Longing for belonging: Adolescents' experiences of living with HIV in different types of families in Swaziland

Shabalala, F.S.

Publication date
2017

Document Version
Final published version

License
Other

Link to publication

Citation for published version (APA):
Shabalala, F. S. (2017). *Longing for belonging: Adolescents' experiences of living with HIV in different types of families in Swaziland*. [Thesis, fully internal, Universiteitsbibliotheek].

LONGING FOR BELONGING:

ADOLESCENTS' EXPERIENCES OF LIVING WITH HIV IN DIFFERENT TYPES OF FAMILIES IN SWAZILAND

FORTUNATE SINDISIWE SHABALALA

LONGING FOR BELONGING:

Adolescents' experiences of living with HIV in different types of families in Swaziland

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor

aan de Universiteit van Amsterdam

op gezag van de Rector Magnificus

prof. dr. ir. K.I.J. Maex

ten overstaan van een door het College voor Promoties ingestelde commissie,

in het openbaar te verdedigen in de Agnietenkapel

op woensdag 18 januari 2017, te 14.00 uur

door

Fortunate Sindisiwe Shabalala

Geboren te Mliba, Swaziland

Promotiecommissie:

Promotor:

Prof. dr. R. Reis	Universiteit van Amsterdam

Co-promotores:

Dr. A. De Lannoy	University of Cape Town
Dr. E. Moyer	Universiteit van Amsterdam

Overige leden:

Prof. dr. A.P. Hardon	Universiteit van Amsterdam
Prof. dr. R. Pool	Universiteit van Amsterdam
Prof. dr. R.A. van Dijk	Universiteit van Amsterdam
Prof. dr. A.M. Zamberia	University of Swaziland
Dr. K.E. Cheney	ISS Erasmus University

Faculteit der Maatschappij – en Gedragswetenschappen

LONGING FOR BELONGING:

Adolescents' Experiences of Living with HIV in Different Types of Families in Swaziland

FORTUNATE SINDISIWE SHABALALA

DEDICATION

This monograph is dedicated to all the young people who are infected with, and affected by HIV and those who have died of AIDS-related illnesses in Swaziland.

TABLE OF CONTENTS

LIST OF FIGURES AND TABLES

ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
AISSR	Amsterdam Institute for Social Science Research
ART	Antiretroviral Therapy/Treatment
ARV	Antiretroviral
CD4	Cluster of Differentiation 4
eNSF	Expanded National Multisectoral Strategic Framework on HIV and AIDS
GNP+	Global Network of People Living with HIV
HIV	Human Immunodeficiency Virus
HTC	HIV Testing and Counselling
MoET	Ministry of Education and Training
MoH	Ministry of Health
MSM	Men who have Sex with Men
NGO	Non-Governmental Organisation
NERCHA	National Emergency Response Council on HIV and AIDS
NSF	National Multisectoral Strategic Framework on HIV and AIDS
PITC	Provider-Initiated HIV Testing and Counselling
PLHIV	People Living with HIV
SAN!	Stop AIDS Now!
SWANNEPHA	Swaziland National Network of People living with HIV and AIDS
UNICEF	United Nations Children’s Fund
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

ACKNOWLEDGEMENTS

‘It always seems impossible until it is done’, said Nelson Mandela. The journey through this doctorate has been a remarkable one, characterised by laughter and tears, celebrations, and frustrations, but it has been mostly a rewarding experience that only those who have gone through a similar odyssey can comprehend.

I am indebted to a number of beautiful and intelligent people whose direct and indirect contributions have led to the fruitful completion of this dissertation. They are too many to name here, but I believe they know who they are, and just how grateful I am for their ideas, critique, support, and encouragement through our conversations, emails, and virtual chats, as well as their prayers. From the bottom of my heart, I thank you for being there and for being willing to listen, critique, motivate, and encourage me.

First and foremost, my sincere gratitude goes to all the adolescents and their caregivers who opened their ‘doors’ and shared the incredible stories about their lives, I thank you from the bottom of my heart. I hope through this dissertation I have told your story as close to how you would have recounted it yourselves.

I extend my deepest gratitude to my Promoters: Prof. Dr. Ria Reis, Dr. Ariane de Lannoy, and Dr. Eileen Moyer for their diligent scrutiny, indelible guidance, and judicious coaching, and their support and enduring patience throughout the writing of the dissertation. Your insightfulness was indeed incredible. I am eternally grateful for your mentorship, openness, teamwork, and friendship. Thank you for putting up with me.

My appreciation also goes to S’celile Zwane and Sibongile Mndzebele who shared the newspaper advert that started my journey into the PhD programme at the Amsterdam Institute for Social Science Research (AISSR), University of Amsterdam. I also extend my appreciation and special thanks to the MaxART Consortium for their immerse contribution to the thesis through feedback on various presentations I made, funding presentations to local and international conferences. In particular, I thank Yvette and Maureen at STOP AIDS NOW!, for facilitating the translation of the summary of dissertation to Dutch. Thank you to all of you! Thank you – this doctorate is for you as well!!!

I thank my employer, the University of Swaziland, who granted me the leave of absence to pursue my studies. My sincere thanks also go to my colleagues at the Faculty of Health Sciences, University of Swaziland, for their support and encouragement. Special thanks goes to Prof. N.A. Sukati who was always there when I needed her and who always checked on my progress; to my sisters Ms. N. Nxumalo-Magagula and Dr. Ruth Mkhonta for their prayers and constantly reminding me that all is possible with God; and to my colleagues Ms. S. Masuku, Ms. N. Nxumalo, Dr. S.V. Dlamini, Mr. M. Shongwe, and Mr. A. Muyre for keeping me on my toes throughout my study.

My appreciation also goes to the secretariat and the immigration advisor at AISSR for their support in many different ways during the course of my study.

I thank the management and staff of the health facilities who opened their doors for me as I went about my data collection, and for providing useful critique, questions, and comments during feedback sessions that enriched this study. To protect my participants I will not mention the facilities or the staff by name, but you know yourselves. Thank you for letting me into your facilities and sharing the stories about your work, all of which enriched the monograph. Thanks to you all!

My gratitude also goes to all my assistant researchers and team supervisors who dedicated their time and showed great enthusiasm during the data collection and preliminary analysis for this project. These were Mbongwa Mhlanga, Wandile Mlangeni, Nkumane, Mbongeni Dlamini, Mxolisi Dlamini, Masotja Dlomo, Tengcina Lukhele, Bong'nkosi Lukhele, Philile Matsenjwa, Thandekile Mbuyisa, Kayise Mhlanga, and Colile Shongwe.The teams were supervised by Sakhile Masuku and Voyivoyi Lukhele. A special gratitude goes to Mxolisi, who passed away almost a year after the survey, and who thus never lived to see this final product to which he contributed so much. May his beautiful soul rest in eternal peace.

My sincere thanks and appreciation goes to Lungelo and Fanele who helped with transcribing and translating the interviews and focus group data, as well as contributed to shaping the title of the monograph, and to Nontsikelelo and Zamashengu for constantly reminding me to finish and come back home. Thank you ladies, you rock my world! Many thanks also go to my house helper, Mrs. Vuyisile Jele, who looked after my family during my absence.

My deepest gratitude goes to the Mlangeni family who accommodated me in their home during data collection at the rural site. Our long chats over dinner contributed immensely to my understanding of the everyday life of the community. In that way you also became my research participants and enriched my understanding of the ways of life in the study area. Thankyou!

This study and the production of this dissertation would not have been possible without the funding provided by the Dutch Post Code Lottery through Stop AIDS Now! (SAN!) and the Amsterdam Institute for Social Science Research (AISSR), University of Amsterdam. Without your financial and other equally important resources, this study would not have seen the light of the day.

Saving the best for last, I would like to extend my sincerest appreciation to my parents: my mother, Mrs. Eleanor Zwane, who dedicated her entire productive life to making mine a better one, and my father –Mr. Titus Zwane – who did not live to witness this day. My sincere gratitude also goes to my wonderful husband and best friend, Jabulane Theodore Shabalala, for always being there – 24/7/365 – to listen to me, laugh with me, cry with me, and motivate and encourage me every step of the way. Indeed, *Mshengu ube Ludvonga lwami mbamba*!!!Thank you for being my rock.

At the beginning of this journey, it seemed impossible that I would one day have a final product, but now that it is done, it is possible! *Kini nonkhe ngitsi UMdali akanisikelele*!

PART ONE: SETTING THE STAGE

This first part provides an introduction and background to the study. It has two chapters: chapter one introduces the study and presents a general overview of the research, and chapter two focuses on the methodological approach.

CHAPTER ONE

INTRODUCTION AND BACKGROUND

Introduction

Sicelo was diagnosed with pulmonary tuberculosis (TB) and human immune-deficiency virus (HIV) in 2009, when he was eleven years old, and was started on anti-TB and antiretroviral (ARV) treatment the same year. When I met him in 2013, he was fourteen, and living with his paternal grandmother and other family members. His biological parents (father and mother) were both alive, but they were not married when Sicelo was conceived and they went their separate ways a few years after his birth. His father lived in one of the industrial towns with Sicelo's stepmother and their two children. Although Sicelo wished to stay with his father, I was informed that his stepmother was against the idea. Sicelo's biological mother spent most of her time in Johannesburg as a cross-border trader selling handicrafts. During school holidays, Sicelo occasionally visited his maternal family. However, his paternal grandmother was against the visits, alleging that it resulted in Sicelo 'defaulting' on (skipping or missing) his treatments because of lack of supervision. Yet according to Sicelo, he intentionally defaulted on his treatment because he wanted to go and stay with his father. Hence, Sicelo has restarted his ART and TB medication three times. On the day I met Sicelo, it was to be his fourth re-initiation, and he was to be switched to a second-line regimen of ARV drugs because, according to the nurse at the clinic, he had developed resistance to the first-line drugs. At the time of the study Swaziland did not have a third-line ARV regimen, so nurses and doctors at the clinic were concerned that if Sicelo failed to take his drugs this time around, he would be out of options for treatment. Sicelo had also developed multidrug-resistant TB (MDR-TB) and needed to be admitted to a facility for stronger and longer TB treatment. At the time of the study, the two families had not met to discuss Sicelo's health and social situation because, according to his paternal grandmother, 'they (maternal family) don't care' (interview, 2013).

Sicelo is one of between ten and twelve thousand adolescents living with HIV in Swaziland (Ministry of Health [MoH], 2014), a country where one-fifth of the 1.2 million people are infected with the virus (Central Statistics Office [CSO] and Macro International, 2008). His story provides a glimpse of the larger context of adolescents living with HIV and illness in a high prevalence, resource-limited setting, as well as how family dynamics and children's tactics impact adherence and the overall health of children living with HIV.

A significant proportion of adolescents are growing up without one or both biological parents, many of whom have died of AIDS-related diseases, in most countries in sub-Saharan Africa (Heuveline, 2004; Hosegood, 2009; Phillips, 2011; Ritcher and Sherr, 2008; Ritcher et al., 2009). Others, like Sicelo, are for different reasons also growing up under the care of just one parent, grandparents, siblings, stepparents, or foster parents (Heuveline, 2004; Phillips, 2011; Ritcher et al., 2009). Studies show the disruption that an HIV-positive diagnosis has on adults' lives, and the important role of family support in coming to terms with the HIV illness and in shaping a more positive identity (Mburu et al., 2014b; Reynolds-Whyte, Mongensen, and Twebaze, 2014; Russell et al., 2015). However, the subject of adolescents living with HIV in different family contexts has received very little attention, and especially not from the adolescents themselves. Without an empirically informed understanding of young people's needs, a mismatch in care needed by adolescents and provided by different caregivers is bound to happen.

The primary objective of this study is to understand how different family configurations influence the experiences and meaning-making – the act of making sense of an experience…to make an interpretation of it (Courtenay, Merriam and Reeves,1998:65) – of adolescents living with HIV in a resource-limited setting that is affected by a high prevalence of HIV. The primary participants in the research were young people aged between twelve and nineteen years in rural and urban settings in Swaziland who were both aware of their HIV-positive diagnosis and on ART. Situating these adolescents' experiences within their familial worlds, this study asks: What are adolescents' motivations for HIV testing? How do they make sense of, and respond to an HIV-positive diagnosis? And how do they navigate treatment, stigma, and the disclosure of their HIV status in their everyday lives? Although a mixed-methods approach was used to collect data, the bulk of the dissertation draws on and presents the findings of my qualitative work with thirteen adolescents (details in chapter three) whom I followed over a period of at least a year and up to eighteen months. I triangulated the data from this qualitative research with that of their parents and health care providers, at facility and community levels, as well as with data collected from key informants. I expand on this methodological approach in chapter two.

The next section of this chapter provides a brief background to and rationale for the study. Following that, I present the conceptual framework and research questions, and conclude with an overview of the rest of the chapters of the dissertation.

Study background

The study was one of four social science studies that formed part of a two-phase intervention project, known as MaxART, which sought to maximise the use of ART for treatment and prevention of HIV. According to the funding proposal posted on the website of one of the main partners of the MaxART Consortium, Stop AIDS Now!, the primary goal of the project is to 'improve the lives of people living with HIV (PLHIV) and prevent new HIV infections in Swaziland' while demonstrating the 'feasibility, cost-effectiveness and clinical outcomes of implementing ART for prevention in a "real life" environment at population level' (Stop AIDS Now!, 2011). The first phase of the project, which ran from 2011 to 2014, focused on addressing the barriers to HIV testing, treatment, and retention in HIV care. The social science research provided evidence on structural and other barriers, and made recommendations regarding innovative interventions to improve access and retention. Phase two was designed and built upon the activities of the first phase, and focused on the universal treatment for all people diagnosed with HIV (Jennisken, 2015). Swaziland was chosen for the implementation of the project because of its high HIV incidence and prevalence, as well as its small population size.

The first phase of the project focused on increasing the number of people who test for HIV, enrol in treatment, and are retained in HIV care. Strategic interventions included community mobilisation and 'fast-track', that is, accelerating the delivery of high impact and focused (UNAIDS, 2015a) HIV testing and treatment services targeting hard-to-reach groups such as men and adolescents. Also instituted at the point of service was a system to assess eligibility for ART (explained further in chapter five): the point-of-care cluster of differentiation 4 (CD4) count. Social science research and mathematical modelling formed core components of the project, with the role of social science research being to provide in-depth empirical evidence on structural barriers to the uptake of services (that is, people's participation in HIV testing and ART and their retention in HIV care), particularly among hard-to-reach groups in Swaziland. In the MaxART project, hard-to-reach groups were identified as men and adolescents because available programmatic data indicated that fewer people in these two population groups were testing for HIV or accessing treatment, and that fewer were retained in HIV care after starting treatment.

At the inception of the study, I had planned to explore how perceptions of gender and sexuality by adolescents, influenced their access to and utilisation of HIV services in both urban and rural settings. In addition, I wanted to examine how these perceptions influenced their experience of living with HIV. Two incidents concerning the disclosure of adolescents' HIV status (described in detail in chapter seven), which occurred two weeks apart during my early field work, caught my interest, and prompted me to focus the study on how the family context in which adolescents living with HIV are growing up shape their experiences and meaning of living with HIV.

The context

Swaziland is a small (17364 km^2) landlocked and sovereign state situated in southeast Africa between Mozambique and South Africa. The country gained its independence from the British in 1968. The last population census, which was carried out in 2007, measures the country's population at about 1.18 million (CSO, 2008) while the World Population Review (2016) suggests a slow population growth with an estimation of about 1.29 million people in 2015. The majority of the population is ethnic Swazi (97%), is female (52.7%), lives in the rural areas (79%), and lives below the poverty line (63%) (CSO, 2011). Like in most countries in Africa, women are disproportionately poor compared to men (CSO, 2011). Fifty percent of the population is below the age of 20 and approximately 25% are adolescents between ten and nineteen years old (CSO, 2008).

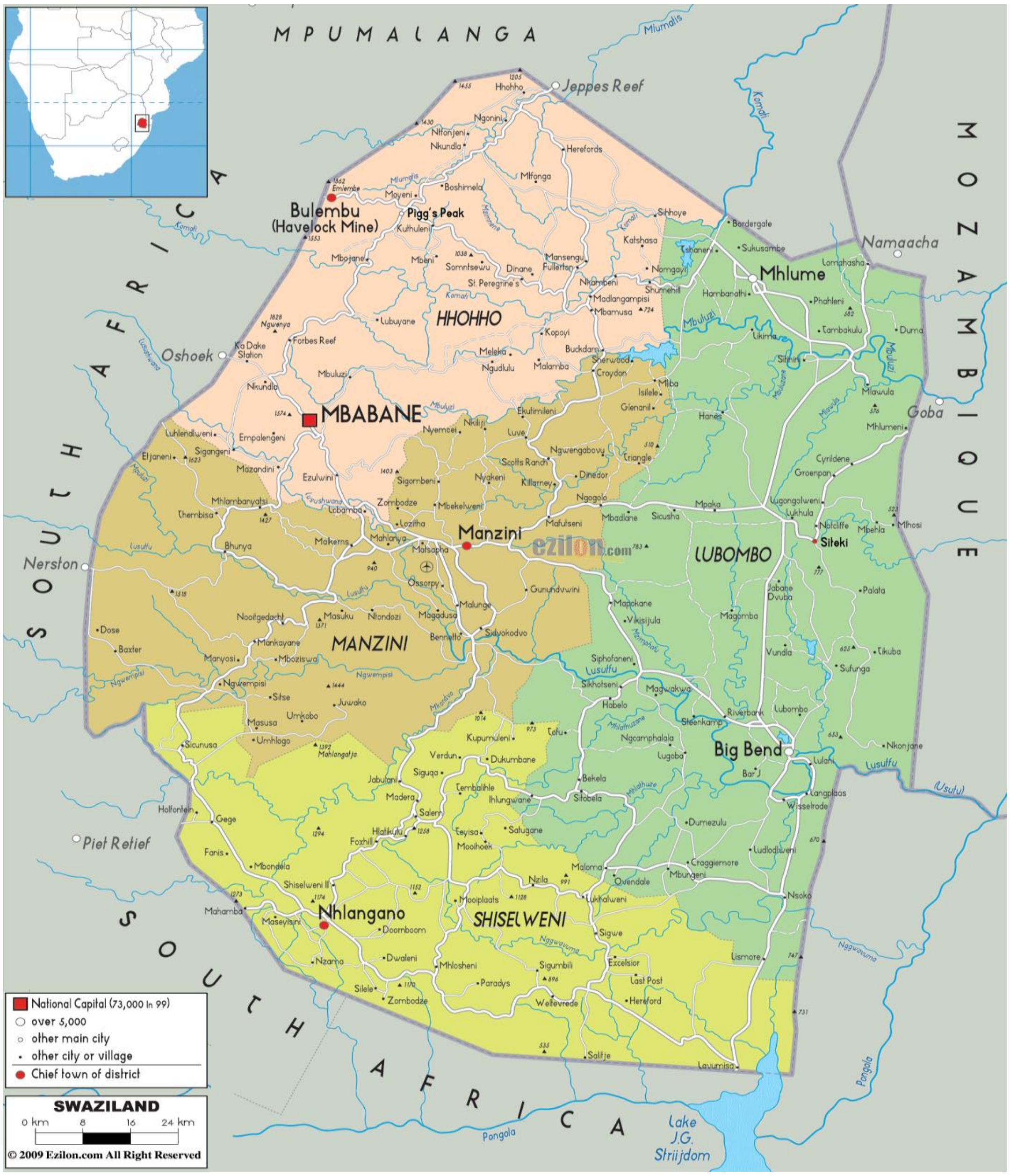

Figure 1: Map of Swaziland, showing the four administrative regions. The study took place in the Manzini Region (shown by a brown shade in the map). ***Source*****:** **http://www.ezilon.com/maps/africa/swaziland-maps.html**

Swaziland is classified as a lower-middle-income country, with a per capita gross national income of USD 2,233.00 (World Bank, 2014b). The country has significant income disparities: in 2012, a high proportion (63%) of the population lived below US$2 per day (World Bank, 2014a). The inequality has been exacerbated by the negative economic growth that the country has experienced over the last two and a half decades, from a gross domestic product of 4.79% in 1980 to -0.10% in 2010 (World Bank, 2014b; see also Mafusire and

Leigh, 2014). Although literacy rates are high (ranging from 87.8% for adults to more than 90% for young people between fifteen and twenty-four years of age) (UNICEF, 2013), negative economic growth has resulted in high unemployment rates ranging from about 30% for the general population (Brixiová, Fakudze, and Kangoye, 2012) to over 60% for youth under the age of 30 years (International Labour Organisation [ILO], 2014; UNICEF, 2015). Other groups experiencing high unemployment and, therefore, high poverty levels include adult women, less educated people, and rural populations (Brixiová, Fakudze, and Kangoye, 2012). The high levels of income inequality, poverty, and unemployment have been cited as indirect causes of the high HIV incidence and prevalence in the country (Mngadi et al., 2009).

HIV and AIDS remain a major public health and human development challenge in Swaziland (Daly, 2001; National Emergency Response Council on HIV and AIDS [NERCHA], 2009; Joint United Nations Programme on HIV and AIDS [UNAIDS], 2012). Since 1986, when the first HIV-positive diagnosis was made in the country, the epidemic has progressed through three distinct phases: an exponential increase in HIV prevalence between 1992 and 2008, a plateauing in 2010, and since then a slow decline. A demographic health survey conducted in 2007 found that one in four people aged two years and older were living with the virus, and that the infection rate was even higher (26%) in the sexually active population, aged fifteen to forty-nine years (CSO and Macro International, 2008). The Swaziland HIV Incidence Measurement Survey (SHIMS) conducted five years after the demographic health survey, reported a similar prevalence, indicating that the epidemic had stabilised (Ministry of Health, 2012). By the end of 2014, estimates suggested that between 200,000 and 230,000 Swazis were HIV positive (UNAIDS, 2014), representing between 19.6% and 22.6% respectively, of the 2007 population. The observed stabilisation in the HIV prevalence is said to have been an outcome of a number of factors including increased access to ART, decline in HIV-related deaths, and declining new infections (Bicego, et al., 2013). The proportion of those newly infected with the virus – HIV incidence – declined from a high of 4.6% of the country’s sexually active population in 2003, to 2.7% and 2.4% in 2009 and 2011 respectively (MoH, 2012; UNAIDS, 2012). Projections suggested that by the end of 2015, the incidence would have further decreased to 1.4% (MoH, 2010). Whether there has been a decline is yet to be proven through the second HIV incidence measurement survey commissioned by the Ministry of Health in early 2016.

Like in most countries in Sub-Sahara Africa, unprotected heterosexual transmission is the main mode of HIV transmission in Swaziland, responsible for more than 94% of HIV among adults (Mngadi et al., 2009). Multiple concurrent sexual partnerships; low, incorrect, and inconsistent use of condoms; poverty and unemployment; and gender inequality are said to be the key drivers of the epidemic (Mngadi et al., 2009) as is migration (Crush et al. 2010; Mngadi et al., 2009).

The epidemic has not only affected the lives of individuals but family structure and socio-economic dynamics as well. The high rate of HIV infections witnessed in the first two decades of the epidemic was accompanied by unprecedentedly high AIDS-related deaths, particularly among the socio-economically productive population of middle-aged adults who were relatively young parents as well. The deaths of young parents led to an increase in orphaned children whose care was taken over by grandparents or extended family members (Whiteside et al., 2003). As a result, by 2012, the number of children who had lost either one or both parents to AIDS-related illnesses was estimated at 78,000, a figure representing 65% of the 120,000 orphans in the country (UNICEF, 2012). When family bread winners died, family resources shrunk, poverty deepened, and kin, particularly grandparents, took on care-giving for, and guardianship of orphaned children (Makadzange and Dolamo, 2011; Pons et al., 2012). Some of these children who were left behind by their parents were infected with HIV and are now in their adolescence.

HIV among adolescents

Swaziland is home to approximately 300,000 (24.3% of the 1.2 million population) adolescents (10-19 years). Although the number of those living with HIV is not readily known, UNAIDS estimated that there were 12,000 HIV positive adolescents in 2012, representing 5.6% of Swaziland's 210,000 PLHIV (UNAIDS, 2013; see also WHO, 2014). In 2013, the estimate was 11,000 (UNICEF, 2014), showing a decline of a thousand. Though the reason for the decline has not been explained, it could be attributed to either under-estimation or it could be an indication of higher AIDS-related deaths in this population alongside a decrease in new infections. However – and most important – the fluctuation could reflect the lack of collection, collation, and production of adolescent-specific HIV data; currently the country uses age ranges that divide the population into children (0–14 years) and adults (15–49 years). Nonetheless, of the 13,000 new infections reported in the country in 2013, between 1,100 and 1,300 were among adolescents (UNAIDS, 2013). This number increases to about

50% of all new infections if the definition of adolescent expands to include the age group of 20–24 years (Bicego et al., 2013; see also MoH, 2012). Sixty-eight percent of the new infections in adolescents were among females, raising a red flag regarding the vulnerability of girls to HIV. The same year, 2012, estimates indicate that about 500 adolescents died of AIDS-related illnesses (UNAIDS, 2015b).

Early sexual debut, delayed marriage, and short-term sexual relationships have been cited as the main risk factors for HIV in young people. According to the Central Statistics Office (2010), in Swaziland the median age of sexual debut is sixteen years, while that of marriage is twenty-six years. The ten-year period between first sex and marriage is marked by premarital sex often with older and more sexually mature people (especially girls with older men), in short-term serial or concurrent relationships, thus exposing adolescents to risk of HIV (CSO, 2010). Recent studies from other countries are, however, challenging the emphasis on sexually acquired HIV among adolescents. A multi-country study carried out in Namibia, Swaziland, and Zimbabwe reported that up to 60% of adolescents who tested HIV positive were virgins (Deuchart, 2010; Tennekoon and Roseman, 2014). This may simply be interpreted to mean that most of adolescents could have been infected through mother-to-child transmission.

Other risk factors for HIV-infection among young people include peer pressure and experimentation with illicit drugs, alcohol, and sexual intercourse, as well as structural factors such as poverty and unemployment (WHO, 2013). Recent estimates, however, report a reduction in new HIV infections among adolescents in Swaziland, attributed to a decline in risky sexual behaviour, as adolescents may be delaying sexual debut, reducing the number of sexual partners, and/or increasingly using condoms consistently during sexual intercourse (MoH, 2012).

Despite the statistics on HIV incidence and prevalence, and the fact that HIV testing is required to access HIV prevention, treatment, and care services, less than one-fifth of adolescents aged eighteen to nineteen years know their HIV status in Swaziland (Bicego et al., 2013) and this percentage drops even lower when all age groups are considered (UNICEF, 2010). The reasons why adolescents have such low uptake of HIV testing and related services have not been studied in the context of Swaziland. Findings from other countries in sub-Saharan Africa indicate that inadequate access to health services, unfriendly and un-welcoming health care environments, age of consent, poverty, lack of comprehensive knowledge about HIV, and the lack of prioritisation of adolescents in national HIV policies and programs are some of the factors contributing to the negative impact of the epidemic on adolescents (De Bruyn, 2000; DiClemente et al., 2008; Silverman, 2013; UNAIDS, 2013). Other studies have pointed to parental reluctance to test their children as the reason for low up take of HIV testing by young people (cf. Bandason, et al., 2013; Fox, et al., 2013; Murphy, Rwemisisi, et al., 2008). The reluctance is because in perinatally transmitted infection, a child's diagnosis reflects back on parents' sexual lives particularly where HIV is predominantly transmitted heterosexually. Hence, parents or guardians are often reluctant to test children for HIV, resulting in delayed diagnosis and treatment, low retention in care services, and poor adherence to ART (Bakanda et al., 2011; Coovadia and Mantell, 2010;Idele et al., 2014; Gary, 2010; Nachega et al., 2009; WHO, 2014).

Adolescence and living with HIV

Adolescence has been described as a 'fascinating period in life . . . a journey of discovery and an age of emerging adulthood' (Arnett, 2010: xii). Adolescence is characterised by accelerated physical growth, and emotional and psychological development (UNICEF, 2015). It is a period in life where preoccupation with the self and the body becomes prominent, autonomy and social identity are pursued, and new relationships are formed (Arnett, 2010). Being accepted, loved, and socially connected are central quests for most adolescents (WHO, 2008). In this time of seeking social (and romantic) attention and belonging, any condition that sets an adolescent apart from others, and that may result in him or her being ridiculed, socially excluded, or rejected, or tainting his or her sense of self and the body, such as an HIV-positive diagnosis, is bound to cause distress (Arnett, 1999; American Psychological Association [APA], 2002; Cluver, Gardner, and Operario, 2008).

Just like adults diagnosed with HIV (see for example Russell et al., 2015), an HIV-positive diagnosis adds a layer to an identity, which adolescents have to embrace, live with, and manage for the rest of their lives. As part of the biosocial and therapeutic demands of living with HIV as a chronic disease, adolescents have to learn and adjust to self-management, a process that has been described as 'complex and dynamic . . . involving activation of resources from health systems and social networks . . . and incorporation of the illness into their identity and everyday lives' (Russell et al., 2015: 2; see also Helman, 1995; Prince, 2016). In essence, adolescents have to manage relationships with themselves, that is, how they feel and relate to their "diseased body" (Helman, 1995; Prince, 2016). They also have to manage relationships they have with those around them, particularly their parents, guardians, and extended family members, upon whom they depend for their care needs. This may create a conflict with their desire for independence or autonomy on the one hand and the everyday disciplined life demanded in managing chronic HIV disease on the other.

Furthermore, adolescents have to learn to manage time. Several studies have noted the salience of time in chronic illness experiences (Corbin, 2003; Charmaz, 1991; Richardson et al., 2008). People living with a chronic illness have to plan and adjust their daily lives around illness activities that need to be performed at particular times (Corbin, 2003; Charmaz, 1991). Adolescents – like all people living with HIV – have to adjust their everyday lives around taking medication at specific times and keeping clinic appointments, in addition to making time for social activities like socialising with friends. Time can also be conceived in terms of the future; adolescence is a period where plans for the future are laid down. For adolescents living with HIV, these plans incorporate thoughts about the future trajectory of the illness, including sexual relations, disclosure to partners, starting their own families, and the prognosis of the disease. As noted by Corbin, time is of particular importance during illness, particularly one that is fraught with uncertainty, in which 'one might not be certain how much biographical time is left and what the time that remains will be like' (2003:259). Thus, to realise optimal health benefits from ART, timely diagnosis, enrolment in antiretroviral treatment and strict adherence to ART every day for the rest of adolescents' lives is critical. Therefore, time becomes of the essence (Corbin, 2003; Sikstrom, 2014).

Adolescents also have to embrace the multiple identities of being adolescents, being orphans, and living with the virus. This may be particularly difficult for adolescents who lack ongoing psychosocial support, as may be the case in some families like that of Sicelo, or who interact with health systems that are not adolescent friendly, that is, health systems that are sensitive and responsive to health needs specific to adolescents, and which are provided in privacy, where confidentiality is held high, and in an environment where there would be no adult interference (WHO, 2002; 2012). Studies have shown that adolescents living with HIV who have little or no psychosocial support may turn to destructive coping strategies such as the use of drugs and/or alcohol, or, worse, may attempt or commit suicide (Cluver and Gardner, 2007; Cluver, Gardner, and Operario, 2008; Palmier, 2011; Schlebusch, Burrow, and Vawda, 2009).

Most HIV programmes expect families to provide the ongoing support that adolescents need as they come to terms and adjust to living with HIV. But to care for adolescents, families need resources. However, HIV and AIDS depletes resources, leaving families with little or nothing to use in their care-giving role, particularly in Swaziland where the state provides little social security support to families and population groups described as vulnerable, such as PLHIV. In such family environments, adolescents are confronted by and have to deal with biosocial disruptions, which may affect their emotional, psychological, and physical well-being and exacerbate their suffering and uncertainty. Despite the realisation that structural factors influence access to services, HIV illness experiences, and disease management, HIV interventions continue to be dominated by biomedical technologies (Idele et al., 2014; Mburu et al. 2014b; Skovdal and Belton, 2014). A focus on social factors is particularly pertinent for adolescents because, as Skovdal and Belton (2014: 2) point out, the health of adolescents is largely determined by factors beyond the biomedical or health system domain and includes those in their micro-, meso-, and macro-environment.

HIV and the family in Swaziland

In their book on African systems of kinship and marriage, Radcliffe-Brown and Forde, state that 'almost everywhere in human societies … the first experience that a person has of society is in the parental family, the intimate domestic group of father, mother and children' (2015:70). This statement also applies to care: the family, in its many forms, is the primary unit of HIV care for adolescents infected with and affected by the epidemic. Hence, adolescents' experience of HIV is influenced by the clinical disease as much as, and largely by, how the illness is perceived and discussed in their social environments, with the primary and strongest direct influence exerted by the family (Miller and Murray, 1999; Petersen et al., 2010). Therefore, to understand the adolescents' experiences, we need to explore and understand their family situations.

In Swaziland, as in other countries in sub-Saharan Africa, the structure of the family has undergone significant changes in the last century in response to political, social, and economic transformations at the global level. Besides the shrinking of the extended family, which has historically been the linchpin of childcare and socialisation in African settings, changes in family structure and composition have led to the prominence of alternative household forms (Penn, 2005:104–110). These include households headed by single parents, step-parents, and children, as well as households in which leadership skips a generation.

At community-level, community-based centres (such as neighbourhood care points and ka-Gogo centres), fictive kin or 'families' provide nutritional and psychological support to orphaned and vulnerable children. This care arrangement is in many ways similar to what used to be in the olden days of multi-generational homesteads, where a child was said to belong to a village, and every old person was regarded as a parent to a child. Support groups have also played a prominent role in the care of children and adolescents infected and affected by HIV in rural Swaziland (Dlamini, 2007; Regional Evidence Building Agenda [REBA], 2007; UNICEF, 2006).

A change in the institution of marriage has also contributed to changes in family structure and composition. Increasingly young adults are having children before marriage. Some of these young parents end up separating and marrying other spouses, resulting in their first child or children being raised in stepfamilies. In some cases young adults, especially the educated and affluent, are choosing to either delay marriage or not to marry at all, and to raise their children as single parents. Single-parent families have also resulted from increasing rates of legal separation or divorce, and some parents are separated by work or other economic related activities, leaving their spouses to raise their children singlehandedly.

HIV and AIDS have affected intergenerational relations and family capital (Ferreira, 2001), and in particular, have led to high mortality rates among the most economically and socially productive segment of the population. Children of the deceased are left under the care of the extended kin and family members, particularly grandparents, and in some cases, on their own, resulting in child-headed families.

How HIV is perceived, talked about, and experienced in these different family environments is bound to influence how adolescents experience HIV illness and meaning of living with the virus. This study aims at exploring the experiences on the adolescents in these family environments.

Rationale for the study

Adolescents are disproportionately affected by the HIV and AIDS epidemic (Idele et al., 2014; Bond, 2010; Cowan and Pettifor, 2009), not only in terms of being infected with the virus or HIV-related illness, but also in terms of experiencing multiple losses in their lives – such as the loss of a parent or both parents, loss of a healthy childhood, amongst others (Cowan and Pettifor, 2009; Domek, 2006), and uncertainty about their life (Brashers et al., 1999; Kerr and Haas, 2014; Mishel, 1988; 1999) and about the future (Bernays et al., 2014).

In resource-poor settings like Swaziland, adolescents have to deal with both the chronic biomedical uncertainty of the HIV illness, which is characterised by episodes of acute opportunistic infections that produce complex care demands, and erratic familial support (Domek, 2006; Russell and Seeley, 2010). These may pose a psychological burden to adolescents, which in turn may influence their experience of living with the chronic illness.

In order to enact relevant policies, create programmatic interventions, and provide relevant supportive care at all levels, it is imperative to understand adolescents' experiences from their perspective. While there is a growing body of research focusing on the lived experiences of adolescents living with HIV in resource-limited settings, the data from studies conducted thus far are derived from their caregivers, such as parents and guardians. Where adolescents' own perspectives have been studied, the heterogeneity of the family environment has not been taken into consideration. Rather the family has been studied as though it were a homogenous structure.

This lack of evidence derived from adolescents' perspectives has resulted in a lack of effective programming to address their specific needs (Idele et al., 2014; Kapogiannis et al., 2014; Li et al., 2010; Pettifor et al., 2013).This study is timely as both the country and the international community have embarked on targeting adolescents through the 'all-in campaign' launched by UNAIDS in 2014, which aims at ending HIV among young people.

Research questions

The primary question of the study is: What are the experiences of adolescents living with HIV in different family contexts in Swaziland?

The research was designed to answer the following seven interrelated questions:

1. What does it mean to be an adolescent and living with HIV in Swaziland?
2. How do the family environment and relational dynamics impact the HIV illness experience and meaning?
3. What are adolescents 'everyday experiences with ART, care, and support?
4. What are adolescents' experiences with and motivations for adherence to ART?
5. What types of stigma do adolescents experience; what perpetuates such stigma, and how do adolescents manage stigma and discrimination?

6. How do adolescents deal with disclosing their HIV-positive status, and what factors promote or hinder such disclosure?
7. What tactics do adolescents use to navigate familial and health system environments to access HIV services?

Conceptual approach

The study uses three interrelated frameworks: the social-ecological framework (Bronfenbrenner, 1989), children- and youth-centred studies (e.g. Christensen, 2004, 2010; Jans, 2004; Kirk, 2007; Powell, 2011), and social navigation theory (Vigh, 2009). According to Skovdal and Belton, 'HIV is experienced, lived and managed within interpersonal relationships, and overlapping and complex social structures. . .' (2014:1), using the three interrelated frameworks will assist not only in exploring adolescents' experiences at individual personal level, but also how the experiences are shaped by the family, community, and societal environments in which adolescents live.

The social-ecological framework was first developed by Bronfenbrenner to look at child development. It has been applied in various studies over the years and in the process modified. The social-ecological framework recognises that direct and indirect interactions within multiple levels of the social environment influence and continuously shape human experiences and relations. According to Bronfenbrenner (1989), these levels include one's immediate environment (micro-system, such as family, friends, and peers), proximal environment (meso-system, such as community, school, church), distal environment (exo-system, such as parents' workplace), and remote environment (macro-system, such as cultural norms and beliefs). Applied in this study, the model suggests that adolescents' perceptions, meanings, and experiences of HIV are influenced and continuously shaped by interactions with their social environment (Mugavero, Norton, and Saag, 2011; Mburu et al., 2014; Viner, 2012). While interactions in the immediate and proximal environment may affect adolescents' illness experience directly, such as how HIV is spoken about at the family and community level, those in the remote and distant environments also have influence, such as HIV policies at the national and international levels. The social-ecological approach has the potential not only to expand and deepen our understanding of the context-specific issues that shape and are shaped by adolescents' experiences, but also to explore what relevant support and interventions are required to achieve better health outcomes, including their larger life projects. However, in order to understand adolescents' experiences and meanings, we need to engage them as actors in their own right, requiring researchers to take a child- and youth-centred approach.

Children and youth-centred studies posit that adolescents are not mere passive recipients of social norms and practices, but are social actors in their own right (Christensen and James, 2000; Caldwell et al., 1998; James and Prout, 1990; Honwana and deBoeck, 2005; Honwana, 2006). Adolescents are capable of challenging, resisting, and shaping – and being shaped by – societal norms and events in their lives (Bandura, 2001; 2006), as well as crafting future dreams and aspirations (horizons) in ways most relevant to them and their social worlds. According to Honwana and de Boeck, adolescents are not 'proto-adults but beings-in-the-present', (2005:4); Caldwell et al. write that they are 'instruments of change' of their own life-worlds (1998:137).They are also not 'passive recipients of HIV treatment, care and support' (Skovdal and Belton, 2014:5; see also Porter, 1996; Skovdal, et al., 2009; Skovdal and Daniel, 2012) but participants in shaping the course of their illness trajectory (Mupambireyi et al., 2014). In this approach adolescents are not simply vulnerable victims (Cheney, 2011) of structural normative beliefs, policies, and practices, but rather active agents who are able to adapt in various ways to the biosocial demands made by HIV.

The concept of social navigation as an analytical lens, according to Vigh (2009), brings to our attention the tactical ways in which adolescents – as active social agents– intentionally and purposively expand the horizons of possibilities in a world of HIV uncertainty. Building upon Bourdieu's theory of practice, Vigh's concept of social navigation states that a person facing a difficult situation, such as war or HIV, employs tactics and strategies to negotiate an undesirable situation. Schafer defines tactical agency as 'the ability to take to find strategies to cope with a difficult situation and to carve out opportunities for improvement or survival, in a context of severely constrained choices and from a position of weakness [or powerlessness]' (2007:3).

With a focus on tactics and agency, this study presents adolescents as actors who are able to carve out strategies and employ tactics to cope and survive in situations of uncertainty. Using the concept of navigation enables us to appreciate how, in a situation of uncertainty, stigma, and deprivation, adolescents are able to find opportunities to access and utilise HIV services and meaningfully manage HIV illness. I show how adolescents and their parents or guardians manage the challenges of living with HIV in environments characterised by social categorisation, stigma, and seemingly diminishing possibilities, as well as lack of psychological and emotional support structures, and material poverty.

Defining terms

Adolescence

Adolescence has been variously defined by different disciplines in the sciences, such as biology, public health, psychology, sociology, and anthropology. To this date there is no universally agreed-upon definition. Anthropologists have defined adolescence as a social construct based on the notion that the meaning of adolescence is 'different in different cultures and at different historical moments' (Saltmann, 2005:16). However, the notion of adolescence as a social construct fails to recognise the role of biology in the physiological changes associated with puberty, which are associated with adolescence as a developmental stage. Sawyer et al. overcome both biological determinism and cultural constructivism by recognising that while the biological sequence of puberty is highly consistent, 'the timing in pubertal change [and] the nature of social-role changes . . . are affected by economic and socio-cultural factors, which are themselves not universal' (2012: 1631). The authors define adolescence as a period starting with the onset of puberty and ending at the 'age at which mature social roles – such as finishing education, getting employment and starting own family – are achieved' (Sawyer et al., 2012:1630).With young people increasingly delaying attainment of some of these social roles, such as starting a family, there is a challenge in determining when adolescence ends. Some researchers and programmes include among adolescents those up to twenty-five years old (see Musinguzi, 2014). This further indicates that age cannot be used as a universally accepted measure of adolescence.

Although in Swaziland there is no age-specific definition of adolescence, there are age-specific rites and practices that mark 'transitioning from childhood to maturity' that are observed by moving from the children's house to sleep in a house designated for older girls (*entsangeni*) or boys (*lilawu*) (Booth, 2004: 933–940). During this period girls are put under the close guidance of mature women (*emachikiza*) and boys are guided by men (*emajaha*), and socialised on how to carry themselves (or behave) as they go through this socially defined developmental stage. This transition is not only practised in traditionally conservative households but also in modern Swaziland. Older boys and older girls are provided their own bedrooms that they do not share with younger children. The defining characteristic for this transition is not age, but the physiological changes marking puberty, which may start as early as ten years of age and as late as eighteen, though among the majority of girls the age is between twelve and fourteen years and among the majority of boys it occurs two years later at the age of sixteen (Booth, 2004; Kuper, 1980). Policies and programmes in the country, however, tend to follow the WHO definition of ten to nineteen years of age as the period of adolescence. In this study, I focused on young people between the ages of twelve and nineteen years for three main reasons; firstly, the current legislation on children in the country, the Child Protection and Welfare Act 2012, has set the minimum age of consent for HIV services at 12 years. Secondly, adolescents who wanted to participate in the study without their parents or guardians consent could do so as they could sign their own consent. However, as I show in the next chapter, all adolescents living with HIV and dependant on their parents or guardians had to seek parental consent to participate in the study (I explain this further in chapter two). Thirdly, one of the inclusion criteria for participation in the MaxART study was knowledge of HIV status, and studies from other countries in the region indicate that parents disclose their children's status to them when they are around the ages of 12-14 years (see Vreeman et al., 2013; 2010). Hence, I choose twelve years of age as my lower limit for adolescent participants.

Illness and disease

According to Kleinman, illness refers to the lived experience of the person being sick or suffering as well as 'how members of the family and wider social network perceive, live with, and respond to symptoms'(1988: 3). An illness is both a socially constructed subjective meaning and an explanation of a biomedically defined pathology or disease (Pool and Geissler, 2005: 53). Throughout the dissertation I use 'illness' to refer to the subjective experience of HIV, which itself is 'shaped and transformed by innumerable factors, such as culture, society, politics and geography, and is inextricably intertwined with the self and others across time' (McElroy and Jezewski, 2000 cited in Bohle, 2013: 20). 'Disease', on the other hand, refers to the changes in the anatomy and physiological functioning of organs and body systems (Pool and Geissler, 2005: 53). As used in this dissertation, HIV disease refers to the bio-pathology of the organs and systems of the physical body as caused by infection with HIV, and as identified through presenting symptoms.

A note about the researcher

One of the key characteristics of ethnographic research is reflexivity, that is, self-awareness in relation to the topic, study participants, and setting, as well as the researcher's personal beliefs and contradictions (DeWalt and DeWalt, 2011), although there are still debates in the social sciences on what exactly should entail reflexivity. Nagar and Geiger define reflexivity as the 'situatedness or analyses of how the production of ethnographic knowledge is shaped by the shifting, contextual, and relational contours of the researcher's social identity and her social positionality (in terms of gender, race, class, sexuality and other axes of social difference), with respect to her subjects', and they argue that scholars should 'discuss more explicitly the economic, political and institutional processes and structures that provide the context for the fieldwork encounter, and shape its effects' (Nagar and Geiger, 2007: 6-7). Green and Thorogood (2009; 2014) and Hardon et al. (2001) contend that reflexivity allows the researcher to recognise and acknowledge her own biases or beliefs that she brings into the field of study, which may affect the relationships she has with research participants. Such biases may include gender, age, and cultural upbringing, as well as power, position, and identity differences. Being aware of her biases enables the researcher to find means of dealing with them in an effort to produce fair and unbiased accounts about the studied situation.

While some might think an ethnographer goes to the research field as a blank slate, or shuts off his or her own cultural beliefs and knowledge during fieldwork, it was not possible for me to do so during my fieldwork. My identity in this study was three-fold: I carried out the study in my home country (Swaziland), my home region (Manzini), and in a field in which I had worked almost half of my twenty years as public health nurse, in the field of HIV. I was conscious of all these identities and it raised many mixed feelings and concerns: how could I maintain an outsider view, how my previous work with health care workers going to affect my current position as a researcher, and, if I talked with the adolescents, how they were going to relate to me as an adult woman. But mostly I struggled with how I was going to balance my previous public health training and experience with my current professional focus: medical anthropology. Studies have shown that there are tensions between the fields of medical anthropology and public health, mostly from different approaches to illness/diseases explanations (Kleinman, 1980), aetiologies and management of the illness/disease (see

Leonard, Greene and Erbelding, 2007), and research methods (see van der Geest and Finkler, 2004).

I am a professional public health nurse who has spent over twenty years, half of which were in middle to senior management, in the field of HIV, and particularly in prevention of mother-to-child transmission (PMTCT) of HIV. During my work as a programme manager for the PMTCT programme, I came across a number of young people including adolescents who sought HIV services as a result of their pregnancy. I found that in most cases health care providers had challenges relating to adolescents' needs. I was called upon to train nurses on adolescent counselling to equip health care providers with the adolescents' counselling skills.

As a trained HIV counsellor, a national trainer on adolescent and child counselling, and a national supervisor within the national PMTCT programme, I trained and worked with health care workers from all over the country's publicly managed health facilities and a few of private ones. I also provided supervision and mentorship to PMTCT workers, as well as adolescent and children counsellors.

Some of the nurses in my study were my former students who I taught at the university after leaving nursing. While this relationship helped me to gain easy access to health facilities for my fieldwork, the challenge, however, was maintaining some distance, staying objective as much as possible, and avoiding role conflict without upsetting my relationship with them.

Being a native researcher worked advantageously for me in several aspects. Unlike ethnographers from other countries who have to learn the language of the country or that of their prospective study participants or respondents, I did not have to because I speak siSwati, the native language spoken in Swaziland. Second, although my research focused on adolescents, it was easy for me to understand some of the common cultural practices that would probably be difficult for a non-native ethnographer to make sense of. However, I found that fieldwork could also be a learning experience for an ethnographer. As native ethnographer, I had thought that I knew the culture of people I was studying, adolescents, but I learnt that there was a lot that I actually didn't know; I found that adolescents have a particular style of language that is uniquely spoken by young people when they are together. Van Dongen (1998, quoted in Dapaah, 2012: 39) points out that 'being a native anthropologist at home does not mean that the identities of the anthropologist and the people in the field are similar, people and cultures are diverse, different and divided from within'.

Hence I had to be open to learn from the adolescents as well as gather data with and from them.

In the community I lived with an elderly couple that had spent almost all their life living in the area, having been born and raised there. The husband, a retired civil servant, was in his late seventies while his wife, a retired nurse, was in her early seventies. Every evening we would have informal talks about their day and my day and they would share stories about how ‘things have changed since our time. We never had these diseases because we respected ourselves, our bodies. Today there is no respect; young and old people are just the same’ (field notes, September 2012). We would talk at length about how men and women carried themselves, how diseases were treated, their beliefs about HIV, and much more. Being a native I was able to engage my hosts in these informal conversations by asking questions and seek clarifications based on what I knew about Swazi culture and traditions.

Structure of the dissertation

The dissertation is divided into three parts. Part one consists of two chapters: this introductory chapter (chapter one) and a chapter on methodology (chapter two).

Part two has five chapters: chapter three presents a brief introduction of each of the adolescents living with HIV with whom I interviewed several times over the course of my fieldwork, and chapter four focuses on the family. It begins with a historical perspective of the family in Swaziland. I show how the family structure has changed over the years, and how these changes have impacted the raising and socialisation of adolescents in general, and the care and illness experiences of those living with HIV in particular. I then present the family from the perspectives of my interlocutors, showing how the meaning of family changed in response to contextual needs overtime.

Chapter five presents adolescents’ motivations to test for HIV and experiences doing so, the meaning of being diagnosed with the virus, and the experience of being on lifelong treatment that requires strict adherence to medicines and time. In this chapter I show that contrary to notion that adolescents are a population that is hard to reach with HIV services, adolescents are in fact willing to test for HIV, to be initiated on ART if diagnosed with the virus, to be adherent once they have been informed about their illness, and to remain in care if they are involved and actively participate in their care planning. Therefore, low testing, low ART enrolment, and high attrition rates can be attributed to structural factors beyond their individual and collective control that limit their involvement and participation in decisions and choices regarding their lives.

Chapter six presents adolescents' experiences and management of HIV-related stigma, and chapter seven focuses on disclosure. These chapters are closely related in that stigma is managed through either non-disclosure or limited disclosure. A majority of the adolescents only learned of their HIV status months or even years after they were diagnosed and started on ART due to fear of stigma. In most cases their parents or guardians eventually told them of their HIV-positive status because the adolescents were not adhering to their ART regimen or because the adolescents beg and asking questions about the medications they were taking. Once informed of their status and the reasons for taking ARV pills, adolescents were highly adherent and actively managed stigma through the use of various strategies and tactics.

Whereas the chronology of the chapters appears to be following the public health HIV continuum of care cascade, this was unavoidable as the HIV illness experience is about the HIV care discourses (prevention, ART, disclosure, and stigma). I present how an HIV-positive diagnosis and being on ART changes the course of adolescents' lives. Stigma, discrimination, and disclosure are the difficult terrains that adolescents have to navigate as part of the experience of living with HIV. Decisions around whether to disclose, to whom, when, how, and why are some of the issues they have to manage, as well as the consequences of disclosing or not disclosing. Here, I focus on how adolescents manage disclosure, their desire to manage communications related to their status, and the challenges they face while trying to stay in control of their privacy. I show that adolescents find meaning in their lives by focusing on their life projects and hopes for the future.

The last part – part three – consists of chapter eight, which provides a general discussion of key findings and a concluding summary. It also presents the limitations and strengths of the study, offers policy and programmatic recommendations, and outlines some of the implications for future research.

CHAPTER 2

RESEARCH METHODOLOGY

Introduction

One of the critiques levelled against qualitative and ethnographic researchers is the lack of detail in their description of the methodological process followed in research (Green and Thorogood, 2004). Ponterotto (2006:539) adds that ‘for a reader of anthropological work to gauge for herself or himself the credibility of the author’s interpretations, the context under which these interpretations were made must be richly and thickly described’. It is for this reason that in this chapter, I present a ‘thick description’ (Geertz, 1973; Denzin, 1989) of the approach I followed in carrying out this study.

Second, the study focused on a population that is considered vulnerable – adolescents– (Alderson, 1995; Christensen, 2004, 2010; Christensen and James, 2000, 2010; James and Prout, 1997; Jans, 2004) and a topic considered to be sensitive – HIV illness (Bekker et al., 2014).Both the topic and study population present a set of ethical challenges for researchers (Alderson and Morrow, 2004; Morrow, 1996). These relate to consent/assent, power relations, and confidentiality (Christensen, 2004; Fox et al., 2013; Kirk, 2007; Strode, Slack, and Essack, 2010), and thus warrant a detailed description of the ethical procedures and principles upheld during the study.

Third, ethnography as a research method for HIV and AIDS topics has not been widely used in Swaziland where this study was carried out,[i] therefore providing an in-depth description of the research process will help in-country readers and researchers relate to and better understand the study, particularly the findings and conclusions derived from them. The methodological description has the potential to draw the interest of other researchers in the country who may want to use it in similar research endeavours with adolescents.

In this chapter, I present an overview of the methodological process, starting with the study design and why I chose to use both ethnographic and quantitative approaches. This is followed by a description of the research methods, the participants, and the processes for data collection, management, and analysis. I then summarise the ethical procedures that I followed to obtain clearance and authorisation from the local research review board, leadership of the communities where the study took place, and the process of obtaining consent and/or assent from participants. I particularly pay attention to the ethical processes because, as mentioned, research with and on adolescents poses a set of legal and ethical challenges. So, 'rather than approaching ethics as a simple code that can be applied at any [research] situation, or an absolute set of principles that governs the acceptability of research', in this dissertation I approach ethics as 'a complex process that emerges from within the networks where it is applied and implicated'(Boulton, 2013: 99).

Study design

The study explored adolescents' perspectives on their motivations to access and use HIV services as well as their experiences of living with HIV in Swaziland. I explored the *emic* (own) perspectives of adolescents regarding their experiences of living with HIV illness and the *etic* (outside) views of community members among whom the adolescents live. The study asked how these perspectives and views influence how adolescents navigate the sociocultural environment to access and use HIV services, and how these shape the meaning and experiences of HIV illness. Furthermore, and in response to a requirement of the MaxART project, I quantified the extent to which HIV-positive adolescents' perspectives were shared by the larger adolescent population in the Manzini region. Therefore, in addition to collecting data from various sources (triangulating data), I used a mixed-methods design –that is a way of triangulating the methods, themselves –for the study. This design has the potential to 'add rigor, breath, complexity, richness and depth to any inquiry' (Denzin and Lincoln, 2000 cited in Silverman 2006: 292; see also Creswell and Clarke, 2007), as well as add value and enhances credibility and trustworthiness of the research findings (Patton, 2002).

The study setting

The study was primarily carried out in the Manzini region of Swaziland. The qualitative part was carried out in the rural chiefdom of e-Tsembaletfu and the urban site ofeku-Thuleni, both of which are located in the Manzini region. The quantitative survey was conducted in thirty-eight systematically sampled enumeration areas – operational geographic units used by the Central Statistics Office for collection of census data – from all sixteen *Tinkhundla (*constituencies) centres in the region. Although the plan was to conduct the research only in the Manzini region, the reality on the ground took me to other two regions, namely Hhohho and Lubombo, because some of the adolescents that I recruited from e-Mpilweni Clinic had their homes in these two regions. I also collected data during the monthly support group meetings run by the clinic and the Sivivane adherence camps[ii] held during school holidays. Support group meetings are held throughout the country, while the adherence camp draws participating adolescents from all over Swaziland to one central place.

The Manzini region

With a total surface area of approximately 4,094km^2, the Manzini region is the second largest of the four regions after Lubombo. The region is bordered by Hhohho in the north, Lubombo in the east, Shiselweni in the south, and the Mpumalanga province of South Africa on the west. The political head is the Regional Administrator who is assisted by the Regional Secretary, who also serves as the administrative authority and correspondent for all state activities in the region.

Figure 2: Map of the Manzini Region. . *Source: National Census Preliminary report, Central Statistics Office, Swaziland*

The Manzini region is the most populated of the four regions of the country; in 2007, it was home to 319,530 (31.4%) of the 1.18 million people living in Swaziland (CSO and Macro International, 2008). Fifty-three percent of the region's population is female, and approximately 77% live in rural areas (CSO, 2008). In addition, the region has the highest proportion of adolescents compared to the other three with 76,690 (31.7%) of the 249,262 adolescents in the country found in the region, and like the national population proportions, 53% of the region's adolescents are female (CSO and Macro International, 2008). The region had a total of 78,105 households (59,015 rural and 13,093 urban) in 2007 (CSO and UNFPA, 2010).

The region has a good network of public, mission-, and private-owned health facilities, with 42.2% of the 287 health facilities in the country found in the region (MoH, 2014). Health facilities in the region include six hospitals (two national referral facilities [TB Hospital and National Psychiatric Hospital], two private hospitals, one mission and one public hospital), two public health units, and 113 clinics (ibid.). Most of these facilities provide HIV services ranging from only HIV counselling to the comprehensive HIV package.[iii] There is also a good representation of traditional and alternative medicine practitioners and faith healers (people who use prayer in treating diseases and other health problems) in the region.

The Manzini region has the third-highest adult HIV prevalence (25%), after Hhohho (29%) and Lubombo (26%) (CSO and Macro-International, 2008). Figures of HIV prevalence and incidence among adolescents in the region are not readily available, but based on national estimates of adolescents aged fifteen to seventeen years (1.4% for males and 6.2% for females), both incidence and prevalence rates are likely to be higher among girls than boys (UNICEF, 2012).

The administrative centre of the region is the city of Manzini, which is the biggest in the country and the main city in the region. It is the geographic centre and economic hub of Swaziland where people from other parts of the country converge in search of employment, shopping, and trade. About eight kilometres west of the city is Matsapha, an industrial area that is the site of the highest number of manufacturing factories in Swaziland, drawing thousands of young men and women who migrate from the rural areas in search of work opportunities.

Sites for qualitative data collection

The qualitative aspect of the study was carried out in two purposively selected sites, namely e-Tsembaletfu (rural) and eku-Thuleni (urban), both located in the Manzini region.

E-Tsembaletfu

E-Tsembaletfu is one of eleven chiefdoms under Simile Inkhundla. The chiefdom lies in the southwest of the Manzini region, about ninety kilometres from Manzini City. The area’s landscape to the south, north, and east is mostly rolling hills that are barely covered with grass and trees. Streams meandering through the valleys below towards the Sompisi River that cuts through the Inkhundla, towards the Little Usuthu River in the east. Part of the flat land is covered with wattle plantations and scattered homesteads, and another part is made up of large fields that are mainly used for maize farming during the summer season. Unlike some parts of the country that suffer from drought, the most common natural hazard in Simile is excessive rains that are often accompanied by hailstorms that can destroy the maize. There is one main dirty road passing through the area. The road is very slippery, particularly during the rainy season.

E-Tsembaletfu is the biggest of all the Inkhundla chiefdoms in terms of both geographic and population size. In 2007, there were reportedly 4,000 homesteads, each with an average of six people per household, (CSO and Macro International, 2008). The same report showed that there were 18,788 adolescents, of which 10,052 were female and 8,736 male.

The chief's residence lies almost central in the chiefdom. About ten kilometres west of the chief's residence is a business centre that has a handful of shops, a police station, two clinics (one public and one private), a primary and high school, a market place, and a hammer mill for grinding dry maize into meal. The business area has a parking bay, locally known as a bus or taxi rank, for public transport connecting Simile Inkhundla with the city of Manzini, and with Mbabane in the Hhohho region and Nhlangano in the Shiselweni region. The public transport also connects people from the area with South Africa through a border control post that lies about forty-five kilometres southwest of the business centre. It also has several small shacks that small entrepreneurs use for their trade, such as hair salons and barber shops. The business area is a most popular spot, one where adolescents frequently meet and just hang around.

Unlike most chiefdoms in the country, where the chief is male, during the time of the study e-Tsembaletfu had a female chief, who was acting on behalf of a yet-to-be-appointed male chief. She had been acting chief since 2001, following the demise of the male incumbent.[iv] Towards the end of the writing of the thesis, the incumbent chief, who was male, was installed. According to the headman and other residents of the area, the acting chief has been instrumental in ensuring development in the area, such that under her leadership the area had recorded enormous progress in terms of community-based initiatives in response to HIV and poverty. These include construction of neighbourhood care points and kaGogo centres, which provide nutritional and psychosocial support to orphaned and vulnerable children in the communities. There were forty-three neighbourhood care points in 2012 when I was in the area, providing care and support to over 3000 children (field-notes, August, 2012). Initiatives also included the establishment of *emasimu endlunkhulu* (communal fields provided by the royal household), which are used to produce maize and vegetables for vulnerable population groups (orphaned children, PLHIV, elderly and disabled people, and child-headed households). I was informed by the area's headman that e-Tsembaletfu was among the first chiefdoms in the region to provide such plots for the production of food for vulnerable populations, with the support of farm inputs solicited by the chief herself from organisations such as NERCHA, UNICEF, World Food Programme (WFP), World Vision, and others.

Health services are accessed from the two clinics in the area and from several traditional and faith healers. The public clinic –e-Kwetsembeni– is the only one that provides HIV services to the community. The clinic primarily offers maternal and child health services as well as treatment of uncomplicated sexually transmitted infections and other minor health problems. HIV services were added as part of a process of decentralisation in the early 2000s, and ART was introduced in 2009, first only to refill ARVs but then in 2011 as a site for initiating treatment through the nurse-led ART initiation program. Prior to the training of nurses to prescribe ARVs to clients in primary health care facilities, doctors were the only ones allowed to do so. At e-Tsembaletfu the nurse-led ART initiative was introduced to achieve universal access to ART, and specifically to help those who were not on ART due to a lack of money for transport to access treatment further away (Humphreys et al., 2010; Mazibuko, 2014; Zuber et al., 2014).

According to the people of the area, a majority of the people in e-Tsembaletfu use a combination of allopathic, traditional, and faith healing systems for their health needs (field notes, 2012). This was confirmed by other participants such as out-of-school adolescents, area leaders, community health workers, clinic staff, and traditional and faith healers. The use of a combination of healing systems is not unique to e-Tsembaletfu; according to available studies in the country, a significant proportion of the population in Swaziland uses both modern and traditional healing systems in times of illness (Green and Makhubu, 1984; Reis, 2002).

Situated about two kilometres east of the chief's residence are the Inkhundla offices. The two high schools in the chiefdom were my data collection sites for in-school adolescents and teachers. Established in 1981, high school A (HS-A) had 254 students in total, 62% of them female, and five classes (grades 8 to 12) with the first two grades double streamed.[v] At the time of the study the teacher complement was fifteen with an almost equal proportion between male and female teachers, including a male principal and a female deputy. In comparison, high school B (HS-B) is newer (established in 1998), bigger in terms of student numbers (408) and teachers (22). While HS-A offered only academic subjects, HS-B offered both academic and technical subjects, and is one of sixteen pre-vocational schools[vi]in the country.

Eku-Thuleni: the urban site

Eku-Thuleni is an urban informal settlement stretching from the western to northern periphery of the city of Manzini. It is the biggest and densely populated peri-urban settlement under the municipal jurisdiction of the city. According to the last population census held in 2007, eku-Thulenihad a population of 39,529 people, of which 53.4% was female, and 2,452 were adolescents (1,021 male and 1,431 female) (CSO and Macro International, 2008). Most of the inhabitants of the area are migrants from rural areas who come to the city and the nearby industrial hub in search of job opportunities. The area consists of un planned and unserviced one-roomed structures constructed of sticks, mud, and corrugated iron-sheet roofing, which are rented out to migrants by owners who themselves live in their rural homesteads (Muzvidziwa and Zamberia, 2006). Like most informal settlements, eku-Thuleni is notorious for its crime, ranging from minor offenses, such as pick-pocketing, to serious crimes such as car theft, gender-related physical and sexual violence, and murder.

There are two clinics located within eku-Thuleni, a public health facility that provides mainly maternal and child health services as well as comprehensive HIV services, and a private clinic owned by a retired nurse, which provides treatment for minor ailments. However, in terms of health care needs, people gain from the area’s proximity to Manzini City, which has multiple health facilities. One of the city’s Christian mission-owned hospitals also serves as the regional referral centre. Within the premises of the regional referral hospital is a children’s clinic that is owned and managed by a non-governmental organisation (NGO), which is dedicated to providing HIV and TB services to children and adolescents. The clinic is one of four such clinics for children in the country, the other two located in Hhohho and Shiselweni regions respectively, and an outreach site in the Lubombo region. There are two high schools ineku-Thuleni: one public and one mission owned by the Methodist church.

Recruitment of participants

The study was designed around two broad objectives: to investigate about adolescents' access to and utilisation of HIV services, and to gain understanding into the experiences of adolescents living with HIV in different types of families. For the first objective, the primary population of the study was adolescents regardless of HIV status, both in and out of school. For the second objective, only adolescents who were aware that they were living with HIV and being treated with ART participated. Below I describe the recruitment process for each of the participating population groups.

All adolescents

To elicit their emic perspectives on access to and utilisation of HIV services, I collected data from out-of-school and in-school adolescents. To be included, adolescents must have been between the ages of twelve and nineteen, continuously lived in the study area for at least six months, and willing to participate in the study. Since HIV status was not a requirement for participation, their HIV status was not asked. All adolescents living in the study sites were eligible to participate in this aspect of data collection.

Recruitment of in-school adolescents

In-school adolescents were reached at their respective schools. Proxy consent for all in-school adolescents was obtained from the Ministry of Education and Training and further endorsed by the school principal (or his/her representative) in each school, hence parental consent was not sought. However, all the participating adolescents provided assent after thorough explanation of the study's purpose, objectives, procedures, and rights of participants. I critically reflect on the issue of consent/assent and gatekeepers in the section on ethical consideration towards the end of the chapter.

The grade nine (form II) class from which adolescents were recruited, was purposively selected, and students were then randomly assigned to different data collection techniques, such as essay writing or focus group discussions. The grade nine classes were selected because it composed almost all the ages (twelve–nineteen) that were the focus of the study. In addition, the data collection took place towards the end of the year, and I was advised that the other classes were busy preparing for their examinations. The composition of focus groups was based on sex and age categories (same-sex groups and mixed-sex groups divided into ages twelve–fourteen, fifteen–seventeen, and eighteen–nineteen). Adolescents from the same grade or class, same sex, and falling within the predetermined age categories formed a focus group. This arrangement was suitable as the homogeneity of a group is essential for group members' comfort, and allows free participation and expression of ideas without being threatened by the age and sex differences that would be present if the groups were heterogeneous (Basch, 1987; Folch-Lyon and Trost, 1981). To ensure ease of management of group dynamics during the discussion, each group had between six and twelve participants.

Recruitment of out-of-school adolescents

I used network sampling to recruit out-of-school adolescents to participate in focus groups. They were reached through local youth clubs that had meetings at the neighbourhood care points, Inkhundla offices, or local churches or any other designated area. Inclusion criteria included being between the ages of twelve and nineteen, being a resident of the study area, and being willing to participate in the study. These adolescents were grouped according to friendship, age, and sex. Unlike recruiting adolescents from school, where it was easy to get participants from all age groups, it was difficult to get younger out-of-school adolescents. Hence the age groups were only two, twelve–fifteen and sixteen–nineteen, and most fell in the latter category.

Adolescents living with HIV

Adolescents living with HIV were recruited through the clinic, support groups, and community based health workers. The recruitment of adolescents took place in two phases. Prior to the recruitment process, I presented the study to clinic staff, support group team leaders, and community health workers, reviewing the purpose and objectives of the study, the recruitment procedure, and the ethical protections regarding confidentiality, and informed consent and assent. I also explained the inclusion criteria of the population of interest: adolescents living with HIV, aged between twelve and nineteen years, knowingly living with HIV, on ART for at least three months, and willing to participate in the study. Further, their parents or guardians had to consent to their participation in the study.

At each of the two clinics, I was assigned a focal person to work closely with during the fieldwork. I found this quite helpful in establishing how we were going to work together. It also helped because it gave the adolescents and their parents/guardians someone in the clinics to consult with regards to the study. Each of the contact persons were given English and siSwati hard copies of the information sheet that outlined the study purpose, objectives, and the entire recruitment process as a reference during the recruitment of adolescents. I also gave each of them a prepaid mobile phone that they were to use to contact potential participants or to have participants contact them for the study. At the support groups and community health groups, team leaders and a senior community health worker assisted with the recruitment in a similar way.

The first stage of the recruitment process involved informing adolescents' parents or guardians who came to the clinics, support group meetings, or neighbourhood care points with their adolescent children about the study, its purpose, objectives, and procedures. The contact persons were asked to share the information sheet with adolescents and their parents or guardians so that they could go through it with them at their own time and place and make their decision on participation without any pressure or coercion. In cases where the parent or guardian was not available the adolescent was informed about the study and given the information sheet to take home to his or her parent(s) or guardian to read and consider. The information sheet had contact numbers (both mobile and landline phone) for the focal persons, the principal investigator and the chairperson of the National Health Research Review Board. This was to allow parents/guardians and adolescents to call anyone of their choice amongst the focal persons or principal investigator if they had questions they needed clarified about the study. Attached to the information sheet was the consent form for parents/guardians to sign and return to the clinic or to the support group or community health contacts if they agreed to the adolescent's participation. The contact persons kept a list of all potential participants with their contact details. On their scheduled return date to the clinic, support group meeting, or neighbourhood care point, adolescents (and their parents/guardians) brought the signed consent form with them and gave it to the contact person who in turn handed it over to me. Verbal consent for those who preferred to do so was also accepted. However, those parents or guardians who agreed to be contacted telephonically were called through their mobile phones[vii] after a week to get their responses with regards to their adolescents' participation in the study.

Of the sixty-seven that were recruited (forty-six in the urban site and twenty-one at the rural site), forty-eight adolescents were allowed to take part in the study by their parents or guardians. Seven adolescents were prevented from participating because they were preparing for external examinations, and five parents did not return the consent forms stating that they forgot them at home, misplaced them, or lost them. An additional four parents stated that they did not want their adolescents to participate in the study, two adolescents transferred out of the clinic, and one did not return to the clinic.

The second phase was a meeting, which took place at the clinic or any place they chose, with each of the fifty-eight adolescents whose parents or guardians had given consent for their participation. Many chose their homes for the meeting, if they opted to meet outside the clinic. Each of the adolescents was presented with an in-depth explanation of the study, including the purpose, objectives, and procedures to be followed, as well as their rights as participants (see ethical consideration below in this chapter). At the clinic, this happened in a private room on the scheduled clinical visit date when the parents/guardians or adolescent brought back the signed consent form or verbal consent was given, and took place while adolescents were either waiting for or after their medical reviews. Some were approached and recruited at their homes with assistance of community health workers or volunteers from the neighbourhood care points in their areas. The process lasted on average twenty minutes, probably because adolescents were already familiar with the contents of the recruitment procedure after having read and discussed it with their parents or guardians. Although this phase involved adolescents, some parents insisted on being part of the process and thus were allowed to do so.

In the second phase, four of the adolescents declined to participate: three stated that they did not have time because they were enrolled in tertiary institutions or employed, and one was relocating to the Shiselweni region. All the adolescents who declined were older (eighteen and nineteen years), female, and from the urban site. The forty-four who agreed to take part in the study were given an assent form to sign, and the three who preferred verbal consent were allowed to do so. Among the forty-four adolescents, sixteen agreed to follow up interviews in which they shared their experiences of living with HIV. These adolescents included ten male and six female; three of whom were aged sixteen, two were aged twelve, thirteen, fourteen, fifteen, seventeen, and eighteen years; and one was nineteen years old. I provide details of the sixteen adolescents in the next chapter.

Although adolescents aged twelve years and above could legally consent without parental involvement, in this study all adolescents who were living with HIV and participating in in-depth interviews had to get parental or guardian consent because part of the data collection involved a visit to their homes for interviews with them and their family members, particularly those involved in caregiving, and also for observation of interactions between adolescents and the people they lived with them in a non-clinical, natural, and familiar setting.

Secondary participants

Secondary participants included parents, guardians, teachers, health care workers, traditional health practitioners, and community leaders. In addition, key informants (program managers, service coordinators, and policy makers at national level) participated through in-depth interviews. Health care workers included expert clients who were responsible for locating patients who had not showed up for their monthly health reviews or ARV refills or who had disappeared altogether from HIV care. Interviewing these expert clients made it possible for me to reach adolescents who were lost to follow up or were not optimally adherent to ART.

While parents and/or guardians of adolescents living with HIV qualified to participate in the study by virtues of their relationship with the adolescents, formal and informal methods were used to recruit other secondary participants through community events such as meetings, church, traditional weddings, the street, clinics, shops, soccer games, or home visits. To contact community and health sector leaders, formal requests were made in writing which were followed up by phone calls to schedule appointments for interviews. Health care workers in the clinic were recruited directly through conversation in their work places while the senior nurse at the local clinic assisted in the recruitment of community-based health workers in collaboration with the lead community worker. Teachers were also recruited through the assistance of the principal or his/her representative. However, all participants reserved the right to refuse or terminate participation, or to not respond to questions they were uncomfortable with. The purpose, objectives, and procedure of the study were explained to all participants, as well as the practices to ensure their rights and confidentiality. All those willing to take part in the study signed a consent form.

Characteristics of participants

A total of 467 participants took part in the qualitative phase of the study, as detailed in the table below. Throughout the study, I use pseudonyms to protect the identity of participants.

Table 1: Number of participants per qualitative data collection technique

Participants	Focus group discussions (n=337)	Individual in-depth interviews(n=109)	Key informant interviews (n=21)	Total (n=467)
All adolescents (HIV status not asked)	184	18	-	202
Adolescents living with HIV	61	44	-	105
Parents/guardians	-	17	-	17
Teachers	22	4	-	26
Health care workers	17	18	-	35
Rural Health Motivators/Community Health Workers	53	-	-	53
Policy makers	-	-	3	3
Programme managers	-	-	18	18
Culture opinion leaders	-	5	-	5
Traditional and faith healers	-	3	-	3
Total	337	109	21	467

Qualitative data collection

Data collection for the entire study took place between July 2012 and July 2014. The qualitative portion of the fieldwork took place between July 2012 and December 2013, lasting eighteen months. During this period, I hired and trained assistant researchers, conducted interviews, interpreted and analysed the data, and wrote biannual reports with and for the MaxART project partners. Preliminary findings were shared at biannual MaxART meetings, and at several national and international meetings and conferences. Feedback from these fora was incorporated into the data.

Recruitment and training of assistant researchers

Prior to data collection, I recruited and trained three young assistant researchers from the areas where the data was to be collected. The reason for engaging young researchers was twofold: first, it was to bridge the age gap between myself and the adolescents, which may have made it difficult for them to freely and honestly express their views to me as an adult woman. This was particularly important given that young people in Swaziland are expected to be respectful and obedient to their elders (Kuper, 1980: 117), a norm that could have affected some of their rights such as refusing to participation. Second, because the assistants were young, they had better understanding of the youth culture than I did, and therefore would make better sense of verbal and nonverbal language used by young people in their respective areas.

While the initial plan was to have two young women and two young men for the ethnographic phase of the study, I ended up with two male (aged nineteen and twenty-two) and one female (aged eighteen) assistant researchers. This was because the other female candidate dropped out due to other personal commitments. Both of the male assistant researchers had previous experience in HIV research working as volunteer recruiters and quantitative (questionnaire-based) data collectors for an international NGO that provided medical male circumcision in the country. My female assistant did not have experience in research, but had experience working with in-school adolescents on HIV prevention and health promotion in general. She was one of the founding members and also the chairperson of a health club that focused on HIV prevention in her former school. After finishing her studies a year before I met her, she volunteered at the local public clinic that was located at the rural research site.

The assistant researchers were trained for seven days in both theory and practical application. The first two and one-half days focused on key concepts, data collection strategies, and ethical issues, and three days were spent on supervised hands-on practice on data collection. The final one and one-half days focused on providing feedback on their practical training and on logistical issues. The training was participatory in that there was more role-playing and discussions using vignettes than formal presentation of training material.

Qualitative data collection methods

I used a variety of qualitative techniques to collect data including essays and question writing, participant observation, focus group discussions, in-depth interviews, informal conversations, and diary entries, which I describe below. Triangulating techniques allowed me to explore themes emerging from the iterative data collection and analysis, thus allowing for validation through convergence of information or data from different sources and methods or techniques (Carter et al., 2014:545). In essence, triangulation is useful in deepening the researchers' understanding of a phenomenon under investigation as well as maximising their confidence in the findings of qualitative studies (Denzin, 1978; Patton, 1999, 2002; Thurmond, 2001).

Questions, essay writing, and brainstorming

I decided to involve school adolescents in the development of the research tools by asking them to participate in one of three activities focused on each of themes of the study: adolescence, gender, and sexuality; access and utilisation of health services; and the meaning and experience of living with HIV. For this purpose, I selected grade nine pupils from two purposively sampled secondary schools (one urban and one rural). As mentioned above, grade nine was chosen because it encompassed a majority of the students within the age range (twelve to nineteen years of age) the study was focusing on.

Students were randomly assigned to a question writing, essay writing, or brainstorming group. After explaining the purpose and objectives of the study to the students and eliciting their consent, I asked each to choose one of three colours of paper according to their colour preference; each colour corresponded to a group. I avoided the gendered colours of pink and blue and used neutral colours of white (for essays), green (for questions) and purple (brainstorming discussions). I limited the number of the purple pieces to fifteen based on the maximum number of students I wanted to involve in the discussion. After they had made their choice, I told them which group each colour stood for. Students had the choice to change the colour if they felt uncomfortable about it. I applied the whole process in both schools and classes, and only one student chose to change their choice of colours, as they preferred writing questions over the brain storming session.

For the questions, each student in that group was instructed to write down a maximum of three questions under each main theme: adolescence, gender and sexuality; access and utilisation of health services; and the meaning and experience of living with HIV. For the essay writers, I prepared hypothetical cases related to each of the themes. Each student in the essay-writing group was to pick a case of his or her choice and write a one-page essay on it. For the brainstorming session, I used the pile-sorting technique to stimulate discussion. I prepared a list of names, biological functions, home/house chores, occupations, and sporting games. I also had three big charts each labelled according gendered categories (female only, male only, and mixed). Students were asked to pin each card under each category according to what they believed was male, female, or shared. An example is shown in the pictures below. After completion of the sorting, we discussed the reasons for their choices of where to pin each card, and what it meant to them as males and females in relation to sexuality and HIV, and in relation to barriers to accessing and utilising HIV services.

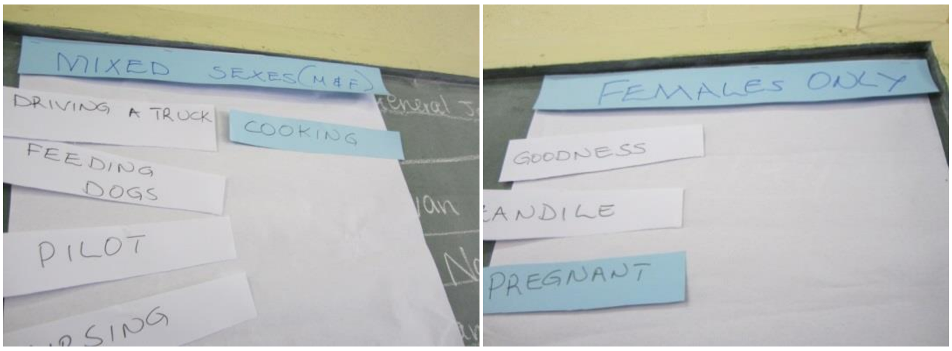

Figure 3: Pilesorting exercise about gender

The exercise generated a total of 536 questions, 108 essays, and six brain storming audio-recordings of thirty-five minutes on average. I analysed the contents of all three and grouped them according to the themes of the study and to themes that emerged from the data. I then used these themes to develop guides for the individual in-depth interviews, key informant interviews, and focus group discussions that I eventually carried out. While the question writing exercise and brainstorming technique were my own innovation, the essay writing technique has been used with adolescents in researching topics that are considered sensitive and difficult to talk about (see James, 1995; Morrow, 2008).

Participant observation

Participant observation has been one of the key techniques in ethnographic research dating back to the early twentieth century when Malinowski used it to study the Trobriand Islanders in 1922. Reflecting on his time living amongst the islanders and engaging in the daily life of the community, he notes:

> Soon after I had established myself in Omarkana Trobriand Islands, I began to take part, in a way, in the village life, to look forward to the important or festive events, to take personal interest in gossip and developments of the village occurrences . . . As I went on my morning walk through the village, I could see intimate details of family life. . . I could see the arrangements for the day's work, people starting on their errands, or groups of men and women busy at some manufacturing tasks. Quarrels, jokes, family scenes, events usually trivial, sometimes dramatic but always

> significant, form the atmosphere of my daily life, as well as theirs', (1961, as quoted in DeWALT and DeWALT, 2011:3)

In the same vein, I lived within the communities I was studying to gain better insight into their daily lives. In particular, I was interested in how families, friends, and peers, and others in their social and community networks, shape adolescents lives, and how adolescents embodied and performed or challenged scripts related to gender norms, sexual practices, and HIV and AIDS. Wolcott (1995: 11) states that

> …fieldwork is a form of enquiry requires the researcher to be immersed personally in the ongoing activities of his or her research subjects' life-worlds for an extended period of time. In this way the ethnographer not only becomes familiar with the spatial dimensions of the research setting and its socio-cultural dynamics, but also how those dynamics may change at certain times of the day, the week or year. . . . [I]t involves the study of human beings in social interactions.

I spent the first month of my stay in each community familiarising myself with the interactions and structures with the purpose of establishing rapport and understanding community members' way of life. This I did by attending community gatherings or events such as going to churches, weddings, sporting events, meetings as well as talking with people in general. Whenever necessary and culturally appropriate, I requested permission to audio-record and photograph events to allow me to review and get a better understanding of community narratives, and compared these with field notes I took during the events. I also visited homesteads in the area to assist them with whatever work they were doing, accompanied them to draw water from the river, and visited the cattle dip tank – a place where domestic animals, such as cattle and goats, are taken to and immersed (dipped) in a mixture of water and chemicals to kill ticks and lice, during dipping days. As families got to know me, I sometimes just visited for a chat. I also hung around the market stall, watched soccer and netball games during sporting periods in the schools, or walked with students home after their school conversing with them.

At the schools, I took part in school assemblies, satin the teachers' staff room, shared tea or lunch with them, and participated in their lessons either as a guest teacher or as a passive observer if the teacher had agreed on me doing so. Similarly at the clinic, I took part in the daily routine particularly in the mornings when the clinic was busy, and in the afternoons I helped with whatever was being done from compiling daily reports to cleaning the floor. This allowed me to earn the trust of the people who were my sources of data.

In addition, I used participant observation with adolescents living with HIV, when I visited their homes after permission was granted by their parents or guardians through the local health clinic staff. During the visits I had in-depth interviews with the family members to get a better understanding of the family history, the family composition, and their beliefs with regards to illness in general and HIV in particular. I was particularly interested in how the family's social and economic situation as well as health beliefs and practices shaped adolescents' day-to-day management of HIV and how it impacted adolescents' navigation tactics and strategies.

Besides being a primary data collection technique in my study, participant observation was useful to triangulate data gained through other means of data collection such as focus group discussions and interviews. Other researchers have reported experiences where during the formal interviewing techniques, participants have shared stories or given answers that are not true, for example, to avoid embarrassment when the topic being discussed is sensitive, or in an attempt to please the researcher (Lambert, Glacken, and McCarron, 2013). This is particularly pertinent in the case of HIV-related research in high prevalence settings, where everyone may have in one way or another been exposed to information about the disease, and what is considered acceptable and not by the biomedical health system. As noted by Agar (1980:70) 'people have different sides to themselves that they display under different sets of circumstances, making it essential to see group members in different situations, not just during a brief interview'. By living alongside participants for a long time, participant observation provided an opportunity to observe the 'real side' of the stories shared by participants that I would otherwise not get from focus group discussions or interviews.

According to Bernard, participant observation is a 'strategic method' that 'puts [the researcher] where the action is and lets [the researcher] collect any data you want, narratives or numbers', (2006: 343). Though referred to as the general approach to fieldwork in ethnographic research (Spradley, 1980), I used participant observation throughout the study during both the qualitative and quantitative phases, sometimes passively and at times more actively. However, I never hid my role as a researcher, as each time I introduced myself I would mention my purpose for being in the community.

Focus group discussions

I used focus group discussions to get the embodied sociocultural views of adolescents in particular and of the communities in general, with regards to sexuality and the practices that adolescents employ to protect themselves and others from HIV or to manage HIV. Focus group discussions are an opportunity for the researcher to collect qualitative data from small interactive groups regarding the perceptions and opinions of research participants (Agar and MacDonald, 1995; Green and Thorogood, 2004; 2009; 2014). Through them, I was able to elicit substantive historical information from diverse members of the population in the community. These discussions allowed exploration of issues and opinions by participants and in the process, issues that needed further exploration emerged and were followed up either in other focus group discussions or in individual interviews. With the help of my assistant researchers, I held focus group discussions with adolescents, community health workers, and teachers. To ensure that all verbal data was captured, all discussions were audio-recorded after permission was given by participants. Non-verbal responses were captured as part of field notes by assistant researchers while I facilitated the discussions. Thirty-eight focus groups were conducted during the period involving a total of 337 participants.

In-depth interviews

I used in-depth interviews to complement the data I gathered from observations, informal conversations, and focus group discussions, particularly on issues that were sensitive or too personal to discuss openly in a group or on issues where I needed more depth. I conducted in-depth interviews to gather data from key informants as well as adolescents living with HIV and their parents or guardians and guidance teachers. I conducted multiple interviews with some of the adolescents and parents or guardians, but interviews with other individuals were a one-off event. A total of 101 in-depth interviews were conducted with adolescents, teachers, parents, guardians, traditional and faith healers, nurses, doctors, and expert clients using a topic guide. In addition, twenty-one key informant interviews were done with health personnel (programme managers, policy makers), traditional leaders, and experts on traditional cultural norms and practices relating to socialisation and gender.

Diary entries

Adolescents living with HIV in both research sites were given A5 notebooks to use as diaries. They were asked to write their day-to-day experiences and stories of living with HIV. According to Milligan, Bingley, and Gatrell, 2005), 'diaries not only offer a means of engaging in participatory research with vulnerable groups but they can provide useful tools for gathering those kinds of data that may be seen as too sensitive to approach through other qualitative approaches', and are useful in capturing the 'meaning and weight that respondents attach to different events and problems in their lives' (2005:1882-1883). This approach not only facilitates capturing the daily experiences and changes experienced by the diarists, but it also allows for some reflection and discussion from the participants during interviews with the researcher. Using diary entries to stimulate one-on-one discussions, I held formal conversations with adolescents to gain insights into what it means to be HIV positive and into their ways of navigating the sociocultural and health system landscape as they manage the disease. However, I abandoned this method as most of the adolescents were not using the diaries, and the two who made an effort to make entries were entering the similar or same information over and over.

Informal conversations

I used informal conversations throughout the study with most of my participants but also with community members with whom I came into contact through my observations and my participation in community events. Informal conversations are particularly useful to overcome the power imbalance between the interviewer and interviewee, especially in interviews with adolescents. It is well documented that formal interviewing negatively affects the ability of an interviewee to communicate particularly if she or he is a child or young adolescent. Hence most authors discourage the use of formal interviews with children and adolescents (Lambert, Glacken, and McCarron, 2013). The assistant researchers engaged in informal conversations with their peers to gather their emic perspectives with regards to a range of issues on HIV. Unlike formal interviews where the moderator has specific questions to ask the interviewee, in informal conversations the direction of the conversation may change, and thus flexibility is essential. The power balance shifts from the interviewer to interviewee in informal conversations as those providing the information take the lead in sharing what is pertinent and important to them, rather than responding to the interviewer as in formal interviews. In this sense, informal conversations provide the researcher an opportunity to come closer to what is at stake for the researched (Fife, 2005; Green and Thorogood, 2004). So while the focus was on access to and utilisation of HIV services, other topics were not disregarded, particularly if they were deemed causally linked to the interest of the study. For example, the drought experienced in the study sites resulted in a meagre harvest, and because food availability is an essential part of ART adherence, we listened to, captured, and further probed stories related to the drought in subsequent discussions.

Through formal interviews with traditional leaders and other key informants, I probed deeper into some of the issues that were raised in the informal conversations to get a better understanding of the issue of interest. All of us (that is, myself and the assistant researchers) had small notebooks that we kept with us at all times. We would write all that transpired after the end of such conversations, and at the end of each day we went through the stories we collected to analyse them for content and emerging themes, and to see if there were issues that needed clarification or to be followed up.

Other sources of information

In addition to the primary data collected through the various methods and sources as explained above, I also collected information from clinic registers and the national HIV monitoring and evaluation database. My interest was to assess historical trends in HIV service uptake by adolescents in the country since ART started 2004. I was interested at comparatively assessing differences in HIV services uptake and retention by adolescents' age (young and old), sex (male and female), residential area (urban and rural), and region (Hhohho, Lubombo, Manzini, and Shiselweni). This helped me to get a general picture on the uptake of HIV services by adolescents in the country. In addition, I studied national archival materials on history, culture, and kinship in Swaziland, as I was interested in getting a deeper understanding of the origins of the Swazi nation and its history in terms of gender and socialisation.

Furthermore, I attended meetings on adolescents and HIV, school debates around adolescents' sexual and reproductive health and HIV, and support group sessions and adherence camps for adolescents living with HIV. I was also invited by various organisations to share my preliminary findings, particularly after a presentation at a national research conference. I used the discussions from these meetings to enrich my data as well as to generate new and suggested areas or themes for further research.

I followed and collected print media reports relating to adolescents and their access to and use of HIV services, and their experiences with ART, adherence, disclosure, and stigma. A review of grey literature and research from other countries also enriched my understanding of adolescents' issues broadly and those relating to my areas of focus in the study.

Qualitative data management and analysis

Most of the interviews and focus group discussions were conducted in the local language, siSwati, and, except where not permitted or impossible to record, all formal interviews and focus group discussions were audio-recorded and field notes taken. These data were saved to a laptop in readiness for transcription from siSwati to English. Fieldnotes were coded similar to the interview where they were taken and stored in a folder. This allowed me to compare and refer to both the field notes and recorded data during transcription and translation particularly for the nonverbal clues that the recording would not pick up.

I transcribed the interviews and discussions verbatim on weekends but as more data was collected, I engaged an independent transcriber to do the work for me. I would then read the transcription while listening to the recorder to check if what was transcribed was indeed what was recorded. This also helped me to get immersed in the data and identify any issues that I needed to get more clarity on. The independent transcriber signed a sworn statement regarding the confidentiality of the material in order to protect participants. During the transcription, all participants' names were removed and replaced with pseudonyms. All the recorded, transcribed, and translated data is kept on my laptop in a password-protected folder, while the completed hard copies of the survey questionnaires (described in next section) are kept in a locked metal box in my home office.

I did the analysis iteratively with data collection during the ethnographic phase of the study, following the constant comparative method using open and axial coding according to Glaser and Strauss (1967) and Lincoln and Guba (1985). At first, I read through the initial transcript to get an understanding of the issues being described. I re-read the transcript while colour-coding similar statements from the text. I then compared and grouped the statements into categories and then into main themes, which formed the framework for coding subsequent transcripts. Where new statements in subsequent transcripts or audio-recorded data did not fit the already generated categories, new ones were created. The new categories were then compared and regrouped into themes. According to Thomas, the general inductive approach 'allows research findings to emerge from the frequent, dominant, or significant themes inherent in raw data collected, without the restraints imposed by structured methodologies' (2006:238).

Quantitative data collection

One of the objectives of the MaxART project was to improve the uptake of HIV services by adolescents. Part of the roadmap to achieving the objective was to understand what either enabled or prevented access to services from the adolescents' perspective. To that end, a survey was conducted between January and July 2014 in the Manzini region to quantitatively explore the themes that came up from the qualitative phase of the study. I obtained enumeration areas from the Central Statistics Office for the Manzini region, which I used as my sampling frame. The Manzini region has 16 *Tinkhundla* and 634 enumeration areas (EAs).The number of homesteads in each enumeration area ranged between 20 and 1,000 (CSO and Macro International Inc., 2008).

Recruitment of respondents

The target population for the study were adolescents from twelve to nineteen years of age who had continuously lived in the Manzini region for at least three months at the time, regardless of their HIV status. Respondents were recruited and interviewed in their homes if they agreed to participate in the survey after the purpose and procedures of the study, and their rights as participants, were explained to them.

Sampling procedure

A multistage systematic random sampling procedure was used to select enumeration areas and homesteads for the survey. First, I used computer-generated systematic random sampling to select every twentieth enumeration area, resulting in a sample of thirty-two areas. A 20% contingency was added to the sample, resulting in a total of thirty-eight areas. I used probability to determine the size, or the total number of homesteads that should be in the sample, in each area. Convenient sampling was applied for adolescents in each sampled homestead, that is, adolescents who met the criteria and who were found in the sampled home were invited to participate in the study. Where there were more than two adolescents meeting the criteria per homestead, age and sex stratification was used as an additional sampling criterion. We wrote the names of adolescents on a piece of paper, folded them tightly, and put them on two separate dishes representing males and females. Then an independent person (usually young children) who was not taking part in the study was asked to randomly select the pieces of paper. The first two that were selected were interviewed. If in a sampled homestead there were no adolescents, or they refused to be interviewed, the next homestead was sampled for the study.

Sample size

The sample size for adolescents was calculated using STATA (StataCorp, College Station, TX, USA) statistical software version 13.0. The formula below was used to calculate the sample size:

$$n = \frac{Z^2 \times (p) \times (1-p)}{e^2}$$

Where:
Z value is 1.96 for 95% CI;
p=.5;
e=0.05

Applying the formula and parameters yielded a sample size of 384.16, which was rounded up to 385 for in-school adolescents and the same number for out-of-school adolescents. To cater for incomplete questionnaires, refusals, and non-responses, 10 %was added to the sample size, making a total of 424 in school and the same proportion for out-of-school respondents, bringing the sample total to 848. The figure was rounded up to the nearest whole, yielding a final total sample size of 850. However, during data collection, 863 adolescents completed the survey questionnaire. The age and sex distribution of adolescents within the sample was based on the region's population proportions: 38% aged 12–14, 40% aged 15–17, and 23% aged 18–19.

Tool development and data collection for the survey

An interviewer-administered questionnaire was developed based on the findings of the qualitative phase of the study as well as a review of the relevant literature. The questionnaire was designed to collect information on six main domains: 1) sociodemographic characteristics and family background (fifteen questions), 2) HIV knowledge (nineteen questions), 3) sexual risk behaviour (fourteen questions), 4) attitudes towards HIV and ART (eleven questions), 5) access to and utilisation of HIV testing and treatment and disclosure (twenty-two questions), and 6) attrition from HIV treatment and care (ten questions).

Some questions were adapted from previous, similar studies. HIV knowledge questions were adapted from a questionnaire used by Carey and Schroder (2002). Questions on sexual risk behaviour were adapted from the CDC (2007) comprehensive sexual and reproductive health survey for adolescents and Guiella and Madise (2007). Questions on attitudes towards HIV and ART were adapted from the K4Health toolkit for adolescents (Duffy, Bergmann and Sharer, 2014).

Recruitment and training of survey collectors and supervisors

Prior to data collection, survey data collectors and supervisors were recruited and trained on the data collection tool, procedures, and ethical conduct. Nine young people aged between nineteen and twenty-six years and three supervisors who were nurses and experienced in quantitative data collection and HIV and AIDS took part in the data collection.

Five of the data collectors were female; all had completed high school, one was a university student, and two were recent graduates from social sciences and nursing respectively. Four (two men and two women) of them were openly living with HIV and were on ART. The survey data collectors attended a six-day participatory training session that covered interpersonal communication, ethical issues, and the questionnaire. Role-playing, discussions, and formal presentations were used for the training.

To ensure that all the data collectors were fully familiar with survey questionnaire and had a uniform understanding of the questions in the tool, they translated the questionnaire from English to siSwati and back to English during the training. Most importantly, because some of them were already living with HIV and have been on ART for a long time, the survey data collectors were able to identify questions or wording that were rather sensitive and unacceptable. This resulted in some questions either being removed because they were too sensitive, or reworded. The questionnaire (both English and siSwati versions) was then handed to an experienced translator. After the survey was finalised, the data collectors participated in testing the questionnaire, which took place among adolescents who presented in two health clinics (one urban and one rural) selected for the purpose in the Hhohho region. Minor changes were made in the questionnaire such as sequencing of questions and improving the clarity of others as suggested by those who completed the survey during this test phase.

The data collectors were divided into three teams each with a supervisor, and the actual data collection was scheduled for twenty days. To ensure completeness and consistency, after the first two days of data collection, the data collectors came together for a day to go through the already completed questionnaires to check for completeness as well as assess whether everyone understood the questions the same way; team supervisors then submitted the surveys to the principal researcher. At the end of each day, the teams all came together for a debriefing on their experiences in the field.

Eight hundred and sixty-three respondents completed questionnaires. However, four were excluded from the analysis because the interviewees were either above or below the age bracket of the participants of the study: two were aged twenty-one, one was aged twenty, and another was aged eleven years. The analysis therefore involved questionnaires from 859 participants.

Characteristics of survey participants

Among the 859, an almost equal proportion of female and male adolescents participated (50.3% female and 49.7% male respectively). Approximately half (n=372; 43.3%) were orphans: consisting of 57% (n=212) maternal orphans, 26% (95) paternal orphans, and 17% (n=65) double orphans. Almost all the participants were single and had never been married (n=856; 99.7%), were Swazi nationals (n=847; 98.6%), were Christians (n=847; 98.6%), and were still enrolled in school (n=767; 89.4%). Almost half of them were rural residents (n=419; 48.8%). Forty percent (n=347) of the adolescents reported that they had been tested for HIV. The table below shows some of the sociodemographic details of the survey participants.

Table 2: Sociodemographic characteristics of respondents for quantitative survey

Variable	***N***	**%**
Age		
12–14	324	37.3
15–17	339	39.5
18–19	196	22.8
	859	**100.0**
Sex		
Male	427	49.7
Female	432	50.3
	859	**100.0**
Nationality		

Swazi	847	98.6
Non-Swazi	12	1.4
	859	**100.0**
Education level		
Primary school	346	40.3
Secondary school	320	37.3
High school	178	20.7
Other (tertiary, none)	15	1.7
	859	**100.0**
Religion		
Christianity	847	98.6
Other (ancestral, Islam, no belief)	12	1.4
	859	**100.0**
Residence		
Urban	194	22.6
Peri-urban	246	28.6
Rural	419	48.8
	859	**100.0**
Length of time living in the area		
Since birth	485	56.5
Less than 1 year	89	10.4
1–4 years	122	14.2
5years or more	163	19.0
	859	**100.0**
Parent’s current situation		
Both alive	487	56.7
One or both parents dead	372	43.3
	859	100

Orphanhood status		
Mother dead (maternal orphan)	212	56.9
Father dead (paternal orphan)	95	25.5
Both parents dead (double orphan)	65	17.5
	372	**100.0**
Ever tested for HIV		
Yes	347	40.4
No	512	59.6
	859	**100.0**

Quantitative data management and analysis

With the assistance of a qualified and experienced statistician, quantitative data was entered into a data screen that was developed using Statistical Package for Social Science (SPSS) version 20. After entry, the data was cleaned before analysis was carried out. Simple descriptive statistics were used for sociodemographic proportion of participants, disaggregated by those who reported they had tested for HIV. The Chi-square test (Fisher's test for frequencies less than five in a cell) was used to examine how socio demographic factors and family type influence decision to utilise HIV services. Multiple binary logistic regression analysis was conducted to determine correlates to utilising HIV testing at $p < .05$, confidence interval 95%.

Scientific clearance, ethical approval, and community authorisation process

The study received scientific clearance and ethical approval from the National Health Research Review Board (NHRRB) of the Ministry of Health as well as the directorate of the Ministry of Education and Training. Approval from the National Health Research Review Board helped speed up authorisation from the Ministry of Education and Training. After receiving clearance from the two government departments, I sought permission to conduct the study from the Manzini Regional Administrator's office and all other relevant community structures in the study sites.

After gaining approval from the community leadership, I asked for their assistance to locate youth groups situated in the area as well as community-based health workers, child-headed homesteads, and adolescents living with HIV. I explained that my contact with adolescents would only be possible after they had agreed to converse with me, meaning the community leader had to explain the purpose of my request to see them. I also did a quick mapping of the area, including where the kaGogo centres and neighbourhood care points are located and the availability of community based health workers and informal youth groups.[viii] Through these I was able to meet out-of-school youth living in the area. I must state, however, that it was more difficult to locate adolescents living with HIV in the urban area than it was in the rural setting. I expand on this in chapter six where I discuss stigma.

All participants were individually informed that their participation was fully voluntary and that they had certain rights: to withdraw from the study, to refuse to answer any questions asked, and to maintain confidentiality and privacy. They were also individually asked to consent in either writing or verbally, but only after the study was explained and participants verbalised that their questions and concerns addressed to their satisfaction. Adolescents below the age of eighteen had to obtain consent from their parents or guardians prior to participating in the study, while they gave assent. Those aged eighteen and nineteen years gave consent without parental or guardian involvement.

Adolescent participants living with HIV were requested to obtain consent from their parents or guardians regardless of age, while they provided assent to participate. This was necessitated by the need to visit some participants at their homes as part of data collection. Parents and guardians of adolescents living with HIV were also asked to participate in the study for the purpose of data triangulation. Although there were counsellors and a professional psychologist on standby should the need for their services arise during the study (see below), the involvement of parents and guardians was to provide ongoing support to adolescents during and after the study. However, I clearly explained to them (parents and guardians) that discussions between the adolescents and the researcher would remain confidential unless otherwise there was a dire need and the adolescent had agreed to share any part of the discussion.

All data was anonymised by use of fictitious names. All focus group discussions and interviews were conducted at a place and time that was convenient to participants, although there were times where this was not possible, particularly for in-school participants.

However, even in such situation participants were asked prior to the discussions if we could continue and they all responded to the affirmative. To protect them, teachers were not involved during the discussions; they only assisted by making a quiet space (a classroom) available. Assistant researchers signed confidentiality agreement as part of their contracts.

Cognizant of the emotional and psychological impact of HIV on those infected and affected, I solicited the services of a professional clinical psychologist and nurses trained in adolescent counselling to help when needed. My training in mental health nursing and adolescent and child counselling came handy here in terms of assessing distress, halting interview sessions, and referring adolescents for counselling. Only one family had to be referred to the psychologist, after permission to do so was granted by the head of the household. In addition, participants had my mobile number to call at any time they had anything to discuss or share, or even if they just wanted to talk to me.

PART TWO

RESEARCH FINDINGS

This section presents the empirical findings of the study. It has four chapters: chapter three introduces each of the adolescents living with HIV with whom I had multiple interviews over the 18 month period of qualitative data collection. In chapter four I present a discussion of the meaning of the family from the perspectives of adolescents, parents, guardians, and community leadership, and as portrayed in national policy guidelines. Here I show that the family is central in adolescents' everyday life, from decisions about HIV testing to ART enrolment, adherence, and disclosure. However, the meaning of the family as deduced from adolescents' narratives constantly changed in relation to the context in which it was used.

Chapter five presents adolescents' motivations for and experience with HIV testing, being on lifelong treatment with ARV medicines, as well as treatment adherence and retention in HIV care. What is significant in this chapter is that almost all the adolescents were only tested for HIV after repeated episodes of sickness, spanning for months or years.

Chapter six delves into adolescents' experiences and management of stigma. While most of the adolescents stated that they did not necessarily experience acts of discrimination, they lived in the fear of being stigmatised. Others experienced discrimination from family members, school, and community. Various tactics were used by adolescents and their parents or guardians to avoid stigma or manage discrimination.

Chapter seven is about experiences of, and with disclosure. The significant finding is that most of the adolescents, for various reasons, were not immediately informed of their HIV-positive status. When eventually informed, adolescents' immediate response was marked with shock, sadness, confusion, and crying at being diagnosed with a sexually transmitted and highly moralised and stigmatised infection; indifference due to a lack of understanding of the meaning of being HIV-positive; or 'relief and happiness' at finally knowing the cause of poor health that characterised childhood.

CHAPTER THREE

THE STUDY PARTICIPANTS

Introduction

As mentioned in the preceding chapter, data for the study was collected from multiple sources, including adolescents living with HIV. This chapter introduces the sixteen participants with whom I had multiple interviews and conversations, whose stories form the core of the study.

All of the sixteen adolescents knew that they were living with HIV, and all were on ART. Their HIV status had also been disclosed to selected members of the family and/or their school communities. Fourteen of the adolescents were infected perinatally, and most of their childhood was characterised by poor health due to recurrent sicknesses. The remaining two were infected later on: one through unprotected sexual intercourse while the other was not sure how he got HIV but thought it was through assisting an injured friend.

Six of the adolescents were born to unwed parents. Six of the adolescents were single orphans (three maternal and three paternal), two were double orphans while the rest had both parents alive though most were not living together as couple. Two of the adolescents were living in stepfamily setting, five were living in skipped-generation families, four were living with single parents (mothers), two were living with both parents, while the rest were living with extended family relatives. All but four of the adolescents were living with either a parent or a relative who was also HIV positive and on ART. Below I share a brief description of each adolescent in no particular order. I use pseudonyms to protect their identity.

Malangeni

Malangeni was twelve years old when I first met him in 2012, though he looked half his age. Besides his physical stature he looked like healthy boy. He lives with his mother and siblings, the fifth born in a family of eight, though two of his siblings passed away due to pneumonia and prolonged diarrhoea, respectively. He has one brother who is younger than him and four sisters who are alive, and are all HIV negative. Malangeni was tested for HIV at the age of four after he suffered from herpes simplex and was found to be HIV positive. He started taking ARVs then. His mother believes Malangeni was infected with HIV through mother-to-child transmission and thus was born with it. His mother is also living with HIV and on ART. Malangeni's father stays at his work place in a government-owned cattle ranch where he herds the cattle. He visits home once a month during month-end. In Malangeni's family, the father is the only one gainfully employed and is thus the breadwinner of the family. Malangeni's mother supplements her husband's salary through handicraft, making and selling grassmats on a small scale. Though the family is reportedly struggling economically, they have not reached a stage where they go without food, as some other families do.

Dudu

Dudu was twelve years old when I first met her in August 2012. She was diagnosed with HIV in 2003 after repeated episodes of illness, and started taking ARVs soon after. Dudu lived with her maternal grandmother. Her mother died when she was two years old, and although her father is alive, he is said to have 'disowned' her after she was tested without his permission. However, Dudu's grandmother stated that she tried several times to have him consent to the test and he repeatedly refused. In view of Dudu's worsening health, a doctor at the local hospital agreed to test her for diagnostic purposes in the presence and consent of the grandmother. She was found HIV positive, and was put on treatment. Upon her discharge from hospital, her grandmother informed her father that Dudu was HIV positive and had been started on ART, at which point he cut all contact with Dudu. This has made the family, and particularly Dudu, to believe that her father hated her because she was HIV positive.

Dudu's grandmother told us that she had seven children and five of them died of AIDS, leaving behind their children, including Dudu. There were twelve people living in her (grandmother's) homestead, including Dudu's uncle and his wife and children, and Dudu's cousins from mother's sisters. None of the family members was working; the only uncle had just lost a job when a non-governmental organisation (NGO) he was working for closed down due financial challenges. Dudu's grandmother, who was the sole bread winner, did not receive the government social security grant for the elderly because she did not have the national identity card required for registration. Her income came from selling fruits at the nearest market and selling handicraft in South Africa, a trade that took her away from home for two weeks every month.

Although her father was employed by the government, he was not assisting Dudu in anyway. She was also not eligible for government assistance for orphaned children because her father, a state police officer, was employed.[ix] When I met Dudu she was having financial problems at school as she had not paid school fees for the whole year. Dudu still hoped to complete school and become a social worker or a lawyer one day so that she could, as she said, 'help other children like me'(interview, September 2012).

Gcinaphi

I met Gcinaphi, a thirteen-year-old girl, in September 2012 in the company of her mother. They had come to collect their ARV medication from the local clinic because they were both HIV positive and on ART. Gcinaphi tested for HIV at the age of five years after being sick with diarrhoea, nausea, and vomiting. Her mother had tested in 2006 after a stroke (an illness episode that resembled cerebro-vascular accident). Gcinaphi's father died in 2005 of AIDS-related illness. It was not clear though how and when Gcinaphi might have become infected with HIV; her mother claimed to have only gotten HIV in 2005 when she was caring for her husband, which means Gcinaphi's infection could not have been a case of mother-to-child transmission. She also had no history of sexual abuse nor had she had a blood transfusion.

Gcinaphi and her mother live with two of Gcinaphi's sisters who are HIV negative; her other older sibling lives at her marital home. Gcinaphi started ART after testing HIV positive in 2007 but only came to know of her diagnosis in 2010. Her mother said she did not tell Gcinaphi about her status because she 'was afraid that Gcinaphi would be angry and resent me for infecting her with HIV, but at the same time I couldn't let her die because if she didn't take the pills, well, the HIV was going to become resistant and then she would get sick and die. So I had to choose between losing her to AIDS or deal with her anger at me. So I chose to tell her. It is not an easy choice for parents' (interview, December, 2012). Her mother was particularly concerned that Gcinaphi was the only one of her children who was HIV positive and that increased her fear that Gcinaphi would blame her for the infection.

The family's source of income was Gcinaphi's father's pension; he had been employed as a civil servant for a long time. The pension, according to Gcinaphi's mother, is paid monthly to her and is just enough to cover the family's basic needs. The family was doing relatively well compared to others in the area they lived. The homestead was one of the few that had a modern three-bedroom house with electricity and digital satellite television. The Central

Statistics Office uses these measures to determine socio-economic level, and such a family is classified as 'middle level'.

Gcinaphi looked healthy when I met her, and with the support of her mother and siblings, I was informed that she has been adhering well to her treatment. Her clinic record also confirmed optimal adherence. Asked how she felt when she was told she had HIV, Gcinaphi stated that she did not blame her mother for the infection nor anyone else for that matter; 'I have accepted it and am focusing on taking my pills so that I stay healthy', she said in one of our conversations. Gcinaphi was very knowledgeable about HIV and ARVs, and said that she hoped to be a doctor when she finished school so that she can treat people living with HIV.

Lungile

I met Lungile, a sixteen-year-old girl who was in grade five at the local primary school, in 2012. She was tested for HIV in 2007 at the age of nine after repeated chest infections. At the time she was diagnosed with HIV, Lungile had been living with her maternal grandmother; her biological mother had died of AIDS-related illness the same year. Her father was also living with HIV and was on ART. He got tested two years after the death of his wife, Lungile's mother, due to his own ill health. At the time of his diagnosis, he had a CD4 count of seven cells per mm^3, something that scared Lungile because she thought that her father 'was going to die as well. Fortunately, he agreed to be initiated on ART which was done two weeks after [the mandatory ART preparation] counselling' (interview, September, 2012). During the time of the study, a person diagnosed with HIV was eligible for antiretroviral treatment if his or her CD4 cell count was ≤ 350 cells/mm^3 or his or her clinically staged as III or IV). Up until 2010 when the treatment guidelines were changed, the eligibility criteria were a CD4 cell count of ≤ 200 cells/mm^3. Anyone starting ART at >50 cells/mm$^{3\ \mathrm{was}}$ defined as late initiation, and carried the risk of developing severe and sometimes fata reactive side effects including immune reconstitution inflammatory syndrome (IRIS).

When I met the family in 2012, Lungile was living with her stepmother and three half-sisters who were all HIV negative. Her father was employed as a bus driver and visited on weekends. He was the bread winner; his new wife also raised chickens and sold fruits and vegetables at the local market to supplement the family income. The family had large fields that they were using for farming maize and vegetables. According to the father, if the rains are good, they get good yield of maize and sell the surplus to supplement their income. The family's home is better off than others in the community, with a four-roomed brick house with corrugated iron roofing and an outdoor room used as a kitchen. There was also an electricity connection and a television set, all of which are not common in the area.

According to Lungile, shortly after testing positive for HIV, she fell sick, coughing a lot and losing weight, and was diagnosed with and treated for pulmonary tuberculosis (TB). 'I was given sixty injections; I also took tablets for three months. After completing the TB medicines I was put on ART. That was still in 2007'. At the time of the study, Lungile was doing pretty well, she looked healthy and was well cared for by her stepmother and father. Her maternal family, particularly her grandmother whom she visits often, still provides her with emotional and psychological support. Besides her grandmother, stepmother, and father, no one else knew that Lungile was living with HIV because her father did not want her to tell anyone else because he was afraid that people would treat her badly. Even her siblings were not aware of her status. Lungile stated that they hardly talked about HIV at home; the only time they do is when she is reminded to take her ARVs. Lungile is doing well at school and plans to be a nurse so the she can help 'other children like me, who are living with HIV'. Her greatest wish was that 'scientists in the rich countries could get a cure for HIV so that all people infected with the virus could be cured and live a normal life' (interview, September 2012).

Mpendulo

I met Mpendulo in 2012, when he was sixteen years old. He was diagnosed with HIV in 2002 at the age of four years. ART was not freely available in the country until 2004, hence he was only initiated on treatment two years after diagnosis. However, he only came to know that he was HIV positive in 2010 after being told by his sister (discussed further in chapter7 on disclosure).

At the time I met him, Mpendulo was living with his uncle (his father's younger brother) in a four-roomed dilapidated house. In total there were eleven people living in the homestead including the uncle's wife and their three children, the uncle's younger brother and his wife and child, and Mpendulo's younger sister.

Mpendulo has three siblings, and although they share the same father, they have different mothers. At the time of the study, Mpendulo's elder brother and sister were employed: the brother worked in a hardware shop situated about 200km from where Mpendulo lived, while the elder sister was a teacher in one of the local primary schools. The elder brother had a wife who was living about a hundred metres from the uncle's house, while the sister lived in her marital home about seven kilometres from where Mpendulo lived. According to family, the house used by the elder brother and his wife was left behind by Mpendulo's father. Despite the close proximity to his elder brother's home, Mpendulo hardly visited them because his sister-in-law did not want him there, as she believed that he would infect them with HIV. Besides Mpendulo, two other people in the household were living with HIV, Mpendulo's uncle's younger brother and his wife, and both are on ARVs. He stated that life in the uncle's household was not easy because no one was employed and there were days when they had no food.

Mpendulo looked small for his age, underweight and had other visible symptoms of chronic ill-health, such as swollen lymph nodes and white patches all over his body. He also often complained of chest pains, coughing, and fatigue. The family did not have money to take him to hospital, relying instead on the local clinic that managed illness symptomatically. On one occasion I was called by the family to assist in taking him to hospital because he had been seriously sick for two weeks, a situation that meant I had to switch my role from that of a researcher to a provider.[x]

Mpendulo mentioned that his father had been employed in one of the leading financial institutions, and was owed a pension that could help with his health needs, but his elder brother, who was the executor of the estate, was not forthcoming, which caused him a lot of stress. The last time I contacted him, Mpendulo had left his uncle's place and was living alone in his father's house after his elder brother relocated his family to his workplace. At the end of 2013, Mpendulo obtained a second-class pass in his external primary education examination, and was planning to be a doctor so that he could 'treat children living with HIV' (interview, November, 2013). He had also joined a support group of children living with HIV where he gets to 'learn more about the disease, the pills and other things. They also provide me with money that I use to buy food' (fieldnotes, November, 2013).

Nomaswazi

Nomaswazi, an eighteen-year-old girl, became aware that she was HIV positive in December 2011. When I met her in September 2012 she had been on ART for just three months. She believes she was infected through sexual intercourse because both her parents were HIV negative. She conceded that besides her boyfriend who lives in South Africa, she had had sexual relations with two other men and thinks one of them could have infected her with the virus. She tested after falling sick with a recurrent sexually transmitted infection that was not getting better after several episodes of treatment. At the time I met her she was living with her family during school holidays; during the school days she lived with her mother's brother, who was a teacher in the high school that Nomaswazi was attending. Nomaswazi mentioned that she was advised and encouraged by her mother, who is a community health worker, to do the HIV test. Her mother has remained her pillar of psychological support. She is the youngest in a family of six boys and two girls and is the only one living with HIV. All her brothers have wives and have built their homes within the family compound hence the homestead is very large. Four of her brothers are working in South Africa while one is finishing a bachelor's degree in law at the local university. Her father was one of the *bantfwabenkhosi* (princes) of the chiefdom and a well-known and respected elder of the community. Nomaswazi had not disclosed her HIV status to her boyfriend or to other family members besides her mother, because 'it is not yet the right time to tell them'. Nomaswazi feared that if people got to know that she was HIV positive, it would reflect badly on her family, a position that was shared by her mother; hence they conspired to keep her status a secret.

I only had face-to-face conversations with Nomaswazi twice during my fieldwork as she relocated to South Africa in 2013 where she had enrolled in a final year of senior secondary education ('matric') that is offered in South African schools; students who want to enrol in tertiary education have to pass national matriculation exams. But also pupils whose homes are situated along or close to South African border with Swaziland may do their matric in South Africa. Through telephone contact Nomaswazi mentioned that she was doing well and was taking her ARVs, which she collects from the local clinic every three months, but had still not disclosed her status to anyone other than her mother.

Menzi

Menzi, who I met in 2012, was a nineteen-year-old young man in form III (or grade 9) at the local high school. He was diagnosed with HIV in 2009 at the age of sixteen, and started taking ARVs that same year. Although his homestead was not very far from school, he lived with his sister and brother-in-law because he and his mother preferred that he stay with them as their home was close to his school, only about 500 metres away. Menzi is not sure how he got infected with HIV but thinks it was through helping a friend who was injured in a fight. Menzi is the fourth child in a family of five and none of his family members were living with HIV. His mother is a community health worker and his father, who was diabetic, passed away in 1999. All his elder siblings were working and his younger sister was doing form IV (or grade 10) in the same school. Though he already had a girlfriend, Menzi was adamant he was not going to disclose his status to her until ‘the time was right’ (interview, October 2012). All his family members knew that he was living with HIV and were very supportive. He hoped to become a police officer so that he could keep law and order.

Lindani

I met Lindani in August 2013. Our first meeting took place at the clinic where he had gone to get his monthly refill of ARVs and TB treatment, and our follow-up interviews were at his home or clinic depending on his preference. Lindani was diagnosed with HIV after being diagnosed with and treated for TB in 2010, and he started taking ARVs in the same year.

Although he stated that he was thirteen years old, he could be mistaken for a ten-year-old. Lindani looked sickly and frail when I first met him; he had white patches all over his body and swollen lymph nodes around his neck, which according to him had been there for a long time, but were getting better since starting ART in 2010. His hearing was poor and the nurse at his clinic stated that it was a complication from one of the TB treatments.

Lindani lived with his maternal grandmother, Gogo Simelane, and an eighteen-year-old cousin, the daughter of his mother’s sister, about fifty kilometres outside of Manzini. Gogo Simelane is their primary caregiver. His cousin is also living with HIV and on ART. Lindani’s parents died when he was six years old, and although he doesn’t know the cause of their death, his grandmother told him that they died of HIV-related illnesses; Gogo believes Lindani got HIV from his parents. According to Gogo Simelane, she had four other children besides Lindani’s mother who also died of AIDS-related illness.

The family lived in poverty in two houses made of stick and mud with thatched roofing. The mud from the walls was falling off, leaving holes in the walls. According to Lindani and his grandmother, when it is raining they have to seek accommodation from neighbours because the rains flood their house. There was a small vegetable garden that was tended by Gogo during the week and Lindani during the weekend. The family also had five goats that were looked after by Lindani. According to Gogo Simelane, two of the goats were given to the family by World Vision, an NGO working to alleviate poverty in the community. The two goats gave birth and multiplied to seven but Gogo Simelane sold one so that she could buy food for the family, and another one was thought to have been stolen.

No one was employed in the family. The only source of income was the government elderly social grant of E600[xi] (USD 60) that Gogo Simelane receives once every three months. This amount, according to Gogo, is barely enough to see them through. For instance, during one of my visits, I found that Lindani's cousin had not been taking her ARVs for the past two weeks because she didn't have transport money (E20, USD 2) to go and refill her ARVs at the local hospital, which was about fifteen kilometres away. Lindani also needed to pay hospital fees of E3,000 (USD 300) for an operation to restore his hearing. But his grandmother could not afford the amount and almost a year later they were still waiting for World Vision to provide financial assistance.

Lindani joined a support group that assists him with food parcels and transport money to collect his ARVs every month. During our conversations he expressed how he misses his parents and how things could be better if they were still alive:

> It hurts very much because there are some things that no one can do for you other than your parents and unfortunately I do not have them. Apart from that, having no parent to listen to your challenges is so depressing. Seeing other children with their parents also hurts. I miss them a lot. (interview, August 2013)

Once in a while Lindani visits his paternal family and they also visit him and pay for his school fees, school uniform, and other needs. His wish is to live with his father's family. He stated that he wants to be a police officer when he grows up so that he can earn a lot of money.

Sabelo

In 2013, when I met Sabelo he was fifteen years old and a healthy-looking young man. He lived with his mother, stepfather, and two younger half-sisters in one of the government housing units just outside the city of Manzini. Sabelo tested and was found to be HIV positive in 2010 after he fell sick with measles. At the time he was tested he was not eligible for ART because his CD4 count was still above the limit required to initiate ART. He was given a prophylactic antibiotic, cotrimoxazole, to take and to continue coming to the clinic for monitoring, but he stopped taking his prophylaxis and his CD4 count decreased remarkably, and he was initiated on ARVs in 2011. Sabelo's mother and maternal grandmother are also HIV positive and on ART; his stepfather and sisters are HIV negative. Besides his immediate family Sabelo has not disclosed his status to anyone because his mother told him not to discuss personal issues with people outside the family. Both his mother and stepfather have gainful employment. Though his biological father is alive, he has no relationship with him. At the time I met him Sabelo was in grade eight in one of the best schools around town and he wanted to continue studying electronic engineering after high school. Although the family is doing pretty well in almost all spheres of life, Sabelo still wishes he could have a relationship with his biological father because 'much as my stepfather is very supportive and we have a good relationship, there are things I feel I cannot talk about with him and need my biological father' (interview, September 2013).

Simangele

I met Simangele, a healthy-looking fourteen-year-old girl, at the clinic where she had gone to refill her ARVs in 2013 September. She was tested for and diagnosed with HIV in 2008 after she fell sick, and her mother, who was also living with HIV, suggested she get tested. She was also started on ARVs the same year because her CD4 count was low. She was eight years old at the time. At the time of the study, she had been on ART for five years. Simangele lives with her mother in a modern house she owns in one of the suburbs in Manzini. Her mother and father never married and she has no relationship with her father, who is married to another woman. Simangele has a strong social support system comprised of her mother and her mother's sisters, some of whom work in international NGOs that focus on HIV and one of whom is a lawyer. Her mother is also employed and also rents out some one-roomed houses that she has built around her home. Simangele is an active member of the support group at the clinic where she is a team leader. She doesn't like it, though, because 'sometimes it can be overwhelming especially if they make you a teen club leader, because the other children look up to you for good behaviour and you have to attend to their problems yet you have your own problems to deal with. Right now I am a teen club leader and I just don't like it' (interview, September, 2013). Simangele is doing very well in school and hopes to earn a degree in commerce one day so that she can support her mother.

Manqoba

Manqoba was a fourteen-year-old boy when I met him in September 2013, though he looked like he was only nine. He believes he was born with HIV but only tested in January 2013 after he was sick and admitted to hospital where, in addition to HIV, he was diagnosed with TB. When I met him he was taking treatment for both conditions. He lives with his mother and three brothers in a four-roomed brick house with corrugated roofing on the outskirts of the city of Manzini. His father passed away in 2007, and he is not sure of the cause of death. His mother and younger brother are also living with HIV and are on treatment while his two older brothers were HIV negative.

The family has a backyard garden where they grow vegetables such as spinach, tomatoes, onion, carrots, and beetroot. Manqoba and his brothers tend the garden after school and on weekends, and he liked it because it provided him, his brothers, and mother with a balanced diet. Besides his immediate family, his father's sister is the only other person who knows that Manqoba is living with HIV, as she was told by his mother.

Manqoba's mother was not employed at the time of my visits to their home, but earned some money selling handicrafts at the market in town and sometimes went to sell in South Africa. In her absence, Manqoba's auntie looks after him and his brother, which is why she was told of Manqoba's HIV status. She also provides them with food and other material support from time to time or whenever they are in need. Otherwise no one else knows about his HIV status because his mother told him not to tell anyone about it, not even his teacher at school.

Although small for his age, Manqoba looks healthy and very lively. He was very knowledgeable about HIV and ARVs. He was enrolled in grade seven at the time I met him and planned to be a doctor one day so that he could help protect children from getting HIV and treat those who already have it. His favourite subjects at school were maths and religious education.

Sicelo

I met Sicelo in October 2013; he was fifteen years old. He had come for a refill of his medication in the company of his paternal grandmother and his father's sister. Sicelo was tested for HIV in 2009 because of chronic ill health, and was started on ARV treatment the same year. He was also being treated for TB. Sicelo was living with his paternal grandmother and auntie at the time I met him but he would often visit his maternal family for long periods, which resulted in him defaulting his treatment. He has been restarted on ART and TB medication three times; on the day I met him he was due to be switched to second-line ARV regimen. His father lived in the outskirts of Manzini with Sicelo's stepmother and their two children. Although Sicelo wished to stay with his father, he stated that his stepmother was against the idea, and that she did not want him there, an assertion also mentioned by his grandmother and aunt in separate interviews. His biological mother lives in Johannesburg and occasionally visits home. During these visits Sicelo gets the chance to visit his mother's family but such visits result in him defaulting his treatment. The two families have not met to discuss Sicelo's health situation; according to his paternal grandmother, 'they don't care' (interview, October 2013). However, according to Sicelo, he defaulted his treatments because he wants to go and stay with his father, and hopes that his father would buy him a bicycle as he had for his siblings. The lack of openness between the families, the stepmother's attitude, and the overall social environment within which Sicelo lives could all contribute to his defaulting. The last time I visited him at home he was still taking his medication, though he was not strictly compliant. Asked what he wants to be in future he stated that he was not sure, but he said he likes driving big trucks (interview, October 2013).

Sizwe

I met Sizwe in 2013 at the clinic where he had come to refill his ARVs. At the time, he was sixteen years old. He stated that he was diagnosed with HIV in 2009 at the age of twelve, after repeated illness episodes, and was initiated on ART the same year. He tested in the company of his paternal grandmother, with whom he still lives together with his biological sister, five half-siblings, and three cousins. His mother died of AIDS-related illness when Sizwe was seven years old; his father is living with HIV and is on ART, and lives by himself a few kilometres from where Sizwe stays with his grandmother. His grandmother is a traditional healer.

Although agreeing to continue participating in the study, Sizwe did not buy to the idea of me visiting him at his home, stating that people would start asking questions about my visits and could come to know that he was HIV positive. Out of respect for his request, all our interviews were held at the clinic premises either in my car or in the office provided by the clinic.

Sizwe seemed very angry and cried throughout the first two interviews. He was angry at his father whom he blamed for infecting his mother, who in turn infected him with the virus. He was also angry at his grandmother, who, after learning that Sizwe was HIV positive, according to Sizwe, went about telling people in the community who then started to avoid him and gossip about him. He stated that he had to change schools due to the emotional and psychological abuse he was experiencing at his school. What also made him angry was that he was the only one among his father's children who was HIV positive and he did not understand how that could be and why it had to be him who was infected.

Asked if he had joined the support group at the clinic, he stated that he did but that he attended only two sessions after which he stopped because it was not helping him in anyway. I felt that he needed support to help him with his anger, but Sizwe turned down my suggestion that he see a clinical psychologist for counselling. Despite his anger, Sizwe was adhering optimally to his ARV medication. He aspires to be a 'successful lawyer one day' (interview, September 2013).

Nomvuyo

I met Nomvuyo in 2012, when she was eighteen years old. She had been knowingly living with HIV for seven years after she was tested when she was aged eleven years and in grade six. She had been very sick and her mother had taken her to several traditional and faith healers for treatment but Nomvuyo did not get better. She was then taken to the clinic where she was tested and diagnosed with HIV. She is the only one among the adolescents in this study who shared that prior to testing she received pre- and post-test counselling in which the nurse told her to accept the outcome of the test, no matter what it might be.

Nomvuyo doesn't know her father who passed away when she was still very young, and her mother died two years after Nomvuyo was diagnosed with HIV. Both her parents are believed to have died of AIDS-related illnesses. Her paternal grandmother, with whom she lives, is a principal in one of the local primary schools. The family seems to be doing pretty well socially and economically.

When I met her, Nomvuyo had just completed her secondary education, was volunteering at one of the clinics, and was also a team leader for the adolescents support groups. She plans to be an accountant and was working towards improving her matric grades so that she could be admitted to the local university for study towards a bachelor's degree in commerce.

Sipho

Sipho was diagnosed with HIV in 2011 following a diagnosis with TB. The country's TB technical guidelines require that all people diagnosed with TB must be tested for HIV; hence, Sipho was tested for HIV. He was already on antiretroviral treatment when I first met him in 2013, and was aged 17 years. Asked to share what made him test for the virus he stated that he was sick and was in the company of his parents when he was tested. His immediate reaction to the diagnosis was shock and anger towards his parents, whom he blamed for ruining his life by infecting him with HIV. With time he made peace with everything because, he said:

> I knew I could not avoid talking to them forever. . . . Having my brother who supported and also made me understand that it was not their intention to infect me with the virus made it easier to forgive and forget. Right now I see HIV as a hereditary disease that I can live with rather than a death sentence (November, 2013).

Both his parents and paternal grandmother are also living with HIV and on ART. Although his parents only disclosed their status to him after he too was diagnosed with the virus, he stated that he already was suspicious that they were HIV positive because 'they were taking the same pills, same time every day. I have heard on radio and television that people on ARVs have to take them the same time every day, so when I observed my parents doing this, I suspected that they could be HIV positive' (interview, November 2013). Sipho is the only one of his three siblings who was living with HIV.

Although his CD4 count was still high at the time of diagnosis, he was enrolled in ART immediately upon his request. Asked why he decided to start ART when his CD4 count was high, he stated: 'I know a lot about the benefits of ARVs in people with HIV and TB . . . so I asked that the nurses should not delay my treatment'. His parents' knowledge about and experience with ART proved to be very helpful to him as he adapted to living with the virus. His mother is housewife and his father is an engineer in one of the big companies in the sugar belt. He attends a private school, and being diagnosed with HIV rekindled his dream of being a doctor when he finishes school, he stated.

Musawenkhosi

I met Musawenkhosi in June 2013 in one of the clinics where he had come for his last counselling session and initiation on ART. He was with his mother on the day. Though he was seventeen years old, he actually looked five years younger. He looked very weak, had suffered significant wasting, and needed support when walking. He had shortness of breath and needed to stop talking between sentences to catch his breath. His mother mentioned that he had been sick for some time but because she was not staying with him, she was not aware until very late. Musawenkhosi had been tested two weeks before I met him and was found to be HIV positive and also had TB for which he had already started treatment. His mother was also living with HIV, and his father passed away in 2010. After his father died, his mother was chased away from the family and went to live in South Africa, which is why she was not home when Musawenkhosi fell sick. Musawenkhosi was initiated on ART the day I met him. I made a follow up visit to his home a week after our initial meeting and found that he was very sick. Two weeks after my visit I got a call from his mother that he had passed on.

Conclusion

In this chapter I briefly introduced the adolescents living with HIV that I interviewed several times during the fieldwork to gain in-depth insight into their experiences of living with HIV. Their stories form the bulk of the data used for the dissertation.

Most of the adolescents in this study were infected with HIV perinatally, were tested after repeated illness episodes, and were diagnosed with HIV during their childhood or early adolescence. Except for two, all the adolescents were diagnosed with HIV while in the company of a parent or guardian, who also gave consent for the tests, and all of them were on antiretroviral treatment.

Although most were diagnosed in their childhood, and although they knew of their HIV status, almost all of adolescents experienced a delay in disclosure to them of their status by their parents or guardians (discussed further in chapter seven). All the adolescents had plans and dreams about their futures which hinged around finishing school, and following career paths that focused on helping other children living with HIV.

A majority of the adolescents were from economically disadvantaged family backgrounds, which did not only affected interpersonal relationships within family members and between paternal and maternal families for some, but also how adolescents perceived the care provided by different family members, which I discuss further in the next chapter on family.

CHAPTER FOUR

RETHINKING THE MEANING OF FAMILY IN THE CONTEXT OF HIV CARE

> Community Leader: We are all affected; no one can say he or she has not been affected. Everyone has a brother, a sister, a child, a parent, a friend, a relative, a work colleague, a neighbour – we have all experienced HIV . . . at home at school, in church, in the community.
>
> FS: When you say 'we', who are you referring to? Who is 'we'?
>
> Community Leader: I am referring to you and me, us, every Swazi. . . . Our roots are traced back to the same forefathers – we belong together; we are all sick with HIV directly or indirectly. . . . We are family and we must care for one another.

Introduction

The extract above is taken from an informal conversation I had with the headman of e-Tsembaletfu in August 2012, during one of the monthly community development meetings. As part of the agreement that permitted me to conduct research at Tsembaletfu, the leadership asked that I occasionally provide them with an update on the progress of my study. On this particular day, I shared my astonishment at the number of child-headed[xii] and skipped-generation[xiii] households in the area. According to data I obtained from the Inkhundla offices, which was confirmed by the chairman of the development committee of Tsembaletfu, 240 (6%) and 440 (11%) of the area's 4,000 households were headed by young people or grandparents, respectively. The chairman stated that a majority of the parents had died, presumably of HIV or TB, or both, leaving behind children–some living with HIV – under the care of siblings or grandparents. Some of the grandparents were themselves frail and poor (fieldnotes, December 2012). In the few households I had visited, poverty was palpable. It was readily noticeable that these households could barely meet their basic daily food requirements. What made their situation worse was that the food parcels they had been receiving from NGOs had stopped a few months back, they mentioned. Such parcels are given to vulnerable households, described as those headed by children or grandparents, or households that have a member who is bedridden, disabled, or HIV positive.

Given their circumstances, I wondered how children growing up in such households survived on a day-to-day basis. How did they fulfil their basic needs, like procuring food, or manage to go to school? How did they deal with sickness? Who and how they were socialised to the realities of everyday life. The headman shared similar concerns, lamenting that:

> HIV has depleted families at a scale never seen before. Parents are dying, leaving children behind, hence we have these children who are now caring for each other. The *Indlunkhulu* [chief's residence] provides material support such as food, but the children need parents – people who will talk with them, discipline them, and tell them stories about growing up. Unfortunately, because the adults are the ones dying, the children are left behind to fend for themselves. In our days, we never experienced this [children growing up alone without an adult]; the community was united'. (Informal conversation, August 2012).

The phrase 'we are family' often came up during focus group discussions, support group meetings, and individual interviews I had with adolescents. The way the phrase was used in everyday language by the participants captured my attention with its fluidity and layered meanings. I was intrigued by the changing nature of the meanings ascribed to the family in adolescents' biographies and life events, and how the meanings were embedded and transformed in the contexts of specific moments. The narratives of the adolescents, as I show in this chapter, suggest that what they perceive as family is not necessarily limited to blood, descent, or legally sanctioned relationships, but rather a shared *biosocial identity* (Rose and Novas, 2005) – of living with HIV and being on ART. Furthermore, I found that a desire for and a sense of belonging – which adolescents described as being accepted, connected, and sharing – was central to adolescents' description of the family.

National HIV policies and guidelines identify families as integral partners in the response to HIV. For instance, the Swaziland National Multisectoral Strategic Framework (NSF) of 2009–2014alludes to the need to promote family members as carers for people living with HIV at home (NERCHA 2009:58). Expanding from the NSF, the extended NSF (eNSF) of 2014–2018 identifies a need for strategies to strengthen families, which will in turn contribute to the care of orphaned and vulnerable children[xiv] and people living with HIV in the home setting (NERCHA, 2014:40–42). Furthermore, the national HIV-prevention policy (MoH, 2012) called for the empowerment of families so that they could be information resources for adolescents, and contribute to prevention of HIV in this population group. These documents list different forms of family – female-headed, child-headed, and those headed by the elderly – as vulnerable to disintegration, hence requiring support. However, what the documents refer to as family differs from that which adolescents talked about and what the headman in the opening caption refers to as family.

It is this ambiguity between who is and is not family, and between what makes a family from the adolescents’ perspective versus that represented in HIV policies and conventional descriptions, that creates the need to consider what constitutes the family in the context of HIV care. In this chapter I explore the multiple, fluid, and ambiguous meanings of the family as referred to by adolescents in different moments and contexts of their everyday life.

While acknowledging the importance of the family as a primary unit of care for adolescents living with HIV, one that provides not only material and physical support but psychological care as well (Richter et al., 2009), in this chapter I challenge the universalised notion of the family. I argue for an HIV service that is sensitive to the different familial contexts of adolescents, and the different meanings of family for adolescents. By illustrating the dynamics that shape the meanings of the family – the contestation between what participants experience as family and what is generally perceived to be family in Swaziland and as represented in the HIV guidelines in particular – I argue for a rethinking of the family in relation to HIV care of adolescents.

In Swaziland, family has long been defined along bloodlines, extended kin networks, and legal relations such as marriage. Multi-generational extended families living together in one bounded homestead have been the norm. Children have been socialised primarily by the family and secondarily by the community and society through shared norms, values, and standards of behaviour. This, however, has changed over the last three or so decades due to several factors including industrialisation, increasing migration from rural to urban areas, and an increasing preference for nuclear family-style living arrangements. Noted though is that even with economic and demographic shifts, the family still remains the basic unit of care for people living with illnesses including HIV and AIDS.

The aim is not to dispute the need for family involvement in the HIV care continuum, but rather to suggest the complexity of what constitutes a family to adolescents, with a view of providing more ‘appropriate’ care and improving their holistic well-being and quality of life. To provide a framework for my arguments, it is important that I first define the family. I then discuss the family from the adolescents’ perspective, based on their narratives and on other studies.

Conceptualising the family

The meaning of the family has been a subject of study for social scientists for a very long time. While several scholars have made attempts to define the family (see for instance, Georgas, 2003; Goode, 1949; Gough, 1971; Levin, 1999; Murdoch, 1949; Tilly and Cohen, 1982), there is no consensus about its meaning. This is not surprising given that, according to Georgas (2003), the family varies in structure and functions across different cultures and at different times within the same culture. He, therefore, proposes that the conceptualisation of the family should not be limited to its structure and/or functions, but should as well embrace the multi layered and complex web of determinants and practices that shape the structures, types, and functions of families at different times across cultures and societies. With that in mind, in the context of this study, I borrow from Levin (1999) to define the family. He states that 'the everyday use of "family" relates to a social group that [could be] biologically, legally [or] emotionally connected . . . [and whose] meaning can be derived from the context in which it is used and the tone of voice of the user', (1999: 96). I would add to Levin's definition that expectations from and interactions with micro- and macro-environments also shape how people conceptualise the family. This broad non-normative definition responds best to my need for an analytical tool to explore adolescents' portrayal of the family in relation to their everyday experiences of and with HIV, which I turn to in the section below, using adolescents' case narratives.

Lindani's story

Lindani was one of the adolescents born to unwed parents. Although his parents lived together as a couple prior to their deaths, they were never married formally, and his father never paid the traditional *inhlawulo* (child price), *timvimba* (a fine, in the form of cattle, paid to girl's family for impregnating her before marriage), or *lobola* (brideprice).The non-conformity to any of these traditional practices meant that although Lindani could use his father's surname, his paternal kin had no claim over him and he belonged to his maternal family.

Lindani mentioned that once in a while he visits his paternal family and they also visit him, pay for his school fees and buy him school uniforms, and take care of his other needs. In our conversations, Lindani expressed dissatisfaction about his living conditions at his maternal grandmother's place. In fact, most of the conversations Lindani had with me centred on his living circumstances rather than the HIV diagnosis and living with the virus. He stated that he did not like staying with his maternal family because ‘life is not good here. I am not accepted’, and that he preferred to stay with his paternal relatives because he believed he would be better cared for by his uncles and aunts there. Besides having to look after goats every day after school and tend the garden every weekend –a common practice for boys of his age in homesteads that own goats or gardens – he stated that he did not feel happy living with his maternal family because:

> they [grandmother and cousin] sometimes remind me that where I live is not my home. . . . They often say I do not bring anything to the table for food when I am from my family [father’s family]. . . . My grandmother here often asks why I do not want to live with them now that she has taken care of me following the death of my parents. She always says that my family never paid dowry for my mother so I cannot go to stay with my family. (interview, October 2013).

When asked if he had voiced his feelings and desires to his grandmother, Lindani stated that he had not. He stated that he was scared of upsetting his grandmother and thus decided to remain silent.

In the following paragraphs I describe how Lindani’s story points to the slippery and contradictory definitions of family and belonging, as found in the larger cultural perspective, public policy, and everyday language on the one hand and the experience of participants on the other. The narrative further shows how in Lindani’s case the perception of being cared for is linked to the sense of belonging. Lastly it reveals how silence is sometimes used to manage relations in the family.

Lindani spoke of ‘my family’ when referring to his paternal homestead and ‘my grandmother’s home ‘when referring to his maternal home where he lived. His use of ‘my’ denotes a strong sense of attachment, ownership, or belonging, showing that Lindani felt a sense of belonging among and attachment to his paternal family. The distinction between ‘my family’ and ‘grandmother’s home’ may be interpreted as signifying the degree of attachment Lindani has with his paternal family. For Lindani, his family gave him a sense of legitimate identity (inheritance of father’s name, which Lindani was using), permanence, psychological security, and a sense of belonging, which he seemingly did not get from his maternal relatives’ homestead where he was constantly reminded that ‘it was not his home’.

In addition, Lindani's story demonstrates the centrality of the cultural norm of *inhlawulo* and *lobola* in the determination of social identity and belonging for children born to unmarried parents in Swaziland. According to Gogo Simelane, Lindani belonged to his paternal family by virtue of his patrilineage, but because neither the inhlawulo nor *lobola* had been paid by the paternal family, Lindani belonged to his maternal family (see also Feirman, 2012; Nhlapho, 1992; Russell, 1993). This contradiction repeatedly appeared in the narratives of adolescents and other participants about the family.

The significance of *inhlawulo* or *lobola* in bestowing social identity upon children, and in the living and care arrangements for children living with or orphaned by AIDS or other causes, is not unique to Swaziland. Mkhwanazi (2012) shows how non-payment of *inhlawulo* or *lobola* is used as the basis for maternal family claims upon children born of un wed teenage mothers in South Africa. Djebbari and Mayr and (2011) also note the important role of *lobola* in decisions of a child belonging between maternal and paternal family. According to Djebbari and Mayrand

> [C]ustomary law practices in South Africa dictates that the transfer of a child from the mother's family to the father's family is usually governed by the payment of bride wealth: if no *lobola* was paid to the bride's father by the groom at the time of marriage, then the child remains with his mother. Since bride wealth is only paid when there is a marriage, an illegitimate child generally remains legally with the mother's family (2011:11).

In her study of children infected and affected by HIV and AIDS in Lesotho, Block (2014) notes how maternal grandmothers base their caregiving claims for their grandchildren on unpaid *inhlawulo* or *lobola*. In her study, Block notes that though the payment of brideprice was not a common practice even in married couples in contemporary Lesotho, the 'lack of brideprice was the cultural lynchpin on which maternal caregivers [who often were grandmothers] based their claims on children' (2014:718).

Lindani also felt that he would be better cared for by his paternal family because some of his father's sisters and brothers are in salaried employment. However, Lindani was so immersed in his desire to live with his paternal family that he seemed not take note or value the everyday basic care practices of his maternal grandmother, such as providing him food and shelter, reminding him to take his medications, and providing transport money for his clinic appointments. Care has been described as central to individual identity, which itself is based on the understanding of ourselves and our environment (Weicht, 2015); care can be understood and experienced as a relational and reciprocal phenomenon in which the carer and recipient share a feeling of family-ness (Moyer and Kageha-Igonya, 2014), connectedness, or belonging (Hendricks and Magano, 2014). Bowlby et al. (2010:15) note that 'how people experience care is dependent on [the quality of] and their beliefs and values about families and relationships'.

Even though Lindani sounded resentful about his grandmother's refusal to allow him to go and stay with his paternal family, he was not confrontational about it but rather managed it by being silent. This is not surprising given that in Swazi culture children are socialised to be respectful and obedient towards their elders, rather than confrontational. The Child Protection and Welfare Act quoted above obligate children to 'work for the cohesion of the family, respect the parents, guardians . . . at all times' (2012: S19). So, in addition to the fear of being rebuked, as he said, it could be that Lindani chose silence as a sign of respect for and obedience to his grandmother.

There has been much empirical research by different disciplines in the social sciences on silence across and within cultures. Most studies note the complex, context-based meanings and interpretations of silence. Depending on the context in which it is used, silence can either sustain or break human relationships (Medubi, 2008: 30) and families (Iliffe, 2006). In a context of an asymmetrical balance of power between children and elders – as was the case with Lindani and his grandmother – silence can be understood as a sign of respect or obedience, but it could also be a tactic used to avoid confrontation and ensure family cohesion. The use of silence by Lindani allowed for a peaceful relationship and family cohesion to prevail between him and his grandmother.

However, at times taking action to protect oneself from harm may be necessary, as was the case with Mpendulo. Unlike Lindani who chose silence as a tactic to deal with the standoff between him and his grandmother, Mpendulo used resources available to him to confront the challenges he faced to make life better for himself.

Mpendulo's story

Mpendulo was fourteen years old when I met him in 2012. He was diagnosed with HIV in his early childhood and started treatment in 2004 when ART became freely available in the country. He was then six years old.

Following his parents' demise, Mpendulo's living arrangement shifted between several maternal and paternal extended family members until he eventually settled in at his late father's house with his elder brother and sister-in-law (the brother did not reside in the house full-time but the sister-in-law did). According to Mpendulo and his uncle (his father's younger brother), he experienced stigma among relatives until the uncle decided that Mpendulo should come and live in his late father's house. However, life became difficult there as his sister-in-law used to call him names and refused to stay with him because, as Mpendulo recounted, 'she said I was going to infect her children with AIDS' (interview, September 2012). (I discuss Mpendulo's experience of stigma in chapter seven). His uncle shared how Mpendulo was stigmatised by his sister-in-law:

> They [Mpendulo and sister-in-law] did not see eye to eye with his sister-in-law who did not like the fact that [Mpendulo] was HIV positive. For example, in one incident the sister-in-law found Mpendulo eating food from a plate that was not designated for him. She scolded Mpendulo for using the plate, stating that if he uses any cutlery other than that designated to him, he would infect her children with HIV. That angered Mpendulo a lot. He said he felt unwelcomed and not wanted. His [Mpendulo's] brother tried to intervene but it did not work out so he decided to leave and came to stay with us. . . . We think he is happy here. . . . The only thing he talks about is that if he had money he would go and stay at his father's house… (Interview Mpendulo's uncle, October, 2012)

When I first met Mpendulo in 2012, he was living in his uncle's household with eleven other family members in a four-roomed dilapidated house. The uncle's younger brother and his wife, who also lived in the same house with Mpendulo, were also living with HIV and on ART, and often were the ones Mpendulo felt comfortable with as 'they accepted me and we discussed our sickness without a problem'. None of the family members were employed at the time of the study, and relied on subsistence maize farming and piece meal jobs for a living.

In our numerous interactions Mpendulo shared that he felt 'unwanted' by his family, singling out his brother and sister-in-law as the people who hated him the most. The relationships in his uncle's household were also not always welcoming. His uncle, according to Mpendulo, would sometimes scold those living in his homestead, such as arguing that everyone should find a way of contributing to the household since he was unable to provide for everyone given that he wasn’t working. Mpendulo stated that the his uncle’s outbursts about contribution to the running of the household hurt him a lot as he was sometimes forced to take his ARV pills on an empty stomach. He often shared that he wanted to go back to his father’s house but because his brother refused to process his share of their father’s estate, it was going be difficult for him to stay there as there was no money to buy food. These and other challenges in relation to his extended family members caused Mpendulo to decide to join a support group at the sub-regional hospital. In the support group he felt a sense of being welcomed, accepted, and loved. Mpendulo described the support group as ‘like having a family when with them [because he felt] welcomed’, something that he did not experience among his extended family. He stated that in addition to ‘learning more about the disease, the pills, and other things, they also provide me with money that I use to buy food. . . . I feel welcomed – like I have a family when I am with them. I always look forward to the meetings’ (interview, February 2013). The coordinator of the support group linked Mpendulo with the social welfare office, which took up the case of his father’s estate with his family. With the assistance of the social welfare office, Mpendulo got his share of his late father’s estate in May 2013, after which he returned to his father’s house. He continued to live there alone as of February 2015, when I last spoke to him. His sister-in-law and her children left to join her husband when Mpendulo ‘reclaimed’ his father’s house.

Mpendulo’s story highlights the difficulties that adolescents go through as a result of stigma exerted by family members, the complexity of living with HIV as an orphaned child, and the socio-relational terrains of suffering that they navigate in their everyday lives. The interplay of being born to unwed parents, being without both biological parents, being poor, and living with HIV result in a complex web of deprivations including the lack of psychosocial care and support from extended kin networks. Mpendulo’s difficulties with ‘his family’, especially his brother and sister-in-law, made him reconsider his living conditions. He took action by joining a support group that help him in seeking assistance from the social welfare office to reclaimed his late father’s house. The support that the social welfare office rendered to Mpendulo is a clear indication of how policy can be used to support and advance the rights of children made vulnerable by HIV and other similar circumstances. Such structures need to be strengthened and supported.

Mpendulo’s story also illuminates how disclosure to children is a contested issue. Although his father knew that Mpendulo was HIV positive, he (father) chose not to tell Mpendulo about his ‘sickness’ but disclose it to family members. While we cannot know the reasons for his decision, it is not uncommon for adults to share stories of children's' illnesses with adult family members with the expectation that family members will provide physical, social, and psychological support to those children. This could be true in the case of Mpendulo, who had lost his mother just a few months before his father learnt that Mpendulo was living with HIV (see chapter seven for further discussion on disclosure).

While Mpendulo's positive experience with the support group could be attributed to lack of acceptance and support from his extended family, Sabelo's story indicates that even support from 'immediate family members 'may not be enough to fill the need for belonging among adolescents living in step family settings. Despite having a good relationship with and support from his stepfather, mother, and other family members, having no relationship with his biological father affected Sabelo's sense of belonging. He described his situation as stressful and often leading to feelings of loneliness.

Sabelo's story

I first met Sabelo in late August 2013 at the e-Mpilweni clinic. He was fifteen years old, a healthy-looking young man who never showed any outward signs of illness. He was friendly and spoke very good English. He told me he attended a private school for his primary education but was currently enrolled in one of the country's highly ranked boys-only public schools. The school is well known for producing top-class male academics.

He stated that his parents were engaged in a premarital relationship when his mother became pregnant with him, and that they separated a few years after his birth. His mother then got married to another man. At the time of the study Sabelo lived with his mother, step father, and two younger half-sisters. He was diagnosed with HIV in 2010 and started taking ART in 2011. Sabelo's mother and maternal grandmother are also HIV positive and on ART while his stepfather and half-sisters were HIV negative at the time. Sabelo's family is, according to Central Statistics Office's socio-economic classification, an upper-middle-class family since they own two cars and have a Wi-Fi connection at home, amongst other possessions. Sabelo stated that he has a very good relationship with his stepfather who treats him like he was his 'real child'. According to Sabelo, his stepfather often takes him to his workplace where he teaches him how to repair computers, something that has nurtured his desire to pursue a career in computer engineering. At the time of the study Sabelo was also part of a support group of adolescents living with HIV and has made very close friends there. He described the support group as ‘very helpful in that we share a lot of things about the illness, treatment, and growing up’. He stated that when he had challenges with adherence, his friend Simangele, one of the leaders of the support group, encouraged him to take his ARVs and also helped him accept his status.

Although Sabelo did not live with his biological father, he had met him on several occasions. He described his biological father as:

> someone who likes women. . . . [H]e has many children from different women. . . . [W]here I stay [a residential compound] there is a boy that is my friend. I didn’t know he was one of my father’s children until one day when we went to town together; we accidentally came across our father. That is when we both discovered that we were not just friends who shared the same surname, but were in fact brothers. (interview, September 2013)

In spite of his disapproval of his biological father’s sexual behaviour of having many sexual relationships, and even though he has a good relationship with his stepfather, Sabelo expressed a strong wish to have a father–son relationship with his biological father because:

> much as my stepfather is very supportive and we have a good relationship, there are things I feel I cannot talk about with him and need my biological father. I just wish I had a relationship with my father . . . we could have a boy’s talk. (Interview, September 2013).

Asked what he meant by ‘boy’s talk’ and if he could not have it with his stepfather, Sabelo stated that there were things that he was afraid to discuss with his stepfather that he thinks he would be comfortable discussing with his biological father. He gave as an example discussing romantic relationships, and thought his father would be ideal on this and other topics. Describing the longing for a relationship as a deeper feeling, Sabelo said:

> [I] sometimes feel like it is empty here [pointing to the left side of his chest], like there is this big hole – like if I had a relationship with my real father, *singavaleka lesikhala lengisivako la* [this hole I feel in here (*pointing at his left side of the chest just below the breast*) would be closed]. (Interview, October 2013).

Sabelo’s narrative not only shows the complexity of belonging in the context of step families, but also the ambiguity of ‘family’. Although his current family provided for all his basic needs, and even though he felt supported by his stepfather and felt they had a good relationship, Sabelo still had a desire and a need for bonding that he felt only his biological father – whom he referred to as ‘my father’– could fill. However, and quite ironically, Sabelo did not consider his biological father as family and seemingly did not know much about him except that he had many children from different women, yet he referred to him as ‘my father’. The contradiction displayed by Sabelo challenges the notion of belonging. It also raises questions around gender and belonging: Do boys have an intrinsic sense of attachment to their biological fathers? How do children experience a sense of belonging in non-biological family contexts such as step families and foster families? Is belonging an intrinsic feeling or more of a socially constructed expectation?

Studies on belonging in stepfamilies suggest that adolescents are susceptible to disengage from the family as a result of identity and role conflict, and ambiguities in relational boundaries (Valerie, 2007). According to Valerie (2007), children who become part of a step family at the time of adolescence experience tension resulting from the desire to individuate and develop a separate identity from that of the step family. While on the one hand there may be a desire and an emphasis on building closeness and belonging at the formation of the step family, adolescents are caught up as they could be still trying to come to terms with the loss of their biological family.

Adolescents’ disengagement in step families could also be affected by the age and sex of adolescents and stepparents (see also Jensen and Shafer, 2013; King, Boyd, and Thornsen, 2015; Leake, 2007). According to Goodenow (1993), for instance, while disengagement in step families tends to be common during adolescence, cohesion increases with age while Hetherington and Jodl (1994, in Booth and Dunn, 2013) state that adolescents tend to be more negative towards stepfathers than they are towards stepmothers. However, this explanation does not hold for Sabelo: his mother married his stepfather when he was only four years old, and there was no sign that he had disengaged from his family.

According to Valerie (2007), adolescents’ disengagement with family could also be caused by the ambiguous boundaries characteristic of stepfamilies, as new rules and ways of doing things are learned. Relational and role ambiguity can result in a feeling of powerlessness and resentment among adolescents, and of blame directed towards the stepparent for causing the disruption (Gosselin, 2010; Gosselin and David, 2007; Stoll et al., 2006). All these studies on adolescents and step families, however, were conducted in developed countries, and it still needs to be seen if the same happens in resource-poor countries where material provision seems to be a key measure of being cared for, and the notion of family is also different.

Sabelo's desire for a relationship with his father is similar to the one described by Lindani, who says, 'there are things that only your [biological] parents can do for you'. Even if other people in the family can provide for material needs, the 'hole in the chest' can only be filled by a biological parent. This meaning challenges the notion of belonging in the context of biological and non-biological family, which is important for sub-Saharan Africa where there is an ongoing shift in family structure and composition due to several factors including HIV-related mortality, and increasing premarital births, and single parenthood, as illustrated in Simangele's story below and those of the other adolescents in similar situations in this study.

Simangele's story

While poor support and poverty underlie the quest for belonging in the cases of Mpendulo and Lindani, Simangele received strong support from her mother and maternal aunts. Yet she too expressed another feeling of belonging, which she described as being 'emotionally connected', to other members of the support groups (or 'teen clubs' as they are called by members), a feeling that is akin to family.

When I first met Simangele in August 2013, she was fourteen years old. She had been diagnosed with HIV in 2008 after she fell sick, and was initiated on ART the same year because the doctor at the clinic told her that her CD4 count was low. Her mother, who was also living with HIV, suggested that she should test for the virus. Like Sabelo, Simangele's parents were never married and went their separate ways after her birth, leaving her to be raised by her mother. Simangele has no relationship with her father, who is married to another woman, nor does she desire a relationship with him.

Simangele lives with her mother in a modern house her mother owns on the outskirts of Manzini. Her mother and her mother's sisters provide her with a strong social support system. Simangele is also an active member and one of the team leaders in the support group at e-Mpilweni clinic, where she feels a sense of emotional connectedness with other members. Simangele stated how her teen club is 'one big family':

> [H]ere [at the clinic], all children who are [HIV] positive are encouraged to join Teen Club. These clubs are for children who have HIV only. In teen clubs we share

> everything with each other about HIV and other things like growing up, dating, medications, food, and other things. . . . I learn a lot from the other club members and from the doctors and nurses who come to teach us in the teen clubs. It's like we are one big family. (Interview, December 2013)

Simangele's story suggests that the sense of belonging that some adolescents' desire is not in contrast to lack of belonging in the family. Rather it seems another layer of self-identity, in addition to that of their biosocial identity. It is possible that the sense of belonging for some adolescents may also have to do with the identity of being an adolescent, and a need to find a sense of belonging outside of the family.

Simangele's story further adds a layer to the belonging and family complexity. Like Sabelo, Simangele received strong support from family members, but unlike Sabelo, she never wanted a relationship with her biological father. This raises the question of whether being a male in societies that are patrilineal, virilocal, and deeply patriarchal, like Swaziland, plays a role in the quest for belonging that is peculiar to male children. I return to this question in the discussion section, after first sharing the narrative of Sizwe who neither found belonging in 'his family' nor the support group.

Sizwe's story

While Lindani, Mpendulo, Simangele, Sabelo, and a majority of the adolescents found a sense of belonging, and thus 'a family' in support groups, it was not the case with Sizwe, a maternal orphan whom I met in 2013. At the time, he was aged sixteen years. He stated that he was diagnosed with HIV in 2009 at the age of twelve years, after repeated illness episodes, and was initiated on ART the same year. He tested in the company of his paternal grandmother.

Sizwe lives in an extended family comprised of his paternal grandmother who is a traditional healer, his sister who is three years older than him, five half siblings, and three cousins. His mother passed away when he was only seven years old and his father lives in another homestead a few kilometres from Sizwe. His father is also HIV positive and on ART. Sizwe is very angry at his father, saying, 'he gave my mother HIV because he was a womaniser'. During an interview in October 2013, Sizwe mentioned he had last talked to his father over a year ago, stating that he had 'nothing to talk to him about. As far as I am concerned I don't have a father'. His father has five other children (Sizwe's half-siblings) from five different women. He is the only child in the family who is HIV positive, which makes him very angry:

> I don't understand why I am the only one with HIV, how can that be? . . . I feel so alone. No one understands the [emotional and psychological] pain I go through everyday. . . . I am constantly reminded that I am HIV positive each time I have to drink those pills. . . . Why me? (Interview, October 2013)

Sizwe was also angry with his grandmother who, after learning that he was HIV positive, 'went about telling anyone who cared to listen that I was HIV positive. I hate her' (interview, October 2013). Because of his grandmother's 'irresponsible disclosure', Sizwe stated that he experienced discrimination from friends and neighbours as well as from his schoolmates such that he had to change schools. He wished he could leave his home and go and stay somewhere else: 'I don't like staying there, I don't like the people and the environment' (interview, October 2013). He joined the support group and took part in activities only twice when he decided to stop attending; he said 'it was not helping me in any way. . . . No one was able to address my problems. . . . I felt I was just wasting my time' (interview, October 2013). According to him, his problems included 'being gossiped about, laughed at, and people not wanting to associate with me, being the only one with HIV, finding a suitable place to stay, and most importantly being cured of HIV. . . It is difficult knowing that I will be taking these pills for the rest of my life, or to think that one day I will die of this thing [HIV]' (interview, October 2013).

Although his biological father was alive, Sizwe did not want to have any relationship with him because he believes his father was responsible for his mother's death through infecting her with HIV. Asked how he knows that, he stated that had his father not had sexual relations with many women, he would not have been infected with the virus, which he passed on to his mother. He further lost respect for his father when he learned that he, too, was HIV positive, having gotten the infection from his mother.

Clearly, Sizwe did not consider what we could call his family as his family; even though he had cousins, a sister, a grandmother, and a father, he still felt alone and not understood. Hence he wanted to relocate. While it could be said that his feelings were aggravated by the anger he has towards his grandmother and father, he also did not find 'family' in the support group like the other adolescents did. Sizwe's anger seemed characteristic of someone who is still struggling to come to terms with his diagnosis and the chronicity of HIV. Because of his anger, he excluded himself from both his family and the support group.

Discussion

The cases presented in this chapter do not only show the fluidity but also the centrality of the sense of belonging in the description of 'the family' from the perspective of adolescents living with HIV in different familial contexts. Unlike Mpendulo, who seemed to have had little support from his extended family, particularly his brother and sister-in-law, or Lindani whose maternal family's refusal to fulfil the traditional practice of paying *inhlawulo* (damages) or *lobola* (brideprice) prevented him from 'belonging' to his paternal family some adolescents like Sabelo and Simangele had supportive family environments but still sought belonging outside their family settings. Sabelo, for instance, felt his 'deep hole' of belonging could only be filled by his biological father, while although Simangele was content with the support she got from her mother and aunties and had no desire for a relationship with her absent father, but still felt the sense of belonging when with peers.

Disentangling belonging

Belonging was repeatedly mentioned by adolescents in describing family. Adolescents defined belonging as being accepted, connected, and welcomed. According to Yuval-Davis, belonging involves emotional attachment, a feeling of being 'at home, a safe place. . . . [It is] an ongoing project entailing a sense of hope for the future [and] a part of everyday practices' (2011:4). Baumeister and Leary describe the need for belonging as a 'combination of frequent [interpersonal] interactions and persistent caring' (1995: 498–499). Belonging could, therefore, be perceived to refer to a sense of attachment, connection, relatedness, and being wanted and appreciated; a sense that is felt by those who share an identity or particular identities. As an 'ongoing project', as described by Yuval-Davis (2011), belonging can be regarded as a dynamic process that adapts to internal (individual or group relational dynamics) and external environmental (social, economic, political) changes.

All the adolescents' narratives show a desire for belonging that transcends the material and caring support received from their parents or relatives. This desire was experienced as an emotional feeling, described metaphorically by Sabelo as a 'deep hole that needed to be filled'. This 'deep hole' was filled when adolescents felt accepted, connected, welcomed.

There are mixed findings in empirical studies on belonging. While some scholars suggest that belonging is an innate human attribute and an intrinsic desire (see Baumeister and Leary, 1995; Bowlby, 1988), others conceptualise belonging as a subjective feeling (see Biehal, 2014; Valerie, 2007). Most of the adolescents in the study shared an HIV-positive identity, having been born with HIV and never experiencing life without the virus in their bodies. All of them also shared the bio-therapeutic identity of being on lifelong treatment with ARVs, which required a disciplined lifestyle. It is this shared subjectivity, shared biosocial and therapeutic identity, which brought them together to interact with and care for each other in the support groups as one big family.

The intersubjective belonging expressed by adolescents has also been noted in other empirical studies of people belonging to illness- or experience-specific support groups. In his study of men on ART in Bushbuckridge, South Africa, for instance, Mfecane shares how his interlocutors ‘felt at home when in the support group’ (2010:12). Similarly, Zambian adolescents in the study by Mburu et al. described support groups as a ‘community, a source of psychosocial support . . . where they feel valued and offer each other a sense of identity’ (2014:13). Goffman (1963:35–36) states that ‘members of a particular stigma category will have a tendency to come together into small social groups whose members all derive from the category’. In a similar vein, the support group provides adolescents with a social space where they can be free and safe to discuss anything, and to express their feelings and thoughts pertaining to their life and HIV. There they experienced a sense of belonging which they described as feeling connected, appreciated, and accepted. Bailey (1988) refers to this type of family as *psychological kinship*, which he defines as a situation where people value others as though they were one’s own family. In 1993, Ankrah suggested that as more people succumbed to AIDS, African families would be distressed as they try to cope with the epidemic, leading to those who are infected and needing care forming social networks with other people living with the virus who are not necessarily part of the family or kin network. People in the psychological kinship group have no legal or blood connections but are brought together by their emotional and psychological experiences and needs, and by a sense of reciprocity. Likewise, HIV and AIDS support groups bring together adolescents living with HIV to share their experiences of living with the virus, amongst other things. It is through this free and open sharing of feelings, thoughts, ideas, and dreams about their futures (life projects), that they develop emotional and psychological connectedness and closeness, a feeling of being safe and secure, and a sense of belonging, which some of them barely receive from family members or elsewhere. In an online news article on the role of gender inequality and HIV in Swaziland, one adolescent remarked that ‘teen clubs [support groups] help young people to live positively. . . . [It] gives us strength to live with HIV and give us love that we don’t get from our parents, and from our relatives’ (Young, 2015).

Participating in the support group meetings and adherence camps (described in note ii), I observed that adolescents enjoyed each other’s company, shared experiences and challenges, and assisted each other with solutions. Adolescents also appreciated the games they played together as well as the food and cash they were given for participating in the meetings, which made a lot of difference to adolescents from poor backgrounds such as Mpendulo. It is this social environment that made them feel ‘at home’. However, I also observed that the support groups and the camp meetings were highly regulated events, and activities were highly structured: there were set objectives that had to be achieved at set times and processes through which they were to be achieved. For instance, some of the games that adolescents engaged in were designed and tailored towards achieving particular biomedical objectives, like the importance of adhering to ARVs. Although I did not explore whether and the extent to which such a regulated environment influenced adolescents’ responses on the usefulness of support groups or camps in terms of belonging and being ‘one big family’, there are mixed findings from other studies, with some reporting positive experiences while others reporting indifference. In his ethnographic study in Ghana, Daapah (2012) reported that his interlocutors preferred disclosing their status and sharing their experiences of living with HIV with support group members as they benefit from such a space. In contrast, in their study on the sexual health needs of adolescents living with HIV in Kenya, Obare et al. (2010) found that about half of the 249 adolescents participating in the study belonged to support groups, and 45% reported experiencing discrimination from members of the support group.

Despite these observations, the adolescents in this study stated that they enjoyed being part of the support groups and the Sivivane camps and always look forward to the meetings, except for Sizwe who found attending or engaging in support group activities a waste of time. While it could be easy to conclude that his reaction was largely based on the anger he still harboured about his status and at his grandmother and father, it could also be that he was still going through denial about his status and thus the support group did not provide him with the answers he was looking for, such as why he was the only one with HIV, rather the emphasis in support groups is on how to ‘live positively with HIV’.

In adolescents' narratives, belonging was also linked to perceptions of care. Despite Lindani's maternal grandmother providing his everyday basic needs (such as shelter, producing and cooking food, etc.) and care (such as taking him to the clinic for HIV testing, providing consent for his treatment, reminding him of his medication and clinic appointments, etc.), with the minimal resources she had, these acts did not count as care for him. Instead, he repeatedly expressed his desire to go and stay with his paternal family because he 'would be better cared for there'. It can be argued that this thinking was not based on the fact that his paternal aunts and uncles occasionally bought him school uniform, food, and met his other financial needs relating to his illness – which his grandmother also provided – but also was rather related to the desired belonging and family-ship he felt he was lacking in his current living environment. To Lindani, being cared for was more about being in a social space where he is accepted unconditionally than being where he 'belonged' because '*inhlawulo* has not been paid', where he was constantly reminded that it was 'not his home'.

Sabelo's narrative further illuminates the complexity of family and belonging. Whereas he received support and enjoyed a 'good relationship' with his stepfather, he still longed for a relationship with his biological father, the only one who could fill the 'deep hole' he felt. Yet, he did not consider his father family. In essence this renders 'family' a slippery concept and supports Levine's (1999) definition that family is about the language and context where it is applied.

Conclusion

In this chapter I have shown how the meaning of the family is fluid and complex not only in terms of its constitution and structure, but also in everyday practices of HIV care, and needs and expectations at different times and contexts. The study shows a disconnect between the idealised family referred to in global and national policy guidelines, practices at the clinic level on the one hand, and adolescents' perceptions of the family on the other. The question of what family is in the context of HIV care has also been raised by other scholars such as Iliffe (2006). Writing about HIV in Africa, he raises the question of family by asking 'what constituted the family in this [home-based HIV care] context: whether it was those who lived together, those who provided reciprocally for one another, or those of the same blood' (2006: 102).

A significant proportion of the adolescents who participated in both qualitative and quantitative phases of the study had been orphaned by the epidemic, resulting in adolescents having to live in single-parent households, or in step families if the surviving parent decided to remarry. Others live with grandparents in skipped-generation households, with siblings in child-headed households, in foster homes or on their own. In some cases, adolescents such as Mpendulo, found themselves having to move from one household to another among the extended family network, leading to a feeling of social insecurity and impermanence. While this fluidity of family forms is not a new phenomenon in Swaziland and indeed other parts of Africa, what is new is the magnitude of orphaned children who are growing up without one or both parents.

Each of the young people discussed in this dissertation had a type of family (in the conventional sense) that they identified with because they shared common biological or legal ties. However, who they considered as family in the context of HIV care differed from our everyday definition of family as a group of people who are either biologically (blood/genetic), legally (marriage or adoption), or socially (fosterage) related. What appeared prominent in the adolescents' notion of family was [is] a sense of belonging, which they described as being connected, accepted, appreciated and secure; an 'emotional attachment, a feeling of being "at home". . . [that is] an ongoing project entailing a sense of hope about the future' (Yuval-Davis; 2011:4).

The meaning of family as perceived by adolescents is different to what the other interlocutors perceived to be family such as the community leader and gogo Simelane who drew from the socio-cultural norms on how children can belong through the payment of *inhlawulo or lobola*– or the guidelines and policies on families through the biological or legal ties. Despite that the members of these families provided the primary care and support for the adolescents, they were not meeting the emotional connectedness or attachment that adolescents were expecting or needed. Thus some adolescents, experiencing a sense of emotional emptiness – a hole in the chest – turned to support groups for the emotional fulfilment. Others though, like Sizwe, found the support groups also not helpful in closing the hole in the chest. Writing on relatedness in the context of ART in Uganda, Reynolds-Whyte et al. (2014:108) underscore the need to reconsider family in everyday practice:

> instead of assuming what family is, [we must take] notice of the process and diversity; the particular kinds of sharing, helping and communicating that are at play in

> relationships people point to as family. [Such a positioning] helps us to see families as networks rather than groups or units. . . . [It] is with this kind of perspective that we can grasp the figurations and reconfigurations that emerge in living with ART.

Likewise, the study shows the dynamism of the family as a fluid set of relationships that is constantly evolving and transforming based on individual meanings, which themselves are derived from needs and expectations of, and responses from and to the social environment. The everyday lives of the adolescents, which were not only disrupted by the death of parents and their own HIV-positive diagnosis, but also shaped by the support they got (or did not get) from those around them, determined who they identified with and valued as family.

CHAPTER FIVE

ON ACCESS TO, AND MOTIVATIONS FOR HIV TESTING, TREATMENT, AND ADHERENCE TO ANTIRETROVIRAL THERAPY

> [W]hen told I was HIV positive I just cried. . . .I was concerned about what will people say; where I got it; why me; when will I die; all those things. . . . But now I am ok – I am focusing on my studies and my future. (Interview with Nomvuyo, November, 2012)

Introduction

When Nomvuyo fell sick her mother took her to different health practitioners including a traditional healer but she did not get better. Her mother eventually took her to the children's HIV clinic where she was tested and diagnosed with HIV. Nomvuyo's immediate reaction after the diagnosis was that of shock and disbelief because she was still a virgin and therefore, or so she thought, could not be infected with the virus. She recalled: 'At first my mother could not tell me how I could have got HIV, but later told me that I got it from her. . . . With time I eventually told myself that this is how I am now and I cannot change it so I have to accept it anyway' (Interview, November, 2012). Nomvuyo is a double-orphaned girl whom I met in 2012. Her story, shared in chapter three, epitomises the life journey of the HIV-positive adolescents I encountered during my fieldwork.

During my fieldwork I met four types of adolescents: a) those who were knowingly living with HIV and on ART, b) those who had been diagnosed with HIV and on ART but were not aware of their status because it had not been disclosed to them, c) those who tested HIV-negative, and d) those who had not been tested and therefore did not know their HIV status. Through focus group discussions, formal and informal interviews, and conversations, adolescents shared their experiences, fears, and frustrations as well as their courage, hopes, and future aspirations. Even those who were HIV positive had dreams and plans for the future, and although they did not think of HIV as a death sentence, it never left their minds that their lives depended on taking ARVs religiously each and every day and adhering to the

ART package of adherence to treatment, eating a balanced diet, monthly visit to health facility for clinical monitoring, and refill of the treatment, as well as bi-annual monitoring of immunological response to the treatment through CD4 cell count or viral load testing.

Using these adolescents’ narratives, in this chapter I present their experiences with regards to access to HIV services particularly HIV testing and treatment, as well as ART adherence, and retention in HIV care. Unlike the chapters that follow (chapters six and seven) data for this chapter is drawn from both the qualitative in-depth interviews and focus group discussions I had with adolescents living with the virus, and those who were either negative or did not know their HIV status. I triangulate the adolescents’ with in-depth interviews data with key informants, parents, guardians and teachers, and as well as results from the quantitative survey.

Results from the quantitative survey that I carried out indicated that a majority (60%) of the 859 adolescent participants reported to have never tested for HIV, and 75% stated that they were willing to test for HIV, but the current structural arrangements make testing inaccessible. This suggest that adolescents’ low rates of testing, ART uptake, and treatment adherence cannot only be attributed to them being a difficult and hard-to-reach group, as conceptualised in the literature, but rather as the result of a complex web of health systems and political, economic, and cultural factors that constrain these young people. I argue that instead of focusing on the diseased body and on homogenising HIV care through strict adherence to policies and guidelines, as I witnessed in the facilities, a more person-centred service-delivery approach is needed. This would include paying attention to the total social environment of adolescents as social beings whose responses to, understandings of, and actions with regards to HIV are shaped by their socio-ecological environment. This chapter shows that adolescents wanted to access services at places that are familiar to them, such as the school, youth centres, and their homes, rather than the health facilities because, as one sixteen-year-old young woman said, ‘the environment [in health facilities] is hostile and judgemental; they [health care workers] think you are already having sex [when seeking HIV services]’ (focus group discussion, October, 2012).

HIV counselling and testing

From voluntary HIV counselling and testing to provider-initiated HIV testing and counselling, HIV testing and counselling (HTC) is the first and critical step to the prevention and treatment of HIV (WHO, 2003). All people who are tested can be channelled to appropriate care based on the outcome of their HIV test. Those found HIV negative can be educated and empowered on how to protect themselves and their partners and families from getting infected with the virus, while those already infected can be provided with ART, which in turn can improve their survival and quality of life (Bakanda et al., 2011), and reduce transmission between discordant couples (Cohen et al., 2011; Sedibe et al., 2014) and between infected mothers and their babies (WHO, 2009).

The consequences of late diagnosis for those already infected are late access to ART, with the result of high morbidity and delayed recovery (Fox et al., 2013; Idele et al., 2014; Lahuerta, et al. 2013; MacPhail, Pettifor, and Coates, 2008; WHO, 2013); increased possibility of side effects such as immune reconstitution inflammatory syndrome (Katusiime, Ocama, and Kambugu, 2010); and premature death (Dias, et al. 2014; Peacock-Villada, Moreira-Silva, Zandonande, and Miranda, 2015; Richardson and John-Stewart, 2011). Yet, despite the overwhelming evidence of the benefits of HIV testing and the call by the UN agencies (notably UNAIDS, UNICEF, WHO) and the global community to prioritise the testing of youth (including adolescents) in high prevalence settings, programmatic and empirical evidence suggests that very few adolescents are testing for HIV in both developed and developing countries (Idele et al., 2014). For instance, low testing rates among adolescents have been reported across several countries in sub-Saharan Africa, including Malawi (Munthali, Mvula, and Maluwa-Banda, 2013), South Africa (Pettifor et al., 2013; Ramirez-Avilaet al., 2012), Uganda (Bakanda et al., 2011), Zambia (Denision et al., 2009), and Zimbabwe (Ferrand et al., 2010). Swaziland is experiencing a similar challenge in that few adolescents access HIV testing, are linked to, and retained in HIV care and treatment. Only 14% of the 252,678 HIV tests conducted in 2012 were of adolescents (Ministry of Health, 2012).

Reasons for not testing for HIV

Adolescents participating in focus group discussions cited fear as the main reason for not testing, taking ART, or continuing treatment. This included fear of a possible HIV-positive diagnosis, fear of parental reaction to a HIV-positive diagnosis, and the fear of stigma. Adolescents also feared losing friends, being gossiped about or bullied, having to take ARVs for life, and dying. They expressed fear about the future. According to the survey conducted, fear was overwhelmingly higher among urban adolescents of both sexes than their rural counterparts, which may explain the higher number of rural adolescents who reported having tested.

Disentangling the fears

Fear is described as an ‘elusive concept, [a feeling] that is overwhelmingly present to the person experiencing it, but barely perceptible to anyone else and almost defies objectification’ (Green, 1994: 230). Fear is a subjective experience in response to a threat to one’s security. According to Furedi,

> Fear is determined by the self and the interaction of the self with others in relation to a situation in the environment. The experience of fear is continually shaped by cultural and historical scripts that instruct people on how to respond to threats to their security . . . and how fear is experienced varies from culture to culture and within same cultures at different times in response to a meaning attached to a situation considered to be a threat. (2007:1-2)

In Green’s description of fear, she states that fear is a subjective personal experience in response to danger real or perceived. Fear has the potential to destabilise social relations and thrives on ambiguity (1994: 227). Although both Furedi’s and Green’s descriptions of fear are in the context of political violence and crime, they are applicable to HIV as experienced by the adolescents in this study. In the case of HIV, the fear is related to first impressions that have lasted a lifetime; in its early years, HIV was depicted as a disease of people with a ‘spoiled identity’, a disease fraught with shame, and a death sentence (Bohle, 2013).

In fact, Furedi (2007) suggests that to understand fear requires the assessment of ‘the influence of culture’. He notes that instead of treating ‘fear as a self-evident emotion or a taken-for-granted concept’, we should explore the ‘meaning attached to fear and the rules and customs that govern the way in which fear is experienced and expressed’ (Furedi, 2007). This is true for HIV because the multi dimensionality and complexity of HIV fears are shaped not only by the moralistic judgements that result in the stigmatisation of the disease, and those living with and affected by it, but also by the historical depiction and responses that remain a part of the disease today. This fear is further deepened by the infectiousness and incurability of HIV, as well as the earlier equating of HIV to imminent death. Even though ARVs reduce the chance of dying, the dependency on them for life creates uncertainty and fear for many adolescents.

During the early years of the HIV epidemic in Swaziland, health education and communication materials on HIV infection carried fearful images and messages. The materials showed severely wasted people who were at the brink of death, moaning people, flowing blood, graves, and in some cases feared animals such as snakes. The images were also accompanied by messages[xv] such as ‘HIV kills; protect yourself by using a condom’. While these messages were meant to instil responsible and safe sexual behaviour and prevent HIV infection, discussion with participants in focus groups suggested that these frightening images and messages remain deeply ingrained in the minds of people and still shape how HIV is perceived: as a shameful disease and a death sentence (focus group discussion with community-based health workers, August 2012). It is therefore not surprising that 66% and 52% of adolescents in the survey, cited fear of an HIV positive diagnosis and fear of stigma respectively, as reasons for not utilising HIV services, particularly testing for HIV. These adolescents have come of age in an environment where HIV is spoken about in terms of shamefulness, fear, and death. One young man (seventeen years old) explained in a focus group that:

> The way I see it, as a youth a lot of us don't think we have HIV. Even if we think we have it, when you think of going to take a test, you hesitate. There's a lot that comes to your mind and you start reflecting on your past. That is why most of them [only] check their status when they are already ill, because they are haunted by their past; they fear that they will be told they have it. (Focus group discussion, October, 2012)

Adolescents also reported that they did not see the need to test as they were either not sexually active or were ‘taking care of themselves’, that is they were faithful to one sexual partner or were using condoms consistently. An eighteen-year-old male adolescent participating in a focus group discussion stated that,

> The chances of getting HIV are very slim if you take care of yourself that is, knowing what you want and sticking to it being honest with your life and your partner. It is important that you use a condom every time you have sex. But the important thing is having one partner and staying faithful to each other (focus group discussion, October 2012)

In academic studies and in health settings, HIV is mainly presented as a sexually transmitted disease, while the other modes only come to be discussed in the context of reproductive health, in the case of mother-to-child transmission, or injuries arising from accidents in the case of transmission through blood and body fluids. Therefore, for adolescents who are not sexually active, the need for testing may not be a priority, and in fact they may not even think about HIV testing as they may not view themselves at risk of being HIV positive, yet some may be living with a ‘vertically acquired’ virus. For instance, in a study in India that explored the epidemiological profile of HIV infection among thirty-three adolescents, Modi et al. (2008) found that a majority of the adolescents (64.5%) got infected vertically while only 12% got infection through sexual intercourse.

Furthermore, adolescents stated an anticipated negative reaction from parents or guardians if they were diagnosed with HIV as another reason for not testing. This, according to the adolescents, is an outcome of the strong association of HIV with sexual activity. Other barriers included fear that they will bring shame to the family if found to be HIV positive, or fear of not being able to deal with an HIV-positive test due to lack of a psychosocial support system in the family and community. In some cases adolescents did not test because they were ‘protecting’ their parents or guardians from emotional strain should they (adolescents) be found to be living with the virus. A sixteen-year-old female adolescent, speaking in a focus group, stated that she was afraid to ask her mother because

> if I told her that I wanted to test for HIV she would think I was already having sex – isn’t that the way how people get HIV?’ (focus group discussion, January, 2013).

A fifteen-year-old male adolescent, also in a focus group, explained that he had not tested for HIV because:

> If I am found to be HIV positive it will cause psychological and emotional suffering to my grandmother (focus group discussion, March, 2013).

In social contexts like Swaziland where adolescents are expected to be abstinent, having a sexually transmitted infection leads to multiple layers of stigmatisation. It has been reported in other studies that adolescents who seek HIV services describe experiencing multiple stigmas, and particularly those whose got infected through sexual intercourse (Black, et al. 2014; Kurth, et al., 2015; Sam-Agudu, Folayan and Ezeanolue, 2016). These adolescents, besides having to live with the stigma of being HIV positive, have to deal with the stigma of having engaged in sex, thus limiting their access to and use of HIV services. In a study on access to contraceptive use among adolescents in South Africa, Woods and Jewkes (2006) found that stigmatisation of adolescent sexual engagement by other adolescents was a significant barrier. Adolescents in that study also reported that when they visited health clinics to seek HIV-prevention services such as condoms or testing, health providers asked them judgemental questions relating to sexual practices and often in a scolding manner, making the health facility space unwelcoming as adolescents feared such scoldings.

Health service providers' judgemental attitudes, health facilities' lack of privacy and limited operational hours, and the perception that the clinic or health facility is a space for sick people were also cited by adolescents as reasons for not seeking HIV testing services. Adolescents reported that they get mishandled and judged by health facility staff. In a focus group with in-school adolescents held in one school in the urban site in March 2013, one fifteen-year-old girl said,

> they [health care providers] will ask you where you think you got it [HIV] from. . . . They start shouting at you. . . . If you want to learn more about AIDS they say you are under age – or that you are already having sex, that is why you want to know about HIV (focus group discussion, March, 2013).

Lungile, in an interview in November, 2012, said, 'They immediately say, "So you are already having sex; that is why you want to test for the virus". It's like everyone gets HIV through sex. . . . I did not get HIV through sex, so it can be annoying'.

According to the national paediatrics ART coordinator who also coordinates adolescent HIV services, the national paediatric ART programme, which also houses adolescents, had been working with health facility staff to make health services 'adolescent friendly', that is, to respond to and meet the specific needs of adolescents. These initiatives include dedicating certain clinic hours to provide services to adolescents only, to have hours during weekends so that even in-school adolescents can access services, and training health care providers with counselling and communication skills relevant to adolescents. Commendable as the initiative is, the limitation of the approach is that adults, rather than adolescents, are defining what is 'friendly' to young people, and it is contrary to what adolescents view as 'friendly'. According to the adolescent focus group discussions in my study, adolescent-friendly services would1) be provided in areas where young people congregate, such as schools and youth centres; 2) be provided by health workers who are specifically trained and qualified in working *with* adolescents in a non-judgemental way; 3) be available throughout the day everyday, not only on specific days of the week or specific hours of the day; and 4) create a forum where adolescents actively participate in the decisions regarding the provision of services.

For the most part, asymptomatic adolescents would not use a health facility-based service. Using the metaphor of panel beating a car to explain his point about health facilities as spaces for the sick, an eighteen-year-old young man, speaking in a focus group, stated that ‘hospitals are places for the sick who require to be panel beaten back to normal through the use of pills and injections’ (focus group discussion, May, 2013), suggesting that health facilities are only for those are sick. Adolescents recommended that HIV services be moved to places that are familiar and less threatening to them. Parker et al. (2015) report high uptake of HIV testing among adolescents and men through home-based testing in the Shiselweni region of Swaziland. Similarly, the number of adolescents testing for HIV increased in Swaziland when services were provided in communities during ‘fast-track events’–a community owned and driven model of service delivery where effort is tailored towards accelerating or expediting access to HIV services by clients – implemented through the MaxART programme[xvi] (Clinton Health Access Initiative [CHAI], 2012).[xvii] According to a 2012 CHAI report, the implementation of fast-track events yielded, on average, a 680% increase in HIV testing, especially noted among male adolescents compared to other demographic categories.

Asked what changes in service delivery would motivate them to test for HIV, among the 439 adolescents who responded to this question in the quantitative phase of the study who had never tested, a majority reported willingness to test for HIV if the services were provided away from the health facility setting: 29% said they would prefer that testing be provided in schools, 25% preferred testing at home, and 19% preferred youth centres. This finding inconsistent with others carried out among adolescents in the Sub-Saharan Africa region. Countries such as Zimbabwe (Morin et al., 2006), Kenya (Grabbe et al., 2010), and South Africa (Black et al., 2014) reported increased testing uptake by adolescents when services are provided outside the conventional health clinic, through use of mobile testing units in communities or youth centres. Studies conducted among students from Gauteng and North West provinces in South Africa reported high acceptability of HIV testing among adolescents when services were provided in schools (Madiba and Mokgatle, 2015a).

The requirement for parental consent to access testing services was the singlemost cited policy/legal barrier mentioned by both adolescents and health care providers in interviews. Adolescents shared that health providers required them to get their parents’ or guardians’ permission if they wanted to be tested, something that was also stated by the health care providers. In an informal conversation I had with a group of school children in November 2012 from the rural study site, a thirteen-year-old girl told me, ‘They [health care providers] dismiss us and tell us we are young, we must come with our parents’. A fourteen-year-old boy in a focus group had a personal experience: ‘I wanted to test for HIV but was turned back to get my parent’ (October, 2012). It turned out this boy was an orphan and getting a parental consent was not possible. In an interview, one health care worker confirmed that it was standard procedure to seek for consent before testing young people for HIV: ‘If they come seeking testing, I turn them back to get consent from parents or relatives. That is the policy’, he stated (in-depth interview, November, 2012).

According to the HIV testing and counselling guidelines that were operational during the time of the study, the minimum age of consent for accessing HIV testing was 16 years. However, this was revised and improved to twelve years through the Child Protection and Welfare Act, 2012. However, there are conditions inherent to the newly revised age of consent. The Child Protection and Welfare Act states that:

> . . . a child may be tested for HIV *only* [italicized for emphasis] after proper counselling of a) the child if the child is of sufficient maturity to understand the benefits, risks and social implications of such a test; *and* [italicized for emphasis] b) the child’s parent or guardian has an understanding of the implications of the result,(2012:S121–122).

The use of *‘only’* and *‘and’* creates an ambiguity, as it would seem that giving consent alone does not necessarily guarantee that the adolescent will be tested; there is need for *parental or guardian’s understanding of implications of the test* [my emphasis] as well before testing, which is additional to the adolescents’ consent. During an interview with the national paediatrics ART coordinator, who also coordinates adolescent HIV services, she stated that the age of consent as stipulated in the Act has been incorporated in updated HTC guidelines (in effect as of 2015), and health care providers were already being sensitised on the age of consent through on-site and national trainings. The coordinator, however, noted that while it is commendable that testing can be provided to adolescents as young as twelve years without the consent of parents or guardians, they (parents and guardians) are still needed to provide psychosocial, financial, and material support to adolescents, whether testing HIV positive or negative. She observed that testing without these critical support structures may have negative outcomes for adolescents who are HIV positive as they may still be dependent on their parents or guardians.

In some cases, even when the adolescents had reached the age of maturity making him/her eligible to consent, parents and guardians still expected that their consent be sought prior to the provision of any HIV service. For instance, one guardian who also is a community health worker was infuriated when her grandson, who was nineteen years old, came home after being tested and circumcised. In a focus group, she stated that she 'was surprised and angry when my grandson came home already tested and circumcised without my consent. . . . I took it up with the clinic nurses' (October, 2012). According to health care providers, they have faced incidents when parents angrily questioned and challenged the provision of health services to adolescents without parental consent. This, they believed, derives from the fact that in Swazi society a person ceases to be a child only when s/he moves out of the family home to establish his or her own. They also referred to the fact that decision making generally is a collective matter, particularly when it relates to issues around health and other social endeavours.

The barriers to testing as shared by the adolescents in this study are similar to those stated by adolescents and young people in other developing countries in sub-Saharan Africa (cf. Beres et al., 2013) and particularly countries neighbouring Swaziland such as Malawi (Munthali, Mvula, and Maluwa-Banda, 2013), South Africa (Francis, 2010; Hutchinson and Mahlalela, 2006; Mohlabane et al., 2016; Ramirez-Avila et al., 2012; Strauss, Rhodes and George, 2015), Zimbabwe (Ferrand et al., 2010; Kranzer et al., 2014), as well as in developed countries such as the United States (Hein 1997; Ho et al., 2005; Meehan, Hansen, and Klein, 1997) and the United Kingdom (Deblonde et al., 2010; deWit and Adam, 2008). Available evidence suggests that when changes in the law allow adolescents to consent to HIV testing, the uptake increases. A study by Meehan, Hansen, and Klein (1997), carried out in the US state of Connecticut, assessed the impact of parental consent on the testing of minors (defined as anyone aged thirteen to seventeen years), and reported a 44% increase in the number of adolescent visits to health facilities providing testing services, a two fold increase in uptake of testing, and a threefold increase of HIV testing of adolescents considered to belong to high-risk populations. The researchers concluded that minors should have the right to consent to HIV testing. It is yet to be seen if the change in age of consent from sixteen to twelve years will yield an increase in the uptake of HIV testing by adolescents in Swaziland.

Motivations for testing

Adolescents who reported during the survey that they have tested for HIV (n=347) were asked to share their motivations for testing. The main reasons included wanting to know their HIV status (50%), being sickly and suspicious that they might be infected (13%), being advised to test by health worker (10%), told by parents to test (8%), and following the advice of community-based male circumcision campaigns (6%). Other reasons included being pregnant (3%), having engaged in risky sexual behaviour (2%), having a partner who was engaging in risky sexual behaviour (2%), and testing as part of research project or to access benefits (2% and 1%, respectively).

The survey also showed that HIV testing varied by age, residential area, HIV knowledge, and mode of transmission. For instance, all ninety-one adolescents aged 12–14 who reported having tested for HIV in the survey stated that they did so because their parents, guardians, or health care providers recommended it following recurrent diseases or health conditions that were not responding to conventional treatments. This was also reported in interviews, focus group discussions or informal conversations with adolescents during the qualitative part of the study, as these statements show:

> My mother told me that I was very ill and she took me to the hospital where they decided to get me tested. (Informal conversation, December, 2013)

> I fell sick with lesions all over my mouth, and then I went to the clinic where I was given treatment. A few weeks later my grandmother decided I should go back to the clinic because I was not getting better from the medication I was given. They then decided to get me tested for HIV after which they told my grandmother I was HIV positive. (Focus group discussion, February, 2013)

> I fell sick with measles, so my mother took me to the clinic for the test. (Focus group discussion, February, 2013)

> I was sick and when my mother took me to the hospital; they found that I had TB and since there had been no one at home with past illnesses, we decided that I get tested for blood sugar, HIV and etc. After I was found to be living with HIV, I then opted to be started on ARVs. (Interview with Sipho, November, 2013)

Older adolescents (17–19 years, n=174) participating in the survey stated that they tested because they just wanted to know their HIV status (46%), or because they had engaged in risky sexual behaviour (39%). This has also been reported in other adolescent studies in Malawi (Munthali, Mvula, and Maluwa-Banda, 2013); South Africa (Anderson, Beutel and Maughan-Brown, 2007); South Africa, the Philippines, and Zimbabwe (Armstrong et al., 2013); and Zimbabwe (Ferrand et al., 2010). Adolescents in this study stated that knowing their HIV status would help them make plans about, and take care of their health, education, and future.

Another commonly mentioned motivation for testing was seeing friends testing (8%) or other people living healthy with HIV (5%), while others did so because they were given incentives to test (1%). The issue of incentives was commonly reported by male adolescents from rural settings who were tested as part of the ‘back to school’ male circumcision campaign, which targets school-going adolescents during school holidays. In the drive to increase the acceptability and uptake of HIV prevention and treatment services including testing, adherence, and retention, and/or HTC provider efficiency and performance (see Angotti, et al., 2009; De Walque et al., 2015), programmes in developing countries have used financial or other material incentives. These have been and still remain a subject of ethical debate among researchers (see Nguyen, 2010; Pettifor et al., 2012).

In terms of residential area and sex, more male adolescents from rural settings reported having tested for the virus compared to urban and female adolescents, although the urbanites were more knowledgeable than their rural counterparts. Among the 347 (40%) who reported to have tested for HIV, over half of those tested were male adolescents (182 or 52.4%), and were rural residents. It would seem that being male, older, and from a rural setting was more positively associated with HIV testing than being female, younger, and from urban or peri-urban settings. When subjected to bivariate analysis, the finding that being male and older did not hold; instead, in the bivariate analysis (chi square test), age (p<.01), level of education (p<.01), length of time lived in the area (p=.03), and condom use (p<.01) were significantly associated with utilisation of HTC services (see Table 1).

Table 3: Sociodemographic characteristics and HIV testing

Variable	N (%)	Ever tested for HIV? Yes (n=347)	Ever tested for HIV? No (n=512)	χ2	P-value
Age				59.36	< .01
12–14	324 (37.7)	91 (26.2)	233 (45.5)		
15–17	339 (30.5)	134 (38.6)	205 (40.0)		
18–19	196 (22.8)	122 (35.2)	74 (14.5)		
Gender				1.75	.19
Male	427 (49.7)	182 (52.4)	245 (47.9)		
Female	432 (50.3)	165 (47.6)	267 (52.1)		
Nationality				0.08¥	.57
Swazi	847 (98.6)	342 (98.6)	505 (98.6)		
Non-Swazi	12 (1.4)	5 (1.44)	7 (1.37)		
Education level				20.12	<.01
Primary school	346 (40.3)	118 (34.0)	228 (44.5)		
Secondary school	320 (37.3)	128 (36.9)	192 (37.5)		
High school	178 (20.7)	90 (25.9)	88 (17.2)		
Other (Tertiary, Never)	15 (1.7)	11 (3.1)	4 (0.8)		
Religion				.008¥	.57*
Christianity	847 (98.6)	342 (98.6)	505 (98.6)		
Other (Ancestry, Islam, None)	12 (1.4)	5 (1.44)	7 (1.37)		
Residence				2.25	.33
Urban	194 (22.6)	74 (21.3)	120 (23.4)		
Peri-urban	246 (28.6)	109 (31.4)	137 (26.8)		
Rural	419 (48.8)	164 (47.30	255 (49.8)		
Length lived in the area				10.14	.02
Since birth	485 (56.5)	180 (51.9)	305 (59.6)		
<1 year	89 (10.4)	48 (13.8)	41 (8.0)		
1–4 years	122 (14.2)	55 (15.9)	67 (13.1)		
≥5 years	163 (19.0)	64 (18.4)	99 (19.3)		
Condom usage					
Always	78 (9.1)	59 (17.0)	19 (3.7)	63.26	< .01
Sometimes	32 (3.7)	22 (6.34)	10 (2.0)		
Do not use	12 (1.4)	8 (2.3)	4 (0.8)		
Never had sex	737 (85.8)	258 (74.4)	479 (93.6)		

¥*Fisher's test*

However, when subjected to multivariate regression analysis after controlling for other covariates in the model, both the descriptive and the bivariate findings did not hold. Participants aged 12–14 years were significantly more likely to utilise HTC services compared to those aged 18–19, with an odds ratio (OR)=3.00 and 95% Confidence Interval (CI)=1.85-4.89. Similarly, those aged 15–17 years were approximately twice as likely to utilise HTC services compared to the 18–19 age group, with an OR=1.90 and 95% CI=1.25-2.85 (see Table 2).

Those who had lived in the area for less than a year were significantly less likely to utilise local HTC services compared to those who had lived in the same area for five years or more (OR=0.48; 95% CI=0.28-0.84). Participants who reported using condoms (always or sometimes) were significantly less likely to utilise local HTC services compared to those who had never had sex (OR=0.27; 95%CI=0.15-0.48, and OR=0.44; 95% CI=0.19-0.98, respectively). Otherwise, gender, educational level, and residence were not significant predictors of utilisation of local HTC services (see table below).

Table 4: Correlates of utilisation of local HTC services

Variable	*B* (SE)	OR	95% CI
Age			
12-14	1.10 (0.25)	3.00**	[1.85 - 4.89]
15-17	.64 (0.21)	1.90**	[1.25 – 2.85]
18-19	-	1	-
Gender			
Male	-	1	-
Female	.10 (0.15)	1.10	[0.82 – 1.48]
Educational level			
Primary school	.87 (0.63)	2.38	[0.70 – 8.15]
Secondary school	.97 (0.62)	2.64	[0.79 – 8.84]
High school	.84 (0.62)	2.30	[0.68 – 7.83]
Other	-	1	-
Length of time lived in an area			
Since birth	-.52 (0.20)	0.95	[0.64 – 1.41]
<1 year	-.74 (0.28)	0.48*	[0.28 – 0.84]
1–4 years	-.33 (0.26)	0.72	[0.43 – 1.20]
≥5 years	-	1	-
Residence			
Urban	-	1	-
Peri-urban	-.07 (0.21)	0.93	[0.62 – 1.40]
Rural	.15 (0.19)	1.16	[0.79 – 1.69]
Condom Usage			
Always	-1.31 (0.30)	**0.27****	[0.15 – 0.48]
Sometimes	-.83 (0.41)	**0.44***	[0.19 – 0.98]
Not at all	-.72 (0.65)	0.49	[0.14 – 1.73]
Never had sex	-	1	-

N=859; **p*< .05, ***p*<.01 (all 2-tailed); R^2 = .11 (Cox & Snell), .15 (Nagelkerke); Model $\chi 2$ (14df)=99.36, p <.01; -2LL = 1059.58; OR, odds ratio; CI, confidence interval; *SE*, standard error

Although the quantitative results do not show a statistically significant difference of testing between urban and rural adolescents, findings in the descriptive part showed a difference in testing rates by length of time lived in residence area. This was particularly surprising for me given that urban and peri-urban adolescents were more knowledgeable about HIV than their rural counterparts, and also had more choice in terms of the number health facilities available than in the rural settings where there is just one health clinic at most. This difference can be partly explained by the high levels of stigma in urban settings as reported by urban adolescents. Adolescents in focus group discussions in the urban setting reported that they knew of adolescents who had contemplated, attempted, or even committed suicide after they were diagnosed with HIV, which was not the case in the rural setting (see chapter six on stigma). This point was reiterated by health care providers. Although they described adolescents as being a difficult group who never show up for HIV or any other health service, health care workers also acknowledged that there could be several reasons for adolescents' poor use of HIV services, and one of the main reasons could be fear of stigma.

Reactions to and meaning of an HIV-positive outcome

In interviews and focus group discussions, adolescents were asked to describe their initial reactions after being informed that they were HIV positive. They were also asked to rank the intensity and length of the initial emotional reaction, using a scale of one to five, in which one represented normal, two represented mild, three represented moderate, four represented severe, and five represented very severe. In terms of length they were asked to recall whether it lasted for a few hours to a few days to a month or more. Their responses indicated that adolescents felt a range of emotions, including shock, sadness, anger, confusion, and disbelief. These initial emotions were eventually followed by acceptance of their HIV status, and then strategizing how to live with the virus. The time to resolution of emotional response varied from just a few minutes or hours to months and years. Furthermore, the intensity of the emotions varied by age, knowledge of and understanding (comprehension) of HIV, previous health history, and availability (or lack) of a supportive and accommodating family environment and health care providers. Those who had never engaged in sexual activity, who were perinatally infected, and to whom disclosure was delayed experienced intense shock, disbelief, anger, and blame while those who were tested and informed when they were young and lacked understanding of what it meant to be HIV positive stated that they were indifferent.

Cognitive theorists have argued that emotions such as shock, anger, and sadness arise from a judgement that the things valued by an individual or group are being threatened, such as health and well-being (Fischer, 1999) or sense of personal security (Furedi, 2007). The emotions help those perceiving the threat to strategize about how to deal with it. Among the strategies used by the adolescents living with HIV (and their parents or guardians) was to conceal their status by remaining silent and secretive about it, in order to avoid discrimination in the form of rejection, bullying, or gossip. Adolescents also adhered to their ART in order to stay ‘normal’, by which they meant to look physically healthy.

Adolescents who were tested for HIV while still young said they were not told the diagnosis, instead health care providers told their parents or guardians. At the time they did not understand what it meant to be HIV positive. As they grew to understand the meaning of the disease and illness better, their reaction was that of sadness, which was followed by disbelief and expectations of the worst, described as taking pills everyday for the rest of their lives. Most of these adolescents were likely to have been on ART since when they were young and as such had ‘grown tired of taking the medicines’. Others, however, simply accepted their HIV status because they could not change it.

In an interview, Lindani said, ‘I felt sad because they told me I was HIV positive. . . . It meant that I will be living with an incurable condition for my entire life. I also thought I would lose all my friends now that I was living with HIV’ (interview, August, 2013). Similarly, Sabelo recounted his experience:

> Just after the nurse told my mother about my status, I was sad and tears started falling down my cheeks. I couldn’t help being shocked by news about my HIV status and how I really got HIV. I was afraid of what people would say and how they would react around me, but as time went by I simply accepted how I was and the changes I had to make in my lifestyle. . . . I met some girl at teen club who was also taking ARVs here at [the clinic], so we would often meet when we had come for refills and share quite a lot about HIV. I then told myself that I was not in this world on my own, so that was how I accepted and got over my pain (interview, September, 2013).

For the older and more knowledgeable adolescents, an HIV-positive diagnosis was met with shock, sadness, and a host of questions regarding how the infection happened. Anger was almost palpable in their accounts; they blamed their parents for infecting them and then keeping the truth from them. Anger was one of the most common emotional reactions and was very strong especially among adolescents who were infected vertically, who, at the time of testing for HIV, were virgins, and therefore did not expect that they could be HIV positive. These adolescents harboured anger towards their parents, whom they blamed for their HIV infection and ruining their lives. In this regard anger was more ‘a judgemental emotion’ towards an offence committed against them (Solomon, 1984, quoted in Ariss, 1993:18).The anger was mostly expressed by female adolescents while males seemed to be more forgiving. Anger, sadness and other emotional reactions lessened over time though not totally gone. Sipho, in an interview, remembered that:

> ‘At first I didn’t want anything to do with both of my parents because I had the idea that they ruined my life, but as time went by I became at peace with everything, since there was no possible way I could avoid talking to them forever (interview, November, 2013).

For others, the sadness and fear was provoked not necessarily by the positive diagnosis of HIV, but by the manner in which the test results were disclosed. During our conversation, Simangele recalled how she became frightened and confused when she realised what being HIV positive meant. She cried not because she was told she was HIV positive but because the nurse told her she was going to die:

> FS: I see. Now let’s talk about HIV. Tell me about the first time you heard that you were HIV positive, how did you feel?
>
> S: Since I was very young and did not understand what this HIV I am living with was all about, I hardly felt a thing. But there was one time when one of the nurses said when I get a headache I will die, it really hurt me bad knowing that whenever I get sick with a headache I could probably stop breathing.
>
> FS: After you got tested, they told you that you were living with HIV and the nurse told you that if it happens you get a headache you will die. Did you ask what she meant by that?
>
> S: My mother asked what she meant by that and she said it came out wrong, she was sorry for that. I was already crying by then.
>
> FS: Why were you crying, if you can tell me?

> S: I was crying because the nurse had said I would die; I did not want to die. So I was afraid and confused at that.

While most of the adolescents expressed that they were shocked and could not believe they were HIV positive, and then felt anger which resolved later on, one adolescent's reaction was peculiar in that being told that he was HIV positive brought relief: he was 'happy' to finally know what was wrong with him. Sandile was fourteen years old when he was diagnosed with HIV and started on ART. When I met him he was sixteen years old. He is a double orphan, having lost both parents when he was still very young. He described how his entire childhood was characterised by sickness, and how his relatives took turns in trying to get him well. He was sent to different healing systems – traditional healers, faith healers, and clinics and hospitals – but none were able to cure him. He only had short intermittent relief. 'Worse is that no one was able to tell us what was wrong with me', he said during our conversation in February, 2013, held during a support group meeting I attended at the health facility. He felt relieved once he knew the cause of his chronic sickness. The nurses who had tested him suggested that he should start ART immediately, which he did without any hesitation because 'I just wanted to be well. I was tired of being sick. After starting ART I got better; I have no sores, no diarrhoea, and no coughing. I am happy and relieved'. When I met him, Sandile was a bubbly, healthy-looking young man who showed no outward signs of HIV. He participates in a support group of adolescents living with HIV that meets at the Lulama health centre, and because of his openness about his suffering and status, and his outgoing nature, he was selected to be one of the team leaders for his age group. In a focus group, he stated:

> Although it never occurred to me or my relatives that I could be HIV [-positive], I was very happy when I was told my blood was dirty. I was happy not because I was HIV [-positive] but because I came to know the cause of my illness. I had been sick for a long time and my grandmother and other relatives had taken me to many clinics, different traditional healers, faith healers, and hospitals for treatment but I was not getting better. No one told us what was wrong with me. It was like they were just guessing. Until one day when I came to this health centre and a visiting nurse from Mbabane suggested to my grandmother that I should test for HIV, which I did, and was told that I was HIV positive and needed to start taking ARVs. . . . I was happy because I was told what the cause of my suffering was. (February, 2013)

For Sandile, the physical and psychological suffering he went through trying to get a cure for his disease he didn’t even know what it was warranted ‘happiness and relief’ when he finally knew his actual diagnosis. Not only did Sandile experience physical suffering as a result of diseased body but psychological suffering as well, arising from his ‘disabled childhood’ as evidenced in the distress he suffered. His relieved reaction was rather unusual, but knowing what caused his recurrent sickness, which was too much to bear, shows that physical suffering also affects the emotional self. Sandile states that ARVs brought him back to ‘normal’: ‘now I am like everyone else’. His medications go beyond just managing the physical symptoms afflicting the body; they restore an identity of ‘a normal self’. This quest for normality was expressed by most of the adolescents on ART which I present in the next section.

Antiretroviral therapy and the quest for normalcy

Antiretroviral therapy is one of the key biomedical interventions for HIV infection. Its use has resulted in HIV changing from a terminal disease to a chronically manageable one. ART refers to the use of antiretroviral medicines to suppress the replication of HIV, resulting in a reduction in viral load, the recuperation of the immune system, and the protection of the body from other diseases often referred to as opportunistic infections. Opportunistic infections are conditions or diseases that one gets when the immune system is depleted and unable to fight the causative agents such as bacteria, viruses, fungi, and protozoa when they invade the body, (Kaplanet al., 1995).

However, not every person who is HIV positive can be started on ART; according to the national guidelines (MoH, 2015), ART initiation needs to be preceded by various biomedical evaluations that include linkage between testing and treatment (interventions designed and implemented to ensure that those diagnosed with HIV are started on antiretroviral treatment), clinical staging (a WHO-developed standard criteria used by clinicians to evaluate the stage of HIV disease in people diagnosed with the virus), further laboratory tests, targeted counselling for ART, and evaluation of readiness to initiate treatment. People living with HIV have to demonstrate psychosocial readiness as well as meet an immunologically or clinically defined threshold before they can be considered for ART. According to the current WHO recommendations, adopted by Swaziland, a person is eligible for ART if his/her CD4 count is ≤500 cells/mm^3 or is in clinical stage III or IV of the HIV disease as defined by WHO (WHO, 2013). The CD4 cell count criterion was an improvement from earlier ones, in which ART was initiated only when the CD4 cell count was ≤350 cells/mm^3 (2009), and ≤200 cells/mm^3 (2004, when ART became widely available in Africa). Pregnant women, children below two years of age, and PLHIV co-infected with TB do not follow the same criteria; these groups are initiated on ART regardless of CD4 cell count or clinical stage of the HIV disease. Since free ART became available in the country in 2004, the number of people initiated on ART has steadily increased, and as of 2013, 90% of all those in need were on treatment. An HIV diagnosis is the first step towards initiation of ART and because very few adolescents have tested, very few have begun treatment. According to a report by UNICEF (2012), only 5% of the people who were on ART in 2012 were adolescents. It is stated in the report that this proportion is far short of what it should be if adolescents were being adequately diagnosed and started on and retained in HIV treatment programme.

Adolescents' experiences of ART

Adolescents that participated in the focus groups and interviews had varying experiences with ART, ranging from feeling like they had no choice but to take the ART to accepting the treatment. Simangele is one of the adolescents living with HIV and had been on ART for six years when I met her. During one of our discussions about her experiences of living with HIV in which we were talking about treatment, she shared that she was just 'okay' with the ARVs, because she had no choice as her life depended on them. This is what she said:

> I am okay with them; after all I have no choice but to take them. But I have not had any side effects, if that is what you mean. … I mean that as a person who is HIV positive, I have to take the ARVs whether I like it or not because my life is dependent on them; they are a part of me. So instead of thinking about them as a problem, I have to accept that they are my life. That makes it easier to take them. But if there was another better way, maybe I would choose it than to take pills everyday, twice a day. Sometimes you forget and sometimes you have to visit friends or relatives and you have to find a secret place to take them. It can be a problem, so you end up not visiting your friends because you do not want that kind of stress. (interview, October, 2013).

Not only did adolescents 'accept' their HIV status and the lifelong treatment, but it became a part of their everyday life. According to Sipho, the embodiment of HIV and ART has made it:

> easier to live with the virus . . . since both my parents and grandmother were living with HIV and taking ARVs, I just told myself that HIV is a part of me, a genetic something. . . . [W]hat mattered most in my life was to be alive and try by all means to be healthy and normal by taking the ARVs as told by nurses and doctors at the clinic. (interview, December, 2013)

But for some adolescents, even though they accepted their HIV-positive status and the fact that they have to be on lifelong therapy, they constantly worried about the incurability of the virus in their body. In a follow up interview, Lungile stated that she:

> got tested at birth. My grandmother told me that I started taking ARVs soon after, starting with suspension [liquid ARVs for children] and as I grew older I started taking ARV tablets. I was six years old. Since I have been taking ARV medication, I hardly experienced complications, although I always ask myself how long I will be taking them. I keep thinking to myself why this virus in me never gets destroyed by these ARV drugs, actually what is the main reason we keep on taking them if they are not getting rid of this HIV virus? (interview, October, 2012)

Although he, too, had accepted his fate, Lindani had challenges with side effects and the number of pills he had to take; instead of the fixed-dose[xviii]combination of ARVs, meaning one pill a day, he had to take two pills twice a day. The frustration he expressed during our conversation was not only about the side effects, but at not knowing why he can't also take one pill a day like the other adolescents in the clinic. The reason, according to the health care providers at the clinic, was because his weight made him ineligible for the single-pill regimen. The health care providers informed me that to be eligible, a person must weigh at least 40 kilograms. Asked if Lindani had been made aware of the reason he was still taking two pills twice a day instead of the fixed dose combination (FDC), the health care providers said they had informed his grandmother with the hope that she would explain it to him. According to Lindani this unfortunately did not happen. Asked if he informed the health care providers about the side effects and ask them why he was not switched to the FDC, Lindani stated that he was afraid to do so because 'they would think I am just being unreasonable and may ill-treat me'. Hence, he continued to suffer in silence.

Lindani's experience speaks to two critical issues: the importance of communication about all aspects of the disease and the treatment, both between health care providers and adolescents and between adolescents and their parents or guardians. Secondly, it speaks to the use of silence as a survival strategy in the face of perceived reprisal in a health care setting or at home. Instead of facing the scorn of the health care providers, Lindani used silence to avoid it, while enduring the suffering from side effects. That the health care providers chose to communicate with a third party on issues affecting Lindani directly arise from the protocols followed by the health care providers in which people like Lindani are considered minors who constantly need the support of their parents or guardians. While psycho-social support is an important part of HIV management, it cannot be universalised to all adolescents and all situations; exceptions may be necessary in matters that directly impact a patient’s experience with medications, which in turn may impact adherence. Lindani’s home situation was wanting; he lived with a grandmother who was very poor, who herself had no support and relied on neighbours for food. Lindani’s grandmother also spent most of her time in a nearby *sheeben* (an informal and unlicensed place, usually a private house, for selling alcoholic beverages to members of the public) where she drinks local brew (*umcombotsi*) and is therefore rarely home for Lindani. The grandmother also had reservations about Lindani’s parental family who had not ‘paid damages’ for Lindani’s mother, who was impregnated by their son before marriage, as required by Swazi custom. The extent to which this standoff between the two families affected the relationship between Lindani and his grandmother is best summarised in Lindani’s words:

> My grandmother here often asks why I do not want to live with them now that she has taken care of me following the death of my parents. She always says that my family never paid dowry for my mother so I cannot go to stay with my family. . . .It is very painful because there are some things that no one can do for you other than your parents and unfortunately I do not have them. . . .Having no parent to listen to your challenges is so depressing. . . . I miss them a lot. (interview, August, 2013)

Lindani’s narrative speaks not only to the ‘standoff’ but also to the psychological distress of having lost both parents. To expect that Lindani’s grandmother was going to explain to her grandson about the reasons for keeping in the two pill twice a day regime instead of the one day FDC, was therefore myopic of Lindani’s social situation. If health care providers could as well pay attention to the socioeconomic context of adolescents as do to the biomedical interventions, better care and information could be provided, which in turn could improve the quality of ART adherence.

Despite the benefits of ART, one adolescent stopped treatment three times, dropping out of care only to be brought back by his grandmother for re-initiation. According to Sicelo he stopped treatment because he wanted to live with his father in town. At the time of the study Sicelo was living with his paternal grandmother in a rural setting while his father lived with his wife (Sicelo's stepmother) and Sicelo's step siblings in town, something that did not go down well with Sicelo. My further interactions with him revealed a lack of understanding or appreciation of being HIV positive, being on ART and the complications of defaulting treatment, the vulnerability posed by an uncaring and unsupportive family environment and how lack of cooperation between the parents affect adherence by adolescents. Sicelo's situation also revealed a reductionist limitation of the biomedical explanatory model (Kleinman, 1980) that focuses on a diseased body, and fails to take into consideration the social aspect of the disease- the illness- in the management cascade of HIV.

Faced with fear, silence, side effects and unsupportive family and health system on the one hand, and the requirement for lifelong optimal adherence and retention in ART on the other, one wonders to what extent are adolescents able to adhere to and be retained in treatment. In the next section I explore adolescents' motivations to adhere (or not) to ART, including what, and how they manage the challenges they come across as they live on their ARVs and on ART.

Adherence to ART

Adherence is defined as 'the extent to which a client's behaviour coincides with the prescribed health care regimen as agreed through a shared decision-making process' (Hardon et al., 2006:89–90). In essence, adherence refers to the extent to which adolescents living with HIV take the right ARV medicines, the right dosage, at the right time, through the right route, and follow the instructions given to them by health care providers. Several studies evaluating adherence among adolescents show mixed findings with some reporting suboptimal adherence (Chandawani et al., 2012; Garvie, Wilkins and Young, 2010; Kim, 2014) and others reporting optimal adherence or better adherence rates in African adolescents compared to those in Europe, North America, and South America (see Kim et al., 2014). Interplay of individual, socio-familial, medication-related, health system, and structural factors influences adherence (Musheke et al., 2012). A study by Armitage (2012) found that adolescents living with HIV on ART were committed to adhere to HIV treatment, but factors beyond their control were cited as the main barriers to adherence. These included health system-related factors, medication-related factors, and socioeconomic status. Sher et al. (2014) reported complex factors within the family as predictors of adherence in a study among perinatally infected adolescents in Cape Town, South Africa. Mutwa et al. (2013) found that living conditions influence adherence among adolescents in Rwanda. Adolescents were likely to skip their ARV doses due to lack of privacy, confidentiality, and social support, and out of fear of stigma in boarding schools, orphanages, or foster care.

Similarly, the adolescents in this study had varying levels of adherence although all stated that they were aware of the importance and benefits of properly taking their ARV medications and were committed to taking them as prescribed for their health benefits. However, and for different reasons, almost all of them were poorly adherent at the beginning of treatment though this improved with time as they realised the improvements in their physical health. Most also mentioned that being informed about their HIV status and the reasons for taking the medicines, or when the number and complexity of the ARVs medicines were reduced,[xix] made adherence easy.

Adolescents who had open communication with their parents who were also living with HIV and on ART fared better in terms adherence, indicating not only the important role of family in management of the HIV disease but also that of open communication about the disease and illness itself as it allows sharing of successes, challenges, fears, and hopes, thus making the disease and illness a shared responsibility.

Adolescents who were poorly adherent and not retained in care shared the common problem of serious family challenges. This was the case with Sicelo, who was introduced in chapter one. Sicelo was referred to me by the health care providers in one of the clinics because of a history of poor adherence and abandonment of treatment altogether and the health workers stated that they had run out of options on how to address his issue. Sicelo had been re-initiated on ART and TB medication three times before I met him, and on all occasions he allegedly abandoned both treatments. On the day I met him he was brought to the clinic because his TB had relapsed and he was generally very weak, wasted, and had sores all over his head and legs. The doctor at the clinic ordered him to be re-initiated on second-line HIV treatment and admitted to the TB hospital because he already had multi-drug-resistant TB (MDR-TB). Because second-line ARVs and MDR-TB treatment involves more pills (quantity), takes longer for MDR-TB (up to twelve months), and has more side effects than initial or first-line medicines, the health care providers were concerned about adherence given

Sicelo’s previous history. According to the doctor at the clinic, had Sicelo been adherent to both treatments in the initial phase, he would not have developed the MDR-TB nor prescribed second-line ARVs.

I held initial interviews with Sicelo’s grandmother and aunt separately at the clinic. On this first day I did not interview Sicelo because he was just too sickly. I also held follow up and repeat interviews with his grandmother, his father, and Sicelo later on. The prominent finding was the disagreements between Sicelo’s maternal and paternal families on where Sicelo should be staying. According to the maternal family, Sicelo belonged to them because the paternal family had not observed the necessary customary practice of paying either *inhlawulo* or *lobola* (see chapter four on this custom). So Sicelo found himself at the centre of the families’ squabble over him. Another problem was that Sicelo’s biological parents had him while they were young and then separated. His father was married to another woman and they lived in town where the father was in gainful employment. According to Sicelo, his stepmother doesn’t like him, shoe stays with his grandmother in the rural area, but he doesn’t want to stay there. According to him, Sicelo had on several occasions discussed with his father that he would like to go and stay with him so that he could access better schools in town, but nothing has come of the discussions. This was corroborated by conversations with his grandmother and father. His mother lived between Johannesburg and Swaziland because she was an informal trader in handicrafts, which she buys in Swaziland and sells in Johannesburg. Sicelo used to visit his maternal family during school holidays but this stopped when, during one such visit, his mother refused to let him go back to his paternal family, who then forcefully came to take Sicelo away. These disagreements and fights have weighed negatively on Sicelo’s will to adhere, and he abandoned his treatments in protest.

Sicelo’s and Lindani’s narratives not only highlight the importance of family support for optimal adherence but also how customary demands can directly affect the lives and lived experiences of adolescents – whether infected with HIV or not. It puts on the table the need for service providers to go beyond the biomedically defined boundaries of disease and treatment adherence to understand and address the complex structural issues that affect adolescents and their families. A better understanding of sociocultural challenges and open engagement and communication could have improved Sicelo’s adherence and avoided his developing MDR-TB and having to resort to the second-line ART regimen.

In addition to family challenges, this study suggests that individual, medication, and health-system factors also interfered with adolescents' adherence to ARVs. At the individual level, and although the adolescents were committed to adhere to their ARV medications, there were times where they skipped doses because they were in a situation where taking them would have exposed their 'secret'. This was common when they were in a group of friends such as on a school trip or when visiting other relatives who were not aware of their status. However, skipping a dose, for whatever reason, caused a lot of fear as adolescents were not sure about the effect it will have on their bodies or on the virus itself. This fear of the unknown motivated them to adhere to treatment, but it robbed them of their time to interact and bond with their friends and peers or other relatives. Sipho shared his fears after he deliberately missed his dose of ARVs while on a school trip:

> I was fearful. . . . The first thing that crossed my mind [after forgetting a dose] was 'what will happen to my body now that I missed my medication?' But then I was fortunate because I hardly noticed any complications. After that incident I tried by all means to never miss taking my medication so that I do not make skipping my drugs a routine. (interview, December, 2013)

According to some of the participants, health-system challenges were the main reason for poor adherence. Frequent stock-outs resulted in adolescents living with HIV being dispensed rationed ARVs, which then required them to come back for more pills within a short span of time, something that had negative financial consequences. For example, participants reported that sometimes they are given a weekly supply of ARVs instead of the monthly or three-month supply. In such a situation, adolescents living with HIV are expected to come back the following week for more until there is enough stock to allow health workers to dispense a month's or three months' supply. Sizwe said:

> 'Sometimes when I come for the pills they give me few. . . . The nurse says they have few and they need to make sure that everybody gets them. So I have to travel back again, like two times in one month (interview, November 2014).

The rationing of ARVs as a result of low stock was confirmed by health care workers and the national coordinator for paediatric ART. One health care worker told me, in an interview, 'Although we try our best to have enough ARVs for everyone, we do run out of stock sometimes. When this happens, we give a few and ask adolescents to come back for more' (interview, December 2013). The national coordinator acknowledged occasional stockouts but said the reasons were beyond their control:

> 'The Ministry try by all means to have enough stock of ARVs at all times. Whenever we have shortages, which are rare, the challenges are usually beyond our control, but lie with the supplier' (interview, March, 2013).

Medication-related challenges to adherence included the number of pills an adolescent had to take and the doses, as well as side effects of the medications. Lindani said: 'I used to [adhere], but lately I am facing a challenge with the ARVs' smell because I tend to have nausea and vomiting, which then makes it difficult for me to take them. . . . I often take them with soft porridge so that I cannot sense the smell (interview, August, 2013). Medication fatigue was also cited reason for poor adherence among adolescents who had been on treatment for longer, that is, those who started ART at childhood.

Normalising HIV and AIDS through optimal adherence to ART

Often when providing counselling to adolescents on being HIV positive, being on ART, and the need for adherence, health care providers spoke of HIV as a normal disease that should be treated no different from other chronic conditions. The extent to which the normalisation of HIV and AIDS influenced adolescents' experiences of the disease is however unclear. Despite the challenges with testing, ART, and adherence, most of the adolescents living with HIV stated that they were committed to take their treatment because it made them appear and feel 'normal'. This 'normalcy', however, had different meanings. One the one hand, being normal was described as being without the obvious signs and symptoms of AIDS, which then made it possible to hide the fact that they were HIV positive. On the other hand, being normal was described by adolescents as being able to pursue life goals. The feeling of normalcy was intermittent: at times adolescents 'forgot' they were HIV positive and at times they were 'reminded' they will never be HIV negative and therefore never be 'normal' – they will always be different from the other adolescents who are HIV negative. Their worry about the future is best captured by Lungile, a fourteen-year-old whose mother died of AIDS-related illness when she was only six months old. Lungile lived in a stable, blended, nuclear family environment with her father who is also HIV positive and on ART, her stepmother who is very supportive ('she treats me like I was her biological child'), and three half siblings who are all HIV negative. Lungile doesn't know when she started ART, but does not remember any time she was never on ART. Her grandmother stated that she started ART when she was less than a year old, which means she has grown up on ART. She also had strong support from her maternal grandmother who frequently visits the family to check on her. However even with such familial support Lungile was worried about the future:

> One moment I am happy and laughing with my friends; the next I am worried about how long this will last, if I will still be there tomorrow or I will die like my mother. . . . I constantly pray for the day the scientists find treatment for HIV. . . . I am so tired of taking pills everyday . . . but I have no choice, it is the only way I can live... This is what is normal for us young people who have HIV. (interview, October,2012)

Adolescents, while appreciating the physical effects of ARVs, felt that HIV imposed limitations on who they can be as adolescents: they had sexual needs and future reproductive desires but were worried about whether they will be accepted by their partners, and whether they will grow to be adults and have a wife or husband and children who are HIV negative. They also worried about whether they will finish school, get good grades, go through university, get a decent job, and be able to take care of their families. To them these are the things that define being 'normal'. Yet on the other hand ART gave them a hope that they will live longer, which motivated them to pursue careers that would make them independent. A majority of the adolescents spoke of pursuing careers in which they would help other young people with a similar condition, such as becoming a doctor, nurse, or social worker. Others spoke of being engineers, police, and accountants; they did not see their HIV status as a limitation or barrier to achieving these future aspirations. Much as HIV is characterised by lingering uncertainties about prognosis, the disease course, and the future, these adolescents hung on to their hopes, dreams, and aspirations about the future. ART was perceived as a greater part of achieving their futures because it made the disease course and the future seem more in their control.

The meanings of normalcy as presented in the adolescents' narratives are also noted in the anthropological literature on HIV and ART (Mattes, 2014b; Moyer and Hardon, 2014; Philbin, 2014; Russell and Seeley, 2010). Mattes for instance states that 'normalcy takes different meanings depending on who is utilising it and to what purpose', and argues that 'the pursuit of continuity and normalcy is non-linear, fragile process, susceptible to diverse forms of interference' (2014:271). For the adolescents in this study such interference may arise from their immediate micro-environment, such as from friends or peers, or the macro level, such as the policies that govern the provision of HIV services. Biomedical discourses have stressed that normalisation of HIV and AIDS can occur through strict adherence to medication and services, and will result in reduction of stigma, improvement of survival chances, and in the quality of life, all of which will make HIV a normal disease like any other. These arguments however, are idealistic interpretations of the realities of the lives of adolescents living with HIV. While ART has enabled adolescents to appear physically healthy, they did not equate this with being normal as long as HIV remains an incurable disease.

Conclusion

When free ART was made available to the global south around 2003, there was great hope that the numbers of those testing for HIV would increase substantially, particularly in the high prevalence countries in sub-Saharan Africa. As the availability of ARV medicines became increasingly accessible to all peoples of the world, there has been a concerted public health effort to increase the number of people who test for and know their HIV status, and enrol those who test positive into long-term care and treatment to improve their survival, longevity, and quality of life (Obermeyer and Osborne, 2007). Such efforts have indeed led to an increase in the number of people on ART. However for adolescents, access to and utilisation of HIV services falls far short when compared to that of adults or children; few adolescents have tested for HIV, fewer have been enrolled in HIV care, and even fewer are retained in care. Adherence remains a challenge as well (see Vreeman et al., 2013; 2010).
This study indicates that several individual, health-system, and policy-level factors contribute to influence adolescents' access and utilisation of services. These include multidimensional fear, including fear of an HIV positive diagnosis and its psychosocial consequences, fear of imminent death, fear of parental reaction, fear of lifelong treatment, and fear of an HIV-positive identity. Others include low risk perception among adolescents, structural organisation of health services, as well as national legal and policy requirements particularly relating to parental consent.

Corrective measures have increasingly tended to focus on biomedical and behavioural factors at the individual and health-system levels, even though some of the barriers occur at other levels. Programmes have, for instance, tried to provide 'youth-friendly services' to increase the number of adolescents who test for HIV and know their status, and to link those testing positive to HIV treatment (see Tylee et al., 2007). However, what constitutes ‘youth friendly’ is defined by adult health professionals at the programme level without the involvement of young people or adolescents. This has led to a failure to attract adolescents to test for HIV, enrol in ART, and remain in care.

Adolescents’ utilisation of testing and ART, and adherence to and retention in HIV care was accompanied by a range of emotions that were mediated by age, knowledge about and understanding of HIV, as well as the availability of support from family. In the case of the adolescents in this study, being informed that they were HIV positive, and knowing what it meant to live with HIV as learned from their social environment, evoked strong emotional reactions. Being shocked, sad, and fearful, or happy and relieved, was based on their understanding of their HIV positive status, their experiences of illness, and the exceptionalism of HIV and AIDS as a disease. Programmes and health care providers need to recognise these emotional dynamics and develop strategic interventions to support adolescents in their life journey lived with HIV.

As shown by the stories of adolescents like Sicelo and Lindani, and others, how adolescents make meaning about and experience HIV diagnosis, ART, and adherence is influenced by factors within and beyond the biomedical understandings and explanatory models of the disease. This shows that a crucial need for a holistic approach in health care interventions. Also critically important is the need for involving adolescents in their own care and treatment plans, taking into perspectives their future projects. Finally, paying attention to social and familial relations should be an important strategic pathway towards creating more supportive environments for improving testing, linkage to care and treatment, and adherence to ART among adolescents.

CHAPTER SIX

NAVIGATING STIGMA

> The biggest disease today is not leprosy or tuberculosis, but rather the feeling of being unwanted, uncared for and deserted by everybody. (Mother Teresa, 1971 cited in Brand, 2005:61)
>
> Care for us and accept us. We are all human beings. We are normal. We have hands, we have feet, we can walk, we can talk, we have needs just like everyone else. Don't be afraid of us, we are all the same. (Nkosi Johnson, 2000, cited in Squire, 2007:22)

Introduction

Spoken decades apart and in different contexts, the words of Mother Teresa and Nkosi Johnson are relevant to the situation of HIV-related stigma today. Some of the adolescents I worked with identify with Mother Teresa's and Nkosi Johnson's words, because although HIV-related stigma is found almost everywhere in the world, it plays out differently depending on location, access to treatment, and historical moment. The case of Swaziland offers something new to our understanding because stigma has hardly been tackled despite the growing availability of and access to treatment.

In this chapter, I present the lived experiences of stigma as shared by adolescents in Swaziland. I define stigma as a pervasive, complex, and dynamic social process that thrives on the negative social and moralistic representations of HIV and AIDS. Stigma is characterised by prejudice, blaming, discounting, discrediting, and excluding people perceived to be infected with or affected by HIV (Herek, 2002; Scambler, 2009), resulting in their limited access to available services and in poor health outcomes. Using their narratives, I discuss how adolescents (and their families) experience and manage stigma in different settings and familial contexts in Swaziland. This thick description shows how being an adolescent, living with HIV, coming from a poor social background, being born out of wedlock, and being orphaned adds multiple and intersecting layers to the stigma experienced by the adolescents. In addition I describe the different tactics adolescents used to manage stigma in their everyday lives. I approached adolescents not as victims of HIV stigma, but as actors who find strategies and tactics individually and collectively to navigate the social environment and to live ‘normal lives’. This approach does not deny or down-play the enormous stigma these young people face and the discriminatory acts they endure, but it shows that despite adversity, adolescents are resilient and often able to overcome many of these experiences.

The chapter is divided into four sections: first, I briefly describe stigma. I discuss how, since Erving Goffman’s (1963) seminal work on stigma, the concept has evolved and expanded in its theoretical application particularly in the field of public health. In the second section, I focus on HIV- and AIDS-related stigma in general, and in Swaziland in particular. I present the magnitude of stigma in the country and discuss interventions put in place to reduce HIV stigma. Despite having the highest prevalence and incidence of HIV in the world, it was only in 2009 that the country included stigma reduction in its HIV strategic plans, and only in 2012 was the first stigma reduction strategy put in place. Even then the proposed interventions focused on changing individual attitudes and behaviours rather than the broader sociostructural issues that have perpetuated HIV stigma and, especially, the stigmatisation of adolescents seeking HIV-related services.

The third section presents adolescent narratives that depict the multiple layers of stigma that were experienced by the participants, and the strategies and tactics they used to manage this stigma. I show how information management about HIV status, optimal adherence to ART to ‘appear normal’, and the embracing of positive status as a springboard to ‘be a better person in the future’ are different strategies used by adolescents (and their families). In addition, I show that while silence and secrecy are ways of managing information, these tactics are also embodied by adolescents as a form of respect to and avoidance of bringing shame to the family. I conclude with a summary of the chapter in the fourth section.

Conceptualising stigma

The scholarship on stigma, and particularly HIV and AIDS stigma, is voluminous. Synthesising this vast body of literature is beyond the scope of this thesis. Rather, I present how, drawing from this body of literature, I conceptualised and defined sigma for this study.

According to Goffman (1963), every society has a system, often implicit, of categorising people, and this system carries with it culturally acceptable norms. People can be categorised by age, sex, race, religion, social status, occupation, etc., and members of each society are expected to behave according to the norms of the category in which they are placed. An individual or group that does not conform to the expected/accepted norms are labelled as deviant, resulting in that person being devalued, discredited, or rejected. This is what Goffman referred to as stigma: 'a special kind of relationship between an attribute and stereotype' (1990:14), i.e. between what is a normative expectation and an undesired differentness from what we [society] had anticipated (1990:15). According to Goffman, there is thus a need to use the 'language of social relations [rather] than language of individual attributions' (1990:14) in our understanding of and interventions directed at reducing stigma. Stigma is a socio-culturally constructed phenomenon, and what is considered normal and acceptable will vary from culture to culture, and within cultures in different contexts. Therefore, interventions need to take into consideration and be responsive to the sociocultural environment where they are implemented (Parker and Aggleton, 2003).

Building on Goffman's work on stigma, the concept has been used in studies and in the process has been refined and expanded, resulting in shifts in definition and characterisation (Kleinman and Hall-Clifford, 2009). Several theoretical frameworks have been developed within the social sciences and the field of public health (see Alonzo and Reynolds, 1995; Scambler, 2009; Scambler and Hopkins, 1986; Reis and Meinardi, 2002). In the process several constructs have been developed, including external and internal stigma, instrumental and symbolic stigma, felt/perceived/internalised and enacted stigma, and vicarious and courtesy stigma. Although these terms are used to expand the definition of stigma, the underlying factor is that they all refer to the differential, often negative attitudes and/or treatment directed towards people or groups. In some cases the stigma is not only directed to the individual with the trait or attribute but also to their immediate contacts, which Goffman (1963) termed 'courtesy stigma'. In my analysis, I used some of the constructs particularly enacted stigma (the discriminatory actions directed at individuals living with HIV), and perceived stigma (the fear of being discriminated against because of being HIV positive).

While there is no consensus with regards to the conceptualisation of stigma or how to measure it, two broad theoretical approaches take primacy in the stigma literature, particularly as it relates to HIV. First, there is the approach driven by social psychologists that focuses on individual traits or attributes. Within this understanding, stigma is explained as caused by ignorance about HIV, which leads to uncertainty and avoidance of contagion by isolating or avoiding those infected with the virus and their associates. This understanding of stigma has dominated interventions globally and in most sub-Saharan African countries, including Swaziland (Iliffe, 2006). Programmes have therefore focused on educating people about HIV, and base stigma education on a human rights discourse. The thinking is that as more people better understand HIV and embrace the concept of human rights, the stigmatisation of PLHIV will subside (see Castro and Farmer, 2005; WHO, 2003). The shortfall of this approach is its failure to acknowledge that humans are social individuals whose behaviour is shaped by their social circumstances and larger structural environment in which they live. Second, there is the approach driven by structural theorists who posit that stigma is a social construct that derives its existence and pervasiveness from macro-social structures that thrive on power and social inequalities (see Castro and Farmer, 2005; Farmer, 1997; Kleinman, 1988; Parker and Aggleton, 2003; Scambler, 2009; Yang et al., 2006). Building on Brown's (1995) theoretical model of the social construction of diagnosis and illness, in which he illustrates the influence of social beliefs and power relations on the meanings and experiences of an illness, Parker and Aggleton (2003, cited in Surkan et al. 2010: 803) note that 'stigma is part of a complex social struggle used to create and perpetuate social inequalities, such that it is through understanding and acting on these social processes that the problem can be addressed'. Hence, structural theorists argue for an approach that will be sensitive to the broader, complex, dynamic, and multi layered structural and moral contexts that underlie HIV and AIDS-related stigma (Parker and Aggleton, 2003).Whereas such an argument is valid especially when applied in the area of HIV management, it overlooks the fact that people are not docile recipients of societal norms who lack the ability to make their own decision and choices about their lives, but rather are able to take action within their specific social contexts to avoid or confront stigma. Those in their social network including caregivers, friends, and relatives can exert agency and choose not to stigmatise people living with HIV.

HIV-related stigma: The third epidemic

HIV-related stigma is as old as the epidemic itself, and has been described as the 'third epidemic . . . that is extremely problematic to address yet critical in preventing HIV' (Mann 1987, quoted in Misir, 2015: 330). Because of the effect that stigma has on the spread of the epidemic – that is, limiting the use of testing and treatment services, adherence to treatment, and disclosure of HIV status – stigma-reduction interventions have long been part of global HIV management plans. Yet, even with better and almost universal access to free ART in both developed and developing countries, HIV-related stigma remains pervasive. The question is why that would be the case. According to several scholars, the complexity of

HIV-related stigma, its diversity in different sociocultural contexts, and the simplicity of existing conceptual frameworks that focus on individual behaviours all limit the impact of interventions (Duffy, 2005; Kendall & Hill, 2010; Kleinman, Das, and Locke, 1997; Kleinman and Hall-Clifford, 2009; Manderson and Smith-Morris, 2010; Parker and Aggleton, 2003; Mills et al., 2010). According to Brandt, 'AIDS makes explicit . . . the complex interaction of social, cultural and biological factors' (1986:199), and therefore 'understanding the unique social and cultural processes that create [and sustain] stigma in the lived worlds of the stigmatised should be the first focus of our efforts to combat stigma' (Kleinman and Hall-Clifford, 2009:418). In essence, there is need for more nuanced models that focus on the micro-, meso- and macro-level structural issues that perpetuate stigma, recognising that stigma is not just a static individual attribute but is 'intimately linked to the reproduction of social difference' (Parker and Aggleton, 2003:13).

HIV-related stigma and adolescence

Besides having to deal with the loss of parents, friends, and other significant people in their lives, young people living with HIV have to deal with stigma directed at them at a time in their lives when they are developing their self-identity, self-esteem, autonomy, and sexuality amongst other psychosocial developments (Abadia-Barrero and Castro, 2006; Bekker, 2015; Hosek, Harper, and Robinson, 2002). Adolescence itself is a predisposition to stigma because it is the least understood human developmental stage that is often characterised by tensions between adolescents and adults (Choudhury, 2006; Higby, 2012). Adults may expect adolescents to still act and behave as children, while adolescents seek independence and intimacy. In the quest for intimate relations with peers, adolescents tend to spend more time with their friends than with their parents or other adult relatives. This may result in them being impatient and less attentive to adult directives, which in turn may be perceived as disrespect by adults (Arnett, 2000). Added to this tension is the adolescent desire to experiment, which in some cases may involve engagement in sexual activities, drugs, and other socially unacceptable behaviours, which may then be labelled as rebellious and defiant (Arnett, 2000, 2007; Choudhury, 2006; Higby, 2012). All these tensions may result in adolescents being stigmatised by the adults in their lives who expect them to behave respectfully and obediently. Those living with HIV, a condition that is associated with sexual deviance, are likely to experience layered stigma (cf. Fielden, Chapman, and Cadell, 2011; Herdt, 2001), that is, the stigma associated with adolescence and that of being HIV positive.

Simultaneously, stigma may also be associated with gender, or with the socio economic background of the adolescent, such as being poor or orphaned. In a study that examined prevalence of child-to-child discrimination among grade six pupils (12–14 years old) across nine countries in southern Africa including Swaziland, Maughan-Brown and Spaull (2014) found that HIV-related discrimination followed the fault-lines of socio-economic and gendered inequality. The study reported that adolescents who were perceived to be from poor families and rural areas were more likely to experience discrimination than their rich, urban counterparts. In terms of gender, the study found that boys were more likely to report having been discriminated against than girls. This finding does not only put to question the gender/power theory which has almost always favoured boys over girls – but importantly highlights the vulnerability that comes with masculinities, which, if not explored further or paid attention to, may make researchers, policy makers, and programmers miss the vulnerability of boys and men. In a study in Zimbabwe for instance, Skovdal et al. (2011a, 2011b) point out how the desire to maintain the status of being a strong 'real man' powerfully inhibits the uptake of HIV services by men and their families. In his study of men living with HIV and on ART in Bushbuckridge, South Africa, Mfecane (2010) points out how men use ART to maintain normal health, and thus regain their powerful status as 'real men' by exerting control over HIV. These few studies make clear that we need a greater understanding of how masculinities and femininities may be driving or inhibiting health-seeking behaviour, and that stigma affects boys and girls differently. This suggests a need to take into account the differences when developing strategies to address stigma.

HIV-related stigma in Swaziland

Stigma has received a lot of attention among scholars from various disciplines including public health and the social sciences. The topic has been well studied through qualitative, quantitative, and mixed methods. Yet since very little stigma-related research has been carried out in Swaziland and none among adolescents, there is paucity of literature that captures the local moral and culture-specific context of HIV-related stigma. This is despite the fact that stigma has been a contentious issue among various groups in the country, such as people living with HIV and advocates for human rights. For example, in 2009, a member of parliament (MP) in Swaziland suggested that HIV testing should be mandatory, and all those who tested positive must be branded with a permanent logo on their buttocks, so as to reduce the sexual transmission of HIV. The MP insinuated that before having sex with anyone, people will check their sexual partner’s buttocks, and then make an informed decision whether to continue having sexual intercourse (Maclean, 2009). There was both public condemnation of and support for the motion, both within and outside parliament. PLHIV, human rights groups, and various members of society condemned the motion, arguing that parliament should be protecting the rights of citizens of the country including PLHIV, rather than perpetuating stigma against them. Those in support of the motion argued that the secrecy and exceptionalism around HIV are why the epidemic has spread so rapidly, despite huge resource investments to curb it (Maclean, 2009). Worth noting is that the MP’s statement came at a time when the country produced its first strategic document designed to address stigma. It was also a year when, at the global level, there was a shift from generalised interventions to targeted populations identified as at risk for transmission. Furthermore, that year results from trials of new approaches to addressing HIV were rolled out, such as ‘treatment as prevention’, that is, using antiretroviral drugs to prevent transmission of HIV through ensuring that PLHIV are put on treatment as soon as they are diagnosed adhere to, and remain in treatment to ensure low to undetectable viral load (Cohen, et al., 2011) The MP may have been suggesting what he thought may have been an innovative idea to help curb the high incidence and prevalence; we will never know because he was silenced.

The handful of studies that have been carried out in the country have reported that stigma levels are high, with most reporting higher levels of perceived (de Vries, 2011; Dlamini, 2007; Kanduza, 2003; Makaoe, 2007; Root, 2010; Shamos, Hartwig, and Zindela, 2009; SWANNEPHA and GNP+, 2011; Zamberia, 2011) and internalised stigma (Kalichman, et al., 2008) than enacted stigma. It has been claimed that stigma, particularly perceived stigma, is also associated with the type of service delivery model or organisation of HIV services. It has been suggested that the separation of HIV sites from mainstream health facilities to stand-alone HIV services increases perceived stigma (IPPF, 2004), while other researchers have reported evidence to the contrary (Colombini et al., 2014). Testing the theory of the organisation of services vis-a-vis perceived stigma in Swaziland, Church et al. (2013) compared the prevalence and levels of perceived stigma across four models of service delivery referring to the level of (non) integration of HIV services to mainstream health care service; namely standalone, partially standalone, partially integrated, and fully integrated. Contrary to the hypothesis that stand-alone models may be more stigmatising than integrated ones, the researchers found that there was less perceived stigma in stand-alone sites compared to the other models, because of high confidentiality and the belief that people seeking care were all HIV infected or affected. The study found high levels of stigma in the partial stand-alone and partial integrated models (Church et al., 2013:7–8).

Reporting on HIV and AIDS-related enacted stigma Root (2010), SWANNEPHA and GNP+ (2011), and Zamberia (2011) found that gossip, rejection, name-calling, social exclusion, and verbal and physical assault were key manifestations of stigmatisation by family members, friends, partners, and community and health care providers. Surprisingly, the study by SWANNEPHA and GNP+ (2011) also found that discrimination against PLHIV was not only by people who were HIV negative or were not aware of their own status, but PLHIVs also discriminated against each other. While this study sheds some light into the levels and types of stigma in Swaziland, its limitation is that the study was wholly quantitative in nature, and thus the experiential voices of the participants are absent.

A study among men who have sex with men (MSM) in Swaziland found that both perceived and enacted stigma were high (Kennedy et al., 2013). In their study, comprised of forty in-depth interviews with twenty MSM and three focus group discussions with twenty-six MSM and sixteen key informants, the researchers found that these individuals face significant and multiple layers of stigma owing to their sexual identity and HIV status, which the authors referred to as ‘dual stigma’. Enacted stigma was not only perpetuated by members of the public but also by families and health care providers.

The studies summarised above underscore findings from previous consultations made in the country between 2005 and 2006 in preparation for the expansion of ART as part of the country’s commitment to universal access. During the consultations, stakeholders singled out stigmatisation of PLHIV as the major barrier to universal access and utilisation of HIV services. In addition the Demographic and Health Survey (CSO & Macro International, 2008) reported that high levels of stigma associated with HIV and AIDS were the reason for low proportions of people who have tested for HIV. At the time only 16% of the population had ever tested and received their results. Furthermore, evaluations of the performance of the national HTC and ART programmes and national annual reports have repeatedly indicated that fear of stigma remains the single most important reason for low uptake of HIV testing, particularly by men and adolescents, as well as low adherence to ART and disclosure of HIV status. Given that stigma is significantly high in Swaziland, I explored how adolescents living with HIV experienced and managed stigma in their everyday lives.

Adolescents’ experiences and management of stigma

Adolescents’ narratives suggest a prevalence of both perceived stigma (internalised thoughts that people are discriminating against you because you are HIV positive) and enacted stigma (discriminatory acts).While some were confronted with multiple layers of stigma, including that of being poor, being orphaned, being born of unwed parents, and being HIV positive, others had to only deal with the fear of being discovered they were living with the virus.

The quantitative survey I carried out as part of this study found that a) stigma was more prevalent in the urban area than the rural setting, b) there were more reports of perceived stigma than of enacted stigma in both settings, and c) there were differences in perceived stigma between male and female adolescents regardless of residential settings, with more male adolescents reporting perceived stigma than female adolescents. Adolescents who were from poor social backgrounds and orphaned reported more enacted stigma than perceived stigma, which may point to the important role of family support or socially supportive environment in the stigma reduction. There were no observed differences in terms of in-school and out-of-school adolescents. Below I share some of the narratives of adolescents gathered from interviews and focus groups to illustrate the multi-layered stigma experienced by adolescents living with HIV in Swaziland. Their stories are not necessarily different from those of the other adolescents I worked with, but each case exemplifies not only the extent and depth of stigma experienced by adolescents, but also the strategic decisions they made and tactics they used to manage the challenges they encountered in their lives, or what Schneider and Conrad (1983) refer to as ‘adjusted’ adaptation.[xx]

Manqoba’s story

Manqoba, whom I met in 2013 in one of the urban clinics, had been living with HIV all his life. In addition to two brothers who were HV negative, at the time Manqoba was living with his mother and younger brother who were also living with HIV and on ART. In addition to them, Manqoba’s mother disclosed his HIV status to his auntie (father’s sister) who often assisted them with food or looked after Manqoba and his siblings in the absence of his mother who often spent time in Johannesburg where she sold handicrafts. According to Manqoba his mother strongly warned him against telling other people his HIV status, not even his best friends at school or in the community. This is because his mother was concerned that if any one learned that he was HIV positive, the news would spread throughout the community because ‘people gossip a lot. Out of respect for his mother, Manqoba has never shared his

HIV status with anyone, not even his teachers at school or his friends. In addition to keeping his status concealed because of his mother's instruction, Manqoba also decided it was the best thing to do. Hence, to ensure that he was permitted time during school days to get his monthly treatment, Manqoba informed his teacher that he had TB because, as he stated, 'people do not gossip about it (TB)'. He shared that although he personally had not experienced any acts of discrimination, he had seen other children in his community and school being laughed at, called names, and gossiped about after their HIV status became known. He stated that some parents in the community had instructed their children not to play with certain children because they were HIV positive. So out of fear of being gossiped about, laughed at or losing his friends, he decided to keep his status a secret.

Manqoba's fears were not unfounded, as Sonto, whom I met in one of the support group meetings, shared how she was stigmatised by her peers at school. This is what she said:

> There was this girl who was my neighbour. Whenever we had a fight she would go and gossip about it [my HIV status] at school. She would tell students I hang around with at school to avoid me because I would transmit my HIV to them. . . . It really felt bad and I even cried because they were making fun of me at school. To make matters worse she shared my most confidential side of life with total strangers who will always label and stigmatise me. (Informal conversation, February, 2013)

Like Manqoba, almost all the adolescents who participated in individual in-depth interviews, informal conversations, and focus group discussions shared that they were instructed by their parents or guardians to keep their HIV status a secret to avoid being gossiped about, laughed at, ridiculed, or bullied. As stated in chapters one and four, obedience is one of the virtues emphasised to children during their socialisation. A child is considered obedient when following instructions from elders without questioning. Silence in the context of obedience is understood as a sign of respect (Booth, 1983; Booth, 2004).

It is not surprising, therefore, that the adolescents adhered to the instruction of their parents or guardians. But also, and more importantly, silence and secrecy between parents/guardians and adolescents may be seen as a form of not shaming parents (such as in the case of perinatal transmission) and the family (Hardon et al., 2012; Illife, 2006). According to one of the key informants, parents sometimes instruct their children to keep their status a secret in order to protect the parents' own HIV status. One ART coordinator explained:

> Parents feel like their sexual life is being exposed. . . . It is also exposing the sexual behaviours of the partner because it means one of them [parents] had unsafe sex and got HIV from somewhere, especially in families where other children don't have HIV. . . . So parents feel the guilt and the sexual exposure. In Swazi they usually say '*kuyabangcunula*'[exposes them] with all the secrets they have been hiding'. (interview, April 2013)

Nomaswazi, an 18-year-old adolescent, became aware that she was HIV positive in December 2011. Her story is illustrative of the silence and secrecy related to protecting family honour. When Nomaswazi found that she was HIV positive, she did not inform anyone about her status except her mother. She feared that her family members were going to ask how she got infected. When I met her in September 2012 she had been on ART for just three months. She believes she was infected through sexual intercourse because both her parents were HIV negative. In fact none of her family members was HIV positive. Nomaswazi's family was one of the homesteads held in high esteem in the local community: her father was a respected man in the community because of his position in various entities. Nomaswazi was the last born of eight children including six boys and two girls.

Nomaswazi conceded that besides her boyfriend in South Africa, she had sexual relations with two other men from her area, and thinks one of them could have infected her with the virus. She tested after falling sick with a recurrent sexually transmitted infection that was not getting better after several episodes of treatment. After testing positive Nomaswazi changed schools; she relocated from the local school and went to live with her mother's brother who was a teacher in a high school that was located in another town about sixty kilometres from Nomaswazi's home. This she did out of fear that once people learned she was HIV positive, they would not only make fun of her but also her family. Relocating was meant to conceal her status, a tactic that was not only protective of her but also her family. Besides her mother, whom she described as her pillar of support, Nomaswazi had not disclosed her HIV status to other family members or her boyfriend because 'it is not yet the right time to tell them. I fear that if I tell them they will ask me how I got it and this will bring shame to my family'.

An HIV-positive diagnosis evokes feelings of guilt and shame especially when the transmission is a result of unprotected sexual intercourse. I must mention that pre-marital sex is common; it is not condoned in Swaziland, especially for girls. Doing so is viewed as shameful and disrespectful to parents and the family. So for adolescents who are not yet expected to be sexually active and for girls who are expected to remain virgins until marriage, being HIV positive is a disclosure of engagement in sexual intercourse. Remaining secretive may protect them not just from the stigma of the diagnosis but also from the stigma of engaging in sex. It also protects the family from the shame of having an adolescent who does not abide by the local norms of staying a virgin until marriage. This was even more expected from Nomaswazi as a daughter of a chief's councilman and health worker, whose jobs entail enforcement of such norms. Besides feelings of guilt and self-blame, her sexually acquired HIV had the potential to evoke feelings of anger, shame, and disappointment from her parents and other family members. Nomaswazi's concern about her family with regard to her sexually acquired HIV-positive status is best captured by Iliffe, who states that 'HIV was inherently dishonourable not only for the individual [infected with the virus] but the entire household . . . and silence was the rule . . . of personal and family honour' (2005:363). This may lead to self-imposed isolation from family and friends for fear of stigma, or coming to terms with the diagnosis, while in some instances families and friends may despise the adolescent. Though Nomaswazi did not report being excluded by her family, it is possible that this would have been the case because they were not aware she was living with HIV.

The experience was different for Mpendulo, Dudu, and Sabelo, each of whom respectively experienced social isolation, rejection, and psychological abuse from family members.

Mpendulo's story

Mpendulo is one of the adolescents who experienced discrimination from members of his family, particularly his sister-in-law. Mpendulo's parents were not married but cohabiting at the time of his birth and his father had neither paid inhlawulo nor did lobola, which culturally meant Mpendulo belonged to his maternal family. After losing both his parents at a very young age, he lived with different members of his mother's and father's families, eventually settling at his father's younger brother's homestead, after an 'eviction' from his father's house by his sister-in-law who did not want him there. Mpendulo told me that he moved out of the house after his elder brother and his wife (Mpendulo's sister-in-law raised concerns that he was going to infect their children with HIV. As a way to protect their children, the couple had confined Mpendulo to one of the rooms in the house with all his belongings, including his own cutlery, blankets, washing basin, and other things. He also had to use the backdoor to enter and leave the house; he was instructed not to use the same pit latrine toilet used by the family and not to touch anything in the house other than what was designated for him. In essence, he was excluded from participation in the house. This situation angered Mpendulo and made him feel sad and unwanted in his father's house. Hence, he decided to move out to live with his uncle. However, he stated that even at his uncle's household the situation was not welcoming. Since no one was working, the family often struggled to get food. Mpendulo increasingly found himself between a hard rock and a hard place as at times he went to sleep without food and his uncle would demand that everyone in the homestead contribute food. With the assistance of the Social Welfare Office, Mpendulo successfully claimed his share of his father's estate, including re-occupation of his father's house. When I contacted him towards the end of 2013, Mpendulo had joined a support group of children living with HIV where he got to 'learn more about the disease, the pills and other things. They also provide me with money that I use to buy food' (informal conversation, December, 2013). Mpendulo uses the money from his father's estate for his school and other needs, and hopes to be a doctor one day so that he can 'help children living with HIV'(informal conversation, December, 2013).

Mpendulo's story illustrates the multilayered and intersecting stigmas that some adolescents have to deal with. Besides the stigma of being HIV positive, adolescents like Mpendulo also carried the stigma of being born out of wedlock, of being poor (Campbell et al., 2007; Campbell etal., 2012; Mburu et al., 2013), and of being an orphan. Having to move between family members, going to bed hungry because he could not afford to contribute food at his uncle's place, and being socially excluded by his brother and sister-in-law because of his HIV status all constitute layers of stigma.

Swazi culture has always frowned upon women who fall pregnant before marriage, and children born under such circumstances were given derogatory labels of being illegitimate. Expanding on Link and Phelan's (2001) argument that stigma is an outcome of political power, Das (2001) state that the power is itself lodged in the apparatus of the state. This has been true for children born out of wedlock in Swaziland. Until recently when the Children's Protection and Welfare Act was enacted in 2012, children born out of wedlock were referred to as illegitimate, and could not benefit from the estate of deceased parent(s), particularly the father. Although section 17 of the 'new' Act states that 'a child has a right to a reasonable provision out of the estate, life insurance or pension fund of a deceased parent whether or not born in wedlock or orphaned' (2012: S19), this statement is still vague as it does not define what 'a reasonable provision' is under the circumstances. Thus, such children still find difficulties not only in accessing these benefits, owing to the long-held notion that they are illegitimate, but also as a result of the vagueness of the law. Worsening the situation is that ever since the Act became law, there have been no sessions carried out to sensitise communities about its contents, and therefore even where the law is evaded, it cannot be challenged because people remain ignorant. Mpendulo could have simply challenged his brother for evicting him from his father's house and refusing a share of 'a reasonable provision' from the estate, but because he was not aware of how to go about claiming his rightful share of the estate, was below eighteen and thus a non-consenting minor who could not sue, and was too poor to hire the services of a lawyer, he continued to suffer. And his suffering in the hands of his family is closely linked to his HIV-positive status, as was the experience with other adolescents such as Dudu.

Dudu's story

Dudu was 'disowned' by her biological father after testing positive for HIV in 2003, a year after the death of her mother presumably from AIDS-related illness. Like Mpendulo, she was born of unwed parents, and Dudu lived with her maternal grandmother because her father had not paid *inhlawulo* or *lobola* (described in chapter four) and because her father disowned her according to her grandmother. Dudu's biological father, a police officer employed by the government, was informed of Dudu's ill-health and the need for HIV testing to which he refused to consent. In view of her progressive ill-health and based on the principle of 'doing what is in the best interest of the child',[xxi] a doctor at the local hospital tested her for diagnostic purposes in the presence and with consent of the grandmother. She was found HIV positive, and was put on HIV treatment. Upon discharge from hospital, Dudu's grandmother informed her father of the outcome of the test and that Dudu had been put on HIV treatment. That was the last time his father had any contact with Dudu. In between sobs, Dudu shared that:

> He doesn't talk to me nor support me [financially and otherwise].It is like I do not exist... Even when we meet he turns the other way. If I greet him he doesn't respond. I think he doesn't like me because I am HIV positive. . . . It hurts a lot, but my grandmother told me not to bother myself. I pray every day that he finds it in his heart to accept me; but I also do not bother myself about him anymore'. (interview, September 2012)

In one of our several conversations, Dudu shared that she had challenges with her school because of her unpaid school fees, an amount less than a thousand Emalangeni (or €71.43)[xxii] per year, with the school threatening to suspend her. This was at a crucial time of her primary school education as she was due to sit for her external examination.[xxiii] She was concerned that failure to write the exam was going to ruin her prospects for a better life. Dudu believed that if she was not HIV positive, her father would have paid her school fees as he could easily afford it from his salary as a police officer. Even the government school fees support for orphaned and vulnerable children (OVC) could not come to her rescue because, as the school principal told me in an interview, ‘she has a father who is in gainful employment’.

Dudu’s HIV-positive status did not only rob hero her mother through death but also of her father through his refusal to associate with her. Her HIV positive status indirectly threatened her education and prospects for a brighter future: had Dudu been not HIV positive, her father would probably not have disowned her and would be paying for her school fees, like he did for his other children, and because her father was I gainful employment, Dudu could not benefit from the funds set aside by government to pay school fees for orphaned and vulnerable children. In his study of adolescents living with HIV and on ART in north-eastern Tanzania, Mattes (2014) states that some of the participants had been rejected by their fathers after the death of their mothers. One of two reasons for the rejection was the fathers’ fear of facing the possibility that they, too, could be HIV positive.

Like some of the adolescents in this study, Dudu was born out of wedlock; her paternal family had neither paid *inhlawulo* nor *lobola* for her mother. In short, although Dudu is identified by and uses her father’s surname, traditionally speaking, she belongs to her maternal family because her father’s family fulfilled the cultural practice of paying *inhlawulo*. This traditional practice is in conflict with the legal position of the Constitution (2005) and the Child Protection and Welfare Act (2012) that ensure Dudu’s right to have her father take parental responsibility such as paying for her school fees and the right to non-discrimination.

Mpendulo and Dudu’s narratives bring to light the conflict between the two systems of governance in Swaziland as they relate to children’s right to identity, as enshrined in article 8 of the United Nations’ Convention on the rights of the child. Swaziland ratified and s a signatory to the convention. Hence the National Constitution, (2005) also promotes the protection of children rights including the right to identity. Mpendulo and Dudu’s stories exemplify the complex lives of adolescents born of single parents, which may intersect with their HIV-positive status to produce multiple stigmas.

Sizwe's story

Sizwe was diagnosed with HIV in 2008 and started ART the same year. He told me that he lives with eleven people in his homestead. While his mother passed away in 2004, his father was alive at the time of the study, and was also living with the virus and on ART. He however lived in a different homestead from that of Sizwe who lived with his paternal grandmother and other family members. At the time of his diagnosis, Sizwe did not fully comprehend what it meant to be HIV positive and thus did not pay much attention to it until his friends at school started to avoid him. He also had to face gossip about him in the community. His grandmother, he stated, disclosed his HIV status to the people in the community, which led to the acts of discrimination he was facing. Visibly angry, his voice shaking and between sobs, Sizwe recounted:

> At first I did not pay much attention [to being HIV positive] but when my friends started to avoid playing with me, and to gossip and laugh at me, I became aware that something was very wrong with me. My grandmother went about telling people that I was HIV [positive], so people in the community told their children not to play with me. . . . This is what the children who used to be my friends told me. If my grandmother had not told people that I am HIV [positive], the people would not have laughed at and gossiped about me. . . .Yes, I am angry at my grandmother. . . . I hate my father for giving my mother and me HIV. . . . He killed my mother. . . . I will never forgive him for that. (Interview, September, 2013)

Sizwe's concern about being known as HIV-positive was further demonstrated by the fact that although he had no problems taking part in the study, he refused to let me visit him at home because he did not 'trust anyone anymore'. Instead he preferred that our interviews take place only at the clinic. Asked what he meant by 'not trusting anyone anymore', he stated that if I visited him at home people in the area would start asking questions about who I was and why I was visiting him, and even those who did not know he was HIV-positive would find out as 'people talk too much'. Respecting his concerns and choices, we had our follow-up meetings in a private room at the clinic or in my car, depending on his choice and comfort.

Sizwe's narrative illustrates the importance of managing disclosure as a way of managing stigma, and to avoid the psychological and emotional consequences of stigmatisation (Boyes and Cluver, 2013, 2015; Boyes, Mason, and Cluver, 2013). Whereas disclosure is necessary and important, indiscriminate disclosure, as seen in the case of Sizwe, is likely to lead to discrimination. I discuss disclosure in depth in the next chapter. But also vitally important in Sizwe's reaction to his HIV-positive diagnosis, is the anger and hatred he harbours towards his father. His refusal to speak to his father or have a relationship with him and to support each other through the illness may be delaying Sizwe's own healing process and his acceptance of his status.

His narrative also illustrates another tactic of managing stigma, which is relocation. By moving to a new school, and refusing to be visited by strangers like myself at home, Sizwe is able to avoid being suspected of being HIV positive. Often as part of HIV management in the country, NGOs use branded cars to conduct home visits especially in trying to locate people who have stopped treatment; if one is seen being visited by a stranger on more than one occasion people may start to question those visits and speculate that the person being visited may be HIV positive, and thus subjected to stigma.

Management of stigma

To define stigma management, I borrow from Fielden, Chapman and Caldell who conceptualise it as the 'shifting and manipulation of internal and external processes in order to address stigma in a given situation or setting' (2011:272). The four narratives above highlight the multiple stigmas that adolescents face in Swaziland, with the most prominent being perceived and enacted stigma. I found that the management of stigma is a complex process, taking place at all levels of the social structure including the individual, micro-, meso-, and macro levels. At the micro-level the key players were the adolescents and their families, at the meso-level they were the health care providers, and at the macro-level waste state.

What became clear from this research is that the processes used in the management of stigma at the different levels of social structure are often conflicted. For example, while macro-level policies and meso-level practices strongly encouraged disclosure, participants at the micro-level preferred to be secretive and silent about HIV status either in fear of or in response to experiences of stigma. Hence the strategies and tactics used to manage stigma differed. At macro-and meso-level the main focus was on educating the public about HIV and AIDS, ensuring universal access to and early initiation of ART, and emphasising optimal adherence, retention in HIV care, and disclosure. The belief that these strategies will lead to the normalisation of HIV and thus reduction of stigma was not supported by the findings of this study. On the contrary, at the micro level, practices to conceal HIV status limited disclosure; adolescents took their ARVs so that they physically appeared in normal health and relocated to avoid people learning their HIV status. These were some of the tactics of managing stigma and made it possible to navigate the social and health system environment. At the family level, silence and secrecy were used, while at meso level and state level the enactment of policies and legal instruments to protect people living with HIV were some of the ways through which stigma and discrimination were managed. I provide details on stigma management and tactical navigation below.

In this part I present how adolescents and their families dealt with stigma. Tactics used by adolescents and their parents or guardians included concealing their HIV-positive status, embracing their status, and helping other adolescents through support groups. Other tactics included managing stigma through resistance, and use of self-destructive behaviours such as suicide and drug abuse. In most cases, the tactics were used in combination, although depending on the social context at a given time, only one would be used.

Concealment of HIV status through silence

Concealment involved keeping the HIV-positive status a secret, lying about the HIV-positive diagnosis and ARV medication and, strategically disclosing HIV status only to selected members of the family, school, or church to solicit support, or because it was unavoidable. Manqoba's narrative shows how he, together with his mother, used secrecy and strategic disclosure to avoid stigma.

Silence about HIV-positive status can be understood as a form of respect and as avoidance. Manqoba's story also shows not only how lying is used to avoid stigma but also how stigma is a social construct related to meanings about particular illnesses; according to Manqoba, lying to the teacher that he had TB made it possible for him to get his HIV medication from the clinic without revealing his HIV-positive status. Because his mother sometimes needed his aunt's help in looking after Manqoba and his siblings, they selectively disclosed his status to her. Through silence, secrecy, lying, and selective disclosure, adolescents and their families are able to avoid stigmatisation and to live a 'normal' life like everyone else. Manqoba's story shows how from his perception, TB and HIV are at the opposite ends of stigma, with TB readily accepted and HIV kept a secret, yet both are infectious diseases. This may be indicative of the strong association of HIV with (risky) sexual behaviour, such that even adolescents who acquired HIV vertically still feel it necessary to keep their status a secret least they risk being discriminated against. Anderson notes that

> HIV has been represented as a condition which marks its “victims” as socially different, and people with AIDS have sometimes been represented as a source of moral and social contamination and danger’(1992a:22).

Some of the distress or discomfort faced by HIV-positive individuals may derive from the ways in which HIV and AIDS have been socially constructed. Similarly, in her study on stigma, discrimination, and illness among HIV-positive women in Tanga, Tanzania, Bohle concurs that people with a discreditable condition, such as HIV or AIDS, conceal their illness to avoid stigma (2013:28). To protect themselves from adverse moral judgements, adolescents’ intentional concealment becomes a way of navigating the social environment in the management of HIV disease (Deacon, Uys, and Mohlahlane, 2010).

Manqoba’s story is similar in many ways to those told by other adolescents. There are mixed and often conflicting views in the literature with regards to secrecy and silence relating to health and disease, and particularly transmissible diseases like HIV. According to Hardon and Posel (2012), secrecy and silence are viewed negatively, problematised, and viewed as an indication of disempowerment, and disclosure is encouraged as it is viewed as psychologically liberating. But secrecy and silence may also be necessary and often therapeutic in certain contexts (Hardon and Posel, 2012), and protective to family who may be embarrassed by one of their own being HIV positive, what Illife (2006) refers to as family honour. At the end of the day the choice remains with the person living with HIV and those close to him or her to make a decision on how they best can manage stigma.

In addition, and as already alluded to above, adolescents avoided situations that had the potential to unintentionally reveal their HIV status, in order to avoid stigma. One tactic that was cited by adolescents was skipping of doses of treatment if there were people around at the time they were supposed to take their ARVs. Sipho stated that he skipped his dose on a school trip one time, to avoid taking his ARVs while with friends, in fear that they would learn his status and stigmatise him. Knowing the consequences of below-optimal adherence, he decided never to take part in school trips again. In a study on adherence involving young adolescents aged twelve to fourteen in Uganda (Kawuma et al., 2014), the researchers found that children failed to adhere to their ARVs out of concerns about secrecy and deliberately avoided being seen taking their treatment. Similar findings were found among PLHIV in Northern Vietnam (Tam et al., 2011).

Avoiding stigma through ART adherence

Some of the adolescents in the study indicated that they adhered to ART so that they could stay healthy and appear ‘normal’, and thus avoid stigma. For instance, Simangele stated:

> I try to take good care of myself by eating healthy food and taking my pills according to the instructions of the doctor. I was told that if I do these things, I will live as normal like someone who has no HIV. . . . [I]f I stay healthy no one can tell I have HIV. (Interview, December, 2013)

One of the ways through which people can ‘know’ is suspicion, based on outward signs of an illness. HIV is a condition that has overt signs through which people can suspect and label one as HIV positive and based on that label, stigmatise them. Berg and Moss (2014) refer to this as stigmata, HIV look, or HIV-related appearance. For some people who are HIV positive, silence doesn’t necessarily keep their status a secret as the physical signs may ‘tell their un told story’ especially if they are not on ART or are not adherent (Moyer, 2012). Having tested for HIV when they were sick and improved after being started on ART, the adolescents trusted the efficacy of the medicines; they reasoned that because ARVs are able to ‘treat’ the outward and visible signs of HIV infection, adhering to ART can help them avoid stigma. Doing so would reduce the speculations people would have if they appeared physically ill. In one of our conversations for instance, Sabelo stated that when he was first put on cotrimoxazole[xxiv]after testing HIV positive, he did not take the pills because:

> I never thought it [adherence] was necessary. . . . I think I was just acting my age, which means I was not taking things serious and of course not really understanding the importance of taking cotrimoxazole. . . [M]y CD4 count dropped and I lost a lot of weight, and was started on ART. . . [B]y the time I was taking ARVs, and seeing the improvement in my health, I understood the need to adhere to my treatment, (interview, December, 2013)

The improvement in his physical health did not only motivate Sabelo to adhere to his medicines but also helped him to avoid stigma. Similar findings have been reported in other countries such as South Africa (Abrahams and Jewkes, 2012; Goudge et al., 2009) and Zimbabwe (Skovdal and Daniel, 2012).

Managing stigma by embracing HIV-positive status

Managing stigma also entailed managing feelings about being stigmatised. One of the ways in which adolescents managed self-stigma was through acceptance of their HIV-positive status. After learning of his status, Sipho's immediate reactions were shock, disbelief, and anger, which were followed by fear. However, with ongoing counselling and support from his family, Sipho stated that his HIV-positive status became a motivator to do well at school, and a springboard for focusing to his future dreams and life goals:

> After being told that I was HIV positive, the counsellor told me, 'Noma *une-HIV impilo iyachubeka. Akusho kutsi sengitakufa, ngisengaphila njengabo bonkhe bantfu, kuphela nje uma ngitinakekela*' [meaning despite being HIV positive, life goes on. It does not mean you will die soon, you can still live a normal, fulfilling life like everybody else if you take care of yourself]. I decided to concentrate on doing well at school. . . . I know that with good grades I can realise my lifelong dream of studying medicine so that I can help other children in a similar situation like me. (Interview, November, 2013)

Regardless of the stigma that adolescents experienced or anticipated, most of them shared how being HIV positive and being able to access ART has motivated them to work harder towards being a better people in the future with a good job and a family of their own. Mpendulo, Lindani, Sabelo, Simangele, and Dudu shared these sentiments, as did other adolescents in the study. Instead of being unhappy about being HIV positive and stigmatised, the adolescents appreciated their status as a reason to beat the odds and achieve their dreams of being doctors, teachers, nurses, or engineers, as well as starting and protecting their own families from HIV. Concentrating on their future and working towards achieving their goals helped them to focus less on the negative aspects of HIV including stigma. The role of hope in coping with chronic illness is well studied. Mburu et al. (2014) and Willis et al. (2014), for instance, report about how adolescents in Zimbabwe and Zambia, respectively, were hopeful about their futures despite HIV; maintaining hope helped them cope better with their illness. Gail-Becker et al. (2015) also emphasise the need to cultivate hope among adolescents living with HIV as a way of promoting positive futures for them.

Managing stigma through helping others

There is a tremendous amount of HIV-related information available to young people in Swaziland, which is provided to those infected or affected by it. This and their experiential knowledge proved especially useful for adolescents in schools where there were teen clubs (also known as support groups). Through these forums adolescents shared information about HIV and several issues of interest, in the process helping each other cope with HIV and the demands of adolescence. Adolescents stated that they felt a sense of personal satisfaction and a feeling of being in control through helping others. This allowed them to be positive about themselves rather than to focus on the stigma surrounding their HIV positive status. They also expressed appreciation towards teen clubs, which provided them a forum to share, learn from each other, and form strong social bonds; they expressed that they 'felt at home' and felt 'a sense of belonging as they felt not judged but accepted and appreciated'. They shared that being part of teen clubs gave them the strength to face the world without fear.

Managing stigma through resistance

One of the key issues in HIV treatment is the need to honour monthly appointments at the clinic, for health monitoring and refilling ARVs. For some of the adolescents who were attending school, this meant that they had to seek permission from teachers at least once every month to miss a class or be absent from school. In some cases this 'habitual absence' raised eyebrows and concerns among teachers. This was the case with Simangele. Each time she sought permission to be absent from school, her class teacher would want to know the reasons for missing class. While it is not unusual for school authorities to seek clarification for absences, Simangele did not like the fact that she had to undergo intense questioning from her teacher every time she sought permission. She viewed it as discriminatory hence she decided to tell her teacher her HIV status in order to silence her from questioning her ever again. Simangele recalled:

> One day I got so angry at having to explain myself every time – I just told her I was HIV [positive] and needed to get my ARVs. . . . I did not mean to tell her about my status but I was frustrated. I was like: if I tell her this once, she will never ask me again. (Interview, November, 2013)

Simangele 'disclosed' her status to her class teacher, not because she wanted her support but rather to silence her from enquiring about her requests for permission to visit the health facility. She reasoned that the teacher was not necessarily concerned about her health but was just 'being nosy; because she is friends with my stepmother, so I think she just did it to spite me. After telling her about my status she went on to tell other teachers'. Even though she disclosed her status in order to silence the teacher, the opposite happened as the teacher went on to disclose Simangele’s status to others, confirming that indeed she was ‘nosy’ instead of being empathetic and helpful.

Silencing to avoid stigma was also noted in family settings where there was very little or no open talk or discussion about HIV. Berg and Moss (2014) refer to this as ‘vociferous silence’. Adolescents such as Menzi and Lungile stated that besides being told to keep their status a secret, discussions about HIV were also rare or silenced in their homes. Menzi shared that when there was a television or radio programme about HIV, his sister and brother-in-law with whom he was living would switch the off the TV or radio. This they stated was done to protect Menzi from some of the discussions. Menzi explained:

> [T]o avoid hurting me, they preferred switching off the TV or radio when an HIV programme was playing. . . . Unfortunately she never even enquired of me how I felt about the discussions, but I understand her position. (Interview, October, 2012)

Lungile, who was staying with her stepmother and half-siblings who were all HIV negative, and her father who was HIV positive and on ART, also shared how the family avoided talking about HIV:

> The only time we ever talk about HIV is when my father or mother reminds me to take my ARVs. They fear that my sisters may learn that I am HIV [-positive] and then tell other children about it at school or here in the community. . . . But I also think that my father is not comfortable talking about his status. . . . So we do not talk about it. (interview, October,2012)

Both Menzi and Lungile wished their families were more open about HIV or would at least ask them if they were willing and comfortable to talk about HIV than to simply be silent. Similar findings were reported by Rydstrom etal. (2013) in their study involving ten young adults, aged 15–21, living with HIV in Sweden. The researchers found that discussion of HIV within family settings was rare. Protecting the person living with HIV or their siblings from stigma was the reason given for the silence on HIV at home. However, the adolescents felt that they were being stigmatised. Parents or guardians should discuss with adolescents how they feel about watching or listening to talk about HIV in the media, than taking decisions on their behalf.

Managing stigma through use of Self-destructive tactics

For some adolescents, the fear of stigma following an HIV diagnosis drove them to engage in socially destructive behaviours, particularly in the urban setting. In three separate focus group discussions with in-school urban adolescents, there were reports of attempted or completed suicide by some of their peers who tested HIV positive, although I did not have first-hand information on this. This is what was shared by an in-school adolescent participating in one of the focus group in the urban setting:

> When you know your status, for example when you are HIV positive, you start to live a reckless life because it feels like it is the end of the world. … Some kill themselves –they are scared to be stigmatised. Most HIV-positive people are being stigmatised or discriminated against. … When you are HIV positive you cannot have a love relationship because nobody is going to ask you out with fear that you will infect them. Even if you look healthy others fear that when they start to show by losing weight or having sores all over the body like *libhande* [local name for herpes zoster], people will start knowing you are HIV [positive] and gossip about you, and [you will] lose your friends and become bedridden, so they kill themselves so no one will know they are HIV. . . . I know of someone who swallowed weevil tablets[xxv]after she had found that she was HIV [-positive].

According to the focus group participants, other adolescents used alcohol and addictive drugs to manage stigma while some decided to get revenge by having unprotected sex. These self-destructive tactics could be indicative of how the fear of stigma experienced by the adolescents also affects their psychosocial health. As already discussed in the first chapter, adolescence is a developmental stage characterised by formation of self-identity, a quest for acceptance by peers, developing intimate relationships, and a sense of being loved and accepted. Therefore, being devalued, discredited, or rejected and excluded may have enormous impact on adolescents' self-esteem and self-perception (Fielden, Chapman, and Cadell, 2011), which may have devastating social, physical, and mental health consequences, such as low grades in school, school abandonment, anxiety, depression, drug abuse, or even suicide (Surkan et al. 2011).

Conclusion

Adolescents living with HIV continue to experience both enacted and perceived stigma, which impacts how they relate to themselves, each other, as well as those in their social environments. The stigma experienced by adolescents was not so much about the HIV disease itself but rather the social environment in which these adolescents have to live with HIV. This highlights that stigma could be an indicator of problematic social relations.

Adolescents and parents or guardians devise strategies and tactics that help them avoid and/or manage stigma and maintain family honour. These include concealment or being secretive about their status, managing information, adhering to ARVs to appear normal and healthy, as well as helping each other and empowering themselves through treatment literacy. Others, however, are said to engage in self-destructive behaviours such drug use or even suicide in response to the fear of being HIV positive.

The effects of stigma on the self and family relations run deep and interventions are urgently needed that will go beyond managing the diseased body, to also focus on the unhealthy communities and society that still discriminate or cause adolescents living with the virus to self-stigmatise. Chapter five showed that HIV-related stigma remains a major reason for low access to and utilisation of HIV services among adolescents in Swaziland, and affects the illness experience. Not only does the fear of an HIV-positive diagnosis and its consequences hold back adolescents from seeking HIV services but also the continued association of HIV-positivity with sexual deviance (moral/symbolic stigma) increases their reluctance to use available HIV services. Not only are adolescents stigmatised for being HIV positive, but they also carried the burden of multiple social stigmas deriving from their social circumstances such as being born of unwed parents, being poor, and being orphaned. Popularised by feminists in the US in the 1960s, the theory of intersectionality provides a framework that allows for the examination of multiple forms of social oppression and how these work together to create and sustain social inequalities (Bowleg, 2012; Kennedy et al., 2013). The intersectional framework has been used in studies of HIV stigma among marginalised groups, such as men who have sex with men (see Kennedy et al., 2013; Mburu et al., 2014).

Despite the fact that stigma experienced by adolescents is embedded in broader social environments, interventions at the meso- and macro- levels still focus on individuals in order to address HIV stigma. Yet, the complexity of HIV stigma requires interventions that will also address the social, cultural, economic, and political inequalities that perpetuate and sustain it. The multidimensional nature of the causes and the many layers of stigma indicate a need for multidimensional and multidisciplinary strategies and approaches to address it. Although not applied in the understanding of adolescents' lived experiences of stigma in this study, the intersectional framework seems useful given the multiple stigmas adolescents experience in Swaziland. Research that will develop adolescent-specific interventions against stigma that are responsive to the drivers at the community and family levels is urgently needed.

CHAPTER SEVEN

THE (MICRO) POLITICS OF DISCLOSURE

> [As a stepmother] I have to think about our relationship, I am just a stranger who has come to her life through her father…it is difficult, very difficult my sister *[long pause; shaking head sideways]* it is very, very difficult…umh, I mean where do I start, what do I say, how do I tell her. (Interview, La-Shongwe, October 2012)
>
> They are both males and are close; I guess they will understand each other better. (Interview, Mrs. Dube, September 2012)
>
> I had to choose between losing her to AIDS or deal with her anger at me. I had to overcome my fear and tell her for the sake of taking the medication, for the sake of her own health. It is not an easy choice for parents. (Interview, Make Khumalo, August 2012)
>
> It is not yet the right time to tell them. I fear that if I tell them they will ask me how I got it [HIV] and this will bring shame to my family. (Interview, Nomaswazi, November 2012)

Introduction

One midmorning in September 2012, I received a call on my mobile phone from the senior nurse of e-Kwetsembeni clinic. She stated that they had a problem with one of their ART clients and that she wanted me to assist them. Upon reaching the clinic about fifteen minutes later, I found the senior nurse chatting with the ART nurse about the dilemma they were facing. As explained in chapter three, the clinic has several departments each staffed by a nurse, with a senior nurse overseeing operations in all the departments. When nurses encountered problems or challenges in their departments, they reported these to the senior nurse. In this case, the ART nurse reported the dilemma to the senior nurse who in turn called me for assistance.

Turning to me and after a brief exchange of greetings, the senior nurse explained that they had a male adolescent, Dumisa, who had been on ART for four years but had not yet been told that he was HIV positive. Dumisa's stepfather, Mr. Dube, who was accompanying the boy, was asking if the nurses could disclose Dumisa's status to him. Dumisa had lost his father in a car accident when he was only four years old. Four years later, his mother met Mr.

Dube and they were married a year later. Dumisa was nine years then, and had already been living with his mother and stepfather. He got tested for HIV at the age of ten and was immediately put on ART. His mother and stepfather were also living with HIV and on ART, but Dumisa was not aware of their HIV status. When the incident at the clinic took place, Dumisa had already been on ART for six years.

According to the senior nurse, Mr. Dube stated that Dumisa had started skipping his ARV medications and that he thought it was because Dumisa did not know why he was taking them. Mr. Dube was concerned that Dumisa would become resistant to the ARVs if he continued to miss his doses. Mr. Dube stated that Dumisa had recently been asking questions about his medication, wanting to know when he would stop taking the pills and why he continued to take them when he was not feeling sick. According to Mr. Dube, Dumisa's mother had on several occasions refused to disclose to Dumisa his HIV status or that the medicines were ARVs. Instead, Mrs. Dube wanted her husband to disclose to Dumisa, arguing that because they were both males and had a close relationship, they would understand each other better. To the contrary, Mr. Dube strongly felt that Mrs. Dube, as Dumisa's biological parent, should be the one to tell Dumisa. The standoff created tensions in the family, and Mr. Dube turned to nurses at the local clinic for assistance.

Two weeks earlier, while attending a support group discussion for women enrolled in the prevention of mother-to-child transmission of HIV programme,[xxvi]I observed one member of the support group, La-Shongwe, as she sought advice from group members on how she could handle a challenge she was facing at her home. She stated that her husband wanted her to tell her stepdaughter, Zinhle, that Zinhle was HIV positive, as the girl had been asking questions about the pills. La-Shongwe told the support group members that it was difficult for her to tell Zinhle that she had HIV as it was going to negatively affect their relationship. She argued that it was her husband's responsibility to tell Zinhle because he was the biological parent. According to La-Shongwe, her husband refuses to listen to her concerns and insists that it was part of her duties as his wife and as a mother to take care of Zinhle, including telling her that she was HIV positive.

These two separate yet similar incidents raised my curiosity about the sociocultural and familial contexts of disclosure in general, and of disclosure HIV status *to* and *by* adolescents living in different family contexts, in particular. What does the adolescents' social and family context have to do with disclosure? What are the practices and everyday life experiences of disclosure in different family contexts? What shapes the disclosure process in the different family contexts? How is personal private information, such as HIV status, managed or communicated in families? How do families decide whose responsibility it is to disclose what information and to whom?

In this chapter, I discuss the processes through which adolescents come to learn about their HIV-positive status, and the significance of this on the illness experience in adolescents' everyday lives. I specifically focus on the decision-making process to disclose, the interpersonal relations before and after disclosure, and the gender dynamics inherent in the process of disclosure. I describe the relevance and applicability (or lack) of national and global policies on the practices at the health facility level and in different family contexts. In short, the chapter is about the micro-politics of disclosure, that is, the interactions and decision-making processes (Willner, 2011:158) at the health facility and family level that influence and shape disclosure practices and experiences. My study suggests a disconnect between policy expectations and the practices of disclosure at the health facility and family level. This is driven by a lack of understanding and or appreciation at the national (and global) policy level of 1) the processual nature of disclosure, 2) the complexity of relations at the family level that impact disclosure, and 3) the structural hierarchies relating to decision-making and communication of sensitive information at the family level, which are shaped by prevailing social norms (Sarangi, 2008, in Markova and Gillepsie, 2013).

The chapter is divided into three sections: after defining and giving a brief synopsis on disclosure in the first section I present how adolescents and their parents or guardians, whom I refer to as 'primary caregivers' in this chapter, managed the disclosure process in different family contexts, and their experiences *with* and *of* disclosure in the second section. I provide an analysis of the disclosure process as shared by adolescents and their caregivers, and existing literature on disclosure to adolescents. I also discuss the role played by disclosure policies in either facilitating or preventing disclosure *to* adolescents. The third section provides a conclusion of the chapter.

Defining disclosure

In defining disclosure, I draw upon the works by Siu et al. (2012), Manderson, (2014), and Moses and Tomilson (2012). According to Siu et al., disclosure is

> a multidimensional and complex process of sharing one's HIV status with other people either verbally, in writing or other non-verbal cues; a form of a relationship . . . [that] incorporates the environment in which the relationship occurs. . . [and] goes beyond the act of telling others about sero-status to include a range of lived experiences. (2012: 606–608)

Similarly, Moses and Tomilson describe disclosure as a 'complex and multifaceted process, and a fluid experience that unfolds in the context of social and familial relationships, and accrues different meanings in different relationships overtime' (2012:667). Manderson states that:

> disclosure occurs at multiple levels: including the proximate context of the telling; the choice of the person who is the recipient of the disclosure; the presentation of self often politically and morally; the role of the discloser to others who are part of the account of disclosure; the nature of social relationships revealed in the context of disclosing; the emotional response of the discloser to the positions that others might have adopted; and the emotionality (or its absence) in the act of storytelling. (2014:11)

In this dissertation, disclosure should be understood to mean an ongoing process of telling and/or being told of an HIV-positive status. The process is characterised by controlling of information and managing of social relationships, and involves multiple and non-linear steps including decisions on when, how, who, and what/how much to tell, the actual revelation of status, and the immediate and long-term responses to the revelation, all of which are embedded in interpersonal relationships. Unless specifically stated, disclosure in this chapter refers to disclosing an adolescent's HIV-positive status to the adolescent by either a primary caregiver or another designated adult including health care workers, and to adolescents disclosing their status to family members, peers, and those within their social network.

Guidelines on HIV care, such as those recommended by WHO, recommend that people testing positive must disclose their HIV status to at least one person of their choice. At every encounter with the health facility, health providers are expected to counsel people living with the virus to disclose their statuses not only for their own benefit, but also to protect their sexual partners and the public from HIV. This is different practice from when HIV was still at its infancy, when people were counselled to keep their status confidential. Much of the emphasis on disclosure is substantiated by bioscientific reasoning that disclosure will lead to early enrolment in ART, better adherence to treatment, and better retention in HIV care (Arrive et al., 2012; Mburu, 2014), all of which contribute to longevity and improvement in the quality of life of PLHIV (WHO, 2013). Indeed empirical studies show that there is truth in these assertions. For instance, in a meta-analysis on the role of community-based HIV programmes in improving ART and health outcomes, Amanyeiwe, Leclerc-Madlala, and Gardi (2014) found that there was a strong correlation between disclosure and retention in care. Disclosure has also been linked to social support and psychological and mental health for both caregivers and adolescents (Lam, Naar-King, and Wright, 2007; Lee et al., 2015; Maman et al., 2014).

Following this line of reasoning, the policy environment and language of HIV disclosure counselling has changed from ‘whether to disclose’ to ‘should disclose’, ‘must disclose’, or ‘have to disclose’. That is, the practice of disclosure has become more of requirement and an obligation than a voluntary choice in some medical contexts (see Moyer et al., 2013).This rhetorical framing fails to acknowledge the socio structural and relational issues that shape the disclosure process (Hardon, Desclaux, and Lugalla 2012), which Bond (2010) describes as requiring continuous negotiation and ‘navigation in the moral’. In such a policy and practice environment, and because of the power inequality between service providers and PLHIV, the latter feel compelled to disclose even when such disclosure may not be beneficial socially or clinically (Moffat, 2014).With this conceptualisation of disclosure in mind, in the next section I present case studies of adolescents and their caregivers that show the complexities, ambiguities, contestations, and tensions inherent in disclosure in different family contexts. Before that I provide a brief review of literature on disclosure policy and practice in Swaziland.

Disclosure policy and practice in Swaziland

According to the country’s national HIV care guidelines, disclosure of HIV status is voluntary and has to be done by the person who is living with HIV. In the case of disclosure by a third party – such as parents disclosing their children’s status to other people – consent has to be sought and granted by PLHIV prior to disclosure. However, observations in my study show that in actual practice the principles of voluntary disclosure or consent prior to third-party disclosure are not adhered to by caregivers or health care workers when it comes to the disclosure of adolescents’ status. All the adolescents stated that neither their parents nor health care workers sought their input with regards to who should be told about their status. I will return to this point later in the chapter. In the next section, I explore disclosure policies and practices in Swaziland

A few empirical studies on HIV disclosure have been conducted in Swaziland, focusing on disclosure to sexual partners by adults living with HIV and on ART (Legasion, 2010), sexual practices of patients on ART after disclosure (Okoth and Van der Walt, 2013), the role of a community-based religious organisation in facilitating disclosure by adults (Root, 2010),the social and gender context of disclosure (Bott and Obermeyer, 2013), and experiences and perceptions of disclosure among adults (Greeff et al., 2008). The latter two were multi-country studies that included Swaziland. At the time of my study I could not find any that focused on disclosure experiences or practices in relation to adolescents in different family contexts specifically or adolescents generally. This chapter thus adds to the literature on disclosure by focusing on the meanings and experiences of disclosure to adolescents, and by adolescents, in different family contexts in a high prevalence and resource-limited setting.

The practice of disclosure in families

Although adolescents and primary caregivers appreciated the need for and benefits of disclosure, their views on when disclosure should take place differed. While adolescents were of the view that they should be told of their HIV status as soon as they were diagnosed, parents and guardians were concerned about whether adolescents would comprehend what it meant to be HIV positive, how they would respond to the knowledge that they were HIV positive, and whether they would be able to keep their status a secret. They felt a need to delay disclosure until such time that the adolescent was cognitively and emotionally ready to process the news. This led to a delay in informing young adolescents that they were HIV positive, with the consequence of poor adherence or abandonment of ART.

Another reason for the delay in disclosing was anticipated anger, blame, and resentment from adolescents who were infected perinatally. Hence, in most of the cases in this study, informing adolescents of their HIV-positive status was not done voluntarily: caregivers usually only did so in response to questions from adolescents about the pills they were taking or the 'sickness', as in the cases of Dumisa and Zinhle, or because adolescents were failing to take their ARVs as prescribed, as was the case with Mpendulo. Asked why he did not take his medication, Mpendulo stated that he was tired of the pills as he did not know what they were for. Mpendulo had been taking the HIV medicine for six years when his sister told him he was HIV positive. Asked to share how his sister disclosed his status to him and how he responded, he said:

> I only learned in 2010 that the pills I was taking were for HIV. My sister told me. . . . I had stopped taking the pills. I would sometimes take them and sometimes I wouldn't. I didn't know why I was the only one taking the pills why the others were not taking them. . . . She said 'you should continue taking the pills because you have AIDS, if you don't you will die', and then I continued taking them. . . . I was very hurt; the manner in which she told me was like she didn't care. (Interview, October, 2012)

Whose responsibility is it? Disclosure in a stepfamily setting

The question of whose responsibility it is to disclose to adolescents featured prominently in stepfamily contexts, resulting in tense relationships between biological parents and stepparents. The case of Dumisa and Zinhle at the beginning of the chapter depict the complexity of the disclosure process as characterised by tension, ambiguity, and gendered role expectations in family settings.

The concerns raised by the stepparents in the two cases broadly relate to who in the family setting is the 'right person' to disclose the adolescent's HIV status to him or her, what attributes the person should possess to be considered the right person, and who makes the decision on who should disclose to adolescents. According to national guidelines, parents or guardians are responsible for disclosing to adolescents, but the challenge is which parent in the case of stepfamilies should shoulder the responsibility. Furthermore, the concerns and debate suggests that disclosure to adolescents presents a social, moral, ethical, and legal dilemma for different families and to different caregivers within families. Both Dumisa and Zinhle were living in stepfamily settings, and did not know that they were living with HIV. Yet at the time their stepparents were called upon to disclose, the adolescents had been diagnosed with the virus and on treatment for six and four years, respectively. Stepparents can become angry when biological parents do not disclose to their children over many years, and then expect the stepparents to handle it.

Second, the two cases underline the importance of the nature and quality of the interpersonal relationship in the disclosure process as well as the management of personal information in different social relations. While Dumisa's mother felt Dumisa's stepfather was the ideal person to disclose to Dumisa because ‘they have a close relationship, they will understand each other’, Mr. Dube – not disputing that he and his stepson were close – felt it was not his responsibility to disclose because ‘his mother should disclose; she is the biological parent afterall’. Similarly, La-Shongwe was concerned that telling Zinhle she was HIV positive was going to affect their relationship negatively, which she described as still ‘shaky’ or ‘not yet concrete’ as she had joined the family less than a year before I met her. Her major concern was that Zinhle might never trust or talk to her again. La-Shongwe had recently married Zinhle’s father and said that she was:

> still getting to know Zinhle and the other children, and then my husband tells me to tell her that she is HIV positive. That is difficult for me. As a stepmother, I have to think about our relationship; I am just a stranger who has come to her life through her father. She is also still mourning the death of her mother who passed away less than two years ago, and then I tell her she is HIV positive? It is difficult, very difficult my sister [long pause; shaking head sideways]. It is very, very difficult [long pause]. Uhm, where do I start, what do I say, how do I tell her that she has HIV and her mother gave it to her? Do you think she will believe me? And will she ever trust me again, like, will she ever talk to me again? (Informal conversation, October, 2012

La-Shongwe was still trying to ‘connect emotionally’ and build her relationship with her stepchildren including Zinhle. In describing herself as a stranger, she makes clear that even though she is married to Zinhle’s father and therefore qualified to assume a mother role to the children, it does not change how she sees herself in the relational context with the children and within the family.

The notion of stepparents as ‘legal strangers’ has featured in studies of developed countries such as the US (see Mason, Svare, and Wolfinger, 2002; Mills in Beer, 1988) and developing countries such as Namibia (Beninger, 2011).Findings from these studies suggest that while marriage provides stepparents with the legal status of being parents, they remain perceived as strangers in the familial context especially in the eyes of their stepchildren. The excerpt from La-Shongwe reveals that the stepparent may view herself as a stranger in the relationship she has with her stepchild. In the excerpt La-Shongwe is also concerned about Zinhle’s emotional health and the fact that she had recently lost her ‘actual mother’.

Another issue evident in these narratives is that of gender roles. Part of the reason that Dumisa’s mother felt Mr Dube was the right person to disclose to Dumisa was that ‘they were both males’ and therefore ‘understand each other’. La-Shongwe, on the other hand, told the support group members that her husband insists that it was part of her duties as his wife to do as he told her, including disclosing to Zinhle. In both cases the disclosure responsibility is shaped by the gender roles expected of a father to his son, in the case of Mr. Dube and Dumisa, or being wife and mother, as in the case of La-Shongwe. I discuss further the role of gender in disclosure later in the chapter.

Lastly, one would have expected that the nurses at the clinic would assist the families by disclosing to the adolescents so that they could adhere to their ARVs, and by extension, realise the clinical benefits of ART. After all, disclosure is one of the goals of ART and the health system generally. However, the nurses were adamant that although they were concerned about the plight of the adolescents and their parents, the parents should work on their relations and decide on how they would handle the disclosure. One of the senior nurses, for example, claimed that policy guidelines state that ‘it is the parents’ responsibility to disclose to their children’ (interview, September 2012). Their role as nurses is to support parents. This senior nurse’s position was confirmed by the national ART coordinator in an interview that the role of nurses and any health worker for that matter is not to disclose HIV status to adolescents but rather to be a support system for parents to disclose. Asked who is considered a parent in the case of stepfamilies, the coordinator stated:

> When it comes to disclosure, that one goes back to biological parents. As a programme, we don’t want to overload the stepparent by expecting him or her to talk to the child about HIV, to test and to support the kid when the biological parent is still alive. So the biological parent must take responsibility – the substantive [biological] parents must not delegate their duties in this issue because it puts the stepparent in a difficult situation. It is different issue if none of the biological parents is alive, there we recommend that the next closest family member who is the primary carer takes the responsibility. (Interview, February, 2013)

The coordinator acknowledged that as a programme they had not anticipated the difficulties and different forms of families in their development of the policies or guidelines. She also mentioned that it would be impossible to have everything written down in policies or guidelines, and hoped that families could use existing structures at the community level to resolve differences amicably, for the sake of their children:

> We cannot dictate how families should run their homes; we trust that the health of children, adolescents and indeed everyone living with HIV in any type or family context will be provided with the necessary care, including information that will improve their health, and our nurses are there to support family members. . . . One just hope that structures at the community and family level work on these issues and put the interests of the child above everything else. (Interview, February, 2013).

The finding of the study suggests a lack of guidance on who should disclose to adolescents in the case of stepfamilies. If stepparents struggle with disclosure to stepchildren due to relationship issues, what is the experience of biological parents and their children? I explore this question in the next section.

Disclosure by biological parents

Just like stepparents, biological parents go through a lot of psychological and emotional struggle while planning for disclosure. According to Gcinaphi's mother, there is no best way and no one-size-fits-all answer, as each case will depend on the obtaining circumstances and the relationship between the parent and the adolescent.

She shared her experience about disclosing to Gcinaphi, her daughter. She stated that her ultimate decision to disclose to Gcinaphi was based on her poor adherence to ARVs, and she knew that if she didn't disclose to her sooner, there were going to be complications later, but still it was not easy. The difficulty in her case was fuelled by the fact that Gcinaphi was the only one of her children who was infected with HIV. Both Gcinaphi and her mother were living with HIV and on ART, while her father passed away in 2005 from an AIDS-related illness. Gcinaphi had three sisters, all of whom were HIV negative. Asked to share how she disclosed to Gcinaphi, her mother said:

> It was very difficult. Hence, it took me sometime thinking about the best way to approach the issue. At the end I found that I had to be direct and honest. It is not easy to tell your child that she has HIV and you, the parent, gave it to her. For me the difficult part was that she is the only one among my children who is HIV. So I feared that she was going to ask me why I only gave HIV to her and not the others. I was afraid that she will be angry and resent me for infecting her with HIV, but at the same time I couldn't let her die because if she didn't take the pills well the HIV was going to be resistant and then she will get sick and die. So I had to choose between losing

> her to AIDS or dealing with her anger at me. I had to overcome my fear and tell her for the sake of taking the medication, for the sake of her own health. So I chose to tell her. It is not an easy choice for parents. (Interview, December 2012)

Disclosure by adolescents

Older adolescents, those aged between 17 and 19 years, also expressed dilemma with regards to the disclosure of their status; they were concerned about disclosure to future sexual or romantic partners, fearing that they may be rejected. Some already had partners but were still struggling with the decision on whether to tell or not. Menzi stated that although the need to tell his girlfriend of three months about his HIV positive status was weighing heavily his thoughts, he had not done so because he feared she might reject him. As a result he decided to delay it until he was totally sure 'she is the one for me' (interview, October, 2012). Similar findings have been reported by Mburu et al. (2014), in their study of adolescents in Zambia, Birungi, et al. (2009) in Uganda, Lee and Oberdorfer (2009) in Thailand and Tassiopoulus, et al. (2013) in the US, respectively. The researchers found that the fear of rejection was one of the barriers to disclosure to sexual partners. These findings show the negative effect of perceived stigma on disclosure, which I discussed in chapter five.

Caregivers' perspectives on disclosure

Caregivers stated that while they appreciate the importance of disclosing to adolescents, they felt there is too much pressure from health care workers to do so without due consideration of their limited skills, which make disclosing difficult. It would seem that the fear of death from HIV is one of the motivating factors to caregivers to disclose to their adolescents, as shown in the cases of Mpendulo and his sister's and Gcinaphi and her mother. For some parents, disclosure was done out of a sense of duty and obligation, something they had to do even if it meant seeking outside help. One mother in a focus group explained:

> I knew about my status ten years ago. I would not say how long I had lived with HIV because I only got tested in July 2003 and I started ARVs in August of the same year. At that time I had a son who was just three years old. Two years after I got to know my status, my son who was then five years old and attending pre-school, started getting sick, so his teachers would often call me about his situation. The honest thing is that I just could not come to terms with the fact that he could also be HIV positive. I

> debated a lot within myself about whether I should test him or not. His situation got worse and then I took him to the hospital where he got diagnosed with HIV, and was started on ART. It is not easy for a parent to know that their child is also HIV positive; it feels like you are telling the child that he is HIV positive because of your mistakes. It appears to him like he is HIV positive because of your fault, but then you try to make him understand. I remember several times I took him for counselling so that he could understand, but there was also an issue of failing to adhere to treatment so I needed help with that as well. My child is now fourteen years old and he is doing well with ARV treatment. I remember that it was a difficult task for me to help him fit and settle in the new lifestyle, because you need to disclose the status to relatives and families since he would want to visit them, in some cases he would want to go camping with the church, so you also need to disclose to the church members whom you do not even know how they will react to those news. . . . It is like as a parent you are always finding ways to make things normal, to take control but it is not easy because sometimes you feel like you are lying to these children and the day they find out they will never trust you again. (January, 2013)

The psychological and emotional struggles expressed by parents and caregivers, and the lack of skills on how to handle disclosure, are appreciated by the national paediatric ART coordinator, who stated that:

> Disclosure is a very difficult thing to do, probably the hardest in the HIV care continuum. In my professional position, I know it is a necessary process and I train health care workers to help parents to disclose, but personally I know it is the hardest decision to make; it is a dilemma. On the one hand you think it is the right thing to do because as a parent you want to protect your child all the time, but you also don’t want to tell the child disturbing news. . . .The challenge is that we cannot predict how the child will take it. (interview, March, 2013)

The fear to inform children (and adolescents) about their HIV by parents or guardians (caregivers) has been cited in other studies in Southern African countries neighbouring Swaziland, such as Botswana (Manye and Madiba, 2015; Matshome and Madiba, 2014), South Africa (Madiba, 2015),

Adolescents' perspectives on disclosure

Adolescents shared a desire to know their HIV status early, and preferably from health care workers or adults who were knowledgeable and able to respond truthfully to questions about HIV and the medications. Not being told about the illness yet being expected to take medications everyday caused them emotional distress and increased self-isolation. This is also reflected in a study on disclosure to perinatally infected children (6–12 years old) in the US, Instone (2000) reports that parents or caregivers delayed disclosure by between two and eight years and that the delay caused severe emotional distress, disturbed self-image, and social isolation among the children of which parents were not aware.

By the time the adolescents in my study begin asking questions they already suspect that they could be HIV positive as they may have learned about the disease at school or from friends. Parental delay or refusal to truthfully tell them of their status is experienced as distrust in their ability to handle their own challenges.

Learning and planning to live with HIV

Adolescents stated that knowing they were living with HIV helped them to make adjustments in their lives to accommodate the disease and illness. This process involved not only managing the disease through optimal adherence to ART, but also managing the social environment where the life with HIV is lived. Managing the environment involved the everyday tactical decisions and practices used by both adolescents and their parents and guardians to manage information about HIV status. Such considerations involved the family and other selected members of the adolescents' social network, such as school, church, and friends. Another component of learning to live with HIV involved planning how to disclose to future sexual partners.

In short, according to adolescents and their caregivers, disclosure is part of their everyday life as long as they live with HIV. How adolescents adapted to and moved on with their life with HIV depended not only on the reactions and responses by family and friends following the revelation of HIV status but also on the framing of the HIV-positive diagnosis in the larger social environment. Where stigma was still evident, information about their status was closely guarded. In this sense, non-disclosure becomes necessary and as part of learning to live with HIV, adolescents have to learn to take the decision independently or in consultation with their parents or guardians.

Disclosure and gender

All the cases discussed in the preceding sections indicate that disclosure is framed and enacted in relation to particular gender norms in different family contexts, a finding similar to other studies in the region. For instance, in their review of studies on disclosure across diverse settings, Obermeyer, Baijal and Pegurri (2011) found that gender shaped the motivations to and reactions towards disclosure of HIV status. In all the cases and indeed, throughout the thesis, mothers and grandmothers take the lead role in providing day-to-day care for adolescents living with HIV, including disclosure. Disclosure – whether to adolescents, family members, or teachers – was done by mothers, grandmothers, or other close relatives such as sisters and aunts. In fact, none of the adolescents ever mentioned being told of their HIV status by their father or a male relative. That all of the disclosures of the adolescents' HIV status were by female family members speaks to the gendered dynamics of emotional work. In the focus group discussion, adolescents themselves stated that they preferred hearing about their statuses from their mothers and grandmothers, rather than from their fathers, grandfathers, or male relatives because, as one young person put it, '*bomake bayanakekelana, futsi baneluvelo nawuva inhlitiyo lebuhlungu* [mothers are caring, and sympathetic when you suffer emotional pain]' (March, 2013). The preference for female members to communicate information considered sensitive, such as sexuality or disclosure of HIV status, has also been reported in developed countries such as the US (DiIroio, Kelly, and Hockenberry-Eaton, 1999; Sneed, 2008), and developing countries in sub-Saharan Africa (Bastien, Kajula and Muhwezi, 2011) such as Tanzania and South Africa (Namisi et al., 2009), Nigeria (Amoran, Onadeko, and Adenyi, 2005), Ghana (Manu, etal., 2015), and Uganda (Karimli, Ssewamala, and Ismaylova, 2012). Based on their study in Uganda, Reynolds-Whyte, Mongensen, and Twebaze note that the everyday care needs for people living with HIV and those on ART have long been taken care of by female members in families, while males provide economic resources (2014: 111).

Conclusion

In this chapter I discussed the practices and experiences of disclosure of HIV status in different family contexts. I showed that disclosure was not a single event of telling adolescents or others about their HIV status, but an ongoing process that was characterised by a number of non-linear steps from diagnosis to telling others, for which adolescents were not involved in the decision on who to tell, when, and how much. I further showed that disclosure to adolescents, other family members, and school or community members was done by female caregivers, typically mothers or grandmothers, thus depicting the gendered role of disclosure. Adolescents were rarely involved in the decisions regarding who to disclose to but took an active role in disclosing to their romantic or sexual partners. Disclosure was experienced as ongoing, a part of the adolescents' everyday life template.

I also show the tensions and ambivalences with regards to who should disclose to adolescents in stepfamily settings, and how gender was used by biological parents as a basis for pressuring stepparents to disclose to their stepchildren. I showed that the policies at the national and global level do not provide clear guidance on whose role it is to disclose their status to adolescents. The guidelines only speaks to assessment of age and cognitive maturity in deciding 'when and how much' to disclose to adolescents. I articulated the limitations of such an approach and suggested that each case should be managed as an individual case. That said, I suggest that disclosure should be the shared responsibility of both parents and used as a stepping stone to promote open communication about HIV. Studies on parent-adolescent communication in the context of HIV suggest that open and honest communication to adolescents about their HIV status leads to better adherence, positive psychological adjustment, and a positive self-image (Mburu et al., 2014; Sahay, 2013; Vaz, etal., 2011; Vaz, etal., 2010), and delay in sexual debut (Kajula et al., 2014). However, in relationships between adolescents and their stepparents, studies report increasing boundary management and topic avoidance especially if the topic is considered secretive, sensitive, or taboo, such as HIV (see Afifi, 2002; Golish and Caughlin, 2002; Marques, et al, 2006; Weaver and Coleman, 2010). In suggesting disclosure in stepfamily contexts, it is important for health care workers and parents (both biological and stepparents) to evaluate the quality of communication between the stepparent and the adolescent with the view of assisting in improving open communication, not just for disclosure but for harmonious living with HIV in the family, which cannot be helped by imposing gendered roles as is the situation in the two cases presented here.

Parents and caregivers experienced disclosure as psychologically and emotionally difficult due to several reasons including fear of anger and resentment, and being blamed for infecting their adolescents with the virus. This finding is also reported by other studies in neighbouring South Africa (Rochat, Mkwanazi and Bland, 2013), There were also concerns that failure to disclose was detrimental to adolescents' adherence and by extension their lives. As such parents had to choose between dealing with anger and blame, or losing their adolescents to AIDS, and all chose to disclose for the sake of their children's health.

How adolescents responded to each of the steps of the process was mediated and continuously shaped by the social environment within which the disclosure occurred. The mediating factors in the social environment included the relationship the adolescent had with the person who was performing the disclosure, the reason for disclosure, the response of the person being told, the involvement of the adolescent in the decision to disclose, and the availability of support following disclosure. Having witnessed discrimination against other adolescents or children living with the virus influenced their perception of disclosure as well as how they managed information about their status through secrecy (discussed in chapter six). Given the importance of the effect of disclosure on adherence and HIV disease progression, the significance of the quality of relationship between the discloser and adolescents, and the impact this has on the practice and response to disclosure, parents and guardians should be actively assisted in disclosing to adolescents.

PART THREE

This part of the dissertation has only one chapter in which I provide a discussion and conclusion of the study, including recommendations.

CHAPTER EIGHT

DISCUSSION AND CONCLUSION

> It is shocking that more adolescents die every year from AIDS-related illness than from any other cause except road accidents. . . . [I]t is even more shocking that the number of adolescents dying of AIDS is not decreasing when AIDS-related deaths have dropped in every other age group. And it is shameful that this is happening when we have the knowledge and tools to keep adolescents living with HIV alive and well, and to prevent new HIV infections. . . .[W]hat can we do to bring back the invincibility of youth? We must begin at the beginning – and stay with adolescents throughout their lives. . . . [W]e must do more to protect all adolescents and empower them to protect themselves and their health. In fact, we cannot end the epidemic without a global movement to end AIDS-related deaths and new HIV infections among adolescents. [T]o end the AIDS epidemic, start focusing on adolescents. (Lake and Sidibé, 17 February, 2015)

Introduction

In this study I explored adolescents' experiences of living with HIV in different types of families in Swaziland. Using the social ecological model, the actor-centred approach as well as the concept of social navigation as analytical lenses, I explored adolescents' motivations for and experiences with HIV testing, the meaning of and responses to an HIV-positive diagnosis, being on lifelong ART, experiences with and the management of stigma, as well as disclosure of their status. The focus on adolescents in different family contexts departs from previous studies that have focused on families as though they were similar or homogenous structures across cultures.

The central argument put forth in this dissertation is that adolescents' experience and meaning of living with HIV derive from the discursive constructions of HIV in their micro environment – families, social networks, and communities– which are themselves shaped by societal and global expectations, norms and practices with regards to health and HIV. Therefore, to understand adolescents' experiences of and responses to living with HIV, it is necessary to consider and situate their interpretations and experiences within the family, community, and societal structures.

In this concluding chapter I provide a synthesis and discussion of the main findings presented in the empirical chapters of the dissertation (chapters four to seven). The chapter presents a brief summary and discussion of the themes that emerged from the data. The second section provides recommendations, while the last section is an overall conclusion.

Discussion of key findings

The findings of the study provide a deeper understanding and appreciation of the experiences of adolescents living with HIV in different family contexts in a high prevalence, resource-limited setting. The primary objectives were to investigate:

1) the motivations for and experiences with accessing HIV services. The services included HIV testing, treatment, and adherence;

2) the meanings of and responses to an HIV-positive diagnosis, in view of it being a chronic disease that can only be managed through the everyday medicalisation of the body, accompanied by stigma and the need to manage disclosure; and

3) how the family context, which is shaped by the broader social environment, impacts adolescents' everyday experience of living with HIV, and the tactics used to manage such experiences at home, in the health facility, and in the community at large.

Motivations for accessing and utilisation of HIV services

Knowing one's HIV status through testing is the critical entry point to other HIV services, including preventing and protecting oneself from getting infected with HIV. Testing is also essential for survival and longevity through enrolment in long-term HIV care including ART, if found to be HIV positive. The study found that although adolescents were aware about the importance of HIV testing and knew where to access the service, less than half of adolescents who participated in the survey had ever tested for the virus. In fact, the survey found that only two in five of participating adolescents had ever tested for HIV. Among those who were already living with HIV, of those who participated in in-depth interviews and focus group discussions, all of them tested following ill-health. This finding is in line with others that have reported low voluntary testing by adolescents (Fox et al., 2013; Idele et al., 2014; Lahuerta et al., 2013; MacPhil, Pettifor and Coates, 2008).

However, and contrary to findings that the low testing rates among adolescents is due to them being a 'difficult and hard-to-reach' group (Dellar, Dlamini, and Karim, 2015; Auld et al.

2014), who are not willing to test (Ntsepe et al., 2014), be enrolled in ART, and retained in HIV care, findings in this study suggest that the limited use of health facility-based HIV services is due to a confluence of individual, family, health system, legal, and policy factors that both individually and collectively impede access to HIV services.

Multidimensional fear was the main barrier to access testing at the individual level. This included fear of an HIV-positive diagnosis, fear of parental rebuke, fear of losing one's friends, and fear of living with a chronic disease. Other studies have also reported on fear as a barrier to testing for the virus among adolescents. When ART was not available or scarcely accessible, the fear of being diagnosed with an incurable disease and of the stigma that might follow seemed realistic, but even today, with the almost universal availability of free ART, the fear of HIV stigma was cited as one of the main barriers to testing among the adolescents. Witnessing stigma perpetuated by some family and community members to those living with HIV deterred adolescents from testing for fear of experiencing discrimination and rejection.

The other reason cited by adolescents was the health environment itself. Adolescents stated that health facilities are places for the sick. This perception may explain why most adolescents in the qualitative phase of the study and almost 40%in the quantitative phase tested after they fell sick. Those who were healthy stated that they were willing to test but the services should be moved from the health facilities and be offered in schools, youth centres, or homes. Zimbabwe (Morin et al., 2006), Kenya (Grabbe et al., 2010), and South Africa (Black et al., 2014) all report increased testing uptake by adolescents when services are provided outside the conventional health clinic, through use of mobile testing units in communities or youth centres. One study carried out by Parker et al. (2015) in the Shiselweni region, Swaziland also reported a similar finding. Studies conducted among South African students from Gauteng and North West provinces also found a preference for school-based testing (Madiba and Mokgatle, 2015a).

At the family level reasons differed between those shared by adolescents and those advanced by parents or guardians but they included fear of parents' anger and blame towards adolescents; and caregivers' concern that a positive diagnosis may cause emotional and psychological trauma to adolescents, who may be cognitively not mature to process the news. Lack of open communication about HIV was also a reason for low uptake of HIV services. Adolescents stated that their parents were often reluctant to discuss HIV with them and thought it was because of the link between HIV and sexuality, which was hardly discussed in family settings. Parents feared embarrassment from the revelation of their (parents') HIV status if adolescents tested HIV positive and had never engaged in sexual activity. They (parents) stated that they feared their children (adolescents) would blame them for infecting them (adolescents) with the virus, and may lose respect for them. Thus parents may delay to have their children and adolescents tested for the virus. These findings are similar to those reported by other researchers globally (Idele et al., 2014) and in southern Africa (see Mahloko and Madiba, 2012; Motshome and Madiba, 2015; Mburu et al., 2014; and Sahay, 2013). Parental fear of testing adolescents (and children) to protect their own HIV status is captured by a number of qualitative and quantitative studies in Africa, as well (see Bandason et al., 2013; Kyaddondo et al., 2013; Rwemisisi et al., 2008).

On the lack of communication, parents and guardians felt adolescents knew 'too much' about HIV in comparison to them. Adolescents learn about HIV in school and from various media outlets. Parents and guardians, therefore, did not see the need for discussing HIV with them.

An additional barrier to testing is health care environment. Unsupportive, unwelcoming, and judgemental health facility environments; unfriendly operating hours of the clinics that coincide with school hours; lack of privacy; and perceptions of health facilities as 'spaces for the sick' made health-facility based HIV services socially and structurally inaccessible. Adolescents complained that health care workers were harsh to them when they sought care, often asking judgemental questions instead of offering services – a finding not uncommon about young people's experiences with health care services in sub-Saharan Africa, such as in Malawi (Munthali, Mvula, and Maluwa-Banda, 2013), South Africa (Pettifor et al., 2013; Ramirez-Avilaet al., 2012), Uganda (Bakanda et al., 2011); Zambia (Denison et al., 2009); and Zimbabwe (Ferrand et al., 2010).

Health workers, on the other hand, stated that they were bound by national policies and guidelines and professional ethics in the delivery of health services, and therefore could not act against those prescriptions. They were of the view that in most cases their conduct towards adolescents, though perceived as judgemental and negative, was in fact to protect them (adolescents). Health care workers stated that HIV is a psychologically and emotionally challenging disease and clients including adolescents have to be thoroughly prepared when seeking HIV testing and be ready to accept the results. Hence they advised adolescents to have some form of ongoing psychosocial support from family should they find that they were HIV positive. These assertions are also reported by Krazner et al. (2014), who evaluated barriers to provider-initiated HIV testing and counselling for children aged between six and sixteen years in Zimbabwe. In addition to concerns about stigma, maltreatment, and abandonment, the researchers found that health care workers were sceptical of offering testing and were of the view that children (and adolescents) were vulnerable and might not adequately deal with the trauma of being HIV positive.

Policy-level reasons cited by adolescents revolved around the requirement for adult consent to access testing and other HIV services if younger than eighteen years. I must mention though that during the course of this study, and as mentioned earlier in this dissertation, the country reduced the age of consent to twelve years through the Child Protection and Welfare Act released in November, 2012. This change in age of consent was incorporated in new HIV testing guidelines released in 2015. It is yet to be evaluated whether the change has been embraced and practiced by HIV services providers, adolescents and their parents or guardians, and how the change influence practice of testing adolescents who seek the services without their parents' or guardians' knowledge.

Like in most societies in Africa (and probably other continents), illness is almost always a family issue amongst the Swazi, particularly so for young people who are still dependant on their parents or elders for support. It may be fool-hardy, therefore, to expect that adolescents would be tested and started on lifelong treatment without the knowledge of the primary psychosocial support structure such as the family. The challenge would be where the family fails to perform its role of providing support to adolescents, as was the case with Mpendulo. In such cases, the government, through the Department of Social Welfare should step in and provide the needed support.

In view of these barriers to access and utilise services, adolescents suggested that HIV testing and counselling services should be offered in social places that they frequent, specifically mentioning the school, home, and youth centres as ideal spaces. The suggestion to provide testing outside health facilities is consistent with that of other adolescents and youth in other countries. Home-based testing has consistently been reported to increase the acceptability of testing by studies in sub-Saharan Africa (Bateganya, Abdulwadud and Kiene, 2007; Kalichman and Simbayi, 2003; Kimaiyo et al., 2010; MacPhail et al., 2008; Negin et al., 2009) and in systematic review and meta-analysis studies (Sabapathy et al., 2012) as well as community-based testing and counselling (Suthar, etal., 2013) and testing in youth centres (Black et al., 2014). Recently, South Africa, a neighbouring country to Swaziland, introduced school-based HIV testing and counselling. A recent review in two provinces (Gauteng and North West) shows a high acceptability of testing in schools by young people (Madiba and Mokgatle, 2015a).

This study found that HIV services in particular and health services in general are not tailored to the needs of adolescents. The effort in clinics included making ‘adolescent-friendly corners’ and training health care workers on the provision of ‘adolescent-friendly services’. However, according to programme managers, health care workers, and adolescents, adolescents were not involved in or consulted on what would constitute ‘adolescent-friendly’ health services. Instead, adults in the programmes defined what would be considered ‘adolescent friendly’, resulting in a disconnect from what adolescents would consider to be truly adolescent friendly services from that espoused by heads of programmes. A similar disconnect is reported by other studies such as Birungi et al. (2009) who found that health services in Uganda were not tailored to, and, therefore, not did not respond to the needs of, adolescents who had been perinatally infected with HIV. Of course the request for adolescent-friendly services is not new. A major review of studies focusing on factors for low testing among adolescents carried out by the World Health Organisation (2013) also reported that services were not considered friendly by adolescents. Instead they preferred non-clinic-based voluntary testing that will be offered by compassionate, friendly, and competent staff.

While appreciating the adolescents’ recommendation for school or home-based testing, other studies have reported concerns about the need to maintain privacy and confidentiality and the need for ongoing psychological support for adolescents testing HIV positive, which cannot be over-looked and need to be strengthening. Furthermore, poor linkage to HIV treatment and care after an HIV-positive result where HIV testing is carried outside the health facility (hospital or clinic) has been reported in Swaziland (Parker et al., 2015). So in planning for HIV services, the focus should not just be about identifying a diseased body through testing but also establishing clear protocols on how and where adolescents should receive ongoing psychosocial care as part of the HIV management package. Ideally, the services should be designed to provide sustainable, comprehensive, and holistic care that will include biomedical care (treatment and follow-up), non-biomedical care (psychological, emotional, and spiritual care), as well as other structural support for issues affecting adolescents and their families – that is to say, HIV services should reach to the ‘heart and soul’ of young people. It is through this holistic approach that HIV services for adolescents can be effective.

Motivations to test for HIV

Among adolescents who reported to have tested, wanting to know one's HIV status to plan for the future, living with or knowing someone who is HIV positive and on ART (parent, relative or friend), as well as repeated sicknesses were main motivations for testing.

While more than 70% of adolescents who reported never having tested in the survey stated that they were willing to test, with 50% of them stating that the motivation was to know their HIV status so that they could plan their futures, I found that the pattern of testing was not consistent with the expressed desire. For those who had tested, they too did not follow there commendations by the national guidelines. The guidelines and policy recommends annual testing for every person not yet diagnosed with HIV, and testing after every exposure or risky behaviour. In this study adolescents reported testing only once in their lifetime, with some having last tested more than ten years before the study. Although aware of the advice on repeat testing, and stating they were willing to test, the fear of a positive result and stigma were reasons for not repeating testing. This underscores the need for interventions to address perceived stigma among adolescents.

Furthermore, I found that primary health care facilities missed opportunities to test and diagnose adolescents early when they presented for sickness. All the adolescents who were living with HIV who participated in in-depth interviews and focus group discussions reported to have tested following several episodes of sickness and visits to the health facilities amongst other health systems. This was the case whether infected perinatally or later in life. However, HIV testing was not offered at their initial visit to the facility. Had they been offered an HIV test at the initial visit, adolescents could have been diagnosed earlier and managed accordingly, thus alleviating suffering. A study by Ferrand et al. (2010) reported similar findings in Zimbabwe. In that study, 594 adolescents were enrolled to explore the incidence of undiagnosed HIV among primary care attendees. Out of the eighty-six adolescents that tested positive for HIV, 81% had been regular patients in the primary care facilities presenting with different health concerns, but also showed overt signs of chronic HIV disease such as stunting. This finding suggests a need to strengthen and reinforce the integration of routine HIV testing at all points of contact that adolescents have with the health system, while letting adolescents make an independent and informed choice to test. There is a need to actively seek and offer HIV testing to adolescents, especially those exposed, even before they fall sick.

Adherence to ART

Adherence to ART by adolescents in the study varied depending on whether they were aware of their HIV status, and therefore knew why they were taking the antiretroviral medicines every day. Before knowing their status, adolescents reported poor adherence; this improved with knowledge of their status. Adherence to ART has many benefits including improvement in physical health and psychological health. Improvement in physical symptoms of HIV and CD4 count motivated adolescents to adhere to ART as it improved their belief in the efficacy of the drugs. Improvement in physical health to normal appearance, making them less readily identifiable or visible as HIV positive, improved their adaptation and psychological adjustment to their HIV positive diagnosis, and thus their health. However optimal adherence was affected by a multiple factors at individual, family, health system, and policy levels, with the fear of stigma, poverty, hunger and food insecurity, and lack of psychosocial support cited as the key barriers. Others included side effects, pill burden for those who were not on fixed-dose combination ARVs, and treatment fatigue.

Meaning of and response to HIV-positive diagnosis

Adolescents who participated in the qualitative phase of the study stated that their initial response to their HIV-positive diagnosis varied from being shocked and sad, being indifferent to being happy. The initial reaction changed over time to acceptance of the HIV-positive status and planning how to live with the virus. Most of the adolescents reported being shocked, sad, hurt, and in disbelief, and crying when they learned that they were HIV positive. Adolescents said they did not expect to be HIV positive because they were virgins and because HIV was known to be transmitted through heterosexual contact with an infected person, they wondered how they could have been infected. These initial reactions were replaced by anger directed towards their parents whom they blamed for infecting them with HIV through mother-to-child transmission. Anger later resolved to acceptance and plans for how to live with the virus.

During the time of the study, all the adolescents had accepted their HIV illness, except for one who seemed to still be struggling to come to terms with the diagnosis. How adolescents responded to a positive diagnosis was influenced by several factors including the manner in which adolescents got to learn of their status, and the availability or lack of psychological, emotional, and material support particularly from their family and health system, but also from the community. Other factors included communication about HIV between them and their parents or guardians, the belief in the efficacy of ARVs to manage HIV, knowing that though they could not change the fact that they were living with the virus, they could embrace it as part of their life and their own personal efficacy (belief in their abilities) to manage the illness. Similar responses to knowledge of HIV status by adolescents have been reported elsewhere in resource-limited countries in the region such as Kenya (Gachanja, 2015), and resource-rich countries such as the US (Lyon and D'Angelo, 2006; Sawyer et al., 2007).

Adolescents whose parents were also living with HIV and openly discussed HIV with them were able to adapt easier and faster than those in families where HIV was silenced. Manqoba and Lungile were able to embrace their diagnosis and ART because of their mothers' open communication about HIV with them while Sizwe still struggled with anger and disbelief three years after being diagnosed with the virus. Those who were indifferent when informed of the positive diagnosis lacked an understanding of what it meant to be HIV positive and the implications of living with the virus.

An HIV positive diagnosis is almost always received with shock, sadness, anger and disbelief. Such reactions were no different for the adolescents in this study. In fact, a positive reaction was mentioned by only one adolescent, which had to do with the relief to finally know what caused his chronic health problems.

Experience and management of stigma

> . . . the study of stigma has focused too heavily on psychological approaches and has neglected to sufficiently incorporate understandings of stigma and stigmatized individuals as embedded in local moral contexts. . . . [U]nderstanding the unique social and cultural processes that create stigma in the lived worlds of the stigmatised should be the first focus of our efforts to combat stigma (Kleinman and Hall-Clifford, 2009:418-419)

Despite almost universal access to free antiretroviral therapy and the change in the HIV disease trajectory from a fatal to a chronic condition, stigma remains pervasive, affecting adolescents' access to testing, enrolment in and adherence to ART, retention in care, and disclosure of HIV status. Empirical studies within and outside the country have reported perceived stigma as the most prevalent among people living with HIV and their families. I also found that perceived stigma was the most prevalent among adolescents, forcing those diagnosed with the virus to actively manage their status through concealment, silence, secrecy, and optimal adherence to or skipping of ART. While most adolescents reported fear of stigma, a few had actually experienced discrimination as a result of their HIV-positive status.

This difference in stigma experience is reflective of the context-based complexity and dynamism of attitudes that people have towards those living with HIV (Mechanic, 1995). Besides being stigmatised for being HIV positive, some of the adolescents faced stigma related to being born to unwed parents, being orphans, being poor, and being born to parents who were HIV positive, all of which added layers of stigma that exposed them to other forms of deprivation, such as a lack of psychosocial and practical support from family members, which compounded a sense of not belonging. Faced with these forms of social suffering, some adolescents found acceptance and belonging in support groups, which provided them with a sense of emotional security and a 'feeling of being at home', of 'belonging together and forming relationships with each other'(Goffman, 1963:23–24).

Similar findings have been reported elsewhere. In a study on experiences of stigma and discrimination among women living with HIV in central Thailand, Liamputtong, Haritavorn, and Kiatying-Angsulee (2009) report that their participants turned to support groups after they were discriminated against on the basis of their HIV status. In the support groups the women stated that they made 'real friendships', and gained emotional support and a sense of belonging. As a result they felt less isolated (ibid., 2009: 866-–867). Other studies have also alluded to the role played by support groups in the enhancement of psychological and emotional well-being, positive self-concept, and confidence among adolescents living with HIV (Bohle, 2013; Mavhu, etal., 2013; Menon and Glazebrook, 2013; Mupambireyi et al., 2014; Sikstrom, 2014). In the support groups adolescents are able to be themselves; to talk and share information about their illness and treatment as well as their challenges and hopes about the medication, the disease itself and about the future (Kajubi, etal., 2014; Mattes, 2014) and feeling loved and valued (Posada, Rincon, and Orcasita, 2014). One participant in a study among men living with HIV and on ART in South Africa remarked: 'I like coming here; here is like home to me. I mean this support group! The support group gives me life [*i-support group iyangiphilisa*]. . . . I like coming here and interacting with people and helping others (Khaya, quoted in Mfecane, 2010: 12). Writing on epilepsy-related stigma, Ablon (2002) noted that support groups enhance participants' self-image and confidence as a result of being accepted and by virtue of having an increased probability of forming lasting relationships.

Empirical evidence suggests that a life-threatening and chronic disease like HIV causes a lot of psychological trauma among adolescents (see Fawzi et al., 2010; Cluver, Gardner, and Operario, 2008). Locke notes that despite the realisation of the enormous psychological impact of the epidemic, 'efforts to reduce suffering have habitually focused on the control and repair of individual bodies. The social origins of suffering and distress, including poverty and discrimination . . . are set aside' (Locke 1997: 210). This is true for adolescents' services: the focus is on using medicines to fight the virus that has invaded the physical body, with little or no consideration of the whole social person. During my fieldwork, I found that psychological care and support services specific to adolescents are very limited, and are often provided by private practitioners in the country. A holistic, adolescent-centred approach that considers the social, psychological, emotional, and relational human being is needed in the delivery of HIV care for adolescents.

Experiences with and management of disclosure

> The issue is not that of managing tensions generated during social contacts, but rather that of managing information. . . . [T]o display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to who, how, when and where. (Goffman, 1963:42)

Despite the acknowledgement of its numerous social, psychological, and physical/clinical benefits (Vreeman et al., 2013; 2010), informing adolescents of their HIV status was experienced as the most contentious component of HIV care among family members, particularly in stepfamilies, and described as psychologically and emotionally challenging across all caregivers in all types of families. Hence disclosure of adolescents' status was delayed in most cases.

The study found that disclosure is closely related with stigma. In fact, the decision to disclose or not, to whom, how, and how much are all planned around the management of stigma. Hence, despite growing consensus on the benefits of disclosure to adolescents and caregivers, a large body of scholarship shows that parents or guardians often delay telling adolescents that the adolescents are infected with HIV (Gachanja, Burkholder and Ferraro, 2014; Kiwanuka, Mulogo, and Haberer, 2014; Mahloko and Madiba,2012;Mburu et al., 2014;

Motshome and Madiba, 2014; Sahay, 2013). The delay is due to the fact that disclosure poses complex challenges pertaining to the transmissibility of the virus in vertical infections, parental guilt, parents’ own HIV status, and the potential for social stigma and isolation, among others.

Although most of the adolescents in this study tested for HIV and started taking ARV drugs when they were still young, very few knew about their HIV status prior to adolescence or that the pills they were taking were in fact ARVs. As they grew older and became ‘tired of the pills’ they started to either default or ask questions about what the pills were for, why they were taking them, and when they will stop taking the pills. Some shared that when they asked the questions they were already suspicious that they might be HIV positive, after they had heard from friends, radio or television, or observed other people taking the same pills at the same time every day, or were taught about HIV in school. So contrary to reports in some studies that adolescents wait to be told of their status by parents, guardians, or health care workers, this study found that adolescents actively seek to know their HIV status and about the medicines they are taking based on information they have from different sources.

Through their stories of disclosure, adolescents demonstrated that how they were informed about their status, and the timing, context and tone of disclosure, had a huge influence on their lived experience of HIV. Some stated that delaying disclosure had a negative influence on their adjustment to living with HIV. The study also showed that the circumstances of telling or disclosing varied based on the relationship between the person performing the disclosure and the adolescent. Adolescents who lived with their parents (particularly a biological mother) who were also HIV positive did not experience as much negative emotions because of the caring tone used by the discloser, while others had negative experiences with disclosure. This finding is also reported by Vreeman et al. (2013). In their systematic review on disclosure of HIV status to children in resource-limited settings, the researchers found that disclosure was delayed, was often done in response to questions by children about their illness or medication, or because of poor adherence. They further reported that delaying disclosure resulted in psychological discomfort to both parents and adolescents, and recommended the provision of supportive resources to parents and children during the process of disclosure.

Adolescents expressed that they preferred to be told about their status by health care workers as this would accord them the opportunity to ask questions and know more about HIV, medications, and how to live better with the chronic illness. However support from health care workers was very limited and in some cases not provided even when parents sought it. The main reason cited by health workers was that the current guidelines do not allow them to disclose to adolescents, but rather it is the responsibility of parents or guardians to do so. This was puzzling given that empirical evidence shows improvement in adherence when adolescents are informed about their HIV status, and educated about the HIV disease and antiretroviral treatment, which in turn improved clinical outcomes of the drugs, a mandate and core function of the health sector. In addition studies have reported improvement in mental well-being, reduction in stress levels, and self-esteem following disclosure. Given the benefits, I would have expected health workers to make exceptions and assist those parents who had difficulty in disclosing the HIV status to adolescents resulting in poor adherence, than to rigidly follow the policies. First, the guidelines and polices on which the health work derive their position have made the blanket pronouncements without taking into considerations the complexities of the family structures from which adolescents come when seeking HIV services. One would expect that with the long period of HIV existence, and the vast studies carried out on how the epidemic has changed the structure in some families particularly in high burden settings like Swaziland, such policy positions would be flexible to accommodate situations where the family is unable to disclose to the adolescents. Second, the health sector has, in many policy documents emphasized a human rights approach in the delivery of HIV services including the right to full information to patients about treatment–treatment literacy. Therefore, given the benefit of knowing one’s status, such as improved adherence, one would expect that the health care providers would do “what is in the best interest of the child [adolescents” by taking it upon themselves to disclose to those adolescents whose parents or guardians agree that they need to be disclosed to, but who find it difficult or impossible to do so themselves.

This finding is also reported in a study in neighbouring South Africa. In their study on health care workers’ perspectives on HIV disclosure to those infected with HIV, Madiba and Mokgatle (2015b) state that health care workers viewed their role as that of preparing the caregiver to disclose. As the national ART coordinator acknowledged that as a programme they had not anticipated the difficulties and different forms of families in their development of the policies or guidelines, it was recommended that the policies be revised and close this gap, in the interest of the health of adolescents and parents/guardians.

A quest for normal life

Despite their HIV-positive status and the uncertainties of living with HIV, adolescents did not experience having HIV as a limitation on their plans and dreams fora normal future, that is, finishing school, enrolling in tertiary education, establishing careers, starting their own families, and protecting others from HIV. ART provided them with hope for a longer normal life, hence they adhered to treatment.

The central role of and fluidity of the family

One of the key findings of the study is the centrality of the family with regards to decisions about testing, the meaning and experiences of living with HIV, as well as managing stigma and disclosure. However, the meaning of family kept changing between the different participants and by the same adolescents at different times in the disease and illness trajectories, as well as in response to different needs. Adolescents have expectations from families such as a sense of belonging – where they want to feel that they are accepted, welcomed, and connected – and having their needs met at different conjunctures of the HIV continuum of care. The need and desire for belonging – a feeling of being connected, unconditionally accepted, welcomed, and valued – was central to the meaning of the family in the lives of adolescents. However, for most of the adolescents in the study, this need was not met or was partially fulfilled. Adolescents who lacked psychological and emotional support from families turned to support groups for such, which some described as 'one big family'.

As discussed in chapter four, HIV policies and guidelines require the engagement of families as primary care units for adolescents living with HIV. These policies – though silent on what or who should be considered family in practice – emphasise the human rights approach in delivering care at every level, which means prioritising 'the best interest of the child'. This approach is articulated in the Child Protection and Welfare Act (2012: S17-S18) which stipulates that a child has a right to an opinion, and to refuse to uphold cultural practices that are likely to affect the child's life, health, welfare, and dignity. The Act orders that the best interest of the child must be held supreme in the execution of decisions pertaining to the child. An arrangement based on this child rights discourse as stated in the Act would allow, for example, Lindani to stay with his paternal family according to his wishes and availability of resources. However, such an approach would be contradictory to the cultural practices of *inhlawulo* and *lobola.*

The central role of the family in the everyday lives of adolescents– in its different forms – was also evident in decisions about HIV testing and enrolment in HIV treatment, encouragement regarding adherence to ART and retention in care, and approaches to managing stigma and disclosure of HIV status. These decisions were made by parents or guardians in consultation with selected family members where possible, but rarely with adolescents. The lack of involvement of adolescents in decisions relating to their health is rooted in the cultural framing of adolescents as passive beings whose needs can best be addressed by their elders. This conceptualisation of adolescents is contrary to the child-centred approach that identifies them as active agents, and also contradictory to the tenets of ART, which emphasises full involvement and ongoing participation of PLHIV, including adolescents, in their care and treatment as 'responsibilised therapeutic citizens' (Nguyen, 2010).

The centrality of the family also became evident in adolescents' meaning making and experiences of living with the virus. Though sharing a biosocial and therapeutic identity – being HIV positive, on antiretroviral treatment, and in chronic care – adolescents' experiences of HIV were uniquely different for each one of them. In addition to family circumstances (type of family, interpersonal relation within and between family members, and socio-economic and living conditions) the adolescents' birth circumstances and current life conditions, and availability (or lack) of support and resources influenced adolescents' meaning and experience of living with the virus, and the tactics they used to navigate their circumstances (see Fenio, 2011). Through strategic and tactical navigation of the micro- and meso-structures, adolescents were able to challenge, resist, and reshape the macro-level policies and beliefs that shape local meanings and practices with regards to HIV.

Recommendations

Policy

There is need for meaningful, proactive, and ongoing involvement of adolescents in the planning and setting of policies that purport to address their health needs with regards to HIV. This should be a priority and starting point towards making services more 'friendly' to adolescents. This is because adolescents know best what they need and how their needs can be met. In their commentary ‘Adolescent health in the 21st century’, Blum, Bastos, Kabiru, et al. (2012: 1568) lament the lack of information about adolescent health in developed and developing countries and propose a ‘greater understanding of the aspirations and concerns of young people to develop [targeted and relevant] evidence based policies and programmes’. Similarly, the findings in this study underscore the need for a socio ecological approach to understanding the needs of adolescents to inform policies, planning, and programming interventions geared towards improving access to and use of HIV services by adolescents, and to reducing stigma.

There is also an urgent need to revisit the policy position that prevents health care workers from informing adolescents of their HIV status even where parents and the adolescent seek the service, so that they can benefit from disclosure. Health care workers should be urged to address each situation individually rather than taking ‘a one-size-fits-all’ approach. This is particularly important for adolescents whose lack of knowledge about their status and ART affects their adherence. Secondly, it is important for adolescents to know of their status as they are at a developmental stage where they may want to experiment sexually or engage in romantic relations. Thus knowing their HIV status may help them make informed decisions such as delaying sex, engaging in non-risky sexual activities, or use protective measures such as condoms to protect their partners and themselves. In doing so, they will be indirectly contributing to reducing HIV transmission.

While acknowledging the need and benefit of reducing the age of consent in increasing the likelihood that adolescents access to services will be improved, it is equally if not most important that support systems at every level of the ecological system be put in place or strengthened. As shown in the study from focus group discussion, some adolescents reportedly took their own lives after learning that they were HIV positive, while others turned to drugs and alcohol or risky sexual behaviour. A strong and readily available adolescent-friendly support system is urgently needed.

Programme

The fact that adolescents present to health facilities for sickness-related care several times before they are tested is not acceptable. Specific strategies for the early identification and diagnosis of adolescents with HIV need to be developed or strengthened, to reduce not only physical symptoms but also social suffering that comes with unknowingly living with a chronic illness such as HIV, in this population while diagnostic measures are available.

Interventions to address stigma should be cognisant of the multidimensional and layered stigma that adolescents experience and thus work towards addressing the non-medical or disease-related stigmas as well such as being disowned by a parent or kicked out of your family house because of your HIV positive status. Such all-encompassing stigma interventions may go a long way in improving adherence and decreasing the shifting to second or third line ART regimen or MDR-TB drugs regimens that are expensive and have more side effects than the first line. Health care workers have to be trained on how to manage structural challenges such as family relations that impact the care of adolescents.

There is need for the country to move away from the current practice of capturing, collating, and analysing data by broad age bands, and toward producing data that specifically captures the vulnerable situation of many adolescents. As mentioned, the current broad bands of children and adults shrouds the scale of HIV among adolescents, and without this statistical knowledge, their needs will remain hidden.

The need to rethink current delivery approaches and to move out of the health facilities and into communities and schools must be explored. There is empirical evidence that when services are moved out of the clinics and hospitals the number of adolescents who test increases. The shift however should also have plans to ensure privacy and to provide ongoing psychological support after testing, given the emotions experienced with a positive diagnosis.

Further research

The role of sexuality, gender, and gender roles in risk and vulnerability perception by adolescents requires further research.

There is also need to qualitatively explore the prevalence of stigma among and the self-destructive tactics by adolescents in the urban settings.

The study showed that despite being knowledgeable, and having health facilities at their disposal, fewer urban adolescents are using HIV services compared to those from rural areas. There is an urgent need to further investigate either quantitatively or qualitatively to understand the dynamics that cause urban adolescents to not test for HIV.

Finally it would be very beneficial for the country to qualitatively explore the reasons for HCW not to provide HIV testing to young people when they come for health care.

Conclusion

In this study I explored the perspectives of adolescents with regards to access and use of HIV services as well as the lived experiences of adolescents living with HIV in different family contexts in a rural and urban setting in Swaziland. Instead of exploring and describing adolescents' experiences from the caregivers' standpoint, in this study my main goal was to demonstrate adolescents' experiences from their own perspective. This I achieved by putting adolescents at the centre of the study while situating their lived experiences within the broader social environment, and engaging with adolescents as active agents in shaping their own social world.

The study has demonstrated that adolescents are willing to access HIV services, such as HIV testing, for their own current and future health and life plans, but context and structural factors limit their access. While efforts have been made to address barriers, by for instance initiating 'adolescent-friendly corners', these still fall short in improving access. Adolescents suggested that services should be provided outside the confines of the health facilities to spaces that are familiar to adolescents such as home, school, and youth centres, and should be provided by compassionate and competent health personnel. Evidence from neighbouring countries suggest that offering HIV services outside the health facility environment increases the reach to adolescents who would otherwise not use the formal health system for various reasons, including not being sick.

The study has shown that adolescents' constructions of meanings and experiences of living with HIV are shaped by their social circumstances. These include the nature and quality of their relationships within the family, the availability or lack of support at the family level, the practices at the health facility level, and policies and legal instruments that govern and direct the delivery of HIV services.

The study demonstrated the dynamism and fluidity of the family, not only in terms of composition or function in different social contexts and by different individuals within same social contexts, but also in terms of the context in which it was perceived by the participants. I have showed the major dimensions of the family from adolescents' perspectives, which include being connected, accepted, welcomed, and sharing, all of which describe belonging. It is important for policy makers and program directors and implementers to appreciate the dynamism of the family, and that the meaning of the family is contextually embedded in adolescents' everyday life experiences at particular junctures of their lives and different aspects of the management of HIV. Policy makers, program staff, and health care workers need to acknowledge and understand the complex and fluid nature of the family as it relates to different contexts and moments in adolescent care, and embrace an approach that individualises the care they provide. This contextualisation of policies and guidelines should happen through the active involvement of adolescents.

The study suggests a need for a socioecological and holistic approach to planning, programming, and implementation of adolescent HIV services. Programmes currently tend to focus on managing the diseased body, and little to no interventions are available for the whole person. Most of the adolescents in the study expressed emotional needs. Although a few facilities provided psycho-emotional care through support groups and camps, these are highly structured and managed. Interventions to address nonmedical individual needs were not available, even though if these needs are not met they would interfere with adherence to the biomedical interventions such as ART.

What was critically apparent in adolescents' narratives was the longing for belonging: a sense of being connected, accepted, and welcomed was paramount to adolescents' descriptions of the family. Being part of a support groups– 'teen clubs'– provided most adolescents a space for social interactions and the filling of the emotional emptiness, described as a 'deep hole', caused by the sense of being 'different from normal adolescents' who were born of and living with married and biological parents, not HIV positive, and not requiring daily treatment and frequent health monitoring.

The study demonstrated the multidimensional, multilayered nature of stigma that adolescents experienced and had to deal with in their everyday lives. The perceived and enacted stigma experienced by adolescents was not limited to HIV, but extended to other forms of deprivation emanating from or perpetuated by their equally stigmatised social identities– being born of unwed parents, being an orphan, and being poor – which added complex layers of stigma that had to be strategically navigated. Concealment of their status through active management of personal information, secrecy, and silence, limited and strategic disclosure, and optimal adherence to ART were tactics used to avoid or manage stigma.

In their narratives, adolescents shared that disclosure occurred as a series of unrelated and discrete occurrences, which lacked any follow-up discussions. This was more common among those who were double orphans and those who were not living with biological parent(s). Disclosure to adolescents by their caregivers was experienced as a difficult but essential responsibility, carried out by mothers or grandmothers, often without consultation with adolescents. Because of the complexity of disclosure, it was, in most cases, delayed and done so in response to poor adherence to ART.

Despite the many challenges that adolescents faced or experienced, which at times caused uncertainty and trepidation, they remained optimistic about the future; being HIV positive was a motivating factor to pursue their studies with vigour so that they obtained good marks and could enrol in tertiary education and become competitive in the job market. They shared their dreams and hopes of being doctors, nurses, and social workers so that they could help other children in situations like theirs. Starting their own families and protecting their spouses and children from HIV were important aspects of their plans for the future. Until an HIV cure is found and made available, optimal adherence to ART was spoken about as an important part of this envisioned future.

Summary English

The main objective of this predominately ethnographic, mixed methods study was twofold: first it was explore adolescents' access to and utilisation of available HIV services including testing, and antiretroviral treatment as well as adherence to the treatment and retention in HIV care. The second objective was to gain in-depth insight into the experiences of adolescents living with HIV in different family contexts in Swaziland, from the perspective of adolescents themselves. While the experiences of adolescents living with HIV have been researched before, the uniqueness of this study lies in its comparative approach by situating the experiences of adolescents in the different types of families in which they lived. Therefore, the study aimed at understanding and describing how adolescents, as agentive actors, experience and navigate the social and health system environment as they manage HIV related illness and disease respectively. The study is one of three social science studies carried out as part of a public health intervention implemented by the Ministry of Health, in conjunction with local and international NGOs and academic institutions– the *Max*ART Consortium. The Consortium's objective was to increase the number of people who access and utilise HIV services in Swaziland. The dissertation is based on two years of fieldwork carried out in two communities in Swaziland: one rural and one urban.

The study is presented in three parts: the first part provides an introduction and background, and the methodological approach. Part two presents the study findings, while the last part presents a discussion and conclusion.

Chapter one provides an introductory background to the magnitude of HIV and AIDS in Swaziland as well as the impact the epidemic has had on families and adolescents. The HIV epidemic became evident in Swaziland in the mid-1980s when the first person with HIV was diagnosed in 1986 while the following year, 1987, another was diagnosed with AIDS. Since then the epidemic has spread rapidly within the population, reaching high prevalence rates of 42% among pregnant women in 2004, before stabilising in 2005 and showing a steady but slow decline from 2008. In 2014, about a quarter of the approximately 1.2 million people of Swaziland were living with the virus, the highest population proportion of HIV in the world. Between the years 1992-2008 the mortality, particularly among middle aged adults who were in the prime of their reproductive and economically productive years, reached alarming

proportions. This was because antiretroviral treatment was not available in the country until 2004, and even when the drugs became available, people were still not accessing services. Access to services was low due partly to stigma and denial, and partly to lack of geographical access as the treatment services were only available in the national referral hospital. The high mortality among young parents and bread winners had a negative impact on individuals, families, communities and society at large. AIDS became the leading cause of morbidity and mortality, taking the lives of more than 7000 Swazi people per year. As a consequence, the number of orphaned children increased: by 2012, the number of children who had lost either one or both parents to AIDS-related illnesses was estimated at 78,000, representing 65% of the 120,000 orphans in the country. In addition, families changed in terms of structural composition, and poverty and dependency increased as families had no access to material and financial resources. Care of children born of the young parents who were succumbing to the epidemic was taken over by surviving family members, often grandmothers in what is now commonly referred to as skipped-generation families. Others were taken care of by other extended family members, while some were left to fend for themselves in what came to be known as child-headed households. In some cases, surviving spouses remarried and children had to live and grow up in stepfamilies.

Chapter two discusses the methodological approach used in the study. Data was collected using qualitative and quantitative techniques (methodological triangulation) from different sources (data source triangulation). Primary sources of data were adolescents whose data was triangulated with that of secondary participants including parents, guardians, teachers, community leaders, traditional and faith healers and key informants. A total of 467 participants provided qualitative data; sixteen of which were adolescents living with HIV that I followed over a period of 18 months. Eight hundred and fifty nine respondents took part in a quantitative survey. I used the social-ecological framework, actor-centred approach and social navigation concept as analytical lenses to understand the experiences of adolescents, as well as the tactics they used to navigate their social and health environment.

Chapter three to chapter seven form part two of the thesis in which I present findings of the study. **Chapter three** gives a brief background about the sixteen adolescents I followed more intensely, with whom I had between two and eight interviews each over 18 months. All sixteen adolescents were knowingly living with HIV and were on antiretroviral treatment. All but two were orphans who were either living with a single parent or other family members, mostly grandmothers. Some adolescents had parents or other family members who were also living with the virus and were on antiretroviral treatment. This was critical for adolescents as these family members formed a support system for each other.

Chapter four provides insight into the different family contexts in which the adolescents lived. Pertinent in this chapter is how the family was variously referred to by the different participants. While adults spoke of family in terms of paternal family having met cultural obligations of *lobola* or *inhlawulo*, central to adolescents' reference to family was the sense of belonging which they described as a feeling of being connected, accepted unconditionally, welcomed, and valued. However, for some of the sixteen adolescents in the study who were living with HIV and on ART, and who were living either with single parents, skipped-generation families, stepfamilies or blended families, the need for belonging was either not met or was partially fulfilled by their families. For others who had family support, such as Simangele, there was still a desire to be part of the adolescents with whom they shared a bio-therapeutic identity. Support groups, though not replacing the family as conceptualised by Levine, provided the forum to connect and share with other adolescents who were like them. Most of the adolescents often spoke of support groups as 'like a family' or 'one big family'.

Chapter five presents findings on access to, motivations for and barriers to HIV testing and treatment, adherence to ART, and retention to HIV care, from the perspective of the adolescents who participated in the quantitative survey and focus group discussions. The adolescents included those who were knowingly living with HIV and on ART who were purposively selected through facility based support groups, while others were from the study communities and were not asked of their HIV status. The study found that a majority of adolescents living with a HIV were tested for the virus after they had had several interactions with the health system as a result of recurrent sickness. Failure to test adolescents for HIV when they present to a health facility offering the service is reflective of a missed opportunity to early and appropriate diagnosis and care, and a poor integration of HIV services to the overall health care. Requirement for parental consent, as well as lack of skill in adolescent counselling by health care workers were cited as reasons for this missed opportunity. While there is evidence that adolescents are a difficult group that is not willing to test for HIV, adolescents participating in the survey and focus group discussions who did not know their status stated they were willing to test for HIV; however several barriers including perceiving the clinic as a space for the sick, fear of HIV positive diagnosis, parental reaction to an HIV positive diagnosis, negative attitudes by health care providers and requirement for parental consent prevented adolescents from finding out their status. Adolescents proposed that HIV services targeting adolescents should be provided in areas frequented by them such as schools, their homes or youth centres, with strict maintenance of confidentiality and privacy. The study also found out that adolescents who were on ART while not disclosed to about their HIV status and not informed about that they were taking ARVs adhered poorly to treatment. Poor adherence was reported by both the sixteen adolescents that I followed closely for 18 months, those who participated in focus group discussions, and those who were part of Sivivane camp with whom I had once off interviews. In fact poor adherence was the reason for bringing adolescents together for the camp to empower them on the importance of taking ART optimally. For adolescents the poor adherence was not deliberate but rather because they didn’t know they were living with the virus, lacked knowledge about ARVs, and were tired of taking the pills every day. However, once they were informed of their diagnosis they achieved and maintained optimal adherence, meaning disclosure is of essence in the HIV treatment and care trajectory for adolescents.

Despite the uncertainty and trepidation of being HIV positive, adolescents remained optimistic about the future, and desired to be “normal”. They stated that being HIV positive motivated them to work hard in their studies so that they could obtain good marks that would enable them to enrol in tertiary education and become competitive in the job market. They shared their dreams and hopes of being doctors, nurses, and social workers so that they could help other children in situations like theirs or being policeman so that they could earn a lot of money. Starting their own families, and protecting their spouses and children from HIV were important aspects of their plans for the future.

Chapter six turns to stigma. Here I found that while a few adolescents had experienced acts of discrimination by family members such as being disowned or socially secluded and segregated, most had not experienced enacted stigma but lived in fear of being stigmatised, that is perceived stigma. This led to adolescents keeping their status a secret and only disclosing to a few family members. In addition to keeping their status secret, managing information about their status was achieved by use of several tactics such as adhering to treatment so that they appeared physically normal with no overt signs of illness, and also to ensure they did not get opportunistic infections that could sell them out. Since adolescents living with HIV and on antiretroviral treatment have to visit a health facility on a monthly basis for health monitoring and refill of their HIV treatment, some lied to their teachers when seeking permission on a school day, stating instead that they were suffering from TB or used free school time such as sports period to avoid seeking permission that would require explanation.

Chapter seven dwells on disclosure. Very prominent in this chapter is the difficulty in disclosure experienced by the different families. Parents, stepparents or grandparents and other family members stated that it was emotionally and psychologically challenging for them to disclose to adolescents, describing it as a traumatic process. However, the cause of the emotional and psychological trauma differed in that while stepparents’ struggle is about who should tell an adolescent about his HIV status, for biological parents the difficulty lies in having to explain how the adolescent may have been infected. This is true for adolescents who were virgins and got infected through mother to child transmission, and led to a delay in informing them of their status, which then influenced adherence as already alluded to earlier. Parents who turned to health workers to assist with disclosure to adolescents met resistance; health workers who perform the tests and diagnose the adolescents, stated that it was parents’ or guardians’ duty to disclose, and their role only was to support the process between parents/guardians and their children. Adolescents on the other hand stated that they would have appreciated to be informed of their status earlier and preferably by health workers as they could ask and be provided with relevant answers. Hence for most adolescents disclosure was delayed. In some of the cases where adolescents were informed of their status, it was done as a form of crisis management when either the adolescents refuse to take treatment, and out of fear about possible resistance and limited choice in antiretroviral treatment. With the increased prospect of death, parents or guardians felt compelled to inform adolescents about their status and treatment. It must be noted that at the time of data collection, that is 2012-2013, Swaziland had only two choices of antiretroviral regimens: first line treatment was given to every person initiated on ART unless there was reason for not giving him/her such as prior exposure to antiretroviral medication. If a person experiences problems with the first line regimen, such as resistance against some of the drugs that form part of the regimen, the person is switched to second line regimen. The second line regimen has several challenges, particularly severe side effects in comparison to the first line treatment. In addition, if a person experiences problems with the second line regimen, then there would be no further treatment to give to the person. Therefore efforts were to ensure that people including children and adolescents remain on the first line regimen as long as possible, through disclosure to enhance their understanding of the need for optimal adherence. So there was fear among parents or guardians that if their children do not take their treatment as prescribed, they run the risk of developing resistance, thus limiting their choice of treatment and increasing the chances of death.

In some cases, adolescents were informed of their HIV status as a response to their persistently asking reasons for, or about the treatment they were taking from parents or guardians.

The last chapter, **chapter eight,** provides a discussion and conclusion of the study, including recommendations. The recommendations are divided into three: those relating to policy, programmatic issues and issues for further research.

Samenvatting Nederlands

Het doel van dit overwegend etnografisch onderzoek was tweeledig. Allereerst was het doel te exploreren hoe toegankelijk de beschikbare HIV zorg voor adolescenten is en hoe zij er gebruik van maken (zowel wat betreft testen en behandeling als therapietrouw en zorggebruik). Het tweede doel was om diepgaand inzicht te krijgen in de ervaringen van adolescenten met hiv in verschillende familieverbanden in Swaziland, vanuit het perspectief van de adolescenten zelf. Hoewel de ervaringen van adolescenten met hiv al eerder zijn onderzocht, is dit onderzoek uniek vanwege de vergelijkende aanpak: de ervaringen van de adolescenten worden in verband gebracht met de verschillende soorten gezinnen waarvan zij deel uitmaken. Het onderzoek beoogde te begrijpen en te beschrijven hoe de adolescenten zich als actieve, zelfstandig denkende leden van de samenleving bewogen binnen de sociale en gezondheidssystemen bij het omgaan met hiv. Dit onderzoek is één van drie sociaalwetenschappelijke onderzoeken uitgevoerd als onderdeel van een volksgezondheidsinterventie geïmplementeerd door het Ministerie van Gezondheid in Swaziland in samenwerking met lokale en internationale ngo's en academische instellingen – het *Max*ART Consortium – die als doel had het aantal mensen dat toegang heeft tot en gebruikmaakt van hiv-diensten in Swaziland te vergroten. Dit boek is gebaseerd op twee jaar veldwerk in Swaziland, in zowel een rurale als een urbane omgeving.

Het onderzoek wordt in drie delen gepresenteerd. Het eerste deel bestaat uit een inleiding met achtergrondinformatie en beschrijft de methodologische aanpak. Deel twee bevat de onderzoeksresultaten en het laatste deel bestaat uit een bespreking en de conclusie.

Hoofdstuk 1 geeft inleidende achtergrondinformatie over de enorme omvang van hiv en aids in Swaziland en de impact van de epidemie op gezinnen en adolescenten. De hiv-epidemie kwam in Swaziland aan het licht toen in 1986 de eerste persoon met hiv werd gediagnosticeerd. Vervolgens werd een jaar later, in 1987, iemand anders gediagnosticeerd met aids-gerelateerde ziekten. Sinds deze twee diagnoses heeft de epidemie zich snel verspreid onder de bevolking, oplopend tot de hoge prevalentie van 42 procent onder zwangere vrouwen in 2004 totdat het zich in 2005 stabiliseerde en een gestage daling liet zien in 2008. In 2014 had ongeveer een kwart van de 1,2 miljoen mensen in Swaziland hiv, het hoogste bevolkingspercentage in de wereld. In de jaren 1992-2008 bereikten met name de sterftecijfers onder volwassenen van middelbare leeftijd in de bloei van hun reproductieve en economisch productieve jaren alarmerende hoogten. De reden hiervoor was dat er tot 2004 geen antiretrovirale behandelingen beschikbaar waren in dit land, en dat zelfs toen de medicijnen beschikbaar kwamen de mensen nog steeds geen gebruik maakten van de zorg, deels vanwege stigma en ontkenning en deels vanwege gebrek aan geografische toegankelijkheid, omdat de zorg alleen werd aangeboden in het nationale referentie ziekenhuis. Het hoge sterftecijfer onder jonge ouders en kostwinners had negatieve gevolgen voor individuen, gezinnen, gemeenschappen en de samenleving als geheel. Aids werd de belangrijkste ziekte- en doodsoorzaak en jaarlijks overleden als gevolg hiervan meer dan 7.000 mensen. Daardoor steeg het aantal weeskinderen: in 2012 was het geschatte aantal kinderen dat één of beide ouders had verloren door aids-gerelateerde ziekten 78.000, een aantal dat neerkomt op 65 procent van de 120.000 wezen in het land. Bovendien veranderden de gezinssamenstellingen en namen armoede en afhankelijkheid toe, aangezien gezinnen geen toegang hadden tot materiële en financiële bronnen. De zorg voor de kinderen van jonge ouders die bezweken aan de epidemie werd overgenomen door de achtergebleven familieleden, dikwijls grootmoeders, in wat we in het Engels *skipped-generation families* noemen, generaties waarin de middelste generatie, die van ouders, ontbreekt. Ook andere leden van de grootfamilie zorgden voor de kinderen, terwijl sommige kinderen zich moesten redden in gezinnen die bekend werden als door kinderen gerunde huishoudens. In sommige gevallen hertrouwden de overlevende ouder en moesten hun kinderen wonen en opgroeien in stiefgezinnen.

In **Hoofdstuk 2** wordt de methodologische aanpak van het onderzoek beschreven. Gegevens zijn verzameld met gebruikmaking van kwalitatieve en kwantitatieve technieken (methodologische triangulatie of driehoeksmeting) en vanuit verschillende bronnen (triangulatie van gegevensbronnen). De primaire informatiebronnen waren de adolescenten. Hun data werden getrianguleerd met die van secundaire deelnemers zoals ouders, verzorgers, leraren, gemeenschapsleiders, traditionele en religieuze genezers en sleutelinformanten. In totaal 467 deelnemers leverden kwalitatieve data; zestien van hen waren adolescenten met hiv die werden gevolgd over een periode van achttien maanden. Aan het kwantitatieve onderzoek namen 859 respondenten deel. Een sociaal-ecologische benadering werd gecombineerd met een aanpak waarin de handelende mens centraal staat (*actor-centred approach*) en met de sociale navigatietheorie. Deze theorieën werden gebruikt als analytische lenzen om de ervaringen van de adolescenten te begrijpen, alsook de tactieken die zij gebruikten om hun sociale omgeving en het medisch landschap te navigeren.

De hoofstukken drie tot en met zeven vormen deel twee van de thesis, waarin ik de bevindingen van het onderzoek presenteer. **Hoofdstuk 3** geeft een korte schets van de achtergrond van de zestien adolescenten met wie ik tussen de twee en acht gesprekken voerde over een periode van achttien maanden. Alle zestien wisten dat ze hiv hadden en kregen een antiretrovirale behandeling. Allen behalve twee waren wezen die bij een alleenstaande ouder of bij andere familieleden woonden, voornamelijk bij hun grootmoeders. Van een aantal van deze adolescenten leefden de ouders of andere familieleden ook met het virus en werden daarvoor behandeld. Dit was belangrijk voor de adolescenten vanwege de sociale steun die ze elkaar konden geven.

Hoofdstuk 4 geeft inzicht in de verschillende gezinssituaties van de adolescenten. Van belang in dit hoofdstuk zijn de uiteenlopende manieren waarop er naar de familie werd verwezen door de verschillende deelnemers. Terwijl volwassenen over familie spraken in termen van patrilineaire verwantschap en culturele verplichtingen zoals *lobola* en *inhlawulo*, begrepen adolescenten familie vooral in termen van het gevoel van erbij te horen, onvoorwaardelijk geaccepteerd te worden, welkom te zijn en gewaardeerd te worden. Voor sommige van de zestien adolescenten die in eenouder- of stiefgezinnen woonden, of met een grootouder, werd deze behoefte om ergens thuis te horen niet of slechts deels vervuld door hun familie. Anderen die wel degelijk door hun familie werden gesteund, zoals Simangele, ervoeren daarnaast toch een verlangen om te horen bij andere adolescenten met wie ze een bio-therapeutische identiteit deelden. Steungroepen vervangen weliswaar niet de familie zoals Levine die beschrijft, maar verschaffen wel een forum om contact te leggen met andere adolescenten zoals zijzelf en hun ervaringen uit te wisselen. De meeste van deze adolescenten spraken over steungroepen als ‘net als een familie’ of ‘één grote familie’.

Hoofdstuk 5 presenteert de bevindingen over toegang tot, beweegredenen voor en barrières voor een hiv-test en behandeling, inclusief trouw blijven aan de behandeling en in de hiv-zorg blijven, vanuit het perspectief van de adolescenten die aan de kwantitatieve studie en aan de focusgroepen deelnamen. Onder hen bevonden zich adolescenten die zich van hun hiv status bewust waren en onder behandeling waren. Deze adolescenten vormden een doelgerichte steekproef, terwijl anderen via de gemeenschap geworven werden en hen niet naar hun hiv status gevraagd werd. Het onderzoek toonde aan dat hiv-diagnostische testen gebrekkig zijn geïntegreerd in het zorgsysteem. De meeste adolescenten kregen namelijk pas een hiv-test nadat ze al vele malen in aanraking waren geweest met het zorgsysteem vanwege terugkerende ziekten, wat wijst op gemiste kansen om een vroege en juiste diagnose te stellen en zorg aan te bieden. De eis dat ouders toestemming moeten geven en het gebrek aan vaardigheden onder gezondheidswerkers om adolescenten voor te lichten, werden genoemd als redenen voor gemiste kansen. Adolescenten die hun status nog niet wisten vertelden daarentegen dat ze wel een hiv-test wilden maar dat ze tegen verschillende obstakels opliepen, waaronder het idee dat de kliniek een plek voor zieken is, angst voor een positieve hiv-diagnose, de reactie van ouders, de negatieve houding van gezondheidswerkers en de eis dat ouders toestemming moeten geven. Adolescenten stelden voor om hiv-diensten gericht op adolescenten aan te bieden op plaatsen waar zij zich vaak bevinden, zoals op school, thuis of in jeugdcentra, met strikte inachtneming van vertrouwelijkheid en privacy. Verder bleek dat adolescenten hun behandeling slecht volhielden, maar als zij eenmaal op de hoogte waren gesteld van hun diagnose, werden en bleven zij maximaal trouw aan de behandeling, hetgeen betekent dat de bekendmaking van de status van essentieel belang is voor de hiv-behandeling en het zorgtraject van adolescenten.

Ondanks de onzekerheid en de zorgen over de hiv-positieve status, bleven adolescenten optimistisch over hun toekomst en wensten ze ‘normaal’ te zijn. Ze vertelden dat de hiv-positieve status hen had aangemoedigd om hard te studeren zodat ze goede cijfers zouden halen waardoor ze een vervolgopleiding zouden kunnen doen en een goede positie op de arbeidsmarkt zouden kunnen verwerven. Ze deelden hun hoop en dromen over dokter, verpleegster of maatschappelijk werker worden, zodat ze andere kinderen in dezelfde omstandigheden als zijzelf zouden kunnen helpen. Belangrijke elementen in hun toekomstplannen waren een gezin stichten en hun echtgenote(s)(n) en kinderen beschermen tegen hiv – allemaal onderdelen van het normale leven dat zij wensten.

Hoofdstuk 6 beschrijft de bevindingen met betrekking tot stigma. Hoewel enkele adolescenten ervaring hadden met daadwerkelijke discriminatie door familieleden zoals onterving of sociale uitsluiting en afzondering (enacted stigma), bleken de meesten daarmee zelf geen ervaring te hebben maar wel bang te zijn om gestigmatiseerd te worden (perceived stigma). Dit maakte dat zij hun status geheim probeerden te houden en die alleen hadden verteld aan enkele familieleden. Naast het geheimhouden van hun status, gebruikten ze verschillende tactieken bij het omgaan met informatie over hun status, zoals het trouw volgen van de behandeling om lichamelijk normaal te lijken zonder opvallende ziekteverschijnselen en om ervoor te zorgen dat ze geen opportunistische infecties zouden krijgen die hen konden ‘verraden’. Omdat adolescenten maandelijks een zorginstelling moeten bezoeken voor een gezondheidscheck en nieuwe hiv-medicijnen, logen sommigen tegen hun leraren als ze vrij wilden vragen tijdens een schooldag. Ze zeiden dan dat ze tuberculose hadden of ze maakten gebruik van vrije schooluren zoals sporttijd, zodat ze geen toestemming hoefden te vragen waarvoor uitleg nodig was.

Hoofdstuk 7 gaat over het openlijk bekendmaken van de hiv-status. Een belangrijke plaats wordt in dit hoofdstuk ingenomen door de moeite die de verschillende gezinnen hadden met het bekendmaken van de status. Zowel ouders, stiefouders, grootouders als andere familieleden vertelden dat het voor hen emotioneel en psychologisch zwaar was om de adolescenten in te lichten over hun hiv-status; ze beschreven dit als een traumatisch proces. Maar de oorzaken van het emotionele en psychologische trauma verschilden: terwijl stiefouders ermee worstelen wie een adolescent moet vertellen over haar of zijn hiv-status, vinden biologische ouders het moeilijk om aan de adolescent te moeten uitleggen hoe de infectie kon plaatsvinden. Dit laatste geldt voor adolescenten die nog maagd waren en werden geïnfecteerd door overdracht van moeder op kind. Als gevolg hiervan werd het informeren van adolescenten over hun status uitgesteld, wat hun therapietrouw beïnvloedde, zoals eerder aangegeven. Ouders die gezondheidswerkers benaderden voor ondersteuning bij het bekendmaken van de hiv-status aan adolescenten, ondervonden weerstand. Gezondheidswerkers die de testen bij adolescenten uitvoeren en diagnosticeren, stelden dat het de plicht van de ouders of verzorgers was om de status bekend te maken en dat het hun taak was om de ouders en verzorgers te ondersteunen. De adolescenten gaven daarentegen aan dat zij het zouden waarderen om eerder te worden geïnformeerd over hun status en bij voorkeur door gezondheidswerkers, zodat zij vragen zouden kunnen stellen en de juiste antwoorden krijgen. De meeste adolescenten werden pas laat over hun status ingelicht. Soms gebeurde dit als een soort crisis management als een adolescent weigerde om nog langer pillen te slikken. Daarbij speelde angst voor mogelijke resistentie een rol en het feit dat daardoor de keuze aan type medicatie beperkt zou worden. Hoe meer ouders of verzorgers zich bewust werden van het risico op overlijden, hoe meer zij geneigd waren adolescenten over hun status te informeren. Toen de data vergaring plaatsvond, in 2012-2013, had Swaziland slechts twee opties voor antiretrovirale regimes. Aan iedereen die met de behandeling startte werd eerstelijns medicijnen gekozen, tenzij er specifieke contra-indicaties waren, bijvoorbeeld als mensen al eerder waren blootgesteld aan antiretrovirale medicatie. Als iemand niet goed reageert op die eerstelijnsmedicijnen, bijvoorbeeld als er resistentie blijkt tegen sommige medicijnen die er deel van uitmaken, wordt hij op tweedelijnsmedicijnen gezet. Maar die medicijnen zijn meer problematisch, zij hebben bijvoorbeeld vaker ernstige bijwerkingen dan de eerstelijns medicijnen. Daarbij is er voor mensen die problemen met het tweedelijns regiem geen verdere behandeling meer voorhanden. Om ervoor te zorgen dat cliënten, inclusief kinderen en adolescenten zo lang mogelijk eerstelijnsmedicatie kunnen gebruiken is therapietrouw belangrijk en om hen de urgentie daarvan te doen begrijpen is het belangrijk dat zij hun hiv status weten. Ouders en verzorgers waren bang dat als hun kinderen de medicijnen niet zoals voorgeschreven innamen zij resistentie kunnen ontwikkelen en dan minder opties voor behandeling hebben en de kans lopen te overlijden.

Er waren overigens ook gevallen waarin adolescenten hun hiv status te weten kwamen omdat zij volhardden in hun vraag waarom ze de medicijnen moesten slikken die hun ouders of verzorgers hun gaven.

Het laatste hoofdstuk, **hoofdstuk 8**, bestaat uit een bespreking en conclusie van het onderzoek, inclusief aanbevelingen. De aanbevelingen zijn onderverdeeld in drie categorieën: aanbevelingen die te maken hebben met beleid, programmatische zaken en onderwerpen voor verder onderzoek.

REFERENCES

Abadia-Berrero, C.E. & A. Castro. 2006. Experiences of stigma and access to HAART in children and adolescents living with HIV/AIDS in Brazil. *Social Science and Medicin*e 62:1219-1228. doi:10.1016/j.socscimed.2005.07.006

Ablon, J. 2002. The nature of stigma and medical conditions.*Epilepsy and Behaviour* 3: S2–29.http://www.ncbi.nlm.nih.gov/pubmed/12609300

Abrahams, N. & R. Jewkes. 2012. Managing and resisting stigma: a qualitative study among people living with HIV in South Africa. *Journal of International AIDS Society* 15: 17330. http://dx.doi.org/10.7448/IAS.15.2.17330.

Afifi, T.D. 2003. "Feeling caught" in stepfamilies: Managing boundary Turbulence through appropriate communication privacy rules. *Journal of Social and Personal Relationships* 20(6):729-755. DOI: 10.1177/0265407503206002

Agar, M.H. 1980.*The professional stranger: an informal introduction to ethnography.* Orlando, FL: Academic Press.

Agar, M. & J. MacDonald. 1995. Focus groups and ethnography. *Human Organisation* 54 (1): 78–86. DOI: 10.17730/humo.54.1.x102372362631282

Alderson, P. 1995. *Listening to children.Children, ethics and social research.* London: Barnado's.

Alderson, P. & V. Morrow. 2004. *Ethics, social research and consulting with children and young people.* Barkingside: Barnado's.

Alonzo, A.A. & N.R. Reynolds. 1995. Stigma, HIV and AIDS: an exploration and elaboration of a stigma trajectory. *Social Science and Medicine* 41 (3): 303–315. DOI: 10.1016/0277-9536(94)00384-6.

Amanyeiwe, U., S. Leclerc-Madlala & H. Gardi. 2014. Do community-based programmes help to improve HIV treatment and health outcomes? A review of the literature.*World Journal of AIDS* 4: 311–320.DOI: 10.4236/wja.2014.43037

American Psychological Association. 2002. *Developing adolescents: a reference for professionals*. Accessed on 13 February 2016 from http://www.apa.org/pi/families/resources/develop.pdf

Anderson, K.G., A.M. Beutel & B. Maughan-Brown. 2007. *HIV/AIDS risk perceptions and first sexual intercourse among youth in Cape Town, South Africa*. CSSR Working Paper No. 196. Cape Town: Centre for Social Science Research, AIDS and Society Research Unit.

Angotti, N., A. Bula, L. Gaydosh, E.Z. Kimchi, R.L. Thornton & S.E. Yeatman. 2009. Increasing the acceptability of HIV counselling and testing with three C's: convenience, confidentiality and credibility. *Social Science and Medicine* 68: 2263–2270. DOI: 10.1016/j.socscimed.2009.02.041

Amoran E, M.O. Onadeko & J.D. Adeniyi. 2005. Parental influence on adolescent sexual initiation practices in Ibadan, Nigeria. *International Quarterly of Community Health Education* 23(1): 73-81. DOI:10.2190/U8VJ-0UFE-HRYU-J48L.

Ankrah, E.M. 1993. The impact of HIV/AIDS on the family and other significant relationships: the African clan revisited. *AIDS Care* 5 (1): 5–22. DOI: 10.1080/09540129308258580

Arnett, J.J. 2010. Adolescence and emerging adulthood: a cultural approach, (4th edition). Upper Saddle River, New Jersey: Prentice Hall. Accessed on 12 June 2015, from http://www.jeffreyarnett.com/aea4efmfinalpages.pdf

—2007. Suffering, selfish, slackers? Myths and reality about emerging adults. *Journal of Youth and Adolescence* 36:23-29. DOI 10.1007/s10964-006-9157-z

—2000. Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychology* 55:469–480. http://www.ncbi.nlm.nih.gov/pubmed/10842426

—1999. Adolescent storm and stress reconsidered. *American Psychologist* 54 (5): 317–326. DOI: 10.1037/0003-066X.54.5.317

Arrive, E., F. Dicko, H. Amghar, A.E. Aka, H. Dior, et al. 2012. HIV disclosure and retention in care in HIV-infected adolescents on antiretroviral therapy (ART) in West Africa. *PLoS ONE* 7(3):e33690. DOI: 10.1371/journal.pone.0033690.

Auld, A.F., S.G. Agolory, R.W. Shiraishi, F. Wabuwire-Mangen, G. Kwesigabo, M. Mulenga, S. Hachizovu, et al. 2014. Antiretroviral therapy enrolment characteristics and outcomes among HIV infected adolescents and young adults compared with older adults: seven African countries, 2004–2013. *Morbidity and Mortality Weekly Report* 63 (47): 1097–1103.

Bailey, K.G. 1988. Psychological kinship: Implications for the helping professions. Psychotherapy: *Theory, Research, Practice and Training* 25(1):132-141. http://psycnet.apa.org/journals/pst/25/1/132/

Bakanda C, J. Birungi, R. Mwesigwa, J.B. Nachega, K. Chan, A. Palmer, N. Ford & E.J. Mills.2011. Survival of HIV-Infected Adolescents on Antiretroviral Therapy in Uganda: Findings from a Nationally Representative Cohort in Uganda. *PLoS ONE* 6(4): e19261. DOI::10.1371/journal.pone.0019261

Bandason, T., L.F. Langhaug, M. Makamba, S. Laver, K. Hatzold, S. Mahere, S. Munyati, et al. 2013. Burden of HIV among primary school children and the feasibility of primary school linked HIV testing in Harare, Zimbabwe. *AIDS Care* 25 (12): 1520–1526. DOI: 10.1080/09540121.2013.780120

Bandura, A. 2001. Social cognitive theory: an agentic perspective. *Annual Review of Psychology* 52 (1): 1–26. DOI: 10.1146/annurev.psych.52.1.1. http://www.annualreviews.org/doi/full/10.1146/annurev.psych.52.1.1

—2006. Adolescent development from an agentive perspective. In: *Self-efficacy and adolescents* (Vol. 5). Edited by F. Pajeris & T.C. Urdan, 1–43. Greenwich, CT: Information Age Publishing.

Basch, C.E. 1987. Focus group interview: an underutilized research technique for improving theory and practice in health education. *Health Education Quarterly* 14: 411–448. DOI: 10.1177/109019818701400404

Bastien, S., L.J. Kajula & W.W. Muhwezi. 2011. A review of studies of parent-child communication about sexuality and HIV/AIDS in sub-Saharan Africa. *Reproductive Health* 8:25. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3192730/pdf/1742-4755-8-25.pdf

Bateganya M.H., O.A. Abdulwadud & S.M. Kiene. 2007. Home-based HIV voluntary counselling and testing in developing countries. *Cochrane Database of Systematic Reviews* Oct 17 (4): CD006493. DOI: 10.1002/14651858.CD006493.pub2

Baumeister, B.E. & M.R. Leary. 1995. The need to belong: desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin* 117 (3): 497–529. DOI: 10.1037/0033-2909.117.3.497

Bekker, L.-G., L. Johnson, M. Wallace & S. Hosek. 2015. Building a future for our youth. *Journal of the International AIDS Society* 18 (S1): 20027. DOI: 10.7448/IAS.18.2.20027

Bekker, L.-G., C. Stack, S. Lee, S. Shah & B. Kapogiannis. 2014. Ethical issues in adolescent HIV research in resource limited settings. *Journal of Acquired Immune Deficiency Syndrome* 65 (S1): S24–S28. DOI: 10.1097/QAI.0000000000000036

Bell, D., J. Martinez, G. Botwinick, K. Shaw, L. Walker, S. Dodds, R. Sell, et al. 2003. Case finding for HIV-positive youth: a special type of hidden population. *Journal of Adolescent Health* 33S: 10-22. DOI: 10.1016/S1054-139X(03)00160-5

Bell, S. & P. Anggleton. 2012. Time to invest in a counter-public health approach: promoting sexual health among sexually active young people in rural Uganda. *Children's Geographies* 10 (4): 385–397. DOI: 10.1080/14733285.2012.726066

Benyoussef A. & A.F. Wessen. 1974. Utilisation of health services in developing countries—Tunisia. *Social Science and Medicine* 8: 287–304. DOI: 10.1016/0037-7856(74)90098-5

Beres, L.K., K. Winsekell, E.M., Nuri, B. Mbakwem & O. Obyerodhyambo. 2013. Making sense of HIV testing: social representations in young Africans' HIV-related narratives from six countries. *Global Public Health* 8(8):890-903.DOI: 10.1080/17441692.2013.827734

Berg, R.C. and M.W. Ross. 2014. The second closet: a qualitative study of HIV stigma among seropositive gay men in a Southern US City. *International Journal of Sexual Health* 26:186-199. http://www.ncbi.nlm.nih.gov/pubmed/25170366

Bernard, H.R. 2006. *Research methods in anthropology: qualitative and quantitative approaches*. Lanham, MD: Rowman & Littlefield Publishers.

Bicego, G.T., R. Nkambule, I. Peterson, J. Reed, D. Donnell, H. Ginindza, Y.T. Duong, et al. 2013. Recent patterns in population-based HIV prevalence in Swaziland. *PLoS One* 8: e77101. DOI: 10.1371/journal.pone.0077101

Biehal, N. 2014. A sense of belonging: meanings of family and home in long-term foster care. *British Journal of Social Work* 44: 955–971. DOI: 10.1093/bjsw/bcs177

Birungi, H., F. Obare, J.F. Mugisha, H. Evelia, & J. Nyombi.2009. Preventive service needs of young people perinatally infected with HIV in Uganda**.** *AIDS Care* 21(6):725–731.DOI: 10.1080/09540120802511901

Black, S., M. Wallace, K. Middelkoop, D. Robbertze, T. Bennie, R. Wood & L.-G.Bekker. 2014. Improving HIV testing amongst adolescents through an integrated Youth Centre rewards program: insights from South Africa. *Children and Youth Services Review* 45: 98–105. DOI: 10.1016/j.childyouth.2014.03.025

Block, A. 2014. Flexible kinship: caring for AIDS Orphans in rural Lesotho. *Journal of the Royal Anthropological Institute* 20: 711–727. DOI: 10.1111/1467-9655.12131

Blum, R.W., F. Bastos, C.W. Kabiru & L.C. Le. 2010. Adolescent health in the 21st century. *The Lancet* 379(9826)1567-1568. DOI: http://dx.doi.org/10.1016/S0140-6736(12)60407-3

Bohle, L.F. 2013. Stigmatisation, discrimination and illness: experiences among HIV-seropositive women in Tanga, Tanzania. Göttigen, Germany: Universitätsverlag Göttigen.

Bond, V.A. 2010. 'It is not an easy decision on HIV, especially in Zambia': opting for silence, limited disclosure and implicit understanding to retain a wider identity. *AIDS Care* 22 (S1): 6–23. DOI: 10.1080/09540121003720994

Booth, A.R. 1983. *Swaziland: tradition and change in a southern African kingdom*. Boulder, CO: Westview Press.

Booth, M.Z. 2003. 'You learn and learn and learn…and then you are an adult': parental perceptions of adolescence in contemporary Swaziland. *Adolescence* 38: 221–238. PMID: 14560877.

—2004. Swaziland adolescents. In: *International encyclopaedia of adolescence.* Edited by J.J. Arnett. 2007, 1(A–J): 934–946.

Bott, S. & C.M. Obermeyer. 2013. The social and gender context of HIV disclosure in sub-Sharan Africa: a review of policies and practices. *SAHARA-J* 10 (sup. 1)S5-S16. DOI: 10.1080/02664763.2012.755319

Boulton, R. 2013. *Children with HIV: The consolidation of medicine, science and the social into the clinical practice of paediatric HIV*. Doctoral Dissertation. Goldsmiths, University of London. Goldsmiths Research Online. Accessed on 19 November 2014 from http://research.gold.ac.uk/8713/

Bourdieu, P. 2003. Participant objectivation. *Journal of Royal Anthropological Institute* 9 (2): 281–294. DOI: 10.1111/1467-9655.00150

Bowlby, J. 1988. *A secure base: parent-child attachment and healthy human development.* New York: Basic Books.

Bowlby, S.R., L. McKie, S. Gregory, & I. MacPherson. 2010. *Interdependency ad Care over the lifecourse*. Oxford: Routledge.

Bowleg, L. 2012.The problem with the phrase *Women and minorities*. Intersectionality –an important theoretical framework for Public Health. *American Journal of Public Health* 102:1267–1273. DOI:10. 2105/AJPH.2012.300750)

Boyes, M.E. & L. Cluver. 2013. Relationships among HIV/AIDS-orphanhood, stigma, and symptoms of anxiety and depression in South African youth: a longitudinal investigation using a path analysis framework. *Clinical Psychological Science* 1: 323–330.

—2015. Relationships between familial HIV/AIDS and symptoms of anxiety and depression: the mediating effect of bullying victimization in a prospective sample of South African children. *Journal of Youth & Adolescence* 44: 847–859.

Boyes, M., S. Mason & L. Cluver. 2013. Validation of a brief stigma-by-association scale for use with HIV/AIDS-affected youth in South Africa. *AIDS Care* 25 (2): 215–222.

Brandt, A.M. 1986. AIDS: from social history to social policy. *Journal of Law, Medicine and Ethics* 14 (5–6): 231–242. DOI: 10.1111/j.1748-720X.1986.tb00990.x

Brixiová, Z., R. Fakudze & T. Kangoye. 2012. Labour markets in Swaziland: the challenge of youth employment. Accessed on 13 February 2016 from http://www.youthpolicy.org/library/wp-content/uploads/library/2012_Labour_Markets_Swaziland_Challenge_Youth_Employment_Eng.pdf

Brashers, D.E., J.L. Neidig, L.W. Cardillo, L.K. Dobbs, J.A. Russell & S.M. Haas. 1999. 'In an important way, I did die': uncertainty and revival in persons living with HIV or AIDS. AIDS Care 11(2):201-219.

Bryman, A. 2004.Triangulation and measurement. Retrieved on 27 October, 2014 from www.referenceworld.com/sage/socialscience/triangulation.pdf

Burnett, S.M., M.R. Weaver, P.N. Mody-Pan, L.A. Thomas & C.M. Mar. 2011. Evaluation of an intervention to increase human immunodeficiency virus testing among youth in Manzini, Swaziland: a randomised control trial. *Journal of Adolescent Health* 48: 507–513. DOI: 10.1016/j.jadohealth.2010.08.015

Buseh, A.G. 2004. Patterns of sexual behaviour among secondary school students in Swaziland, Southern Africa.*Culture, Health & Sexuality: An International Journal for Research, Intervention and Care* 6 (4): 355–367. DOI: 10.1080/13691050410001668711

Buseh, A.G., L.K. Glass & B. McElmurry. 2002. Cultural and gender issues related to HIV/AIDS prevention in rural Swaziland: a focus group analysis. *Health Care for Women International* 23 (2): 173–184. DOI: 10.1080/073993302753429040

Buseh, A.G., L.K. Glass, B.J. McElmurry, M.S. Mkhabela & N.A. Sukati. 2002. Primary and preferred sources for HIV/AIDS and sexual risk behaviour among adolescents in Swaziland, Southern Africa. *International Journal of Nursing Studies* 39: 525–538. DOI: 10.1016/S0020-7489(01)00058-X

Caldwell, J.C., P. Caldwell, B.K. Caldwell & I. Pieris. 1998. The construction of adolescence in a changing world: implications for sexuality, reproduction and marriage. *Studies in Family Planning* 29 (2): 137–153. DOI: 10.2307/172155

Campbell, C., Y. Nair, S. Maimane & J. Nicholson. 2007. 'Dying Twice': A Multi-level Model of the Roots of AIDS Stigma in two South African Communities. *Journal of Health Psychology* 12(3):403-416. http://www.ncbi.nlm.nih.gov/pubmed/17439992

Campbell, C., M. Skovdal, Z. Mupambireyi, C. Madanhire, L. Robertoson, C.A. Nyamukapa & S. Gregson. 2012. Can AIDS stigma be reduced to poverty stigma? Exploring Zimbabwean children's representations of poverty and AIDS. Child: Care, Health and Development 38(5):732-742. DOI: 10.1111/j.1365-2214.2011.01311.x

Carter, N., A. Bryant-Lukosius, A. DiCenso, J. Blythe & A.J. Neville. 2014. The use of triangulation in qualitative research. *Oncology Nursing Forum* 41 (5): 545–547. DOI: 10.1188/14.ONF.545-547

Carey, M.P. & Schroder, K.E.E. 2002. HIV Knowledge Questionnaire-HIV-KQ-18 (18 item version: Development and psychometric evaluation of the brief HIV knowledge questionnaire (HIV-KQ-18). *AIDS Education and Prevention* 14:174-184

Castro, A. & P. Farmer. 2005. Understanding and addressing AIDS-related stigma: from anthropological theory to clinical practice in Haiti. *American Journal of Public Health* 95(1):53-59

Central Statistics Office. 2008. *Swaziland national census report, 2007*. Mbabane, Swaziland: Central Statistics Office.

—2010. *Multiple indicator cluster survey report, 2012*. Mbabane, Swaziland: Central Statistics Office.

—2011. *Swaziland household and income expenditure survey report, 2010*. Mbabane, Swaziland: Central Statistics Office.

Central Statistics Office & Macro International. 2008. *Swaziland demographic and health survey 2006–2007*. Mbabane, Swaziland: Central Statistics Office & Macro International.

Central Statistics Office & United Nations Population Fund. 2010. *Population and housing census volume 6: housing and living conditions report 2007*. Mbabane, Swaziland: Central Statistics Office & United Nations Population Fund.

Centre for Disease Control and Prevention (CDC). 2007. Behavioural Risk Factor Surveillance System Questionnaire, 2007. Retrieved on 9 December, 2013 from http://www.cdc.gov/brfss/questionnaires/pdf-ques/2007brfss.pdf

Chandwani, S., L.J. Koenig, A.M. Sill,S. Abramowitz, L.C. Conner, &L. D'Angelo. 2012. Predictors of antiretroviral medication adherence among a diverse cohort of adolescents withHIV. *Journal of Adolescent Health*51(3): 242–251. doi:10.1016/j.jadohealth.2011.12.013

Charmaz, K. 1991. *Good days, Bad days: the self in chronic illness and time*. New Brunswick, New Jersey: Rutgers University Press.

Cheney, K.E. 2011. Children as ethnographers: reflections on the importance of participatory research in assessing orphans' needs. *Childhood* 18 (2): 166–179. DOI: 10.1177/0907568210390054

— 2013. Malik and his three mothers: AIDS orphans' survival strategies and how children's rights translations hinder them. In: *Recognising children's rights in international development: living rights, social justice, translations.* Edited by K. Hanson & O. Nieuwenhuys, 155–171. Cambridge: Cambridge University Press.

Clinton Health Access Initiative (CHAI).*Clinton Foundation Annual Report, 2012*. Accessed on May, 2015 from https://www.clintonfoundation.org/files/clintonfoundation2012annualreport.pdf

Choudhury, S., S. Blakemore & T. Charman. 2006. Social cognitive development during adolescence. *Social Cognitive and Affective Neuroscience* 1 (3): 165–174. DOI: 10.1093/scan/nsl024

Christensen, P.H. 2004. Children's participation in ethnographic research: issues of power, and representation. *Children and Society* 18 (2): 165–176. DOI: 10.1002/CHI.823

Christensen, P. & A. James (eds.). 2000. *Research with children: perspectives and practices*. London: Falmer Press.

—2010. *Research with children: perspectives and practices* (2nded). New York: Routledge.

Church, K., A. Wringe, P. Fakudze, J. Kikuvi, D. Simelane, S.H. Mayview & The Integra Initiative. 2013. Are integrated HIV services less stigmatising than stand-alone models of care? A comparative case study from Swaziland.*Journal of the International AIDS Society* 16:17981. http://dx.doi.org/10.7448/IAS.16.1.17981

Cluver, L. & F. Gardner. 2007. The mental health of children orphaned by AIDS: a review of international and southern African research. *Journal of Child and Adolescent Mental Health* 19 (1): 1–17. DOI: 10.2989/17280580709486631

Cluver, L., F. Gardner & D. Operario. 2008. Effects of HIV stigma on mental health of adolescents orphaned by AIDS. *Journal of Adolescent Health* 42 (4): 410–417. DOI: 10.1016/j.jadohealth.2007.09.022

Cohen, M.S., G.M. Shaw, A.J. McMichael & B.F. Haynes. 2011. Acute-HIV-1 infection: basic, clinical and public health perspectives. *New England Journal Medicine* 364: 1943–1954. DOI: 10.1056/NEJMra1011874

Cohen, M.S., Y.Q. Chen, M. McCauley, T. Gamble, M.C. Hosseinipour, et al. 2011. Prevention of HIV-1 infection through early antiretroviral therapy.*The New England Journal of Medicine* 365:493-505. DOI: 10.1056/NEJMoa1105243

Colombini, M., R. Mulewa, J. Kuvananga, L. Stackpool-More, & S.H. Mayhew. 2014. Experiences of stigma among women living with HIV attending sexual and reproductive health services in Kenya: A Qualitative Study. *BMC Health Services Research* 14:412

Coovadia, H.& J.E. Mantell. 2010. Adolescents and HIV in Sub-Saharan Africa: a timely issue and missed opportunity. *Clinical Infectious Disease* 51(7): 852-854. DOI: 10.1086/656362

Corbin, J.M. 2003.The body in health and illness.*Qualitative Health Research* 13 (2): 256–267. DOI: 10.1177/1049732302239603

Courtenay, B. C., S.B. Merriam, &P.M. Reeves. 1998. The centrality of meaning-making in transformational learning: How HIV Positive adults makes sense of their lives. *Adult Education Quarterly* 48 (2):65-84.DOI: 10.1177/074171369804800203

Cowan, F. & A. Pettifor. 2009. HIV and adolescents in sub-Saharan Africa. *Current Opinion on HIV/AIDS* 4 (4): 288–93. DOI: 10.1097/COH.0b013e32832c7d10

Creswell, J. & V.L. Plano Clark. 2007. *Designing and conducting mixed methods research.* Thousand Oaks, CA: Sage Publications.

Crush, J., I. Raimundo, H. Simelane, B. Cau & D. Dorey. 2010. *Migration induced HIV in rural Mozambique and Swaziland.*Migration Policy Series No. 53.Cape Town: Idasa.

Daapah, J.M. 2012.*HIV/AIDS treatment in two Ghanaian hospitals: experiences of patients, nurses and doctors.*PhD Dissertation. Leiden: African Studies Centre

Daly, J.L. 2001. AIDS in Swaziland: the battle from within. *African Studies Review* 44 (1): 21–35. DOI: 10.2307/525390

Das, V., A. Kleinman, M. Locke, M. Ramphele, & P. Reynolds. 2001. *Remaking a World: Violence, Social Suffering, and Recovery.* Berkeley: University of California Press.

de Vries, D.H., S. Galvin, M. Mhlanga, B. Cindzi & T. Dlamini. 2011. "Othering" the Health Worker: Self-stigmatisation of HIV/AIDS among HCPs in Swaziland. *Journal of the International AIDS Society*; 14:60.doi: 10.1186/1758-2652-14-60

De Wit, J.B.F. & P.C.G. Adam. 2008. Tot test or not to test: psychosocial barriers to HIV testing in high income countries. HIV Medicine 9(supp.2):20-22. DOI: 10.1111/j.1468-1293.2008.00586.x

Deacon, H., L. Uys & R. Mohlahlane. 2010. HIV/AIDS stigma in South Africa 25 years on. Accessed on 17 February 2016 from https://www.academia.edu/924074/HIV_and_stigma_in_South_Africa?auto=download

Deblonde, J., P.De Koker, F.F.Hamers, J. Fontaine, S.Luchters&M.Temmerman. 2010. Barriers to HIV testing in Europe: a systematic review. *The European Journal of Public Health* 20(4):422-432. DOI: http://dx.doi.org/10.1093/eurpub/ckp231

De Bruyn, M. 2000. *Gender, adolescents and the HIV and AIDS epidemic: the need for comprehensive sexual and reproductive health responses*. Paper presented at an expert group meeting on The HIV/AIDS Pandemic and Its Gender Implications at Windhoek, Namibia, on 13–17 November 2000. Accessed on 13 March 2015 from http://www.un.org/womenwatch/daw/csw/hivaids/De%20bruyn.htm

De Walque, D., P.J. Gertler, S. Bautista-Arredondo, A. Kwan, C. Vermersch, J. de Dieu Bizimana, A. Binagwako, et al. 2015. Using provider performance incentives to increase HIV testing and counselling services in Rwanda.*Journal of Health Economics* 40: 1–9. DOI: 10.1016/j.jhealeco.2014.12.001

Dellar, R.C., S. Dlamini & Q.A. Karim. 2015. Adolescent girls and young women: key populations for HIV epidemic control. *Journal of the International AIDS Society* 18 (S1): 19408. DOI: 10.7448/IAS.18.2.19408

Denison, J.A., A.P. McCauley, W.A. Dunnett-Dag, N. Lungu & M.D. Sweat. 2009. HIV testing among adolescents in Ndola, Zambia: how individual, relational and environmental factors relate to demand. *AIDS Education and Prevention* 21 (4): 314–324. DOI: 10.1521/aeap.2009.21.4.314

Denzin, N.K. 1978. *Sociological methods*. New York: McGraw-Hill.

— 1989. *Interpretive interactionism*. Newbury Park, CA: Sage.

Denzin, N.K. & Y.S. Lincoln. 2006. Handbook of qualitative research. In: *Interpreting qualitative data* (4th ed). Edited by D. Silverman. London: Sage.

Deuchart, E. 2010. The virgin HIV puzzle: can misreporting account for the high proportion of HIV cases in self-reported virgins? Available from http://www1.vwa.unisg.ch/RePEc/usg/dp2010/DP-1024-De.pdf

DeWalt, K.M. & B.R. DeWalt. 2011. *Participant observation: a guide to fieldwork* (2nd ed.). Plymouth, United Kingdom: AltaMira Press.

Dias C.F., S.F. Moreira-Silva, M.A. Reis, L.R. Patrício, C.F. Gavioli & A.E. Miranda. 2014. Late diagnosis and HIV infection in children attending a service of specialized care for paediatric AIDS in Brazil. *Rev Soc Bras Med Trop* 47(1):93–6.http://dx.doi.org/10.1590/0037-8682-1737-2013

DiClemente, R.J., C.P. Crittenden, E. Rose, J.M. Sales, G.M. Wingood, R.A. Cosby & L.F. Salzaar. 2008. Psychosocial predictors of HIV-associated sexual behaviours and the efficacy of prevention interventions in adolescents at-risk for HIV infection: what works and what doesn’t work*? Psychosomatic Medicine* 70: 589–505. DOI: 10. 1097/PSY.0b013e3181775edb

DiIroio, C., M. Kelly and M. Hockenberry-Eaton. 1999. Communication about sexual issues: mothers, fathers and friends. *Journal of Adolescent Health* 24(3):181-189. http://www.ncbi.nlm.nih.gov/pubmed/10195801

Djebbari, H. & H. Mayrand. 2011. *Cash Transfers and Children’s Living Arrangements in South Africa.* Université Laval. Pas publié. Retrieved on 23 July, 2015 from http://www.ipc.umich.edu/pdf/childfostering_hdjebbari.pdf

Dlamini, S. 2007. Neighbourhood care points in Swaziland: a case study, report prepared for the Regional Evidence Building Agenda (REBA) of the Regional Hunger and Vulnerability Programme (RHVP), November, 2007. Accessed on 23 July, 2015 from https://www.k4health.org/sites/default/files/NCPsForOVCs.pdf

Domek, G. 2006. Social consequences of antiretroviral therapy: preparing for the unexpected futures of HIV-positive children. *Lancet* 367 (9519): 1367–1369. DOI: 10.1016/S0140-6736(06)68584-X

Duffy, M.H., H. Bergmann, & M. Sharer. 2014. Toolkit for Transition of Care and Other Services for Adolescents Living with HIV. Arlington, VA: USAID’s AIDS Support and Technical Assistance Resources, AIDSTAR-One, Task Order 1. Accessed from http://pdf.usaid.gov/pdf_docs/pnaec759.pdf

Duffy, L. 2005. Suffering, shame, and silence: the stigma of HIV/AIDS. *Journal of the Nurses in AIDS Care* 16(1):13-20. DOI: http://dx.doi.org/10.1016/j.jana.2004.11.002

Farmer, P. 1997. On suffering and structural violence.*In A. Kleinman, V. Das and M. Locke (eds). Social Suffering.* Berkeley, California; University of California Press: 261-280

Fawzi, M.C., E. Eustache, C. Oswald, P. Surkan, E. Louis, F. Scanlan, et al. 2010. Psychosocial functioning among HIV-affected youth and their caregivers in Haiti:

Implications for family-focused service provision in high HIV burden settings. *AIDS Patient Care & STDs* 24(3):147-158. doi: 10.1089/apc.2009.0201

Feirman, S. 2012. Men's susceptibility to HIV in Swaziland.*Culture, Health and Sexuality* 14 (7): 723–735. DOI: 10.1080/13691058.2012.681704

Fenio, K.G. 2011. Tactics of resistance and evolution of identity from subjects to citizens: the AIDS political movement in southern Africa. *International Studies Quarterly* 55: 717–735. DOI: 10.1111/j.1468-2478.2011.00666.x

Ferrand R., S. Lowe, B. Whande, L. Munaiwa, L. Langhaug, F. Cowan, O. Mugurungi, et al. 2010. Survey of children accessing HIV services in high prevalence settings: time for adolescents to count? *Bulletin of the World Health Organization* 88: 428–434. DOI: 10.2471/BLT.09.066126

Ferrand, R.A., L. Munaiwa, J. Matsekete, T. Bandason, K. Nathoo, C.E. Ndhlovu, S. Munyati, et al. 2010. Undiagnosed HIV infection among adolescents seeking primary health care in Zimbabwe.*Clinical Infectious Diseases* 51 (7): 844–851. DOI: 10.1086/656361.

Ferreira, M. 2001. *HIV/AIDS and family wellbeing in Southern Africa: towards an analysis of policies and responsiveness*. A brief synthesis paper prepared for a United Nations Department of Economic and Social Affairs division of Social Policy and Development Policy workshop held in Windhoek, Namibia; 28-30 January. Accessed on 15 August, 2015 from http://www.un.org/esa/socdev/unyin/workshops/Windhoek-backgroundpaper3.pdf

Fielden, S.J., E.G. Chapman and S. Cadell. 2011. Managing Stigma in Adolescent HIV: Silence, Secrets and Sanctioned Spaces. *Culture, Health and Sexuality: An International Journal for Research, Intervention and Care* 13(3):267-281. doi: 10.1080/13691058.2010.525665

Fife, W. 2005.*Doing fieldwork: ethnographic methods for research in developing countries and beyond.*New York: Palgrave Macmillan.

Folch-Lyon, E. & Trost, J.F. 1981.Conducting focus group sessions.*Studies in Family Planning* 12: 443–449.

Fox, K., Ferguson, J., Ajose W., Singh,J., Marum, E. and Baggaley, R. 2013. Adolescent consent to testing: a review of current policies and issues in sub-Saharan Africa. *In: HIV and Adolescents: Guidance for HIV Testing and Counselling and Care for Adolescents Living with HIV: Recommendations for a Public Health Approach and Considerations for Policy-Makers and Managers. Geneva: World Health Organization; 2013. ANNEX 15*. Accessed on 6 May, 2016 from http://www.ncbi.nlm.nih.gov/books/NBK217954/

Francis D. 2010. "They should know where they stand": attitudes to HIV voluntary counselling and testingamongst a group of out-of-school youth. *South African Journal of Education*. 30(3):327–342.www.ajol.info/index.php/saje/article/download/60026/48283.

Furedi, F. 2007. We have nothing to fear but the culture of fear itself. How human thought and action are being stifled by a regime of uncertainty. *Spiked*, 4 April, 2007. Accessed on 2 November, 2014 from http://www.spiked-online.com/newsite/article/3053#.V14CcmRf1jo

Gachanja, G. 2015. A rapid assessment of post disclosure experience of HIV-positive and HIV-negative school-aged children in Kenya.*PeerJ* 3: e956. DOI 10.7717/peerj.956

Gachanja, G., G.J. Burkholder & A. Ferraro. 2014. HIV positive parents' accounts of disclosure preparation activities in Kenya. Journal of Social, Behavioural and Health Sciences 8(1):18-37. DOI: 10.5590/JSBHS.2014.08.1.02

Garvie, P.A., M.L. Wilkins & J.C. Young. 2010. Medication adherence in adolescents with perinatally acquired HIV: evidence for using multimethod assessment protocol. *Journal of Adolescent Health* 47(5):503-511

Gary G.E. 2010. Adolescent HIV: cause for concern in southern Africa. *PLoS Medicine* 7 (2): e1000227.

Geertz, C. 1973. *The interpretation of cultures: selected essays*. New York: Basic Books.

Georgas, J. 2003. Family: variations and changes across cultures. *Online Readings in Psychology and Culture, 6* (3).Accessed on August 6, 2015 from http://scholarworks.gvsu.edu/cgi/viewcontent.cgi?article=1061&context=orpc

Glaser, B. & A. Strauss. 1967. *The discovery of grounded theory*. Hawthorne, NY: Aldine Publishing.

Goffman, E. 1963.*Stigma: notes on the management of spoiled identity*. Harmondsworth, United Kingdom: Penguin.

—1990 [1963]. *Stigma: Notes on the management of spoiled identity*. Eaglewood Cliffs, New Jersey: Penguin Books

Golish, T. and J. Caughlin. 2002. "I'd rather not talk about it": adolescents' and young adults' use of topic avoidance in stepfamilies.*Journal of Applied Communication Research*, 30(1):78-106. DOI: 10.1080/00909880216574

Goode, D. 1994. The national quality of life for persons with disability project: a quality of life agenda for the United States. In: *Quality of life for persons with disability*. Edited by D. Goode, 139–161. Cambridge, MA: Brookline Press.

Goodenow, C. 1993. Classroom belonging among early adolescent students: relationships to motivation and achievement. *Journal of Early Adolescence* 13: 21–43. DOI: 10.1177/0272431693013001002

Gough, K. 1971. The origin of the family.*Journal of Marriage and Family* 33 (4): 760–771.

Goudge, J., Ngoma, B., Manderson, L. and Schneider, H. (2009) Stigma, identity and resistance among people living with HIV in South Africa.*SAHARA-J: Journal of Social Aspects of HIV/AIDS* 6(3): 94–104.http://www.ncbi.nlm.nih.gov/pubmed/20485849

Gosselin., J. 2010. Individual and family factors related to psychosocial adjustment in stepmother families with adolescents. *Journal of Divorce and Remarriage*51(2):108. DOI: 10.1080/10502550903455174

Gosselin, J. & H. David. 2007. Risk and resilience factors linked with psychosocial adjustment of adolescents, stepparents and biological parents. *Journal of Divorce and Remarriage* 48(1/2):29-53.DOI: 10.1300/J087v48n01_02

Grabbe K.L., N. Menzies & M. Taegtmeyer. 2010. Increasing access to HIV counselling and testing through mobile services in Kenya: strategies, utilisation and cost-effectiveness. *Journal of Acquired Immune Deficiency Syndrome* 54 (3): 317–323. DOI: 10.1097/QAI.0b013e3181ced126.

Greeff, M., R. Phetlho, L.N. Makoae, P.S. Dlamini, W.L. Holzener, J.R. Naidoo, et al. 2008. Disclosure of HIV status: experiences and perceptions of persons living with HIV/AIDS and nurses in their care in Africa. *Qualitative Health Research* 18(3):311-324. DOI: 10.1177/1049732307311118

Green, E.C. & L. Makhubu. 1984. Traditional Healers in Swaziland: toward improved cooperation between traditional and modern health sectors. *Social Science and Medicine 18(12):1071-1079.* http://www.ncbi.nlm.nih.gov/pubmed/6463675

Green, L. 1994. Fear as a way of life. *Cultural anthropology 9(2):227-256.* DOI: 10.1525/can.1994.9.2.02a00040

Green J. & N. Thorogood. 2004. *Qualitative methods for health research.* London: Sage Publications.

—2009. *Qualitative methods for health research (2nd edition).* London: Sage Publications.

—2014. *Qualitative methods for health research (3rd edition).* London: Sage Publications.

Guiella, G. & N.J. Madise. 2007. HIV/AIDS, Sexual-risk behaviours among adolescents: factors affecting the use of condoms in Burkina Faso. *Africa Journal of Reproductive Health* 11 (3): 182–196.

Hardon, A.H., P. Boonmongkon, P. Streetland, M.L. Tan, S. van der Geest, A. van Staa, C. Varkevisser, et al. 2001. *Manual for applied health research: anthropology of health and health care*. Amsterdam: Het Spinhuis.

Hardon, A., S. Davey, T Gerrits, C. Hodgkins, H. Irunde, J. Kgatlwane, J. Kinsman, A. Nakiyemba, & R. Laing. 2006. *From access to adherence: The challenges of antiretroviral treatment–studies from Botswana, Tanzania and Uganda*. Geneva, Switzerland: World Health Organization. Accessed on 27 March 2015 from http://apps.who.int/medicinedocs/en/d/Js13400e/

Hardon, A.P., A. Desclaux & J. Lugalla. 2012. Disclosure in time of ART: a relational analysis of social practices. *SAHARA-J: Journal of the Social Aspects of HIV/AIDS* 10 (S1): S1–S4. DOI: 10.1080/02664763.2012.755317

Hardon, A. & D. Posel. 2010. Secrecy as embodied practice: beyond the confessional imperative. *Culture Health and Sexuality: An International Journal of Research, Intervention and Care* 14(sup.1): S1-13. doi: 10.1080/13691058.2012.726376

Hein, K. 1997. Adolescent HIV testing—who says who signs? *American Journal of Public Health* 87 (8): 1277-1278. PMID: 9279260.

Helman, C.G. (1995). The body image in health and disease: explring patients' maps of body and self. *Patient Education and Counselling* 26(1-3):169-175. doi:10.1016/0738-3991(95)00753-M

Hendricks, N.G.P. & M.D. Magano. 2014. Emotional needs of urban HIV/AIDS affected learners in the intermediate and senior phases. *Journal of Human Ecology* 48 (3): 451–459.

Herdt, G. 2001. Stigma and the ethnographic study of HIV: Problems and prospects. *AIDS and Behavior* 5(2), 141-149.DOI: 10.1023/A:1011378811611

Herek, G.M. 2002. Thinking about AIDS and stigma: a Psychologist's perspective. *The Journal of Law, Medicine and Ethics* 30(4):594-607. DOI: 10.1111/j.1748-720X.**2002**.tb00428.x.

Hetherington, E.M. & K.M. Jodl. 1994. "Stepfamilies as settings for child development". *In: A. Booth and J. Dunn (eds). Stepfamilies: who benefits? Who does not?(3rd edition).* 2014. New York: Taylor and Francis.

Heuveline, P. 2004. Impact of the HIV epidemic on population and household structure: the dynamics and evidence to data. *AIDS* 18 (S2): S45–S53. PMC39291

Honwana, A. & F. de Boeck (eds.). 2005. *Makers and breakers: children and youth in postcolonial Africa*. Oxford: James Currie.

Honwana, A. 2006.*Child soldiers in Africa*. Philadelphia: University of Pennsylvania Press

Hosegood, V. 2009. The demographic impact of HIV and AIDS across the family and household life-cycle: implications for efforts to strengthen families in sub-Saharan Africa. *AIDS Care* 21 (S1): 13–21.

Hosek, S.G., G.W. Harper & W.L. Robinson. 2002. Identity development in adolescents living with HIV. *Journal of Adolescence* 25 (4): 355–364. DOI: 10.1006/jado.2002.0480

Humphreys, C.P., J. Wright, J. Walley, C. Mamvura, K.A. Bailey, S.N. Ntshalintshali, R.M. West, et al. 2010. Nurse-led, primary care based ART versus hospital care: a controlled prospective study in Swaziland. *BMC Health Services Research* 10: 229. DOI: 10.1186/1472-6963-10-229

Hutchinson, P. L., & X. Mahlalela. 2006. Utilization of voluntary counselling and testing services in the Eastern Cape, South Africa. *AIDS Care* 18(5):446e455. http://dx.doi.org/10.1080/09540120500213511

Idele, P., A. Gillespie, T. Porth, C. Suzuki, M. Mahy, S. Kasedde & C. Luo. 2014. Epidemiology of HIV and AIDS: current status, inequities and data gaps. *Journal of Acquired Immune Deficiency Syndrome* 66 (S2): S144–153.

Iliffe, J. 2005. *Honour in African history*. Cambridge: Cambridge University Press

—2006. *The African AIDS epidemic: a history.* Oxford: James Currie.

Instone, S.L. 2000. Perceptions of children with HIV infection when not told for so long: implications for diagnosis disclosure. *Journal of Paediatric Health Care* 14: 235–243.

James, A. & A. Prout (eds.). 1990. *Constructing and reconstructing childhood*: *contemporary issues in the sociological study of childhood*. London: Falmer Press.

James, A. 1995.*Methodologies of competence for a competent methodology?* A paper presented to Children and Social Competence Conference Guildford, Surrey, July 1995.

James, A. & A. Prout. 1997. New paradigm for the sociology of childhood?Provenance, promise and problems. In: *Constructing and reconstructing childhood: contemporary issues in the sociological study of childhood*. (2nd ed). Edited by A. James & A. Prout, 7–33. London: RoutledgeFalmer.

Jans, S. 2004. Children as citizens: towards a contemporary notion of child participation. *Childhood* 11 (1): 27–44. DOI: 10.1177/0907568204040182

Jenniskins, F. 2015. Strengthening community systems for treatment scale-up: a case study on MaxART community interventions in Swaziland. Accessed on 13 February 2016 from http://stopaidsnow.org/sites/stopaidsnow.org/files/MaxART_community_interventions_2015_casestudy.pdf

Jensen, T.M. & K. Shafer. 2013. Stepfamily functioning and closeness: children's views on second marriages and stepfather relationships. *Social Work* 58: 127–136. DOI: 10.1093/sw/swt007

Johnson, N. 2000.Speech given at the XIII International AIDS Conference, Durban, South Africa.*In: C. Squire. HIV in South Africa: Talking about the big thing.* 2007, pp22.London: Routledge

Joint United Nations Programme on HIV/AIDS.2012a.*Adolescents, youth and HIV: fact sheet*. Geneva: UNAIDS. Accessed on 16 June 2014 from http://www.unaids.org/en/media/unaids/contentassets/documents/ factsheet/2012/20120417_FS_adolescentsyoungpeoplehiv_en.pdf

— 2012b. *Swaziland country report on monitoring the political declaration on HIV and AIDS.*Geneva: UNAIDS. Available from http://www.unaids.org/sites/default/files/en/ dataanalysis/knowyourresponse/countryprogressreports/2012countries/ce_SZ_Narrative_ Report[1].pdf

— 2013. *Special update report: how Africa turned AIDS around*. Geneva: UNAIDS.

— 2015a. *Understanding fast track: Accelerating action to end the AIDS epidemic by 2030.*Geneva: UNAIDS. Accessed on 6 May, 2016 from http://www.unaids.org/sites/default/files/media_asset/201506_JC2743_Understanding_FastTrack_en.pdf

— 2015b. *All in to end adolescent AIDS campaign.* Geneva: UNAIDS. Accessed on 10 June 2015 from http://allintoendadolescentaids.org/wp-content/uploads/2015/02/Swaziland.pdf

Kalichman, S.C., L.C. Simbayi, C. Allanise, P.P. Mthembu, R.N. Mkhonta & T. Ginindza. 2008. Measuring AIDS stigmas in people living with HIV/AIDS: Internalised AIDS-related stigma scale. *The Psychological and Socio-Medical Aspects of AIDS/HIV*; 21(1):87-93

Kalichman, S.C. & L.C. Simbayi. 2003. HIV testing, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa. Sexually Transmitted Infections 79(6):442-447. http://www.ncbi.nlm.nih.gov/pubmed/14663117

Kajula, L.J., N. Sheon, H. De Vries, S.F. Kaaya and L.E. Aarø.2014. Dynamics of parent-adolescent communication on sexual health and HIV/AIDS in Tanzania. *AIDS Behaviour* 18:S69-S74. DOI 10.1007/s10461-013-0634-6

Kajubi, P., S. Bagger, A.R. Katahoire, D. Kyaddondo & S. Reynolds-Whyte. 2014. Spaces for talking: communication patterns of children on antiretroviral therapy in Uganda. *Children and Youth Services Review* 45: 38–46. DOI: 10.1016/j.childyouth.2014.03.036

Kanduza, A.M. 2003.Tackling HIV/AIDS Stigma in Swaziland through Education. *Eastern Africa Social Science Research Review* 19(2):75-88

Kaplan, J.E., C. Benson, H. Masur, K.K. Holmes, J.T. Brooks, A. Pau & H. Masur. 1995. USPHS/IDSA guidelines for the prevention of opportunistic infections in persons infected with human immunodeficiency virus: introduction. USPHS/IDSA Prevention of Opportunistic Infections Working Group.*Clinical Infectious Diseases.* 21 (S1): S1–11. http://www.ncbi.nlm.nih.gov/pubmed/8547495

Katusiime, C., P. Ocama & A. Kambugu. 2010. Immune Reconstitution Inflammatory Syndrome among adolescents: A report of cases in a resource-limited setting (Uganda). *Southern African Journal of HIV Medicine* 11(2):18. DOI: 10.4102/hivmed.v11i2.225

Kawuma, R., S. Bernays, G. Siu, T. Rhodes & J. Seeley. 2014. ‘Children will always be children’: exploring perceptions and experiences of HIV-positive children who may not take their treatment and why they may not tell. *African Journal of AIDS Research*; 13 (2):189-195.doi: 10.2989/16085906.2014.927778.

Kendall, C. & Z. Hill. 2010. Chronicity and AIDS in three South African communities. In: *Chronic conditions, fluid states: chronicity and the anthropology of illness.* Edited by L. Manderson & C. Smith-Morris, 175–194. New Brunswick, NJ: Rutgers University Press.

Kennedy, C., S.D. Baral, R. Fielding-Miller, D. Adams, B. Sithole, V.A. Fonner, Z. Mnisi & D. Kerringan. 2013. “They are Human Beings; They are Swazi”: Intersecting Stigmas and the Positive Health, Dignity and Prevention Needs of HIV-positive Men who have Sex with Men in Swaziland. *Journal of the International AIDS Society* 16(S3):18749

Kerr, A.M. & Hass, S.M. 2014. Parental Uncertainty in illness: Managing uncertainty surrounding an “orphan” illness. Journal of Pediatric Nursing 29:393-400. http://dx.doi.org/10.1016/j.pedn.2014.01.008

Kidia, K.K., Z. Mupambireyi, L. Cluver, C.E. Ndhlovu, M. Borok & R.A. Ferrand. 2014. HIV disclosure to perinatally infected adolescents in Zimbabwe: a qualitative study of adolescent and healthcare worker perspectives. *PLoS ONE* 9 (1): e87322. DOI: 10.1371/journal.pone.0087322

Kidd, P.S. & M.B. Parshall. 2000. Getting the focus and the group: enhancing analytical rigor in focus group research. *Qualitative Health Research* 10 (3): 293–308. DOI:10.1177/104973200129118453

Kim, S.-H., S. Gerver, S. Fidler & H. Ward. 2014. Adherence to antiretroviral therapy in adolescents living with HIV: a systematic review and meta-analysis. *AIDS* 28: 1945–1956. DOI: 10.1097/QAD.0000000000000316

King, V., L.M. Boyd & M.L. Thornsen. 2015. Adolescents' perceptions of belonging in stepfamilies. *Journal of Marriage and Family* 77 (3): 761–774. DOI: 10.1111/jomf.12181

Kirimli, L., F.M. Ssewamala & L. Ismaylova. 2012. Extended families and perceived caregiver support for orphans in Rakai district of Uganda. *Children and Youth Services Review* 34 (7): 1351–1358. PMC: 3505487.

Kirk, S. 2007. Methodological and ethical issues in conducting qualitative research with children and young people: a literature review. *International Journal of Nursing Studies* 44 (7): 1250-1260. DOI: 10.1016/j.ijnurstu.2006.08.015

Kiwanuka J., E. Mulogo & J.E. Haberer. 2014. Caregiver perceptions and motivation for disclosing or concealing the diagnosis of HIV infection to children receiving HIV care in Mbarara, Uganda: a qualitative study. *PLoS ONE* 9 (3): e93276. DOI: 10.1371/journal.pone.0093276

Kleinman, A. 1978.Concepts and models for comparisons of medical systems as cultural systems.*Social Science and Medicine* 12: 85–93. DOI: 10.1016/0160-7987(78)90014-5

—1980. *Patients and healers in the context of culture: an exploration of the borderline between anthropology, medicine and psychiatry.* Berkeley: University of California Press.

—1988. *The illness narratives: Suffering, healing and the human condition.*New York: Basic Books.

Kleinman, A. & R. Hall-Clifford. 2009. Stigma: a social and moral process. *Journal of Epidemiology Community Health* 63:418-419. doi:10.1136/jech.2008.084277

Kleinman,A., V. Das and M. Locke (eds). *Social Suffering*. Berkeley, California; University of California Press

Kranzer, K., J. Meghji, T. Bandason, E. Dauya, S. Mungofa, J. Busza, K. Hatzold, et al. 2014. Barriers to provider-initiated HIV testing and counselling for children in a high HIV prevalence setting: a mixed methods study. *PLoS Medicine* 11 (5): e1001649. DOI: 10.1371/journal.pmed.1001649

Kurth, A.E., M.A. Lally, A.T. Choko, I.W. Inwani & J.D. Fortenberry. 2015. HIV testing and linkage to services for youth. Journal of International AIDS Society 18(2suppl 1): 19433. http://dx.doi.org/10.7448/IAS.18.2.19433

Lake, A. & M. Sidibé. 2015. To end the AIDS epidemic, start focusing on adolescents. http://www.unaids.org/en/resources/presscentre/featurestories/2015/february/20150217_oped_all-in

Lambert, V., M. Glacken & M. McCannon. 2013. Using a range of methods to access children's voices. *Journal of Research in Nursing* 18 (7): 601–616. DOI: 10.1177/1744987112475249

Lahuerta, M., F. Ue, S. Hoffman, B. Elul, S.G. Kulkarni, Y. Wu, H. Nuwagaba-Biribonwoha, et al. 2013. The problem of late ART initiation in sub-Saharan Africa: A transient aspect of scale-up or a longterm phenomenon? *Journal of Health Poor and Underserved* 24(1): 359–383. DOI:10.1353/hpu.2013.0014.

Leake, V.S. 2007. Personal, familial and systematic factors associated with family belonging for stepfamily adolescents. *Journal of Divorce and Remarriage* 47 (1/2): 135–155. DOI: 10.1300/J087v47n01_08

Lee, B. & P. Oberdorfer. 2009. Risk-taking behaviours among vertically HIV-infected adolescents in northern Thailand. *Journal of International Association of Physicians in AIDS Care* (Chic)8(4):221-228. DOI: 10.1177/1545109709341082

Legasion, M. (2010).*A study of factors associated with non-disclosure of HIV positive status to sexual partners by adult patients attending the VCT clinic at Nhlangano Health Centre, Swaziland*. Unpublished Master thesis: University of Limpopo: Pretoria. http://ul.netd.ac.za/handle/10386/543

Leonard, L., J. Greene & E. Erbelding. 2007. Persons, places and times: the meanings of repetition in an STD clinic. *Medical Anthropology Quarterly* 21 (2): 154–168. DOI:10.1525/maq.2007.21.2.154

Levin, I. 1999. What phenomenon is family? *Marriage and Family Review* 28 (3–4): 93–104. DOI: 10.1300/J002v28n03_08.

Li, R.J., H.B. Jaspan, V. O'Brien, H. Rabie, M.F. Cotton & N. Nattrass. 2010. Positive Futures: A qualitative study n the needs of adolescents on antiretroviral therapy in South Africa. *AIDS Care* 22(6): 751-8. doi: 10.1080/09540120903431363.

Liamputtong, P., N. Haritavorn & N. Kiatying-Angsulee. 2009. HIV and AIDS, stigma and AIDS support groups: perspectives from women living with HIV and AIDS in Central Thailand. Social Science and Medicine 69(6):862-868. doi: 10.1016/j.socscimed.2009.05.040.

Lincoln, Y.S. & E.G. Guba. 1985. *Naturalistic inquiry*. Beverly Hills, CA: Sage.

Link, B.G. & J.C. Phelan. 2001. Conceptualising stigma. *Annual Review of Sociology* 27: 363-385. DOI: 10.1146/annurev.soc.27.1.363.

Locke, M. 1997. Displacing suffering: the reconstruction of death in North America and Japan.*In: A. Kleinmann, V. Das & M.M. Lock (eds.). 1997. Social Suffering.* Berkely: University of California Press, pp. 207-244.

Lyon, M.E. & L.J. D'Angelo (eds.). 2006. *Teenagers, HIV and AIDS: insights from youths living with the virus*. Westport, CT: Praeger Publishers.

Maclean, S. 2009. *Outrage as Swaziland MP Suggests Branding the Buttocks of HIV sufferers to Promote Safe Sex*. Mail and Guardian accessed on 19 March, 2015 from http://www.dailymail.co.uk/news/article-1187328/Outrage-Swaziland-MP-suggests-branding-buttocks-HIV-sufferers-promote-safe-sex.html

Macintrye, K., N. Rutenberg, L. Brown & A. Karim. 2003. Understanding perceptions of HIV risk among adolescents in KwaZulu Natal. *AIDS and Behavior* 8 (3): 237–250.

MacPhail, C.L., A. Pettifor, T. Coates & H. Rees. 2008. 'You must do the test to know your status': attitudes of HIV voluntary counselling and testing among South African youth and parents. *Health Education and Behaviour* 35 (1): 87–104. DOI: 10.1177/1090198106286442

MacPhail, C., A. Pettifor, W. Moyo & H. Rees. 2009. Factors associated with HIV testing among sexually active South African youth aged 15–24 years. *AIDS Care: Psychological and Socio-Medical Aspects of AIDS/HIV* 21 (4): 456–467. DOI: 10.1080/09540120802282586

Madiba, S. 2015. Parental disclosure of HIV positive status to uninfected children and their reactions to disclosure in Ekurhuleni district, Gauteng Province, South Africa. African Journal of Physical Health Education, Recreation and Dance 21(sup 2:1):75-85.

—2014. The impact of fear, secrecy and stigma on parental disclosure of HIV status to children: a qualitative exploration with HIV positive parents attending an ART clinic in South Africa. Global Journal of Health Science 5(2):49-61. DOI: 10.5539/gjhs.v5n2p49.

Madiba, S. & M. Mokgatle. 2015a. 'Students want HIV testing in schools': a formative evaluation of the acceptability of HIV testing and counselling at schools in Gauteng and North West provinces in South Africa. *BMC Public Health* 15: 388. DOI 10.1186/s12889-015-1746-x

— 2015b. Health care workers' perspectives about disclosure to HIV-infected children: cross-sectional survey of health facilities in Gauteng and Mpumalanga provinces, South Africa. *PeerJ* 3: e893. DOI 10.7717/peerj.893

Mafusire, A. & F. Leigh. 2014. *Africa economic outlook: Swaziland*. Accessed on 13 March 2015 from http://www.africaneconomicoutlook.org/fileadmin/uploads/aeo/2014/PDF/CN_Long_EN/Swaziland_EN.pdf

Mahloko, J.M. & S. Madiba. 2012. Disclosing HIV diagnosis to children in Odi district, South Africa. *African Journal of Primary Care and Family Medicine* 4 (1). DOI: 10.4102/phcfm.v4i1.345

Makadzange, K. & B.L. Dolamo. 2011. Care of HIV-positive orphans by elderly people in Swaziland. *Continuing Medical Education* 29 (2): 60–64. Accessed on 13 February 2016 from https://www.k4health.org/sites/default/files/OrphansCare.pdf

Makoae, L.N., M. Greeff, R.D. Phethlu, L.R. Uys, J.R. Naidoo, T.W. Kohi, P.S. Dlamini, M.L. Chirwa & W.L. Holzemer. 2007. Coping with HIV/AIDS Stigma in Five African Countries. *Journal of the Association of Nurses in AIDS Care*; 19(2):137-146

Malinowski, B. 1961.Argonauts of the Western Pacific. In: *Participant observation: a guide to fieldwork* (2nd ed).Edited by K.M. DeWALT& B.R. DeWALT. 2011. Plymouth, United Kingdom: Alta-Mira Press.

Manderson L. 2014. Telling points.*In: M.D. Davies & L. Manderson. Disclosure in Health and Illness*. New York: Routledge. Pp1-15

Manderson, L., & C. Smith-Morris. (eds.). 2010. *Chronic conditions, fluid states:Chronicity and the anthropology of illness.* New Brunswick, New Jersey: Rutgers University Press.

Manu, A.A., C.J. Mba, G.Q. Asare, K. Odori-Agyarko & R.K. Asante. 2015. Parent-child communication about sexual and reproductive health: evidence from the Brong Ahapo region, Ghana. *Reproductive Health* 12: 16. DOI 10.1186/s12978-015-0003-1.

Manye, P. & S. Madiba. (2014). Communication between caregivers and children perinatally infected with HIV about the diseases and medication without disclosure: qualitative data from Nyangabwe Hospital, Botswana. *PULA: Botswana Journal of African Studies* 28(1):28-40. http://www.ub.bw/ojs/index.php/pula/article/viewFile/535/246

Marques, H.H., N.G. Silva, P.L. Gutierrez, R. Lacerda, J.R. Ayres, M. Dellanegra, I. França Jr, et al. 2006. Disclosure of HIV infection from the perspective of adolescents living with HIV/AIDS and their parents and caregivers.*Saude Publica* 22 (3): 619–629. DOI: 10.1590/S0102-311X2006000300017

Marwick, B.A. 1940.The Swazi.*In: M. Russell (1993). Women, children and marriage in Swaziland.International Journal of Sociology of the Family* 23 (1): 43–57.

Mason, M.A., G.M. Svare & N.H. Wolfinger. 2002. Stepparents: de facto parents or legal strangers? *Journal of Family Issues* 23 (4): 502–522. http://jfi.sagepub.com/content/23/4/507.full.pdf

Mattes, D. 2014a. ‘Life is not a rehearsal, it’s a performance’: an ethnographic enquiry into the subjectivities of children and adolescents living with antiretroviral treatment in north-eastern Tanzania. *Children and Youth Services Review* 45: 28–37. DOI: 10.1016/j.childyouth.2014.03.035

— 2014b. Caught in the transition: the struggle to live a ‘normal’ life with HIV in Tanzania.*Medical Anthropology: Cross-cultural Studies in Health and Illness* 33 (4). DOI:10.1080/01459740.2013.877899

Maughan-Brown, B. & N. Spaull. 2014. HIV-Related Discrimination among Grade Six Students in Nine Southern African Countries. *PLoS ONE* 9(8): e102981. doi:10.1371/journal.pone.0102981

Mavhu, W., J. Berwick, P. Chirawu, M. Makamba, A. Copas, J. Dirawo, N. Willis, et al. 2013. Enhancing psycho-social support for HIV positive adolescents in Harare, Zimbabwe.*PLoS ONE* 8 (7): e70254. DOI: 10.1371/journal.pone.0070254

Mazibuko, S. 2014. *Decentralisation of antiretroviral treatment in Swaziland: outcomes of nurse initiated versus doctor initiated treatment*. Master’s Thesis. University of Pretoria, South Africa. Accessed on 17 August 2015 from http://repository.up.ac.za/bitstream/handle/2263/40715/Mazibuko_Decentralization_2014.pdf?sequence=1

Mburu, G., M. Ram, M. Skovdal, D. Bitira, I. Hodgson, G.W. Mwai, C. Stegling & J. Seely. 2013. Resisting and challenging stigma in Uganda: the role of support groups of people living with HIV. *Journal of International AIDS Society* 16(3supp.2):18636. doi: 10.7448/IAS.16.3.18636

Mburu, G., I. Hodgson, S. Kalibala, C. Haamujompa, E.D. Lowenthal & D. Ross. 2014a. Adolescent HIV disclosure in Zambia: barriers, facilitators and outcomes. *Journal of International AIDS Society* 17: 18866. DOI: 10.7448/IAS.17.1.18866

Mburu, G., M. Ram, D. Oxenham, C. Haamujompa, K. Iorpenda & L. Ferguson.2014b. Responding to adolescents living with HIV in Zambia: a social-ecological approach.*Children and Youth Services Review* 45: 9–17. DOI: 10.1016/j.childyouth.2014.03.033

McElroy, A. & M.A. Jezwski. 2000. Cultural variation in the experience of health and illness. In: *Bohle, L.F. 2013. Stigmatisation, discrimination and illness: experiences among HIV-seropositive women in Tanga, Tanzania*. Göttigen, Germany: Universitätsverlag Göttigen.

Medubi, O. 2008. A cross cultural study of silence in Nigeria: an ethnolinguistic approach. Retrieved on 10 September, 2015 from http://www.unilorin.edu.ng/publications/medubi/Oyin%20A%20cross-cultural%20of%20silence.pdf

Meehan T.M., H. Hansen & W.C. Klein. 1997. The impact of parental consent on the HIV testing of minors. *American Journal of Public Health* 87: 1338–1341. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1381096/

Menon, J.A. & C. Glazebrook. 2013. Randomized control trial to evaluate yoga-based peer support group for human immunodeficiency virus (HIV) positive Zambian adolescents. *Journal of AIDS and HIV Research* 5 (1): 12–19. DOI: 10.5897/JAHR12.027

Mfecane, S. 2010. *Exploring masculinities in the context of ARV use: a study of men living with HIV in a South African village*.Unpublished Doctoral Dissertation.University of Witwatersrand, Johannesburg, South Africa.

Miller, R. & D. Murray. 1999. The impact of HIV illness on parents and children, with particular reference to African families. *Journal of Family Therapy* 21: 284–302. DOI: 10.1111/1467-6427.00120

Milligan, C., A. Bingley, & A. Gatrell. 2005. Digging deep: using diary techniques to explore the place of health and well-being amongst older people. *Social Science and Medicine* 61: 1882–1892. http://www.ncbi.nlm.nih.gov/pubmed/15913863

Mills, D. 1988. Stepfamilies in context. In: *Relative strangers: studies of stepfamily processes*. Edited by W.R. Beer, 1–28. Totowa, NJ: Rowan and Littlefield.

Mills, J.E., N. Edwards, R.C. Jackson, L. MacLean &J. Chaw-Kant.2010. Stigmatisation as a social control mechanism for people living with HIV. *Qualitative Health Research* 20(11):1469-1483. DOI: 10.1177/1049732310375436.

Ministry of Health. 2010a. *Analysis of social behaviour and interventions related to adolescent sexual and reproductive health in Swaziland.* Mbabane, Swaziland: Ministry of Health Sexual Reproductive Health Unit & United Nations Population Fund.

—2010b. *Second behaviour surveillance survey adult and youth component report, 2010.* Mbabane, Swaziland: Ministry of Health.

— 2012a. *HIV testing and counselling annual report, 2012*. Mbabane, Swaziland: Ministry of Health, Strategic Information Department.

—2012b. *Swaziland HIV incidence measurement survey, 2012*. Mbabane, Swaziland: Ministry of Health.

—2012c. *Swaziland national HIV prevention policy*. Mbabane, Swaziland: Ministry of Health.

—2014. *Service availability mapping final report, 2013*. Mbabane, Swaziland: Ministry of Health.

—2015. *Swaziland Integrated HIV Management Guidelines, 2015*.Mbabane, Swaziland: Ministry of Health.

Mishel, M.H. 1988.Uncertainty in illness.*Journal of Nursing Scholarship* 20: 225–232.DOI: 10.1111/j.1547-5069.1988.tb00082.x

—1999. Uncertainty in chronic illness.*Annual Review of Nursing Research* 17: 269–294.

Misir, P. 2015. Structuration Theory: a conceptual framework for HIV/AIDS stigma. *Journal of International Providers of AIDS Care* 14(4):328-334. DOI: 10.1177/2325957412463072

Mkhandawire-Valhmu, L. & P.E. Stevens. 2009. The critical value of focus group discussions in research with women living with HIV in Malawi. *Qualitative Health Research* 20 (5): 684–696. DOI: 10.1177/1049732309354283.

Mkhwanazi, N. 2012. A tough love approach indeed: Demonising early childbearing in the Zuma era.*Agenda: Empowering Women for Gender Equity* 26(4):73-84. DOI: 10.1080/10130950.2012.759440.

Mndzebele P., T. Dlamini, S. Matsebula, L. Dube, B. Simelane, et al. 2013. Fast Track - Increasing uptake of HIV Testing and Counselling (HTC) services among men and adolescents through locally-owned solutions. A paper presented at the International HIV Treatment as Prevention Workshop, April 22–25, 2013. Vancouver, BC, Canada. Abstract No 4046.http://www.treatmentaspreventionworkshop.org/wp-content/uploads/2013/06/TasP-Report-2013-FINAL.pdf

Mngadi S., N. Fraser, H. Mkhatshwa, T. Lapidos, T. Khumalo, S. Tsela & H. Odido. 2009. *Swaziland: HIV prevention response and modes of transmission analysis*. Mbabane, Swaziland: National Emergency Response Council on HIV and AIDS.

Modi M, N. Sharma, A. Sharma, Y.S. Marfatia. 2008. HIV infection in adolescents: a rising concern. Indian Journal of Sexually Transmitted Diseases 29:73–5. Available at http://medind.nic.in/ibo/t08/i2/ibot08i2p73.pdf

Moffat, C.V. 2014. *Seciritisation of HIV and AIDS in Southern African policy processes: an investigation of Botswana, South Africa and Swaziland, 2000-2008.*Unpublished PhD Thesis; University of Stellenbosch.Accessed in August 2019 fromhttp://scholar.sun.ac.za/handle/10019.1/95864

Moreira-Silva, S.F., E. Zandonande, & A.E. Miranda. 2015. Mortality in children and adolescents vertically infected with HIV receiving care in a referral hospital in Vitoria, Brazil. *BMC Infectious Diseases* 15:155. **DOI:** 10.1186/s12879-015-0893-0

Morin S.F., G. Khumalo-Sakutukwa & E.D. Charlebois. 2006. Removing barriers to knowing HIV status: same-day mobile HIV testing in Zimbabwe. *Journal of Acquired Immune Deficiency Syndrome* 41 (2): 218–224. http://www.cbvct.med.ucla.edu/pubs/morin2.pdf

Morrow, V. 1996. The ethics of social research with children and young people: an overview. *Children and Society* 10:90-105. Retrieved on 7 August, 2015 from http://www.ciimu.org/webs/wellchi/reports/workshop_1/w1_morrow.pdf

—2008. Ethical dilemmas in research with children and young people about their social environments.*Children's Geographies* 6(1):49-61. Retrieved on 7 August, 2015 from http://eprints.ioe.ac.uk/19205/1/morrow2008ethical49.pdf

Moses, S. & M. Tomlinson. 2013. The fluidity of disclosure: a longitudinal exploration of women's experience and understanding of HIV disclosure in the context of pregnancy and early childhood. *AIDS Care* 25 (6): 667–675. DOI: 10.1080/09540121.2012.736606

Mother Teresa. 1971. *In: A. Brand. Positively Alive: Living with HIV and AIDS: A path to inner healing.* 2005, pp 61. Johannesburg: Jacana Media,

Motshome, P. & S. Madiba. 2014. Perceptions, reasons and experiences of disclosing HIV diagnosis to HIV infected children in Kweneng district, Botswana. *International Journal of Health Sciences and Research* 4 (2): 129–139. http://www.scopemed.org/fulltextpdf.php?mno=152984

Moyer, E.M. 2012. Faidha Gani? What's the point: HIV and the personal politics of (non)disclosure among activists in Zanzibar. *Culture, Health & Sexuality: An International Journal for Research, Intervention and Care* 14 (S1): S67–S79. DOI: 10.1080/13691058.2012.662524

Moyer, E. E. Kahega-Igonya, R. Both, P. Cherutich & A. Hardon. 2013. The duty to disclose in Kenyan health facilities: a qualitative investigation of HIV disclosure in everyday practice. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*. 10(S1):S50-S72. DOI:10.1080/02664763.2012.755339

Moyer, E. & E. Kageha-Igonya. 2014. When families fail: shifting expectations of care among people living with HIV in Nairobi, Kenya.*Anthropology and Medicine* 21(2):136-148. DOI:10.1080/13648470.2014.924298

Moyer, E. & A. Hardon. 2014. A disease unlike any other: why HIV remains exceptional in the age of treatment. *Medical Anthropology: Cross Cultural Studies in Health and Illness* 33(4):263-269. **DOI:**10.1080/01459740.2014.890618

Mugavero, M.J., W.E. Norton & M.S. Saag. 2011. Health care system and policy factors influencing engagement in HIV medical care: piecing together the fragments of a fractured health care delivery system. *Clinical Infectious Diseases* 52 (S2): S238–S246. DOI: 10.1093/cid/ciq048

Munthali, A.C., P.M. Mvula & D. Maluwa-Banda D. 2013. Knowledge, attitudes and practices about HIV testing and counselling among adolescent girls in some selected secondary schools in Malawi. *Africa Journal of Reproductive Health* 17(4 Spec No):60-68. http://www.ncbi.nlm.nih.gov/pubmed/24689317

Mupambireyi, Z., S. Bernays, M. Bwakura-Dungarembizi & F.M. Cowen. 2014. 'I don't feel shy because I will be among others who are just like me . . .': the role of support groups for children perinatally infected with HIV in Zimbabwe. *Children and Youth Services Review* 45: 106–113. DOI: 10.1016/j.childyouth.2014.03.026

Murdock, G.P. 1949. *Social structure*. Glencoe, IL: The Free Press.

Musheke, M., H. Ntalasha, S. Gari, O. Mckenzie, V. Bond, A. Martin-Hilber & S. Merten. 2013. A systematic review of qualitative findings on factors enabling and deterring uptake of HIV testing in sub-Saharan Africa. *BMC Public Health* 13: 220. DOI: 10.1186/1471-2458-13-220

Musinguzi, L.K. 2014.*Sexual and reproductive health decisions among adolescents vertically exposed to HIV and AIDS in Uganda*. Unpublished Master's Thesis.Makerere University, Kampala, Uganda.

Mutwa, P.R., J.I. Van Nuil, B. Asiimwe-Kateera, E. Kestelyn, J. Vyankondondera, R. Pool, J. Ruhirimbura, et al. 2013. Living situation affects adherence to combination antiretroviral therapy in HIV-infected adolescents in Rwanda: a qualitative study. *PLoS ONE* 8 (4): e60073. DOI: 10.1371/journal.pone.0060073

Muzvidziwa, V.N. & A.M. Zamberia. 2006. *Urbanisation and development in Swaziland*. Manzini, Swaziland: JAN Publishing Centre.

Nachega, J.B., M. Hislop, H. Nguyen, D.W. Dowdy, R.E. Chaisson, L. Regensburg, M. Cotton, & G. Maartens. 2009. Antiretroviral adherence, virologic and immunologic outcomes in adolescents compared with adults in Southern Africa. Journal of Acquired Immune Deficiency Syndrome, 51 (1):66-71. doi: 10.1097/QAI.0b013e318199072e.

Nagar, R. & S. Geiger. 2007. Reflexivity and positionality in feminist fieldwork revisited. In: *Politics and practice in economic geography*. Edited by A. Tickell, E. Sheppard, J. Peck & T. Barnes, 267–278. London: Sage.

Namisi, F. S., A. J. Flisher, S. Overland, S. Bastien, H. Onya, S. Kaaya and L.E. Aarø. 2009.Sociodemographic variations in communication on sexuality and HIV/AIDS with parents, family members and teachers among in-school adolescents: a multi-site study in Tanzania and South Africa. *Scandinavian Journal of Public Health* 37(S2):65-74

National Emergency Response Council on HIV and AIDS. 2009. *National multisectoral strategic framework for HIV and AIDS, 2009–2014*. Mbabane, Swaziland: National Emergency Response Council on HIV and AIDS.

— 2014. *Extended national multisectoral strategic framework for HIV and AIDS, 2014–2019.* Mbabane, Swaziland: National Emergency Response Council on HIV and AIDS.

Nhlapho, R.T. 1992. *Marriage and divorce in Swazi law and custom.* Mbabane, Swaziland: Webster Printers.

Negin, J., J. Wariero, P. Mutuo, S. Jan & P. Pronyk. 2009. Feasibility, acceptability and cost of home-based HIV testing in rural Kenya. *Tropical Medicine and International Health* 14 (8): 849–855. DOI: 10.1111/j.1365-3156.2009.02304.x

Nguyen, V.K. 2010.*The republic of therapy: triage and sovereignty in West Africa's time of AIDS*. Durham, NC: Duke University Press.

Ntsepe, Y., L.C. Simbayi, O. Shisana, T. Renhle, M. Mabaso, N. Ncitakalo, A. Davids, et al. 2014. Perceptions about acceptability and prevalence of HIV testing and factors influencing them in different communities in South Africa. *SAHARA: Journal of Social Aspects of HIV/AIDS* 11 (1): 138–147. DOI: 10.1080/17290376.2014.937355

Obare, F. A van der Kwaak, B. Adieri, D. Owuor, S. Okoth, S. Musyoki, E. Muga & H. Birungi. 2010. *HIV-positive adolescents in Kenya. Access to sexual and reproductive* *health services.*Bulletin 393: KIT Development Policy and Practice. Accessed on 16 September, 2015 from http://www.bibalex.org/Search4Dev/files/375056/213610.pdf

Obermeyer, C.M. & M.Osborne. 2007. The utilisation of testing and counselling for HIV: A review of the social and behavioural evidence. *Journal of American Public Health* 97(10):1762-1774. DOI: 10.2105/AJPH.2006.096263

Obermeyer, C.M., P. Baijal & E. Pegurri. 2011. Facilitating HIV disclosure across diverse settings: a review. *American Journal of Public Health*, 101:1011–1023. DOI:10.2105/AJPH.2010.300102

Okoth, P.P. & D.M. Van der Walt.(2913). HIV disclosure and sexual practices of ART patients at one centre in Swaziland.*African Journal of Nursing Midwifery* 15(1):123-138. http://uir.unisa.ac.za/handle/10500/13040

Padgett, D.K. 2004.Mixed methods, serendipity, and concatenation. In: *The qualitative research experience.* Edited by D.K. Padgett, 279–288. Belmont, CA: Wadsworth/Thompson Learning.

—2012. *Qualitative and mixed methods in public health*. Thousand Oaks, CA: Sage Publications.

Palmier, J.B. 2011.*Prevalence and correlates of suicidal ideation among students in sub-Saharan Africa*.Master's Thesis. Georgia State University, Atlanta, GA. Available from: http://scholarworks.gsu.edu/iph_theses/183

Parker, L.A., K. Jobanputra, L. Rusike, S. Mazibuko, V. Okello, B. Kerschberger, G. Jourquet, et al. 2015. Feasibility and effectiveness of two community-based HIV testing models in rural Swaziland.*Tropical Medicine and International Health* 20 (7): 893–902. DOI: 10.1111/tmi.12501

Parker, R. & P. Aggleton. 2003. HIV and AIDS-related Stigma and Discrimination: A conceptual framework and implications for action. *Social Science and Medicine* 57(1):13-24.

Patton, M.Q. 1999. Enhancing the quality and credibility of qualitative analysis.*Health Services Research 34* (5, Part 2): 1189–1208. Available from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1089059/

—2002. *Qualitative evaluation and research methods* (3rd ed.). Newbury Park, CA: Sage.

Peacock-Villada E., B.A. Richardson & G.C. John-Stewart. 2011. Post-HAART outcomes in paediatric populations: comparison of resource-limited and developed countries. *Paediatrics* 127:e423–41.DOI: 10.1542/peds.2009-2701

Penn, H. 2005. *Unequal childhoods: young children's lives in poor countries*. London: Routledge.

Petersen, I., A. Bhana, N. Myeza, S. Alicea, S. John, H. Holst, M. McKay, et al. 2010. Psychosocial challenges and protective influences of socio-emotional coping of HIV+ adolescents in South Africa: a qualitative investigation. *AIDS Care* 22 (8): 970–978. DOI: 10.1080/09540121003623693

Pettifor, A.E., L.G. Bekker, S. Hosek, R. DiClemente, M. Rosenburg, S.S. Bull, S. Allison, et al. 2013. Preventing HIV among young people: research priorities for the future.*Journal of Acquired Immune Deficiency Syndrome* 63: S155–S160. DOI: 10.1097/QAI.0b013e31829871fb

Pettifor, A., C. MacPhil, N. Nguyen & M. Rosenberg, 2012. Can money prevent the spread of HIV? A review of cash payments for HIV prevention.*AIDS Behavior* 16 (7): 1729–1738. DOI: 10.1007/s10461-012-0240-z

Pfaff-Czarnecka, J. 2013.*Multiple belonging and the challenges to biographic navigation.* MMG Working Paper No. 13-05. Accessed 16 September 2015 from http://www.mmg.mpg.de/fileadmin/user_upload/ documents/wp/WP_13-05_Pfaff-Czarnecka_Multiple%20belonging.pdf

Phibin, M.M. 2014. "What I got to go through": Normalisation and HIV-positive adolescents. Medical Anthropology: Cross Cultural Studies of Health and Illness 33(4):288-302. **DOI:**10.1080/01459740.2013.847436

Phillips, C. 2011. *Child-headed households: A feasible way forward, or an infringement of children'srights to alternative care?* Accessed on 6 May, 2016 from http://www.charlottephillips.org/eBook%20Child-headed%20Households.pdf.

Pons, J., W. Mapham, B. Newsome, L. Myer, R. Anderson, P. Courtright & C. Cook. 2012. The potential impact of a cataract surgery programme on the care of orphans and vulnerable children in Swaziland. *South African Medical Journal* 102 (3). Accessed on 13 February 2016 from http://www.samj.org.za/index.php/samj/rt/printerFriendly/5568/3916

Ponterotto, J.G. 2006. Brief note on the origins, evolution and meaning of the qualitative research concept thick description.*The Qualitative Research Report* 11 (3): 539–549. http://www.nova.edu/ssss/QR/QR11-3/ponterotto.pdf

Pool, R. & W. Geissler. 2005. *Medical anthropology*. Maidenhead: Open University Press.

Porter, K. 1996. The agency of children, work and social change in the South Pare Mountains of Tanzania.*Anthropology of Work Review* 17(1-2):8-19. DOI: 10.1525/awr.1996.17.1-2.8.

Posada, S., L.P. Rincon & L.T. Orcasita. 2014. The characterisation of perceived social support of HIV-diagnosed adolescents. *Procedia – Social and Behavioural Sciences* 132: 302–309.

Powell, M.A. 2011. *International literature review: ethical issues in undertaking research with children and young people*. Lismore, Australia: Southern Cross University, Centre for Children and Young People & Dunedin, NZ: University of Otago, Centre for Research on Children and Families.

Prince, R.J. 2016. The diseased bodyand the global subject: the circulation and consumption of an iconic AIDS photograph in East Africa. *Visual Anthropology* 29(2):159-186. http://dx.doi.org/10.1080/08949468.2016.1131517

Ramin, B. 2007. Anthropology speaks to medicine: the case of HIV and AIDS in Africa. *McGill Journal of Medicine* 10 (2): 127–132. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2323482/

Ramirez-Avilla, L., K. Nixon, F. Naubary, J. Giddy, E. Losina, R.P. Walensky & I.V. Bassett. 2012. Routine HIV testing in adolescents presenting to an outpatient clinic in Durban, South Africa. *PLoS ONE* 7 (9): e45507. DOI: 10.1371/journal.pone.0045507

Redcliff-Brown, A.R. & D. Forde (eds). [1950] 2015.*African systems of kinship and marriage*.New York: Routledge

Regional Evidence Building Agenda. 2007. *Neighbourhood care points for OVC in Swaziland.*REBA Case Study Brief No. 14.Accessed on 13 February 2016 from https://www.k4health.org/sites/default/files/NCPsForOVCs.pdf.

Reis, R. 2002.Medical pluralism and the bounding of traditional healing in Swaziland. In: *E. Waltraud (ed.). Plural medicine, tradition and modernity, 1800-2000.* London: Routledge, pp.95-112.

Reis, R. & H. Meinardi. 2002. ILAE/WHO: 'Out of the Shadows Campaign" stigma: does the flag identify the cargo? *Epilepsy and Behaviour* 3:S33-S37

Reynolds-Whyte, S., H.O. Mongensen & J. Twebaze. 2014. Families. In: *Second chances: surviving AIDS in Uganda.* Edited by S. Reynolds-Whyte, 104–117. Durham, NC: Duke University Press.

Richardson, J.C., B.N. Ong & J. Sim. 2008. Experiencing and controlling time in everyday life with chronic widespread pain: a qualitative study. *BMC Musculoskeletal Disorders* 9: 3. DOI: 10.1186/1471-2474-9-3

Richter, L. & L. Sherri. 2008. Demographic evidence of family and household changes in response to the effects of HIV/AIDS in southern Africa: implications for efforts to strengthen families.

Richter, L.M., L. Sherri, M. Adato, M. Belsey, U. Channdan, C. Desmond, S. Drimie, et al. 2009.Strengthening families to support children affected by HIV and AIDS.*AIDS Care: Psychological and Socio-Medical Aspects of AIDS/HIV* 21 (S1): 3–12.

Rochat, T.J., N., Mkwanazi & R. Bland. 2013. Maternal HIV disclosure to HIV-uninfected children in rural South Africa: A pilot study of a family based intervention. *BMC Public Health* 13:147. http://www.biomedcentral.com/1471-2458/13/147

Root, R. 2010. Situating Experiences of HIV-related Stigma in Swaziland. Global Public Health: *An International Journal for Research, Policy and Practice*; 5(5):523-538

Rose, N. & C. Novas. 2005. Biological citizenship. In: *Global assemblages: technology, politics, and ethics as anthropological problems.* Edited by A. Ong and S. Collier.Oxford: Blackwell Publishing.

Russell, M. 1993. Women, children and marriage in Swaziland.*International Journal of Sociology of the Family* 23 (1): 43–57.

Russell, S., S. Namukwaya, F. Zalwango & J. Seeley. 2015. The framing and fashioning of therapeutic citizenship among people living with HIV taking antiretroviral therapy in Uganda. *Qualitative Health Research*, 1–12. DOI: 10.1177/1049732315597654

Rwemisisi, J., B. Wolff, A. Coutinho, H. Grosskurth and J. Whitworth. 2008. “What if they ask me how I got it”: Dilemmas of disclosing parental HIV status and testing children for HIV in Uganda.*Health Policy and Planning*; 23(1):36-42. DOI: 10.1093/heapol/czm040

Rydstrom, L.L., B.M. Ygge, B. Tingberg, L. Naver, and L.E. Eriksson. 2013. Experiences of young adults growing up with innate or early acquired HIV infection: a qualitative study. *Journal of Advanced Nursing*; 69(6):1357-1365. doi: 10.1111/j.1365-2648.2012.06127.x.

Sabapathy, K., R. Van den Bergh, S. Fidler, R. Hayes & N. Ford. 2012. Uptake of home-based voluntary HIV testing in sub-Saharan Africa: a systematic review and meta-analysis. *PLoS Medicine* 9 (12): e1001351. DOI: 10.1371/journal.pmed.1001351

Sahay, S. 2013. Coming of age with HIV: a need for disclosure of HIV diagnosis among children/adolescents.*Journal of HIV/AIDS and Infectious Diseases* 1: 1–7. http://www.jscholaronline.org/full-text/JAID/103/ Coming-of-age-with-HIV-a-need-for-disclosure-of-HIV-diagnosis-among-children-adolescents.php

Saltman, K. 2005. The social construction of adolescence. In: *The critical middle school reader*. Edited by E.R. Brown & K. Saltman. New York: Routledge.

Sam-Agudu, N.A., M.O. Folayan & E.E. Ezeanolue. 2016. Seeking wider access to HIV testing for adolescents in sub-Sharan Africa. *Pediatric Research*.doi:10.1038/pr.2016.28

Sarangi, S. 2008. The Micropolitics of disclosure, stigma and (dis) trust surrounding HIV in India. *In: I. Markova&A. Gillespie (eds). Trust and Distrust: Sociocultural Perspectives* Charlotte, NC: Information Age Publishing, pp. 153-177.

Sawyer, S.M., S. Drew, M.S. Yeo & M.T. Britto. 2007. Adolescents with a chronic condition: challenges living; challenges treating. *Lancet* 369: 1481–1489. DOI: 10.1016/S0140-6736(07)60370-5

Sawyer, S.M., R.A., Afifi, L.H. Bearinger, S.J. Blakemore, B. Dick, A.C. Ezeh, & G.C. Patton. 2012. Adolescence: A foundation for future health. *The Lancet*379(9826):1630-1640. DOI: 10.1016/S0140-6736(12)60072-5.

Scambler, G. 2009. Health-related stigma.*Sociology of Health and Illness* 31 (3):441-445. DOI: 10.1111/j.1467-9566.2009.01161.x

Scambler, G. & A. Hopkins. 1986. Being epileptic: coming to terms with stigma. *Sociology of Health and Illness* 8(1):26-43. DOI: 10.1111/1467-9566.ep11346455

Schafer, J. 2007. Review of Honwana, Alcinda, *Child soldiers in Africa*. Accessed on 23 February 2016 from the H-Net Reviews website: https://www.h-net.org/reviews/showpdf.php?id=13726

Schlebusch, L., S. Burrows & N. Vawda. 2009. Suicide prevention and religious traditions on the African continent. In: *Suicidology and suicide prevention: a global perspective.* Edited by D. Wasserman & C. Wasserman, 63–69. Oxford: Oxford University Press.

Schneider, J.W. & P. Conrad. 1983. *Having epilepsy? The experience and control of illness*. Philadelphia: Temple University Press.

Shamos, S., K.A. Hartwig & N. Zindela. 2009. Men’s and Women’s Experiences with HIV and Stigma in Swaziland. *Qualitative Health Research* 19(12):1678-1689

Sher, R.Y.N., G. Norton, K. Nickell, J. Biggs & P. Roux.2014. Family stability as a predictor of treatment outcomes in HIV-infected adolescents. *International Journal of Infectious Diseases* 21:295. DOI: 10.1016/j.ijid.2014.03.1031

Sikstrom, L. 2014. ‘Without the grandparents, life is difficult’: social hierarchy and therapeutic trajectories for children living with HIV in rural northern Malawi. *Children and Youth Services Review* 45: 47–54.

Silverman, E.A. 2013. Adolescent sexual risk taking in a psychosocial context: implications for HIV prevention. *HIV Clinician* 25 (2): 1–5.

Siu, G.E., S. Bakeera-Kitaka, C. Kennedy, A. Dhabangi and A. Kambugu. 2012. HIV status disclosure and lived experiences of adolescents at the transition clinic of the infectious diseases clinic in Kampala, Uganda: A qualitative Study. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*: 24(5):606-611. doi: 10.1080/09540121.2011.630346

Skovdal, M.,V. Ogutu, C. Aoro, &C. Campbell. 2009.Young carers as social actors: Coping strategies of children caring for ailing or ageing guardians in Western Kenya.*Social Science and Medicine* 69 (4):587-595. DOI: 10.1016/j.socscimed.2009.06.016

Skovdal, M., C. Campbell, C. Madanhire, Z. Mupambireyi, C. Nyamukapa & S. Gregson. 2011a. Masculinity as a barrier to men’s use of HIV services in Zimbabwe. *Globalisation and Health* 7: 13.

—2011b. When masculinity interferes with women’s treatment for HIV infection: a qualitative study about adherence to antiretroviral therapy in Zimbabwe.*Journal of the International AIDS Society* 14: 29. DOI: 10.1186/1758-2652-14-29.

Skovdal, M. & M. Daniel. 2012. Resilience through participation and coping-enabling social environments: the case of HIV-affected children in Africa. *Africa Journal of AIDS Research* 11(3): 155-164. DOI:10.2989/16085906.2012.734975

Skovdal, M. & S. Belton. 2014. The social determinants of health as they relate to children and youth growing up with HIV in Sub-Saharan Africa. *Child and Youth Services Review* 45:1-8. doi:10.1016/j.childyouth.2014.03.024

Sneed, C.D. 2008. Parent-adolescent communication about sex: the impact of content and comfort on adolescent sexual behaviour. *Journal of HIV/AIDS Prevention in Children and Youth* 9(1):70-83. DOI:10.1080/10698370802126477

Solomon, R.C. 1984. Not passion’s slave: emotions and choice. In: R. Ariss. 1993. Performing anger: emotion in strategic responses to AIDS. *The Australian Journal of Anthropology* 4(1):18-32.

Southern African HIV and AIDS Information Dissemination Service.n.d. *MaxART—For Better Health and Zero New HIV Infections: SAfAIDS Project in Swaziland*. Accessed on 24 July 2015 from http://www.safaids.net/files/MaxART.pdf

Spradley, J.P. 1980. *Participant observation*. New York: Holt, Rinehart and Winston.

Stoll, B.M., G.L. Arnaut, D.K. Fromme & J.A. Felker-Thayer. 2006. Adolescents in stepfamilies. Journal of Divorce and Remarriage 44(1-2):177-189. **DOI:**10.1300/J087v44n01_10

StopAIDSNow!. 2011. MaxART: reaching out to youth and men. Accessed on 6 May 2016, from http://www.stopaidsnow.org/maxart-reaching-out-youth-and-men.

Strauss, M., B. Rhodes & G. George. 2015. A qualitative analysis of the barriers and facilitators of HIV counselling and testing perceived by adolescents in South Africa. *BMC Health Services Research* 15: 250. DOI 10.1186/s12913-015-0922-0

Strode, A., C. Slack & Z. Essack. 2010. Child consent in South African Law: Implications for researchers, service providers and policy makers. South African Medical Journal 100(4):247-249. Retrieved on 7 August, 2015 from http://www.samj.org.za/index.php/samj/article/view/3609

Surkan, P.J., J. S. Murkhejee, D.R. Williams, E. Eustache, E. Louis, T. Jean-Paul, W. Lambert, et al. 2010. Perceived discrimination and stigma toward children affected by HIV/AIDS and their HIV-positive caregivers in Central Haiti. AIDS Care: *Psychological and Socio-medical Aspects of HIV/AIDS* 22(7):803-815. DOI: 10.1080/09540120903443392.

Suthar, A.B., N. Ford, P.J. Bachanas, V.J. Wong, J.S. Rajan, A.K. Saltzman, O. Ajose, et al. 2013. Towards universal voluntary testing and counselling: a systematic review and meta-analysis of community based approaches. *PLoS Medicine* 10(8):1001496. DOI: 10.1371/journal.pmed.1001496

Swaziland National Network of People Living with HIV and AIDS & Global Network of People Living with HIV and AIDS. 2011. *Stigma Index Report, June 2011*. Mbabane, SWANNEPHA and GNP+

Tassiopoulus K, A.B. Moscicki, C. Mellins, D. Kacanek, A. Malee, S. Allison, R. Hazra, G.K. Siberry, R. Smith, M. Paul, R.B. Van Dyke, & G.R. Seage. 2013. Sexual risk behaviour among youth with perinatal HIV infection in the United States: predictors and implications for intervention development**.***Clinical Infectious Diseases* 56(2):283–290. DOI: 10.1093/cid/cis816

Tennekoon, V. & R. Rosenman. 2014. 'Behold a virgin is with HIV!' misreporting sexual behaviour among HIV positive adolescents. *Health Economics* 23 (3): 345–358. DOI: 10.1002/hec.2918.

The Government of the Kingdom of Swaziland. 2012. *Child protection and welfare act, 2012.* Mbabane, Swaziland: Ministry of Justice and Constitutional Affairs.

—The National Constitution Act. 2005. Mbabane, Swaziland: Ministry of Justice and Constitutional Affairs.

Thomas, D.R. 2006. A general inductive approach for analysing qualitative data. *American Journal of Evaluation* 27 (2): 237–246. DOI: 10.1177/1098214005283748.

Thurmond, V.A. 2001. The point of triangulation. *Journal of Nursing Scholarship* 33 (3): 253–258. DOI: 10.1111/j.1547-5069.2001.00253.x

Tilly, L.A. & M. Cohen. 1982. Does the family have a history? A review of theory and practice in family history. *Social Science History* 6 (2): 131–179.

Tylee, A., D.M. Haller, T. Graham, R. Churchill & L.A. Sanci. 2007. Youth friendly primary care services: how are we doing and what more needs to be done. *Lancet* 369: 1565–1573. DOI: 10.1016/S0140-6736(07)60371-7

United Nations Children's Fund.1999. *Children and HIV/AIDS: Government and community response in a multi-sectoral context*.Mbabane, Swaziland: UNICEF. Accessed on 13 January, 2015 from https://books.google.com/books/about/Children_and_HIV_AIDS.html?id=VfEeAQAAIAAJ

—2006.*Neighbourhood care points: making the vulnerable children visible*. Mbabane, Swaziland: UNICEF. Accessed on 13 February 2016 from http://www.unicef.org/swaziland/Sz_publications_2006ncpbooklet.pdf

—2012. *Preventing HIV infection among adolescents and young people*. Accessed on 13 January 2015 from http://www.unicef.org/esaro/5482_HIV_prevention.html

—2013. *Swaziland country statistics*. Accessed on 13 March 2015 from http://www.unicef.org/infobycountry/swaziland_statistics.html

—2014a. *Children, adolescents and AIDS: 6th stock-taking statistical update, 2013*. Accessed on 13 March 2015 from http://www.childrenandaids.org/files/Stats_Update_11-27.pdf

—2014b. *Statistical update: children, adolescents and AIDS*. New York: United Nations Children's Fund.

—2015. *Profile of adolescents in Swaziland.* Mbabane, Swaziland: United Nations Children's Fund, Swaziland Office.

Valerie, L.S. 2007. Personal, familial and systematic factors associated with family belonging for stepfamily adolescents. *Journal of Divorce and Marriage* 47 (1/2): 135–155.

van der Geest, S. & K. Finkler. 2004. Hospital ethnography: an introduction. *Social Science and Medicine* 59: 1995–2001.

van Tam, V., A. Pharris, A. Thorson, T. Alfven & M. Larsson. 2011. 'It is not that I forget, it's just that I don't want other people to know'. Bariers to and strategies for adherence to antiretroviral therapy among HIV patients in Northern Vietnam. AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV 23(2):139-145. DOI: 10.1080/09540121.2010.507741

Vaz, L.M., E. Eng, T. Tshakandu, and F. Behets. 2010. Telling children they have HIV: Lessons learned from findings of a qualitative s in sub-Saharan Africa. *AIDS Patient Care and STDs* 24(4):247-256. DOI: 10.1089/apc.2009.0217.

Vaz, L.M., S. Maman, E. Eng, O.A. Barbarin, T. Tshakandu, and F. Behets. 2011. Patterns of disclosure to HIV-infected children in sub-Saharan African setting. *Journal of Developmental Behaviour Paed* 32(4):307-315. DOI: 10.1097/DBP.0b013e31820f7a47.

Vigh, H. 2009. Motion squared: a second look at the concept of social navigation. *Anthropological Theory* 9(4):419-438. DOI: 10.1177/1463499609356044

Viner, R.M., E.M. Ozer, S. Denny, M. Marmot, M. Resnick, A. Fatusi & C. Currie. 2012. Adolescence and the social determinants of health. *Lancet* 379: 1641–1652. DOI: 10.1016/S0140-6736(12)60149-4.

Vreeman R.C., Nyandiko W.M., Ayaya S.O., Walumbe E.G., Marrero D.G., Inui T.S. 2010. The perceived impact of disclosure of pediatric HIV status on pediatric antiretroviral therapy adherence, child well-being, and social relationships in a resource-limited setting. *AIDS Patient Care and STDs*, 24:639–49

Vreeman, R.C., A.M. Gramelspacher, P.O. Gisore, M.L. Scanlon & W.M. Nyandiko. 2013. Disclosure of HIV status to children in resource limited settings: a systematic review. *Journal of International AIDS Society* 16: 18466. DOI: 10.7448/IAS.16.1.18466.

Weaver, S.E. and M. Coleman.2010. Caught in the middle: Mothers in stepfamilies. *Journal of Social and Personal Relationships* 27(3):05-26. DOI: 10.1177/0265407510361729

Weicht, B. 2015.*The meaning of care.The social construction of care for elderly people.* Palgrave Macmillan

Whiteside, A., A. Hickey, N. Ngcobo & J. Tomilson. 2003. *What is driving the HIV/AIDS epidemic in Swaziland and what can we do about it?* Mbabane, Swaziland: National Emergency Response Council on HIV and AIDS & Joint United Nations Programme on HIV/AIDS.

Willis, N., L. Frewin, A. Miller, C. Dziwa, W. Mavu & F. Cowan. 2014. "My story": HIV-positive adolescents tell their story through film. *Children and Youth Review* 45:129-136. doi:10.1016/j.childyouth.2014.03.029

Willner, R. 2011. Micro-politics: an underestimated field of qualitative research in political science. *German Policy Studies* 7(3):155-185. Accessed on July 2015 from https://www.wiso.uni-hamburg.de/fileadmin/sowi/politik/methoden/Roland/GPS_3-2011_Willner.pdf

Wolcott, H.F. 1995. *The art of fieldwork* (2nd ed.). Walnut Creek, CA: AltaMira Press.

World Bank. 2014a. *Poverty and inequality database, 2014.* Washington DC: World Bank.

—2014b. *World development indicators, 2014.* Washington DC: World Bank.

World Health Organisation. 2002. *Adolescent friendly health services: an agenda for change*. Geneva: WHO. Accessed on 7 May, 2016 from http://apps.who.int/iris/bitstream/10665/67923/1/WHO_FCH_CAH_02.14.pdf

—2003. *The right to know: new approaches to HIV testing and counselling*. Geneva: WHO. Accessed on 14 March, 2012 from http://www.who.int/hiv/pub/vct/en/Right_know_a4E.pdfhttp://www.who.int/hiv/pub/vct/en/Right_know_a4E.pdf

—2008. *Child and adolescent health and development progress report, 2006–2007*. Accessed on 13 February 2016 from http://www.who.int/maternal_child_adolescent/documents/9789241596497/en/

—2009. *Rapid advice: use of antiretroviral drugs for treating pregnant women and preventing HIV infection in infants*. Accessed on 12 September 2015 from http://www.who.int/hiv/pub/mtct/rapid_advice_mtct.pdf

—2012. *Making health services adolescent friendly: Developing quality national standards for adolescent friendly health services*. Geneva: WHO. Accessed on 7 May, 2016 fromhttp://apps.who.int/iris/bitstream/10665/75217/1/9789241503594_eng.pdf

—2013. *HIV and adolescents: guidance for HIV testing and counselling and care for adolescents living with HIV*. Geneva: WHO. Accessed on 10 November 2014 from http://www.who.int/hiv/pub/guidelines/adolescents/en/

2013. *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection*.Geneva: WHO. Accessed on 10 November, 2014 from http://www.who.int/hiv/pub/guidelines/arv2013/art/arv2013_chapter07_low.pdf?ua=1

—2014. *Health for world's adolescents: a second chance in the second decade*. Geneva, Switzerland: World Health Organisation.

World Population Review. 2016. Swaziland Population 2016. Accessed on 6 May, 2016 from http://worldpopulationreview.com/countries/swaziland-population/

Woods, K. & R. Jewkes. 2006. Blood blockages and scolding nurses: Barriers to adolescent contraceptive use in South Africa. *Reproductive Health Matters* 14(27):109-118. http://www.ncbi.nlm.nih.gov/pubmed/16713885

Yang, L.H., A. Kleinman, B.G. Link, J.C. Phelan and S. Lee. 2007. Culture and stigma: adding a moral experience to stigma theory. *Social Science and Medicine* 64(7):1524-1536. PMID:17188411

Young, S. 2015. *Swaziland has world's highest HIV/AIDS rate; young women most affected*. Retrieved on 14 October 2015 from Free Speech Radio News website: http://fsrn.org/2015/05/swaziland-has-worlds-highest-hivaids-rate-young-women-most-affected/

Yuval-Davis, N. 2011.*Power, intersectionality and the politics of belonging*.FREIA's Working Paper No. 75. Aalborg, Denmark: Institute for Cultural and Global Studies, Aalborg University. DOI: 10.5278/freia.58024502

Zaman, S. 2005. *Broken limbs, broken lives: ethnography of a hospital ward in Bangladesh*. Amsterdam: Aksant.

Zamberia, A.M. 2011. HIV-related stigma and access to health care among people living with HIV in Swaziland.*Development Southern Africa* 28 (5): 669–680.

Zuber, A., C.F. McCarthy, A.R. Verani, E. Msidi & C. Johnson. 2014. A survey of nurse-initiated and -managed antiretroviral therapy (NIMART) in practice, education, policy and regulation in east, central and southern Africa. *Journal of the Association of Nurses in AIDS Care* 25 (6): 520–531. DOI: 10.1016/j.jana.2014.02.003

---

[i] At the beginning of the study, I was only aware of one ethnography carried out in Swaziland. Sanctioned by NERCHA, the study focused on perceptions.

[ii] Adherence camps are designed to assist adolescents with adherence challenges to peer mentorship under the supervision and guidance of an adult, often working with the adolescents. Led by the adolescents themselves, adherence camps are part of teen clubs, and are held twice a year during school holidays. At them, adolescents engage in a range of structured activities designed to empower them with knowledge about HIV, ART, nutrition, adherence, and life skills. In addition, adolescents are able to build positive relations with other adolescents during the one-week-long camp meetings.

[iii] A comprehensive HIV services package includes HTC, ART initiation and refills, laboratory services, health monitoring, and ongoing counselling.

[iv] In Swazi traditional leadership, a chieftaincy position is determined by, amongst other criteria, sex of the child. Only male children can inherit the chieftaincy from their father. However, in rare cases when the chief dies before having children or only had female children, or if the male child is too young to take over chieftaincy, the eldest daughter (or any other close member of the family chosen by the elders of the clan) can be appointed as acting chief until the rightful male child is appointed. This was the case with the acting chief of e-Tsembaletfu.

[v] This refers to a situation where there are two classes of the same grade. In this school there were two classes for grade 8 (Grade 8 A and B) and two for grade 9 (Grade 9 A and B). This classification is done when the number of students is too large to be accommodated in one class. The Ministry of Education and Training allows a maximum of thirty students per class, though it is not uncommon to find higher numbers in actual practice.

[vi] Pre-vocational schools are designed to provide not only academic and technical subjects for students but also develop their entrepreneurial skills.

[vii] These were given to the clinic contact person by the parents/guardians or adolescents on the first day of the recruitment process.

[viii] These are social groups that young people form to keep themselves occupied. They are not formal in that they are not registered entities, but they are known and recognised in their communities.

[ix] This and other (social, structural, economical) challenges faced by adolescents living with HIV are dealt with in the chapters that follow.

[x] I came across a number of situations where I was directly asked to provide my participants material goods (food, school fees, clothes) or expert support (intervention or advice). I had to balance between what is ethically right and what would compromise my data. Most often if life was in danger I intervened as in the case of Mpendulo who was sick, but in most cases I referred the families to what I considered appropriate structures based on the issues raised.

[xi] The local currency in Swaziland is lilangeni (singular) and emalangeni (plural), and is abbreviated as E. It is linked to the South African rand (ZAR), that is, one lilangeni is equivalent to one rand.

[xii] 'Child-headed household' refers to a household where all its occupants are eighteen years old or younger, and one of them has assumed the status of the head of the household. These children are usually without a full time adult who stays with them as a result of the death of or abandonment by parents. In some cases there may be an adult present but they maybe wholly dependent on the child household head. This is common when the adult is bedridden or too old.

[xiii] According to UNICEF, a 'skipped-generation household' refers to a family headed by a grandparent, who assumes the responsibility of raising grandchildren with or without support from the children's biological parents. In the case of Tsembaletfu, the natal parents of the children had died leaving orphaned children under the sole care of grandparents.

[xiv] In the Human Development report, Swaziland (2007) defines an orphan as a child below the age of eighteen who has lost either one or both of his/her biological parents. Vulnerable children are those whose parents or guardians are incapable of caring for them, those whose grandparents are too old, those who are staying alone in child-headed households or with poor elderly guardians, those who have no place of abode, those who lack basic needs such as shelter, food, clothing, and access to health care, psychological care or education, those exposed to sexual or physical abuse including child labour, and those who are disabled or handicapped.

[xv] Rogers (1983, cited in Smerecnik and Ruiter, 2010) defines 'fear appeal' as a persuasive message that arouses fear in order to promote healthy behaviour. The message combines threat and coping information, and usually starts with presenting the harmful consequences of

---

a certain risk behaviour and continues to propose how best the negative consequences can be prevented.

[xvi] 'Fast track' is a problem-solving approach used to address a well-defined challenge through tangible actions and measurable outcomes within a specified timeframe (Mndzebele et al. 2013; UNAIDS, 2015a). In the context of the MoH's MaxART Project, the fast-track approach is used to overcome the challenge of low uptake of HIV testing and counselling among men and adolescents within a period of ninety days. During this period, communities are encouraged by locally based selected and trained community mobilisers to test for HIV in community-based mobile services provided by various organisations under the leadership of the Ministry of Health.

[xvii] The report was presented at the biannual face-to-face meeting of the MaxART Consortium held at Mountain Inn, Swaziland, in June 2013. In this report the CHAI representative shared that through implementation of sixteen fast track initiatives they were able to increase the number of adolescents who had tested for HIV by 420 per cent, noting a 'very substantial increase among adolescent males'.

[xviii] Fixed-dose combination ARVs are a combination of two or more active drugs in a single pill. According to the ART guidelines in Swaziland, the fixed-dose combination consists of three drugs in one pill which has to be taken only once a day instead of two or three ARVs taken separately two times a day.

[xix] When ART became available, fixed-dose combination drugs were not available. Hence PLHIV had to take many pills.

[xx] Individuals defined as 'adjusted' were those able to effectively neutralise the negative impact of epilepsy on their lives. They fell into three categories. The 'pragmatic type' downplayed their epilepsy by attempting to pass or cover, only disclosing when strictly necessary and then to a select few. The 'secret type' opted for elaborate tactics to conceal their epilepsy, which they regarded as 'a stigmatizing, negative and "bad" quality of self' (Schneider and Conrad, 1981: 215). The 'quasi-liberated type' went beyond pragmatism by publicly proclaiming their epilepsy in an attempt to sidestep any antagonism and to educate others (see Scambler, 2009: 445).

[xxi] According to the national HTC guidelines, a health care professional can decide to test a child if it is in the best interest of the child as enshrined in the United Nations Convention on

---

the Rights of the Child. To provide appropriate health care to Dudu, the doctor had a professional and ethical obligation to make a decision to find out the cause of her ill-health, hence the HIV test.

[xxii] The exchange rate between lilangeni and the euro at the time was E14 to €1.

[xxiii] Swaziland has three levels of school education: primary level, which consists of seven grades; secondary, which has three grades; and high school, which has two grades. To move from one level to the next, pupils are expected to pass an external examination at the last grade of each level. It is only after the high school level that pupils can be considered for tertiary education.

[xxiv] Cotrimoxazole is an antibiotic given to PLHIV prophylactically as part of preventing or managing opportunistic and bacterial infections such as pneumonia, diarrhoea, and malaria. It is also called cotrim or Bactrim.

[xxv] This is a highly toxic pesticide containing aluminium phosphide, and it emits phosphine gas. It is used for killing weevils in tanks of maize. It is almost 100 per cent fatal in humans if ingested.

[xxvi] I attended the support group meeting at the suggestion of the expert client I had interviewed earlier in the week, regarding what I observed as high numbers of pregnancy among young girls in the area. I wanted to find out what the underlying factors could be, from her observation and conversations with adolescent mothers. After our interview the expert client invited me to attend the support group meeting that is held once a month at the clinic after securing verbal consent from group members on my behalf. My role in the support group meeting was that of a passive observer.

After almost thirty five years since the strange illness that was later to be called HIV-related was first reported, and when other populations groups are realising the gains provided by antiretroviral treatment and other prevention interventions, adolescents seem to remain diproporitonately affetcted by the epidemic, especially in developing countries such as Swaziland. According to UNAIDS and WHO, new HIV infections remain high, and deaths are increasing among adolescents. Many of those living with the virus are not aware of their status and therefore cannot access treatment, and even those who have been tested and diagnosed are not aware beasue they have not been informed. Most of the adolescents have been orphaned by AIDS and are living in different families such as skipped generation, single parent, child headed or extended households, who themselves are often poor. This study explored the experiences of adolescents infected with HIV and living with the virus in the different family contexts and how they navigate the challenges that they face in their everyday life. A key finding of the study is the adolescents need for belonging that is, of being accepted, welcomed and appreciated, and a desire for connectedness and to be normal. Although families provide material and psychosocial support, according to most of the adolescents in this study support groups have played a major role in making them feel connected and at home; hence they refer to support groups as ‘one big family’.

Fortunate Sindisiwe Shabalala is a nurse and possesses diploma in general nursing and diploma in psychiatric nursing from the Swaziland Institute of Health Science; a diploma in midwifery science and a Bachelor’s degree in Community Health Nursing from the University of Swaziland, and Masters’ degree in Public Health from The George Washington University, in Washington DC, USA. She has attended several short courses in HIV management, qualitative and quantitative research methods, and child and adolescent counselling. She is currently a lecturer at the University of Swaziland, Faculty of Health Sciences where she teaches courses in community health, psychiatric nursing and health promotion to undergraduate students. She is also the founder nd executive director of the Centre for Child and Adolescent Counselling and Health Research.