainly funded by the CDC, and she chairs the nation PMTCT working group. She is highly respected by both local and international actors and her authority is evident in the meetings she chairs or attends.

I present this book as an introduction to the methods of studying the transformation of practices. How can anthropologists begin to isolate the relative importance of different actors in a process of transformation, and is it even possible? How can anthropologists study historical processes? Can genealogy and history be effectively combined to study transformations, in order to interpret the present?

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SUMMARY

Zambia's first official case of AIDS was reported in 1984. It is argued that HIV, a virus that causes AIDS possibly reached the country two or more decades earlier. Starting as an insignificant health problem, the epidemic grew to significant proportions in the late 1980s, attracting different funders and actors on the scene. This dissertation shows how differently positioned actors, including people with HIV, their friends and families, local health providers and officials, policy makers, local and international NGOs, bilateral, multilateral and transnational organisations, economy and technology interacted to shape care practices for people with HIV and AIDS. I argue that it is the interactions between different actors at the different times and spaces that shaped both HIV/AIDS care practices and its evolution.

This dissertation is organised into four parts. Part One gives an introduction to the research and highlights the theoretical lens used to tell and reflect on the ethnographic story that shapes the arguments. In chapter one, I engage with multilevel perspective as a lens used to understand the views and interactions of different actors. The local HIV/AIDS scene is decorated by a complex group of local, national and international actors who, through interaction and friction, shape each other's care practices. I argue and demonstrate that resilient forms of existing care interacted with guidelines from 'outside' to shape international guidelines, which were later institutionalised through transnational bodies. The friction between these actors and their concepts and practices results in the emergence of new forms and practices that are shaped by both the pragmatism and agency of local actors and knowledge of international agencies.

Part two (Ethnography) is an ethnography of counselling within an urban clinic setting. This part sets a tone for the main story of this dissertation. I provide a thick description of HIV counselling practice in its main care tra-

jectories. I walk you through the VCT, ART and Maternal and Child Health Departments at Chelston clinic in Lusaka and focus on their counselling practices before turning to their historical evolution. This part describes counselling practices as a form of care for people with HIV as well as showing the inequalities in accessing care in urban spaces.

Part three (history), details the Zambian history of HIV/AIDS care and support and shows how local and international actors interacted to shape HIV/AIDS care and support in general and HIV counselling in particular. It provides a historical evolution of HIV/AIDS care. It starts from the early 1980s when the first AIDS case was officially reported by the State to the time of my fieldwork in 2012 and beyond. I highlight the main care models during the pre- HIV treatment era, VCT era and the ART era, with a focus on counselling as care for people with HIV/AIDS. I use this history to explain how the HIV/AIDS care practices have evolved and transformed to the present. I show how antiretroviral medicines have not only changed the management and treatment of HIV and AIDS, but have also contributed to the transformation of care and support for people with the disease. The section further demonstrates how friction among actors has transformed care giving for people with HIV/AIDS in Zambia. While chronic care as evidenced by the presence of the key elements of care and support as prescribed by the World Health Organization is evident, local concepts and values continue to suffuse care practices, demonstrating that it is friction between actors and concepts and not imposition that has shaped HIV/AIDS counselling.

Chapter four focuses on community-based forms of care giving that have emerged and evolved over time and details their evolution and 'integration' into the health system in Zambia. This chapter examines how patients' needs and caregivers' roles have transformed in the last twenty-five years, evolving from home-based care (HBC) to community based care (CHBC) before transforming once again to hospital-based community care. It demonstrates that care giving has been shaped by both actors and technology, shifting the roles of caregivers from traditional home-based physical and psychological care of bedridden patients in their homes to monitoring of clients' adherence to HIV medicines alongside overall changes in home-based care models. I argue that current forms of care, where hospital-based volunteers go to the community for treatment defaulter tracing (community outreach to find clients who do not continue to take their medicines), draw on pre-existing forms of care from the early pragmatic responses to the HIV/AIDS epidemic.

Chapter five brings the focus to counselling, presenting a history of HIV-related counselling practices and how they have evolved since emerging in Zambia in 1987. Initially, the goal of HIV counselling was to provide psychological support to the dying and their families, but as knowledge about (and treatment for) HIV grew, counselling objectives expanded to include encouraging behaviour change such as safer sexual practices, disclosure of HIV status, convincing people to test, encouraging people to begin and continue antiretroviral treatment and shaping the sexual and productive choices of HIV positive people. The chapter highlights a number of key shifts in counselling practices in Zambia over the last 25 years, demonstrating the relationship between those shifts, changes in medical technology, local resilience and agency, (inter)national political will, and the epidemiological maturity of the disease. Chapter six continues to examine HIV/AIDS care and support practices in the HIV treatment era and highlights further shifts in counselling practices and how different actors shaped the transformation.

In Part four (Frictions in Counselling Policy and Practice) I discuss policy agenda setting and the difference between policy and practice. I highlight the shifts in HIV/AIDS policy and practice as the epidemic matured from the pre-HIV test era through the Pre-HIV treatment era to the treatment era and beyond. I demonstrate the relationship between those shifts, the agency of different actors, the technology and age of the epidemic and shows how friction between these actors has shaped HIV/AIDS care transformation in Zambia. Drawing on the ethnographic material in Part three, chapter seven shows how both counsellors and their clients resist guidelines, and highlights the contested terrain of disclosing HIV-positive status. The shift from disclosure as a tool for fighting stigma to non-disclosure as a way of protecting reputation and moral dignity has given birth to an emerging new form: stigma management.

Chapter eight examines models of community engagement and highlights the contestations in the HIV/AIDS policy landscape and how local, national and international actors interact to shape policies and guidelines and demonstrates that this process is neither linear nor unidirectional. By highlighting the micro dynamics of power, I highlight the workings of local agency and the resilience of existing forms and practices. I conclude in chapter nine with insights gained from the chapters and reflect on the main issues and their implication for policy, practice and further research. While I do not draw conclusions from the data, I attempt to show the challenges of drawing conclusions from multi-level perspectives.

SAMENVATTING

In Zambia werd het eerste officiële geval van AIDS gemeld in 1984. Er wordt gesteld dat HIV, het virus wat AIDS veroorzaakt, het land twee of meer decennia eerder bereikte. Wat begon als een triviaal gezondheidsprobleem, groeide in het einde van de tachtiger jaren uit tot een epidemie van significante omvang en trok verschillende financiers en actoren aan. Dit proefschrift laat zien hoe de interacties tussen verschillend gepositioneerde actoren, waaronder mensen met HIV, hun vrienden en families, lokale zorgverleners en bestuurders, beleidsmakers, lokale en internationale NGO's, bilaterale, multilaterale en transnationale organisaties, de economie en technologie, de zorgpraktijken vormen voor mensen met HIV en AIDS. Ik betoog dat de interacties tussen verschillende actoren, op verschillende tijden en plekken, zowel de HIV/AIDS zorg praktijken vormen evenals de ontwikkeling ervan sturen.

Dit proefschrift bestaat uit vier delen. Het eerste deel introduceert het onderzoek en belicht de theoretische lens die wordt gebruikt om het etnografische verhaal te vertellen en erop te reflecteren. In hoofdstuk één gebruik ik het *multilevel* analyseperspectief als een lens om de opvattingen en interacties tussen verschillende actoren te duiden. Het lokale HIV/AIDS tafereel wordt gekenmerkt door een gecompliceerde groep van lokale, nationale en internationale actoren die, door hun interactie en frictie, elkaars zorg praktijken beïnvloeden. Ik beargumenteer en demonstreer dat de wisselwerking tussen veerkrachtige vormen van bestaande zorg én richtlijnen van 'buitenaf' de internationale regelgeving beïnvloedde, die later werd geïnstitutionaliseerd door transnationale instanties. De frictie tussen deze actoren en hun concepten en praktijken heeft geleid tot het ontstaan van verschillende vormen en praktijken die zowel beïnvloed worden door pragmatisme en *agency* van lokale actors alsmede door de kennis van internationale organisaties.

Deel twee (Etnografie) is een etnografie van counseling in een stadse kliniek. Dit deel geeft de toon aan voor de grote lijnen van het proefschrift. Ik verschaf een '*thick description*' van HIV counseling praktijken in de voornaamste zorgtrajecten. Ik neem je mee in de VCT, ART en moeder- en kindzorg afdelingen van de Chelston kliniek in Lusaka en richt me eerst op de praktijken van counseling trajecten voordat ik hun historische ontwikkeling bespreek. Dit deel beschrijft counseling praktijken as een vorm van zorg voor mensen met HIV en toont de ongelijkheden in toegang tot zorg in stedelijke omgevingen.

Deel drie (geschiedenis) geeft een gedetailleerde beschrijving van de Zambiaanse geschiedenis van HIV/AIDS zorg en ondersteuning en toont hoe de interacties tussen lokale en internationale actoren de zorg en steun omtrent HIV/AIDS beïnvloedde, en bespreekt HIV counseling in het specifiek. Het beschrijft de historische ontwikkeling van HIV/AIDS zorg vanaf begin tachtiger jaren toen het eerste geval van AIDS door de overheid werd gemeld tot aan het begin van mijn veldwerkperiode in 2012 en de jaren daarna. Ik behandel de belangrijkste modellen van zorg in de periode voordat er antiretrovirale (ART) middelen beschikbaar waren, tijdens de VCT periode, en tijdens de ART periode, met een focus op counseling als zorg voor mensen met HIV/AIDS. Ik gebruik deze geschiedenis om uit te leggen hoe HIV/AIDS zorg praktijken zich hebben ontwikkeld en getransformeerd tot aan de huidige tijd. Ik laat zien hoe antiretrovirale middelen niet alleen management en behandeling van HIV en AIDS hebben veranderd maar ook hebben bijgedragen aan de transformatie van zorg en steun for mensen met de ziekte. Dit gedeelte toont verder hoe de frictie tussen actoren de zorg voor mensen met HIV heeft getransformeerd in Zambia. Terwijl chronische zorg evident is, blijkende uit de aanwezigheid van de belangrijke componenten van zorg en steun zoals voorgeschreven door de Wereldgezondheidsorganisatie, blijven lokale concepten en waardes zorgpraktijken veranderen. Dit laat zien dat het de frictie is tussen actoren en concepten die HIV/AIDS counseling vormt en dat het niet enkel wordt opgelegd van buitenaf.

Hoofdstuk vier richt zich op gemeenschapsvormen van zorgverlening die ontstaan zijn en zich in de loop van tijd verder ontwikkeld hebben, en beschrijft de ontwikkeling en 'integratie' ervan in het gezondheidssysteem in Zambia. Dit hoofdstuk onderzoekt hoe in de laatste vijfentwintig jaar de behoeften van patiënten en rollen van zorgverleners zijn getransformeerd van thuiszorg (HBC) naar gemeenschapszorg (CHBC) en later ziekenhuis-gebaseerde gemeenschapszorg. Dit laat zien dat de zorgverlening zowel door actoren als door technologie wordt beïnvloed, waarbij de rollen van zorgverleners veranderden van het bieden van traditionele fysieke en psychische thuiszorg aan bedlegerige patiënten naar het monitoren van therapietrouw van cliënten, naast algemene veranderingen in modellen van thuiszorg. Ik betoog dat de huidige vormen van zorg, waarbij ziekenhuis-gebaseerde vrijwilligers naar de gemeenschap gaan om *defaulters* op te sporen, teruggrijpen op bestaande vormen van zorg ten tijde van de vroegere pragmatische aanpak van de HIV/AIDS epidemie.

Hoofdstuk vijf richt de aandacht op counseling en schetst een geschiedenis van HIV-gerelateerde counseling praktijken en de ontwikkeling ervan in Zambia sinds 1987. Het aanvankelijke doel van HIV counseling was psychosociale steun bieden aan stervenden en hun families, maar omdat de kennis over (en behandeling voor) HIV toenam, breidden de counselingdoelstellingen zich uit tot het bevorderen van gedragsveranderingen zoals veilige seks, openbaarmaking van de HIV status, mensen overtuigen om zich te laten testen, aansporing om te beginnen en door te gaan met antiretrovirale middelen, en beïnvloeding van seksuele en reproductieve keuzes van HIV positieve mensen. Dit hoofdstuk belicht een aantal essentiële verschuivingen in counseling praktijken in Zambia in de laatste 25 jaar, waarbij de verbanden worden besproken tussen deze verschuivingen, veranderingen in biomedische technologie, lokale weerbaarheid en *agency*, (inter)nationale politieke wil, en de epidemiologische looptijd van de ziekte. Hoofdstuk zes onderzoekt HIV/AIDS zorg- en ondersteuningspraktijken in het tijdperk van hiv-remmers en benadrukt veranderingen in counseling praktijken en hoe verschillende actoren de transformaties beïnvloedden.

In deel vier (Fricties in Counseling Beleid en Praktijk) bespreek ik de agendasetting van beleid en het verschil tussen beleid en de praktijk. Ik bespreek de veranderingen in HIV/AIDS beleid en praktijk gedurende de looptijd van de epidemie vanaf de periode voordat er HIV testen beschikbaar waren, tot aan de periode tot voordat er medicatie beschikbaar was, gevolgd door de periode van medicatie en daarna. Ik duid de relaties tussen deze periodes, de *agency* van verschillende actoren, de technologie en het verloop van de epidemie, en laat zien hoe de frictie tussen deze actoren transformaties in de HIV/AIDS zorg heeft gevormd in Zambia. Op basis van het etnografische materiaal uit deel drie, toont hoofdstuk zeven hoe zowel counselors als hun cliënten zich verzetten tegen richtlijnen, en belicht het betwiste terrein van het bekendmaken (*disclosure*) van de HIV positieve status. De verschuiving van *disclosure* als instrument om stigma te bestrijden, tot *non-disclosure* als een methode om reputatieschade te voorkomen en morele waardigheid te behouden, heeft een nieuwe vorm geproduceerd: stigma management.

Hoofdstuk acht onderzoekt modellen van maatschappelijk engagement en belicht de betwistingen in het HIV/AIDS beleidslandschap en hoe de wisselwerking tussen lokale, nationale en internationale actoren, beleid en richtlijnen heeft gevormd en toont aan dat dit noch een lineair proces, noch eenrichtingsverkeer is. Door de microniveau dynamieken van macht te beschrijven laat ik de lokale *agency* en weerbaarheid zien van bestaande vormen en praktijken. Ik sluit af in hoofdstuk negen met inzichten verkregen uit de hoofdstukken en reflecteer op de belangrijkste kwesties en de implicaties voor beleid, praktijk en aanvullend onderzoek. Terwijl ik geen conclusies trek uit de data tracht ik de uitdagingen te laten zien van het trekken van conclusies met een *multilevel* analyseperspectief.

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An Ethnography of HIV/AIDS Care Transformation in Zambia

Joseph Simbaya