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**Normality, Resilience and Agency: The Experiences of Young
People living with HIV within
the Socio-Cultural Context
of
KwaZulu-Natal (South Africa)**

Maud Nombulelo Mhlongo

**A thesis presented in partial fulfilment of the requirements for the degree
of**

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Abstract

The availability of ART has transformed HIV infection from a terminal illness into a disease that is manageable. South Africa bears the greatest burden of the AIDS epidemic, having the highest proportion of adults and young people living with HIV in the world. Studies of the experience of living with HIV have largely been dominated by a medical approach which tends to ignore the subjective experience and meaning of living with HIV.

This study uses constructivist grounded theory to explore the subjective experience of living with HIV for young people who live in KwaZulu-Natal, South Africa. Qualitative methods were used to collect data; these consisted of individual interviews and focus group discussions with young people living with HIV, carers of young people and community members.

This study presents a multifaceted understanding of the experience for young people of living with HIV. Disclosure, young people's interpretation of the meaning of living with HIV and maintaining normality were core categories identified in the young people's narratives. Disclosure created a space for young people to negotiate the social and personal meaning of living with HIV. Maintaining normality was an active process whereby young people engaged themselves in tasks which they perceived to be helpful in managing HIV stigma, negative social interpretations associated with living with HIV and the uncertainty of living with HIV. 'Normalisation' was used in this process, which refers to the combination of strategies that young people employed to survive and maintain a state of wellness; however, it was a negotiated process rather than an outcome, and young people were actively balancing their lives in the midst of uncertainty. Young people's active agency and resilience permeated their narratives and the study.

Dedication

This work is dedicated to all adults and young people living with HIV in South Africa, who continue to live positively with the disease and strive to be the best they can be. This work is also dedicated to those participants who died during the course of this study.

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Thank you, God, for being the pillar of my life and for directing my feet up to now.

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List of Acronyms

HIV	Human Immunodeficiency Virus
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
UNAIDS	Joint UN programme on HIV/AIDS
UNCRC	United Nations Convention on the Rights of the Child
ACRWC	African Charter on the Rights and Welfare of the Child
WHO	World Health Organisation
PMTCT	Prevention of Mother-to-Child Transmission Programme
TAC	Treatment Action Campaign
CCMT	Comprehensive plan for Care and Management and Treatment of HIV/ AIDS
NGO	Non-governmental organisation
CBO	Community-based organisation
NEPAD	New Partnership for African Development
PCR	Polymerase Chain Reaction test
HAART	Highly active antiretroviral treatment
UNICEF	United Nations Children's Fund

Glossary

Izinkosi	Local chiefs
Izangoma	Seers
Ukuhlonipha abadala	Respect for elders
Ubuntu	An African world view or humanist philosophy which states that one's fulfilment and being can be found through relations with the next person
AbaZulu	One of the Nguni tribes in South Africa residing mostly in KwaZulu-Natal
AbaSotho	One of the South African tribes
Ingane yami,ingane yakho	It signifies a sense of Ubuntu, meaning that your child is my child
Ngizogqashuka	An informal word that refers to dying
Lento idinga isibindi	An idiom that refers to being brave
Kunalento elokhu ikudla kancane kancane-	An idiom that refers to something that affects one gradually
Amagama amathathu-	Three words (HIV euphemism)
Usibani bani uyagula	So and so is sick (HIV euphemism)
Lesisifo	This disease (HIV euphemism)
Lento	This thing (HIV euphemism)

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Chapter One: Introduction and Background to the Study

The aims of this study were to understand the experiences of young people living with Human Immunodeficiency Virus (HIV) and taking antiretroviral treatment (ART) within the context of KwaZulu-Natal, South Africa. Young people that participated in the study were between the ages of 12 and 18 years. Most of the participants were perinatally infected by HIV, however, in cases of some of the participants, the mode of HIV transmission was not clear since they had a history of having been sexually abused when they were very young and their parents were deceased. South Africa is widely regarded as the epicentre of HIV because of the high HIV prevalence rate among its population, including young people who are born with HIV (Heywood, 2003).

Globally, much has been written about the experiences of young people who were perinatally infected by HIV, and these studies have indicated the negative psychological, neurological and social implications of living with HIV (Koekkoek et al., 2008; Avabratha et al., 2011; Brackis-Cott et al., 2009). In the South African context, literature relating to HIV/AIDS in young people has focused on the impact of the epidemic on young people, and has raised a discourse which has been criticised for its narrow focus and for sensationalising the impact of parental death on young people, especially the creation of ‘AIDS orphans’, young people with no visible means of support (Earls et al., 2008). The representation of young people’s voices and their perspectives on the meaning of living with HIV tends to be limited (Li et al., 2010), and young people living with HIV from rural areas tend to be even less visible in research studies when compared with those from urban areas in South Africa (Panelli et al., 2007). There is recognition in literature that living with HIV is a unique experience for young people, hence some researchers consider it a ‘separate HIV epidemic’ because of the unique challenges it poses for the infected young people as they grow up (Naswa & Marfatia, 2010). Moreover, young people are perceived to be less prepared to deal with a health crisis of such magnitude (Lyon & D’Angelo, 2006).

The few studies that explore the experiences and meaning of living with HIV in the South African context tend to be based in tertiary hospitals and urban places (Li et al., 2010) and when young people’s experiences of negotiating the illness are sought, they are often based on carers’ interpretations (Kouyoumdjian et al., 2005; Moodley et al., 2006; De Baets et al.,

2008). These studies often miss the young people's voices and the meanings for them personally of living with HIV.

The importance of locating young people's experience within their own context, and understanding childhood experiences within their localized environment, has been an overarching feature in current childhood literature (see James & Prout, 1990; Aitken et al., 2008; Jenks, 1996; Best, 2007). Since most childhood studies seem to be conducted in developed countries, the experiences of young people from less developed countries are often not sought (Steele & Graue, 2003). Through the use of child-centred methods, this study has explored how young people negotiate their lives with HIV within their own social and cultural context.

1.1: My Interest in the Phenomenon under Study

I have been a practising social worker for the past ten years in a clinic that offers treatment, care and support to families infected and affected by the Human Immunodeficiency Virus (HIV). My social work career began during the period when antiretroviral treatment (ART) was not available in public hospitals. During that time, all individuals who presented with HIV-related illnesses were given symptomatic treatment, which often provided only temporary relief once Acquired Immunodeficiency Syndrome (AIDS) had developed. At that time, ART was not available in public hospitals; therefore, only people with sufficient financial resources could access this treatment privately from independent pharmacies. One of the people that started ART during that time was Judge Cameron, an HIV activist who lives with HIV and is open about his status; he is a judge at a high court. Judge Cameron started ART when treatment was not accessible to ordinary South Africans, and he argued that he could only access ART because of his high salary as a judge. He stated that he could afford the cost, which was about US \$400 per month (Cameron, 2005), and that it was an unfair position that being alive or dying as a result of AIDS was a decision based on financial affordability rather than a right to health for all. He regarded this practice as unjust and unconstitutional. Influenced by high-status activists such as this, as well as growing national and international pressure, in 2004, the Department of Health made a major decision to make ART accessible to the public at no cost, a decision that drastically changed the course of HIV in South Africa. This decision made this life-saving treatment accessible to ordinary South Africans who would otherwise be unable to afford it. Consequently, the majority of people with HIV who are taking ART in South Africa are living longer and more healthily.

South Africa, as mentioned earlier, has the largest proportion of children and young people living with HIV in the world (Joint United Nations Programme on Acquired Immune Deficiency Syndrome (UNAIDS), 2010), and KwaZulu-Natal, the province where the study was conducted, has the highest HIV prevalence rate in the country. While practicing as a social worker, I observed numerous challenges associated with being HIV positive, as well as psycho-social problems that arose after being diagnosed. Adults had to deal with various psycho-social issues such as disclosure, stigma and mental health problems such as depression. When patients were at an advanced stage of AIDS, the pain and trauma that families had to endure was unbearable for most. This is a new era now, where the availability and accessibility of ART is changing the course of HIV diagnosis from that of a terminal disease to a chronic illness. Young people with HIV are now surviving and reaching adulthood. With the increased longevity of young people and young people, new challenges such as disclosure, development from adolescence to adulthood which includes forming peer and sexual relations, and the consequences of long-term adherence to ART have emerged.

This initiated my interest and ultimately that interest grew to a desire to understand how young people were navigating the process of living with HIV in this era of ART, through the pursuit of doctoral study.

1.2: HIV/AIDS in South Africa: Pre-ART Period

Research carried out against a contemporary landscape can never be disconnected from its historical past. In South Africa, the intersection of children and HIV is linked to several factors which include the history of the HIV epidemic in the country, the government's poor response in curbing the spread of HIV which include the delayed response to introduce programmes to prevent HIV transmission from mother-to-child, as well as measures to ensure that children exposed to HIV are tested timeously and those infected are adequately cared for. In the 1990s, the prevalence of HIV in South Africa was low, and only about 1% of people were estimated to be living with HIV. However, the rate of transmission of the virus was rising rapidly and a decade later the prevalence had risen to 16.1% (UNAIDS, 2011). Several potential factors have been put forward as having contributed to the AIDS epidemic in South Africa. Some point to the social determinants of HIV which create high-risk situations for HIV infection to spread. These include impoverishment, rapid urbanisation, labour migration, population movements and displacement. Zwi & Cabral (1991) argue that often, in such situations, daily survival may have been prioritised, rather than attending to risk-taking

behaviour. Black migrant workers left their families in rural homesteads to search for employment in mines, which were located in urban areas. In those places, men had to survive hazardous health, work and living conditions. Campbell (1997) argues that those circumstances contributed to the change of men's identity to one of wanting to be seen as fearless and 'real men'. Associated with this identity was the notion that real men had "insatiable urges to have sex with an unlimited number of women" (Campbell & Williams, 1999, p.1635).

The comprehensive and progressive AIDS plan that was introduced by the Government to deal with HIV in the country was characterised by conflict between the civil society, government and the medical professions (Schneider & Fassin, 2002). At the heart of this conflict was the then President Thabo Mbeki's denial of the link between HIV and AIDS. During the period of his presidency, he surrounded himself with AIDS denialists, who expressed the view that HIV was a harmless virus and AIDS was caused by malnutrition (Heywood, 2003).

President Thabo Mbeki's public announcement of support for AIDS denialism attracted widespread criticism until he finally withdrew from making public comments on the subject in 2000 (Nattrass, 2007, p.35). The then Minister of Health, Dr Manto Tshabalala, took this negative agenda forward and during the period of 2001 and 2002, she refused to implement the Prevention of Mother-to-Child Transmission programme (PMTCT), which included the use of AZT for the prevention of HIV being transmitted from a mother to a child. She expressed the view that AZT, an antiretroviral drug that had shown positive outcomes in preventing HIV transmission from mother to child, was toxic, and that more research was needed into its toxicity and effectiveness before state support would be given for its administration (Heywood, 2003; Nattrass, 2007).

This trend continued through the refusal to make Nevirapine, a drug that had also shown effectiveness in reducing HIV transmission from mother to child, available for PMTCT in the public health sector. In response, the Treatment Action Campaign (TAC), an advocacy group, instigated legal proceedings against the Minister of Health on the 17th July 2001; the court ruled in favour of TAC, but the Minister of Health opposed the judgement and took the matter to the Constitutional Court. On the 5th July 2002, the court ruled in favour of TAC and stated that there was no evidence of the Government's claim that Nevirapine was not safe for PMTCT. Finally, in 2002, the Minister of Health, Dr Tshabalala, made a public

announcement that Nevirapine could be used for the PMTCT in South Africa (Heywood, 2003; Nattrass, 2007).

The introduction of ART to public hospitals as the standard care and treatment for adults and young people with AIDS was the next battle that was fought with the Minister of Health, who continued to undermine the positive outcomes of ART. It was not until late 2003 that the Minister of Health, Dr Tshabalala, forced by internal dissent and civil disobedience led by TAC, announced that highly active antiretroviral treatment (HAART) would be made available in the public healthcare sector through the Comprehensive Plan for Care, Management and Treatment of HIV and AIDS (CCMT Plan) (Nattrass, 2007, p.118). This plan was not implemented in public hospitals until late 2004.

The impact of AIDS denial in South Africa was heavy in terms of human cost, and also contributed to high rates of infection among children born to mothers living with HIV. It is estimated that 343,000 people died from AIDS-related illnesses, and 171,000 children were infected with HIV during this period (Nattrass, 2007). This is an era in South African HIV history that Peter Mandelson referred to as ‘genocide by sloth’ (New Statesman, 18 February, 2002), referring to the period in South Africa when HIV was spreading rapidly among heterosexuals because of the South African government’s denialist position and inaction in dealing with HIV.

1.3: Young people and HIV/AIDS: Current Status

Sub-Saharan Africa, of which South Africa is part, is home to about 90% of all young people living with HIV in the world (UNAIDS, 2011). In 2010, 330,000 young people under 15 years old were estimated to be living with HIV in South Africa (UNAIDS, 2010), of which 70,000 were estimated to be taking ART (Statistics South Africa, 2009). Sixty-three thousands young people in South Africa were estimated to be infected with HIV in 2011 alone (Statistics SA, 2011). This indicates a high burden of HIV in South Africa, and therefore greater effort is still required to prevent HIV transmission from mothers to children, the most common source of HIV infection among young people.

Shisana et al. (2009) reported that a large proportion of young people exposed to HIV in South Africa remained untested up to two months of age and, despite efforts being made to improve early testing among children by expanding services and improving access to early testing and treatment, the uptake of young people onto ART remained poor. Availability and

access are not the only challenges that prevent children from being tested and enrolled in a timely manner onto an ART programme. Phili (2009) in a qualitative study offered an alternative perspective on social and cultural determinants of poor child uptake of HIV care; s/he suggested that factors such as: inadequate knowledge about ART; use of traditional medicine and alternative therapies in preference to ART; fear of ART side effects, and disintegration within families were pivotal in understanding this challenge and how it affects access to treatment and care. Moreover, studies examining timing of enrolment of young people on ART indicated that rural areas of South Africa have slightly higher rates of delayed enrolment on ART programmes compared to their urban counterparts (Fatti et al., 2010; Cooke et al., 2009). The late enrolment of children on ART has been reported to have devastating consequences for children; they are more likely to be enrolled at an advanced stage of the disease and consequently, by that time, the effects of some of the major opportunistic infections may be irreversible. Since the introduction of ART in public hospitals, greater efforts have been made to make antiretroviral drugs freely available to children; however, treatment coverage for children remains low in South Africa and globally when compared to the numbers of children that need it (UNAIDS, 2011). In 2007, 32,000 children and young people in South Africa were on treatment, and in 2010, 108,682 were on ART; that leaves an estimated 196,000 children who are in need, but who are without access to medication (WHO, UNAIDS, UNICEF, 2011).

Nevertheless, guidelines to improve HIV testing for HIV-exposed infants are being revised and implemented in South Africa, in line with recommended guidelines from the World Health Organisation (WHO), (National Department of Health; South African National AIDS Council, 2010). Instead of waiting for 18 months for conclusive HIV results, the polymerase chain reaction test (PCR) is now part of standard care for children less than six weeks old who are exposed to HIV in South Africa. This test can detect the presence of HIV in infants at an early stage compared with the Rapid HIV test that gives conclusive results only at 18 months of age. Introducing timely HIV testing for infants has reduced the risk of the child being lost to follow-up care, a situation that existed prior to this form of HIV testing.

The availability of and access to ART is slowly reversing the tide of premature HIV-related deaths (Shisana et al., 2009), and there is a steady increase in the number of young people growing up and reaching adulthood while taking ART. Greater awareness and commitment to improving access to testing and treatment has been observed from the current government (UNAIDS, 2010) as a result of this commitment, HIV prevalence among children of 2-14

years declined from 5.6 in 2002 to 2.5 in 2008, indicating the positive impact of PMTCT programme (UNICEF SA, 2010). In spite of this progress, little is known about the experiences of these young people, the psycho-social issues associated with growing up whilst taking ART, and how young people manage their diagnosis and their HIV status within this context.

Numerous studies conducted in Europe and the USA have reported various mental health challenges, neurological and neuropsychological deficits, poor language and poor school functioning among young people living with HIV (Malee et al., 2011; Brackis-Cott et al., 2009; Mellins et al., 2009; Koekkoek et al., 2008; Mellins et al., 2003; Wachslar-Fielder & Golden, 2002). Although young people living with HIV are at an increased risk of developing these conditions, Mellins et al. (2009) and Brackis-Cott et al. (2009) locate the aetiology of these conditions within an ecological theory which points to the impact of environmental challenges on these risk factors. Growing up in poverty-stricken environments, exposure to alcohol and drug abuse, as well as family-related challenges, are cited as contributory factors to the difficulties young people were experiencing.

Few studies have been conducted in Africa about the psycho-social experiences of young people living with HIV; Rao et al. (2007) affirms that position by arguing that there is no published evidence about the levels of psychiatric symptoms related to HIV in infected young people from developing countries. There is also a dearth of literature on HIV disclosure to young people; a process which refers to telling a young person his/her HIV diagnosis and HIV related information. Lesch et al. (2007) observe that studies examining current HIV disclosure practices among children and young people living with HIV are sparse, and more so in the sub-Saharan region. The few that have been conducted in the region are often based on the perspectives of healthcare workers or caregivers (Myer et al., 2006; Kouyoumdjian et al., 2005). Li et al. (2010) remark that there is a paucity of studies which explore the experiences of living with HIV from the viewpoint of young people, particularly in settings with few resources.

In the light of this obvious gap in understanding, a three-dimensional methodological approach was employed to understand the lives of young people who live with HIV within the context of KwaZulu-Natal. The first approach explored the community context of young people and its impact on the functioning of families and young people that live with HIV, whilst the second approach examined the construction, responses and functioning of the

family in the era of HIV, as well as how young people are affected by these factors. The third approach zoomed in to explore the experiences of young people that live with HIV and who are taking antiretroviral treatment.

1.4 Research Problem

South Africa has the largest proportion of young people living with HIV and the highest cohort of young people on ART, yet very little is known about the experiences of these young people from their perspectives and how they manage their HIV status within their cultural context. This study aimed to explore the lives of these young people within *their* context and to understand *their* interpretation of these experiences. Much is written on behalf of young people but little work has focused on their own perspectives on living with HIV.

1.4.1 Research questions

Although a grounded theory study (and therefore did not set out to test apriori theory), several questions were generated from this initial incursion into the literature:

1. What are the experiences of young people living with HIV from KwaZulu-Natal, South Africa?
2. Do young people from KwaZulu-Natal experience stigma, and if so, how is it managed and understood?
3. How do young people living with HIV learn about their HIV status, and how do they negotiate the process of knowing?
4. What are the caregiving practices and family patterns for young people living with HIV?

1.4.1: Significance of the study

This study makes a number of significant theoretical contributions. Firstly, it outlines the issues that are critical in the lives of young people that live with HIV in KwaZulu-Natal, whilst attaching meaning and interpretation to them. Secondly, the ability to live a normal life is important to these young people; therefore this study identifies how normality as a continuous process, rather than as an achievement is negotiated and managed. This process is one that involves maintaining and balancing different facets of living (health, loss, adolescent development, identity formation, family, education, friendships, secrecy, medication etc.) as part of daily life, and is often surrounded by uncertainty. Critical issues such as HIV disclosure, the 'position' of young people in the family and family construction in the era of HIV are raised in order to locate and interpret young people's experiences. This study also

challenges the dominant problematic and disease-centred approach that has characterised most literature on young people that live with HIV. In this approach, young people living with HIV are associated with many challenges, such as psychological, neurological, psychiatric, cognitive, behavioural and developmental issues. Whilst these challenges may be significant, this approach tends to ignore the diversity, strength, agency and capability of young people living with HIV in negotiating their lives. This study has therefore demonstrated young people's own agency and resiliency in maintaining normality within their contextual vulnerabilities.

South Africa bears the greatest brunt of the HIV epidemic and, as mentioned earlier, many children were born with HIV, many of whom are now reaching adulthood. Previous studies conducted in Europe and the USA on young people living with HIV globally have recommended a more contextual approach to understanding the negative impact of HIV on young people. However, there is limited literature on how young people from South Africa navigate through the various tasks related to HIV. The value of this study lies in its methodology, which includes young people's narratives, those of families and community participants. These combined sets of data indicated that, although young people's experiences can be studied on their own, in this context, young people's ways of life and experiences cannot be entirely separated from the situations where they are lived.

1.5: Outline of the Structure of the Thesis

This thesis has begun with an introduction providing a broad context for HIV in South Africa and a discussion of the role of South African politics in the construction of the HIV epidemic in the country. That discussion has provided a backdrop for understanding the context behind the overwhelmingly high prevalence of HIV infection among young people in the country. Within this broader discussion, the rationale for this study has been introduced, as well as key research questions.

Chapter Two: Review of Literature

This section contains a review of literature conducted prior to commencing the study. In this review, theoretical positions relating to childhood, child participation, child agency and how childhood is conceptualised in KwaZulu-Natal are outlined as background. This review also discusses the meaning that children and young people ascribe to living with a chronic illness. That section focuses on key literature regarding living with a chronic illness such as cancer or

HIV and young people's perspectives. Since this is a grounded theory study, the more extensive literature review was conducted during data collection and analysis in response to emerging themes and emerging assumptions and this is integrated with the findings chapters.

Chapter Three: Research Methodology

This chapter introduces the methodology section of the study by locating the study within the relevant theoretical framework, which is that of social constructionism, child agency and children's rights. Constructionist grounded theory is introduced as a method of collecting and analysing data, and described in relation to its use in this study. The last part of this chapter contains the reflective section which includes key ethical issues; these are issues that emerged during the study, such as the position of the researcher during the research practice and my reflections on the research process and data analysis.

Chapter Four: Findings Chapter - Community Attitudes and Responses to HIV

This chapter is one of the findings chapters, and outlines community attitudes and responses to HIV. An understanding of the socio-cultural context in relation to the experience of children living with HIV was important. Therefore this chapter describes the broader community response to HIV. Since meaning is constructed and shared during various social interactions, the community as a public space was an important institution in this study. Issues that were raised during the community engagement include HIV and stigma, HIV silence and secrecy, community deprivation and healthcare workers' perceptions about HIV in this community.

Chapter Five: Families and Caregiving in the Era of HIV

This is the second findings chapter and is centred on young people's immediate context, which is the family. Central to this thesis are family functioning and caregiving practices for young people living with HIV. This chapter examines families of young people that live with HIV, with reference to change, adjustment and survival in the era of HIV. The nature of caregiving practices is pivotal to the care and protection of young people that live with HIV. Some of the traditional patterns of adult-child interaction which located young people in a subordinate position are gradually being challenged in the era of HIV since young people were expected to express their feelings when they were not feeling well. Similarly to the issues revealed in the young people's narratives, the intersection of HIV stigma, silence and the nature of the child-adult relationship were shown to be central to caregiving practices.

Themes that emerged include the nature of caregiving practices for young people in the era of HIV and the management of, perceptions of, and response to young people's needs by carers.

Chapter Six: 'I am alright' - Maintaining Normality and Managing HIV Tasks within the Secrecy and Silence of HIV/AIDS

This is the final findings chapter and contains young people's own subjective experiences of living with HIV and negotiating their lives. This chapter delves into the narratives of young people and their perspectives of living with HIV whilst trying to maintain a normality of living. At the centre of this discussion is the intersection of young people's agency in maintaining normality of self within the context of HIV secrecy and silence, the 'subordinate position' of young people in families, and surviving family and environmental vulnerabilities. Topics covered include: young people's negotiation of HIV silence and secrecy; complexities of HIV disclosure; young people's agency in maintaining normality, and discussion of factors that threaten a healthy sense of self and of being a young person. In summary, this chapter describes the young people's unique way of negotiating HIV trajectories to maintain self and normalise the experience of living with HIV within the context of HIV secrecy and silence.

Chapter Seven: Discussion Chapter - Maintaining Normality and a Sense of Self within a Context of Vulnerabilities and HIV Uncertainty

This chapter integrates the three findings chapters described above by locating young people's interpretations of meaning and of maintaining normality whilst managing HIV tasks within their context. Moreover, young people's agency in managing HIV tasks is described, to indicate the insider's perspective of managing a potentially fatal and stigmatised illness and trying to normalise the experience. This study also redefines the nature and patterns of families and how they respond to the impact of HIV. Topics discussed include the use of agency in managing disclosure and managing HIV tasks and finally, the chapter explores the changing nature of families and caregiving practices and their impact on young people.

Chapter Eight: Conclusion and Recommendations

This chapter concludes this thesis by providing a summary of the thesis and outlining core themes that have emerged from the study, which are young people's disclosure, meanings of HIV and young people's process of maintaining normality whilst living with HIV. The implications of the study, as well as its contribution to knowledge, are also discussed in this chapter.

Chapter Two: Literature Review

2.1: Introduction

This chapter presents a preliminary literature review as a background to the study. The key issues that relate to young people living with HIV and the gaps that exist in the literature are explored. The review illuminates the problematic nature of living with HIV for young people. Adherence to treatment, HIV disclosure and psychological and developmental issues have been seen as central to the lives of young people who live with HIV (Vaz et al., 2010; Benton & Ifeagwu, 2008; Kang et al., 2008; Roberts, 2005; Pontali, 2005). Whilst the personal impact of living with HIV for young people has been a key focus in the literature, there is a growing body of knowledge which indicates that the personal impact of HIV for young people who live with the disease is a negotiated process between individual factors and the environmental context. Studies that forward this thought suggest that HIV may not be the only major cause of many problems such as behavioural, cognitive, developmental and mental health challenges that have been identified among young people living with HIV; instead, an intersection of environmental challenges such as poverty, overcrowding, family dynamics and caregivers' issues contribute to young people's development and wellbeing (Johnston, 2009; Kang et al., 2008; Mellins et al., 2003; Coscia et al., 2001).

Although literature that focuses on experiences of young people within the African context is sparse, issues that pertain to young people's negotiation of HIV, silence and secrecy within their environment have been reported. This literature indicates that, within the African context, communicating about issues that are considered to be 'sensitive' such as death and sex is challenging, and young people are often excluded from participating and talking openly to adults about such issues (Clacherty & Donald, 2007; Clark, 2009; Richter & Muller, 2005; Thupayagale-Tsheneagae & Benedict, 2011; Preston-Whyte, 2003). One of the studies conducted in South Africa with young people who had lost their parents as a result of AIDS-related death indicated that HIV stigma and the silence that surrounds HIV complicates the grieving process, because young people cannot share their experience of their parent's death (Thupayagale-Tshweneagae & Benedict, 2011).

This review also examines how childhood is conceptualised in literature, and how it is experienced in specific contexts such as the communities where the study was located. The construction of childhood has received much attention in literature during the twentieth

century, a period which even earned the title of the ‘century of the child’ (James & Prout, 1990) because of the emerging thinking about the position of the child. The acknowledgement of young people as active and autonomous participants in society, instead of being seen as passive subjects within social structures and processes, and silent objects of concern, dependent on adults, has gained momentum (Skelton, 2008; Kjørholt, 2008; Prout & James, 1990). Young people are acknowledged as active agents in spheres of economy, household and caring roles (Abebe, 2008; Lund, 2008; James et al., 1998). In this rethinking, childhood is conceptualised as socially constructed and a young person’s position is understood within the cultural and societal context to which he/she belongs (Lund, 2008; Prout & James, 1990). The relevance of acknowledging young people as social actors with rights within the discourse of childhood and illness goes beyond the recognition of young person’s right to being informed about his/her condition; young people are also seen to be active participants in their illness management. As mentioned earlier, roles and responsibilities are socially structured; therefore, how these roles are negotiated and validated by adults largely depend on how the position of the young person is constructed and validated within a localized context.

Exploration of the voices of young people and their experience in managing their lives whilst living with a chronic illness is sparse. Although much has been written about young people who live with various chronic illnesses, analysis of the young person’s interpretation of the meaning of living with a chronic illness tends to be limited (Hampel et al., 2003; Sartain, 2000). This gap in the literature is largely attributable to the methodological approaches employed. Since quantitative studies tend to be the dominant method of conducting such studies, discussion of young people’s lived experiences and personal voices tend to be minimal.

This review, therefore, is centred on three areas that are pertinent to the themes that later emerged from the study. The theoretical constructs of childhood and the global shifts that have occurred in the discourse of childhood are introduced. This discussion is carried forward with an exploration of the position of young people in South Africa, both through the lens of children’s rights and also within the family context (considering that a legal definition of a child in South Africa is anyone under the age of 18 years). The interplay between the young person’s position within the family and the maintenance of silence and secrecy in families on issues of death is also addressed. The last section explores the international and national literature on young people who live with HIV and, where appropriate, parallels are drawn

with literature which is based on young people with cancer and how they negotiate living with a chronic illness.

2.2: Childhood and the Position of a young person

2.2.1: Theoretical reflections on childhood

As mentioned earlier, the concept of childhood has been changing over time and also varies in terms of place. Whilst it is generally accepted that all societies have a conception of childhood, this conception varies across societies. In a South African context, for example, the conception of childhood is informed by different cultural dynamics and is experienced differently within different racial groups (this topic is discussed later within this chapter). Childhood conceptions often differ in terms of boundaries, dimensions and divisions (Archard, 1993); however, there is a general consensus in literature that young people have agency and are social actors and agents within their world, regardless of cultural variations.

In an attempt to conceptualise childhood, different perspectives and theoretical constructs have been put forward. The psychological perspective of child development was the dominant perspective in childhood studies during the twentieth century (Prout & James, 1990). Central to this perspective are assumptions that childhood is a natural and evolutionary process, and that maturation is a natural and inevitable progression. Child development is therefore perceived as a self-propelled process that is derived from biological processes and functions (Archard, 1993).

Piaget's theory of development is one of the most influential theories relating to child development. Piaget's theory proposes that child development proceeds within clearly defined stages of intellectual growth that begin from *sensory-motor* intelligence and proceed to *pre-conceptual* thought, *intuitive* thought and *concrete* thought, and then up to the level of *formal operations* (Nielsen, 1996). These steps imply a pre-ordained and a predetermined movement and destination; a process that has been widely questioned since, as Archard (1993) argues, children possess some critical competencies long before Piaget says they do. One of the major criticisms of Piaget's theory has been the view that it is inherently Eurocentric and is based on western concepts and principles of logic (Ansell, 2005, p.16; Archard, 1993, p.66). The attachment theory developed by Bowlby in the 80s and later elaborated on (1996) has also been influential in childhood discourse. Bowlby suggests that children should not be deprived of contact with their primary caregivers (mothers) during the first three years of their lives; failure to maintain this contact will contribute to unstable

attachment relationships that he considers crucial to subsequent social and cognitive development. This approach to child development has been criticized for failing to take into account the fact that in many non-western countries, cultural and traditional systems and practices allow for multiple relationships to be formed between children and adults (Ansell, 2005, p.17). These relationships outside of the mother-child relationship are crucial and are a significant part of child development in non-western contexts.

The influence of dominant psychological perspectives on childhood development was evident in the sociological conceptualisation of childhood (Ansell, 2005; Prout & James, 1990).

These sociologists argued that, rather than developing naturally, children were socialised into roles and into different societies through the ways that society treated them (Ansell, 2005).

This essentially minimised children's agency since, as Prout & James (1990) point out, children were portrayed as being, like laboratory rats, at the mercy of external stimuli.

The new social studies of childhood problematise and transform the 'natural' categorisation of the child into a 'cultural' category (Jenks, 1996; Prout & James, 1990). Key features of this paradigm are outlined by Prout & James (1990, pp.8-9), who are highly acclaimed for their contribution to childhood studies:

1. *Childhood is understood as a social construction. As such it provides an interpretive frame for contextualizing the early years of human life. Childhood, as distinct from biological immaturity, is neither a natural nor universal feature of human groups but appears as a specific structural and component of many societies.*
2. *Childhood is a socially variable construct. It can never be entirely divorced from other variables such as class, gender or ethnicity. Comparative and cross cultural analysis reveals a variety of childhoods rather than a single and universal phenomenon.*
3. *Children's social relationships and culture are worthy of study in their own right, independent of the perspective and concerns of adults.*
4. *Children are and must be seen as active in their own construction and determination of their own social lives, the lives of those around them and of the societies in which they live. Children are not just passive subjects of social structures and processes.*
5. *Ethnography is a particularly useful methodology for the study of childhood. It allows children a more direct voice and participation in the production of sociological data than is usually possible through experimental or surveys styles of research*
6. *Childhood is a phenomenon in relation to which the double hermeneutic of the social sciences (see Giddens, 1987) is acutely present. That is to say, to*

proclaim a new paradigm of childhood sociology is also to engage in and respond to the process of reconstructing childhood in society.

James et al. (1998) classify work within social studies of childhood into four distinct conceptual and perhaps methodological approaches to studying childhood. These approaches position children as, firstly, “socially constructed, implying that there is no universal childhood and childhood is constructed within the cultural and social settings which children inhabit; secondly, as ‘tribal’, worthy of being studied on their own and separate from the adults, the focus is on the uniqueness of local childhoods; thirdly, as a minority group, subject to discrimination and marginalization and lastly, as ‘socio-structural child’, a view which sees childhood within a structural point of view where the lives of children are universally affected by structural differentiations” (James et al., 1998). These four approaches have been criticised in that they indicate dichotomies in childhood research between global (i.e. those studies that examine the importance of global processes in shaping children’s position in different societies across the world) and local (i.e. studies which show children’s agency in creating their culture and their own world) (Holloway & Valentine, 2000)

While each of these theories make a significant and useful contribution to childhood discourse, I find myself being drawn to the work of Prout & James (1990) which emphasizes the importance of social factors in conceptualisation and experiencing childhood. I also recognise that although young people have agency, the use of agency is not entirely separated from families and communities. In South Africa, the intersection of social factors, race and class in creating risks and vulnerabilities for young people is evident in areas such as health, education and access to resources. In South Africa, the childhood experience varies along racial lines, where poverty and HIV/AIDS are also central features in childhood (Rochat et al., 2008). The country has a high prevalence of child poverty; it is estimated that nearly 11.8 million children live in poverty in South Africa (UNICEF SA, 2010) and the prevalence is higher and more severe in rural areas of KwaZulu-Natal. However, poverty has racial dimensions which are linked to the legacy of previous apartheid policies. As a consequence, child poverty is higher among black and ‘coloured’ (this term, meaning ‘mixed-race’ is part of the popular (and official) discourse on racial categorisation and segregation and thus its use in the context of this thesis is appropriate) children when compared to other racial groups (UNICEF SA, 2010). The challenges of childhood begin at infancy stage, where nearly 100,000 infants die each year before they reach the age of five (Bradshaw, et al., 2003; UNICEF SA, 2008). Their deaths are associated with various illnesses such as respiratory

problems and diarrhoea as well as HIV/AIDS. Children that live up to five years have to survive within the context of poverty, deprivation and HIV/AIDS. As a result, before reaching older childhood, most children, especially black and coloured children have survived health, social, racial and environmental factors, and the impact of these on their health.

The childhood experience and the use of children's agency in this context can be interpreted within the social, cultural and political sphere, in that the choices and resources available for children to exercise their agency are shaped by these elements, and their re-organisation can enable children to exercise their agency better. Below, the construct of the child is explored in relation to the position of the child according to dominant views on children's rights in South Africa, as well as within the community of KwaZulu-Natal.

2.2.2: The Conception of Childhood in KwaZulu-Natal and its Contested Position

Various studies have indicated that within the community of black South African ethnic groups, whether abaZulu or baSotho, '*ukuhlonipha*', loosely translated as 'respect', is a highly valued trait which includes both performative and linguistic elements, meaning that respect is demonstrated in personal interaction with others as well as in communication with adults (Thetela, 2002; Norman, 2011; Clacherty & Donald, 2007; Dlamini, 1996). Children and young people are therefore brought up with a strong emphasis on '*ukuhlonipha abadala*' (respect for adults) and a non-confrontational way of disagreeing with adults. Within this approach, young people and children have designated roles and responsibilities; they are expected to contribute within the household by taking part in cleaning the house, preparing meals, running errands, making the fire and being helpful within the home (Clacherty & Donald, 2007; Norman, 2011). These values are enforced from an early age, and young people grow up participating in these roles and responsibilities. Conversely, young people's participation in decision-making and in affairs of the family tends to be limited (Van der Heijden & Swartz, 2010).

Thetela (2002) further reiterates respect as an important value within black South African society and notes that, despite the influence of modernisation and education, it is still highly emphasized. Moreover, the roles and responsibilities that young people are expected to perform have not diminished with time; they are perceived by young people as an important part of their contribution in the household (Norman, 2011). Whilst these roles are designated as a normal part of childhood, the relationship between young people and adults is

characterised by power disparities in which young people are expected to be obedient to adults' instructions and not to express their opinions openly (Clacherty & Donald, 2007). This non-confrontational way of communicating is a norm within isiZulu culture; however, literature has pointed out that among young people, there are shifts in how young people respond to the expected role of being non-confrontational. Norman (2011) contends that there has been an outcry among adults within this context, who perceive young people of today as asking too many questions, perhaps asking questions on issues that are considered by adults to be out of 'young people's domain' in terms of what young people should know, and young people are seen as being forceful when they express their opinions. In studies of young people in South Africa, they have sometimes been described by adults as disrespectful and not understanding their place or the adults' space (Norman, 2011; Hearle & Ruwanpura, 2009). Perhaps this points to the dynamic position of the child-adult relationship in this era.

At the heart of this debate is the perception of the children's rights approach as having been imposed on adults, leaving young people too empowered and adults disempowered. The South African government's decision to ban the use of corporal punishment on children and young people has exacerbated this view, and has been received with mixed reactions by adults. There were concerns among adults who perceived the banning of children's corporal punishment as an act of taking away the parental right and obligation to reprimand children and young people. As a result, young people were displaying behaviour that was perceived by adults as disrespectful (Hearle & Ruwanpura, 2009). However, the violation of the rights of children in South Africa is well documented (UNICEF, 2008), implying that although the concerns that are raised by adults may be genuine, they cannot negate the benefits associated with the adoption of the child's rights approach.

The term 'child' is often used as an umbrella term in international children's rights documents such as the UN Convention on the Rights of the Child (UN CRC 1989, Part 1, Article 1), which defines children as "every human being below the age of eighteen years unless, under law applicable to the child, majority is attained early." However, some researchers have pointed out the fluidity of both this term and the idea of adulthood in isiZulu culture (Dlamini, 1996; Norman, 2011). Dlamini (1996) implies that there is actually a distinction between the concept of elderliness (being old through age) and that of adulthood (matured individual). Both are referred to as adults; thus a 13-year-old is an adult to a 10-year-old, and therefore an element of respect is expected from a 10-year-old. In the event of an argument between two people of different age groups, the younger person will back off,

and the older person will have the last statement. Being the last to speak would not be an indication of being right; it would be interpreted as a sign of respect. Within this frame of reference, the term ‘children’ in this section has been used to indicate the socially constructed meaning of how the child was defined in families and in communities where the study was conducted. Whilst this cultural upbringing may be seen as contradicting the children’s rights approach as outlined in the international and domestic child protection instruments, it is based on the premise that adults or anyone in charge of a child will not do any harm to the child, and furthermore, all decisions made will be in the best interest of the child. The common isiZulu phrase which says ‘*ingane yami, ingane yakho*’, loosely translated as ‘your child is my child, my child is your child’ implies that a child belongs to the community, and hence everybody in the community has a duty to protect the child, regardless of the biological relationship to the child.

In South Africa, the evolution of children’s rights sparked interest in the mid-1970s and 80s as a result of the widespread brutality that was inflicted against children during the apartheid era, such as child imprisonment and violence during that time. Children’s rights activism was initiated through community-based organisations (CBOs) and non-governmental organisations (NGOs) to advocate against the maltreatment of children. This activism in favour of children’s rights culminated in the inclusion of children’s rights and all human rights in the new South African constitution at the end of the repressive era in 1994. In the post-apartheid era, children’s rights were included in the South African constitution (Act of 108, 1996). Section 28 of the constitution specifically makes provision for children’s rights in line with UN Convention on the Rights of the Child (1989), which includes rights to parental care or alternative care (if the child has to be removed from the home for purposes of child protection), rights to basic nutrition, shelter and basic health, and rights to be protected from maltreatment, neglect, abuse or degradation.

Moreover, South Africa has since become a signatory to various international and regional treaties and agreements that advocate for the rights of the children, such as the African Charter on the Rights of the Child (1990), UN CRC (1989) and New Partnership for African Development, 2001 (NEPAD). Children’s rights have found expression in domestic laws and policies such as the South African constitution and Children’s Act No. 38 of 2005 (amended by the Children’s Amendment Act No. 41, of 2007). The Children’s Act outlines sections that elevate the position of the child, such as child participation and consideration of the child’s best interests when making decisions that affect children. It further mandates the government

to ensure substantive equality of opportunity and equal access to social services for children with disabilities and chronic illnesses. These changes in legislation indicate significant milestones pertaining to the realisation of children's rights in South Africa.

However, within the context of Zulu families, children's rights have been welcomed with mixed reactions. Whilst they are generally thought of as necessary for the protection of children, they have also been viewed as too empowering to children and as a threat to the traditional conception of the child's position (Norman, 2011; Hearle & Ruwanpura, 2009). In both these studies, which were conducted in KwaZulu-Natal, adults noted that children lacked respect for adults, an important value in the Zulu way of life. Perhaps more concerning to adults was that they thought children were misbehaving because they knew that they could not be punished as physical punishment is against the law, as indicated earlier. Norman (2011) noted in her study that there was a dichotomous position of empowered young person versus angry and disgruntled adult who felt powerless to manage this shift of the young person's position. These traits were perceived by adults to be the result of modernisation and the changing nature of childhood in South Africa, which is viewed by many as becoming dominated by the imposition of these children's rights (Norman, 2011; Hearle & Ruwanpura, 2009). The perceived disappearance of respect was seen by adults in those studies to be as a consequence of the loss of morality among young people, which manifests itself in teenage pregnancy, HIV infections and pre-marital sex among young people (Thetela, 2002). However, gross violations of children's rights in South Africa have been reported through various media instruments. The country has a high rate of child abuse and violation of children's rights such as physical, emotional and sexual abuse. UNICEF South Africa (2010) reported that in the 2010/2011 year cycle, 54,225 crimes against children were reported to South African police stations and half of these were cases of sexual offenses. Therefore, the advocacy of the rights of child within such a context is viewed by many child rights activists as critical to the protection of children in South Africa.

Grief and bereavement present yet another critical intersection for the recognition of children's rights at the family level in Zulu families. The literature has been critical of the apparent non-participation of children in grief and bereavement processes after parental death, as a result of cultural beliefs and practices. The Zulu cultural practice of grief and bereavement excludes children from participating in rituals surrounding the burial, even if it is a parental death. This practice was meant to protect children from harm, since death was considered to be too traumatic for children to cope with and was generally associated with

pollution (Richter & Muller, 2005). However, the literature has indicated that this exclusion, although meant to protect, tends to marginalise children (Van der Heijden & Swartz, 2010; Thupayagale-Tshweneagae & Benedict, 2011). The prevailing culture of silence, as well as the use of euphemism when talking about death and the deceased, has been indicated as being detrimental to children's management of grief. It has been described as creating a culture of silence where children were unable to talk about the personal impact of loss to adults and as a result, children were reported to be grieving on their own (Richter & Muller, 2005; Norman, 2011)

Norman (2011) argues that young people's exclusion from some of the death and bereavement rituals, and the limited adult-child communication regarding death, continues. However, the nature of the HIV and AIDS epidemic in South Africa has fundamentally challenged these norms in that young people are now attending funerals, whilst others are witnessing illness and death within their households, an experience which previously excluded young people. Despite this evidence of increased knowledge and participation in bereavement rituals, Norman (2011) remarked that young people were still silenced in other ways. The subjugated position of the young person and the expectations regarding a young person's place within the generational hierarchy remained a barrier for young people in terms of posing questions about specific details such as the cause of death or illness. Thupayagale-Tshweneagae & Benedict (2011) argue that young people continue to grieve on their own, even though they desire to speak to adult family or community members, because of the inconsistencies about their place when talking about loss. If the loss is related to HIV/AIDS, the stigma attached to HIV creates an additional barrier for young people who wish to talk openly to family members and their peers about parental loss.

This discussion has aimed to bring to light the contested position of childhood and the young person in South Africa, more specifically in KwaZulu-Natal. In this section, I have introduced the theoretical constructs of social childhood studies which position the young person as an active agent in the creation of his/her experience of childhood; however, I have argued that the childhood experience, although socially constructed, it is not independent of global and local determinants. Young people negotiate childhood experience within these contexts. This discussion was followed by a brief review of the position of the young person in South Africa as displayed within the legal framework as well as the young person's position within the family.

Moreover, as I have explained, South Africa is a signatory of various international, regional and domestic instruments of legislation that are aimed at protecting the rights of young people. However, within the family context, the young person's position is a contested position. Young people seem to be caught within a situation where there are inconsistencies about what they should know or be told, and barriers to their desire to talk openly about what loss means for them. The generational relationships, as well as historical perceptions of culturally defined roles, however, are gradually shifting. I have preferred to use the term 'young people' in this study to refer to children older than 12 years and to avoid the infantile image that is associated with the term 'children'. However, these terms (children, young people, teenagers or adolescent stage) that categorize children according to various stages and their social and behavioural implications do not have a similar meanings within the context of the study and within the IsiZulu culture and language interpretations differ. The word *Izingane* meaning a child is the known form of referring to young people.

2.3: The intersection of childhood in the era of HIV/AIDS

The intersection of HIV/AIDS and young people has received substantial focus in literature where HIV/AIDS is seen to be disrupting the lives of young people in various ways. There is evidence to suggest that young people can be directly infected by HIV and be affected by HIV/AIDS through loss of parents. Therefore, the impact of HIV/AIDS in the lives of young people cannot be conceptualised only in terms of direct HIV infection. Studies conducted in Africa and Southern Africa highlight the plight of young people whose lives are affected by parental death, which is often due to AIDS. Young people are reported to be; heading households with limited or no adult supervision, forced to migrate from their households to live with extended families or be placed in residential homes after parental death and sometimes they become carers for their sick parents (Kipp et al., 2010; Francis-Chizororo, 2010; Young & Ansell, 2003; Ansell & Bleck, 2004; Moses & Meintjes, 2010; Skovdal, 2009; Mavise, 2011).

Using qualitative and child- centred methods to collect data, these studies highlight the experience of young people who have experience parental death and how that experience has shaped their childhood.

The psycho-social challenges being experienced by young people in child-headed households¹ after parental death have been reported in Africa, for example in Zimbabwe (Francis-Chizororo, 2010) and Uganda (Atwine et al., 2005; Kipp et al., 2010). These studies indicated that the physical, material and psychological needs of young people were not being met adequately. Young people would often be without food and they lacked basic necessities. In the context of HIV/ AIDS, young people experience multiple challenges such as death of the parents, death of a sibling, siblings being separated, school disruptions as well as grief and bereavement. Moreover, the impact of cultural silence restrict open communication about death between adults and young people, which further complicates the grieving process of young people (Daniel et al., 2007).

Whilst the experiences of young people in child-headed households may not be dissimilar to the plight of orphans in general (Henderson, 2006; Meintjes et al., 2010), however, young people in child-headed households bear responsibilities that are unique such as making complex decisions and taking a leadership role to manage their households (Mavise, 2011). The prevalence of child headed household can generally be expected from countries with high concentration of HIV since AIDS related death may be more common. However, despite the high prevalence rate of HIV and AIDS related deaths in South Africa, the responsibility to provide care to young people after parental death has largely been absorbed by the extended family (Beegle et al., 2010). As a result of the extended family system being at the centre of caregiving after parental death, the prevalence of young people who live alone and manage a household without adult supervision is reported to be low (0.47 in 2006) and it does not appear to be increasing (Meintjes et al., 2010). Whilst these findings may be positive, the study which was conducted in South Africa to understand the changing family structure and composition indicated that the extended family system may be collapsing as result of the burden of care for orphans, which is fuelled by AIDS related deaths. This suggested that families carry a heavy burden of providing for financial and physical needs of young people who have lost their parents.

Young people who participated in the study conducted by Young & Ansell (2003) and Atwine et al. (2005) reported the difficulties they experienced after being absorbed by the extended family households which include being stigmatized, discriminatory practices and

¹Although the definition of a child-headed household is contested because of its socially constructed nature, it is generally accepted that it is a where a household which is managed by a young person, without adult supervision

abuse. The challenges that are posed by parental death on young people cannot be underestimated, however, there is also an acknowledgement of young people's resilience and that young people are sometimes able to survive such circumstances (Henderson, 2006).

The impact of HIV/AIDS on young people is now well documented and the clinical trajectory of HIV in young people is more predictable, however, there is a dearth of literature on how young people interpret the experience of living with HIV. Moreover, literature on young people who live with HIV and in residential care² is also limited (Moses & Meintjes, 2010). The study that was conducted by Moses and Meintjes (2010) focuses on the provision on care for young people in the era of HIV. In that study, a high proportion of young people were found to be living with HIV. Although these young people were receiving adequate support and care; their psychological, behavioural and developmental needs appeared to be ignored. HIV disclosure to these young people was also a challenge as these residential centres did not seem to have a standardized approach of managing HIV disclosure.

Disclosing HIV status to young people seems to be a challenge also in contexts where young people reside with their parents or caregivers. The study that was conducted with young people who live with HIV who were between the ages of 15 and 24 years in United Kingdom, indicated that HIV disclosure to young people was a complex process and not always straight-forward as there seems to be a reluctance among adults caring for young people to disclose to them (Dorrell & Katz, 2013). HIV disclosure among young people living with HIV and its complexities has received a lot of attention in literature in Africa (Moodley et al., 2006; Vaz et al., 2010; Brown et al., 2011; Kallem et al., 2011; Biadgilign et al., 2011) and in other parts of the world (Wiener & Battles et al., 2006; Oberdorfer et al., 2006; Arun et al., 2009). The study conducted in Ghana with caregivers of young people living with HIV who were between the ages of eight and 14 years, indicated that one of the reasons for the reluctance to disclose to young people include concerns that; young people may tell others, young people's reaction to disclosure as well as that young people may be too young to know and deal with such information (Kallem et al., 2011). Clearly, there is a need to understand HIV disclosure from young person's own perspective and how they interpret the experience of knowing. Below, I briefly look at the experience of living with a chronic illness among young people and how young people manage such experiences.

² In South Africa, residential care or child and youth care centres refers to "any residence or home maintained for the reception, protection, care and bringing –up of more than six children apart from their parents, but does not include school, industry or reform school" (Children's Act of 2005)

2.4: Childhood and Living with Chronic Illness

As in social studies of childhood, there has been a continuous global shift in the conceptualisation of chronic illness, in relation to the patient and the meaning ascribed to the experience of living with a chronic illness (Thorne & Paterson, 1998; Williams, 2000). Current literature on chronic illness elevates the position of patients to one of knowing and of active participants in the management of their illness (Thorne & Paterson, 1998). This perspective recognises the validity of the patient's experience and the meaning attached to living with a chronic illness. Whilst the recognition of the patient's role has been a central feature in literature relating to adult chronic illness, Sartain et al., (2000) posit that in healthcare, young people's agency, although important, is not receiving the attention it deserves, and young people's perceptions of their lives and developmental trajectories are not known (Taylor et al., 2008; Woodgate, 2006).

Cancer is one of the widely researched chronic illnesses and the impact of cancer illness on young people has a profound impact on their lives, as they not only have to cope with the developmental issues associated with growing up and everyday stressors within their context but, unlike their healthy peers, they also have to manage illness-related stressors. These stressors include hospitalisation; complex treatment regimens; treatment side effects and changes in physical appearance; low energy levels; mobility problems; cognitive function issues, and negative body image (Wallace et al., 2007; Larouche & Chin-Peuckert, 2006; Farrant & Watson, 2004; Hampel et al., 2005; Abraham et al., 1999).

Although these studies raise the problematic nature of living with a chronic illness, current studies are exploring young people's own perceived meaning and interpretation of living with a chronic illness. The focus is on the meaning for young people of these negative illness experiences (Wallace et al., 2007; Larouche & Chin-Peuckert, 2006). This is critical since the meaning and beliefs regarding one's illness is associated with the ability to cope and manage the illness experience (Halligan, 2007). The meaning and the illness experience can be seen to be part of the socially constructed process since beliefs and interpretation are constructed during the interaction with others. These perspectives became central to this study as I explored how young people from KwaZulu-Natal experience HIV and how these experiences need to be explored by taking into account young people's childhood experience and their socio-cultural context.

While the multiplicity of childhood was a central feature of the study, the nature of childhood, as impacted on by global discourse such as children's rights, was recognised; particularly so since a children's rights approach features prominently in national policies which apply to children's programmes in South Africa and globally. The children's rights approach is now well entrenched internationally since the endorsement of the UN Convention on the Rights of the Child (1989). This is an international instrument against which governments who are signatories align their children's domestic policies. Within this framework, children's rights relating to protection, provision and participation are encompassed. The UN Convention on the Rights of the Child, as well as the 1990 African Charter of Rights and Welfare of the Child (ACRWC), provide an interpretative lens for the policy implications of this study.

Chapter Three: Methodology

3.1 Introduction

This study explores the experiences of young people living with HIV within the socio-cultural context of KwaZulu-Natal. In this chapter, I discuss the methodology that was used for this study. I begin by stating the key research questions, and the ontology, epistemology and the theoretical framework for the study. This discussion is followed by a discussion of grounded theory, how it has evolved since its development in 1967 by Glaser and Strauss and how I locate myself as a researcher in relation to this approach. I also provide a rationale for choosing a constructivist approach to grounded theory, as described by Charmaz (2006). This background is followed by a description of data collection methods, as well as how grounded theory was used in this study. This chapter concludes with a reflexive section, discussing my field work experiences.

3.2: Research questions

Although a grounded theory study does not involve the investigation of pre-determined theory, the preliminary literature review revealed gaps in knowledge and raised the following questions:

1. What are the experiences of young people living with HIV in KwaZulu-Natal, South Africa?
2. Do young people in KwaZulu-Natal experience stigma, and if so, how is it managed and understood?
3. How do young people living with HIV learn about their HIV status and how do they negotiate the process of knowing?
4. What are the caregiving practices and family patterns for young people living with HIV?

3.3: Research ontology

Social scientists hold different views about what they study and how they go about studying it. Ontology, a concept that refers to the researcher's perception about the nature of reality and what can be known, is closely related to epistemology, which refers to the views about the ways knowledge is constructed. The researcher's ontological position determines the approach and methods used to conduct the study. To explore the experiences of living with

HIV among young people, I espoused the idea that young people's experiences consist of multiple realities, and that interpretations of reality are constructed during interaction with participants. This implies knowledge to be a product of construction between the researcher and participants. In line with this perspective of knowledge production, a social constructionist perspective was the theoretical position that influenced the execution of the study.

The 17th and 19th centuries witnessed the dominance of positivism, an ontological position which entailed the identification of universal and scientific laws deemed to be essential to an understanding of the social world, and the view that science represents the most valid form of human knowledge. Sociologists such as August Comte and Wilhelm Dilthey viewed these advances as useful to apply in social science research and to ensure replication of results. Positivism, a term that was first used systematically by Saint-Simon (Dalys, 1997) uses a deductive approach to come to conclusions about reality, which implies that a research process begins with broader theoretical predictions and speculations about reality and thereafter tests their ability to be applied to a specific phenomenon.

The approach described above is in contrast with anti-positivists whose ontological position uses an inductive approach, which begins from the specifics obtained from data in order to develop general assumptions about the reality. These anti-positivists resist the application of universal laws to human science and the principles that underpin it, such as uncovering the facts, and the objective approach to research and realism which refers to an idea that the truth exists out there, independent of what and how we think and that this truth or reality can be uncovered if the right and precise techniques are developed to measure and test the phenomenon (Dalys, 1997). Social constructionism, a theoretical orientation, takes a critical view to taken-for-granted knowledge, and social interaction is considered to be critical in the creation of knowledge.

3.4: Epistemological position

An anti-positivist position was adopted in this study as a perspective for understanding the multiple ways that young people construct their reality. Since the study was aimed at exploring the young people's voices and the meaning of their experience, I needed to use in-depth qualitative methods that provided space for young people's interpretations and experiences to be heard. A qualitative approach, also known as an interpretative approach, stems from an anti-positivism stance (de Vos, 2002; Gomm, 2008). This approach is described

by Boxill et al. (1997, p.44) as an “approach or attitude to data gathering, which comprises in-depth investigation of human perceptions, attitudes and experiences, as well as the associated processes by, and /or contexts in which these occur.” Qualitative methods aim to capture the participants’ interpretation of the meaning of their reality, an understanding that cannot be defined objectively through the use of quantitative methods which use measurements and instruments to collect data.

In qualitative research, the researcher and research participant interact to produce knowledge; as Bryman (1988, p.16) notes, the most fundamental characteristic of qualitative research is its express commitment to viewing events, actions, norms and values from the perspective of the people who are being studied.

3.5: Theoretical Framework

The study is underpinned by theoretical positions which are based on the interpretative perspective. Social constructionism provides a theoretical approach to understanding the nature of reality. As previously mentioned, social constructionism is a theoretical approach that is underpinned by key assumptions as opposed to a singular description (Burr, 1995). Burr (1995) further outlines the following key assumptions for social constructionism:

1. A critical stance towards taken-for-granted knowledge
2. Historical and cultural specificity
3. Knowledge is sustained by social processes
4. Knowledge and social action go together.

Therefore this approach argues that reality is socially constructed, with multiple meanings which co-exist and compete for legitimacy. A socially constructed nature of reality is also central to the premise of the new approach to childhood studies (James & Prout, 1990). This perspective acknowledges childhood as a socially constructed process and, as a result, childhood is considered to have multiple conceptions rather than a single and universal meaning. These perspectives became central to this study as I explored how young people from KwaZulu-Natal experience HIV and how these experiences need to be explored by taking into account young people’s childhood experience and their socio-cultural context. James & Prout (1990), who pioneered this approach to understanding childhood, outline key features of this paradigm, which include the principles referred to in chapter two (see chapter 2).

3.2: Overview of Grounded Theory

Given that this study was centred on a perspective that recognised young people as active participants in the construction of their reality, grounded theory provided a relevant data collection and analysis method to position the themes that emerge, constructed from and driven by young people's narratives. This situates the study as one driven by young people, in that the key theoretical positions derived from the study were generated from young people's narratives.

The social constructionism approach provided a useful lens for analysing the young people's social context as well as the interaction between their social world and their experience of living with HIV. The grounded theory approach ensured that the study remained grounded in young people's experiences.

Grounded theory was developed by two sociologists, Barney G. Glaser and Anselm L. Strauss, in response to a positivistic approach to research that was dominant in the mid-1960s (Charmaz, 2006). Glaser & Strauss's method was first articulated in their book entitled *The Discovery of Grounded Theory* (1967). This method emerged from the studies of dying people in hospitals which Glaser and Strauss conducted. Based on these studies, a systematic methodological strategy was developed that could be used by social scientists to study various topics. Grounded theory is based on symbolic interactionism, a theory about human behaviour which proposes that human beings construct and create their own reality, and the central tenet is the symbolic meaning which words, gestures and clothing have for people during interaction (Chen & Boore, 2009).

Since grounded theory was developed in 1967 by Glaser & Strauss, it has continued to evolve (Heath & Cowley, 2004; Bryant & Charmaz, 2011). The most noticeable variation has been between the two authors, Glaser and Strauss. Their initial version of grounded theory, which reflected both positivism and pragmatism (despite its anti-positivist aspirations), was intended to construct abstract theoretical explanations of social processes. Charmaz (2006) argues that the epistemological assumptions, logic and systematic approach of the earlier version of grounded theory reflect Glaser's quantitative background. Glaser's approach has remained consistent with the earlier version of grounded theory as a method of discovery, and a method where theory emerges from data, thus maintaining a traditional Glaserian version, as opposed to Strauss, whose conceptualisation of grounded theory has evolved, giving rise to a Straussian grounded theory.

Strauss & Corbin's version offers a reformation of the classic version by introducing analytical techniques which Glaser contends as forcing data and analysis into preconceived categories, thus rejecting the foundations of grounded theory. Charmaz (2006) argues that both versions of grounded theory come close to positivism because of their assumptions of objectivity in the rendering of data. However, she also notes that a growing number of scholars have moved away from the positivist stance in Glaser & Strauss (1967) and Strauss & Corbin (1990) versions of the method. Charmaz presents an alternative form of grounded theory which is constructivist in its approach (Plakas et al., 2009; Charmaz, 2006).

The key difference between the two previously mentioned versions of grounded theory and the constructivist approach to grounded theory is that a constructivist approach views the development of theory as being constructed during the interaction between the researcher and research practices, perspectives and participants during data collection. Therefore, rather than a theory that is discovered or that emerges from data, separate from a neutral observer, theory is derived from research which is constructed and interpreted by the researcher who is part of the studied world (Charmaz, 2006). This is a view that is firmly embedded within the interpretative tradition. A constructivist approach acknowledges the multiplicity of realities as well as how meaning and participants' experience may be connected to the wider social structure, thereby acknowledging the localised experience of participants (Charmaz, 2006; Bryant & Charmaz, 2011).

Charmaz (2006) further states that during data analysis, rather than data fitting preconceived codes, codes are constructed by a researcher and words that constitute codes are chosen by the researcher. Since this is an interactive process between a researcher and a studied world, Charmaz (2006) warns that researchers, not participants, are obligated to be reflexive about what they bring to the scene, what they see and how they see it. The constructivist approach to grounded theory was seen as relevant to this study, as it fitted my ontological and epistemological views. Rather than fitting data to preconceived categories, codes were constructed during the interaction with data. This approach to grounded theory is congruent with an interpretative approach, which is in line with the epistemology of this study in that the findings render an interpretation of reality rather than a declaration of absolute truth.

3.2.1: Data collection and analysis in grounded theory

Data collection and analysis in grounded theory occur simultaneously. Analysis of data begins early in the data collection process. Constant comparison analysis involves comparing

data with data and then data with codes and is one of the analytic techniques in grounded theory (Glaser & Strauss, 1967; Charmaz, 2006). The analytical journey in grounded theory begins with coding during the early phase of data collection to further the understanding of what is happening, as well as to direct subsequent data gathering.

Through coding, labelling of themes and categories of data are based on what is seen and interpreted from collected data, as well as through interaction with participants (Charmaz, 2006). This initial stage, also known as open coding, gives meaning to data by using words and statements that closely relate to data without being conceptual. Open coding forms the initial steps of developing tentative themes about what is seen from data. This process can be conducted through word-by-word, line-by-line or incident-by-incident coding. These initial stages of data analysis force a more intimate relationship with the data being analysed, and are critical in ensuring that the analysis is relevant to the data collected.

An *in vivo* code, which refers to the use of participants' own words to label data, can be useful to preserve exact words which may give a fresh understanding of that particular phenomenon. Initial coding allows for more comprehensive labelling of data, whereas in focused coding, codes that have conceptual significance are used to sift through preceding data. Charmaz (2006) argues that this is not a linear process; therefore one can still identify significant concepts that may not have been discovered previously.

Through constant comparison, new thoughts and ideas about data may arise which can give a fresh approach to data. Axial coding, a third form of coding introduced by Straus & Corbin (1990), links categories with subcategories and evaluates how they relate to each other in terms of their properties and dimensions. Charmaz (2006) notes that axial coding provides a framework which researchers could apply to analyse data; she also argues that this form of coding can be cumbersome. In this study, axial coding was not used. Theoretical coding specifies relationships between categories identified through focused coding (Charmaz, 2006; Heath & Cowley, 2004).

3.2.2: Assessing quality in grounded theory studies

Charmaz (2006) suggests that grounded theory studies should aim to meet four criteria for assessing research quality:

a) Credibility

- Are there strong links between gathered data and argument?

- Are data sufficient to merit claims?
- Do categories offer a wide range of empirical observations?
- Has the research provided enough evidence for the researcher's claims to allow the reader to form an independent assessment?

b) Originality

- Do the categories offer new insights?
- What is the social and theoretical significance of this work?
- How does grounded theory challenge, extend or refine current ideas, concepts and practices?

c) Resonance

- Do the categories portray the fullness of the studied experience?
- Does the grounded theory make sense to the participants?
- Does analysis offer them deeper insights about their lives and worlds?

d) Usefulness

- Can the analysis spark further research in other substantive areas?
- How does the work contribute to knowledge?
- Does the analysis offer interpretations that people can use in their everyday lives/ worlds?

(Charmaz, 2006, p.182)

In the next section I describe the methods and strategies that I used in the study and later, in the findings chapters, I demonstrate the application of Charmaz's quality assurance criteria in the interpretation of data.

3.3: Research Methods

In this section, I describe the research methods that were used to conduct the study. This discussion begins with the description of the recruitment process and method used to recruit participants, the process and tools used for data collection as well as the description of the process for data analysis. Below, I describe the two settings where participants were recruited.

3.3.1 Recruitment sites

The study was conducted in KwaZulu-Natal, and recruitment was conducted in two sites. The first period of data collection was undertaken in Site one (further discussed below) and in that site, seven young people living with HIV were interviewed. The second stage of data

collection which consisted of the focus group discussions, community engagement project, interviews with community members and interviews with caregivers was conducted in Mpilo, a rural community. Although this is not a comparative study, the rationale for recruiting from two sites with distinct characteristics was largely driven by a desire to include a range of young people's voices and particularly 'hard to get at' young people from rural areas.

3.3.1.1: Site one: North Community Crisis Centre

North Crisis Centre is situated in one of the townships in Durban, South Africa. Whilst townships are generally defined as residential areas that are close to towns, in South Africa, townships have a unique history that is associated with racial segregation. The implementation of the Group Areas Act of 1950³ by the white minority government ordered the segregation of Black Africans, Indians and Coloureds to live in separate residential areas according to their racial groups. Black Africans were only allowed to be in town as labourers or they had to carry a special permission called pass. This legislation separated people socially and geographically in that they lived and socialized according to their racial groups (O'Malley, 2005)

As a result of the apartheid policies, townships were developed to accommodate Africans labourers who came to cities in search of employment. Early townships first sprang in Kimberly to accommodate labours who migrated from rural areas to urban areas to meet the economic requirements of inexpensive labour after the discovery of diamonds in 1867, soon townships sprouted across other cities including Durban as the need for cheap labour continued to grow. It is beyond the scope of this study to describe the development of townships and their impact on Black Africans and their way of life, however it is clear that the effect of Group Areas Act lingers on as most townships continue to be mostly inhabited by Black Africans and are characterized by poverty, unemployment, high HIV prevalence, overcrowding and informal settlement (Raab & Terway, 2000).

North Crisis Centre is situated in such residential area, with a high rate of unemployment and poor access to adequate basic resources such as health care services and quality education (Kwa-Care annual report, 2011). The township where this study was conducted consist of approximately 175 000 inhabitants who are Black Africans (Kwa-Care, 2011 annual report).

³ Group areas Act was the act that was enacted by the previous apartheid government of South Africa. This Act assigned different racial groups to different residential places and Black African were assigned to less developed areas a

The early settlers of this township consisted of people that migrated from rural areas to cities in search of employment. Since these labourers could not live in cities because of Group Areas Act, townships were the only alternative accommodation available for them. Although the country now enjoys democracy, townships are still populated by Black Africans who often migrate from rural areas and they live in these residential areas for many generations because rural areas are still poorly developed and resourced.

As mentioned earlier, unemployment is a major challenge in most townships and this township was no exception. Tear fund (2008) estimates that about 38% of the population in this population was reported to be without any financial income. Moreover, the burden of AIDS related infections such as Tuberculosis is high and it further exacerbates the financial situation. However, progress to curb the spread of HIV in the area has been reported by Department of Health ((KwaDabeka Newsletter, 2010) and non-governmental organisations such as North Crisis Centre and Kwa- Care continue to make a significant impact in the community. North Crisis Centre serves the needs of the people residing in this township by responding to various psycho-social needs of this population by providing the following services:

- Psycho-social support to families infected and affected by HIV/AIDS
- Income-generating projects for the unemployed, such as sewing, agricultural projects and beadwork
- Counselling (addressing HIV-related issues, domestic violence and sexual abuse).

Additional services such as medical care are referred to appropriate institutions within the area. Employees and volunteers of the centre are mostly recruited from the community; therefore they have a good understanding of community issues. The centre is a non-governmental organisation (NGO) which was established by a Black South African woman from the area who won a bursary to study community development, after which she became fully involved in community issues and projects. The rate of poverty and unemployment is high in this area, a situation which reflects one of the common features of townships in Durban.

3.3.1.2: Site two: Mpilo Community - demographic details

The second site for recruitment was a hospital situated in a rural community, with several satellite clinics located in different sections of the community. The recruitment was conducted through one of the satellite clinics located in Mpilo community. Mpilo is part of Hlangana Local Municipality, which is situated in KwaZulu-Natal. The municipality is administratively demarcated into 15 wards. Hlangana has a land area of 3,698 square kilometres with a population of 140,964 (South African census, 2001). Housing consists largely of self-built houses and spacious land. It is predominantly rural, with villages often being sparsely populated. As a result of the availability of land suitable for crop farming, most community members cultivate the land and plant various crops for family consumption such as maize and peanuts.

The major towns are Mpilo, Manzi, Moya and Lwandle⁴. These settlements are largely occupied by Zulu-speaking black people. MPilo is one of the areas that was reserved for blacks during the apartheid era and fell under the government of the homeland (previously Zulu Government). The traditional leadership, which consists of *izinkosi* (local chiefs), was dominant in the area, given that during the apartheid period, chiefs provided legitimate leadership and governance of the community. However, since 1994, when the democratic government was elected, leadership has been shared by chiefs as well as municipalities. Homelands were grossly underfunded during the apartheid government, therefore basic services such as education, health services, economic development and infrastructure were neglected.

The election of the democratic government in date has brought significant changes in the allocation of funding and resources; even so, the inequality and breakdown of structures within the society will take some time to be eradicated. The migrant labour system continues to be a huge challenge because people in the productive age group often leave their villages in search of better working opportunities in bigger cities. The employment sectors in the area are health and education; the remaining sectors, such as hotels, forestry and administration, are characterised by semi-skilled labour. The nearest tertiary institution is approximately 350 kilometres away, and as a result, young people that pass well in their final year at school tend to leave home early to study elsewhere. Lack of employment opportunities in the community have also contributed to a high migration rate of young and skilled people.

The Integrated Development Plan Report of 2007-2008 for Hlangana Municipality reported the following challenges in the area:

- High rate of unemployment.
- Poor educational and health facilities.
- Poor institutional development.
- Poor social services and infrastructure with inadequate recreational facilities.
- Inadequate community response to agriculture and tourism opportunities.
- The entire municipality has no formal and/or proclaimed town.

The dominant religion of the area is Christianity, which has been integrated with the observation of traditional practices. This is evident in ceremonies such as burial services and weddings, where animal sacrifices may be performed to acknowledge ancestors alongside Christian rituals. These traditional rituals co-exist despite the dominance of Christian values which have taken centre stage.

The role of *izangoma* (seers) and the use of traditional healers is strongly embedded in this community; however, this is not surprising since the number of traditional healers is estimated to be between 250,000 and 400,000 in South Africa, compared with 270,000 medical doctors, and eight out of every ten black South Africans rely on traditional healing⁵ alone (Keeton, 2004, cited by Ross, 2007). One of the medical doctors from Mpilo estimated the use of traditional healing to be as high as 99%.

The community has well-defined expectations of social roles, including a sense of courtesy and respect. There are also expectations associated with how an adult is addressed, the position and role of the child in the family and how children are expected to relate to adults, the use of language between men and women, as well as child-adult relationships. The use of gestures, language during communication and body language formally convey a sense of respect and reinforce traditional social order. The cultural upbringing of the Zulus places a strong emphasis on the spirit of '*ubuntu*', which is described by Manda (2007, p.38) as the "comprehensive ancient African worldview based on the core values of intense humanness ,caring ,sharing ,respect, compassion and associated values ,ensuring a happy and qualitative community life in a spirit of family." Manda further argues that *ubuntu* calls on us to believe

⁵ Traditional healing uses a holistic approach to examine and treat the person as a whole and the treatment process considers the person as a whole not simply a collection of symptoms. Treatment may include herbs for the sick ,sacrifices for the ancestors, performing rituals and sometimes part of a healing process may consist of exposing fractured relationships (Manda, 2007)

and feel that “your pain is my pain, my wealth is your wealth, and your salvation is my salvation”.

3.3.2: Recruitment and mode of engagement with research participants

Being aware of one’s HIV status as well as other additional criteria, further described below, were prerequisites for young people to participate in this study, and therefore purposive sampling was seen as most appropriate. In the first site, recruitment was conducted by counsellors employed by the centre to ensure confidentiality. They approached potential carers from the community known to be caring for young people living with HIV. They informed them about the study, and those who were interested were referred to the researcher for further explanation about the study. Young people were only approached when carers had given their consent, and if young people declined, they were not included in the study. Similarly, if carers declined, the young people were not approached either. The method of recruitment in the second site was a multi-stage process. Since this was a hospital setting, young people would come to the clinic unaccompanied, or carers would come on their own or send a representative to collect medication on behalf of young people, and therefore recruitment was difficult. Moreover, most young people attending the clinic had not been told that they were living with HIV and it was not clear among the young people who had been told and who had not.

The recruitment of participants in this site was therefore a multi-stage process that involved the healthcare workers as gatekeepers and me as the researcher. Carers of young people living with HIV were invited for a one-day workshop to explore the issue of disclosure and any difficulties they encountered or anticipated encountering if they disclosed HIV status to the young person. This was seen as a valuable intervention by the hospital but it also provided an opportunity to tell carers and members of the community about the study and recruit potential participants. In this way, difficulties associated with disclosure were discussed as well as conducting recruitment for the study; only young people that met the set criteria were included in the study. The young people who participated were recruited on the basis they met pre-determined inclusion criteria.

3.5.2.1: Inclusion criteria for young people participants

1. HIV positive and on antiretroviral treatment
2. Young people who have been told about their HIV status
3. Young people between the ages of 13 and 18 years.

3.5.2.2: Exclusion criteria for young people participants

1. Young people who were assessed as vulnerable and/or known to have experienced traumatic event such as rape
2. Young people currently diagnosed and being treated for psychiatric illness
3. Young people under the age of 18 years who consent to be part of the study but whose caregiver/parents do not consent.

3.5.2.3: Theoretical sampling

The inclusion and exclusion criteria of this study focused the sampling process to participants that met the criteria. Since the inclusion criteria for young people to participate in this study included being aware of their HIV diagnosis, most young people who were not, were excluded. Although this was a purposive sampling in that participation depended on age of young people, awareness of HIV status as well as being on anti-retroviral treatment; further sampling was conducted after analysis. This form of sampling is called theoretical sampling and it refers to purposive sampling which is conducted according to categories or themes that one develops from one's analysis.

In this study, theoretical sampling was conducted after the emergence of three categories 1) family context and caregiving, 2) disclosure complexities and 3) socio-cultural context. On the basis of these emerging themes, carers who provided care to the young people were sampled. Moreover families that could be described as 'extended family networks' were theoretical sampled to explore the dynamics of caregiving practices for young people whose care depended on multiple carers who did not share the same household. The potential participants were recruited from Mpilo community through the community clinic and community workers provided valuable advice on who the potential participants were. Health care workers within the clinic approached potential carers for participation, if they agreed, they were sent to me for further explanation about the study and participation. However, most carers of the young people were already familiar with me because I had consulted them during the recruitment of young people participants.

Theoretical sampling to explicate disclosure complexities was conducted through recruiting young people who were defined as openly disclosed to because it was difficult to recruit young people who fitted the different patterns of 'open' HIV disclosure since these disclosure patterns had not been identified. However, it was not difficult to identify these different patterns of HIV awareness among young people who were considered to be openly aware of

their HIV status. Through this method, I identified different HIV awareness patterns and I clarified the emerging themes and I described different variation and how they occur in young people's lives.

3.4: Profiles of Participants

In this section, I present the profiles of all participants that took part in this study. I begin with the profiles of seven carers who were recruited from Mpilo site. This is followed by the profiles of young people who were recruited from the North Crisis Centre and Mpilo site. All names of participants have been changed to protect anonymity and confidentiality, instead pseudonyms are used. Morrow (2008) argues that the use of pseudonyms is not always straight forward especially among young people, who may prefer that their views and experiences be recognised. However, I understood that participants in this study expected a highest degree of anonymity and confidentiality because of the sensitive nature of the research. I could have asked participants to choose their own pseudonyms; however that opportunity was missed as I focused more on ensuring that the pseudonyms I created protect the identity of participants. I choose pseudonyms that were of different language to that of participants such as English and Sotho names since most participants had IsiZulu names. I conclude this section with the table that summarises the relationship between young people and carers (pls note, carers of young people from Community crisis centre were not recruited)

3.4.1: Carer profile

Participant 1: Mary

Mary is a 34-year-old unmarried woman. She cares for her 14-year-old daughter who is living with HIV. Mary was diagnosed with HIV in 2007 after the death of her partner (father of her daughter) from AIDS. Mary and her daughter take antiretroviral treatment from the local clinic ten kilometres away from their home. She does not have any qualifications, as she left school before finishing. To earn an income, she makes traditional floor mats and sells them. She lives with her mother who is a pensioner, and she has a sibling who is migrant worker. She lives in a poor neighbourhood with no access to electricity. Her home consists of three small thatched one bedroom houses: one is used by her brother when he visits, the grandmother uses one and she shares the third one with her daughter.

Participant 2: Mama Elizabeth

Elizabeth is a 42-year-old woman who lost her husband in 2005. She has two children: the older child is in tertiary level education and the younger child is ten years old. Elizabeth also cares for Tsepiso, her 16-year-old adopted son. She has been caring for him for the last ten years. Tsepiso was diagnosed with HIV in 2009 and is now on antiretroviral treatment. Elizabeth supports herself by selling fruit and vegetables at the market. Tsepiso's father, who is now deceased, was Elizabeth's husband's brother, who left home at a young age and became a migrant worker. Tsepiso's mother is unknown, as he was born where his father was working and his mother abandoned him at a very young age. Elizabeth was the only participant with a brick house and access to electricity.

Participant 3: Ethel

Ethel is a 24-year-old woman providing care to her boyfriend's son J, a 13-year-old boy who is living with HIV and is on antiretroviral treatment. Ethel has two children, aged four and two years old respectively, by J's father. She did not complete high school and is unemployed. Ethel does not live in the same household as J, but she decided to take the responsibility for his clinical care after noticing that he was not being cared for properly by his father. J's mother is deceased and he lives with his father and his grandmother who works as a labourer in the forestry department. J's father works at temporary jobs but he spends most of his money on alcohol. Ethel lives three kilometres away from J, but she visits often when she is not in conflict with J's father. Ethel's HIV status is unknown and J's father had not undergone a test (at the time of the interview), and so his HIV status is unknown.

Participant 4: Ruth

Ruth is a 26-year-old woman who is a carer to Thabang, a 14-year-old child living with HIV and on antiretroviral treatment. Thabang was born physically disabled and when she was three months old her mother passed away. Ruth had to leave school at a young age to care for her. Thabang lives with her mother and brother and his wife. Ruth has never worked but now she supports herself by making floor mats, which she admits is hard work. Once a month, Ruth walks approximately 45 minutes to the station, where she takes a taxi and then travels a further 30 minutes to reach a local clinic where she collects antiretroviral treatment. Access to transport is a challenge in her community.

Participant 5: Elaine

Elaine is 34 years old and unmarried. She provides partial care to Tony, her deceased sister's son, who is 13 years old, HIV positive and on antiretroviral treatment. Elaine does not live in the same household as Tony. He stays with his maternal grandmother's sister five minutes away. Elaine is also HIV positive and she collects her own treatment from the same clinic which Tony attends. The clinic is situated nearly ten kilometres away from where she lives. When Tony's maternal grandmother passed away, Elaine took over his HIV care, which includes collecting his medication and taking him to the clinic for his visits. Elaine is unemployed and she lives with her elderly father in a three roomed house with six other children, all the children of her deceased siblings. Their house is very small. Tony's mother reportedly left home when she was young and her family gave up on her a long time before she died. Tony has an older sister but she has left home and no one in the family knew where she was.

Participant 6: Gogo Queen

Gogo Queen is the carer to Tsepo and Tom (both aged 13 years). These two boys live with HIV and both take anti-retroviral treatment. Tsepo and Tom have different sets of parents and both are deceased. Gogo Queen is a paternal aunt to Tsepo and paternal grandmother to Tom. She is a pensioner who has two other daughters who both work far from home but visit during holidays. Tsepo is the last born of five children; all his siblings except one are migrant workers, and one sibling who is at home has left school and has two children. Tom has one sibling, who is older than him.

Participant 7: Mrs Ndlovu

Mrs Ndlovu (51 years old) lives with her two children. The youngest is Ziyanda, who is 14 years old. Mrs Ndlovu sells fruit and vegetables at the local market. Ziyanda's father was a migrant worker but he had to leave work because of ill health. He now receives a disability grant. Mrs Ndlovu and her husband are both living with HIV and on antiretroviral treatment. In the table below, the different relations carers had with the young people they provided care for, are summarised below.

3.4.2: The profiles of young people participants

Fifteen young people participated in this study; seven were interviewed individually and another seven participated in a focus group, whilst one was a case study participant. I will

begin with the profiles of the participants interviewed individually. All participants were from an urban area (U) with the exception of one young person. This will be followed by profiles of participants from the focus group, all of whom were recruited from a rural area (R). The gender of the participants is represented by either M (male) or F (female) and the location of the participant is also identified.

J: 13 years ⁶(M, U)

J lives in a household with six adults including his grandmother and father. His mother is deceased; she died just after the death of his younger sibling. J was not told the cause of her death. J was taken to be tested for HIV by his father's girlfriend, who lives approximately six miles away. J's father's girlfriend takes care of his physical needs; however, when there is conflict between her and his father, J's care is affected. As a result the girlfriend has taught J to read his clinic visit notes and to take medication so that he can be independent. No one from J's household has ever accompanied him to the clinic.

J has not been told his status; however, when the girlfriend was interviewed, she said she had told him that he would now take medication and he needed to take the medication every day to prevent getting sick like before. J only began treatment with ART once he was at an advanced stage of the disease.

Ben: 13 years (M, U)

Ben lives with his grandmother and his older siblings. Ben could not remember when he started ART because he was very young at that time; he knew, however, that he had been on treatment for many years, since before 2007. His doctor had told him about his HIV diagnosis when he was about 11 years old. He was not sure how he had been infected but he thought he might have been born with HIV.

Sne: 14 years (F, U)

Sne lives with her grandmother and her aunts. Sne's mother is deceased and her grandmother is her main carer, helping her with medication and clinic visits. Sne did not know when she had been tested or when she had started ART, but said she had been on ART for a long time. She was told about her diagnosis by her grandmother after she had inquired about the cause

⁶ The gender of the participants is represented by either M, which stands for male or F, which stands for a female participant. The location of the participants is represented by U, which stands for an urban location or R, which stands for a rural context.

of her frequent illnesses. At that time she was about seven years old. She feels stigmatised and ill-treated by her aunts because of her HIV status and she has tried to commit suicide.

Nto: 14 years (F, U)

Nto lives with her mother who is an HIV activist. She is her mother's only child and her father passed away when she was still a baby. She was told about her HIV status by her mother and two social workers in her home when she was 13 years old. At that time, she was already on ART, which she had started in 2007. She is very active in her church and she loves sports. She reported that her mother was her main source of support and inspiration.

Sam: 15 years (F, U)

Sam lives with her paternal aunt, who has been caring for her since she was two years old. Sam was abandoned by her mother when she was less than two years old and was left with a neighbour. Whilst in the neighbour's care, she was sexually abused. The neighbour looked for Sam's relatives and eventually they found her aunt, who then assumed her guardianship; at that time she was very sick. Her aunt took her to the hospital, where she was tested, but she did not start ART until 2009.

Ron: 13 years (M, U)

Ron is in the care of his maternal grandmother who is a pensioner. He is living there with his older sister and other children who are the offspring of his uncles, who are deceased. Ron's parents passed away. His mother died after a short illness and later his father committed suicide in 2008. He has five siblings, who are older than him, but they do not live together; they were placed with different extended family relatives after the death of their parents, and Ron and his older sister were placed together. At the time of the interview, Ron was unwell; he was battling to breathe properly and he complained that his chest was not getting better and he was often in hospital because of it. His schooling was being constantly disturbed and he had learning difficulties.

Brian: 16 years (M, U)

Brian lives with his grandmother; both his parents are deceased. He started antiretroviral treatment when he was 13 years old, and later he was told about his diagnosis. He has learning difficulties at school, but he reported that his class teacher, who was aware of his

status, was supportive of him. Brian is very quiet and he speaks softly, and even at home his relatives find it difficult to communicate with him.

Zonke : 16 years (F,U)

Zonke lives with her paternal grandmother who is 68 years old. Her mother passed away when she was 12 years old, and her father is also deceased, having died when Zonke was still a baby. She recalled that as a young child, she used to have recurrent flu-like symptoms, but eventually she became seriously sick and her paternal grandmother decided to take her. Her grandmother had her tested for HIV but did not tell her about the diagnosis immediately. She was only told later when she was on antiretroviral treatment. Zonke sings in her church and she writes poetry.

Mpho: 14 years (F, R)

Mpho lives with her mother and grandmother. Mpho's father passed away as a result of HIV-related illness. Before his death, he told Mpho's mother that he was HIV positive. As a result, Mpho and her mother were tested early and started ART before they could experience any AIDS-defining illness. Mpho and her mother are supportive of each other. Mpho reported that she was doing well at school and that she had dreams of having a brighter future upon completion of her schooling. She is very active in her church and she often participates in church youth camps.

Thabang: 14 years (F, R)

Thabang lives with her aunt and grandmother. Thabang's mother passed away when Thabang was still a baby, and she was left in the care of her aunt. Thabang is HIV positive and she receives antiretroviral treatment from the local clinic that is 15 kilometres away from her home. Thabang was told about her diagnosis in 2009 by her aunt and grandmother. She was not sure how she had been infected, but she thought she had been born with it because her mother had passed away when she was really young. Thabang does not attend school because she is physically disabled and has difficulties in learning within a mainstream school. Her carer reported that there was no school in their community with facilities that catered for the needs of children with learning difficulties. Thabang receives a monthly disability grant⁷.

⁷ Financial support from government for people with disabilities

Tsepo: 13 years (M, R)

Tsepo is a 13-year-old boy who is HIV positive and has been on antiretroviral treatment since 2009. His parents passed away because of HIV-related illnesses, and Tsepo witnessed his parents' painful deaths. Tsepo still finds it hard to deal with the loss of his parents. He now lives with his maternal grandmother, who supports him. Although he has been tested, he did not remember when he had done the test. His grandmother told him about his status when he was already taking antiretroviral treatment.

Tom: 13 years (M)

Tom is HIV positive and on antiretroviral treatment. He did not remember when he had been tested, but he had been told about his HIV status when he was 11 years old and was started on antiretroviral treatment when he was 12 years old. He had repeated HIV-related illness when he was younger, and that prompted him being tested for HIV. He recovered well after starting ART. Tom's parents are both deceased and he is now in the care of his paternal grandmother, a pensioner. Tom reported that he liked the school he was attending and that he had many friends.

Tsepo: 16 years (M,R)

Tsepo is HIV positive and on ART. He was tested in 2010 after a prolonged case of chronic diarrhoea. He was the only participant in this study that gave consent for his HIV test, because when he was tested, he was already 15 years old, and according to South African laws therefore of legal age to give consent for HIV testing. He lives with his adoptive parent and his younger siblings. At the time of the focus group, Tsepo was still battling with HIV-related opportunistic infections and side effects of antiretroviral treatment. Tsepo's recovery from his previous illness was very difficult; he lost a substantial amount of weight as a result.

Ziyanda: 13 years (F,R)

Ziyanda is HIV positive and she lives with her mother. She did not remember being tested for HIV, but she remembered being sick. Ziyanda and her mother are both taking antiretroviral treatment and they support each other. Ziyanda lives in a rural area and her mother is unemployed. Although Ziyanda is 13 years old, she appeared much younger than her age. She had a loud and infectious laugh, which gave one a gleam of her personality. Ziyanda's father passed away shortly before the end of this study.

Tony: 13 years (M, R)

Tony is HIV positive and on antiretroviral treatment. Tony's mother is deceased and his father is not known. Tony lives with his great-aunt, the sister to his grandmother. Prior to this arrangement, he was staying with his uncle and his wife, where he was abused and stigmatised. He then left that household and his whereabouts were not known for many days, until he was later found and his great-aunt decided to take care of him. Tony could not remember when he had been tested or when he had started ART. During the period of this study, he appeared to be battling with chest problems and had a persistent cough. Tony was the quietest of the participants. He sometimes appeared as if he was lost in his own world, unable to follow the discussions. He does not perform well academically; he has been repeating the same grade for more than three years at school.

3.4.3: Table of carer-young person relationship

	Child	Male/ Female	Age	Carer	Age	Relationship to child
1	Mpho	F	14	Mary	34	Biological mother
2	Tsepiso	M	16	Elizabeth	42	Child fathered by husband's brother
3	'J'	M	13	Ethel	24	Child is boyfriend's son
4	Thabang	F	14	Ruth	26	Aunt
5	Tony	M	13	Elaine	34	Aunt
6	Child 1: Tsepo	M	13	Gogo Queen	Over 60	Child 1: Paternal aunt
7	Child 2: Tom	M	13 years			Child 2: Paternal grandmother
8	Child: Ziyanda	F	14	Mrs Ndlovu	51	Biological parent

Table 3.1 Child-carer relationship from North Crisis community Centre

3.5: Data collection processes

As mentioned earlier, constructivist grounded theory techniques, as described by Charmaz (2006), such as constant comparison analysis and theoretical sampling, asking questions,

coding of data and integrating theory as part of data analysis, were used. The use of constant comparison established analytic distinctions as one set of data was compared with another to identify and clarify differences and similarities, while noting gaps that existed in the data. The results of this process informed the next stage of data collection and theoretical sampling. The process of constant comparison continued until theoretical saturation was reached.

Data collection and analysis was a cyclical process, whereby the processes of data collection, analysis and theory integration as iterative processes moved back and forth until theoretical saturation was reached. Below, the sequence of data collection that informed this grounded theory study is listed.

1. Preliminary literature review to identify research questions
2. In-depth interviews with a purposively selected sample of young people (site one)
3. Community engagement project
4. Focus group with young people
5. Interviews with caregivers of young people
6. Single case study
7. Individual interviews with young people (site two)

3.5.1: Interviews with young people

Semi-structured interviews were conducted using an interview guide which facilitated better preparedness for conducting the interviews. Interviews began with less sensitive and less personal questions such as school and community-related questions; thereafter, more sensitive and personal questions were asked. The flow of the interview and the participant's openness in talking about his/her story had an effect on the structure of the interview, as some interviews needed more probing, whereas for others, information was flowing and therefore minimal questioning was necessary. In most interviews, I started with little questioning and allowed participants to tell their story, and when they stopped, I intervened to either ask for clarification or sometimes to paraphrase, to ensure that I had understood clearly what the participants meant.

De Vos (2002) suggests three basic approaches to conducting qualitative interviews. The first one is the informal conversational interview, which resembles a chat, during which participants may even forget that they are being interviewed and most information flows from the immediate context. The second one, a guided interview, uses a checklist to ensure that all

specific topics are covered. The last approach is the standardized open-ended interview, where the researcher prepares an open-ended list of questions, carefully worded and arranged for the purpose of minimising variation in the questions posed to the participants. This study adopted a guided interview approach, with predetermined topics to cover during the interview; however, the interview itself was not structured to follow the topic list chronologically. The length of each interview was between 45 and 90 minutes, and was largely determined by the level of openness and engagement with participants. Some of the participants became distressed during the interview, and consequently, 'time out' was suggested and they took breaks; then, once they had rested, with their agreement, the interview was continued.

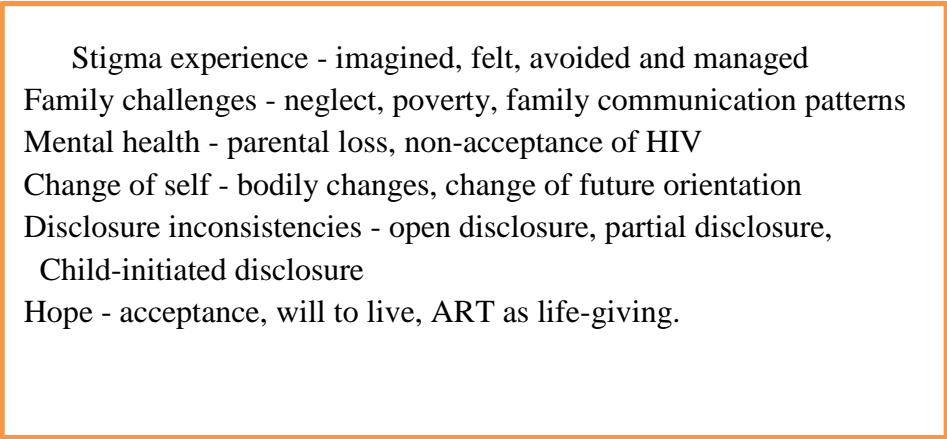
Research contexts raise issues of unequal power relations between participants and the researcher, where the researcher holds a superior position compared to the participants; this can be more pronounced when participants are young people. Moreover, the cultural context of the participants, which encourages obedience to adults, further heightened this power imbalance. Clacherty and Donald (2007) point out that the power disparity between young people and adults interferes with the research process in that young people may be unable to openly express their views. However, when conditions of trust are met, young people can express their opinions and views openly. The use of interviews with young people as the data collection tool facilitated understanding of the young person's experience, however questions which asked 'why?' or 'how?' were sometimes difficult for the young people to answer, and sometimes they would respond by stating that they did not know or simply remained quiet. This could be an indication of the prevailing cultural context where young people regard being silent or withholding their opinion as part of maintaining a respectful behaviour towards an adult rather than a lack of an opinion.

Young people were reminded and reassured that they could take a break or terminate the interview if they wanted to. For example Ron, one of the participants, was asked while the interview was going on whether he needed to take a break, after I observed that he seemed hungry and tired after thirty minutes of talking. Furthermore, he had cried uncontrollably for some time during the interview when he raised the issue of his mother's death, and he seemed to have respiratory problems. When a break was offered, he immediately said yes, and I realised that he really needed it, perhaps an indication that he was exhausted both emotionally and physically. During the break, he rested, had his lunch and the interview was terminated

with a discussion of issues that were less sensitive such as things that he enjoyed at home and things that were important in his life.

The first seven in-depth interviews with young people living with HIV and taking antiretroviral treatment were conducted at the first recruitment site (North Crisis Centre) in February 2008 for a period of two weeks and one interview was conducted in each day to allow for tentative data analysis to occur. These interviews were conducted in IsiZulu, tape recorded and transcribed verbatim by the researcher. The transcription was done in IsiZulu and later translated to English. During the translation process, the original IsiZulu recorder was still consulted to ensure that the translation to a great extent carried the same meaning as the original meaning. When the original word had no direct translation, that word was used in its original form and a phrase describing it was written to maintain its contextual meaning. To maintain confidentiality and anonymity of all participants in this research, pseudonyms were created and used instead of real names.

All interviews were coded using line-by-line and incident-by-incident coding to explore initial ideas and understanding from the data. Charmaz (2006) defines coding as “naming of segments of data with labels that simultaneously categorise, summarise and account for each piece of data.” The early stages of coding indicated tentative themes and gaps in data; for example, through early coding, what emerged was that the young people’s narratives could be classified into three categories, which were HIV-related experience, family experience and experience within young people’s social world. Therefore, whilst HIV-related experience was important, as it was a core theme of the study, the intersection with non-HIV-related factors created a distinct childhood experience for participants. Themes identified from initial interviews are summarised in figure 1.



Stigma experience - imagined, felt, avoided and managed
Family challenges - neglect, poverty, family communication patterns
Mental health - parental loss, non-acceptance of HIV
Change of self - bodily changes, change of future orientation
Disclosure inconsistencies - open disclosure, partial disclosure,
Child-initiated disclosure
Hope - acceptance, will to live, ART as life-giving.

Figure 1: Initial individual themes

Driven by insights obtained through the initial seven individual interviews, the next data collection focused on understanding the context within which young people resided; this further data collection included interviews with more young people living with HIV, as well as caregivers of young people. This stage of data collection was collected between February and July 2009 from the second site called Mpilo. To understand young people's HIV experience and how it was being negotiated within their socio-cultural context, I immersed myself in their environment and collected data from young people and their carers, as well as other community informants such as healthcare workers working with young people and regular community workers. This involved:

1. Community engagement
2. Focus group with seven young people living with HIV and on ART
3. Individual interviews with carers of young people living with HIV
4. Interview with carer and young person living with HIV and taking ART.

3.5.2: Community engagement

Data collection started by familiarising myself with the clinic, which was a recruitment site for the study that was located in Mpilo. I started by exploring the clinic and how it was being used by young people and adults living with HIV. Healthcare workers such as nurses and HIV counsellors, as well as the clinic doctor, provided valuable insights about their experiences of working with young people in this context.

These early discussions highlighted that HIV openness was a challenge in this community. Secrecy and fear that surrounds HIV exacerbate the isolation experienced by those affected by HIV. Young people living with HIV were raised in an environment where HIV was treated as a private matter and open communication about HIV was difficult. These constraints affected the disclosure patterns for young people and prevented timely HIV testing.

Observations, interviews with key informants and informal discussions provided very rich data about HIV-related issues in this community including the challenges related to access to resources and challenges faced by parents/carers and young people. Disclosure of HIV status to young people was a major challenge identified by most healthcare workers from the clinic and conducting the study in this clinic actually highlighted that young people who were

disclosed to and those who were not, was a challenge since records of HIV disclosure to young people attending this clinic were not kept. However, the majority of young people were not told about their HIV status and health care workers reported that non-disclosure prevented open communication about HIV and treatment with them, a situation which health care workers believed to be exacerbating young people's non-adherence to treatment. On the basis of this, the health care workers at the clinic were keen to understand barriers to HIV disclosure to young people, and to work with carers on how best to support them in this regard. A one-day workshop with carers was organised, in which carers and clinic workers participated, as well as members of two non-governmental organisations that worked with young people including some who live with HIV. This workshop provided a valuable opportunity to get to know carers and build a relationship with them. It also facilitated recruitment of potential participants. During this process, I became engaged with community members and the two non-governmental organisations that were working with young people, including those living with HIV and orphans. A participant observer role was part of this process, a role in which the participants are aware of the dual role of being a researcher and a participant (Burns & Grove, 1993).

My participation served several purposes:

1. Strengthening rapport with healthcare workers of the clinic, carers of young people living with HIV and community members;
2. As part of data collection, through this project I obtained insights from community members and carers of young people living with HIV about key issues that were considered to be critical for carers and young people.

3.5.3: Focus group: Its development and utility

Focus groups in health-related research are increasingly being used successfully in studies with young people (Morgan et al., 2002; Onya & Flisher, 2004). Three focus group sessions were conducted with the same participants. A focus group with young people requires participants to have sufficient verbal and social skills to meaningfully participate in a discussion (Fiedler & Posch, 2009, p.86); however, it also requires that the researcher develop the relevant vocabulary to engage with young people appropriately. This method of data collection was preferred since it had the potential to enhance communication and reduce unequal power between the researcher and participants. In this group, some of the participants had delayed developmental milestones such as language development, which

may be a consequence of HIV infection (Gosling et al., 2004). Therefore, holding three communication sessions with the same group helped to address communication barriers such as this.

The focus group consisted of three girls and four boys from 13 to 16 years of age. The parental HIV status was not always known, especially of those who passed away without disclosing their HIV status, however, most young people living with HIV were believed to have been born with HIV. Carers of these young people included biological parents, grandparents, aunts and extended family members. A discussion guide was developed to ensure that topics were not missed. As the focus group discussion was driven by inputs from participants; some issues that were not in the guide were raised by the young people themselves. All the discussions were conducted in IsiZulu, the language of the participants.

Three sessions were held with the same young people. The first session focused on getting to know the participants, obtaining assent, explaining the research project in more details with opportunity to ask questions and building rapport with the participants. This process was essential to minimise the effect of power imbalances between young people and me.

Accepting young people's views about when and how they wanted the group to be structured was also important for increasing their participation and acknowledging their views.

Therefore, most planning of the group's logistics and activities was discussed with the young people and their input was sought. All the participants were living at a distance (approximately five miles) from each other and from the clinic where meetings were held. The logistics of arranging transport to pick them up on time was a challenge, since public transport in the village was infrequent and some participants had to travel long distances to reach a 'station' where public transport picked them up and transported them to the main town where the clinic was located. Therefore, we agreed that I would pick them up from home or from the 'station' that was closest to home. Travelling with the young people in this way afforded me an opportunity to understand their environment better, in terms of where they came from and their neighbourhood.

The second session focused on young people's lives in relation to HIV, beginning with less sensitive issues such as how their week had been, what they had done during the week and other informal questions. Thereafter, HIV-related questions were asked, such as how they felt about coming to the clinic, their diagnosis, who told them and who else in the family was

aware of their diagnosis. The last session focused on clarifying outstanding issues, identifying gaps in the shared information and dissolving and withdrawing from the group.

Group sessions were tape recorded and extensive field notes were written immediately after each session. The focus group approach was useful for observing the interaction of group members and the group's dynamics. Often one person in the group would say something and others would deliberate on it, offering an alternative or sharing a similar sentiment, thus enabling new meanings to be constructed during the sessions. Some topics such as parental loss were not easy for participants to talk about in the group sessions; such issues raised-up deep-seated pain for most participants.

Conducting a focus group with young people on private issues such as HIV can be intimidating for them as well as for the researcher. For most of these young people, this was the first time they had come together as a group of young people living with HIV, to talk about their experiences. Therefore the focus group was also a space for self-disclosure and sense making through interaction with others. Occasionally, there would be silence when participants would be lost for words, and sometimes non-verbal gestures indicated the intensity of feelings generated by talking about HIV in their lives. When participants appeared uncomfortable about discussing a particular issue, it was not probed further. For example, parental loss was a very sensitive topic and when it was raised, most members were uncomfortable about talking about it openly. However, valuable insights were collected from the young people during our trips from their homes to the clinic and when I was taking them back to their homes. They shared insights about their neighbourhood and how they felt about their environment.

This second set of data was transcribed and coded by me. The themes developed from the initial set of data were compared with those constructed from the focus group discussions. These themes were constantly compared to previous collected data, in order to identify new insights, similarities and any contradictions. At this level, different patterns of disclosure became clearer, however they had occurred. For example, in the first set of data, young person-initiated efforts to HIV disclosure were identified; however this was not a clearly articulated category at that stage. The focus group discussions both contributed to construction of categories and clarified categories.

The young people's narratives were coded and were compared with codes that emerged from the seven initial individual interviews. Similarities and differences were identified and some

of the categories were explicated and become more dominant, with many properties attached to them, whilst some of the concepts were integrated to develop major categories as illustrated in figure 3.4.

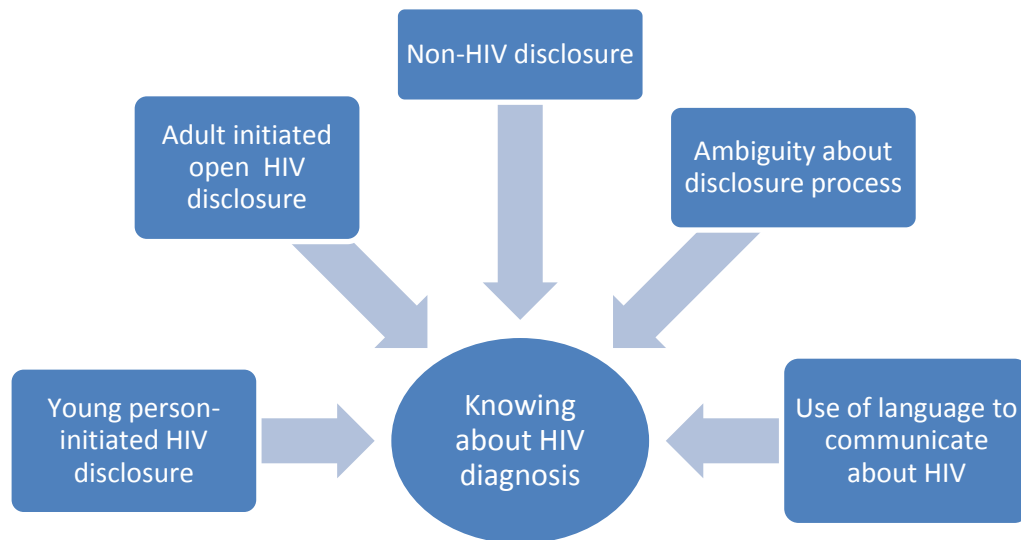


Figure 3.4 Example of explicated theme

The analysis of knowing about HIV diagnosis indicated that telling young people about their HIV diagnosis was a negotiated process between young people and their carers and I believed that understanding how carers facilitated this process could explicate this theme further. Therefore, data collected from young people living with HIV showed that a greater understanding of carer's perspectives and social environment was needed, hence the decision to then interview carers.

3.5.4: Interviews with carers/parents

Participants were theoretically sampled through face-to-face contact to explicate emerging themes. This process entailed sampling carers who provided care to young people living with HIV and explore how they managed disclosure process and in turn understand how carers' approach to disclosure impact young people's awareness of their HIV status. Moreover, since the family context emerged as critical to young people's experience of HIV, sampling carers provided an opportunity to explore different family units and how these various forms of families shape young people's lives and subsequently their experience of HIV.

In line with this thinking, seven interviews were conducted with carers in their homes: two were biological parents, one was the culturally adoptive mother (meaning the child was

placed with this carer because of culturally formal family arrangements) and the other four carers were extended family members. A rapport already existed with participants because all of them were carers of young people who had participated in the young people's focus group. All interview appointments were confirmed by telephone with carers. The participants preferred being interviewed at home because it saved travelling time, as they had competing demands, and they could then fit the interview within their schedule. Moreover, this ensured that while conducting the interview, carers could continue doing their household tasks such as making handwork (e.g. *amacansi*⁸) or managing the household, which was especially important if some of the family members were either performing tasks outside the home or were away. In this way the research process was less invasive and the control of the interview was more within the power of the participant. Mills et al. (2006) contend that establishing a relationship with participants and counteracting power imbalances within the interview setting are critical since the researcher-participant relationship is traditionally a hierarchical one, with the participant in a subordinate position.

One interview was conducted per day, as the carers lived far away from each other and some of the homes were difficult to reach. The interviews were conducted under a tree, sitting on the floor mat or inside a room. In line with the constructivist approach of grounded theory, efforts were made for the interview process to be based on a reciprocal relationship where participants shared their experience and equally and they were able to ask me questions. I treated their questions with respect and where I had answers, I would respond. However, I also acknowledged their experience, and when I missed the point that participants were making during the interview, they would clarify it. This, together with the use of self and knowledge that I brought to the interview, facilitated better engagement with participants; I felt they could relate to me. I had prepared an interview guide to ensure that all relevant topics were covered during the interviews

Each interview began with light talk such as greetings and comments about my walk to their house and a few questions about the neighbourhood. My familiarity with the language and manner of approach towards the participants facilitated a comfortable setting which allowed me not to have to have to ask many opening questions. The participants seemed to want to share their stories from the beginning to the present time. I tended to ask questions later to get clarification and to probe further. Their narratives did not contain very descriptive emotional

⁸ Floor mats hand made by women from rural areas to sell and generate income.

reactions. The content tended to lean towards external issues such as challenges and responsibilities. When asked about their emotional reactions, they tended to use expressions such as “*It was difficult*”, “*I will never forget*”, “*I had to do it*” or “*Nothing is impossible with God*”. Some of the participants became tearful during the interview as they tried to control their feelings. Shorthand was used to document data and write carers’ responses. Notes, observations and reflections were written on the same day.

There were a few disadvantages to conducting interviews in the participants’ homes: sometimes there would be more than one person in the room, and sometimes the interviewee would be disturbed. Moreover, travelling to these homes was sometimes difficult: roads were bad, and sometimes my car would be trapped in sandy soil while trying to reach their home. Some of the interviews had to be cancelled after my car was trapped and I had to arrange an alternative day; all time consuming.

The interviews with carers provided information about the context of the young people’s lives, as well as giving insight into the nature of families. Furthermore, they enhanced the meaning of the daily lives of young people that were not always clear when discussed with them, as a result of complexities in their families. This aspect of this study also raised questions about ways in which the construction of families impacts the provision of care to young people in the era of HIV and this provided the rationale for further exploration through a case study.

3.5.5: Case study

The case study examined was of a 13 year boy (J) who was living with HIV and taking antiretroviral treatment. This young person was purposively selected because his family structure and composition had an impact on the structure of his care and how he managed his diagnosis. His source of support came from a wider social network which included people who were not in the same household. Interviews were conducted with J and with the person who provided most support in the management of his HIV – his father’s girlfriend.

This was the final method used for data collection; having started with young people’s perspectives, which revealed the importance of social context and disclosure patterns. This provided the theoretical justification for examining the implications for young people’s experiences of family structure, carers’ approaches to disclosure and the impact of environmental factors by interviewing carers. In circular fashion, I then explored the meanings of these aspects of social life for a young person (J) in managing living with HIV.

3.6: Data analysis

Data coding and data collection are parallel processes in grounded theory. This type of coding differs from other qualitative methods in that it involves constant comparison methods, whereby incidents that are noted from data are compared with other incidents for similarities and differences. The resulting concepts over time are grouped to develop categories and their properties are described. This was an active process that involved questioning what was emerging and consulting relevant literature for clarification and answers. Therefore the review of literature for this study is interwoven with the study itself and explains why an extensive review of literature was not conducted prior to the study's commencement. The findings chapters are therefore a reflection of core emerging themes integrated with a discussion of these themes as highlighted within the literature –data driving the literature rather than the other way around.

Since a constructivist approach to grounded theory was used, axial and theoretical coding methods were not used; instead, data analysis began with line-by-line coding to identify all possible codes that could be developed to form categories (see table: 3). This involved repeated readings of transcribed data and field notes and listening to the original audiotapes to understand the mood and context of the interview. This was particularly important since all interviews were transcribed from IsiZulu to English, and consequently, meaning was sometimes lost during the translation. IsiZulu contains interpretative statements and metaphors, so in order to preserve contextual meaning, line-by-line coding was used interchangeably with paragraph-to-paragraph coding.

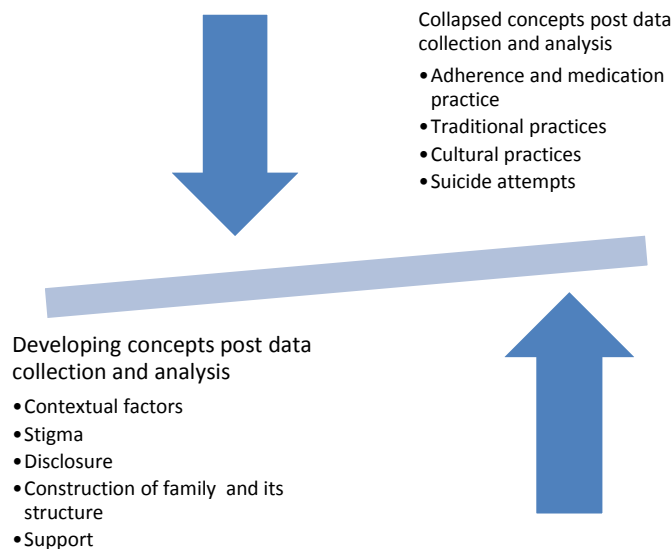
In vivo coding was particularly useful, since the interviews had words and statements that were difficult to translate into English, such as *ngizogqashuka*; this was an informal word which referred to dying. During coding, I often referred to the Zulu interviews to capture the nuance which may have been lost during translation. For example, when participants talked about the importance of taking medication, and that non-adherence could lead to early death, it was less formal and did not carry a negative interpretation.

Later in data collection, focused coding was used to sift through large quantities of data to a focus on emerging categories. Initial coding identified several codes and some of those codes became non-significant as data collection and analysis progressed. Medication practice, for example, was one of the issues I was interested in exploring before starting the research;

however, it did not emerge as a dominant category during data analysis. Young people had more concerning issues than medication.

Below is an example of some of the codes that collapsed and those that became significant.

Figure 2: Movement of codes



While identifying significant themes was critical, openness to exploring new developing interests was also important, to avoid what Charmaz (2006) calls forcing pre-conceived ideas and theories upon data. In this research, non-significant themes were not readily discarded just because they were insignificant. What emerged as a non-significant theme, such as adherence to medication, was more important to research participants such as nurses and doctors. While exploring themes that were significant, non-significant themes were still probed to ascertain their relevance; however, the focus in terms of analysis and data collection shifted to more significant themes.

Data analysis was not a linear process; I was actively constructing codes and simultaneously conducting data collection as well as searching relevant literature. An example of my coding activity is given below.

An example of coding from an interview with an HIV positive 14-yr-old girl (site 1)

Excerpt from data	Codes	Concept
<p>Interviewer: Is there anything that you would like us to talk about first?</p> <p>Participant: <i>(smiling)</i> No...you start first.</p> <p>Interviewer: Alright, tell me about your family.</p> <p>Participant: <i>(crying)</i> ...My mom passed away when I was four years old. I then stayed with granny and when I was older, maybe about five or seven years old, I asked my mom...oh...my granny, what killed my mother; then she told me.</p> <p>Interviewer: Mhh.</p> <p>Participant: ...I then started getting sick, when I asked her I was already sick.</p> <p>Interviewer: Mhh</p> <p>Participant: I was just getting sick often and sometimes I would be hospitalised until she told me what was wrong. When I tried to eat I would vomit. I would have severe headache (<i>ikhanda eligxabhayo</i>); my stomach would be very painful.</p> <p>Interviewer: What did she say?</p> <p>Participant: She said my mother died because of HIV...which means...when she was tested, she was pregnant with me; that means I also have it and I should accept the situation.</p>	<p>1. Death of parent (still painful);</p> <p>2. Change of carer</p> <p>3. Child's self-initiated plan to know about her illness</p> <p>4. Links mom's death and her own (thoughts of dying?)</p> <p>5. Sickness as a suspicious event</p> <p><i>(Subsequent to this interview, I asked participants whether they had any suspicions about their illness before being disclosed to)</i></p> <p><i>Open disclosure</i></p>	<p>Self-initiated process of knowing</p> <p>Suspicion-raising event</p>

Figure 3: Example of data coding

3.6.1: Memo writing

Memos are known as informal analytical notes which form an on-going process of thinking and writing about codes as they develop and take shape. Charmaz (2006) suggests that memo writing has to be started early, as an on-going process between data collection and analysis. It can serve as an early draft of the analysis. One can identify relationships among different categories and interrogate categories as they develop at an early stage. It is a helpful process, as it can still be treated as a private and personal reflection without there being too much pressure about the style of writing.

Memo writing for this research began with an open-ended question such as: “What is happening here?” Therefore memos initially contained thoughts, open-ended questions with no answers and multiple interpretations of what I was seeing from data. It was an active process which happened concurrently with coding and beyond.

One of the memos traced the pattern underlying young people’s entry into healthcare establishments for HIV medical care and their subsequent participation in their own care. This revealed that young people’s entry to care was a process that was determined by multiple factors, including historical factors linked to HIV secrecy and silence. Memos were useful to construct a story and a pattern from this data. Furthermore, these memos contained some of my own reflections and thoughts of the research process.

Below I present my ethical considerations as well as my reflections on the research process. Charmaz (2006) argues that the importance of reflexivity about the research process in the field must not be undervalued by researchers who use constructive grounded theory. It is important to reflect on the research process since it is a co-constructed activity and a researcher’s role in the field, and the interaction with data, must be transparent.

3.7: Reflections on the Research Process

3.7.1: Introduction

The previous section outlined the methodology and methods that were employed in this study; the purpose of this section is to reflect on the research process and practice as a co-constructed process, as suggested by Charmaz (2006). Key issues that are discussed in this section of the chapter include the ethical considerations of the study, the researcher's position in the research field, reflections on working in these communities and the intersection of researcher's role and social worker's role.

3.7.2: Ethical considerations

Conducting research with young people brings to the fore a variety of ethical dilemmas that relate to issues of assent/consent and gatekeeping; these issues become more pronounced when research subjects are minors. Gallagher (2009) contends that ethical principles for childhood studies are similar to those in social and medical research, which are informed consent, anonymity and confidentiality. However, I agree with Leonard (2007) and Clacherty & Donald (2007), who note that conducting research with young people raises issues of power inequality, marginality and powerlessness of young people. Negotiating issues of consent and assent to participate in research are some of the potential areas where young people's position and marginality often surfaces. As mentioned earlier, in this study, young people who wanted to be part of the study were excluded from participating if their carers withheld their consent. Although the participation of young people in research is widely acknowledged in literature, this acknowledgement does not lead to automatic validation of children's rights at a micro level. Therefore despite this promotion of inclusivity, the exercise of children's rights can sometimes be within constraints imposed by adults.

Conversely, if young people give their assent to be part of the research process, their authentic participation must be assured, and they must feel comfortable that they can withdraw their participation and have a right to choose how and which questions to answer. Lund (2008, p. 136) contends that young people's participation in research implies "listening to them, giving them space to articulate their concerns...it is about giving young people a role in decision making and it is about seeing the participation of young people in relation to older people's control and power." Rather than being seen as a potentially intrusive process, it can be argued, as suggested by Norman (2011), that involving young people in research is a process that validates young people's views and opinions if their participation is authentic.

The ethical approval to conduct this study was obtained from the University of Huddersfield's School Research Ethics Panel and the study was conducted according to ethical guidelines as indicated. In South Africa, approval and permission to conduct the study was requested from two organisations. One was a community organisation and the second one was a government hospital, and both agreed to allow the study to take place in their institutions. All data collection tools, such as informed consent, young person's assent, information sheet and interview guide, were designed by me and reviewed by my supervisory team. I then translated them into IsiZulu, the participants' language.

Both parental consent and young people assent were sought to ensure that both the young person and the carer understood the implications of participating in the study (Creig et al., 2007, p.174). Whilst Creig et al. (2007) suggest that young people of age 16 and 17 with sufficient maturity to understand may consent to therapeutic research, this may not always be acceptable in other contexts. Age may not be a determining factor for one to consent if an adult has refused to give consent, particularly in projects that involve young people as research subjects for the study of sensitive issues such as HIV. For example, one of the ethical dilemmas encountered during this study was that one of the potential participants, 16 years old, with a child of her own, was refused permission to participate in the study by her non-legal guardian. Consequently, she did not participate despite her desire to do so. This raised issues of the young person's cultural position in the family as well as in her society; the power dynamics between young people and adults and how childhood was defined and understood in that context.

After parental consent, young people were informed about the study and their assent was sought. None of the participants declined to participate; however, they were assured repeatedly that they could terminate the research if they preferred, without fear of being reprimanded or questioned. Signing of consent forms raised another dilemma. My experience in this study indicated that, although consent forms and information sheets were a prerequisite for giving informed consent as required by the University's Ethics Committee, many participants were uncomfortable about signing. Furthermore, those that did sign and took information sheets hardly read them. This act raised issues of power and young people's social position, where young people in this context generally trust adults to act in their best interest. Gallagher (2009) further warns that, although giving consent must be voluntary and negotiated, putting these practices into place can be challenging, and young people may not perceive their assent as voluntary as a result of many factors, which may include their

relations to adults who are their gatekeepers. Clachery & Donald (2007) suggest that trust and openness must be established before assent is obtained, to ensure that young people feel comfortable about giving their permission to be part of the study. In this study, consent was a two-staged process. In the first site, counsellors recruited potential participants and they explained about the study; if potential participants were interested, they were referred to the researcher for formal explanation and discussion. If they agreed, an appointment was made for an interview. The opportunity was offered for information leaflets and consent to be signed at home and brought back during the appointment, but most preferred not to take the information sheet or consent forms home. Perhaps they were concerned about it being known that they were participating in a research project.

Often, most participants preferred to give verbal rather than written consent. Participants valued the discussion and verbal explanation of what the study entailed and how it would be used. Spending quality time explaining the details of the study was important for them, and information sheets served as reminding tools. The participants' greater concern was often about confidentiality and anonymity. The principle of anonymity is that research subjects should not be identifiable in research outputs, and they were assured that their original names would not be used; instead, pseudonyms would be created to replace their names in the final thesis.

In this study, assuring confidentiality as an ethical principle did raise ethical dilemmas. All participants were assured that our discussions would be treated with confidence. However, young people were told that if incidents of abuse arose, or if the young person's life was in danger, such matters would be reported to the social worker. Although most young people did not have life-threatening incidences, some of the young people did need intervention from social workers. Consequently, some of the information had to be disclosed. Moreover, since some of the young people were not interviewed with their carers, the carers were interested in knowing what the young people said, which may be important for them to know.

Understanding that most carers were asking out of concern rather than prying, they were assured that if there was anything that was life threatening to the young person, the matter would be dealt with professionally. Since a social work visit at home did not carry a negative label, most carers were comfortable with that answer.

Gatekeepers, as mentioned earlier, can have a considerable impact on the research process; they can provide good advice as they may understand the environment better, but sometimes

their advice may undermine the values that underpin child participation and autonomy in research. The issue of reciprocity, for example, raised issues of power in a considerable way in this study. Staff from organisations that were gatekeepers suggested that since most families participating in this study were destitute, money was a more appropriate form of compensation (five pounds) than a gift. However, the suggestion was to give it to adults rather than young people participants, as they were concerned that young people could misuse the money. Although I was of a different opinion, and thought that perhaps engaging young people in considering how best to manage this would have been appropriate, I felt powerless to change their minds. I agreed to this proposal and instead I bought young people life-books as personal gifts that they could use to write their thoughts and keep special memories.

Talking about their HIV experience and the distress in their lives was sometimes a very emotional experience for young people, as other studies have reported (Gallagher, 2009; Zwiers & Morrissette, 1999). It evoked deep-seated pain as they talked about their loss and harmful practices against them; this was difficult for me as well. One of the ethical issues I had to address during data collection was the extent to which I would manage the distress of participants that could occur as a result of participating in the study. During the interviews, some of the participants cried. This required an immediate response to the participants as well as an option for more in-depth intervention. Moreover, some of the participants had to be referred for social work intervention as a result of the distress and challenges they experienced such as child maltreatment. During the interviews, I acknowledged the distress that was reported by participants and I did not disturb them whilst they talked. As a Social Worker, I also understood that perhaps talking about their negative experiences could be helping participants to ventilate their experience in a non-threatening environment. When participants were crying, I did not ask them any question but offered them an option to terminate the interview or take a break. Most young people would often decide to take a break but when I observed exhaustion after that break, I would ask lighter questions and terminate the interview.

Both sites had counsellors and the hospital had social workers, but none of the young people took up those options. However, some of the participants reported issues that required social work intervention as mentioned before; these were referred for intervention appropriately. Some of the reports involved people that were providing care to young people therefore these cases needed to be handled with sensitivity therefore, I personally arranged meetings with the

social worker who was to handle the matter and discuss the situation so that the intervention by the social worker is conducted in a sensitive manner to avoid creating unfavourable condition for the young person and negative reactions by the family of the young person. This was my major concern, however, social workers were familiar with such conditions that when the young person disclose sensitive information which could results into an intervention by a professional such as a social worker; such conduct could have negative consequences for the young person if it is not managed in a sensitive way.

Moreover, I had arranged for all my interviews to end with lighter questions, and for the young person to have something to eat and drink. This was especially useful with focus group participants and it helped participants to feel comfortable again.

Some of the interviews were conducted at participants' homes; while this enhanced my relationship with participants, I also witnessed the extent of poverty in some of the participants' lives. In one such home interview, the participant, a 13-year-old boy, was at home with a few other young people. He was preparing a fire to make steamed bread for lunch. The food he was preparing was in a very poor state for consumption. Given that it was already midday, and the last time he had eaten something was in the morning, he was hungry but had no food prepared for him or his siblings. His grandmother and his father were not coming home until late afternoon. I asked myself whether continuing the interview with a participant that hungry was appropriate or not. I asked him whether we should continue or whether he wanted to get something to eat first; he preferred to continue and then get something to eat. After the interview, I gave him money to buy bread and something to drink. Although this was not a prerequisite, sometimes as researchers we find ourselves in positions that are driven by being human and values of respect and belief about what is appropriate. This indicates that ethical practice in childhood is a contested and messy process; hence Gallagher (2009) contends that ethical practice should be seen as a practical application of wisdom achieved through a process of reflexivity, rather than as a universal prescription.

Reflections on the researcher's position in the community and the possible impact it had in the field are discussed below.

3.7.3: My position as a researcher in the community

One of the data collection sites was a community with which I had a strong connection. I was born in this community and my early childhood was spent there. The community had strong values of acknowledging extended relatives and kinships; consequently, people knew each

other and valued these relationships. Since I grew up in this community, and my family and extended family members were still residing in the area, many people still remembered me as a little girl growing up. I had left the area many years ago, but coming back created a sense of familiarity with many people in the area. My childhood friends orientated me about what had happened in my absence; however, many things had changed and I had changed. I was looking at this community with fresh eyes both as a researcher and as part of this community.

This background had an impact on my research practice, since some of the participants knew me and I knew them, and some of them knew my family. I shared many similarities with them: my background, language and culture. I was also a young woman with credentials of being a researcher and a social worker, which made me different. The intersection of these factors were not perceived as disadvantageous; instead, I was viewed as someone who would have a good influence, particularly because of the challenges that many girls experience who had succumbed to the difficulties that confronted most girls in that community, such as repeated pregnancy and dropping out of school. Therefore I was generally perceived as someone who had ‘made it’. Moreover, my experience as a social worker provided valuable skills in terms of building relationships with participants and facilitated rapport and trust.

The relationships I developed with participants was such that in some cases it continued even after the study had ended and young people would still call and ask for advice or update me about what was happening in their lives. However, I do acknowledge that the nature of my position with some participants especially those from the Mpilo site, could have raised issues of trust and confidentiality, considering that the study was about personal impact of HIV/AIDS which required a high degree of disclosure of information that could be considered as sensitive. This could have resulted in participants being selective about what they could and could not disclose. Conversely, it may have afforded participants an opportunity to consider the interviews as a ‘disclosure’ in itself as some of the may have not talk about the experience of being affected by HIV or AIDS.

However, to reduce potential tension that could have been a consequence of my positionality, prior to individual interviews, I had close engagements with community members including carers that participated in the study. In that role, I was collaborated with the health care team from the clinic that consisted of people from the community. Although I clarified my role clear during these encounters with the community members, I considered

such engagements that as an important breaking point since I was able to build relationships and perhaps break potential tension.

The relationships I developed with participants was such that in some cases it continued even after the study had ended and young people would still call and ask for advice or update me about what was happening in their lives. I considered that as an indication of the trusting relationship that had been established during the research practice. Since I had knowledge of HIV, I shared it with some of the participants; for example, one of them was concerned about lipodostrophy⁹. I asked her which medication she was taking and the length of time she had been on that medication. When she told me that she had never discussed this problem with her doctor, I mentioned that since one of her medications was well known for causing lipodostrophy, this particular medication could be changed and that she should discuss this situation with her doctor.

Considering that my study was delving into sensitive issues of HIV, which carries stigma, talking about HIV in relation to young people may have been easier for some participants, but for others, talking about their personal stories may have been difficult even though a trusting relationship had been established. These thoughts became pronounced when one of the participants, who was a carer, passed away as a result of HIV-related illness, having categorically stated that she was not HIV positive. This participant was caring for her adopted child who participated in this study since he was living with HIV, and during the interview the carer had stated that she considered being HIV positive to be similar to other chronic diseases. Within a period of six months after conducting the interviews, this woman succumbed to the disease without a chance of starting ART. I wondered whether she knew about her HIV diagnosis at the time of the interview, and if she did, was she maintaining a picture of being HIV negative only to me, or to everybody else and perhaps to herself also. I guess I will never know. Since I was in the community, I was aware that her story, regarding how she died and who may possibly have infected her was discussed by many people. Keeping information private in this community was a complicated matter that was not easy to maintain.

Conducting research in the area of HIV brings to the fore issues of stigma, and although these can sometimes be minimised, in this context the stigma was deep-rooted. Being raised in this

⁹ This is one of the possible side effects of ART where there is disturbance in how the body produces, uses and stores fat. (AIDS infor,2005)

community did not prepare me for such encounters; I realised that I had to be re-educated since I had changed, and so had the community. For example, one of the informants, when asked about the communication patterns with children in the area, simply commented: *“You are from this area, you know how people are.”* I realised then that actually, I did not know and I had to ask for clarification. However, some of the informants did realise that perhaps I had been gone for too long and I needed reorientation, as this participant noted: *“You need to try to come home often...I have to orientate you again because you seem to have lost touch with what used to happen here.”* This remark was made after my informant had watched my approach to adults during the disclosure workshop for carers; tea had been arranged on the table and I informed carers that they could stand up and make themselves a drink. To my surprise, no one stood up, and after some time the informant reminded me that you do not ask people to stand up and make tea for themselves; tea is brought to them, then they proceed from there.

Since this experience occurred at the beginning of data collection in this community, it served as a reminder throughout the course of my stay in that community to consider my participants’ frame of reference, and to be mindful of taken-for-granted knowledge that could be inferred with regard to community members as well as research participants.

I also carried professional experience as a social worker with many years in the HIV field, an area with which I had a personal and emotional connection. Mills et al. (2006) caution that the researcher’s passion for the research area can be problematic, in that it can potentially serve as a lens through which data can be viewed. However, Charmaz (2006) asserts that as researchers, we are not neutral; we enter the field with perceptions, beliefs and experience. Therefore the process of reflection about what we see and how we see it becomes an integral part of the research practice. The use of memos in the grounded theory approach becomes an important tool for reflecting on the research process and its construction.

While reflecting on some of the interviews, I wondered about my use of the term ‘neglect’ to refer to some of my observations during data collection about children’s care. This is a commonly used word in social work practice and it has serious consequences for child protection services. However, in communities with severe deprivation, the dividing line between the intent to neglect, and neglect as a result of conditions and circumstances beyond the family’s control, was difficult to define and some of these practices were a common childhood experience in this context. I had to reflect on the lens I was using to make these

distinctions. I concluded that, even though some of the practices were common and perhaps accepted as normal childhood experience, if they threatened the wellbeing of young people, they should be defined as such, in spite of whether they were intended or circumstantial.

3.7.4: Reflections on data analysis

Conducting data analysis for this thesis was an intensive process that ran parallel with data collection. Conducting theoretical sampling, which is a major strength of grounded theory, enabled me to explicate key themes from the data. One of the obstacles associated with theoretical sampling among the participants in this study was the sensitivity of the study topic, as well as the difficulties associated with purposively sampling new respondents based on the principle of theoretical sampling as reflected by emerging themes. For example, in relation to a young person's disclosure, the complexities associated with it were not known by either carers or their healthcare workers; young people were categorised as either aware or not aware of their diagnosis. Identifying young people who were told indirectly, yet presented as knowing, was challenging since participants who fitted that category were not in the first place presented as such; they were presented as young people to whom there had been full disclosure about their status. It was only when young people were asked directly about their illness that such discrepancies appeared. Identifying these patterns among young people indicated that, to understand how they emerged, carers had to be theoretically sampled to examine further the emerging themes related to disclosure.

Finally, two themes related to child disclosure were identified. The first one was young person-initiated disclosure, a term I used to refer to young people's various actions towards knowing about their HIV status, and the second was the identification of different contexts of awareness about young people's disclosure. These themes were supported by extracts from young people's narratives. Therefore young person disclosure became one of the core themes with subcategories (subthemes) related to the core theme also being identified. Literature also served as a subsequent source of information and was integrated in to the discussion of the themes.

3.8: Conclusion

In this chapter I have described the methodology and methods used for this research. The cyclical nature of data collection has been described, which started with a literature review to identify key research questions. A constructivist approach to grounded theory was used during data collection and analysis. The chapter concluded with a reflective process that

described ethical considerations as well as my personal reflections on my role in the community, as well as possible influences whilst in the field.

In the next chapter, I present the background of the community and the common prevailing community attitudes towards HIV. This begins the presentation of the findings chapters, and is followed by carers' experiences of caring for young people living with HIV. Finally, I describe young people's interpretations of the meaning and subjective experience of living with HIV.

Chapter Four: Findings Chapter - Community Attitudes and Responses to HIV

4.1: Introduction

The narratives of young people and carers who participated in this study indicated that particular perceptions and experiences are part of the broader social context in which they live. This chapter presents an analysis of the participant's environment as it shapes their lives in relation to availability of resources, community way of life and, prevailing norms and beliefs about HIV/AIDS. In this chapter, general community beliefs about HIV and the social context of participant's lives are presented. Some challenges in this community are also a reflection of what is occurring in other parts of South Africa and perhaps in other countries too. However, the poorly developed state of this community is a legacy of its history, which for many years was rooted in apartheid policies that inhibited any financial, economical, and developmental and health investment being made in the community. The consequence of this past is that this place, and other places that were previously reserved for Black African, are often characterised by widespread poverty, high illiteracy levels, poor health care and educational facilities and poor development in general. However, the communities that reside in these places tend to have a strong sense of community cohesion, an indication of a sense of Ubuntu that is well entrenched among African people. As previously mentioned, Ubuntu is an advocated concept among the African people and it refers to the act of humanness towards others through values such as love, care, respect and peace (Manda, 2007)

The findings are based on field notes written over three months while collecting data from: interviews with members of non-governmental organisations; one hospital social worker; one medical doctor from the hospital; informal discussions with two teachers, notes taken during the community engagement project with parents/carers of young people living with HIV and the NGO's from the community and my ethnographic observations.

In the section below, the demographics of the community are outlined, and this is followed by a review of services available for young people and their families in the community, as well as of the psycho-social support that is provided by the community clinic specifically for young people and adults that are HIV positive. This is further followed by the discussion on key issues that were raised by the community in relation to HIV.

4.2: Geographical and Organisational context of MPilo¹⁰

Situated in the northern part of KwaZulu-Natal, Mpilo is a small rural community that is part of Hlanganani Municipality. As mentioned in chapter three, it is mostly populated by Zulu-speaking people who are governed by the traditional system of Izinkosi¹¹ and a more recent municipality system established in 1994, after the election of democratic government. This community is characterised by a strong sense of kinship and acknowledgement of extended relatives. Therefore people that are considered to be family members include the immediate as well as an extended family; relations are deeply respected and acknowledged. This is a way of life for most Zulu people (Mturi et al., 2006). Such relationships and social networks can be a source of support for families during a time of distress.

However, such wide net of relations and close sense of kinship can be threatening to the community members in this era of HIV because with such a wide network, privacy and confidentiality after HIV diagnosis cannot be guaranteed. Moreover, disclosing HIV diagnosis to some people within the household may be considered as unsafe since privacy may be compromised, a situation that others can view as threatening to self. Preston –Whyte (2003) argues that such disabling fear and silence isolates individuals, thereby keeping them from receiving verbal utterances of love and acceptance from families and significant others at a time of fear and uncertainty.

Conversely, while HIV secrecy was preferred among respondents, my engagement with the community members and NGOs revealed that HIV diagnosis was beginning to be perceived with a degree of acceptance since people with HIV are now seen to be living healthily. Moreover, there was a growing acknowledgement of HIV as ‘simply’ one of the chronic illnesses, particularly if those infected were also taking care of themselves and they could function and maintain a state of normality when compared to other people. This perhaps suggests that a gradual shift was occurring in how living with HIV was perceived by the community. Whilst this finding about community perceptions can be viewed as positive, when referring to the personal impact of HIV, differences were observed. HIV was still associated with negative perceptions of pain, sickness, and rejection, which implied that although there was change in the community, perhaps internal HIV stigma was still persistent.

¹⁰ Pseudo name has been added to preserve anonymity of the community.

¹¹ Inkosi refers to a tribal chief that governs the tribal land and the people residing in that land.

The relationship between HIV and difficulties encountered by young people was well-recognised and challenges of children and young people affected and infected by HIV were described by teachers and health care workers. The community has child protection services that are provided by three main organisations: the Department of Social Development, hospital social workers and local non-governmental organisations (NGOs). These agencies provide distinct services to vulnerable and needy families. For example, hospital social workers focus on clientele that are in hospitals and clinics operated by the hospital, but their role does not involve statutory¹² work such as placing children in foster care homes and referring them for adoption. Social workers employed by the Department of Social Development have a wider scope, which includes statutory work and community development. Non-governmental organisations sometimes employ social workers and community workers to manage programmes for orphans and vulnerable children in the communities; however, most NGOs in this community did not have social workers as employees.

This division of labour and work demarcation prevented the replication of services, though interagency cooperation and partnership were a challenge. As a result of these interagency challenges, some of the cases were perceived by the community members as not attended to in a timely manner. Social workers employed by Department of Social development had offices that were situated less than 500 metres away from the clinic and Hospital Social Workers were located about 15 kilometres away but social workers that were nearest were not involved in any direct work with the clinic. Moreover, hospital social workers could only come once a week to the clinic. This compromised the provision of social work intervention to families that required it.

“If there is a patient that needs to be seen in a hospital, the clinic has hospital social workers that are employed for that; we cannot see those clients unless they decide for themselves to come here. We also have many places to cover...” (Social worker, Department of Social Development)

Findings also suggest that there were poor sharing and consultative processes between NGOs, hospital social workers and the Department of Social Development. As a result of this, working relationships were strained. Although some of the NGOs had the capacity to add

¹² This is part of social work practice where social workers provide legal intervention such as removal of children, adoption, arranging foster care and other interventions that have legal implications. According to the Children’s Act no.38 of 2005, statutory work can only be performed by a designated social worker employed by the state or child protection services organisation.

value to psycho-social support for young people living with HIV, their capacity seemed to be underutilised.

“We do not have a problem with working in the clinic and assisting children and their families, but the hospital social workers need to engage us so that we do not appear as if we are doing their job. We are able to see children and families affected by HIV if the child is an orphan because those are the children that we are assisting.” (Informant, NGO)

Most families in this community relied on traditional forms of support, which consisted of extended family members and family relations, to manage family issues such as marital problems, relationship challenges and behavioural issues within the family. Moreover, the community had traditional leadership representatives in the community that managed complicated family conflicts. The perception of social work services in this community was associated with the provision of financial support and tangible resources to families, as well as the provision of advice when all other resources have been sought and there has been no improvement. This could perhaps be one of the reasons for the overemphasis among social workers on providing task-related services rather than therapeutic services to children and families. The value and the perceived impact of therapeutic counselling may not be fully appreciated in situations where the priority is still on meeting basic needs such as food and shelter.

4.2.1: Provision of HIV and Psycho-social Support in the clinic

This clinic caters for the healthcare needs of thirteen different surrounding communities. At the time of the study, an estimated two thousand (2,000) people per month were being attended to at the clinic, by three qualified nursing sisters and a doctor that visited three times a week to attend outpatients in a general primary healthcare clinic. HIV testing and a mother-to-child HIV prevention programme (PMTCT) were integrated into the HIV care. At the time of the study, the clinic was complemented by three HIV counsellors, whose responsibility was partly to offer support to over three thousand (3,000) adults and just over a hundred (100) young people on antiretroviral treatment, as well as to conduct the administrative duties of the clinic. My observations during the three months I spent in the community and the clinic indicated that a shortage of skills and capacity to conduct comprehensive and integrated support for young people living with HIV and their families was a gap in HIV care and support. The HIV clinic did not have a structure for psycho-social support. Young people and families with indicators for social work services were referred to the social worker who

came to the clinic once a week, and if that appointment was missed, the chances were that those young people and families would be lost to follow-up.

This was an on-going challenge for social workers, who felt they could not cope with the responsibilities; they also had limited access to resources, such as a car to conduct home visits to families that were on the outskirts of the community. The social worker allocated to the clinic indicated these challenges:

“I come to the clinic once a week, because I have other clinics to attend. Nurses make a referral and when I come, I have a list of families and children to see. I cannot see everybody; in that time I also need to conduct home visits. It is impossible to do all this work with the few hours that I have in the clinic.”(Social Worker)

4.3: Attitudes and Responses to HIV in the Community

4.3.1: HIV infection as unavoidable

Most community members that participated during the community engagement were personally affected by HIV in various ways; either through their extended family networks or among their peers and known people in the community. Most admitted that HIV was one of the biggest threats in their lives. Therefore most people in the community had had close encounters or experience with people that had HIV. However, attached to that knowledge was an attitude of being fatalistic about being infected.

“I know that HIV is there...I know many people that have died because of HIV... Almost everybody has AIDS...it means all of us will eventually die as a result of AIDS. How can you run away from this?” (27-year-old community member and part-time teacher)

One of the interesting findings was that some people believed that the unavoidability of HIV infection was partly linked to the efficacy of ART. There was a perception that since ART was making it possible for people to live healthily with HIV, other people who lived with HIV were hiding their HIV status and purposefully infecting their partners. The view held was that it is getting easier to conceal one's HIV status. Since ART is working so well, people can manage to hide their HIV status and also hide that they are on treatment.

Consequently, being infected with HIV was seen as a likely and perhaps an unavoidable event, since so many people were considered to be infected and it was getting easier to conceal one's HIV status and perhaps pass as 'normal'. This raised issues of labelling of

people who are HIV positive; they were regarded as risk carriers who had a responsibility to protect those who were not infected by HIV.

Other community members articulated the view that the nature of HIV-related illness was problematic, since after HIV infection, symptoms are often not visible and for many years the infected person may not present with any HIV-related infection. This long incubation period was regarded as problematic because a person who is not tested can infect others.

“The problem here is that you can think that you are still well and healthy when you are already dead. You will only find out later when you are sick after many years. All this time you could be infecting others.” (47-year-old community member, teacher)

This section outlines how community views are being re-shaped in the context of HIV treatment. In this community, the importance of being tested timeously for HIV was generally perceived as critical. Conversely, fear of living with HIV, the perception of HIV as a ‘deadly’ virus and perceptions of HIV as a threat to sense of self, were persistent. This may partially explain the low rates of HIV testing in this community, as one of the clinic doctors observed. Knowing about the availability and success of ART did not necessarily lead to a generalised willingness to be tested. However, there was solid evidence of community perceptions being re-shaped in this new era of treatment.

4.3.2: The normality and abnormality of HIV

Community attitudes to HIV are a powerful indicator of the degree of acceptance given to people that live with HIV. There has always been an interest in the literature on how HIV is perceived in the community, and in South Africa particularly, a number of studies have indicated that HIV attitudes at a community and individual level have an impact on health-seeking behaviour (Abdool-Karim, 2011). Although a degree of acceptance for people living with HIV is noted, this does not always encourage HIV testing (Phakathi et al., 2011; Abdool-Karim, 2011). The HIV survey conducted in South Africa in 2009 revealed that 74% of those most at risk of acquiring HIV were unaware of their HIV status (Shisana et al., 2009). In Shisana’s study, it was found that there was a very high degree of acceptance of people that lived with HIV within the community. There was a general consensus that HIV was similar to other chronic illness, and that when HIV positive persons took care of their health, they could live a healthy life. Whilst the community generally had positive attitudes

towards HIV, people that were seen to be dying of AIDS without being tested when treatment was available were blamed for their inaction and for causing unnecessary deaths.

Healthcare workers also indicated that sometimes patients would decline HIV tests in clinics, and later they would die as a result of an HIV-related illness. Community responses suggested that, in theory, HIV was perceived as a normal illness, as this community member indicated: *“This thing is now similar to all the disease, because there is treatment and there is no need to die from it...but it is hard to go for testing.”* However, the degree of acceptability and understanding of HIV as a threat did not correlate with acceptance of individual choices and behaviour in terms of being tested on time and knowing about one’s HIV status. There was a noticeable fear of knowing about one’s HIV status among most community members interviewed during this research. One of the members indicated that it was easier when HIV was not directly affecting the person, but for people that lived with the disease, it was not easy: *“Lento idinga isibindi,”* which loosely translated means “This thing requires you to be brave”. The major concern was not about the pain and suffering as a result of HIV-related illness, but about the mental state after knowing that one was infected with HIV. The challenge was to live with this knowledge *“kunalento elokhu ikudla kancane kancane,”* which can be loosely translated to mean that one has to live with the knowledge that one has a disease that is gradually taking life away. This was seen as a major problem and one of the community members (a teacher) jokingly asked whether one could be tested and not told, but be given treatment to take every day with no formalities being asked. Perhaps that was the rationale among some couples, who assumed that since one partner was HIV positive, this was indicative of the other spouse’s HIV status, and some would go as far as sharing ART without testing, according to one ARV clinic nurse.

The community engagement indicated that it was gradually getting easier in this community to accept people with HIV, and most people knew that they could live with HIV because treatment was available. However, this knowledge was not always enough to persuade people to volunteer for HIV testing and to know their HIV status timeously. These findings concur with those obtained in other studies, where HIV knowledge on its own was not found to have a major impact on risk-reduction behaviour (Abdool-Karim, 2011). It is important to understand both the individual and community factors that hampered voluntary HIV testing and access to appropriate healthcare within this community.

4.4: The Silence and Secrecy of HIV

Promoting HIV testing among the community was a challenge for healthcare workers. Moreover, silence and secrecy were among the biggest challenges for healthcare workers and non-governmental organisations that were trying to provide support in this community. Encouraging people to be tested was a major issue, as this healthcare worker indicated:

“Other people are so much in denial, in such a way that even when they have all the symptoms associated with HIV, they still maintain that they are HIV negative, and I ask them where are the results and they would say they have lost the results. I tell them that they have to repeat again; they would refuse until I tell them that I will not treat them until they had an HIV test. Really, how can we continue to treat when it is obvious that the illness is HIV-related yet they refuse to test, especially the young pregnant mothers?” (Nurse, clinic)

The secrecy surrounding HIV diagnosis had major implications for the success of the prevention of mother-to-child transmission programme (PMTCT) in the clinic. One of the healthcare workers indicated that previously, pregnant mothers would be advised to have an HIV test, but this testing was optional. As a result, many children in the community were born with HIV infection which could have been prevented had they been tested and included in the PMTCT programme. However, healthcare workers were now insisting that pregnant mothers be tested for HIV and referred to the PMTCT programme to reduce the risk of infecting the unborn child with HIV. Denial of being at risk, and fear of being stigmatised once tested, were clearly two challenges faced by this community. Generally, people tended to refrain from using the correct term to refer to HIV or AIDS. The use of various HIV euphemisms such as *“amagama amathathu”*, loosely translated as “three words”, and expressions such *“usibani bani naye uyagula”*, meaning that “so and so is now sick” or “she/he is taking tablets”, was common and the meaning of such words seemed to be mutually understood by the community members to refer to HIV.

The perception of young people with HIV as ‘victims’, as opposed to adults who acquire HIV behaviourally and were therefore largely considered as responsible for their behaviour resonated in the narratives of most community members. There was more sympathy and more positive sentiment for young people with HIV, and there was a general perception that, since they were infected by their parents, their journey of living with HIV would be easier as they did not carry the blame for being infected, as one of the members indicated: *“...shame...it is*

difficult for young people because they do not know anything about this, but at least they did not go out to look for it, there is nothing that they could have done.”

HIV-related silence as secrecy was also a barrier for volunteers from NGOs trying to reach out to families that needed support. One of the volunteers from an NGO indicated that whilst conducting routine home visits, they would often find young people whose parents were deceased and perhaps through that engagement, they would get to know about those young people infected by HIV. Other than such accidental encounters, it was difficult to know which families were severely affected by HIV. This was the only window of opportunity available for them to know that families were affected by HIV, and to provide support. Again, there was a major concern about perceived stigma and people's fear of being subjected to gossip, as one of the volunteers indicated: “...because we live in the area and they [people with HIV] are scared to be known... You know the issue...[referring to silence]...How we can help when we do not know who needs help? They have to let us know” (Informant from NGO).

One of the informants, noting the state of secrecy in this community, remarked that there were many issues that were being kept as secret within families and HIV was just one of them. Issues of sexual abuse, rape and physical abuse were also mentioned. Since the informant was a teacher, he shared his experiences of interaction with students and explained how he used drama to connect with students so that they would trust him and not regard him as an adult that is disconnected from them. Through this process, many young people had come to trust him and they would often confide in him about many difficult experiences they had. None of them went to professionals such as social workers for help, and they did not want to be referred. This was especially true of teenagers.

“...one of my students was often sleepy and tired in the classroom and she could not tell me the reason for this behaviour. I kept on asking her and building a relationship with her until one day she disclosed that she was living with a man who was abusive to her and who did not want her to go to school; she eventually dropped away from school at 17 years. She was a child during the day and the wife at night. This happens all the time.”
(Informant, teacher)

4.4.1 HIV silence and young people with HIV

Most nurses, counsellors and social workers cited HIV non-disclosure as a major challenge among young people and adults that live with HIV in the community. People were concerned

about talking to their families about their own diagnosis, as well as about telling young people of their own HIV infection. Furthermore, parental HIV disclosure to young people was almost non-existent and it seemed as if most young people were not told about the HIV status of their parents. The biggest challenge that was reported by healthcare workers in relation to non-disclosure was that it was difficult to communicate with young people when they came for their clinic visits. Moreover, the clinic doctor reported major challenges in relation to adherence to ART among young people. Health care workers considered most young people to be old enough to be told about their health and they were ready to be told yet parents wanted to delay the process. Difficulties associated with taking medication without adequate explanation, prompted young people to ask questions about the reason for taking tablets and indicated to health care workers that young people wanted to be informed. The medical doctor in the clinic suggested that young people were severely impacted when not told about their HIV diagnosis: *"...some of the young people are just angry and they hate taking tablets because they have not been told what is happening, yet they are already suspecting and nobody is talking."*

Most parents believed that hiding unpleasant news from the young person was a protective mechanism, as it prevented unnecessary distress to the young person. Similarly to distressing information such as death and parental HIV diagnosis, secrecy was therefore viewed through the lens of protection. Allowing young people to be 'free' of distress was regarded as protecting young people from the burden of knowing painful information. Therefore, keeping the HIV diagnosis hidden from an infected young person can perhaps be seen as a continuation of an existing pattern of the child being viewed as unable to deal with, or manage distressing information. Most people in the community associated going for HIV testing with bravery, and saw it as a decision that indicated that one was strong enough to deal with the implications of living with HIV. Given this perception, young people were seen as immature, with limited capability and therefore not brave enough to manage the distress associated with HIV testing and the implications of being HIV positive.

4.5: Conclusion

These community attitudes and beliefs indicated that there was an increased awareness of HIV and treatment options available for people with HIV. However, internal stigma, which Holzemer et al (2007,p 547) define as "thoughts and behaviours stemming from the person's own negative perception about themselves based on their HIV status" was a powerful factor

since it paralysed the efforts of people to volunteer for HIV testing and be treated, despite knowing about the benefits of antiretroviral treatment. Although there was a high degree of acceptance of other people who were HIV positive, fear of living with HIV at the personal level was still real. One of the critical issues that this community engagement process raised was that there was an expectation that people who knew they were HIV positive would take more responsibility towards protecting others, and there was a general sense of admiration for people that were living with HIV who demonstrated resilience and survival in spite of their diagnosis. In that sense, keeping HIV secret and maintaining silence about it was not necessarily viewed in a negative light; however, it was viewed as a problem when it prevented health-seeking behaviour and when other people were being put at risk as a result of secrecy. The next chapter outlines the experiences of carers/parents of young people that live with HIV, the construction of family life and the impact of these issues for the young person living with HIV.

Chapter Five: Families and Caregiving in the Era of HIV/AIDS

5.1 Introduction

This chapter outlines the findings obtained from the in-depth interviews conducted with carers of young people living with HIV/AIDS in KwaZulu-Natal. Young people that were in the care of these carers all received antiretroviral treatment from the clinic situated in Mpilo, the rural area of KwaZulu-Natal. The chapter begins with a summary of the participants' demographic information, the young people for whom they care and the type of relationship the carer had with them. The decision to include carers was made during the data collection, after the analysis of young people's initial interviews which demonstrated that young people's lives were intertwined with their families; therefore using an individualistic approach which disregards the context where young people grow up may not be a useful approach for studying the lives of young people living with HIV. In essence, a great deal of the understanding about young people's experiences was obtained by investigating the families they came from and the specific caregiving practices in this community. It was on the basis of furthering this understanding that carers were theoretically sampled. Their interviews were intended to answer the following questions: 1) What are the existing caregiving practices for young people that live with HIV and the shifts of these practices in the era of HIV? 2) How is disclosure managed and understood by carers? 3) How do carers perceive and understand the needs of young people that live with HIV?

These questions emanated from the data collected from young people living with HIV, which formed the initial stage of this study. These interviews were therefore intended to explicate some of the existing themes, in line with the grounded theory method used. The final section contains a summary of the chapter.

5.2: Caregivers' Interviews

Several themes emerged from the interviews and the interpretation of these reflected the context of the participants' lives, such as the nature of normal childhood within their environment, child-carer relationships and expectations of the carer. Figure 5.1 is an outline of the themes and the meanings that emerged from carer's interviews.

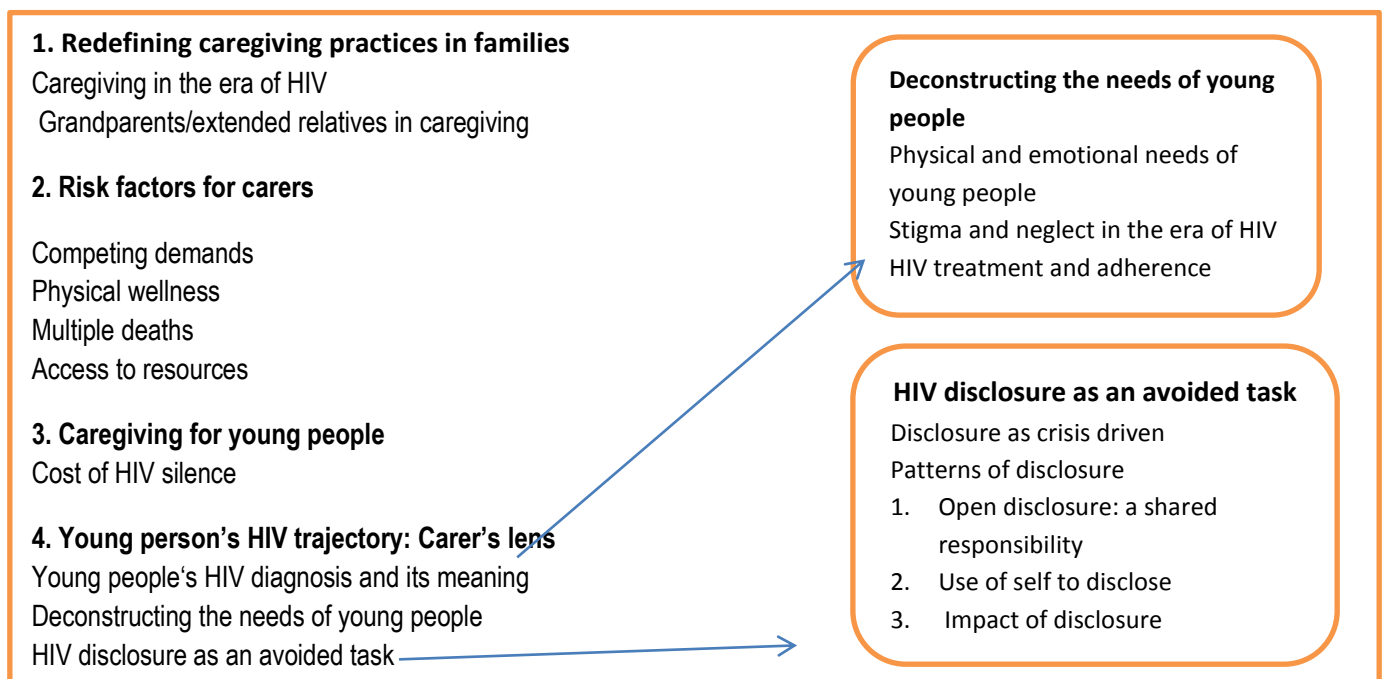


Figure 5.1 Carer's themes and subthemes

5.3: Re-defining Caregiving Practices in Families

Caring for young people remains a gendered role within the Zulu culture and it is a role that is primarily assumed by women including grandmothers. This is partly attributable to the high rate of households which are headed by women, often because of non-marriage or as a result of men migrating from rural areas to urban areas for employment. However, Manda (2007) argues that within the African context, women have always played a critical role in caregiving; furthermore, it is a long held view that women are indispensable in nurturing and caring for their families as well as their communities. Perhaps that could explain why most carers took caregiving responsibilities with little hesitation despite the challenges they posed.

As mentioned earlier, carers in this study had different types of relationships with young people, ranging from aunts and stepmothers to grandmothers of maternal or paternal relatives, and very few were biological parents. This indicates the active role that women have in caring responsibilities.

The role of carers for young people whose parents were deceased was largely exercised within the family unit, negotiated and supported by multiple members of the family who sometimes were neighbours. For example, in this study, Mary (a carer) was responsible for medical care for Tony, her 13-year-old nephew. However, Mary was not sharing the same household as Tony; he was staying with a maternal aunt not far from Mary household. Most of Tony's time was spent with Mary family, since that family was larger and had many children with whom Tony played and who attended the same school. Moreover, Tony's aunt

was often home very late in the afternoon. Tony's legal guardianship was with neither of these family members; his uncle was his legal and customary guardian.

The multiple relationships and adults involved in young people's lives was common practice, regardless of the orphan or HIV status. Therefore the role of primary carer varied based on the family structure and the proximity and availability of family members, who often played various roles in providing support and a sense of belonging for the young people. However, the impact of the migrant labour system was evident, as in some families most of the productive family members had migrated to work in urban areas; in other cases the family had few members because many had died.

Caregiving was therefore an activity in which many members of the family participated and supported each other. Conversely, other studies have indicated that older caregivers experience secondary stigma from extended family members as a result of caring for their HIV positive children or family members and there is evidence of being isolated from family members and experiencing verbal stigma in the form of being gossiped about (Ogunmefun et al., 2011). However, in this study, this was not reported by participants, instead families were more likely to provide support when informed. This study indicated that to better understand the functioning and adjustment of young people within this context, analysis of caregiving practice should extend beyond the 'primary caregiver' to include the range of people and division of labour that characterised caregiving practice in this context. As indicated earlier, although most participants in this study identified themselves as carers, their caring responsibilities were often shared with other members of the family and wider social networks. Sometimes the carer was not living in the same household as the young person, but was active and responsible for specific aspects of the young person's care. This participant indicated such sharing of responsibilities:

"J stays with his father, grandmother and his uncles... I help him with his clinic visits and medication... I take him to the clinic and help him understand how to take care of his medication...these are the things that his father does not help him with. His grandmother and father remind him about his medication every day." (Ethel)

This young person was staying with his family yet his care was divided between his father, his father's girlfriend and his grandmother, and each had an informally negotiated role in his care. However, there were times where these roles would be blurred, and more responsibility would be bestowed on one person as a result of changes within the family structure and its

operation, such as death, migration and the general functioning and health of those involved in caregiving. This study therefore indicated that caregiving practice for young people was a shared activity and changing with multiple people involved. This has critical implications for social work practice, which will be discussed in Chapter Eight of this thesis.

5.3.1: Caregiving in the Era of HIV

This section examines specific caregiving practices in the era of HIV. Although the focus of this study was not on orphan care, a significant number of young people that participated in this study had lost one or both parents. Orphan-hood is a growing phenomenon in South Africa and HIV is at the core of parental deaths. The care of young people that have lost parents has been receiving attention in the literature and several studies in Africa have examined the burden of caring for those who are orphaned through HIV/AIDS (Kiggundu & Oldewage-Theron, 2009; Foster, 2002; Onuoha et al., 2009; Abebe & Aase, 2007; Mathambo & Gibbs, 2009). Some of these studies were conducted in KwaZulu-Natal where this study was undertaken. Most discussions of orphan care in KwaZulu-Natal depict the family system as either collapsing under the strain of the epidemic (Mturi et al., 2005), or as capable of surviving the burden of the epidemic through extended families, kinships and other social networks such as neighbours (Chirwa, 2000). This perhaps is a polarised view of the capability of families to cope with the AIDS burden.

This study demonstrated that to share caring responsibilities was not necessarily a new phenomenon for many of the carers. After parental death, most young people are absorbed by family members and relatives, and the traditional system of determining the appropriate guardian was often used to decide who could take on this role among the surviving members. When young people were expected to change households, they were at least familiar with the carer because of close family ties. Therefore, young people had some familiarity with the carer who would be looking after them after their parent's death. Caring for non-biological young people was a familiar pattern for most carers, since the proportion of young people who co-reside with their parents, regardless of their orphan status, is much lower in South Africa than in many other places (Hosegood, 2009; Desmond, 2009). This pattern has a historical origin, in that most families became fragmented as a result of the massive migration of men who, in the 1970s and 1980s, went away to work in big cities, leaving their families behind (Hosegood, 2009; Norman, 2011). These findings indicated that orphaned young people with HIV who were taking ART were at least residing with extended families with which they had a close relationship. The findings did not suggest that the families were

unable to absorb young people or that carers were collapsing due to caring burdens, as some studies have indicated (Mturi et al., 2005; Kikkundu & Aldewage-Theron, 2009).

The discussion with participants further indicated that young people, regardless of their orphan status, were affected by widespread poverty which resulted in challenges such as lack of nutritious food and short supply of school necessities. Young people from families where both parents were unemployed were also experiencing deprivation. However, the economic hardships and inadequate financial resources did not diminish the capacity of families and carers to provide non-material resources of nurturing and love for young people. Whilst these forms of care were critical for the welfare of young people, families did have to adjust to the change of having an added family member, and during that time young people did not always receive adequate care or support that met their health, emotional and financial needs. The lines of responsibility for the young person's maintenance would be disturbed while the family was still negotiating and adjusting itself to the change. The carer below talked about the young person she was partially caring for, who was placed with paternal relatives because the maternal family was too poor to provide for him, and the adjustments that had to be made:

"...This child came here sick already; no one was bothered to take the child to the clinic, and even his father was quiet. I had to take him because I could see that this child was going to die... His father [mother deceased] has never been to the clinic; even his grandmother does not go to the clinic. I am the only one that takes him there, and they do not even know what it is like...he has learnt to attend the clinic on his own." (Ethel)

After parental death, some young people experienced an increase in mobility and instability, as this carer indicated:

"...his mother died...he stayed with his granny...his granny died...he was taken by his uncle; he was ill-treated there, so he was on the street until he was taken by his granny's sister...who he now stays with." (Elaine)

Young people who changed households were moved to familiar environments with relatives that had a relationship with parents and young people prior to death. These results confirm the findings of Ford & Hosegood (2005), that parental death was associated with increased levels of mobility of young people in KwaZulu-Natal.

None of the carers reported having a plan or provision that was left by the biological parent on behalf of the child prior to parental death; often a plan had to be made by surviving

members of the family. Literature indicates that very few parents living with HIV make plans or provision for their children's future (Drimie & Casale, 2009, p.31). This leaves the remaining family to assume both the financial and physical care of the child.

Assuming care was sometimes expected, especially for young people with strong maternal or paternal ties with the family, in line with the traditional system of guardianship; for example, if a family man dies, his family's affairs would be managed by his biological brother as the man of the house. If both the man and wife die, with no surviving brothers, sisters of the man often took over. However, in most negotiations within the families, any respectable surviving male member in the family line will be involved, as well as grandparents on the paternal side if still alive. In the case below, the carer's son had died without leaving any surviving brothers and the care of his children was taken over by the grandmother and the man's sisters.

"My son died a few months after the death of his wife; at that time, we did not know about these diseases...we thought these are the sicknesses of the big cities. They were not sick for long; by the time we thought they were getting better, they died... I was then left with these children." (Gogo Queen)

For some carers, assuming care was 'crisis driven', meaning that the responsibilities were bestowed on them by other members of the family on the basis of capability, not necessarily because the carer had close family ties with the young person. The young person described below was rejected by his paternal grandfather and his family, despite the grandfather being the expected guardian since the child's uncle was also deceased. Instead the young person was taken by this carer, who was wife to the brother of the child's father:

"This child was staying with his father and his girlfriend in big cities. His father died, the child was left with his partner that we assumed was the mother of the child; she told us that this child was not hers...she abused the child and ill-treated him until her sister, witnessing this, looked for us and brought the child to me...the child's grandfather did not want this child..." (Mam Elizabeth)

The decision to provide care was negotiated by families and kinships and blood ties were important criteria for placing young people; however, families with fewer members would often also use resources in their communities, such as neighbours and extended family members. This study suggests that families used traditional forms of negotiating and providing care for young people who were orphans and living with HIV. One of the protective factors was the close proximity of family members and extended relatives, as well

as large families with enough capacity to take care of children. It was not uncommon to have three family generations sharing the same household; for example, Ruth, a biological carer, was living with her mother, her daughter and her brother, who was married and had children. This type of arrangement was effective for building capacity to meet the ever-increasing needs of families and young people. Below, the role of the grandparents is discussed, to indicate the pivotal role they play in caregiving and supporting families.

5.3.2: Grandparents and caregiving roles

Death in the family signified a loss that was experienced in various ways such as the permanent physical absence of the individual, and the conducting of rituals associated with loss and mourning. However it also had a deeply personal meaning for individuals, which was largely propelled by the kind of relationship that existed between the deceased and the person who, as a result of the death, took on the role of carer. Moreover, within the family loss shaped the structure and its growth, family capabilities, resilience and human resources. Therefore, death in addition to its literal meaning can be conceptualised as having social, psychological, economic and health-related effects on the family. The concept of loss of potential and the denied possibility for on-going family life also surfaced. The loss of families that *could have been*, was evidenced as some of the carers reported losing their fiancés before their families could begin. Losses such as those of a partner, son, daughter-in-law, brother, cousin, sister or a relative indicated the different types of relationships that existed between carers and the parents of the cared for young people.

This study showed that families were surviving the strain of caregiving despite facing both risks and vulnerabilities. The suggestion that families are either coping or disintegrating may miss important variations in families where resources to provide some aspects of the young person's care are available, such as human resources, love and a sense of belonging and familiarity. However, it is perhaps the financial means which are lacking to meet the other needs of the young person. Families may be perceived as adjusting well to the crisis, but when faced with additional needs, further crisis and attendant vulnerability may resurface. Therefore, the ability to access resources, the state of family dynamics and the nature of the crisis may determine the strength of the family to survive a crisis. In line with the findings of Abebe & Aase (2007), this study suggests that families do not fit perfectly into a polarised view, where families are either seen to be in crisis or they are seen as having the ability to restructure and adjust well when faced with a crisis if the required support and resources are available.

The role of grandparents in the era of HIV has become even more pivotal. This study concurs with Beegle et al. (2010), that grandparents are increasingly taking more responsibility, but that they consider this role as *their* responsibility rather than a forced responsibility. Their roles need to be understood within the relationships they have with their family members as well as inter-family relationships which are characterised by reciprocity. Grandparents kept most households together and functioning. In this study, they were often left behind with children whilst the rest of the members of the family within productive age migrated to urban areas in search of work. For example, Gogo Queen, despite having four children, was left as the only adult in the household to care for two of her grandchildren whose parents were deceased, because the rest of the family members were living in urban areas because of work. They would often visit monthly or come home when the family had a crisis. Although she was concerned about her poor health and had difficulty walking, her other children provided additional support to her and the young people in her care, thereby limiting the impact of the loss of the children's parents.

Grandparents also supported carers and grandchildren simultaneously. For example, Thabang lost her mother at a very young age and her aunt, Ruth, took over responsibility for her; but her grandmother, with whom she shared a household, was actively involved in her care as well as supporting Ruth with issues such as child disclosure and staying with the young person when Ruth was at the market managing her small business of selling floor mats. Since most young people acquire HIV perinatally, their mothers are often HIV infected as well and the grandparent's role of supporting a mother that lives with HIV, in addition to the young person, was critical. Although such openness about HIV and maternal HIV disclosure to the family members was, in this case an exception rather than a norm, it nevertheless indicated the intra-family relationships and the role of grandparents in maintaining the functioning and resilience of the family affected by HIV/AIDS. Therefore, instead of seeing the social rupture of families, the study identified families with strengths and vulnerabilities that were constantly negotiated within their context. Below I highlight the critical risk factors that increased the vulnerability of carers in providing appropriate care for young people.

5.4: Risk Factors for Carers

5.4.1: Competing demands

One of the responsibilities of being a carer was finding the time to fulfil caring duties. Time was an important factor for these participants as it involved taking the young person to collect

medication on scheduled visits, as well as additional caring when the young person was sick. Time for caring for an HIV positive young person was shared with other responsibilities, such as taking care of other children or income-earning activities, e.g. selling or making floor mats. In most families, although there may have been many people to call on, these often resided in different areas and also had their own responsibilities and therefore, day-to-day management of various household tasks for carers of young people living with HIV was difficult at times. This was a potential source of stress for carers.

“I have another son that needs medical attention. He has problem with his eyes and I need to take him regularly to the eye specialist in Durban and sometimes both their appointments are on the same day and I do not have anyone to take... I am forced to cancel the other appointment.” (Elizabeth)

“I also have my own children and there are things that I need to do; I do not have a job so sometimes I go to other places to see if I cannot find a job, so sometimes it is not easy to always be there for him. I have taught him to make sure that he does not miss his clinic appointments.” (Ethel)

“Sometimes they are sick, then I need to take care of that or take them to the clinic and then I had to go to social workers to request a grant to take care of them and nothing was happening; and then sometimes it is their clinic day to take their medication and sometimes it is also my day to collect pension.” (Gogo Queen)

“I am also responsible for caring for my husband who is sick most of the time. I take care of most of the things in this home because my husband does not work anymore, and since he was boarded, he has ill health. He cannot do much. It is difficult sometimes.” (Mrs Ndlovu)

5.4.2: Physical wellness

Some of the carers reported that their own health was making it difficult to function optimally because of various illnesses. Three of the carers were themselves HIV positive and one was a pensioner. One could not help but notice that one of the carers, although she did not talk about her own health, was drained physically. This could be an indication of the hard life and various stressors in her personal life or perhaps ill health.

5.4.3: Multiple deaths

Multiple deaths had a negative impact on the family structure as well as the participants and the young people for whom they cared for. Loss affected the family's functioning and it reduced the financial support and other resources available to strengthen the resilience of the family. One of the challenges was that often, deaths were cumulative, even during the study;

in the year in which data was gathered one of the carers, as well as two close family members that were providing partial care to the young people she was responsible for, passed away. Such deaths had direct implications for families, caregiving practices and the capacity of families to continue providing adequate care to family members.

One of the participants, Ethel, reported that she did not have a father and that her mother had passed away. She had two children and they all lived with her grandmother, who was very old. Her aunt was also living with HIV and she worked as a domestic worker far from home. She too was struggling on her own, and her own children would be at risk if anything were to happen to her. Elizabeth mentioned that she was already preparing her children, in case she was not there in the future to take care of them:

“I teach them independency; they can do housework and clean...the youngest sells at school and he is very responsible with money. Sometimes I ask money from him... Should anything happen to me, they have to go on because their father is deceased. That is why worry when Lungile does not take responsibility. He has to learn; I do not want him to have problems when I am not there.” (Elizabeth)

Unfortunately Elizabeth passed away while still helping her boys to learn to stand on their own.

5.4.4: Access to supportive resources

Among the common challenges of rural areas in South Africa are unemployment, which is high, and low literacy levels. The widespread poverty and financial difficulties in these communities were major sources of stress for most carers. Moreover the absence of adequate support services, such as mental health services, had a direct impact on children with HIV. Elaine, for example, cared for a young person with HIV who had repeated the same grade at school more than four times, yet the carer reported that no intervention was being provided to assess the cause of this young person's poor school performance, and since the community did not have psychological services, this young person's education was hampered. Ruth, another carer, was herself semi-literate, and therefore her skills to help the young person she cared for with his school work were limited.

Poverty was widespread in the community and most carers reported that financial support was a problem and they had learnt to survive within their means; as a result, nutritious food was not always available. Below I explore the carers' specific caregiving practices for young

people that lived with HIV and were taking ART. I begin by discussing the cost of HIV silence in relation to the negative impact it had on young people. This is followed by the carers' perceptions of the trajectory of HIV for these young people, and how carers perceived, identified and managed young people's needs related to HIV and other issues that affected young people in their care.

5.5: Caregiving for young people with HIV

Amongst the range of risks and vulnerabilities families faced, HIV posed the greatest threat. Below I explore the carers' narratives, beginning from when they started to provide care for the young people. The majority of these carers were not biological parents and so had not cared for these young people since birth. This experience was analysed in relation to the impact it had on the young person and on the family's capability to provide adequate health care to young people at the onset of the illness.

5.5.1: The cost of HIV silence

The combination of secrecy, silence and HIV stigma has had devastating consequences for families affected by HIV/AIDS. Nowhere was this clearer than when carers who were caring for orphans narrated their stories of not knowing about the HIV status of either the biological parents or the young people until the onset of illness. Most carers assumed caregiving responsibilities before knowing about the HIV status of young people; consequently, most young people in their care were tested after prolonged illness and some had suffered irreversible clinical conditions. This study concurs with findings obtained from the study conducted by Fatti et al. (2010), which indicated that young people from rural areas tend to be tested when they are at an advanced stage of immunosuppression, and thus present with greater wasting when they start antiretroviral treatment. Some of the young people that were on treatment had severe respiratory problems, and some had poor school performance because they had suffered complications of the illness. Furthermore when they started ART, they experienced complications as a result of starting treatment at an advanced stage of the disease.

Young people's parents may have died without being tested or if they were aware of their status, they may have felt ashamed about informing their families about their diagnosis because of the stigma that is attached to HIV, or they may have been tested at an advanced stage of HIV. It was common in this context for HIV diagnosis to be kept secret and not be revealed up to the point of death. However, the study showed that this silence threatened the

lives of parents and of the young people. Moreover, the stigma attached to HIV often prevented health-seeking behaviour. The relationship between HIV stigma, reluctance to test and failure to seek health assistance in South Africa is well documented (Kalichman & Simbayi, 2004; Visser et al., 2009; Goudge et al., 2009; Demmer, 2011). Being in a rural community and lacking basic literacy skills are factors that are associated with powerful stigmatising ideas (Visser et al., 2009).

The onset of recurrent infections, the duration and severity of these, alerted carers that the young person's illness was serious. HIV drained the family's financial resources as well as becoming an emotional burden. Most carers in this study were not biological parents, as indicated earlier, and they had limited knowledge of the young person's health history. Most carers did not know the cause of death of the young people's parents, and consequently, testing of young people for HIV was not done at an early stage. Early infections were treated as ordinary ailments until major infections surfaced, by which time the seriousness of the illness was indicated

"This child started by having boils...I thought it was just boils, they were going to go away, but they were not getting any better; if one disappears, a new one will come and they became worse and worse... He had boils almost all the time...even sleeping and sitting became a problem. I used Umanyazima¹³ but it was not getting better. I was asking myself what was wrong with this child." (Gogo Queen)

"...she had fits, but they were getting worse and worse. Even when she was on treatment, she was not responding well. Even as a young child, she was sick often, but we thought she was reacting because her mother was dead." (Elaine)

"He started getting sick after the death of her mother... We took him to the doctors and the clinic repeatedly...he would get better for a short period of time, then he will start again; the private doctor told us to test the child at the clinic, then we were told what was happening." (Gogo Queen, referring to Tsepo)

"...this child started staying with maternal granny when he was eight months; when he started being sick, his granny took him to traditional healers, private doctors and clinic, but he would get better for a while and then he will be sick again..." (Ruth)

¹³ Traditional medication for general ailments

HIV testing for children remains a challenge globally as well as in South Africa (UNAIDS, 2009). Children account for 6% of all HIV infected individuals, 12% of new infections and 13% of HIV deaths and this high proportion of deaths among children is indicative of the poor access to HIV testing among children globally (UNAIDS, 2009). In South Africa, timely access to HIV testing of children continues to be a challenge and the situation in rural areas is even more of a problem (Cooke et al., 2009; Fatti et al., 2010; Demmer, 2011).

“This thing started when my partner came back from Durban looking sick; I became worried, but he assured me that it was nothing... When he came back the second time, he was too sick, I had to care for him. He told me about his status and the death of his two previous girlfriends due to AIDS two weeks before he die; I knew then that I was at risk.” (Mary)

In a few cases where the deceased had disclosed an HIV status early, the difference in management was evident, as was indicated by this biological parent who was tested after her partner, who had been working as a migrant labour, came home with AIDS and disclosed his status to her and his family:

“I am not angry with him because at least he told me before his death what the problem was; I was able to get tested and test my child before we could be sick... I have never been sick and my child has never been sick because I tested early and I also tested my child, even though her granny was against it... She [daughter] also started treatment before being sick.” (Mary)

5.6: Young person’s HIV Trajectory through the Carer’s Lens

The young person’s illness trajectory and subsequent HIV testing was often the indicator of the young person’s HIV status. It was a journey that the carer and the young person underwent together; however, the young person was not informed immediately about the cause of the illness. Rarely was information and feedback given to the young person directly, and as a result, the young person’s knowledge about his/her illness was limited to the symptoms or awareness of a disease that did not carry a stigma, such as tuberculosis or diarrhoea.

Disclosing to a young person was a challenge for most carers and this was reported as a major concern by workers at the clinic where young people were obtaining their medication. Participants that had disclosed to their children did so after being encouraged to do so by healthcare workers, because the young people were getting older and it was getting difficult to hide information from them. These findings concur with those obtained from other studies

conducted in South Africa, which indicated that disclosure to young people was very low and occurred rarely (Moodley et al., 2006; Kouyomdjian et al., 2005). However, as young people grew older, carers knew that they had to be told, but were concerned about how to disclose and the young people's reaction to it.

The early days after diagnosis were challenging for most carers; they had to deal with the young person's diagnosis and their illness, and they also had to educate themselves about HIV and antiretroviral treatment. In the following sections of this chapter, carers' experiences of caring for these young people after the onset of the illness are discussed, as well as the perceived impact on carers and young people. Three themes are associated with the young people's HIV trajectory: 1) Young people's HIV diagnosis and its meaning; 2) deconstructing the needs of young people with HIV, and 3) HIV disclosure as an avoided task.

5.6.1 Children's HIV Diagnosis and its Meaning

HIV testing in South Africa is conducted within healthcare settings. Two types of HIV tests are conducted for children: the first one is a highly sensitive and specific polymerase chain reaction test (PCR), which is conducted within three to four weeks after the child is born. The second type is rapid testing for children older than 18 months. These tests have been part of HIV standard care in South Africa since 2005 (South African Department of Health, 2010). All participants reported that their children were tested at a much older age, and therefore rapid HIV testing was conducted by an HIV counsellor. Prior to testing, participants were asked questions related to the health history of the child, as well as that of the biological parents. Young people were mostly excluded from discussions, perhaps to avoid accidental disclosure.

Carers described their feelings while waiting for the blood test results as "*nervous*", "*I was praying in my heart*" and "*anxious*". Being told about the child's diagnosis brought extreme shock to most participants. Clearly the young person's diagnosis indicated HIV's permeation into the family and for some of the participants, this was a significant psychological burden.

5.6.2: Carers' responses to HIV diagnosis

A young person's illness triggered most carers to seek healthcare and eventually to test the young person for HIV. Often this marked the young person's entry into HIV care and the carer's acknowledgement that the family was affected by HIV. One of the pivotal issues for young people who live with HIV is the carer's response and what the situation subsequently means for them after learning about the young person's HIV diagnosis. Given that the young

people were cared for by different categories of extended family members, biological parents, foster parents or carers from the children's home, HIV diagnosis had different meanings and implications for each. For example, the biological parents' response to a young person's HIV diagnosis was significantly traumatic, as it brought a sense of guilt and responsibility. One of the parents whose child was diagnosed after being sick indicated that, although she knew about her own diagnosis, she had hoped that her child was not infected, and therefore receiving the positive results was particularly distressing.

"When I was told about my daughter's illness, I was already aware of my own status, but we never tested her because she was fine. I only started to worry when she was getting sicker and sicker, and sometimes she will be brought from school, unable to cope. I got worried. We had to test her because we already knew about us. What can we do? Hey...ngaphelelwa amandla¹⁴, I could not believe that my child had this disease; it was OK when it was me...but her?" (With a very downcast look, Mrs Ndlovu)

This suggests that perhaps it is pivotal to explore the intersection of maternal HIV infection, caring for a young person with HIV by these mothers and the implications for the caregiving practices. The study had few participants who were biological mothers of children with HIV (two), but it was noticeable that these mothers exhibited greater HIV openness and support to their children, and treatment adherence became normalised and part of the family schedule. Although there was no evidence of in-depth verbal communication about the long-term implications of being HIV positive for the young person, or about how the young person was feeling, the young people did have constant affirmation and encouragement from these mothers. Therefore, having a mother who was living with HIV and on ART was a strength rather than a weakness.

Non-biological carers had to deal with their own sense of shock; however, they did not carry the burden of responsibility that biological parents felt. The pain of knowing that their children had to deal with all the complications of living with HIV, as they did, was difficult for biological parents. Carers that were not biological parents also experienced sadness and shock, as these participants indicated:

"I was shocked, my child...I knew that children with this disease die when they are young, but they do not even go to school, but this child was old; he was sickly as a child like most children, I did not suspect this." (Gogo Queen)

¹⁴ Loosely translated as: "I lost my strong will"

“Lungile was 15 when he was tested; he was already a big man. It was my first time to see a child as old as him with this thing. I think he got it from his mother. I have been taking care of him since he was three years; he never got sick, it was the usual flu like all the other children, but nothing that could make me suspect HIV. I was shocked. I had to accept and help him adjust.” (Elizabeth)

Most young people had prolonged illness prior to starting taking ART; they suffered from many infections, such as recurrent chest infections, sores all over the body, chronic diarrhoea and other opportunistic infections. Consequently, carers consulted various healthcare providers including traditional medicine for assistance and this experience was very distressing for them. Therefore, when the HIV test was offered and the child was diagnosed, there was a sense of relief as well as distress. The stress of caring for a sick child, compounded by limited resources, was cumbersome and being assured of effective treatment and later seeing the child’s improvement seemed to increase the carer’s hope for a positive outcome:

“...We went all over the place to try and help this child... I had a young child then and granny was old, she had to be up and down trying to get help for the child. It was hard for her, but I could not help. We were relieved when we were told what was wrong because we did not know, and when he started treatment he got better...” (Elaine)

The study indicated that the immediate response of carers to HIV diagnosis, although it was characterised by shock, sadness and hurt, was that they accepted it, and most were committed to providing the best support available for the young person. The availability of ART played an important role in restoring hope to these carers.

“I knew that treatment was available because I was already using it, so I thought my child will be OK and she will be like any other child. There are many people that live with this thing, and when they take treatment they are able to live and be like any other person.” (Mary)

The study showed that prior to HIV testing and starting treatment, most carers had to deal with the uncertainty posed by living in an environment in which HIV was prevalent, caring for a young person suffering illness and as some of the carers had to spend more time at home and had to give up in income-generating activities, the level of financial hardship increased. However, it is important to note that most carers did not focus much on the emotional pain associated with caring responsibilities. This could be attributed to two reasons. Firstly, for

most carers, caring for the sick had become a normalised experience, since most carers had experienced multiple adversities and difficulties in their lives and many had cared for several family members who had AIDS. Secondly, similar to how grief and bereavement is dealt with in this context, it is possible that the focus tends to be on providing the practical and physical aspects of caring rather than internalising the emotions. However, this study indicated that although mothers who live with HIV carry the burden of guilt and responsibility for their children's infection, having the same illness as their children meant that these parents shared important illness management tasks and experiences with their children, such as taking regular medication, routine clinic visits, and exposure to HIV information; something that often had benefits for the young person. Therefore, being HIV positive and on ART under these circumstances, rather than being perceived through a lens of risk, should perhaps be seen as an important protective resource for young people with HIV. Moreover, the fluidity of caregiving practices within this context, rather than being seen as a risk factor, should be viewed as a protective factor for young people, since these diverse arrangements can strengthen, helping ensure that the family survives its adversities. Below, I explore how young people's needs were identified and managed by carers and their families within this context.

5.7: Deconstructing the Needs of young people with HIV: Carers' Lens

This theme relates to the carers' perceptions and experience of caring for young people with HIV and who are taking ART. Carers narrated how they perceived the young people's needs and the subsequent meaning and response relate to these. All participants were either illiterate or semi-illiterate, and therefore their worldview of young people's needs was often through the lens of what they had been taught at the clinic where they were collecting the children's medication, and through their own experience within the community context. Three subthemes associated with this theme were identified: 1) Young people's physical and emotional needs, 2) Abuse and stigma and 3) Treatment and adherence. These are discussed below.

5.7.1: Physical and emotional needs of young people

The demands of caring for young people physically were described as difficult by most participants particularly, young people who had prolonged illness before starting ART.

“In Lungile's case, HIV showed itself through chronic diarrhoea... It was difficult because everything he ate was coming out, nothing was staying in;

he lost so much weight during that time and on top of that, when he had the chest X-ray, they noticed that he had TB.” (Elizabeth)

“Cebo was very sick; when he was tested he was already skin and bones, he had really bad diarrhoea and TB, I did not think he was going to recover. His face was so small, he looked like a baby, his hair had changed, and you could see that this child was really dying. I moved from my home during that time and I stayed with his father so that I could take care of him...” (Ethel)

Carers’ narratives about young people’s health indicated that prior to starting ART, most young people had experienced prolonged illness, and when they recovered, carers assumed that the young people were emotionally well and had recovered from the stress of being ill. The impression was that the young people were ‘alright’. This phrase of being ‘alright’ was re-iterated by many carers, perhaps suggesting that when young people were perceived to be physically well, with no externalised behavioural change, the young person’s wellness was also considered to be good. This could perhaps be an oversight, where carers were unable to identify the internalised emotional difficulties that young people had. Moreover, the expression of young people’s opinions on their health was not encouraged; on the contrary, most young people that participated in this study indicated issues that were problematic in their lives, yet most of them did not share these with their carers, perhaps for fear of hurting them (young people’s experience and the meaning of distress is further expounded in Chapter Six). This study therefore showed that carers may underestimate the distress that young people experience. However, when carers observed significant changes in behavioural patterns, or when young people’s conduct became inappropriate, that was the time when they began reaching out and seeking assistance, as this participant indicated:

“Lungile has been repeating classes for some time now; he is supposed to be in Grade 11 but he is in Grade 8. This year I do not think he will pass. I think this is caused by problems he had when he was younger. I do not think it is related to being sick because, besides the illness that started last year (2009), he has never been too sick after that...” (Elizabeth)

Lungile, the young person described above had experienced a great deal of distress in his life (his life history is summarised in Chapter Six); however, he did not inform his carer about his previous experiences, given the established patterns of child-adult communication which do not encourage the expression of opinions. Young people may use alternative sources to

express their feelings: in this case the child told his peers about his previous life, although he did not talk to them about his HIV diagnosis.

As indicated earlier, prior to starting ART, most young people had experienced a prolonged illness and some of these illnesses had had irreversible implications for young people, such as chronic respiratory problems and poor cognitive development. Moreover, most families were poor and illiterate themselves, and therefore did not have resources to stimulate young people's cognitive development. The implications of HIV illness and poor environmental factors clearly had negative implications for some of these young people. Carers recognised these difficulties, yet the unavailability of resources in the community meant that these challenges remained unresolved:

"Nhlanhla (13 years) is failing at school; he is in Grade 3 with much younger children. I think even now they are just pushing him to even reach Grade 3... He repeated Grade 1 four times." (Elaine)

Again, sometimes young people's behaviour was assumed to be 'normal', such as Nhlanhla's lack of verbal communication. During the interview with him, his carer remarked that he did not talk much and when asked the reason for that, the carer's response was that *"He is like this"*.

Most carers noted that generally, young people did not to express their feelings openly, therefore most carers relied on their observations of the young person's behaviour. When carers did observe changes in young people's behaviour, they expected young people to talk openly about it and often young people did not. This may have been a continuation of the prevailing intergenerational gap between young people and adults which affects open communication, and thus the young person may mistrust shifting from the generally expected position of the young person, which is one of non-consultation, to a situation where the young person is suddenly expected to voice opinions about sensitive issues.

Young people were dealing with parental loss, HIV infection and complications associated with HIV diagnosis within a prevailing cultural context that expected young people to be obedient and respectful to adults. On the other hand, in the era of HIV, there is a growing shift from the previously disempowered young person, whose opinion and expression are hardly taken into consideration, to the young person that is confident to express his/her feelings, and this is gradually becoming accepted by adults. This gradual shift of the position

of the young person has been observed in other studies. In Norman's study of the conception of childhood in KwaZulu-Natal, adults interpreted young people's inquisitive minds as being disrespectful, and others perceived young people of today as being too opinionated, with little acknowledgement of their place as young people (Norman, 2011). However, that was not indicated in this study; instead, young people were conscious of their 'subordinate' position when compared to adults, and they understood what they could or could not ask; therefore they negotiated their agency astutely.

Conversely, adults expected young people to verbalise their problems, especially when young people were externalising their emotions through behaving inappropriately, or when they became emotionally withdrawn and were not taking instructions well. This study posits that there is a gross underestimation of young people's mental health needs by carers. This lack of recognition of young people's needs and the inability to manage these challenges may be caused by limited skills and knowledge to correctly identify these needs, as well as the unavailability of resources in the community to deal with them when they are identified.

Below, I discuss carers' perceptions of stigma and abuse that may be instigated against young people in their care, and the positioning of the family and intra-family systems of care that intervene in those situations.

5.7.2: Stigma and neglect in the era of HIV/AIDS

One characteristic that is common in HIV diagnosis is stigma. Goffman (1963) uses this term to refer to an attribute that is deeply discrediting. The discrediting attribute differentiates between the 'normals' (people without a stigmatising attribute) and the discredited, those with a spoiled identity. Therefore, those who possess a stigmatising attribute such as HIV may be treated differently compared to the 'normals'. The abuse, maltreatment and abandonment of children living with HIV have been reported in the literature (Abadio-Barrero & Castro, 2006). Consequently, most carers who care for young people living with HIV often decide to prevent the young person from finding out about his/her diagnosis, fearing that the child may disclose to friends who potentially may stigmatise the child (Ostrom et al., 2006).

Most carers were concerned about stigmatising attitudes towards their children, such as being laughed at, or subject to gossip, but none of the carers reported instances of actual stigmatising behaviour directed towards them or the young people for whom they cared.

Whilst most young people were generally protected from stigma and abusive behaviour, there

was a difference between young people who were orphans and those who were not, since young people who were orphans were more likely to have experienced a history of abuse or neglect. Although the extended family system largely absorbed the care of young people with HIV who were orphans, they were more likely to have been subject to family stigma as indicated in Elaine's account of the care of Tony. Tony had previously lived with his uncle where his eating spoon and plates were kept separately and his clothes were washed separately. Moreover, physical abuse against some of the young people was reported.

"Tony is treated better now because he is staying with granny; his uncle did not treat him well. When he used to stay him, he had his own plate and spoon and his clothes were being washed separately from others. He was treated so badly until he absconded. No one knew where he was. I could not take him because his uncle was in charge...he was eventually taken by this granny, but she leaves early to sell and comes home in the afternoon. Tony earns a grant, but it is collected by his uncle and he does not give granny all the money. I do not know what he does with the rest of the money and we cannot ask him." (Elaine)

Being without parents and living with HIV increased the vulnerability of young people. These findings corroborated those obtained from a Nigerian study which compared the socio-demographics and clinical characteristics of young people living with HIV who were orphans and those who were not. Olakun et al. (2009) reported that although the extended family system was coping with the absorption of orphans who were living with HIV, they were at risk of neglect (Olakun et al., 2009).

Whilst most carers stated that young people were receiving adequate care, some reported that they believed the young people were not. However, the way in which abuse or neglect was defined and understood within this context was somewhat problematic. At the heart of this debate is how members of households define appropriate and inappropriate care for the child. An example is the case of J (13 years); a child cared for by Ethel (24 years), a stepmother, but who lived with his father, grandmother and the rest of the family members as his mother was deceased. Ethel reported that J was not treated well because he was being asked to perform difficult tasks that she considered to be inappropriate for him, given that he also was HIV positive and therefore prone to illness. She also felt that he was too young to be asked to perform these tasks, especially as they were often required when it was too dark and he was sometimes sent to another household at night when it was raining. Ethel also questioned why

J was the only child within the household who was constantly being asked to perform tasks when there were other children in the household.

“...I do not like the way they treat J. When it is cold and dark they send him (referring to J) to do things. What if he gets sick? Why they can’t ask other children? He works till late; now and again they ask him to do things and one day it was raining heavily, they had asked him to go and buy something. I do not think that is right. Why they do not ask their children to do that?” (Ethel)

Mary, a carer to Thabang, a child living with physical disability, epilepsy and HIV, reported that she was concerned about the type of care that the child might receive if anything happened to her and the child’s grandmother. She did not trust her family members to provide adequate care for the child because of their current caring practices towards her. These issues raised debates on how child protection versus neglect was being debated and defined in families.

Given that young people within this context are generally expected to contribute to the household by participating in family errands and working within the household, making a distinction about whether it is appropriate or not can be difficult to discern. Moreover, the young people concerned did not perceive it as a major issue. For example, in the case of J, he was more concerned about other issues, such as the way the adults in the family talked to him, and his father who was abusing alcohol and using his grant money for himself. Being asked to run family errands was the least of his concerns. These findings demonstrate the relevance of engaging young people and seeking their perception on issues that concern them, a practice that may ensure that young people’s specific needs are considered when planning an intervention.

5.7.3: HIV treatment and adherence

Living with HIV in the era of ART was reassuring for all carers whose children were living with HIV. HIV care was provided in the clinic, which for some of the carers was some distance away and they had to use transport to get there. Most carers had to travel between five kilometres to twenty kilometres to reach the nearest clinic. Transport in some of these locations was poor, and carers walked long distances to reach the nearest ‘station’ where they could get transport to take them to the clinic. Although this was not raised as a major concern by carers, perhaps because it had become a normal experience, it was a challenge for health management in that when young people missed appointments and collection of medication,

clinic staff did not have capacity to reach these families. Moreover, most carer's homes did not have a physical address.

A concern was also raised about ART side effects. Some of the carers had previous experience of using ART since they were also taking it but carers with no prior knowledge were concerned about its side effects and the safety of using it.

"I often hear that these tablets can make one sick...I was worried about that. He complained of nausea and bad dreams at night. After taking these tablets he would be dizzy and want to sleep, but they caused him really bad dreams." (Ethel)

Most carers reported that although young people had side effects initially, most of them had recovered well. However, a few were worried about side effects that had an impact on body image.

"When...started this treatment she was not sick at all, but after starting the medication she was unwell for few days. She was tired most of the time and she did not want to eat. The only problem that is ongoing is that her legs are getting thinner; this thing is also happening to me...I cannot wear short skirts anymore. Her body has changed. It can be embarrassing, but I do not care..." (Mary)

Carers were grateful that young people were on ART; they considered it as something that kept the young people alive and they had observed a noticeable difference between the time when young people were not on treatment and their current health status. Most carers had a clear understanding about the consequences of not being on treatment. Despite being illiterate, and in some cases being elderly and unwell themselves, their understanding of what it meant to have to adhere to strict requirements of treatment was clear.

As mentioned earlier, ART requires strict adherence to the instructions of taking it. It is argued that in order to obtain an optimal and durable suppression, 90-95% adherence rate is required (Pontali, 2005). Carers reported that young people were taking three different drugs, and some were taking other treatments for opportunistic infections, as well as preventative treatments such as Bactrim¹⁵. The major challenge for most carers was to remind young people to take medication at the prescribed time every day, to minimise chances of

¹⁵ Bactrim is an antibiotic that is used to prevent and treat conditions such as *Pneumocystis Carinii* pneumonia (PCP) in people with weakened immune system such as people with HIV or AIDS

developing resistance¹⁶ to ART. A greater responsibility was therefore expected of young people to take their medication appropriately every day, but the carers were disappointed in this at times.

“I do not know what is wrong with Lungile. He has to be reminded all the time that it is now time to take medication. One day I was away for a week and he was supposed to go and collect his medication from the clinic, but he did not go; for more than a week he did not have medication. I was very upset because I know how important it is for him to take medication. It is like he does not care...I have to remind him every day; it seems as if this is not his health. What will happen if I am not here?” (Elizabeth)

Although some carers were expecting young people to take greater responsibility in administering ART, some young people were often poorly supported by those who were meant to help them with their medication.

“With J, medication is another problem. He does not stay with me [the carer provides partial support to the child since she is the girlfriend of the father of the child and she does not share the household with the child; she helps with medication and clinic visits], so I expect his father and his grandmother to help him, but I do not think that he takes his medication well. When he started treatment he was very unwell but he recovered very well after that. Recently, he has been having recurrent infections, which show that something is wrong.” (Ethel)

“...Tony was not taking his medication when he was staying with his uncle, they were not reminding him. I used to ask him whether he was still taking his medication and he used to say yes. One day I decided to check his medication; I was surprised that all boxes were sealed. I was shocked...” (Elaine)

It was noted that the lack of adequate supervision by the family of a young person taking medication, and in some cases, a carers' unrealistic expectations for the young person to independently manage his/her treatment, were associated with decreased adherence to medication. Excellent adherence was reported in families where taking the medication was approached as a family task; for example, two carers who were HIV positive reported that since they had disclosed to their daughters, taking treatment was a team process. They reminded and supported each other; therefore it was not easy to miss their doses.

¹⁶ The ability of HIV virus to mutate and reproduce itself in the presence of ART

“We use a cell phone to remind us; it is seven to seven. We may miss the time by few minutes but we do not miss the medication itself.” (Mary).

Carers’ responses indicated that they understood the importance of young people being on ART, and side effects did not deter them from helping young people to take treatment. However, there was a clear indication that carers sometimes struggled with enforcing treatment adherence, and perhaps carers expected young people to have strict adherence without taking into consideration their developmental stage. Young people may have other priorities than taking medication; however, that did not mean that young people were not concerned about their health. This raised serious concerns among carers about the implications of missing doses and the young people thereby developing ART resistance, which could have direct implications for their health.

Below I delve into the critical issue of disclosure which has also been raised in the literature. Most young people are not told about their HIV status and carers are reluctant to disclose. Here, the carers’ management of the disclosure process is explored, as well as how they negotiated this process.

5.8: Disclosure: an Avoided Task

Informing young people who are HIV positive about their HIV status was an uncomfortable task for most carers, as corroborated by the literature which indicates that carers have difficulty performing this task (Brown et al., 2011; Moodley et al., 2006). Carers were concerned about how young people would react after being told, perhaps fearing that they may be depressed and lose hope. Therefore, carers would often delay and hope that as they got into older childhood, the young people might handle disclosure better.

“...how do you tell child things like these? Even an adult cannot handle it, what about a child?” (Gogo Queen)

Carers reported that they were not against disclosing to the young people, and they understood that it was important that the young person be informed; however, the challenges were about the appropriate age for telling them about their HIV status, how to tell and the young person’s reaction to knowing.

“They [clinic healthcare workers] told me that I had to tell him...it is right to tell him, but you do not know how the child will take this...I was worried

that he may tell others or he will be too sick because he knows...”(Mrs Ndlovu)

Carers’ uneasiness to disclose may be the cause for the use of ‘less threatening words’ during young person’s disclosure. Carers’ narratives indicated that some of the carers avoided using the name of HIV or AIDS during informal or formal conversations about HIV. Instead, euphemisms such as *‘lesisifo’* (this disease) or *‘lento’* (this thing) were used, as if the use of euphemisms tames or minimises the impact of HIV. Although the meaning of these codes seemed to be understood by most adults in the community, it was not clear whether young people shared a similar understanding.

Four subthemes related to child disclosure were identified: 1) motivation to disclose; 2) patterns of disclosure; 3) use of self to disclose, and 4) perceived impact of disclosure.

5.8.1: Motivation to disclose – HIV disclosure as crisis driven

Informing the young person about his/her HIV status was not a process that was often initiated by carers on their own; they were often driven to disclose by difficulties associated with the young person’s condition, such as the young person’s refusal to take medication and the complexities of keeping the young person’s HIV status secret. Therefore, health workers would encourage carers to consider telling the young person. Consequently, disclosure was often crisis driven; meaning that it was conducted when there was a problem with the young person, rather than a process that was pre-planned and which the young person was prepared for by healthcare workers and carers. Disclosure was often delayed until the child had reached older childhood (in this study, all young people were informed when they were ten years old or older). These delays have also been reported in literature (Oberdorfer et al., 2006; Wiener et al., 2007; Kallem et al., 2011).

This study indicated multiple issues that were barriers to timely disclosure to young people. All participants regarded this process as difficult to perform, since they were expected to inform young people about an illness that was stigmatised and potentially fatal. They reported that they felt helpless about performing such a task and they were concerned about the young person’s reaction, as this participant indicated:

“It was hard to think about telling her; we delayed for some time because we did not know how to do it, and you know it is hard to tell the child about these things, but the nurse encouraged me for a long time until I felt maybe

I should tell him because also he was not taking his medication sometimes.”
(Ruth)

Nevertheless, once young people had been told, carers utilised the opportunity that was afforded by disclosure to increase the young people’s active participation in their care. For example, J (13 years) was told about his HIV status, even though he was only given partial information (partial disclosure), and shortly after that he started collecting his medication from the clinic on his own.

“I did not want to tell him, but the situation at home was forcing me to tell him because I could not continue taking him to the clinic; I wanted to teach him to manage his clinic visits on his own and to collect his medication. I told the nurse about all the problems with the child and he advised me to tell him, and because he is older now, he can come on his own, but he needed to be told.” (Ethel)

This study indicated the complexities of making a decision to disclose to the young person, and disclosure was often driven by factors such as age, the need to involve the young person in taking responsibility for his/her care and the urgency to encourage adherence to medication. This concurs with the studies conducted in Nigeria and the USA, where age was one of the predictors of disclosure (Brown et al, 2011; Mellins et al., 2002) and with Brown et al. (2011), where disclosure was seen as facilitating improved adherence to medication. Although most carers in this study were concerned about young people’s adherence, most reported that after knowing about their status, young people were adhering to medication and they were taking greater responsibility for their own health. Whilst all carers in this study reported that they had disclosed to their children, there were significant variations in how this disclosure was achieved. Below I explore their methods of telling the young people and the implications of these variations.

5.8.2: Patterns of HIV disclosure to young people

Carers used different ways of informing young people about their diagnosis. Some opted for open disclosure (the young person is told the name of the disease, and HIV or AIDS is mentioned as the cause of the illness). Other carers could not openly disclose to their children; instead, local euphemisms were used to refer to HIV during disclosure. Carers who openly disclosed to the young person reported better openness and improved co-operation, especially in relation to medication adherence. These findings concur with those obtained from several studies which reported positive benefits associated with telling the young person

about his/her HIV status (Bachanas et al., 2001; Oberdorfer et al., 2006). In both these studies, young people who knew about their status were shown to have a better adjustment to their illness and less psychological distress.

In the cases where this was relevant, open disclosure was also an opportunity for biological mothers to disclose their own HIV status, and to inform young people how they were infected.

5.8.3: Open disclosure - a shared responsibility

Open or full disclosure is described as the type of disclosure where the child is informed about his/her diagnosis and the name HIV or AIDS is used to refer to the illness (Lesch et al., 2007). As mentioned earlier, most participants were caring for young people that were orphans, and so the young people's HIV status was not necessarily an indication of their own HIV status. Therefore the young person's status was shared with most members of the household and sometimes other members of the family were involved during disclosure. One common factor among carers who openly disclosed to the child was that in telling the child, the support of another family member was sought. This additional member supported the carer in managing disclosure as well as providing support for the child; this suggests an existing culture of shared responsibility.

"Her grandmother and I sat down with her. We told her that we wanted to tell her something. We told her that she is now living with HIV, that is the reason for all this recurrent infection and she now needs to take medication to prevent being ill again. She may have been infected though her mother but we do not know for sure because she died long time ago. She knew about HIV because people talk about it all the time. We also told her that she will live, as long as she takes medication..." (Ruth)

Healthcare workers' role in supporting the carer during the disclosure process was highly valued by participants. They provided information and guidance that was helpful to the child as well as the carer.

"It [disclosure] was the hardest thing I had to do; I asked the nurse to help me because I could not do it. The nurse explained very well what HIV was, so that she does not become afraid and think that she will die. We also told her about me and we encouraged her that she was going to be OK..." (Mrs Ndlovu)

5.8.4: Partial disclosure

Partial disclosure is defined as a form of disclosure where the young person is told that she/he has a disease but HIV is not specified (Oberdorfer et al., 2006; Funck-Brentano et al., 1997). Carers used local terms to refer to HIV non-specifically; ‘taking medication’ was contextualized during the disclosure discussion to refer to HIV diagnosis.

This study indicated that for carers, disclosing did not always mean that they had used the term ‘HIV’ or ‘AIDS’ during disclosure. This was a critical distinction, since all these carers introduced their children as having been informed about their HIV status. However, the distinction was discovered when carers were asked how they disclosed. Various communication patterns were discovered which often involved the use of euphemisms. The children of these carers also seemed confused when asked about their diagnosis, which may indicate the state of confusion or fear of breaking the family code and talking blatantly about HIV.

“...I told him that he now has to take medication to prevent being sick again; if he does not take these medication, he may get sick. I think he knows, he knows what that means...” (Ethel)

Two carers who partially disclosed to their children were convinced that despite not being informed explicitly about their HIV status, their children were already aware, perhaps suspecting that the young person had discovered on his/her own and telling him/her this would be just confirming what they already knew. The participant below thought that as long as the young person was told something, *“he can figure it out what the tablets were for”*. She was convinced that at the time of the interview, he had indeed ‘figured it out’.

“...I told him that he has to take these tablets now; he would find out later what the tablets are for as he goes along. I think he knows now, he can tell that he has HIV...” (Elaine)

These participants assumed that the use of this euphemism was known to young people, and that they would understand its meaning and implications. However, despite the inconsistencies of HIV disclosure, all young people were encouraged to take medication and to participate fully in their healthcare, and they were introduced as young people who knew their status. The impact of these patterns of disclosure and the meaning that young people attached to them are discussed in Chapter Seven, where young people’s experiences are outlined.

5.8.5: Use of self to disclose

One of the differences between carers who were biological parents and those who were not was in how they managed disclosure. This study indicated that during disclosure, parents also informed young people about their own HIV diagnosis. Parental disclosure served two purposes for the young person: it offered an explanation about the source of the young person's HIV status, and it played a supportive and a reassuring role. One of the carers openly disclosed to the young person and simultaneously disclosed her own status to the child, to reassure her that all was going to be well. She told the young person about her father's illness and reminded her how he died because he was not tested in time, and because of that he was not started on treatment that could have saved his life.

"I could not hide this from her, but I told her that you see your father passed away because he did not test, but you and I are lucky because we have known about this before we could get sick. You see I am well, have you ever seen me sick? It is because I take care of myself and I take medication to keep myself well. I told her that if she does that she will be OK. Nurses at the clinic also reassured her. We are open about everything. I have never seen any problem. She is OK." (Mary)

5.8.6: The impact of disclosure: carers' perceptions

Carer's reports about their perceptions of the young people's responses varied. All participants reported that when the young people were told, they did not say anything. One young person responded by crying, but most participants reported that they thought the young people had become relatively 'OK' about their HIV status.

"...I could see that she was not OK, but I talked to her and I told her that she was going to be fine; it took some time, but after a while she was OK, she was not as worried as she was. She slowly started being herself again..." (Mary)

"It has helped us because she reminds me as well to take medication, and I do not have to remind her all the time about the importance of taking medication. She is taking more responsibility." (Mrs Ndlovu)

"Telling him has helped us so that we can talk about HIV openly without secrets. He does not talk much about HIV, but it has helped me so that when I talk to him I do not have to pretend as if I do not know what is wrong with him, and when I discipline him I remind him that he knows how serious this disease is and he needs to take his medication. I do not think, though, it has helped him to be more responsible in taking his medication well. Instead I still remind him to take his medication. Even his younger

siblings remind him sometimes. He has a watch in his room; therefore he does not have an excuse for not taking his medication.” (Elizabeth)

Participants often did not know whether what they said to the child had any positive or negative outcomes.

“I do not know whether it has helped him or not, but he now collects his medication and attends the clinic on his own.” (Ethel)

“Tony keeps quiet. It is difficult to talk to him. I do not know whether he is OK or what.” (Elaine)

Child silence is not uncommon in childhood literature within the African context. In the study conducted by Richter & Muller (2005, p.1011) on grief and silence, children’s responses are described as sometimes “numb and virtually devoid of emotion after the death of the parent - they were beyond emotion.” Van der Heijden & Swartz (2010) point out how grief among children is managed within the cultural norms which discourage death-talk and embrace silence. Within this study, a similar phenomenon was observed, where open communication about sensitive issues such as HIV was not easy for adults to embrace; children had therefore learnt to deal with their issues on their own, and this had become a normalised experience. These findings corroborated those of the study that was conducted in Botswana (Sub-Saharan Africa), which indicated that parents were reluctant to discuss issues of HIV, which they regarded as sensitive, with their children (Nam et al., 2009). The problematic nature of this practice is that young people tended to internalise their feelings and sometimes they would begin to have behavioural issues, yet could not express their feelings.

“My problem with Tsepiso is that when he is sick, he sleeps and he does not want to wake up, and even if he has just been sick for a day, he looks as if he has been sick for a long time and he becomes very quiet and sad looking. We do everything for him, and even my children ask him about what is wrong, he does not say. This thing of failing at school is a problem. I told his class teacher that they need to pay attention to him, but when I went to talk to them, the teacher told me that he cannot remember his face...what is that? I do not know how to help him.” (Elizabeth)

“Tsepo saw his parents when they were sick; I think it is still in his mind, but we do not want to raise these things because we do not want to keep on reminding him about what happened in the past and he has never talked about it.” (Gogo Queen)

Although participants had difficulty interpreting children's emotional reactions, young people were clearly exhibiting difficulties associated with learning, as well as behavioural problems and psychological problems. Clearly, these difficulties may not only be related to HIV disclosure; however, HIV is an addition to an already stressful experience for many young people. Carers' narratives indicated that disclosure is a complex process which is layered by varying communication patterns within the family and the ability of the carer and family to talk openly about HIV to the young person.

5.9: Conclusion

This study indicated that caregiving is a gendered role, and that caregiving practices are a shared responsibility between surviving family members and the extended family. Although there has been a long-held traditional system of caring for young people in families, in the era of HIV this was becoming a necessity for survival. Whilst this was a protective mechanism, these families were not immune to additional risks that destabilised families. As a result, most families were constantly adjusting themselves to change, whether this was loss, migration for employment, sickness or financial instability. Therefore, in this study, caregiving practices were provided within a context which had the protective elements of social networks, but where additional risks significantly destabilised young people's family life.

Secondly, this chapter has raised important issues about carers of young people with HIV and the taking of ART. Most carers had a strong intention to provide material resources such as financial support and shelter for young people, as well as non-material resources such as love, a sense of belonging and solace. However, some of the needs of these young people were not being met adequately by families. These needs included providing support to young people by managing HIV-related tasks such as open disclosure, meeting mental health needs and open communication about issues that affected young people. The consequences of this can be identified within the young people's narratives (Chapter Six). Some of these young people presented with grief and bereavement issues; poor school performance; disclosure difficulties; unidirectional communication between adults and young people, and young people's inability to express their opinions to adults. These findings suggest that most young people have to depend on their own agency to manage HIV tasks and other challenges they confronted.

The next chapter specifically looks at the meaning and interpretation of living with HIV from the perspectives of young people. Issues such as agency and maintaining normality which were central to the young people's narratives are discussed.

Chapter Six: 'I am alright' - Maintaining Normality and Managing HIV Tasks within the Secrecy and Silence of HIV /AIDS

6.1: Introduction

In this chapter, I present the findings from interviews and focus group with young people living with HIV/AIDS and who are taking antiretroviral treatment. Young people's perspectives turn the attention away from the clinical dynamics that so often dominate the literature on young people that live with HIV/ AIDS, and focus instead on what the experience meant to young people. Having said that, the intention in presenting these findings is not to minimise the impact of HIV/AIDS as a medical problem, but rather, to describe how young people define, manage and make sense of the experience of living with HIV. Although this is not a comparative study, the participants were recruited from an urban district and a rural area, and whilst most of the themes identified from data collected from these sites were similar, differences were observed in how young people responded to and managed certain aspects of their lives based on their social realities and resources to which they did or did not have access. This chapter begins with a summary of the core themes that emerged from young people narratives and the analysis of the themes that emerged.

6.2: Core Themes: Young People's Narratives

These findings are based on data that was collected through in-depth interviews conducted in an urban setting with young people attending a community centre. In figure 6.1, a summary of themes that emerged from young people's narratives is presented and figure 6.2 shows the core themes.

Figure: 6.1

1. Context of young people

- Intersection of risk and protective factors in families
- Child migration
- Rural poverty

3. Complexities of HIV disclosure

Disclosure as a child- initiated process
Closed awareness
Suspicion
Mutual pretence
Open disclosure

4. Maintaining normalcy and healthy self

Positive reframing
Strong will to live
Valuing disclosure
Efficacy of ART
Maximising chances of survival
Carrying a risk label
Controlling personal secrecy

2. HIV trajectory: young people's lens

1. Negotiating through HIV indistinctness
 - The need to know
2. Negotiating HIV silences
 - Adult-centred disclosure

4. Negotiating meanings associated with HIV diagnosis

Turning point
Adjusting to knowing
Managing personal risks

- Adherence to medication
- Enforcing ART adherence
- Autonomy development
- Illness as anxiety provoking
- Managing parental loss

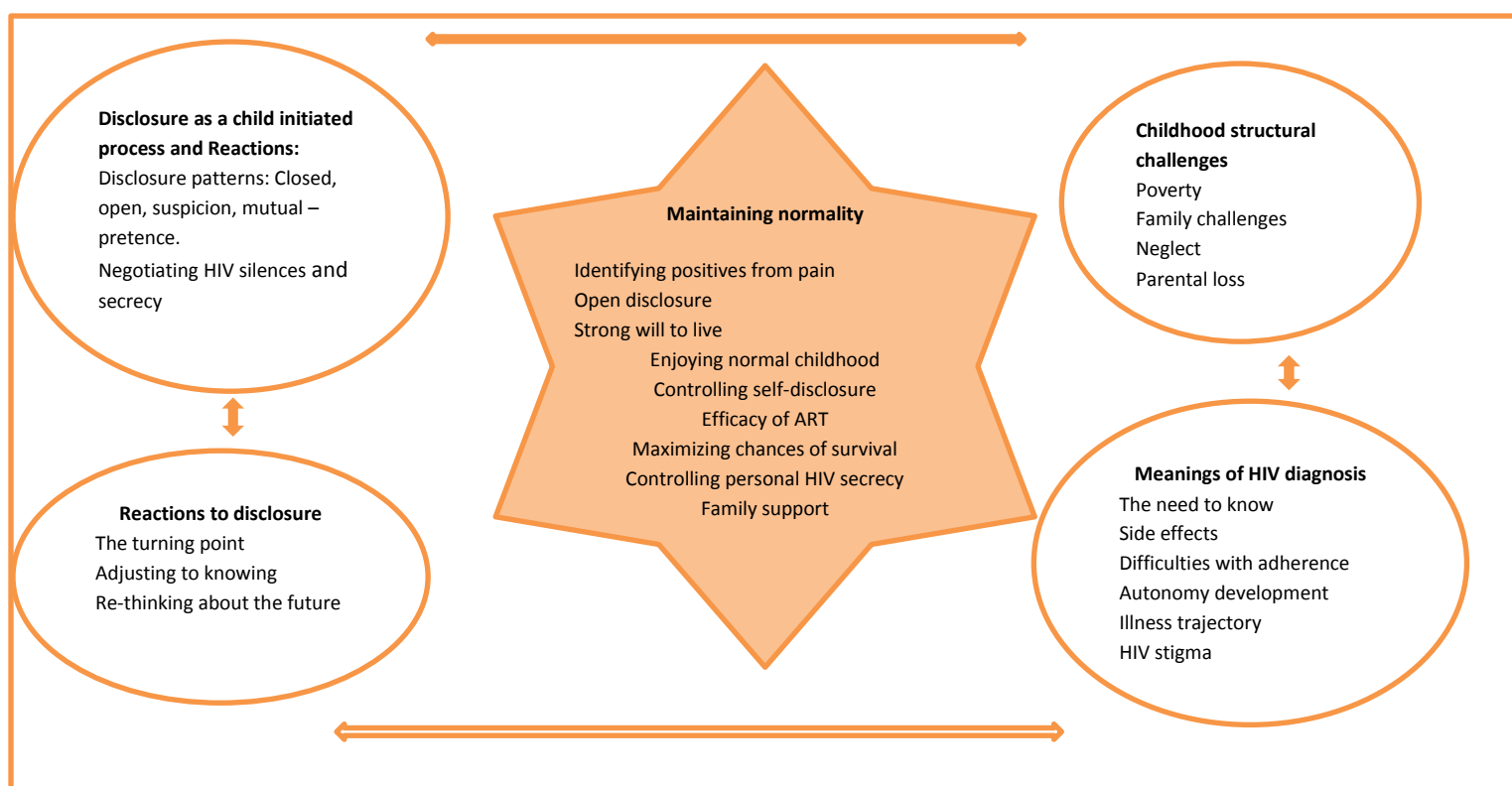


Figure 6.2: Young people's core themes

6.3: Participants' Context: Background, Families and caregiving

Previous sections have highlighted caregiving practices and how these practices are negotiated in families, which are conceptualized to include the wider extended family. Furthermore, the resilience of families to reconfigure roles and responsibilities after multiple deaths and to provide support for young people has been explored. That discussion explored how families managed to absorb the care of young people in the context of multiple losses, the construction of families as fluid and caregiving practices are negotiated in relationships of expectations of reciprocity which include wider social networks. These types of relationships indicate prevailing social relationships in communities, as well as a protective response that enables families to survive the impact of multiple deaths. This section therefore seeks to elaborate on the family context through the lens of young people, explore young people's perception of their family and the impact of social and health factors.

Extended family members are an integral part of the young people's socialisation, and households often include the extended family (Mathambo & Gibbs, 2009). The extended family often play an active role in decision making, the protection, care and upbringing of young people. These roles are often gendered in that males may be significant in decision

making about where a young person may be located but not necessarily responsible for caregiving, whereas women are nominated as primary caregiver. Despite the negative outcomes associated with HIV/AIDS for young people, family has been identified as one of the mediating factors, although in some instances it poses risks for young people (Coscia et al., 2001). The quality of the relationship between the carer and the young person, which includes open communication and involvement, has been correlated with better mental and coping outcomes for young people living with HIV (Elkington et al., 2011).

6.3.1: The intersection of protective and risk factors after parental death

The majority of the participants came from female-headed families and the main carers were all female, secondly, the majority of carers were grandparents and aunts. In instances where mothers were still alive, caregiving was often a shared task, with members of the family such as grandmothers or other significant members in the households contributing in various ways. Thirdly, most participants' narratives highlighted vital inter-household relationships that sustained the wellbeing of the family, as well as mitigating stressors within their households.

Since most of the young people were maternal orphans, meaning that they had lost their mothers, or they were orphans, implying the loss of both parents, young people had to change homes and stay with extended family. Before this could occur, family members had to negotiate how the young people would be cared for. These decisions were fragile, were negotiated by adults, and were often based on adults' terms, and thus if the relationship became unstable and conflicted, support for the young people could be compromised. Notwithstanding this, the strength of these relationships was in blood ties and family ancestry, which are important elements in isiZulu culture. Therefore these ties were not easily broken; instead they were being renegotiated to respond to the needs of the young people and their families.

It may be worth noting that female-headed households are not a new 'AIDS or death driven' phenomenon, though it would be myopic to deny their pervasiveness as a result of AIDS-related deaths (Schatz et al., 2011). The migrant labour system, non-marriage and AIDS deaths have all contributed significantly to female-headed household patterns in South Africa (Schatz et al., 2011; Chazan, 2008). However, grandmothers have always played a significant role in most households, especially in child rearing (Chazan, 2008), and even in this study some of the young people had always been cared for by their grandmothers whilst biological parents contributed financially, an informal arrangement that Marais (2005) terms 'traditional

reciprocal care arrangements'. Parental loss therefore exerted tremendous pressure on grandparents, and sometimes extended family members, to provide for the financial, emotional and day-to-day needs of the young people.

As mentioned earlier, after the loss of the biological parents, extended family members often intervened to provide appropriate care. This was the case when the maternal grandparent was deceased or too old to assume care. Sometimes the participant's care was shared by family members who did not live in the same household as the participant. Although these arrangements were useful and they sustained the survival of the family, sometimes they were unsuitable for young people.

"After the death of my mother, I was taken by my uncle and his wife; there was this thing that she [uncle's wife] did not really like me; she would scold me for something that I have not done. When we grew up, if one person has done something wrong, all of us would be given hiding, and be asked why we did not advise each other. With her it was different; it was like she would not call all of us, she would call me only and ask me. She would tell me that she knows that I am not her child, she would say all nasty things, she would not give me food or pocket money, but if my uncle was around, she would pretend as if she cared. If my grandmom did not take me away from them, I would be dead by now..." (Zonke, U)

Traditional family systems can be useful when available and appropriate however such arrangements may not always be in the best interest of the young person and may be a source of stress, or a source of risk, as previously indicated.

Interviewer: *How can you describe your life right now?*

Participant: *It is right, but if I have done something wrong, I am reminded about my thing* ¹⁷*[crying]. I am always reminded about it.*

Interviewer: *How does that make you feel?*

Participant: *It makes me feel as if I am a lost person crying...a person that is nothing in this world...*

Interviewer: *Mhhh... So at home when they discipline you as a child, they remind you about your illness?*

Participant: *Yes, even younger children from home. When I have a fight with other children from home who are younger than me, they also remind me about my illness. (Sne, U)*

The young person's narrative shows that the construction of the family was being negotiated constantly to respond to the changing needs of its members. However, the flexibility of

¹⁷ 'This thing ' was used as a euphemism to refer to HIV

families to respond to the needs of young people should not be taken for granted as always being in the best interest of the young person. Equally important, was a recognition that traditional arrangements, though vulnerable, could be renegotiated and re-evaluated, propelled by factors such as material provision, traditional systems of lineage or poverty, as happened to this participant:

“I was living with my grandmother [maternal grandmother]. I started getting sick; where we were staying, there was no good food and the food we were eating was making me to be sick. I was brought to my father and my paternal grandmother.” (‘J’, R)

Since this young person’s mother was not married to his father, it was culturally inappropriate to allow him to stay with his paternal family; however, such ‘bending’ of rules may be a common occurrence to meet prevailing needs.

The recognition of these family survival patterns is important; however, the complex nature of child-adult relationships that often characterise these relationships in the South African context may need closer inspection. Young people’s opinions hardly surface (Clacherty & Donald, 2007), and as a result, if these arrangements have unintended consequences for young people, they may not voice their trauma and ill-treatment. Without an ongoing monitoring system that is aligned to the rights of the young person, intervention for young people in distress may be difficult to access.

6.4.2: Child migration

The families of some of the young people living with HIV reflected many social problems such as poor living conditions, unemployment, poverty, multiple deaths and substance abuse. These problems contributed to a wide range of negative outcomes for young people. For example, Ron, a 13-year-old participant who used to live with his parents in a crowded and poverty-stricken neighbourhood, had experienced cumulative stressors in his life. These included witnessing his mother being abused by his father, his mother’s death, alcoholism, his father’s suicide, multiple deaths in his family and ultimately his family’s disintegration and his siblings being taken by different family households, since the maternal grandmother could not cope with caring for all of them.

“I grew up with my mother and father and my five siblings; we were staying together. My father went to drink. At night my mother awoke us up and hired a car to take our thing and we all left to stay in my grandmother’s house. My mother was crying...they used to fight with my father and my

siblings would cry...at that time I was young and sickly so I was always in bed, asleep. I would be awoken by noise...I would not know some of the things, but we left and the next day, my mother was dead; she slept and when we tried to wake her up she did not wake up...my father hanged himself [crying hysterically].” (Ron, U)

Although this was part of his history, at the time of the interview he was in the care of his maternal grandmother, and he reported that he was much happier, but his current family did not have resources to draw from and therefore the struggle to cope was still evident in many areas of his life, such as schooling, inadequate health and malnutrition. The separation of this young person and his siblings was a survival strategy, adopted by the family to cope and sustain the family in the midst of a myriad of challenges. It may have been ideal to keep all the siblings together to maintain familiar social structures, but the prevailing circumstances could not afford them that opportunity. These young people had to learn early in their childhood to survive and cope in their respective environments.

6.4.3: Rural poverty: a normalised experience for young people

Child poverty has been reported as having enduring impact on a range of child outcomes. To properly determine the level of the young people’s deprivation, five specific domains were looked at: income and material deprivation; family employment; education; living environment, and adequate care deprivation. Even though young people were not asked directly whether they experienced poverty, within their narratives and through the researcher’s observations it was evident that the level of poverty was high and more pronounced for young people from rural areas. This was not unexpected, because KwaZulu-Natal is one of the provinces in South Africa with the highest rate of deprivation in South Africa among young people (Barnes et al., 2009).

The families of participants from rural areas had the highest level of unemployment; it was common to have a household where none of the family members had a wage income. This meant that young people had food shortages and material deprivation such as lack of adequate clothing and proper housing.

“When there is no food, I sleep without any and when I wake up, I feel hungrier.....my mother does not work, but sometimes she plants vegetables and she works in a community project ¹⁸[a poverty alleviation project] where she earns 35p each time she cuts grass there...” (Ziyanda, R)

“I get angry sometimes...sometimes they do not cook at home...I do not know why and when they do that, I get upset and I do not talk to anyone. I refuse to take medication when I am hungry...then sometimes they cook porridge for supper...” (Thabang, R)

Most of the young people reported that they did not eat meat and bread often. They ate leftover meals, such as cabbage, mealie meal, potatoes or beans. Only one of the participants’ from the rural area lived in a household with electricity; the others all used candles for lighting and wood fires to cook.

All participants from urban and rural areas were attending school, except for one child who had a physical disability and learning difficulties, and the lack of appropriate learning facilities in her community meant that she could not continue with education in a mainstream school.

Although most of the participants were in school, many of them experienced major educational challenges and some were repeating each grade,¹⁹ sometimes up to four times. This brought shame and embarrassment to the young person and the carer/parent. None of the young people with these problems were being professionally assessed to receive appropriate intervention; as a result, they were struggling through mainstream education.

“I do not go to school anymore; I used to go but the school was too far and we could not afford to pay the school fees...I just stay at home and do nothing.” (Thabang, R)

Poor living conditions were a significant problem especially for participants from rural areas. Some of them were living in places with very poor transport facilities: one of the participants had to travel about 10 kilometres to reach the station which had transport to take them to the clinic, which is 15 kilometres away. Some of the families had problems of overcrowding, where the household had few rooms yet there were many members. Though it is usual to share sleeping spaces among this community, some of the houses were just too small and some appeared as if they were falling down.

¹⁹ The South African formal education begins from grade R to grade 12. Grade R begins from age 6 years and the child is expected to finish Grade 12 in order to proceed to tertiary school. Each grade is one year, therefore failure to pass a grade means that the child will be behind by a year.

Hardships to access resources necessary to meet basic needs of young people were an on-going challenge for young people. One of the young people who had lost his mother and was staying with his father reported that his father was not providing for him adequately:

My father earns my grant²⁰, but he misuses the money and he does not buy food or clothing for me, my stepmother has to buy. I do not know whether he drinks all the money; it is only granny and my stepmother that help.”(J, R)

Unfortunately, such hardships were exacerbated by multiple losses for example the grandmother that J referred to passed away before the end of this study. He was left with other members of the family; however, he lost a significant figure in his life. The challenges these participants were experiencing were observed during data collection visits to their homes. In one of the homes visited, a 13-year-old child was trying to make a fire to prepare his own lunch using flour and water. He said he was making steamed bread. He reported that no one had left lunch for him, so he decided to make a fire and cook as he was hungry; it was already midday. I wondered about his safety while making this fire and the nutritional value of the food he was trying to make. His uncle was in his room with his partner, and there were other young people and children present. The grandmother was at work and the child’s father was reported to have gone to look for contract work in a nearby construction firm.

Parental death, especially maternal death, significantly increased the risk of the child being cared for inadequately and not being provided with the love, attention and care that was needed to develop and be competent. However, poverty was a further critical factor that increased the vulnerability of both non-orphans and orphans; in some families one could almost predict that the cycle of poverty that was repeating itself in that generation, where most family members were unemployed and illiterate and young people were also struggling academically. HIV/AIDS has been cited in literature as increasing young people’s vulnerability to poverty and material deprivation (Hearle & Ruwanpura, 2009). However, in rural areas, the impact is made worse by the absence of resources that could potentially improve the opportunities available to young people.

As already indicated above, young people were not asked about poverty directly; however, within their narratives, the young people described experiences which gave a glimpse of the extent of poverty within their lives. When some of the young people described their

²⁰ Government financial assistance to children with no visible means of income

experiences, they were not lamenting or complaining, they were just stating what was occurring in their lives. It had become a normalised plight for most young people. This section has described the impact of challenges that existed within most of the families of these young people. The impact of parental death was associated with risk factors. Families were willing to absorb young people and provide care, yet risks and vulnerabilities were evident, such as inadequate food supply, school-related challenges and lack of mental health services for young people.

Below, I outline young people's experiences of managing HIV 'tasks'. I begin by describing the young people's trajectory of managing HIV silence in the family, and the use of agency in dealing with disclosure.

6.4: HIV Trajectory: Managing Secrecy and Silence

6.4.1: Negotiating through HIV indistinctness

Secrecy and silence, as Preston-Whyte (2003) notes, has always played an integral part in maintaining existing relationships and patterns of power and authority in society. Secrecy serves as a boundary keeper between those who belong and those who do not; furthermore, a clear divide between the child and the adult world of knowing has always been in existence, dividing what belongs to the adults' world and the young people's world. Sex and reproduction remain among the generational secrets in our society, and have always been closely guarded by adults yet viewed as exciting by young people. Preston-Whyte (2003, p 90) argues that "Things hidden, not normally spoken about, carry the irritation of exclusion but also the excitement of achieving entry." In this study, young people's navigation of secrecy and silence is an overarching theme and is a significant event in the HIV trajectory of their lives. Secrecy and silence were characteristic of the young people's way of knowing; they had become tools that separate the adults' and young person's space, and as such, they had become a norm. Striving for a sense of knowing from within an indistinct environment was a common occurrence for these young people, and this pattern extended to include the HIV journey.

Young people's narratives of HIV therefore represented a progression from the unknown to a gradual self-initiated reconstruction of their perception about their HIV reality. Consequently, young people's narratives sometimes lacked detailed factual information about past events. This was a significant finding because, despite not having been explicitly told, young people retold the story as it emerged and as they perceived it.

6.4.2: The need to know

As alluded to above, the evolution of the young people's narratives in relation to HIV was gradually built from silence and secrecy. In contrast, young people valued being informed about critical things that affected them, even if that knowledge was incomplete or painful, indicating a sharp contrast with the beliefs of the carers, who believed that hiding painful things from young people was a form of protection. The desire for openness and information had to be balanced with recognising the inherent position of being a 'young person' who is not expected to have any desire to know about 'adult stuff', and the ability to handle the painful reality once adults have deemed it 'OK' to release it from the adult space. The following interview describes how important it was for this young person to be informed about things that had an impact on her life:

Interviewer: *You have not told me much about your mother.*

Participant: *Mhh, I do not know anything about my mother.*

Interviewer: *What do you mean?*

Participant: *She disappeared long time ago. I think I was about two years old, I guess...she left me somewhere...somewhere I do not know...there is someone that brought me to my aunty; this person said to aunty, "Here is the child of your brother." That was how I was left to my aunty... It is painful 'cos I want to see her someday, 'cos lot of people talk about their mothers and I feel bad. When I was left to my aunty I was sick, so my aunty took me to the hospital and they told her that I was raped and sick, I could even die.*

Interviewer: *Has it been helpful for you to know?*

Participant: *Yes, it has helped me to know who I am.* (Sne, U)

Young people valued being told about things that pertained to their lives; the benefits of knowing clearly outweighed the pain associated with knowing. Some of the young people from the focus group described this in few words:

"It is good to know." (Tseviso, Tsepo and Tom, R)

In situations where participants were not told anything, young people *did* take the initiative and began asking questions, hoping to get information that could help them understand what was happening in their lives. One of the participants, whose mother was deceased, asked her grandmother about the cause of her mother's death.

Interviewer: *Can you tell me about your family?*

Participant: [crying] *My mother passed away, maybe when I was four. I then stayed with my grandmother, then when I was...mhh older...maybe five or seven years, I asked granny to tell what killed my mother; then she told me [crying] (Sam, U)*

This interview illustrates that sometimes young people can and do take an active interest and use their own initiative to obtain information that is important to them. The overarching theme was the importance of knowing. In the next section, the need to know whilst negotiating the secrecy and silence of HIV is expounded upon.

6.5: Negotiating HIV Silence and Secrecy

6.5.1: Adult-centred disclosure process

Akin to most decision-making areas of young people's lives, 'formal disclosure' was initiated by carers/parents after being advised and supported by healthcare workers. I have differentiated between 'formal disclosure', which I have defined as an adult-centred initiative of offering an explanation about the young person's health, and the state of knowing, which is young person-driven, and is an active process where the young people aim to understand what is happening around them when they are not informed by adults. When young people described how they were told, they reported that they were called, asked to sit down and thereafter they were told, signifying a top-down approach. Although this top-down approach sounded like a common occurrence, there was an undertone of reticence when they were talking about it, as if they were forbidden to mention it.

The majority of these young people were told about their HIV status through formal disclosure, meaning that HIV was directly mentioned; however, three participants did not have this experience, and HIV or AIDS were never actually mentioned. Prior to disclosure, all young people recalled a series of events that were characterised by illness, repeated visits to hospital and taking medication with minimal explanation provided to them.

"I never asked my granny why I am taking medication, she just decided to call me and tell me why I am taking it." (Thabang, R)

"My granny called me and told me that we need to go and test at the clinic. I did not ask her why...I was scared...she did not tell me the results, she started collecting medication for me...I did not ask her." (Tsepiso, R)

Analogous to findings from other studies conducted within the African context, the majority of the young people reported that they were informed by their carers/parents at home, rather than by healthcare professionals (Heeren, 2011). Despite self-initiated actions to seek information that could provide insight about their health, young people reported uneasiness about asking direct questions of their carers/parents. It can be argued that this tendency is propelled by the prevailing societal values, characterised by the dominant discourse of adult respect and obedience which consequently deter active expression among young people (Clachery & Donald, 2007) and sustain dividing boundaries between a young person and an adult.

This type of relationship can also prevent supportive interaction between a young person and carer, and the child may not feel comfortable talking with the carer, even when she/he was not feeling well. Open communication about *'izinto zabantu abadala'*²¹ was not encouraged, and young people were aware of these sometimes unspoken rules and roles; as one of the participants remarked, *"You cannot ask such things from an old person."* (Tsepo, R)

The adult-centred disclosure was complicated by two factors: the perception of the young person by adults, where the young person was regarded as too young and immature to handle what was considered to be a heavy burden, and fear of disclosing to the young person, as most adults were unsure about what to tell, how to say it and what the impact of disclosing HIV status to the young person would be. Considering that the relationships between young people and adults in this context are often characterised by unilateral and unidirectional communication, with adults taking an authoritative role, HIV disclosure mimicked those prevailing communication styles. Young people's lack of response during disclosure and after disclosure may have been characterised as shock; however, this may equally be an indication of the complexities of open communication.

6.6: Complexities of Disclosure

There was a pronounced duality in how disclosure was negotiated among these young people. Young people's HIV status was treated as a closely guarded secret until the carer/parent decided to disclose. Conversely, young people were involved in their own active yet unconventional process of making sense about their health prior to being told. Some managed to 'crack the code', whereas others remained caught up in the web of confusion and only had

²¹ Loosely translated as 'adult stuff'

partial knowledge about what was happening; however, these young people were not just passively waiting to be told, they were actively trying to understand.

As mentioned earlier, young people described their perceptions of the ‘formal’ disclosure process, and its domination by adults as decision makers, as useful, but often falling short in terms of providing comprehensive answers about their health. In the next section, the participants’ own journey towards understanding their health and the meanings elicited are described.

These young people had taken remarkable strides towards advancing their understanding about their health, as well as being capable of facing the poignant adversities that came with knowing. With minimal information and insights, young people negotiated this silence and secrecy that surrounds HIV through observation and by making connections between the series of events in their lives. Despite the accepted notion that young people should not step across adult boundaries, some of the young people reported asking their carers direct questions about their health.

The inability and fear to disclose openly to young people about their HIV status has contributed to different patterns of disclosure being identified in literature. Kallem et al. (2011) delineated the following patterns of disclosure: complete disclosure, partial disclosure and non-disclosure among children living with HIV. Whilst this categorization has provided a germane departure from looking at disclosure as a single event, it has not offered a comprehensive description of the different patterns of disclosure among this cohort, and it has not accounted for the young person’s agency in disclosure discourse; therefore, disclosure has largely been analysed from an adult perspective.

The current categorisation of disclosure certainly ignores the perspective of the strength of the young person, and it fails to build on the young person’s existing knowledge and understanding. It falls short in terms of evaluating how a young person’s understanding is built, beginning from what the young person knows and connecting ‘the known’ to what the young person does not know. Dominant understandings of disclosure assume that, before formal disclosure, the young person is in a state of innocence or ignorance of their HIV status; however as this study shows, this is not necessarily the case.

Although the desired end result of formal disclosure was open awareness of HIV, the state of knowing among some of these young people was contrary to that. Instead of promoting

openness about HIV, it created another scenario of mutual pretence. This could be attributed to the carers'/parents' inability to create an atmosphere of openness about HIV. The dichotomy of disclosure, where the carer insists that the young person knows and the young person denies being told about HIV, remained a challenge, because they had never been specifically told that they had HIV or AIDS.

Glaser & Strauss's theory of awareness (Glaser & Strauss, 1965) provides a useful analytical tool to understand levels of HIV awareness among young people living with HIV. Awareness theory is based on a study that was conducted in a hospital which focused on the interaction between the medical personnel and terminal ill patients. Awareness of dying by either the dying patient or the hospital personnel emerged as an important element that influenced the social interaction process between a dying patient and the hospital personnel. Four typologies of awareness contexts are identified in this theory - closed, suspicion, mutual pretence and open awareness. In closed awareness context, there is a complete lack of awareness of the impending death by the patient even though everyone else knows, in the second level of awareness, the patient may have suspicions about his/her imminent death and may try to confirm or refute this suspicion and this context is known as suspicion. In the third level of awareness, the patient and those around may know that the patient is dying yet they may choose not to talk about it openly thereby creating a situation of mutual pretence. The most complete level of awareness refers to the open knowledge that the patient is dying. This may be discussed openly by both the patient and the hospital personnel, thereby creating an open awareness context.

This theory provided a useful framework for analysing the awareness context in relation to HIV diagnosis among these participants. In this study, although the awareness typology has some resonance, awareness was characterised by fluidity, meaning that boundaries separating these contexts occasionally became blurred, as participants moved from one awareness context to another. Prior to formal disclosure, participants' state of knowing about their health varied; this was to be expected, as this process was influenced by a number of factors which either raised a suspicion or reduced it. These different contexts of knowing, which were identified from young people's accounts about the period prior to disclosure and after disclosure, are discussed below.

6.6.1: Closed awareness

Closed awareness in this context is used to refer to the participants' complete unawareness about the possibility of being HIV positive. Within the participants' narratives, this context was sustained by the absence of major HIV-related illnesses or parental health problems and by situations where carers/parents managed to prevent any leak of information or behaviour that could raise suspicions. These participants did not suspect the possibility of being HIV positive; although some reported the sudden death of their parents and persistent chronic ailments, these were insufficient to raise suspicions, as this young person reported:

"...I never really suspected it; my symptoms were like getting more flu. I did not lose weight nothing, or TB; I did not get nothing. The only thing I had was really flu, there was not anything that could raise those suspicions."
(Zonke, U)

Disclosure therefore revealed new information pertaining to the participant's health as well as the presence of HIV within the household. Disclosure forced carers/parents to talk about sensitive issues such as maternal death and, if the mother was alive, it may have included disclosure of maternal status. This context was well guarded by parents/carers, and healthcare workers were complicit appearing to respect the carer's request of keeping status a secret. Any clue or sign that could raise a suspicion was dealt with immediately to ensure that the secret was kept until the carer decided to tell.

Similarly, the young person's illness trajectory allowed carers/parents to have sufficient information to delay telling the child the real reasons underlying the recurrent illness. The child's initiative to seek information was stopped prematurely when a valid alternative reason for being sick was provided. The participants therefore had no other concerns that warranted further inquiry. The following interview illustrates how this happened:

Participant: *I was told about this by my mother and two social workers at home. I did not suspect it at all. I was always sick as a child till 2001, when I started medication. The main problem was TB and heart problem. I have had TB so many times now, I have lost count. When I was growing up, I was told that I had TB and heart problem.*

Interviewer: *At that time, did you suspect that you might also have HIV?*

Participant: *I did not, because I really had a heart problem; I even had heart operation, so I knew that this was true.* (Nto, U)

In this case, the young person's HIV status was camouflaged by a heart condition, which made it easier to withhold information from her. Her family and healthcare workers sustained this pattern of secrecy until the carer's decision to inform the young person. Health care workers played a significant role by refraining from naming HIV during the consultation with the young person and the carer and if the young person was not aware of their status they would be asked to wait outside while the carer and the health care worker discussed specific HIV related information.

6.6.2: Suspicion

This context depicts the young people's active process of trying to understand the changes that were occurring in their lives. Young people mentioned significant events that raised their suspicions, such as: recurrent or prolonged illnesses; structured treatment and sometimes being on the same treatment regimen as a parent; death of a parent, and access to HIV information from school. Being exposed to these experiences yet remaining uninformed about what is happening has been reported to be associated with young people who are HIV positive experiencing severe emotional distress (Abadia-Barrero & LaRusso, 2006).

Young people who suspected that they were HIV positive made efforts to obtain information that could provide 'clues' and actually confirm their suspicions. Two scenarios of managing the suspicions were identified from young people's narratives. The first one was direct *confrontation* of the carer/parent, and the second one was *being suspicious* but refraining from voicing the suspicions.

Some of the carers took advantage of the participants' direct confrontation and disclosed to the participant about diagnosis and other issues considered too sensitive to talk about, as happened to this young person:

"My mother passed away, maybe when I was four. I then stayed with my grandmother. Then when I was...older...maybe five or seven years, I asked granny to tell what killed my mother. Then she told me (crying)...and then I started getting sick; actually when I asked her, I was already sick. I was sick...sometimes I will be admitted in hospital...I was sick often. She eventually told me what I had. When I ate...when I ate, I would throw up and I would have headache as if my head is boiling, and I would have stomach ache and diarrhoea... Other tablets that I take are am love...amlovedo...I do not know their name, but my granny knows them well." (Sne, U)

As mentioned previously, participants managed their suspicions by keeping this knowledge to themselves, even after they had confirmed it as truth.

“I was told by my mother at home, my father was not there. My father does not take medication. She told me when I was already taking medication. I could see that there was something because of the tablets I was taking. When she told me...I was already aware because of the tablets I was taking, but I did not tell her; my mother and I take the same medication.” (Ziyanda, R)

“My parents both died and I saw them being sick...I also started being sick later...I was tested but I was not told about the results and I started tablets. I knew what those tablets were for...but I did not say anything, till they called me and told me....” (Tsepo, R)

It is interesting to note that young people with these suspicions did not tell their carers/parents that they were already aware about their diagnosis before formal disclosure; none of them reported what they knew to be true. Similar behaviour of young people living with HIV has been reported in other studies (Kouyomdjian et al., 2005). Although the rationale for this behaviour cannot be confirmed, reasons for it may include fear of breaking the family code of what a child is supposed to know and what they should not know, and the awkwardness associated with talking about sensitive and ‘adult’ issues.

Based on these findings, the process of disclosure may be viewed as controlled and initiated by adults, whilst in reality, it was initiated by young people. Young people began the process of making sense about what was happening in their lives with little awareness on the part of the carer and often without their support. Adults only made decisions about informing the young person of their status when it was appropriate for them, yet young person often began the process of making sense about their HIV status prior to being informed.

6.6.3: Mutual pretence

Mutual pretence refers to a context where both the carer and the young person know about the young person’s HIV diagnosis yet HIV is never mentioned. This context can be difficult to detect because it is embedded in the family system and prevailing cultural systems of what can be discussed and how to talk about certain issues. It can also be influenced by family codes of communication that are learned through interactions within the family system. These codes may regulate appropriate and inappropriate communication within the family.

In this study, carers/parents sometimes used euphemisms such as '*ukudla amaphilisi*', loosely translated as 'taking medication', and '*lesisifo lesi*' ('this disease') to refer to HIV diagnosis, and they used those euphemisms during disclosure. The carers'/parents' believed that the meaning would be understood as it was part of their everyday language and therefore the young people would also infer the same meaning on hearing that euphemism.

Although the use of euphemism and its meaning can be understood if it is commonly used and known, in this study, it created ambiguity and silence, and it perpetuated HIV secrecy. Both the young person and the carer knew what they were referring to, yet it was not openly discussed. One of the young people who were disclosed to in this way later said to his carer: "*I know I will live because others are also living and surviving*". The carer's interpretation of this statement was that it did not make a difference that the young person was not told openly about his status because 'he could read between the lines' that he was HIV positive and such statements are a reflection of that. However, this perhaps could also indicate that this young person had understood that he was living with HIV but he wanted to engage his carer to a more open conversation; however carers sometimes missed these opportunities to engage young people

The use of euphemism and indirect language when communicating about HIV to young people created challenges. Young people disclosed to this way could not openly admit that they were living with HIV when asked about their HIV status. However, carers defended this method of disclosing to young people and argued that even though an HIV euphemism may not be understood initially by the young person, the young person would eventually "*discover by himself*".

Whether they had indeed discovered on their own and maintained the state of mutual pretence by not using the word HIV in discussing their experiences is unknown. However, this form of communication was maintained and seemingly understood by the family. What is interesting to note is that all these young people were involved in HIV-related activities and often they took responsibility for their own healthcare, as well as being supported and encouraged to take their medication. This is one of the rules of pretence interaction which Glaser & Strauss (1965, p.72) refer to as the avoidance rule. This rule dictates safe topics, and unsafe topics which are to be avoided. Therefore it can be customary to talk about being ill and what it means without naming the illness itself.

The line between being suspicious, knowing and maintaining the family code of silence was difficult to detect. Though this form of disclosure was characterised by secrecy and lack of open communication, it cannot be described as partial disclosure as mentioned by Kallem et al. (2011), which refers to the young person's knowledge that he/she has an illness, without being told the name of the illness. In mutual pretence, carers would talk about the participant's health in a manner that displayed that the young person knew that he was HIV positive. One of the participants who was disclosed to in this manner shared that his grandmother sometimes shouted and said "*If you do not take your tablets, you will die like your brother and mother.*" They both knew what that meant but it was never discussed openly and the young person did not follow it up. This form of disclosure creates a barrier of open communicating about HIV and perhaps this barrier may delay the young person's exploration of other HIV related tasks such as young person's self- disclosure and discussing challenging HIV related experiences with health care workers and peers.

6.6.4: Open disclosure

Open disclosure refers to a complete openness about the HIV diagnosis. In this context, HIV was named during disclosure as the cause of illness and therefore there was no ambiguity or confusion. However, in this study, even when there was this degree of openness, HIV was not always mentioned in discussion and there was still a sense of reticence about mentioning HIV, as if this word brought fear. Although there was a certain degree of openness, silence was still prevailing except on 'safe' topics such as medication. Awareness contexts pivot around open disclosure, but the process is complex and boundaries between these awareness contexts are not always straightforward. Below I discuss young people's perceptions of the impact of knowing about their HIV status. This section begins with the young people's reactions shortly after being told about their HIV status, which were of shock and sadness. Thereafter, it describes how young people talked about knowing their HIV status from the viewpoint of a rights-based approach and within an empowering perspective which helped them to normalise the experience of living with HIV.

6.7: Negotiating Meanings of HIV Diagnosis

This theme was initially labelled 'reactions to HIV diagnoses'. It was meant to convey the participants' descriptions of their reactions after HIV disclosure. However, young people's narratives went beyond their initial reactions. They differentiated between immediate reactions to disclosure, and their responses to knowing over time. It was interesting to note

that young people's descriptions of their immediate reactions had psychological descriptions attached and these were more pronounced. Once the secret was out, in whatever form it came, young people immediately understood that it had to be managed and kept as a secret; however, they also learnt to manage this secret in their social spaces.

6.7.1: Turning point

Shock and numbness was a dominant reaction after HIV diagnosis; this response was reported by most participants.

"I did not cry, but I was shocked..." (Tsepo, R)

"I did not cry either. After being told, I did not do anything, but I was sad...I did not speak to anyone about it though." (Tom, R)

"I was told when I was 13 years; I was already in school...I did not say anything to her [grandmother] but I cried." (Thabang, R)

Reactions similar to these have been reported in adults receiving an HIV diagnosis (Baumgartner & David, 2009). Most young people reported that they could not ask any questions; this could be as a result of being shocked, fear of an adult or not knowing what to say, but clearly it was difficult for young people to engage in any meaningful discussion with people after diagnosis. Most young people reported that after formal disclosure, there was little or no follow-up discussion in relation to their diagnosis, which then defined this type of disclosure as an event that happens only once. Although the usefulness of disclosing to young people cannot be denied, the communication style may be inadequate to prepare young people to confront their fears and deal with all the tasks of living with HIV (Abadia-Barrero & LaRusso, 2006).

Recovery from numbness and shock was accompanied by many questions and feelings that were difficult for young people to deal with and answer alone, as this young person indicated:

"I became so speechless, I...mhh...I did not know what to say, but I was fine. I did not cry, I did not scream. I was so quiet there. I was shocked...very shocked because I could not understand; at that time I always thought to myself that you only get HIV if you sleep with someone, you know, doing unprotected sex, so that how I told myself that. I have never done things like that in my life, how did I get it? It did not come in my mind that maybe I got it from like someone within the family and then when I went home, that was when everything started to come together, my mind was coming back again. I started thinking more things that I should not be

thinking of, like take a knife, kill myself, drink any tablets, anything like that. I locked myself in my room. I started crying because that was the time when I was thinking what did the social worker said to me, is it true? Or maybe they are just putting me on shock so that I can stand up for myself, like I should live like this, because things are like this now.” (Zonke, U)

6.7.2: Adjusting to knowing

The responses of young people to HIV disclosure extended to include short term psychological disturbances which were sometimes characterised by deteriorating school performance and difficulties relating to peers.

“...I then started lacking at school; I could not perform so well. Like the way I use to. Every time when I had to do a speech in front of the whole class, everybody would just stare at me; it was like everybody, bayabona ukuthi, Unondu, is like this now...on top of that my friends were just turning their backs on me. I could not understand that...” (Zonke, U)

Although most young people experienced sadness and hurt after being informed about their diagnosis, after some time, young people reported that they had to adjust, indicating a situation where young people felt they were compelled by circumstances to accept. For other young people, HIV diagnosis brought to the fore a questioning of their lives and whether it was still valuable, as this young person indicated: *“When I was told I felt my life has been destroyed...I felt as if I was a dead person”* (Sne, U).

The sociological constructs on chronic illnesses suggest that living with a chronic illness can create varying degrees of disruptions in the person’s life, which can be described as ‘life destroying’. This essentially refers to the biographical disruption which Bury (1991) describes as a ‘disruption of self’, where future intentions have to be renegotiated because the ideal self-image has been altered by the presence of the illness. Although most young people in this study did not present with visible symptoms of AIDS, their future orientation was perceived as changed. This perception of self, created a sense of difference in relation to others, as one of the participants noted: *“I see myself as different...I am different because I have this thing”* (Ben, U).

This profound rethinking of self-identity and self-image is one of the dominant discourses in chronic illness literature, and HIV diagnosis was perceived by these young people as life changing. There was a shared sense of being normal yet different as a result of the diagnosis. The self-image and identity were seen as being different from others and as a result, future

endeavours had to be aligned with their newly acquired identity which included HIV. Being different was related to the realisation that their lives may not be the same in many ways, yet young people also wanted to remain visibly normal.

The uncertainty that characterises chronic illness is widely recognized in literature; therefore, change and uncertainty in the young people's lives were to be anticipated, even though the course was unclear. Unveiling the secret of HIV did have a profound effect on many areas of young people's lives; however, there was still a great deal of silence that accompanied the disclosure. Yet this silence was neither unexpected nor unwelcomed; young people were familiar with negotiating their lives in the midst of secrecy and silence.

6.7.3: Managing personal risks and uncertainty

This theme encapsulates potential threats to the survival and resilience of the young people. Many factors continued to threaten the survival of these young people because of the imminent and cumulative stressors in their lives. Their survival was entrenched in vulnerabilities and conditions that were not static. HIV as a disease can be unpredictable, and with it come all sorts of challenges associated with illness, medication and side effects. The family context is also vulnerable and often unstable because of deaths and changes that continue to affect the coherence of the family system. The environment where these young people live is characterised by deprivation in many levels. These factors are likely to affect the quality of care of these young people in many ways. For example, before the end of this study, one of the participants had lost his grandmother, who was the main carer and the stable person in his life, and shortly after that he developed herpes zoster²² on his face which disfigured his face tremendously. This has changed his life for the worse; he had to find courage in himself to cope with these changes. In the next section I delineate the potential challenges identified by participants.

6.7.4: Side effects

The benefits of being on ART were acknowledged and appreciated but young people were also conscious of side effects. In cancer literature, adolescents also reported noticeable changes that affected their self-image (Lauroche & Chin-Peuckert, 2006). Being normal was being threatened by side effects which affected their self-image.

“When I started, mhh, it is just that, there is thing...tablet that you take at night, it is sort of a drug, you will be high and you just laugh. You will have

²² A viral infection that causes very painful sores in the body and often this disease leaves permanent scars

bad dreams, you start acting weird. You gain weight in your upper part and lose weight in your lower part; I discussed it with my doctor. My breast became larger and then my face became smooth, and older man started to worry me...” (Zonke, U)

Minimising these changes was important to young people to avoid unwanted attention and questioning. One of the participants with lipodystrophy, which was noticeable on her legs, reported that she was wearing long skirts to prevent people from seeing the thinning of her legs and commenting about them. Side effects such as lipodystrophy, if not managed well, have been associated with non-adherence among young people who are sensitive about their body image (Desai et al., 2008). Although the association between lipodystrophy and non-adherence to treatment was not identified in this study, lipodystrophy caused distress among the young people who experienced it.

6.7.5: Adherence to medication and its challenges

Adherence to medication was based on self-report by young people and their carers/parents, and they reported challenges such as forgetfulness, secrecy and lack of support rather than issues with the medication itself. This was a threat to their health and longevity. Young people reported that it was sometimes difficult to remember to take medication as prescribed. They indicated that minor things such as playing, watching TV, doing home errands and being preoccupied with other things such as school work distracted them. To remember, most young people used watches or cell phones, and those with parents on ART reported that they supported each other and this was helpful.

“Sometimes I am so tired and I sleep early and my granny has to wake me up to remind me because I have forgotten.” (Tsep, Ro)

“I forget sometimes, especially the time. I sometimes take the medication very late ‘cos I am busy with other things...like my school work or home chores; well... sometimes I watch TV till it is late.” (Sam, R)

HIV secrecy contributed to non-adherence as participants struggled to take their medication in front of people that did not know their HIV status. Participants reported interruptions of their schedule when they had visitors at home.

“Sometimes I was not taking them because there would be visitors at home and my tablets stay in the lounge, in a lockable cupboard; now I could not take them in front of people.” (Ben, R)

The perpetuity of taking treatment was sometimes difficult to comprehend for most of the participants; perhaps the burden of being conscious about taking medication as prescribed was becoming cumbersome, which may threaten adherence to medication.

6.7.6: Enforcing ART adherence

The success of antiretroviral treatment in reversing symptoms associated with HIV brought hope to young people, and it changed the negative perception of HIV from that of a terminal illness to a chronic illness.

The availability and efficacy of ART was often used by carers/parents to initiate HIV disclosure to young people. The focus would often be on treatment and treatment adherence. Young people reported that they were always reminded that they needed to take ART and told that if they did not, they would die.

“...I get so...scared if I have not taken my tablets...” (Ziyanda, R)

“Ha!! I will, I... [showing a non-verbal sign of dying] if I do not take my medication” (Tsepo, R)

“We always have that feeling all the time that if we do not take medication, we will die. They told us that.” (In unison, focus group)

This was anxiety-provoking for most young people and the messages that they were receiving were threatening rather than providing support.

6.7.7: Autonomy development

There was a generally normative developmental expectation from carers/parents that the participant's age, together with disclosure, would also increase the young people's independence in managing his/her healthcare and treatment management. Although most young people welcomed this expectation, it often created tensions as parents sometimes doubted their children's commitment to treatment. It raised issues of trust and mistrust, as it happened to this young person:

“I am assisted by my grandmother because they do not trust me when I tell them that I have taken medication, they want me to take it in front of them.”
(Brian, U)

Kang et al. (2008) argue that this ‘miscarried helping’ may not be in the best interest of the young person, as it can create a sense of inadequacy and incompetence in the face of the parents'/carers' expectations.

Some of the young people reported that they were taking medication on their own, but that their carers/parents assisted them. This autonomy was welcomed by young people; there was a sense of pride among the participants when they talked about their autonomy:

“I collect medication on my own, though my granny reminds me to take medication...I forget sometimes.” (Tom, R)

“...I collect my medication from.... hospital; it is easy because those with HIV collect the medication from their own clinic and we meet with others who have the same condition as us...so it is ok.” (Nto, U)

Developing autonomy was a negotiated process between these young people and their carers/parents, but it was also a contested issue. Parents/carers were sometimes entrusting these young people with enormous responsibilities in managing their care; given that some of these participants had difficulty in talking about their HIV status, the question is raised as to how were they representing themselves when they were alone in the clinic. The other question that this autonomy raised was how carers/parents responded when mistakes happened because, as Brackis-Cott et al., cited in Kang et al. (2008) observe, young people may have developed skills to make certain decisions, such as choice of peers, but they may lack the maturity to make future-orientated decisions and carry out tasks required to independently take their medication; Mellins et al. (2004) suggest that the high prevalence of behavioural challenges and neurodevelopmental delays among young people living with HIV and taking ART may further compromise their ability to manage their healthcare independently.

Although young people's autonomy in managing their treatment is welcomed, those decisions should be managed with care and they should be age and context appropriate, because if mistakes happen, they may lead to parental distress and frustration, and eventually the young person may be labelled as lazy, ungrateful and oppositional (Anderson & Coyne, 1993). This phenomenon is described in detail in the carers'/parents' narratives.

6.7.8: Illness as anxiety provoking

Recurrent infections are one of the issues that young people living with HIV/AIDS have to deal with. Many of these perinatally infected young people had survived a decade of life because of antiretroviral treatment, and they had survived various opportunistic infections associated with HIV. Most of the young people in this study reported that they were terrified of being ill. Most participants had recovered or were recovering from prolonged sicknesses

such as TB, pneumonia, chronic diarrhoea, etc. Others could still remember that even at a young age, they had been sick and hospital visits were familiar. Knowing their HIV diagnosis and being on antiretroviral treatment did not provide an assurance of perfect health; therefore the possibility of being ill and eventual AIDS death was an ongoing fear. The onset of any illness raised uncertainty and anxiety about the nature and course of the illness, which Heyman (2010, p.124) note is to be expected in such instances.

“...I do worry about my health, because I do not know how long I’ll be living, how I will suffer...all that...” (Sam, U)

For HIV positive young people, being ill can be a frightening experience, and these feelings could be expressed in various ways; however, young people rarely spoke of or communicated these feelings.

“Sometimes when I start to have headache, I sleep or sometimes I would cry a lot, then they will give me medication.” (Thabang, R)

“When I am sick, I just cry because of pain.” (Mpho, R)

For some of the participants, the anxiety could be disabling, often presenting with physical symptoms

“When I am sick, sometimes I feel myself being very cold, as if I am dying...hhha [form of exclamation]. I feel like I am running out of breath when I am sick...”(Thabang, R)

The young people’s accounts of anxiety are similar to the narratives of young people living with cancer, who also experience anxiety with any slight ailment and about what the future holds (Grinyer, 2007).

Illness caused significant changes in the lives of young people, such as severe loss of weight; one of the participants noted that other young people in her class started teasing her because of her loss of weight. The pressure to maintain ideal weight can also be exacerbated by HIV-related stereotyping in South Africa, which associates thinness with being HIV positive. The study that was conducted in South Africa to explore the perception that people who are thin are HIV positive indicated that 69% of the participants associated being thin with being HIV positive (Matoti-Mvalo & Puoane, 2011).

6.7.9: Managing parental loss and its aftermath

The cumulative loss in the lives of these participants was striking. For most participants, the pain of losing parents was still raw, entrenched by the pain of losing support at a critical point in their lives. Parental loss seemed to add further complication to living with HIV, as it deprived them of the parental support. It did not seem as if talking about their loss was getting easier; their loss was still uncomfortable and private to share with others. The introduction of this topic, however, evoked hidden vulnerabilities. Although they could talk about other events in their lives that were traumatic, parental loss was an all-encompassing pain that permeated all areas of their lives. One of the participants responded briefly while gazing down, “*Kuyasilimaza emoyeni*”, which is loosely translated as “it hurts our innermost being”.

Parental loss included loss of a parent because of abandonment. One participant, whose mother abandoned her at a very young age had been sexually abused, indicated that not knowing her mother was distressing and she longed to know and forgive her. This young person said: “*I also miss her [mother] when I hear other children talk about their mothers; it is painful because I do not know what happened to my mother*” (Sam, U). The emotional pain was too distressing and any additional pain, trauma and maltreatment would trigger feelings of the loss of safety and security from the parent. This void among young people was so unbearable at times that it affected school performance and day-to-day living and at times it was an underlying issue for most of the psychological problems such a suicide attempt in one instance. This was the pain that they had to learn to live with in addition to subsequent traumas. Although families do manage to reconstitute themselves, as reported earlier, the cumulative effects of loss may deprive these young people of emotional stability and threaten their overall wellbeing.

Below I discuss the young people’s perceptions of how they maintained normality. I describe young people’s thoughts, actions and interpretations of managing the conditions that they perceived to be de-normalising their lives, and how they counteracted those conditions.

6.8: Maintaining Normality and a Healthy Self

Maintaining a healthy sense of self after knowing about HIV diagnosis was a central theme in the lives of the young people. Given that most young people were growing up in families where expression of opinions was not encouraged, and open communication about HIV was considered an ‘unsafe’ topic often characterised by being vague and unidirectional, it was

important to understand how young people normalised their experience of living with HIV and other challenges within their context. Zeigler and Nelms (2009) define normalisation as a process whereby a person with a chronic illness chooses to function and be perceived as normal while focusing on the positive things rather than the negative experience, while Charmaz (2000) stresses that normalisation involves attempts to contain the impact of the illness on everyday interaction. Whilst these conceptualisations are useful, applying these definitions in this study might be problematic. Firstly, most young people in this study did not have physical or visible ailments that prevented normal everyday functioning; they were functioning normally and participating in daily interactions. Normalisation in this context was an active process that began with knowing about their health, implying that without open disclosure, beginning a process of normalisation of HIV was perhaps impossible, since the major focus was the ability to manage HIV identity and its meanings rather than managing physical changes only. Secondly, rather than being a cognitive-based choice of focusing on the positive rather than negative, normalisation in this study also encompassed activities to minimise the onset of illness, thereby maintaining a healthy sense of self and identity while minimising the likelihood of being known to be HIV positive. It also involved negotiating everyday stressors within their environment to maintain a state of wellness and normal functioning.

I begin this section by outlining participants' perceptions of the meaning of HIV diagnosis, which portrayed that young people did not focus only on disruptive events associated with being HIV positive; there was also an active process of striving for continuity of life and maintaining a normal sense of self. These experiences were captured in two major categories, which are: 1) positive reframing: identifying the positives from pain, and 2) managing personal secrecy and shame.

6.8.1: Positive reframing: identifying the positives from pain

Young people valued being told and there were personal benefits derived from the experience. At the core of the young people's experience was the perception of what HIV diagnosis meant to them. Young people gradually redefined the negative impact associated with HIV, and focused on the positive experience associated with knowing about their HIV and being on effective treatment that made them able to enjoy normal childhood. Therefore, positive reframing referred to participants' reinterpretation of a potentially negative situation to identify what was positive within it. Three subthemes associated with this theme emerged

from their narratives. These were: 1) strong will to live; 2) valuing disclosure, and 3) efficacy of ART.

6.8.1.1: Strong will to live

One of the consistent themes among young people's narratives was a strong will to live and not die. This theme was associated with being hopeful about the future whilst acknowledging the uncertainty that accompanied their life. Young people's narratives indicated different concepts associated with a strong will to live. These concepts included specific references to '*acceptance of HIV status*', '*being hopeful*', '*not wanting to die*' and '*need for self-care*', as this young person indicated after knowing about his status: "*What came into my mind was that now I need to take care of myself and to take medication well.*"

Whilst the will to live was associated with the mental willingness to persevere through life, it was associated with specific actions to keep themselves well. One of the things that young people valued was being aware about their HIV diagnosis, as described below.

6.8.1.2: Valuing Disclosure: "It is good to know"

Being uninformed about HIV diagnosis was perceived negatively by most participants. Being informed suggested that young people were being valued and respected, as this young person suggests:

"It is good; it helps me to cope better and I would be angry if they did not tell me, they just gave me medication." (Sam, R)

Similarly to adults living with HIV, after the shock of the diagnosis, these young people felt empowered by being informed formally, as it helped them to understand why they needed to take medication and the implications of not taking it, as these participants described.

"It is very good that I know; it has helped me to take medication and to understand why I am taking them." (Brian, R)

Non-disclosure was perceived as a health risk factor, whereby one's health is deteriorating without one knowing and one is unable to minimise the risk of dying. Disclosure introduced 'risk thinking' among participants (Heyman, 2010, p.3).

"It is good, a...if you do not know, you can die without realising that you are dying." (Tom, R)

Disclosure afforded the participants opportunities to take an active role in their healthcare and increased their autonomy. This is consistent with their stage of adolescence, where the desire

for independence is heightened because of cognitive and physical changes as well as expanding social networks (Kang et al., 2008). Although these participants were being assisted by their carers to take their medication, they had a sense of pride as they talked about their increased independence in managing medication, which for some included collecting their medication from the clinic without adult supervision.

“I remind myself to take medication; I have a watch which tells me the time.” (Tom, R)

“My grandmother reminds me, but most of the time I remember on my own.” (Mpho, R)

“When the doctor told me about this thing, I told myself that I have to take care of myself and take medication well.” (Ben, U)

6.8.1.3: Efficacy of ART

Medication was an important aspect of maintaining health that all participants valued. Medication was more than a pill; it meant wellness, prevention of death and continuity of life. For others, the availability and efficacy of ART facilitated the acceptance of HIV status after disclosure.

*“When my mother told me, I was already aware that a person living with HIV can have access to treatment and **life can go on**. My mother was constantly talking about it; maybe if that was not the case, it was going to be hard for me to accept.” (Nto, U)*

Focusing on treatment and being conscious of taking medication as prescribed was commendable. The use of negative reinforcement to communicate to participants about treatment, such as ‘if you do not take medication you will die’, was not welcomed by most young people. Although it may have produced a certain degree of compliance, it also reportedly created unintended consequences of inducing anxiety and fear

6.8.2: Maximizing chances of survival: being a risk carrier and at risk

Young people had to consider the riskiness of being HIV positive and its uncertainty, which included managing personal risk and risks to others. Being protective of themselves was interpreted as avoiding adversity to themselves to maximize their chances of survival.

“I cannot afford to do bad things; I have to be protective of myself in things like sex and when I have blood from a wound.” (Sam, U)

Good planning and being prepared was important to some of the participants, so that they could enjoy their lives better. Some reported that they understood that they had to take care of themselves and that included being prepared when they were going away

“...I worry about that when I am travelling, if it is cold, and that my body would react, I would have flu and cold sore; however, I do not allow that to disturb me. I enjoy to the fullest because I still have time. If I go to church camps I carry all my medicine in case I get sick.” (Zonke, U)

The perception of minimising the risk to others was also evident among the participants; it was a notion that most carers/parents instilled in young people, they had to learn to carry a risk label, and Heyman (2003) refer to people who carry such risk as ‘carriers of riskiness’.

“My grandmother told me that I cannot have a girlfriend because I can infect her.” (Ben, U)

Participants therefore understood that they had a responsibility to minimise risks to others. Heyman (2010) argue that this sense of responsibility to others could be driven by a moral judgement, in this case from those who expect the young people to manage risks to others and to play a more active part in protecting others from them. Clearly young people living with HIV may already be experiencing what Heyman (2010) term ‘adversity foregrounding’, where young people are seen under the same umbrella as adults living with HIV, a perception which is often based on AIDS stigma and beliefs that people living with HIV are “Intrinsically different from others; responsible for their own behaviour; and should have their behaviour restricted so that they do not threaten others with HIV transmission”

6.8.3: Controlling personal secrecy

Keeping and sustaining one’s HIV diagnosis secret was seen to be helpful in maintaining normality. Most young people were informed by their carers that they should keep this information to themselves and not share it with others, but young people wanted to keep this secret for personal reasons as well. They wanted to maintain control of whom they told, how and when, even though this was not always easy. Calculated decisions were being made to maintain their diagnosis as a secret but the possibilities of information leaks were always present. Although most young people reported that they were not ashamed about their HIV status, they were however aware that their illness carried stigma and a negative perception among their peers. The decision to tell or not to tell was a tactful, self-negotiated process which was not straightforward. This section therefore outlines the participants’ management of their illness and disclosure from within different social domains. Three subthemes were

identified that were associated with this theme. They are: 1) the paradox of HIV secrecy, 2) negotiating peer disclosure and 3) negotiating intimate relationships.

6.8.3.1: The paradox of HIV secrecy

HIV has always been associated with stigma, secrecy and negative perception. Participants were therefore careful to keep their diagnosis secret and not risk it being known unintentionally and, as Goffman (1963) describes it, to ‘pass as normal’; it was a survival strategy which maintained a sense of normality. Whilst keeping HIV secret was important for young people, parents/carers reinforced this behaviour.

“My granny always says, ‘If you tell other people about my...I will give you a serious hiding’...I do not ask her why.” (Thabang)

“My grandmother told me not to tell this to anybody, so I have never told anyone.” (Tony)

“My granny told me not to tell other people, but I also do not want to tell.” (Tom)

“I have never told anyone; I do not want them to know that I am sick because they will tell other people and people will laugh at me.” (Tsepo)

Keeping HIV diagnosis secret was also related to protection of self and avoidance of perceived risk. Although secrecy was considered a safer option than facing the unknown consequences of telling others, it was undesirable. Yet it created a safe space to prepare oneself for openness whilst being in control about who to tell and when to tell. This was an important function of keeping the secret and it maintained the sense of normality and, to a certain degree, a healthy sense of self. Young people were concerned about the impact of losing that control if they told other people, such as their peers, and about possible rejection and unwanted negative attention. Whether the risk was real or perceived was difficult to determine, as the young people’s perceptions were mainly based on imagined situations. Having said that, Saffer et al. (1979) argue that this ‘burden’ of keeping the family secret can be detrimental to the young person’s psychological wellbeing; this is an issue that Sherman et al. (2000) refer to as a cruel paradox: wanting to share the secret with others yet being afraid of the possible outcome and rejection. However, this study did not suggest that young people perceived it as a burden; instead it provided time to deliberate how they could negotiate HIV tasks that involved peers, such as social disclosure, and to calculate the risk and uncertainty associated with informing others.

“...I would like to tell my best friend, but I am scared that maybe she will tell everybody...I do not know... It is really...really...good sometimes to keep it, people will be passing...passing it to the community. Eventually the whole community will know.” (Sam)

Below, I explore this notion of secrecy and openness among these participants within two social domains: peers and intimate partnerships.

6.8.3.2: Negotiating peer relationships

Intimacy and self-disclosure have been hailed as important hallmarks of friendship development and sustenance among young people (Berndt & Hanna, 1995; Sherman et al., 2000). Friendships often involve a certain degree of self-disclosure, yet Clark (2009) cautions that self-disclosure does not always have positive effects; sometimes unintended consequences do occur and this points to the risky part of self-disclosure. In this study, the following categories were identified: participants who perceived benefits and risks yet had a desire to disclose; those who perceived risks yet identified no benefits and therefore had little desire to disclose; and finally those who did not consider disclosure as important to them at that time, therefore it was not considered. Peer relationships had to be negotiated within the sphere of secrecy about their HIV diagnosis. In order to achieve that, the goals for most participants were minimising unintentional disclosure and minimising suspicions. This could be seen as understandable, since the lives of the young people were characterised by repeated hospital visits to collect medication and some had chronic illnesses which they believed could attract unwanted attention. These experiences were fully guarded and negotiated carefully to minimise the risk of raising any suspicion. It was for this reason therefore that being confronted by their peers about their HIV status jarred their ‘safe haven’ of secrecy, as happened to this participant:

Interviewer: *Is there anyone among your friends who has ask you directly about your HIV status?*

Participant: *Yes, Zamo has asked me whether I have HIV.*

Interviewer: *How did you respond when he asked you?*

Participant: *I said no I do not, but I got scared that maybe he knows.*

Interviewer: *Do you wish to talk to your friends about this?*

Participant: *Yes, but I am scared.* (Ben, R)

For young people who had a desire to tell others about their diagnosis, yet were concerned about perceived risks, this process had to be negotiated on their terms.

“...if I want to go in public, if I have not decided that people around me should know that I am this and this and that, I do not think that it is right for them to tell. It should be my decision to tell.” (Zonke, U)

For most of the participants, disclosure was a process that was complicated and most participants opted for avoidance strategies.

“...I have not told anyone, I am not ready...I am not sure when I will be ready but when I am ready, I will tell only those that are important.” (Nto, U)

Participants that disclosed to their peers considered the benefits and risks when they disclosed; some openly disclosed and others used ambiguous words such as euphemisms, or an indirect reference to HIV.

“I told my friend...I trust her; I said to her, ‘If I am not at school, I am at the clinic to collect medication, am now taking medication.’ I told her because I did not want her to be confused when I am not at school...I also told her not to tell anyone and I know that she has not told anyone.” (Ziyanda, R)

The perceived risks associated with disclosing did not deter this young person from taking the initiative to tell her trusted friend:

“Mhh...I could not talk to my friends, but there was this time,...mhh...I became strong and I called one of my friend and when I called, I said there is something that I have been told, would you run away if I am HIV positive? And she said, ‘Come on, why would I run away because of your status? Because it does not mean you will infect me, I know how to take precautions.’ I told her and she was so shocked. She started touching and asking how I was...what I like about this one, she calls me on the side, whispering to remind me to take medication if I have missed my time...” (Zonke, U)

The positive feedback obtained from this single disclosure event could affect subsequent disclosure processes and encourage more openness, as this participant continued to purposefully disclose later. However, negative responses can deter the desire to disclose in the future as was evident in this young person’s experience

“It is like...like when I play with other children, they do not even wanna...there is this child from the neighbourhood that does not want me to touch her; I guess even children from the neighbourhood do know now. That means they have been told by children from home... It is better not to tell anyone [crying]” (Mpho, U)

Negative response from disclosure does have devastating outcomes for the young people and often they are unsure about how to handle those dilemmas.

“...there is this other girl that used to stay near my home. I think she [a friend that she told] went there, and she said to her “uZonke (name of the participant) is this and that”. She was my friend and I trusted her that she would not go and expose me to other people. What I expected from her was to protect me if I am doing something wrong and tell me that I should not be doing this, but when she did this, I went to ask her. Those people came to ask me that this girl has said you are like this and that; I kept quiet and said ‘Hawu²³! Has she said that?’ And they said yes and I said ‘Hey I will ask her where she gets this information from.’ I went to talk to her and said, ‘Girl...I trusted you,’ and she said she does not know what came over her, she does not why she said it and she had thought that because these are also their friends it is OK for them to know, and I said, ‘Girl, if I wanted to tell all of you I was going to call a group meeting and tell you all, but I trusted you since we have been friends for like, for long nine years, so why would I tell people that I have known recently in our friendship?’ And she was like, ‘I am sorry,’ and my trust with her was broken, and then I realise that since she is now aware I must be prepared to handle whatever comes my way...” (Zonke, U)

Peer disclosure in this study is anchored around the young person’s right to self-determination and trusting the young person that she/he can make a decision about what is best for her/him when she/he is well supported. The adults’ instruction to young people to hide their HIV diagnosis was not adhered to all the time. There was evidence to suggest that keeping HIV secret may be a temporary measure for some, so that they can maintain a healthy sense of self; with time, participants made their own decisions about how to manage self-disclosure. Others kept it to themselves yet they desired to tell, whereas others decided to tell. They may have taken a risk by telling others but this was a learning process that served as an antecedent for future disclosure goals. Maintaining control of self-disclosure reduced being overwhelmed by these experiences, as they risked losing control of their secret once it was passed to the next person.

²³ A Zulu version for being astonished

6.8.3.3: Secrecy and silence in intimate relationships

Similarly to peer self-disclosure, intimate and sexual relationships among these participants were another platform where HIV secrecy and silence were maintained. Even though intimate relationships were desirable, decisions about the onset of an intimate relationship brought the complications of disclosure and its morality; again this has been widely reported in literature (Levine et al., 2006). If disclosure was contemplated, the next challenge was how to do it, and preparedness to deal with its consequences. One of the participants, relating her paradox, said:

...there is this other guy, I used to like him a lot but I could not go out with him, was held back because I knew I was like this, because if you are in a relationship with someone, you have to be honest, so what is the point of having a relationship when you know that you have a secret that you are hiding from him? I was like, you know, I am still young; I will still find someone that will love me for who I am. Eh, but then I worry about my granny and then this thing is here...I can handle this thing. I even practice in the mirror and change the voice, practicing to tell somebody. So I do not date anyone because I am worried that if he finds out, then he would leave, thinking that I would infect him, he would go like that.” (Zonke, U)

Most young people did not report being in sexual relationships, but clearly HIV disclosure in intimate relationships was a challenge. It was associated with benefits if accepted and risks of rejection.

“...I have a partner, but he does not know. In fact he does not know anything about me and I do not know much about him either. It is just a casual relationship. I do not want him to know; besides, we do not have a sexual relationship.” (Sam, U)

Self-disclosure in peer and intimate relationships were attempted in relationships that were perceived to be close and intimate; however, young people that disclosed had a motivation and a desire to do so. Most studies have indicated that young people living with HIV do have desires to have a sexual relationship, and some are already in sexual relationships (Levine et al., 2006; Birungi et al., 2009). However, open communication between young people and their carers was uncomfortable for most carers.

“I discuss my thoughts with my grandmother, but I can see that when I introduce this issue, her face changes, she does not like talking about this; she told me that one day I may meet someone who is the same like me, and then I will not worry about infecting him.” (Zonke, U)

6.8.4: Enjoying normal childhood

Enjoying childhood may be an automatic process to most children but to these participants it had a significant meaning because of illness and changes within the family. Grinyer (2007) notes that regaining normality was also significant in young people with cancer, and it relates to participating in routine activities which may appear insignificant to others, yet are important to these young people. I have already outlined previously how significant it was for young people to manage the process of disclosure to their peers. Since they could not accurately predict the reactions of their peers, most of them were choosing to keep their HIV diagnosis secret so that they could integrate with their peers without fear.

Moments of sadness were reported as unavoidable and certainly not a one-off experience, as children living with HIV experience good and bad days (Sherman et al., 2000). In reference to this, one participant reported how he coped with bad days and he said, *“I go and sleep and I try not to think about it.”* Although this may be interpreted as avoidance, these young people certainly did not have any other way of dealing with sad moments, which they were bound to experience often. Part of enjoying childhood meant that these young people had to find their own way of managing sadness and pain in their lives. Whilst some reported avoidance, other participants reported that acceptance was helpful.

“When I was told about this, I was hurt, but I have accepted this, it does not worry me anymore.” (Nto, U)

Young people talked about various things that were important to them and these included the ability to play, have friends and to be in their own homes (*ekhaya*), where they could perform household chores and be with their families. Participants from the rural setting expressed these sentiments:

“When I come from school, sometimes wash the dishes and then I go away to my friends and we play till late.” (Tom, R)

“My favourite thing is to hunt birds; I made my own isihlilingi²⁴ with rubber and when I come back from school, me and my friends will either play out in the field or we hunt the birds; if we catch one, we come back and make fire to roast them. I have made many of these...” (Tsepo, R)

²⁴ A Zulu word that comes from an English word called ‘sling’. Sling is a projectile weapon typically used to throw a blunt projectile object such as a stone. It is commonly used by boys in this community to kill birds.

“I do not want to talk about this all the time, it hurts. I wish it would not come to my mind but I think about it every day; when that does happen, I let it pass from my mind.” (Brian, U)

Young people described school as an important social institution where they met and talked to their friends. Most young people reported that HIV was not one of the issues they talked about with their friends; they talked about ‘general stuff’. School served an important function: it was identified as a source of HIV information and a social institution. The approach that was being used by teachers when referring to HIV was being noticed and analysed by the participants. On the basis of their teacher’s approach to HIV when talking in class, they were able to conclude whether their teachers were likely to be supportive or not. However, most participants identified a school as an environment where it was important to maintain their HIV diagnosis as a secret to avoid the negative reaction from peers.

As previously mentioned, most young people did not feel that they wanted to tell their friends about their diagnosis, but they valued peer support and friendship, as it normalised their childhood. Acknowledging the use agency in managing disruptive and painful events in young people’s lives is critical; this approach moves away from problematising and seeing the lives of young people living with HIV within a ‘diseased’ frame of reference.

6.8.5: Family support

The role of a loving family can never be underestimated in the care and support of young people living with HIV and taking antiretroviral treatment. If the family cannot provide that necessary care and support, it becomes difficult for young people to feel secure and loved. Despite poverty and lack of resources, many were content with what was available to them. One of the participants said the following, in relation to her grandmother:

“...I found that I am not short of friends; my grandmom is my friend, my nurse my grandmom, and a doctor, and she is my adviser. I talk to my grandmom about everything, but when it comes to boyfriend stuff, she changes her facial expression. I can see that she is not interested in that...” (Zonke, U)

“I am happy about my life... ’cos...I have a family that supports me and everything I need I get it.” (Sam, U)

In this section I have discussed how young people maintained a sense of normality, a helpful process in maintaining a sense of self after HIV diagnosis. ART and disclosure were at the core of this discussion, because knowing about HIV and ultimately understanding how HIV

treatment worked and its impact on their health contributed to improving the young people's perception of having HIV, from being negative to being a condition that they could live with. Moreover, young people engaged in HIV tasks that enabled them to negotiate HIV identity and HIV secrecy in their social spaces without being at risk of their status being known unintentionally.

6.9: Conclusion

In this chapter, young people's interpretations of their experiences of living with HIV and taking antiretroviral treatment have been presented. The complexities associated with HIV disclosure, navigating the meanings associated with living with HIV, maintaining normality as well as managing family and environmental challenges emerged as the main core themes of this chapter. Moreover, this chapter raises significant themes in relation to young people's use of agency to manage the experience of living with HIV, to know about their HIV status, negotiate the uncertainty of living with HIV and maintain normality. This chapter indicated that despite many challenges that young people face in relation to the experience of living with HIV and family challenges, young people were not passive recipients of whatever was doled out to them and in many ways young people were making sense of their diagnosis and taking an active role in determining what was happening in their lives.

In the next chapter, I integrate the main themes that emerged from the three findings chapters and their implications for young people living with HIV.

Chapter Seven: Discussion Chapter - Maintaining Normality and a Sense of Self within a Context of Vulnerabilities and HIV Uncertainty

7.1: Introduction

Young people's agency is a concept that is widely used to refer to the young people's competence, intelligence and action (Valentine, 2011; Smith, 2009; Blue-Bond Langner & Korbin, 2007). There is a growing uneasiness in literature about the conceptualization of young people's agency, which tends to focus on young people's competence and rationality without acknowledging the impact of non-cognitive factors such as the young people's environment, culture and class. These non-cognitive elements can contribute to how young people exercise their agency within the different contexts (Valentine, 2011). In this study, young people who are HIV positive and how they negotiate meanings that are attached to the experience of living with HIV are discussed. These experiences and meanings are discussed in relation to how young people use their agency to negotiate HIV related experience, manage changes that occur in their families, which in turn affect the quality of care that is given to young people.

Young people's experience of managing HIV can be traced back to their positioning in families and how such positioning impacts the involvement of young people in issues that are considered by adults to be 'sensitive' and perhaps distressing for young people to manage. The unequal power relations between young people and adults that exist globally and in South Africa are widely recognized in literature (Van der Heidjen & Swartz, 2010; Preston-Whyte, 2003; Norman, 2011), whereas young people's social standing in families limits their voice from being heard in family and public spheres. Furthermore, the silence and secrecy that continue to feature prominently in most families affected by HIV seem to maintain the status quo of voicelessness among young people. The culturally based expectations of how young people should participate in relation to decision making seems to disregard the inputs that young people make and can make. To a large extent, this was a normalised cultural experience for young people, however, in the era of HIV, the expectation from health care workers was that young people should be told about their HIV status and the source of their HIV infection. In most instances, telling young people about the source of their HIV infection inevitably discloses parental HIV status or if parents are deceased, HIV disclosure brings to the fore discussions of parental death. These discussions were considered by carers to be too sensitive for young people and perhaps best kept a secret by adults who were viewed as

capable of managing such knowledge. Involving young people to such an extent was a new experience for most carers, since most young people had never been consulted or informed formally about such issues. This was also a threatening experience for carers and parents.

In this chapter, four themes that emerged from the study, in relation to the young people's experiences of living with HIV and the use of young person's agency, are discussed. The first theme is young people's use of agency in relation to HIV disclosure and their journey towards knowing about their HIV diagnosis within a context characterised by HIV secrecy. The second theme is inextricable linked to HIV disclosure where young people carry a 'title' of being considered as 'disclosed to', regardless of how disclosure was conducted and being disclosed to is characterised by specific expectations from carers and health care workers. Young people appeared to understand these expectations which tended to focus on the clinical and health aspect of the HIV such as treatment compliance and participation in their health care. Conversely, young people's perspectives of knowing about their HIV diagnosis had multiple meanings which included social, personal and health meanings. Therefore, the second theme delves into young people's multiple meanings associated with living with HIV and how young people negotiate these meanings. The third theme describes young people's use of agency to maintain normality whilst negotiating the meanings and interpretations of living with HIV. The fourth theme focuses on young people's family context and caregiving practices and young people's use of agency to manage changes that occur within their immediate context. Young people's agency and resilience permeate these four themes and indicate that even in most challenging circumstances, young people have agency to negotiate their lives, but that their use of agency is limited by structural and familial constraints.

7.2: Children's Agency and Disclosure Complexities

7.2.1: Challenges of disclosing to the child

The literature has indicated that young people's HIV disclosure is associated with complexities where carers may recognize the importance of disclosing to the young person but be hesitant about actually telling the young person (Arun et al., 2009; Moodley et al., 2006).

"...how do you tell child things like these? Even an adult cannot handle it, what about a child?" (Gogo Queen)

Carers were concerned about young people's reactions and the distress it would cause if young people were told that they were living with HIV. Whilst protecting young people was a

central concern for carers, carers appeared to have underestimated the negative impact associated with not telling young people about their HIV diagnosis. Moreover, concerns about openly disclosing HIV to young people appeared to have contributed to the emergence of various patterns of HIV disclosure. These patterns include disclosing without mentioning the exact name of the disease such as HIV or AIDS, mention that the young person has a disease that is similar to that of his/her mother, or mention that the young person has an illness based on the young person's clinical condition at that time (Oberdorfer et al., 2006; Funck-Brentano et al., 1997).

Funck-Brentano et al. (1997) categorize these patterns of disclosure into three, namely open, closed and partial disclosure, the latter being where the exact name of the disease is not used and the young person may be deceived or selectively told information, and HIV is hidden under other conditions that are unrelated to HIV. These patterns of HIV disclosure indicate the different methods that are used by carers to manage HIV disclosure to young people. Conversely, studying young person's disclosure through a young person's lens reveals a complex and active process where young people were trying to get information prior to being formally told by carers and were dealing with emotional difficulties associated with knowing by themselves.

This study adopts four awareness contexts as described by Glaser & Strauss (1963) (see Chapter Six). Glaser & Strauss introduced a theory for understanding different awareness contexts of dying and how informing patients about their impending death was played out during the interaction between dying patients and healthcare workers. Four different awareness contexts, i.e. closed, suspicion, mutual pretence and open, are described. These classifications illustrate the interaction between patients and health care workers and how such knowledge can be managed by both 'actors'. Health care workers and those around patients can facilitate or inhibit the achievement of awareness of impending death by patients.

The avoidance of telling plays itself out in a 'drama' between patients and healthcare professionals, where the patient may be unaware about his impending death, even though everyone else knows, and that information is kept from the dying person. The dying person may also suspect and attempts may be made to either confirm or invalidate the suspicion.

In this study, these four awareness contexts were adopted to illustrate young people's level of awareness in relation to their HIV diagnosis. Below, I discuss young people's interpretation

of the HIV disclosure and their perceptions about the role of HIV disclosure in managing the experience of living with HIV.

7.2.2: Open disclosure as a recognition of the young person's right

This study indicated that HIV disclosure was critical to young people. Being told about their HIV status was symbolic and seen as recognition of their right to know. The term '*kufanele ngazi*' (loosely translated as 'it is right for me to know') was used to symbolize the high value that young people accorded to knowing about their HIV status. The qualitative study conducted by Vaz et al. (2010) with young people, ages 8-18 years, who live with HIV in Congo, indicated that young people felt that knowing about their HIV status was "important and necessary" to them. Some of the studies conducted with carers of young people living with HIV indicated that after knowing about their HIV status, carers noted that young people were more likely to actively participate in their health care and their adherence to treatment improved, moreover young people indicated willingness to know about their condition (Kallem et al., 2011). The right base discourse for young people to know about their HIV status has been raised in the study that was conducted in South Africa, with carers of young people living with HIV. In that study, 98% of carers that participated in the study indicated that young people had the right to know about their HIV status (Moodley et al., 2006). Therefore there is greater emphasis among young people living with HIV that being told about their HIV status is critical and participants in this study viewed knowing about their HIV status as carrying a symbolic value of participation in their health, taking responsibility for their health and being informed. Disclosure was a gateway for taking responsibility for their lives. One of the participants, stressing the urgency of open disclosure, indicated that without it, "...*singafa singabonanga*" (loosely translated as 'we can die without knowing') (14 year-old-boy).

South Africa is a signatory to important international children's rights instruments that seek to promote the rights of children to be informed and to participate in decision making. International instruments such as the UN Convention on the Rights of the Child (1979) (article Nos. 12, 13 and 17), as well as South African legislation such as the South African Constitution, Act 108 of 1996 and Child Care Act (No. 38 of 2005) contain sections which seek to promote the best interests of the child and the right to participate and to be informed about issues that affect them. Being informed was not only seen as beneficial by young people, it is clearly also well within their rights.

As mentioned earlier, few young people living with HIV are told openly about the cause of their illness, especially in resource-limited contexts (Kallem et al., 2011), and these findings were corroborated in this study. Most participants were told about their HIV status when they were 10 years old or older. At the time of disclosure, some young people were already suspicious that they could be HIV positive. Failure to disclose about an HIV diagnosis has been reported as increasing the young person's anxiety, fear, loneliness and sadness (Vaz et al., 2010; Instone, 2000; Abadia-Barrero & LaRusso, 2006). Although this study did not isolate these psychological outcomes, it can be assumed that young person's active process of looking for information about their health was partially encouraged by the need to know. Deteriorating health without adequate explanation, unconfirmed suspicions of being HIV positive and fear of death are some of the factors that perpetuate fear and anxiety among young people who may be suspicious about their health, yet be unaware whether they will get better or not. Below, I describe the young people's process of achieving a state of knowing, which was driven by young people themselves with minimal adult intervention.

7.2.3: Young person-initiated process towards knowing

The current literature on disclosure is predicated on adult perspectives which place disclosure as an adult-initiated process. Disclosure is perceived as a process that begins when the carer/parent decides to inform the young person about his/her HIV status (Fielden, 2011; Mellins et al., 2002). I have labelled this as a *formal* disclosure process, a term that distinguishes it from a process of knowing that is initiated by a young person. Information about young people's efforts to obtain information about their health has been reported in South Africa and also in Burkina Faso (Hejoaka, 2009; Kouyoumdjian et al., 2005).

These studies indicated that young people with HIV and taking antiretroviral treatment were constantly asking their carers about the cause of their illness, and carers would either avoid the question or attribute the illness to some other aetiology. Conversely, Kouyoumdjian et al. (2005) reported that carers confirmed that young people sometimes knew about the cause of their illness prior to being informed by adults, as one of them overheard her child pleading with God to remove HIV from his body. Although these studies have indicated that young people can know about their HIV status without being formally told by adults, how young people arrive to knowing about their HIV status on their own is often not understood.

Nevertheless, these studies have shown that young people have an active interest in understanding and accessing information about their health prior to *formal* disclosure.

Therefore this study bridges this gap by discussing young people's own journey towards knowing about their HIV status. Two significant issues related to disclosure were raised: the young people's use of agency to gain knowledge about their HIV status within an environment that is characterised by secrecy and silence about HIV, and secondly, to do so within a culture where the young person's right to be informed and to express him/herself is not necessarily congruent with the prevailing social position of the young person which encourages a subservient stance. As mentioned earlier, Glaser & Strauss's analysis of awareness context was employed to analyse young people's states of knowing in relation to HIV, namely, closed, open, suspicion and mutual pretence (see Chapter Six). The suspicion and mutual pretence periods were managed in a gentle yet intelligent way. Young people delicately negotiated these processes within the constraints of adult-child power disparities, structural barriers, and the silence and secrecy that are dominant among HIV-affected families. Young people who indicated that they knew about their HIV status prior to formal disclosure had kept this information to themselves. It can be argued that although young people discovered this information, they recognized that it was outside of their boundaries to know it. This parallel world of adults and young people, where adult issues are not supposed to be known and discussed by young people, was understood by these young people. In the KwaZulu-Natal context, this secrecy is widely referred to as '*izinto zabantu zabadala*', translated as 'these are adults' issues'. Preston-Whyte (2003) points out that this secrecy is a mechanism that maintains relations and power between young people and adults, and it is closely related to respect, a pervasive concept in the African context.

One study that was conducted with young people with leukaemia, exploring their awareness of dying, argued that formal reasoning, which is defined as rule-governed, does not offer an adequate explanation for the use of skills that young people employed to understand their ill health. This study indicated that in the midst of silence and secrecy, young people used a wide range of skills obtained through formal and non-formal reasoning, that is, the ability to use innate skills such as intelligence, experience and creativity, to reach more robust information about themselves and their families (Hoffmaster, 2011).

This study has indicated that knowing about their HIV diagnosis was an important step towards building young people's resilience and strength to manage their illness. Without knowing, their participation in illness management would be compromised, and they would not think about their health as in need of protection, as one of the participants indicated: "*It is very good that I know; it has helped me to take medication and to understand why I am*

taking them” (Brian, R). In this study, young people employed different methods accessible to them to understand what was happening in their lives and to advance their knowledge of HIV. These included using observation, past experience, knowledge, illness experience and adult confrontation as tools to acquire knowledge. These methods, as I call them in this study, were not used uniformly by young people; some relied only on their observation without confronting their carers, whereas others confronted their carers after observing suspicious events. Therefore, the use of these tools was dependent on how relevant they were to suspicions that had been raised, as well as on young people’s agency and confidence to act on them. This reframing of the lives of young people living with HIV shifts the dominant discourse of seeing young people who are HIV positive only from a paradigm of vulnerability and riskiness, to a perspective that recognizes young people’s agency.

7.2.4: Building knowledge: child-initiated processes

7.2.4.1: *Observation and listening*

Observation is a readily available tool that young people employ every day. However, when young people were sick, these observations became even more specific as they looked for information that could provide explanations for their questions. Activities and communication among family members was a useful source of information. When young people attended clinics and hospitals, they got a sense of the critical nature of their illness and feedback about their illness. The young people’s ill health may not have been talked about openly, but the covert ways that were used by adults to hide information from young people became a source of curiosity for young people, and they observed this interaction. Through their observations, young people began the process of making connections and slowly built their information. When young people were asked during the research what they had noticed, often they would simply say *‘ngangibona kodwa mina’*, meaning ‘I could see’.

One of the participants, talking about how she discovered that she was living with HIV, said: *“The treatment that I was taking was the same treatment as my mother’s; I knew what the treatment was for, and so when they started giving me this treatment, I realise that it was for HIV”* (Ziyanda, R). School played an important role in educating these young people about HIV /AIDS, and was cited as the main information provider since most families did not have television sets and they did not read newspapers.

7.2.4.2. Illness experience

Recurrent and prolonged infections provided valuable information to young people. Illness experience may not have provided direct answers pertaining to the cause of the illness, but it raised questions about the source of their recurrent infections and/or ongoing treatment, even in the absence of any visible or felt illness. Young people who observed their parents' and siblings' ill health, and their subsequent demise as a result of HIV, gained valuable knowledge which became the basis for associating their illness with that of their parents. Illness experience raised questions and suspicions about what was happening to their health and whether their illness was similar or different to their parents'. One of the participants who had seen his parents' ill health and their demise began to suspect HIV when he fell ill:

"I began to be sick...I had sores all over my body and I was losing weight ...my parents had been sick and they passed away...so when my granny told me, I was suspecting it because I had seen the same illness to my parents."
(Tsepo, R)

7.2.4.3: Adult confrontation

One of the readily available sources of information is parents/carers; however, rarely do they provide the complete truth about the nature and course of the young person's illness. In this study, some of the participants did confront their parents/carers and they were told what was happening about their health. Parent/carer confrontation often took place after the young person had made a substantial investment on his/her own to try and understand what was happening about his/her health. They asked because they wanted to know and they were concerned; this may also be an indication of the fear and anxiety that young people experienced as a result of not knowing about the cause of their illness.

"[crying]...my mother passed away, maybe when I was four. I then stayed with my grandmother; then when I was...older...maybe five or seven years, I asked granny to tell me what killed my mother. Then she told me [crying] ...and then I started getting sick; actually when I asked her, I was already sick, I was sick...sometimes I will be admitted in hospital...I was sick often. She eventually told me what I had." (Sne, U)

7.2.4.4: Young person-initiated process of knowing: what does this tell us?

The young person-initiated process of knowing indicated several things; firstly, it challenged assumptions that young people were a 'clean slate' prior to formal disclosure. Young people came with experience and knowledge that they had accumulated from various sources, as indicated above. It also demonstrated young people's use of agency in contexts with limited

resources and resilience in navigating the process of knowing. Thirdly, this process showed that young people wanted to know and they were active in the process of knowledge acquisition. Although the current literature relating to disclosure regards adults as gatekeepers of disclosure, this study indicated that while the young people's process of knowing relied on their carers for information, if it was not provided, they used other sources accessible to them. In figure 7.1, young people and carers 'different approaches to HIV disclosure is presented.

Summary of the process of knowing: for the adult and for the child

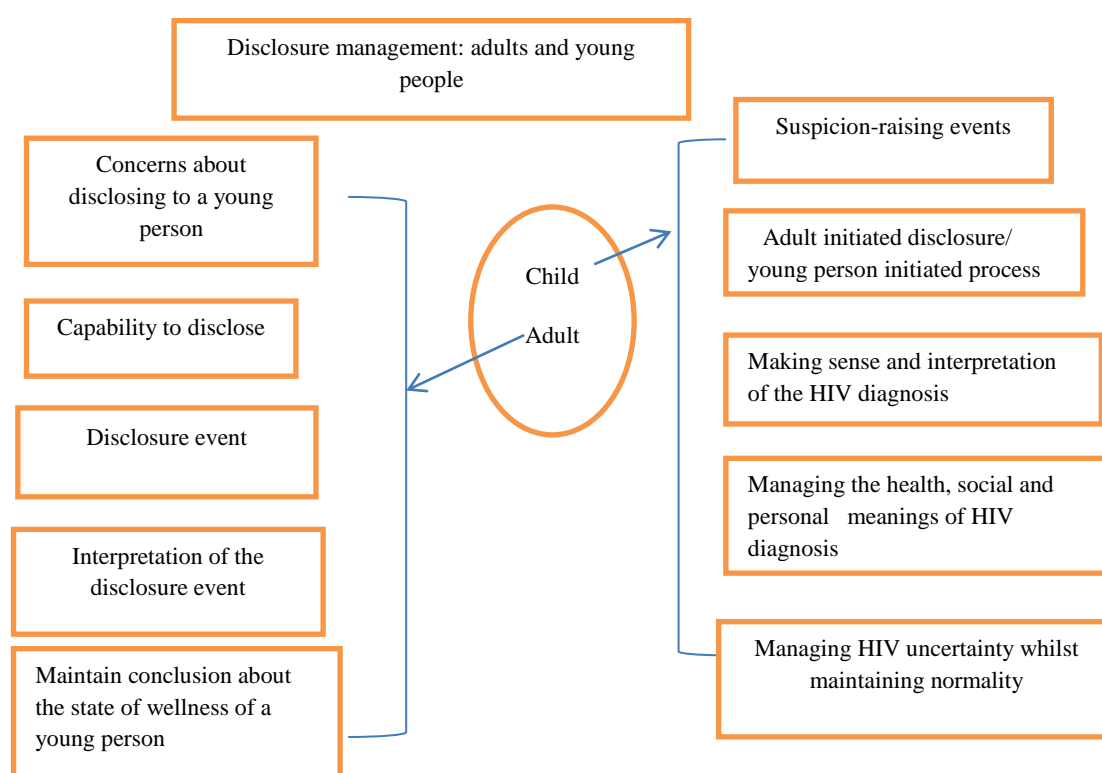


Figure7.1: Young person and adult initiated disclosure process

7.3: Young people and agency: Managing the meanings associated with living with HIV

Antiretroviral treatment has made it possible for young people living with HIV to remain largely unidentifiable and to maintain a state of wellness that enables them to participate in activities that other people without HIV participate in. However, sociological studies indicate that chronic illness is also a largely social issue (Nettleton & Gustafsson, 2002; Giddens,

2006; Nettleton, 1995). HIV diagnosis may not have effected a profound physical or visible change among the participants in this study, in that participants maintained their independence and they were mostly physically well; however, living with HIV had specific meanings for the young people in the sense of being the same yet changed, and the implication of possessing a discreditable image, which Goffman (1963) describes as a carrying an attribute that is invisible yet potentially stigmatising. Bury (1982; 1991) suggests that there are two meanings to illness: one is meaning as a consequence, which relates to the effects of the illness on everyday tasks and life; secondly, there is 'meaning as significance', which refers to the inferences given to the illness and people's reaction to it. HIV, as an illness that has a negative and moral judgment attached to it, impacted on young people's future prospects; it raised health uncertainty and issues of being at risk of being ill and being a risk to others. Young people had to think about their lives and future alongside these uncertainties. Moreover, young people had to think about how they positioned themselves as young people living with HIV within meanings and interpretations about HIV which tend to be negative.

In chapter six, nine sub-themes that emerged from young people's narratives as tasks that they had to negotiate and make meaning of, were discussed. These themes are: HIV diagnosis as the turning point, adjusting to knowing about the diagnosis, managing personal risks and HIV uncertainty, treatment side effects, adherence to medication, autonomy development, illness as anxiety provoking, managing parental loss and its aftermath. The overarching theme was that young people's interpretations focused on various dimensions which included their social, personal, health and family life. Young people recognised the challenges associated with living with HIV; however this experience was re-framed to resist the negative label and meaning associated with the disease. The meaning was therefore associated with balancing the negative meaning and experience while considering how the negative experience could be minimised.

The deconstruction of needs of young people by carers indicated that carers seemed to minimize or did not identify many of the issues that were central to young people living with HIV. Most young people used their agency to negotiate the experiences mentioned above since adult involvement was either minimal or lacking. Carers were being challenged by two factors; firstly, communication with young people openly about their HIV diagnosis. Secondly, carers who had openly told young people about their HIV diagnosis seemed to have difficulty carrying the discussion forward with young people to include issues that were

critical for young people, most carers seemed to place a major emphasis on treatment related issues with minimal consideration of others issues that were critical for young people.

The gap between young people and carer's meanings of some of the issues that were central to young people was seen in relation to maintaining HIV secrecy. Maintaining HIV secrecy was considered to be important by young people as well as carers, and often carers would advise young people to keep their HIV diagnosis secret with little awareness that young people were making their own interpretations of what such decisions meant for them. The decision to tell others about their HIV status was complex and young people reviewed the decision to maintain HIV as a secret in terms of their needs at that time, the risks they were willing to take to keep the secret, potential risks they were exposing themselves to by telling others about their HIV status and the risks exposed to others by not telling them about their HIV status. Moreover, the decision to tell was not only based on young people's perceived ability to tell, consideration for other factors such as fear of possible rejection, concerns about being perceived as different and possibilities that they would be gossiped and laughed at, were important. Therefore, maintaining HIV secrecy was not only an adult-determined process, it was also constantly negotiated by young people themselves.

Below, I describe young people's agency in maintaining normality whilst managing different tasks of living with HIV in the midst of the interrelated factors which included structural challenges and normal childhood difficulties.

7.4: The meanings of living with HIV and Maintaining Normality: young people's experiences

Normality is used in this study to refer to the young people's ability to balance the distress and uncertainty in their lives, as well as to manage other challenges and be like other children. Young people negotiated environmental challenges within the family as well as HIV-related challenges. Whether their survival methods are perceived as helpful in achieving long term wellness can be debated. Normality was associated with survival and being resilient. Young people redefined what HIV diagnosis meant to them and they reconstructed how they could negotiate the experience of living with HIV in their own terms. They knew that they were dealing with a disease that was potentially terminal if not well managed, and this was anxiety provoking since most of the participants had been ill previously; therefore HIV-related illnesses were a reality. They also knew that HIV was associated with stigma,

and if they openly talked to peers and friends about their HIV status, people might view them differently.

In Chapter Six, I described key themes associated with achieving normality which were identified in young people's narratives. The first one described the young people's reinterpretation and reframing of HIV diagnosis. This theme encapsulated a wide range of intrapersonal and interpersonal actions that were carried out by young people to maintain normality, and these actions were focused on elements that young people perceived as important in helping them maintain their sense of self. The subthemes of this category included perception of the disclosure process as empowering, developing a strong will to live, valuing being on treatment and managing risks to self. The second theme had to do with ability to manage the social interpretations of living with HIV within social spaces such as peer and intimate relationships. This study suggests that maintaining HIV secrecy is not a passive process, young people may keep their diagnosis as a secret, but they are also thinking and observing how this process could be managed with minimal risks to the young person, an indication of young people's use of agency.

Balancing the contradictory feelings of death and hope was one of the significant tasks that young people had to manage. They were hopeful about their future but the reality of death was still evident, as this participant indicated: *"...lots of times, sometimes I would sit in my room, watch myself; I ask myself what if I die before doing this or I have not told someone things?"* (Zonke, U). Whilst the possibility of death from AIDS related illness was a reality, young people were also hopeful about their future and about their lives. Young people had a strong will to live, as most participants strongly agreed during one of the focus group sessions that they did not want to die, they wanted to live. This determination to live manifested itself through being hopeful about their future, as one of the participants who was partially disclosed to by his carer later remarked: *"I will live 'cos other people are also living."* He may not have understood what his journey of living with HIV might comprise of, but he had an innate desire to be well and alive.

Young people were concerned about their health; consequently being on ART was valuable to their health and general wellness. Some studies conducted with carers of children perinatally infected have indicated that young people with HIV and on ART seem to have challenges with adherence to treatment (Roberts, 2005; Hammami et al., 2004; Pontali,

2005). An adherence rate to ART of 95% is needed to ensure maximal HIV suppression (Allison et al., 2010; Hammami et al., 2004).

Whilst managing medication was seen to be challenging, in terms of the strict adherence that was required, young people's active agency in their treatment was noted and this was a trait that was generally expected by carers/parents. Most young people collected their own medication from the clinic or hospital unaccompanied. Many of them knew the names of their drugs as well as the times for taking them. Reminding aids such as cell phones and watches were reported as useful tools for improving adherence. Young people reported self-efficacy in this role and an excitement to be taking responsibility for staying healthy with minimal adult involvement, as one participant reported with pride during the focus group: *'I take my medication myself...and I sometimes remind my mother.'*

Despite young people's self-confidence and commitment to taking medication, barriers to non-adherence were reported by carers as well as young people. Forgetfulness was indicated as a major barrier, as well as competing demands where young people would be doing another task and may not always be mindful of the time. Whilst the positioning of young people as active participants in their care has been reported in a few studies, it has primarily been through the carers' lens (Hejoaka, 2009; Kouyomdijan et al., 2005); therefore the young people's subjective meanings attached to such engagement has not been adequately explored in literature. This study evinced the young people's deep appreciation for being on medication and for recovering from various opportunistic infections several of them had experienced. Treatment brought hope for their future and it normalised their lives. Instead of seeing their HIV diagnosis as a death sentence, they had learnt to love themselves and value their lives. This reinterpretation and reframing of their lives included being hopeful about their future.

"No, I love myself, I love my talents. I do not regret that I have HIV. It open my eyes and it does not mean my dreams have stopped. I think my life is gonna be great...I have goals, my house, my car and my wonderful husband." (Zonke, U)

Access to treatment for young people meant that they could have dreams and enjoy good health and a sense of wellbeing and not be reminded they were living with HIV. One of the participants indicated that prior to starting ART, she was extremely thin and always sick, and peers in her class would tease her for being thin. At the time of the interview, she had just started ART and she was gradually recovering and gaining weight, something that made her

feel better. Similar findings were obtained from a qualitative study conducted in KwaZulu-Natal, which indicated that adults valued ART as life-saving and that it brought a sense of hope (Phakathi et al., 2011). This study was conducted in KwaZulu-Natal to explore the views of community members regarding the use and accessibility of antiretroviral treatment. This study indicated that the availability of treatment encourages early HIV testing and it brings hope to people. Another qualitative study conducted in South Africa with young people living with HIV indicated that while they were facing a number of contextual challenges in their communities and families, they were hopeful about their future and about their health, despite the uncertainty of living with HIV (Li et al., 2010).

Disclosure as a tool that facilitated active participation of young people in their healthcare was critical. When young people understood the reasons why they had to take medication they seemed to be able to better manage living with HIV. However the young people still needed support; for example, this participant indicated her appreciation about her friend that she had told: “...*like about this* [referring to her friend]...*She will ask me, whispering...it is time* [reminding her to take medication].”

The identity of being *a risk* (potentially infecting the next person) and *at risk* (being ill, being stigmatised, being judged and ridiculed, being rejected) was critical to these young people. Being a risk and at risk was a challenge that they had to contend with throughout their lives and involved active decision making, awareness of behaviours that pose riskiness and ways of reducing the riskiness yet still experiencing the ‘normal’ life that is experienced by peers (see Chapter Six).

“I cannot afford to do bad things, I have to be protective of myself in things like sex and when I have blood from a wound.” (Sam, U)

Literature has cited risk-taking in relation to the sexual behaviour of young people that have been perinatally infected (Bauermeister et al., 2010; Birungi et al., 2009; Mellins et al., 2005). Mellins et al (2005) reported that younger people living with HIV between the age of 12 to 14 years were less likely to be sexually active and similar findings were also obtained from the study conducted by Bauermeister et al. (2010), where young people within a similar age range were found to be four times less likely to be engaged in penetrative sex when compared to HIV negative young people of a similar age. Conversely, a study conducted in Uganda among young people perinatally infected with HIV between the age of 16 to 19 years

indicated that participants had a strong desire to explore sexuality and a significant number of the participants (33%) had been involved in sexual intercourse (Birungi et al., 2009).

In this study, part of learning to live with HIV was negotiating one's position in terms of intimate relationships, an area of the young people's lives that was associated with the interplay of stigma, 'risk thinking' and fear of rejection.

"I even practice in the mirror and change the voice, practicing to tell somebody. So I do not date anyone because I am worried that if he finds out, then he would leave, thinking that I would infect him; he would go like that..." (Zonke, U)

Sometimes, in their quest to maintain normality among their peers, Young people that had a desire to have intimate relationships had started relationships, but they had refrained from any sexual behaviour or close intimacy with their partners.

"I have a partner, but he does not know. In fact he does not know anything about me and I do not know much about him either. It is just a casual relationship. I do not want him to know; besides, we do not have a sexual relationship." (Nto, U)

Self-disclosure, as a normal part of young people's development, was threatened by HIV stigma and concerns about impression management. Socio-cultural norms and standards about the appropriate image for being in a specific developmental stage, and young people's own internal image of themselves as evaluated within the broader social conventions, were seen to be contributing to a greater need to project a normal image (Buhrmester & Prager, 1995). This study indicated that among young people living with HIV, the negative impact associated with HIV was a great concern and young people were more likely to engage in tasks that regulated self-disclosing interactions, such as keeping their HIV diagnosis secret, being very discreet and highly selective about who to disclose to and when to disclose, and analyzing the effect of disclosing in relation to the benefits and risks

Perceiving young people's desire to keep their HIV status secret as a negative trait may not take into account young people's efforts to control their self-presentation. Buhrmester & Prager (1995) note that self-disclosure serves an important function in terms of gaining social input which addresses developmental concerns such as self-understanding and identity, in that the self-reflective discussion during self-disclosure can help clarify who the young person is and what he/she will become. However, among young people living with HIV, that conversation and validation through their peers was often a missing component; instead, most

young people were concerned about preserving their image. Very few young people in this study had disclosed to their peers, some of the young people reported being ridiculed when they were sick, some were being asked by their peers whether they were HIV positive and others were hearing negative HIV sentiments from their friends (see Chapter Six) and these negative experiences did not promote self-disclosure. Whilst keeping HIV status as a secret was preferred by many young people, the need to self-disclose was evident. Some of the young people 'tested' self-disclosure by using non-direct words (euphemisms) to drop information about their HIV status into the conversation. In this way, they were able to evaluate whether self-disclosure was threatening or not. Others were highly selective about whom they told. Although gender differences were not explored fully in this study, in terms of self-disclosure, females seemed likely to disclose whereas none of the male participants seemed to be contemplating self-disclosure at the time of the study.

Dealing with painful feelings could not always be avoided and young people had developed individualised ways of dealing with them, as this participant indicated: *"When I feel sad...I try not to think about it...I go outside and play"* (Ben). Perhaps in an environment that may not have many resources to express distress, young people find their own ways of dealing with pain and maintaining their sense of wellbeing.

The supportive family structure which included the extended family was a significant protective resource to young people who had access to it. Being protected from stigma, accepted and loved by their families was a key factor that enhanced young people's ability to deal with any distress they faced.

"I stay with my aunt...but her children [who do not live with her] support me, they pay for my school fees and they buy clothes for me." (Sne, U)

7.5: The young person's Agency and Structural Challenges

As indicated earlier, understanding the lives of young people living with HIV included understanding the dynamics of their lives and socio-cultural context. The demands of living with HIV, future uncertainty, fear of death, perceived stigma, treatment burden and side effects, parental loss, family related difficulties and normal developmental tasks all converged to increase the emotional burden on young people.

"I also miss her [referring to her mother] when I hear other children talk about their mothers who are coming back from work, who will bring nice thing [crying hysterically]." (Sne, U)

“When they talk to me like that...I do not like it...I go to the house and stay alone. I cry sometimes and I do not talk to anyone until I feel better... No one notices when I am like that.” (J, R)

Findings from this study indicated that parental loss exacerbated emotional distress for young people living with HIV. The psychological impact of parental loss was a significant theme among young people. Most of these young people had lost their parents many years previously, yet deep-seated pain was still evident and sometimes the pain was not easy to verbalise. For example, Mpho, one of the participants, simply cried loudly during the focus group when the topic of parental loss was discussed; she was unable to articulate verbally how she was feeling but her non-verbal response said much. Although some young people were happy with the care of their secondary carers, they still missed parental love and the security that they had felt when their parents were alive. However, the psychological and emotional needs of young people who had lost their parents were often overshadowed by the immediate concern of meeting economic and physical needs (Foster, 2002).

Since most of the young people were not told about the cause of parental death, some of their questions were left unanswered. Despite this, HIV disclosure was sometimes an opportunity for young people to hear about their parents’ death, as it mandated carers to refer to the cause of parental death when explaining the source of young people’s HIV infection. Whilst it was common practice in Zulu culture to discourage young people from death-related talk (Richter & Muller, 2005; Van der Heijden & Swartz, 2010), the difficulty of talking about their loss was an issue for young people. One study conducted in South Africa indicated that for young people who had experienced parental loss, their needs tended to be outward focused, implying that instead of presenting with internalised psychological distress, young people were concerned about their economic and social conditions after parental loss. However in this study, young people displayed greater emotional distress associated with parental loss. One of the members remarked softly that *‘kuyasilimaza emoyeni’*, loosely translated as ‘it kills our spirit’.

One of the studies conducted in South Africa with young people who had lost their parents as a result of AIDS indicated that those young people were unable to grieve openly about their parents’ death, or to talk to their families or friends as a result of HIV-related stigma, and young people had to bear this silence (Thupayagale-Tshweneagae, 2011; Richter & Muller, 2005). In this study, most young people were unable to describe openly how their parents had

died or specifically the cause of death if it was HIV-related, perhaps because no one had clearly described to them how their parents had died and what the cause of death was, or perhaps because they felt uncomfortable about associating their parents' death with HIV.

“Mhh, OK, I am not so sure what happened to my mother, but the only thing that I know is that she was sick, and ok...it went like this...I was still in primary, OK, she got sick and everything, she could not do anything. I was there, like, I had to help her out, every way that I could. After that they took her to the hospital; when they took her to the hospital, they had to leave me with my neighbours.” (Zonke, U)

It was interesting to note that when the cause of parental death was not HIV-related, the cause of death was clearly mentioned. For example, one of the participants lost his father as a result of suicide and the child clearly articulated the cause of death. Whilst parental loss as a result of HIV-related death may have limited their openness about their parents, being an ‘AIDS orphan’ did not seem to have made a difference in terms of how young people were treated within their families. Instead, risk factors of young people in families were associated with parental loss regardless of the cause of parental death.

It is now generally accepted that young people's development and wellbeing are influenced by a wide range of factors in the environment in which they live (Rochat et al., 2008; Richter et al., 2009) as well as family factors such as parental poverty, poor housing and an unstable family context (Farran & Cooper, 1986; Hosegood, 2009). This study indicated that poverty in the lives of young people living with HIV was common and it was affecting many areas of their lives, such as school attendance and access to regular and nutritious food.

“I get angry sometimes...sometimes they do not cook at home...I do not know why and when they do that, I get upset and I do not talk to anyone. I refuse to take medication when I am hungry...then sometimes they cook porridge for supper...” (Thabang, R)

Childhood poverty has long been reported as a critical issue in South Africa, and rural areas have been reported to have a higher prevalence than other areas (UNICEF SA, 2010). Moreover, deprivation in the environment and in families was associated with exacerbating poor educational outcomes for young people. Some young people would repeat each class several times without intervention or professional assessment. Since most of the young people also came from families with very low literacy levels, educational support and stimulation from their families was minimal. This had far-reaching consequences since young

people's lives would be difficult, not only because they lived with HIV, but because of the interrelated factors, including poverty and absence of opportunities in their environment, that provide space for young people to develop. Some of these young people seemed to be trapped in the cycle of poverty, with very little way out.

Whilst cognitive impairment among young people perinatally infected and living with HIV has been reported in literature (Koekkoek et al., 2008; Brackis-Cott et al., 2009), cognitive impairment has also been associated with the interrelationship between the young person's family factors and environmental difficulties such as violence, overcrowding and drug abuse. In a study conducted with school-attending children between the ages of 9 and 15 years, who were perinatally infected with HIV and on ART, poor verbal and reading abilities were identified (Brackis-Cott, 2009). However, similar findings were also obtained from non-HIV infected young people who were residing in impoverished environments, implying that perhaps risk factors for poor educational performance among young people living with HIV can be attributed to the intersection of HIV risks with those posed by environmental and family vulnerabilities. Violence and drug abuse were not reported as a major theme in this study; however, poverty and financial difficulties were major threats to young people's wellbeing.

Family-related factors had a significant impact on young people's lives. Young people's perceived support from families (including extended family members) was consistently associated with better coping among participants. These young people felt valued and supported by their carers, and this support enhanced their own perceptions about themselves and their lives, in spite of the deprivation of their families and communities. This requires understanding the complex lives of families, and perhaps it is necessary to consider that the inability of families to provide adequate economic and material support does not necessarily diminish the capacity to provide comfort and a sense of belonging for young people.

This study also indicated that whilst families were an important source of comfort for young people, some families were a source of distress and discomfort. Perceived stigma and neglect were reported by young people. This raised the importance of recognising young people's voices as significant contributors to understanding family functioning and how young people cope in their families. The recognition of the young people's voice in family issues and discussion appeared to be a significant factor, especially in relation to issues such as movement of young people after parental death. Whilst young people's participation in

decision-making relating to their care has been legitimised in South Africa through child protection legislation and instruments such as the Children's Act (No. 38 of 2005), this has not been easy to replicate in traditional family systems such as the fostering of young people after parental loss.

Most young people reported that they were not informed when they were moved to other households after parental loss. They were not necessarily against being moved, as they were being taken by people who were part of the family and shared care was an established norm in most families. What was questionable from the young person's perspective was the lack of the young person's involvement in the decision prior to being moved, and lack of follow-up within the traditional care system to monitor the young person's settlement in the new household. Often, feedback was obtained from adults in charge of the young person. In cases where young person's movement was not in the best interest of the young person, young people were uncomfortable about reporting negative experiences happening in those households.

Moreover, the capability to recognise inappropriate behaviour within their household was evident, as this participant indicated when we discussed his care: *"...things can be better if my father can stop drinking and use money from the grant²⁵ appropriately...he uses it to buy alcohol."* When asked whether he could stay with his stepmother, he replied by saying *"I cannot stay with that one because she fights a lot with my father..."* (J). The intersection of the child's right to participation, as articulated in the UN Convention on the Rights of the Child (1989) and the Children's Act (No. 38 of 2005), and the culturally defined position of the child in the family which leaves little space for the child's expression of opinion, seem to contradict each other. Young people's opinions were not actively or purposefully sought by adults, whereas clearly young people had their own perceptions about the situation in their households. Although the traditional care system for young people did not encourage the participation of young people in decision making as its core tenet, it was based on the need to ensure that young people grow up in a safe and family-based environment, confirming that family care and a sense of belonging is an important concept in the African way of life.

Perceived HIV stigma occurring in the household and in other social settings such as school was reported by young people, and it was a source of great distress. Some families would

²⁵Grants refer to the government's financial assistance programme given to carers of children under the age of 15 years whose parents have limited financial support. It is called the child support grant and about 25 pounds is given per month.

sometimes talk about the young person's HIV status inappropriately, and use this as point of reference when disciplining the young person. Whilst this was not common among all participants, it raised issues of how young people were being disciplined in families. Several studies conducted in South Africa with carers of young people that are orphans and non-orphans seem to indicate that carers have serious challenges in disciplining young people using corporal punishment, especially in an era where there is greater awareness of children's rights (Kiggundu & Oldewage-Theron, 2009; Nyasani et al., 2009; Norman, 2011). In these studies, young people were reported to be disrespectful, too demanding and too opinionated. Whilst these findings were not obtained in this study, young people showed awareness of inappropriate behaviour, including verbal abuse, which was instigated against them.

Interviewer: *How can you describe your life right now?*

Participant: *It is alright, but If I have done something wrong, I am reminded about my thing [referring to HIV diagnosis] [crying]. I am always reminded that I have HIV...my mom's sisters, they do not treat us well at home, they scold us and we do not know why...they tell me that I am nothing and I will die like my mother. (Sne, U)*

This seemed to be a common practice, where young people would be reminded about the death of their parents or about their own death when they were being disciplined; this was very hurtful to young people and they would deal with it on their own: *'I knew when I am not feeling well...they would ask me to buy Vodacom airtime and I would buy MTN [indicating that he gets confused]...I would go the room and stay there alone and cry sometimes...no one will notice.'* The experience of being stigmatised in the family was closely related to the orphan status of the young person. These findings indicate that among the young people that participated in this study, there were serious risk factors associated with living with HIV and parental loss. Most young people who reported a history of maltreatment, neglect and emotional problems were those who had lost their parents.

Whilst young people felt stigmatised and ill-treated by this behaviour, young people rarely used direct reference to HIV in their narratives and tended to use euphemisms like their carers/parents, such as 'my situation', 'this thing' and 'this disease', which Clark (2009) argues may indicate a conscious decision by the speaker to avoid using the 'actual' name, thereby avoiding the stigma attached to the disease.

Most young people presented with various kinds of emotional distress, however, these difficulties were often unnoticed by carers. Moreover, most young people did not verbalise their emotional distress to carers/parents; instead they tended to internalise their feelings or find a different way of dealing with the pain until they felt better. In addition, carers/parents tended to minimise young people's psychological wellbeing. They saw physical wellbeing as an indication that young people were also emotionally well.

In this section, I have discussed the structural challenges for young people living with HIV and highlighted specific risk factors with reference to parental loss and its impact on people's participation in decision-making, grief and subsequent care. Poverty, and its impact on the lives of young people living with HIV, was discussed in relation to young people's access to food and resources necessary for their development. Finally, caregiving to young people in families was discussed. Although the traditional system of care, whereby the extended family and wider social networks absorbed young people after parental death was often effective and some young people reported being well-taken care of, issues of neglect and perceived stigma in families were also reported. These difficulties also indicate that whilst the lives of young people living with HIV may be dominated by an 'HIV label', and focus may tend to be on clinical wellness and adherence to medical prescriptions, young people were still facing other vulnerabilities which need to be considered when working with families and young people affected by HIV.

Below, I discuss the prevailing family and caregiving practices for young people living with HIV.

7.6: Family and Caregiving Practices for Young People Living with HIV

The capacity of the family to provide appropriate care for young people living with HIV, and the family's response within the era of HIV, are key elements in shaping the type of care that young people receive. The literature on families and their response to caring for young people living with HIV has put forward three competing theories (Mturi et al., 2005; Beegle et al., 2010; Madavan & DeRose & Abebe & Aase, 2007). The first one is grounded on social rupture theory, which suggests that families and extended families are disintegrating under the strain of the HIV epidemic, and consequently the care of young people is severely compromised (Mturi et al., 2005). By contrast, the second theory suggests that the flexibility and strength of informal care practice and the active role of grandparents in caregiving of young people, if supported, can still meet the needs of young people (Beegle et al., 2010) and

The third theory looks at families in terms of a continuum of survival, where each family mobilises and responds to the crisis based on the type and level of distress being experienced and the type of resources available to it (Abebe and Aase, 2007), as indicated in figure 7.2

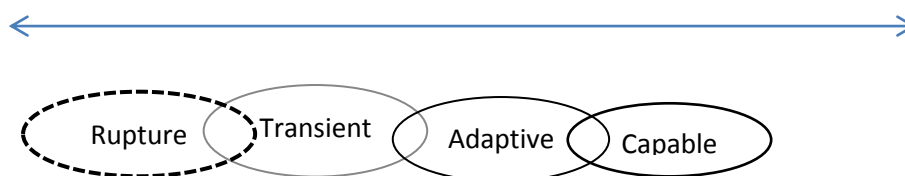


Figure 4.2: Continuum of household survival (adapted from Abebe & Aase, 2007)

Whilst all these three theories were helpful in understanding the responses of families during the time of distress, the functioning of the family and the intra-family dimensions of its members seem to be missing in this discourse. The capacity of families to meet the needs of young people has been deconstructed by Abebe & Aase (2007) who suggest that families have different capabilities and that the absence of financial support does not necessarily diminish the capability of the family to provide non-financial support to the child.

This study, however, indicated that there was a greater need to deconstruct the *inward* capacity of the family as well as the *outward* capacity. The inward process refers to the functioning of the family as a whole and the functioning of its members in relation to meeting the needs of young people and acting in the best interests of the young person, whether the capacity to care is adequate or not. The impact of poverty, social oppression or lack of opportunities for personal development appeared to have had an impact on the functioning and stability of families, because some families were characterised by social ills such as substance abuse, violence, conflict and family instability.

The outward capacity refers to the family's material resources to meet the needs of young people, and this includes the economic factors and availability of human capacity in the family or within the extended family network to provide care to young people, and to socialise them with cultural and social skills appropriate for their development.

Although poverty was a common feature that affected the economic status of most families, the government social grant²⁶ system mitigated the impact of this. For example, most young

²⁶ South Africa provides different welfare grants such as old age pension, child support grant, foster care grant and disability grant. Old age pension is given to women (60+ years) and men (65+ years) with no old age income. Child support is based on a means test; it is given to parents on behalf of children from birth to 15 years. The foster care grant is for children up to 18 years whose parents are deceased, while the disability grant is for children and adults with disabilities as determined by a medical doctor. All these grants are paid monthly.

people were in receipt of different social grants such as the foster care grant (for orphans) and child support grant (for young people whose parents have no visible means of support), and one young person was on a disability grant (for children with disabilities). This study indicated that although some families were well positioned and had access to the basic resources (human and economic), the needs of young people were not being met adequately and some young people were distressed because of dysfunction within the household. Conversely, other families had limited financial and human resources, yet within the resources available, they provided most of the basic needs of the young people such as food, shelter, education, adequate health care and the sense of belonging that the young person needed, in a way that respected and valued the young person. Rather than seeing families through the lens of their ability to survive distress and to meet the needs of young people, this study showed that, regardless of means and resources available, the healthy functioning of families is important for young people's wellbeing. Three different caregiving practices were delineated from this study and are discussed below.

7.6.1: Deprived yet childcare mindful

Some families were surviving the strain of the epidemic with very limited resources accessible to them. Although these families did not have adequate financial and material resources at their disposal, young people reported contentment with the support and love that was provided. These families were also at risk of further deprivation, yet its members were focused on building the family's resources to meet the needs of its members. An example is the case of Zonke, a 16-year-old participant who resided with her paternal grandmother, who was a pensioner. Previously, she had lived with her uncle and his wife and other siblings in another household. Whilst this couple had the means to meet most of Zonke's needs, she reported that she was ill-treated and neglected in that household until she was taken by her grandmother. Despite being old and a pensioner, the grandmother took her new role seriously and ensured she had relevant knowledge to understand more about HIV. Zonke reported that although her grandmother was old, she could talk to her about anything, and she indicated that her grandmother was the reason why she was alive and coping well with her diagnosis. A similar situation was observed with the Tembe family. Brian (16 years old) had lived with his maternal grandmother since both his parents passed away. The family had migrated from Mozambique more than ten years previously. This was a large family with seven members and they lived in a three room house, which was small for such a family. No one in that family had stable employment, although sometimes Brian's uncles would be called for part-

time contractual jobs. Brian's grandmother had a garden where she planted vegetables for consumption as well as to sell. Brian was attending school, although he had learning difficulties. His grandmother and uncles were supportive to him and he felt that he was well cared for. He thought that his grandmother sometimes made too much fuss about him but, despite the level of poverty around him, he reported being content with being around his family.

7.6.2: Capable yet unstable

Some of the families were capable of providing basic support and care for young people yet the functioning of family members led to an unhealthy environment for the young people. These are the environments in which young people reported neglect, domestic violence and substance abuse. While challenges such as violence in families are generally regarded as adult issues, young people are not passive actors. As reflected in this study, they witnessed abuse and violence, and it affected them emotionally. These families had the potential to meet the needs of the young people, yet young people's emotional and physical needs were not being adequately met. These young people exhibited much distress as a result of the conduct of their family members towards them.

Sne, one of the participants, came from a modest family. This was a large family with many children who were the offspring of her three aunts. Her maternal grandmother, a pensioner, was also in the household. Although the family was capable of meeting most of Sne's needs, Sne was unhappy and very sad because of the way she was being treated by her family. She felt that her HIV diagnosis was known by most people in her neighbourhood, and as a result, other young people did not want to play with her; she also felt that her aunts were stigmatising her for being HIV positive because they would often use her HIV diagnosis when reprimanding her and tell her that she would never be anything. She was concerned that her family treated her as if she was to be blamed for being infected. Although her grandmother was caring, she felt she was powerless to protect her when the aunts ill-treated her. Despite this family's ability to survive multiple loss and other family burdens, the behaviour of some of the family members was destructive to her, and consequently she was often distressed and appeared to have lost the will to live.

As stigmatising behaviour contributes to low self-esteem, exclusion and disadvantage (Holzemer et al., 2007), the intersection of these factors with children's 'minor' status results in their powerlessness and may lead to their rights being violated. This indicates that young

people's wellbeing can be compromised by the adults who are responsible for their care in families. Although focusing on the macro and mezzo needs of families was seen as critical in this study, this does not diminish the importance of working with families at a micro level.

7.6.3: Capable and childcare mindful

Some households had survived distress such as multiple deaths, poverty and deprivation and were stronger and capable of providing adequate care for young people. Young people in these households reported that they were happy and all their needs were being met. Although the young people had multiple needs, the family had the financial and human capacity to respond to these. An example here is the family of Sam: she was initially taken in by her mother's neighbours, having suffered a history of sexual abuse, after being abandoned by her mother. Her aunt then raised her and provided all the support that she needed, and her cousins were contributing financially to her education as well as being supportive to her. Unlike other young people in her neighbourhood, Sam was attending a multiracial school some way from her neighbourhood, and her family paid for her daily transport, school fees and lunch. She felt that her aunt was treating her like her own daughter. Whilst Sam was concerned about some of the HIV-specific aspects of her life, and the fact that she did not know her biological mother, she reported being content with her family and the support she had from them.

This classification of caregiving practices seeks to highlight the importance of understanding the specific risks and vulnerabilities that inhibit the optimal use of available resources that can enhance the functioning of young people. Reciprocity, willingness to care and capacity of caregivers to avail the necessary resources have been cited as key to provide good care to young people (Abebe & Aase, 2007). While willingness to care was considered as a duty by most carers in this study, in some families, it was undermined by long-held disunity among family members and specific risk factors such as substance abuse. Carers that were willing to care for young people provided non-material support such as protection, a sense of belonging and comfort, despite risk factors such as poverty, old age and illiteracy. This insulated young people from seeing their environment in a negative sense and caused them to admit that although their families could not provide all their needs, they were very happy and they felt loved.

The second type of caregiving case shows that the availability of financial and human resources is not necessarily a guarantee that the needs of the young person will be met. Issues such as perceived stigma and child maltreatment were evident. The third type of caregiving is

one characterised by close-knit families which had the means, willingness and commitment to meet the young person's emotional, physical and financial needs. Whilst young people from these families also experienced HIV-related challenges and other forms of distress, they were confident about the love and acceptance from their families.

7.7: Conclusion

This chapter has raised four themes in relation to the experiences of young people living with HIV. The first one is about young people and HIV disclosure and how HIV awareness is perceived and negotiated by young people. The second theme is centred on the premise that young people living with HIV attach meanings and interpretations to the experience of living with HIV and this meaning is negotiated within their context and through various social interactions. However, young people use their agency to manage various negative interpretations of being HIV positive. The third theme relates to the young people's use of agency to maintain normality, a term that is used in this study to refer to the use of various techniques by young people to balance the negative life experiences and lead what young people consider as the normal life that is similar to the life of other young people. This was a continuous process that young people had to navigate. The third theme describes the complexities of caregiving for young people living with HIV and the family construction and its impact on young people. This study has provided a detailed background of young people's community context and family life, and has argued that an understanding of young people's experiences of HIV must take into consideration these complex relationships and contexts. Analysis of the relationships and situations in young people's lives illuminates the importance of interpreting young people's narratives and taking into consideration their cultural context, history and the era in which the young people live. Whilst the experience is culture and location specific, the impact of wider social processes on the lives of young people cannot be underestimated.

This chapter is followed by the conclusion and recommendations chapter, which provides a summary of the study and highlights the distinctive contribution to knowledge that it makes.

Chapter Eight: Conclusion and Recommendations

8.1: Introduction

This study has explored the experiences of young people that are living with HIV and taking antiretroviral treatment in KwaZulu-Natal, South Africa. Drawing upon new social studies of childhood, childhood is conceptualised as a socially constructed process and young people are seen as active social actors within their environment (James & Prout, 1990). In a similar vein, this study has demonstrated that young people living with HIV are active in managing the experience of living with HIV as well as their health care. Similarly to social constructivism, childhood is seen as time and place specific, meaning that childhood experience is a localised experience. Therefore, the experience of living with HIV was impacted by the disease itself as well as other environmental and family factors such as care and support given to young people and access to resources that can mitigate the negative effects of living with HIV.

The clinical aspect of HIV is critical, however this study aimed to shift the focus from the medicalisation of HIV, where the lives of young people living with HIV are viewed through a lens of illness, medication, hospitalisation and HIV-associated pathologies, to a consideration of young people's interpretation of the meaning of their social, structural and illness experience, and how the combination of these factors shapes their lives.

Situating the experience of living with HIV within the context of structural and family issues, as well as that of young people's subjective experience, this thesis has illustrated a multi-layered approach to understanding the interaction of childhood experiences, which recognises young person's use of agency in managing their HIV experience and the social and personal meanings of living with the disease, as well as young people's navigation of social issues such as poverty, multiple loss and access to resources. While this study has demonstrated that social factors such as family deprivation, neglect and stigma do shape the childhood and HIV experience, young people's agency and resilience in managing the experience of living with HIV were also demonstrated, although these were exercised with constraints. This was evidenced within three domains: managing HIV disclosure as a young person-initiated process; managing the meanings of HIV diagnosis, and young people's active process of normalising and reinterpreting their lives with the disease. Being on ART reduced the overt illness identity of young people, since most of them did not present with visible indications of the disease; however, normalising also aimed at minimising the risk of being known to be

HIV positive, thereby avoiding being tainted by the moral judgement and stigma associated with HIV.

I have also argued that young people are often depicted in literature as waiting to be informed about their HIV status by adults, and young person HIV disclosure is presented as an adult-initiated process; however, this study demonstrated a different view: that disclosure can also be young person-initiated and young people's use of agency in this process was described. Young people's passivity may be possible if they are not exposed to any suspicion-raising contexts, such as ill health; parental death; use of ART in the household, and regular medical care and being on medication as these young people were. In communities where many people are living with HIV or have died as a result of AIDS, keeping the young person's diagnosis secret until they reach older childhood may not be feasible because of exposure to many suspicion-raising events. This study indicated that prior to adult-initiated disclosure; young people initiated their own informal process of trying to understand what was happening with their health status. They used resources available to them, such as adult confrontation, listening, observation and past illness experience to make connections between key events. One of the key findings in relation to disclosure was the value that young people placed on knowing about their diagnosis. This was viewed by young people in three ways: as a young person's right, as a process that enhanced young people's participation in their healthcare and as a way of improving access to information. Whilst literature has presented mixed findings in relation to the impact of HIV disclosure to children (Hammami et al., 2004; Mellins et al., 2004), this study indicated that short-term reactions may be characterised by sadness and hurt, but that in the long term young people were accepting of their situation. Disclosure was about taking care of their health, minimising risks, understanding the meaning of taking medication and negotiating the meanings attached to living with HIV.

This study indicated that, to understand the experiences of young people living with HIV, one has to recognise the interrelated factors that are beyond the disease aspects, and consider the social aspects of the young people lives, such as orphanhood, and context-related factors such as the environment of the child as well as the family structure and relationships therein. The intersection of these factors creates a distinct childhood experience. Whilst young people's experience of poverty, poor access to educational resources, parental illiteracy, parental unemployment and multiple losses had a direct impact on young people's emotional and physical wellbeing, understanding of the *needs* of young people needs to be multi-dimensional and take into account young people's subjective accounts. Growing up in a

family characterised by poverty, having a father who abuses alcohol and misuses the government grant money, and conflict in the home may not necessarily diminish the capacity of the family to provide a sense of belonging and social relationships that may be considered by the young person to be important; however, the capacity to provide adequate emotional and financial support may not be available. This calls for social work practitioners to consider that, although families may be affected by HIV, these families may also face social and family challenges that may exacerbate their distress. Focusing on the medical aspect of HIV with limited consideration of the family's functioning may have limited benefits or none.

Social ills such as poverty in the family, an unstable family context and parental loss exposed young people to violation of their rights, such as the right to appropriate education and the right to protection from maltreatment, neglect, abuse and degradation, as articulated in the Children's Act (No. 38 of 2005, Section 2 (b)). Moreover, the young person's right to have his/her HIV status kept confidential was sometimes violated by carers (Children's Act, No. 38 of 2005, section 133:2), who did not consider the young person's right to confidentiality and consent when deciding to reveal the young person's status to others, and sometimes such acts would create an uncomfortable and stigmatising environment for the young person.

Secrecy and silence as a result of perceived stigma about HIV may be seen as creating a burden on young people; however, it also created a 'safe' space within which to navigate the impact and meaning of HIV to self over time since perceived stigma was a concern. Whilst very few participants reported being stigmatised in healthcare establishments, schools, at home or by their peers, the concern to maintain their HIV status as a secret was an important task. Most participants reported that they had never been subjected to any stigmatising attitudes, but clearly that did not mean that they were not concerned about self-disclosing. Maintaining information control and secrecy had multiple meanings: they were associated with normality and negotiating self-disclosure. Other studies have indicated that the inability to communicate to others about being HIV positive, and HIV-related loss, can create a burden for young people (Sherman et al, 2000), this study indicated that actually, keeping their HIV a secret was not necessarily a negative trait. It was part of young people's own process of thinking, negotiating, testing the feasibility of self-disclosure before actually doing so. Secrecy was therefore an active rather than a passive act.

One of the key elements in young people's narratives was a desire to be normal and enjoy a normal childhood experience despite the negative effects associated with poverty, illness,

HIV stigma, medication or parental loss. Normality was a two-dimensional process of acknowledging the negative aspects of being HIV positive, such as illness uncertainty, fear and managing death-related thoughts, and seeing the positive aspects within the negatives. Young people used their agency to deal with negative aspects that were within their scope. Managing riskiness, perceived stigma and the meaning of being on treatment were some of the critical components of being normal.

8.2: Reflections on the Research Journey

This study was conducted in KwaZulu-Natal, South Africa, with young people who are HIV positive and taking anti-retroviral treatment. It was a cyclical process that began with seven individual interviews with young people. The data from these interviews was coded and analysed to identify key themes that were constructed, and a literature search was conducted to explicate these themes. The initial categories of meaning indicated that the socio-cultural context of young people and the conception of childhood itself were critical to understanding young people's responses to HIV.

Young people's family context, values and way of life, as well as communities' and young people's responses to HIV were found to be interlinked. On the basis of this, the next set of data collection included entering a community and concurrently collecting data from young people living with HIV, community informants and healthcare workers. Thereafter, semi-structured interviews were conducted with carers/parents of young people living with HIV. These data were coded and a further review of the literature undertaken to develop deeper understandings of the themes that emerged. Theoretical sampling was conducted with a child/carer family and another young person living with HIV and taking ART.

The journey of this research therefore began with a young person-centred approach and ended with a young person-centred approach, i.e. the further explication of key categories through interviews with a young person and his carer. This study involved being immersed within the community of Mpilo, where most data was collected.

8.2.1: Revisiting the Background

The conception of childhood and young people's experience of childhood are largely shaped by social, cultural and political factors within the environment; however, young people are also social participants in societies in many respects. This study was conducted in KwaZulu-Natal, South Africa, a country with a distinctive social and cultural background which has

shaped the childhood experience. This study was conducted in an urban site and a rural site, and both these sites had relatively common social and cultural characteristics, such as norms, values and connections. However, the rural community carried a greater legacy of apartheid policy and as a result there had been little development. Transportation, housing, access to clinics and hospitals, quality education and employment opportunities were still great challenges. Skill drainage, as a result of a high migration level which was largely circular, had become a key characteristic of most families, where people left their homes in search of employment opportunities in urban areas. As a result of this pattern, most young people grew up with extended family relatives or with single parents because of parental migration; being born out of wedlock was also a common occurrence in these communities (Mathambo & Gibbs, 2009). Young people grew up with multiple adults in their lives to whom they would become attached, rather than being accustomed to biological parents only.

Communality, extended families and their networks, as opposed to individuality and nuclear families, were important features of the way of life of most people within this context. The extended family and its social networks, such as neighbours and other groups in the community, are important relationships and connections that promote resilience. This communality alleviated the strain and burden of the HIV epidemic in families. Most young people whose parents had died had largely been absorbed by the extended family, as opposed to being sent to orphanages or government children's homes.

One of the most dominant cultural practices of the black people in South Africa, whether in urban or rural areas, is '*ukuhlonipha*' and a sense of '*ubuntu*'. The former refers to great respect which can be demonstrated behaviourally and linguistically. It can cover a wide range of circumstances from addressing elders or those senior to you, personal conduct during bereavement and child-adult communication (Dlamini, 1996). The concept of *ubuntu* acknowledges that 'I am because you are', which indicates the mutual dependence of humanity. These cultural beliefs underscore a way of life and the interaction between people in this context. Young people were brought up with a strong emphasis on respecting elders and being non-confrontational when approaching elders. This functioned as a means of regulating power differences between children and adults; as a result, young people may have had difficulties in expressing their opinions openly, especially regarding issues that are considered to be within the domain of adults. While young people were expected to respect their elders and to be obedient to them, expression of young people's opinions was not encouraged to a great degree, and consequently the recognition of young people's position as

beings with potential input and perceptions about their reality hardly surfaced. Norman (2009) noted in her study that although *ukuhlonipha* was an important value among the Zulu people, adult participants complained that modernisation and urbanisation was affecting young people's behaviour and respect was deteriorating among young people. This study indicated that adult-child power disparities were still dominant and it often affected young people's open expression and communication with adults. Young people were actively participating in clearly defined roles which were sometimes gendered. Females cooked, prepared fire for cooking, washed clothes and were sometimes left at home while parents went out to sell or were working in gardens. Girls were mostly involved in tasks at home, while males did not have such a structured role. Whilst this may be gradually changing, expectations of roles and responsibilities remained highly gendered.

As mentioned earlier, this study was conducted in an environment with a high prevalence rate of HIV; consequently, death occurrences were widely witnessed by young people and talking about loss and death had become a common occurrence rather than an exception and young people had to navigate the experience of living within limited means.

8.2.2: Main theoretical perspectives

As mentioned in Chapter Three, the theoretical framework for this study was social constructivism, a perspective which is centred on anti-realism, implying that our version of reality is socially constructed rather than existing 'out there'. This approach challenges researchers to take a critical view of our assumptions about the nature of reality and to question taken-for-granted knowledge about reality; and central to this approach is the importance of social interaction and socially constructed reality. This theoretical perspective was adopted since it recognised knowledge as historical and culture specific, implying that childhood can be seen as context specific. Moreover, since young people's language and interpretation of the meaning of their HIV experience was critical, it was appropriate to explore the multiplicity of young people's experience rather than search for objective truth.

This study utilised the approach that underpins new childhood studies which suggests that childhood is socially constructed. This premise gives prominence to the impact of variability of context and culture in shaping childhood experience. While this may be so, young people's agency in constructing their social lives is also recognised. Young people are not seen to be passive recipients of what their context reproduces. Ansell (2005) raises a key question as to whether all forms of 'doing childhood research' are acceptable if childhood is socially

constructed. As can be seen in this study, this raises issues of understanding the historical and cultural context of childhood and the children's subjective interpretations of their reality. Moreover, exploring childhood as a product of social interaction indicates how childhood constructions are reproduced in communities. While I recognised childhood experience as being socially constructed, the interpretative lens for data collected in this study was underpinned by the 1989 UN Convention on the Rights of the Child. In this convention, children's rights to protection, participation, survival and development have been clearly articulated, and South Africa is one of the signatories. Therefore the question that is raised by Ansell (2005), as mentioned above, is addressed in this study through the use of the child's rights lens when interpreting data.

8.2.3: Key research questions

1. What are the experiences of young people living with HIV from KwaZulu-Natal, South Africa?
2. Do young people from KwaZulu-Natal experience stigma, and if so, how is it managed and understood?
3. How do young people living with HIV learn about their HIV status and how do they negotiate the process of knowing?
4. What are the caregiving practices and family patterns for young people living with HIV?

8.3: Key Findings

8.3.1: Managing HIV Disclosure as a young person-initiated Process

In Chapters Six and Seven, I indicated that young people viewed HIV disclosure as critical and necessary for them. It was depicted as a process that *has* to be done, implying that being told about their HIV diagnosis was their right. Disclosure was viewed by young people as an important tool that opened avenues towards accessing information that enabled them to negotiate the social, health-related and personal meanings of living with HIV. This study indicated that there was a *formal disclosure event* that adults initiated, as well as a *young person--initiated process* that often began prior to adult disclosure. The young person's initiated process include the use of agency to access and look for information through available resources and knowledge, such as past illness, adult confrontation, observation and listening. This young person initiated process raises the importance of making technical medical information available to young people in a way that was understandable to them. In

this study, I have argued the importance of understanding young people's prior knowledge and past experience, and of adopting a participatory process where an adult and the young person both contribute during disclosure, rather than the unilateral process that seemed to characterise disclosure processes in most cases. Disclosure should begin from what the young person is aware of and proceed to what is not known. This process would thus become crafted and co-constructed in the interaction between the young person and the person disclosing. This then becomes a young person-led process and the focus is on allowing the young person to share information about his/her life in a non-threatening environment. This approach is based on social constructionism as well as a child's social ecology; through this approach, a young person's voice, experience and strengths are acknowledged. The person disclosing is not seen as an expert, since young person's prior knowledge and experience become the focus during disclosure and the person disclosing is guided by the young person's progress and need for information. One of the most disempowering scenarios in this study was the indication that often, the disclosure process was a unilateral discussion. Engaging young people as important contributors and experts in their lives and their care may increase young people's active participation as well as recognising their strengths and agency.

Treating disclosure as a process rather than an event was a central theme in this study (Fair & Walker, 2010). For most young people, the period after knowing was a journey that was filled with uncertainty; consequently, communicating patterns that encouraged asking of questions and expression of opinions was helpful. One of the interesting findings of this study was the use of euphemisms and indirect references to HIV or AIDS by carers when disclosing to young people. This was confusing, perpetuated shame and imposed silence on young people. As a result, despite being described as knowing about their status, young people disclosed to in this manner would not admit their HIV status, yet would talk about HIV-related experience; this suggested that perhaps they were uncomfortable about naming the disease. Helping carers to disclose to young people through open communication is clearly critical.

8.3.2: Managing the Meaning of HIV Diagnosis

Felt stigma, which is described as the innate feeling of being ashamed as a result of the illness, was a major concern, rather than an enacted stigma, which refers to negative reactions and discriminatory practices against people on the grounds of the stigmatising illness they have (Nettleton, 1995; Goffman, 1963). Whilst most young people did not report direct

stigmatising behaviour, they were concerned about their status being known and people's reactions to that, which they assumed were likely to hurt them.

Most secondary carers displayed acceptance and understanding about HIV; furthermore, there was familiarity with HIV since most of them had experienced personal losses, some were themselves living with HIV and taking ART. Few young people reported maltreatment by family members as a result of their HIV diagnosis. Whilst this was so, young people were aware that their illness was stigmatised, and therefore much effort was directed towards keeping their HIV diagnosis secret. Maintaining secrecy was often initiated by their families, who encouraged them to maintain their HIV diagnosis as a secret and referred to HIV or AIDS through the use of euphemisms and indirect speech. Terms such as '*this thing*', '*my thing*', '*taking medication*' and '*being sick*' were purposefully used to avoid naming HIV or AIDS, and perhaps this also served as a form of self-protection from the negative sentiments associated with HIV. The terms HIV or AIDS were felt to be more stigmatising than the disease itself. The use of these euphemisms was common in families and among all participants.

In the context of young people's care and peer support, HIV stigma and secrecy erected a barrier that prevented young people from sharing their stories openly with their peers. Self-disclosure could have generated a co-constructive dialogue through sharing of ideas and gaining deeper clarification and a better self-understanding about their lives and identity; however, young people had to negotiate this process carefully to manage the impression their disclosure would make.

Intimate and sexual relationships are kept secret from adults in IsiZulu culture; however, the added burden of HIV, with its stigma and risk label, was a barrier that prevented open relationships. Maintaining secrecy about their HIV diagnosis had contradictory effects for young people: it helped them to prevent perceived stigma, while it also robbed them of potential support from peers. Being silent and secretive was not an indication that they were not contemplating self-disclosure. Older children (aged 15-16) were seriously thinking about it and rehearsing mentally and practically, while others had already self-disclosed. Therefore the conceptualisation of young people's silence and secrecy would be best seen as a continuous process that was being negotiated, rather than a fixed state. This has important implications for practitioners who work with young people living with HIV. It raises issues of exploring young people's own active and continuous process towards self-disclosure.

8.3.3: Normalising the experience of living with HIV

This study indicated that the experience of living with HIV among young people was characterised by several key elements that enabled them to manage specific HIV-related challenges, such as illness, medication and health uncertainty, as well as context-specific challenges in their families and their social environment. Despite suspecting and knowing about their HIV diagnosis prior to being informed by carers, young people's initial reactions to being told were characterised by sadness and hurt; those that did not suspect described their reactions as being shocked. Living with HIV raised uncertainty about the future in relation to health, longevity, illness experience and social relations. Moreover, visible changes in their body, such as being ill and changes in body shape, as well as changes in how they perceived themselves, were evident. Their lives were engulfed by an HIV identity which they had to manage to maintain normality.

Families became an important source of much needed validation, acceptance and hope during the early days after knowing about the infection. However, HIV and illness-related challenges were not the only challenges the young people had to deal with; the social meaning of living with HIV was also a concern. They were concerned about being laughed at, people gossiping about them and being known to be HIV positive in their social circles. Consequently, being secretive about their HIV had multiple meanings: it was about preserving their image as untainted by HIV stigma and it relieved the fear of being perceived differently and of perhaps having to face the possible negative consequences of being known to be HIV positive whilst negotiating self-disclosure. This was an active process where sometimes young people had to lie to their peers and hide information that could potentially reveal their HIV status prematurely. While for most young people secrecy was preferred, it was sometimes also undesirable. Buhrmester & Prager (1995) contend that generally, self-disclosure to peers appears to increase during early adolescence as young people become more preoccupied about their sense of self-worth which emerges during this period. The meaning attached to approving and disapproving reactions by peers becomes more significant as compared to disclosure to parents. Fear of being 'disapproved of' by peers restricted open sharing and receiving feedback in relation to being HIV positive. Although maintaining secrecy may be perceived as an added burden on young people, they interpreted secrecy as necessary.

Most children came from families characterised by challenges such as poverty, cumulative loss, lack of income in the household, sometimes inadequate access to food, stigma and neglect, parental loss and maltreatment. The intersection of these factors and finding the resilience to deal with these issues was difficult for many (Elkington, 2011); sometimes their personal agency to deal with the distress was not enough (Atkin & Ahmad, 2002). However, the study indicated that it was important to recognise the subjective meaning of the situation for young people.

Whilst most families and carers were supportive of young people, regardless of whether they were orphans or not, evidence of neglect and maltreatment of young people, especially orphans, was evident. Maintaining normality was a key task identified in young people's narratives; it enhanced resilience to manage the distress in their lives. Whilst in some areas young people's agency was limited in the light of dealing with neglect and maltreatment, these challenges did not take away young people's agency to survive and recognise certain aspects within their families that were positive and which enabled them to cope, such as other members of the family within the wider extended network, friendships and playing.

Maintaining normality in this study was a combination of various factors that worked together to help young people maintain a state of wellness and survive the distress in their lives (as described in Chapters Six and Seven). Figure 5 presents key elements that were identified in young people's narratives as being important to them in maintaining normality and wellness. These elements were about young people's own interpretation of how they were dealing with the negativity surrounding being HIV positive, and they were task-orientated as well as cognitively based. The most important task was to know about their illness and navigate through the disclosure process.

Keys tasks in maintaining normality

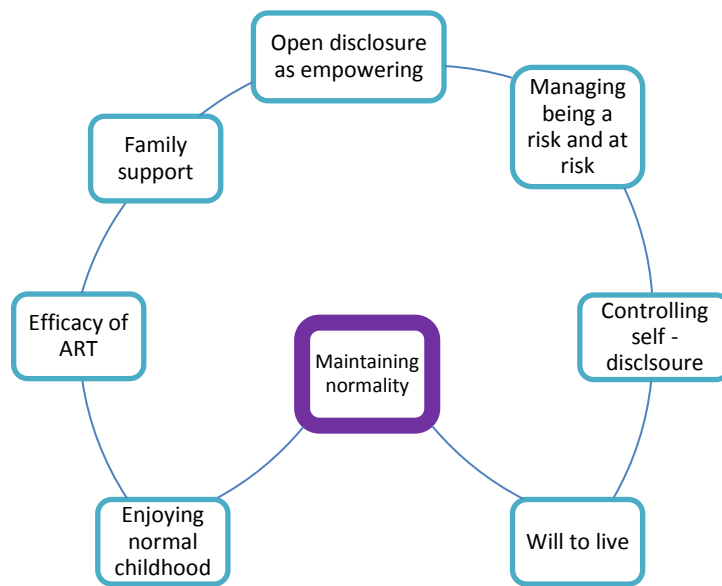


Figure 5: Maintaining normality

8.4: Practice, Policy Implications and Recommendations

8.4.1: Critical social work practice with young people

Social constructionism and the ecological model are two perspectives that were central to this study. Social interaction, meaning and contextual understanding of participants' lives and use of language as a construction tool were key social constructionist concepts that shaped the analysis of this study. These theories were particularly useful in deconstructing the experiences of young people living with HIV from a perspective 'outside of the disease'. In this way, the impact of multiple factors that intersected to create different childhood experiences for these young people was presented. This, I would argue, shifts the focus away from the dominant label of HIV to the multi-layered process that was the context of the young person living with HIV. The significance of these findings was that they challenged social work practice to critically deconstruct the lives of young people and move beyond the disease model, and to consider the structural analysis of young people and families affected by HIV and the young people's use of agency. Through this structural analysis, the lives of young people living with HIV may be seen to be confronted by widespread childhood difficulties common to most young people in this context, where multiple loss, poverty and

deprivation is common, as well as young people's social tasks and the meanings associated with living with HIV. I further argue that working with young people living with HIV should be a co-constructed process that enables young people to meaningfully participate, and that their concerns should be understood from their perspective.

Notions of power imbalance between young people and adults were raised in relation to the participation of young people in decision making, such as the movement of young people after parental death, expression of opinions and acknowledgement of young people's agency in managing HIV experience. This study evidenced young people's agency and resilience in managing a wide range of areas in their lives. It also indicated that young people, if appropriately involved, can offer valuable input from their experience of their lives and context.

This study challenged the current disclosure practices which seem to be centred on intentions to encourage medication adherence and enhance young people's participation in their healthcare. Young people's views of disclosure were centred on the need to know, participation and access to information that would empower them to make informed decisions. The study indicated that most young people came to the 'disclosure event' with prior knowledge and experience that could be shared during disclosure, so that the process could be co-constructed by the young person and the person disclosing rather than being a unilateral event dominated by the 'expert', who might be a parent, social worker or doctor. This type of practice can only be possible when the power imbalances between young people and adults are reduced, and when young people are considered to be competent, with knowledge that is valid. This is even more relevant within this context, where young people's expression of opinions is not encouraged. This challenges the social work profession to reflexively think of ways to reduce power dynamics between them as 'experts' and young people during sessions. Payne (2005) argues that this reflection should be more than reflecting on the situation; it should include thinking-in-action, when we are doing it, and reflection-on-action, after the episode. Social work practitioners may need to consider how power differentials between young people and adults are manifested in families in ways that perhaps undermine young people's participation and their use of agency. This is important when considering that young people have multiple risk factors which include living with HIV, a disease that carries a stigma, the fact that some are orphans, the cultural position of a young person and poverty. These factors may intersect to reduce the young person's use of agency and increase vulnerability.

This study also indicated that young people were hopeful and optimistic about their lives and future. Life uncertainty, fear and illness were acknowledged by young people as a reality, but they also had a strong will to live and to normalise the experience of living with HIV. They redefined what it meant for them to live with HIV. This shifts the focus from conceptualizing the needs of young people living with HIV from a ‘victim’ frame of reference, to using a strength-based approach to make sense of young people’s navigation of the process of living with HIV. This understanding leaves room for acknowledging young people’s unique process of navigating HIV experience, instead of labelling it in terms of whether it is appropriate or inappropriate, detrimental or not detrimental.

8.4.2: Young people’s agency and children’s rights

It was important to understand, in terms of the young people’s experience of childhood within their context, that in the era of HIV, young people were being shaped by their context and at the same time they were also shaping their context. Young people negotiated the experience of living with HIV and normalised their experience within a context that did not fully recognise young people’s participation in issues that were considered to be outside of their domain. However, despite these barriers, young people’s agency was demonstrated. This suggests that while young people living with HIV have different vulnerabilities, they are nevertheless actively engaged in their social world. Young people negotiated complex tasks of ascribing meaning to their diagnosis in relation to their identity, as well as to the social and psychological meaning of living with HIV in relation to stigma, self-disclosure to peers, managing silence and HIV secrecy, as well as learning to normalise their HIV experience.

The implementation of policies and programmes that seek to ensure that the rights of children in South Africa are met is one of the key strategies of the Government; however this is an ongoing challenge in South Africa. For example, this study showed that young people with disabilities were less likely to attend school, and generally, 10% of children between the ages of 7 and 15 years, regardless of their HIV status, do not attend school (UNICEF, 2011). Moreover, 11.9 million young people in South Africa live in income poverty, and young people from female-headed households and the poorest households have significantly higher levels of child hunger (UNICEF, 2011). Whilst maltreatment and neglect reported to the police is said to have decreased, it is of concern whether this is as a result of low prevalence or under-reporting. This study indicated that young people were unlikely to report their experience of maltreatment or neglect. This has significant implications for the identification and reporting of cases of young people abuse. A more young person-centred practice that

facilitates young person participation and open communication in a non-threatening context is thus recommended, to allow young people to be vocal about their negative experiences, which may not necessarily be related to their HIV diagnosis but are, however, critical to their survival.

Family construction and caregiving practices in the era of HIV are worth mentioning. Whilst most young people affected by HIV were absorbed by extended family and they were adjusting well in those families, understanding of the needs of young people within the family context was identified as crucial. Therefore it is reasonable to assume that enhancing the capacity of families to function and survive is critical. Acknowledgement of families' unique and healthy methods of survival, such as the use of wider networks of relationships which may include neighbours and friends to cope with the impact of multiple losses in families, was seen as crucial. Therefore, rather than importing familiar concepts that may have been used to define families prior to the HIV era, consideration must be given to recognition of the flexibility and multiplicity of family concepts, where sometimes the childcare is shared by multiple persons, sometimes residing in different households. This can be a method families may use to survive the impact of multiple losses.

8.4.3: Young people-centred practice for young people living with HIV

Principles: Open communication
Recognition of the child's rights
Maximise young people's participation
Young person -worker partnership
Recognition of young people as experts of their lives

A. Child disclosure

- Recognition of the child's right to know
- Maximise child participation
- Encourage open communication
- Improve child's access to information
- Disclosure as a co-construction process vs event
- Identify post disclosure short-term reactions
- Identify long-term child's reactions

B. HIV-related tasks

- Identification of medication related challenges
- Self-disclosure and rehearsals
- Mental health wellness
- Educational difficulties
- Management of perceived stigma
- Enhancing child's capacity to maintain normalcy

C. Family and environmental issues

- Recognition of family and the extended network in child care.
- Capacity of the family to care
- Family functioning and stability
- Intra-family challenges
- Carer wellness and capacity to care
- Poverty
- Family communication patterns
- Child-carer relationship

8.5: Strengths and Limitations of the Study

The strength of this study lies in the centre-ing of young people. Young people's personal experiences have remained key features throughout this thesis. The use of multiple sources of data provided a detailed analysis of the context of these experiences. Although this study has important contributions to make, it also had several limitations. One of its limitations was that most participants came from poor socio-economic backgrounds and most of them were either illiterate or semi-illiterate. The experiences of young people from more affluent communities in South Africa were not included. Although this was not intended, the two research sites where participant recruitment was conducted would be considered as communities with less affluent families.

The study was aimed at exploring the experiences of young people living with HIV residing in KwaZulu-Natal; however, as a small qualitative study, the universality of these findings cannot be generalised and regarded as the objective truth of young people's lives.

Nevertheless, the study raises valuable interpretative insights into the lives of young people living with HIV.

HIV affects all racial groups in South Africa; again this study did not include any participants from other racial groups such as whites, Indians or coloureds. This was again not a deliberate intention, and nor did the study have a specific aim to exclude other racial groups. The recruitment sites simply did not have any other racial groups. This may be largely as a result of the apartheid policies which segregated people along racial lines, and therefore residential areas are still predominantly exclusive.

8.6: Suggestions for Further Research

This study has focused on the overall experience of living with HIV and it has raised specific issues that need to be further examined in other studies; these include:

1. Examination of the lives of disabled young people who are HIV positive. Whilst this study has revealed important issues, it would be useful to conduct a longitudinal study that explores young people's ongoing responses to the experience of living with HIV. This may include how young people manage their lives over time, the gender dimension and its role in the lives of young people living with HIV.
2. Another other critical aspect would be to examine young people's services and programmes in South Africa, and specific ways that the needs of young people living

with HIV are integrated in those projects, as well as how they are used by young people.

3. The issue of young people living with HIV and palliative care was not raised in this study; however, not all young people that live with HIV survive to adulthood. Some young people become sick and eventually die from AIDS. Examining how palliative care and services for young people living with HIV are provided, and how families manage palliative care for these young people, is an important area of study.
4. Gender differences and their impact in young people's management of HIV tasks were not taken into account in this study; however, doing so could add an important dimension to how the lives of young people are understood.

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Appendix One: Summarised profile of young people

Participant	Sex	Age	ART collection point	Description of caregiver	Length of time on ART	School grade	Home language
Participant 1	Female	14	Public sector	Grandmother	Over 5 years	Grade 6	Zulu
Participant 2	Male	13	Private sector	Mother and grandmother	4 years	Grade 5	Zulu
Participant 3	Male	17	Public sector	Grandmother	1 year	Grade 4	Zulu
Participant 4	Male	13	Public sector	Grandmother	4 years	Grade 2	Zulu
Participant 5	Female	15	Public sector	Biological mother	2 years and 5 months	Grade 8	Zulu
Participant 6	Female	15	Public sector	Paternal Aunt	1 year	Grade 8	Zulu
Participant 7	Female	16	Public sector	No legal guardian except adults in her life	8 months	Not attending school. Left at Grade 8	Zulu
Participant 8	Female	13	Public sector	Biological mother; father deceased	4 years	Grade 7	Zulu

Participant 9	Female	15	Public sector	Aunt and grandmother. Mother deceased	2 years	Not in school	Zulu
Participant 10	Male	13	Public sector	Aunt	3 years	Grade 3	Zulu
Participant 11	Male	16	Public sector	Adoptive mother	8 months	Grade 10	Zulu
Participant 12	Female	13	Public sector	Biological mother	2+ years	Grade 6	Zulu
Participant 13	Male	13	Public sector	Grandmother	3 years	Grade 6	Zulu
Participant 14	Male	14	Public sector	Grandmother	2+ years	Grade 7	Zulu
Participant 15	Female	16	Private sector	Grandmother	4 years	Grade 11	Zulu

Appendix 2: Interview guide for individual interviews with young people

Themes and examples of the prompting questions

(Please note that these questions will be translated to a local language (Zulu) and the interview will be conducted in Zulu)

Introduction: Self introduction, name and general affiliation

Purpose of Interview:

1. General:

Example of the prompting questions:

- (Note respondent's) gender
- How old are you?
- Place of residence
- Tell me about your family (who is at home)

2. Education

Examples of the prompting questions:

- Which school are you attending
- How are you managing at school?
- Are you experiencing any problems at school? (if yes, what are the those problems and how are you dealing with them
- How are you managing friendship at school?

3. DISCLOSURE

Examples of the prompting questions:

- How did you found out about your status?
- What was your reaction? (is it helpful that you now know, if so how)
- What happened after knowing about your HIV status
- Have you told anyone about your HIV status?
- Has any family member disclosed on your behalf?
- How do you feel about public disclosure

4. Communication

Examples of the prompting questions:

- How comfortable are you to talk about HIV/AIDS and participate in the activities related to HIV/AIDS
- When people that you know talk about HIV/AIDS, how you do feel?
- How do you feel about the language that people use to refer to HIV/AIDS?
- Do you feel that the way you talk about HIV/AIDS is different from the way others talk about HIV/AIDS? (if yes, in what way)

5. Stigma

Examples of the prompting questions:

- Do you feel you have been treated differently because of your HIV status? (if so how ,by whom and how did you managed that process)
- Do you feel you are different because of your status? If so how?
- Have you been discriminated against because of your HIV status
- Are you aware of any person that has been discriminated against because of his/her status?

6. MEDICATION PRACTICE

Examples of the prompting questions

- Tell me about the medication you take?
- How have you been taking your medication
- How important is it for you to take your medication
- Have you experience any side effects (if so, has it affected the way you take medication)
- Have you missed any doses of your medication?
- How do you remember to take medication?
- What encourages you to take medication

7. Grief and bereavement issues

Prompting examples:

- Have you experience any loss (if yes who passed away ,how did she/he pass away)
- How have you been affected by loss?

8. Relationships

Prompting questions:

- Do you have a partner
- Can you tell me about your relationship (how do you feel about it. does it meet your needs ,in what way, is it your first relationship)
- How would you feel if you can be pregnant?
- Have you told anyone about the relationship (if yes who)

Closing

- How do you feel about the quality of your life
- What would you like to change
- What do you do to have fun
- What are some of your hobbies
- Who is the most important person in your life(why)
- What are some of your weaknesses and strengths
- What makes you laugh and cry
- What are your future plans (education, family)

Appendix 3: Discussion guide for the focus group with young people

Themes and prompting questions

Introductions

a) Self-introduction

b) General affiliation

Biographical information

- a) Age
- b) Gender
- c) School and educational grade
- d) Family

General questions

1. Do you know each since you all attend the same clinic?
2. How often do you come to the clinic?
3. Who do you come with?
4. What do you normally do during clinic visits?
5. What do you like most about visiting this clinic?
6. What do you not like about being in this clinic?

Family

Examples of prompting questions

1. Who do you stay with at home?
2. Have you always stayed in this household?
3. Who do you consider to be supportive and helpful to you?
4. Do you have family members that do not stay with you at home?
5. Tell me what you do in a typical day?
6. Do you do any household tasks, if yes what are those tasks?

Illness experience

1. Have you been ill before?
2. What type of illnesses have you had?
3. Who told you about the type of illness you had?
4. Have you been admitted in a hospital before, if yes why were you admitted?
5. Have you been too sick to attend school before?
6. How do you feel when you are sick?
7. How do you feel when you are sick?

HIV Disclosure

Examples of prompting questions:

1. Do you remember when you tested for HIV? If yes:
2. Can you share with us how it was like for you to be tested for HIV?
3. What were you told?
4. Who informed you about your HIV results?
5. If you do not know when you were tested for HIV, when did become aware that you are living with HIV?
6. How did you found out?
7. What was your reaction when you were told?
8. How important is it for you to know about your HIV status?
9. Have you told anyone about your HIV status?
10. Do you have any concerns about telling someone that you are HIV positive?
11. Is it important for you to share your HIV diagnosis with anyone?

Managing HIV diagnosis

1. What are the difficulties that you face as a young person living with HIV?
2. How do you deal with those difficulties?

Relationships

Case scenario

Nathi is a 16 years old boy who is living with HIV. He has just met a girl that he really likes and her name is Nomsa. She is 15 years old. Nathi wants to tell Nomsa that he really likes her but he is very concerned about Nomsa's reaction when he tells her about his HIV status. Nathi believes that he has to be honest to her.

1. What do you think Nathi should do?
2. If you can be in a similar position as Nathi, how would you manage it?

Treatment

Examples of prompting questions:

1. Are you taking any treatment?
2. What type of treatment do you take and what is it for?
3. How do you take it?
4. How do you feel about taking treatment?
5. Who helps you with taking treatment?
6. Do you have difficulties remembering to take your treatment?

Stigma

Examples of prompting questions:

1. Do you feel you have been treated differently because of your HIV status? (if so how ,by whom and how did you managed that process)

2. Do you feel you are different because of your status? If so how?
3. Have you been discriminated against because of your HIV status?
4. Are you aware of any person that has been discriminated against because of his/her status?

General questions

Is there anything else that you would like to share with me?

Appendix 4: Assent Form

The study of the experience of young people (13-18 years) living with HIV/AIDS within the socio-cultural context of KwaZulu Natal.

Assent form FORM

INTRODUCTION: Hello. My name is Maud Mhlongo. I am a research student, studying at the University of Huddersfield in UK.

You are invited to take part in this project which is about the experiences of young people living with HIV/AIDS in KwaZulu -Natal.

ABILITY TO SAY NO: If you decide that you would like to take part in this project, you will participate in the interview process. You are free to take part and not to take part. Your non-participation in this research will not interfere with the services you are receiving from the clinic. You should not feel under pressure to take part.

RISKS AND BENEFITS: It might be uncomfortable for you to talk about personal information. If anything that we discuss during this interview makes you feel uncomfortable, you can choose not to answer that question.

It may be rewarding for you to take part in a research as it can allow you to express your feelings and talk about your experiences with someone. If during the interview process, you mention things that are causing harm to you or may harm you in future, I have a duty to report that information to the relevant people.

ACCESS TO INFORMATION: The researcher and my two supervisors, Professor Adele and Professor Annie Topping will have access to the information. All the information collected will be kept safe.

ANONYMITY AND CONFIDENTIALITY: Your real names will not be used in the research; you can choose your own pseudo-name. Your name will not be used in any publication related to this research.

SEEKING COMPREHENSION: Do you have any questions about any of the things I have just said?

I _____ (name)

would like to take part in the study of the experience of young people living with HIV/AIDS IN kwaZULU-Natal. The research participation has been explained fully to me and I have had an opportunity to ask any questions. I am aware that it may be risks and benefits of taking part in this research

SIGNED _____

Date _____

In case of any queries contact MAUD MHLONGO, TEL.031-2685727

Appendix 5: INFORMATION SHEET FOR CAREGIVERS OR PARENTS

Research topic:

The study of the experiences of young people (13-16 years) living with HIV/AIDS within the socio-cultural context of KwaZulu- Natal.

Introduction and study purpose: Hello. My name is Maud Mhlongo. I am conducting a study to try and understand the experiences of young people who are HIV positive. This research will focus on how young people take medication, how they choose to talk and tell others about their HIV status and their experience of stigma. I am inviting your child to participate in this study.

Risks and benefits: Talking about one's personal information to another person may be uncomfortable for other young people. If during this interview the young person is feeling uncomfortable to answer any question from the interviewer, he/she is free not to answer that question or to ask to leave the research project. Please understand that should the young person decide to leave the research project, his or her services from the clinic will not be affected.

Study support for participants: We have asked someone within the clinic who is familiar with the young person to offer support should the young person wishes to talk to someone else or if the young person is feeling distressed.

Access to information: I will not be able to share with you the information that your child will share with me during because confidentiality with the child has been assured. However, should young people disclose information that has the potential to cause harm to them now or in future, relevant personnel will be contacted and you may be told.

Confidentiality: Young people's right to confidentiality will be maintained throughout the research. I shall make sure that everything they tell me is not divulged to anyone else without their permission or when it is not necessary. Interviews will be conducted in an environment that does not compromise confidentiality. If during the interview process your child discloses information that has a potential to cause harm to her/him currently or in future, I will disclose that information to the relevant personnel after I have informed the young person about it. I will only do this if it is in the young person's best interest.

Information from the interviews will be securely locked away in a safe place and my computer is password protected so no one will be able to access the information you give me.

Anonymity: I will have the details of all participants – which will be stored securely as outlined in the confidentiality section above.

I will ensure that you are not identifiable in any of the documentation that is written or published from this research – unless you explicitly request to be identified.

Research findings: I believe that the research process is still incomplete until the findings have been disseminated to relevant people who could then act on them either in the form of practice, policy or further research.

Dissemination of findings from this research will therefore be another priority.

In the first instance, I will share information from the research process with you, the study participants.

A copy of the resulting thesis will be kept in the University library as well as being accessible online via the University repository. I will ensure that I publish papers resulting from the data collected in peer reviewed / academic journals and also look at the possibility of authoring parts of a book.

Appendix 6: Interview Guide for interviews with carers

Study Title : The experiences of young people living with HIV within the socio-cultural context of KwaZulu-Natal

Interview Guide for Carers of young people living with HIV: Themes and prompting questions

(Please note that these questions will be translated to a local language (isiZulu) and the interview will be conducted in isiZulu)

Introduction: Self introduction, name and general affiliation

Purpose of Interview

You have been asked to participate in this study because you are caring for the young person that is living with HIV and taking antiretroviral treatment. I am interested in knowing about your experiences of caring for your child and how you manage this in your family .I will appreciate if we could spend some time together to discuss this issue.

Interview Begins

General

- I. Gender
- II. Age
- III. Type of relationship between the carer and the young person
- IV. Source of income for the family
- V. Family members

Knowledge of HIV status of the young person

- I. How did you found out about the HIV status of your child?
- II. How were you informed about the child's HIV status?
- III. What prompted HIV testing?
- IV. How did you react to knowing about the results?

Managing HIV disclosure of the young person

- I. When did you tell your child that she/he is living with HIV?
- II. Did you experience any difficulties when you told your child about his/her HIV diagnosis?
- III. How did you tell him/her about his HIV status?
- IV. What did you say?
- V. Is there any one that was present when you told the child and what was that person's role?
- VI. Do you think the child had any suspicions about his/her HIV status before you informed him/her?

Perceptions about the coping abilities of young person living with HIV

- I. How do you think your child is coping with living with HIV?
- II. Do you think your child faces difficulties sometimes? If yes, what do you think are the challenges that your child faces?
- III. Do you think your child faces specific challenges that are related to HIV? If yes, what are those challenges?

Perceived ability to care

- I. Do you experience any difficulties in fulfilling your caregiving responsibilities? If yes, what are those

- difficulties?
- II. Do you receive any support that will enable you to care for the child better?
 - III. What support is available and accessible to you?
 - IV. What support do you need that is unavailable to you?
 - V. Do you feel confident in your ability to continue providing care to the young person?

Defining caring

- I. Can you tell me about your typical day when you provide care to your child, what exactly do you do?
- II. What is your role in helping the child with treatment?
- III. Do you talk to your child about HIV? if yes, what do you normally talk about?
- IV. Do you share caring responsibilities with someone?

Stigma

- I. Have you been treated differently as a result of the child's HIV diagnosis?
- II. Do you think your child is treated differently because of his/her HIV status?
- III. Have you or your child been discriminated against because of the child's HIV status?

Additional information

Is there anything else that you would like to tell me which might be useful for this study?

Appendix 7: Sample of the interview with the young person

(The interview was conducted in both isiZulu and English because of the participant's use of both languages in the same sentence; therefore there is limited translation from IsiZulu to English. Most sentences contain the participant's exact words)

Participant 8: Zonke, 16 years

I: Thank you for coming, how are you doing?

P: I am well

I: Good, can we start now?

P: Yes

I: Alright, tell me about your family?

P: I live with my grandmother, just the two of us

I: Any siblings?

P: MMhh,I do like lot of them, but we do not live together, well, *bona* (they) live in different places for example Yellow wood park, the other one is in Welkom in Bloemfontein, others *nje* (*like*) they live around Durban.

I: Are those your relatives?

P: Yes they are my relatives

I: Are you the only child from your mother?

P: Yes, but I have many sisters and brothers within the family

I: Alright, tell me about your mother?

P: MHh, Ok I am not so sure what happened to my mother, but the only thing that I know is that she was sick, and ok ... it went like this. I was still in primary,ok she got sick and

everything, she could not do anything. I was there like; I had to help her out. Every way that I could after that they took her to the hospital, when they took her to the hospital, they had to leave me with my neighbours, and then when she came back home it was like she was ok, and we thought she was fine, like she is coming back home for like ever and then like she only like few days at home and she started getting more sick and it was time to take her to the hospital. The ambulance came late and when she entered into the gate, there is this hospital in..... called,yes.. and you know like by the gate, when the ambulance was getting in there, they started putting in drips, they just lost her and then after that they thought maybe she was going to come back again, but no and that was the end of the day for her and that is how she died, but they did not explain anything to me like what made her sick and what happened to her and all that stuff. I found out when I went to live with my grand mom, but before that I was living with my uncle and his wife and his four children. We were all living together in like, it was not like a huge house, but a small house. It was two bedrooms, kitchen and a dining room.

I: Where is that?

P: Where is that, it is like Mhh Mzinyathi

I: Oh yes

P: We used to live there and then I was living with them for half a year and because I was not like the person who was like...had good health I was getting sick more often. We did not know what was wrong with me, they also did not know what was wrong with me ,maybe I am saying this in my own words, maybe they knew but they did not tell me anything and then they saw that my health was becoming more.... like I am getting more sick, they could not handle it. They contacted my grand mom and my grand mom was like no it is fine, she can take me. When I went to live with my granny

I: How old were you then?

P: MHH ,I came to live with my grandmom in 2000, ya ..that was when I went to live with my grandmom. I remember this other time that was when I was so sick I had sinusitis, my eyes were swollen, and I went to Dr e ... Centre, when I went there, he took blood tests, I think he found out something that you know I was HIV. And then he told my grand mom that she had to take me to hospital because they have a good service there for people that are HIV positive. My grand mom did not know how to tell me this, I went to the hospital to get X-rays, to drain the pus out that was

coming from my eyes and then when I started the hospital I think it was 2005 if I am not mistaken, that when I started attending the hospital. when I started there, they ask my grandmother whether they should they tell me earlier or maybe they should put me on treatment or whatand my grandmother was like the best thing will be to tell me so that I would know what was going on, what is the reason for me to take these tablets and then they called a social workers and then they had a meeting, my granny was there, a social worker was there and then the other person. They started asking me questions about HIV and I was ok I did tell them few answers and then they asked me how I feel about people that are living with HIV, would I live with those people. I said they are the same like us and they live the same life as us, the only thing is that their blood has been affected. That is the only difference, we are all the same, and then they were like what could you say when we tell you that you are HIV positive ,I became so speechless, I mhh I did not know what to say, but I was fine. I did not cry I did not scream I was so quite there.

I: How would you describe your feelings then? Were you shocked?

P: Yes was shocked, I was very shocked because I could not understand, at that time I always thought to myself that you only get HIV if you sleep with someone, you know doing unprotected sex, so that how I told myself that. I have never done things like that in my life, how did I get it, it did not come in my mind that maybe I got it from like someone within the family and then when I went home ,that was when everything started to come together, my mind was coming back again. I started thinking more things that I should not be thinking of like take a knife kill myself, drink and tablets anything like that. I locked myself in my room, I started crying because that was the time when I was thinking what did the Social Worker said to me, is it true or maybe they are just putting me on shock so that I can stand up for myself, like I should live like this because things are like this now,and then when I went to school, I remember the first day when I went to school, I was standing by the gate everyone was like u Zonke is back from school and everybody was turning around looking at me and I thought these people they know the same thing, they know that Zonke is in this state now ,she is HIV ..uZonke is like that .It was as if everybody knew about my status and I did not know what to do.

I: How old were you then

P: Mhh In 2008, doing grade 6.I think

I: mHH

- I: I then started lacking at school; I could not perform so well. Like the way I use to. Every time when I had to do a speech in front of the whole class, everybody would just stare at me it was like everybody *bayabona* (they could see) ukuthi UZonke she is like this now. On top of that my friends were just turning their backs on me. I could not understand that, but when I went home and I told my grandmother all that, she is like that it is like friends if they see that you are not their type, since you trust God and do these things, everything that you do is based on Christianity, you are boring them, they for something for a fast life. I took that advice everything was fine and then I went to grade 7, I think I found out towards the end of the year about my status, I started to join the group. The life that we live now is a real life. We need to be awake and open our ears and see what is happening around us. That was how I found out with my granny. Without her, I would not know not know anything.
- I: Before being told, did you have any suspicions?
- P: Before I was told, I did not suspect anything. However I had that in me that I care for people who are HIV positive. Every time I wrote speech or poem it was based on HIV, It means I had a sixth sense that maybe I have HIV, or one day you will be part of those people so you better start preparing yourself, like how to live with it. I never really suspect, my symptoms were like getting more flue, I did not lose weight nothing or TB I did not get nothing, the only thing I had was really flue, there was not anything that could raise those suspicions.
- I: You said you went through a phase where you thought other people are seeing what you had, How long did that phase last?
- P: It did not last very long because my granny was very supportive, maybe the first term, when my results came back, they were very low, I was almost left behind, during those days I used to think that what will be the use of going to school because I am gonna die early and my granny was like no it does not mean that if you have HIV you are gonna die early, there are tablets that are gonna help you, though they will not cure HIV but they will help to get life. I then started in June, I trusted my granny that she would not tell other people that uZonke is like this. There is no one that I stay with. from the start when I was still mom and my mom was alive ,I spent most of the time with my granny, this is the person that I grew up seeing in front of me. Our relationship it became strong because of that
- I: How old is your granny?
- P: She just turned 66 January 5

- I: Does she work?
- P: No, she is a pensioner in Jan. 6. She was a health adviser in the clinic
- I: Do you think she understood health related issues then?
- P: Yes, I think she does because to understand how supportive she was, she even joined HIV group in her church and the meetings were held at night ,so she took her time to know more about this, Even at home she has certificates for studying this so that when she helps me she will have knowledge of helping
- I: Does your granny accompany you for your hospital visits?
- P: No, unless they need her to be there, for example issues in the hospital or there are issues regarding my health
- I: After you had been told about your status, were you able to talk to your friends about your status?
- P: Mhh I could not talk to my friends ,but there was this time ,Mhh I became strong and I called my friend and when I called them I said there is something that I have been told, would you run away if I am HIV positive and she said, “common why would I run away because of your status? Because it does not mean you will infect us I know how to take precautions.” I told her and she was so shocked. I told her in 2009. She started touching me and asking how I was. I do not know what happen, there is this other girl that she is used to stay near my home. I think she went there, and she shared this information that uZonke is this and that and that, and then they came to ask me. She was my friend and I trusted her that she would not go and expose me to other people. What I expected from her was to protect me if I am doing something wrong and tell me that I should not be doing this but when she did this ,I went to ask her.

Those people came to ask me that this girl has said you are like this and that..., I kept quiet and asked “has she said that? , they said yes and I said I will ask her where she got this information from. I went to talk to her and said “girl... I trusted you” and she said she does not know what came over her, she does not why she said it and she had thought that because these are also our friends it is ok for them to know, and I said “Girl if I wanted to tell all of you I was going to call a group meeting and tell you all but I trusted you since we have been friends for like for long 9 years, so why would I tell people that I have known recently in our friendship?”. She was like I am sorry and my trust with her was broken, It lacked.. and then I realise that since she is now aware I must be prepared to handle whatever comes my way because I have already told her,

because there is this other guy from church, I am a teenager and guys do ask you out, and I was already prepared that people would start asking me about my status; no one came to ask. I think my friend realised her mistake and then somehow, somewhere, she corrected the situation or she went back and said she was lying but after that no one came to ask me anything about this. The only thing that they said was that I have another kind of a friend and I asked them why... they said my friend came and told them that she was joking and asked them if they actually took this thing seriously? I said OH Ok. I did not manage to say anything, I was speechless

I: Are you still friends?

P: Yes we are, we are still friends, but I do not think she is a true friends but she apologised. I tested her with one thing I said to her..” ok eh girl did you know that my granny that I stay with is not really my grand mom”. I kept quiet and she said really, I said yes. I waited that she may go and tell others that my granny is not my real granny. No one came to ask me, so maybe she learnt from her mistake. I think she did but we are still friends.

I: Are you open to any of your friends about your HIV status?

P: I am but not about this, because I found that I am not short of friends my grand mom is my friend, my nurse my grand mom, and a Dr and she is my adviser. I talk to my grand mom about everything, but when it comes to boyfriend stuff, she changes her facial expression. I can see that she is not interested in that. However we talk about everything,

I: Besides talking to your granny and friend, have you tried to talk to anyone else?

P: I was asked once to talk at the clinic in public. The person that inspires me the most is Sis She is from Mashu Christian Centre. She inspired me and she said if you are like this it does not mean you cannot talk in public .When she did an interview she said especially if a person is young and living with HIV, going public and telling people will learn that one can live with HIV, even young people are coming out. It was like she was talking to me .I love being a public speaker, I know that I am good and I like working in places that will expose me to public.

I: How did you feel after disclosing in public?

P: It was not easy, but I told myself that I am not doing this for me; this is for people that do not know about their status, so my talking is helping other people. You can find that there is another person in there and he wants to talk about it but she does not know how to talk about. I felt so appreciated. I felt so proud about myself, I was so

- proud of who I am ,I was really proud and I was proud that probably I have helped many people. People will then go to the Drs and test themselves
- I: How did you choose who you were going to tell or not to tell
- P: I did not choose who I can and cannot tell. I told myself that I am me in front of people. I wanted to inspire people to test
- I: Among your friends you have told one person?
- P: I told my friend and another one because her father treats me like her own daughter. I have 3 friends but the one that I told; we were friends for a long time. I also told the my third friend. What I like about this one ..they ask me.... whispering..., they call me on the side and remind me to take medication. I am distanced from them now because they have started to be sexually active. I said to my friends “you are not going to be like that”, really we are friends but I do not scheme with them anymore. We talk, we sing together in church. I told myself that I was not going to tell them any of my personal stuff. I feel as friends, you stick together
- I: Do you expect your friends to keep this information to themselves?
- P: Yes, that is what I want, because if I want to, I would go in public, if I have not decided that people around me should know that I am this and this and that, I do not think that it is right for them to tell.it should be my decision to tell. It does not help to hide this thing, because sometimes you will hide things from someone who can help you be something in life. Just because you are hiding yourself and you have put yourself at the back, you will end up being nothing. There are many people who are so talented, yet they fear public speaking
- I: Do you have any fears?
- P: MhMh ,no,no I do not ,no no no
- I: Have you ever been treated differently because of your HIV status?
- P: No,but when I was young and living with my uncle’s wife, there was that experience. she did not really like, She did not like me and she would scold me for something that I have not done. When we grew up if one person has done something wrong, all of us would be given hiding, and be asked why we did not advise each other. With her it was different. It was like she would not call all of us, she would call me only and ask me. She would tell me that she knows that I am not her child, she would say all nasty things. She was failing to pretend that she did not love me. When I found out (*about my status*), no one really ill-treated me or say nasty things. My cousins and my

granny's family are also aware, in case when I visit them they would know what to do. They love me, the way they love me, they love me more than their kids.

I: MHH..can I ask you about your medication.. have you had any bad experience from taking it ?

P: Medication (*long pause*) when I started, Mhh It is just that,..... there is thing tablet that you take at night ,it is sort of a drug, you will be high and you just laugh. You will have bad dreams, you start acting weird. You gain weight in your upper part and lose weight in your lower part, I discussed it with my doctor. My breast became larger and then my face became smooth and older man started to worry me. I discussed this with my granny and I told my doctor what was happening, I went to the doctor and he changed my medication, there are lots of things that were happening left and right. I take Stocrin and Combivir. It is treating me well. I am over the moon.

I: MHH....do you experience difficulties remembering to take your medication?

P: No..I use my watch and my granny makes sure that I do not forget when I visit my other relatives, they are aware, so they remind me.

I: MHH. Ley talk about your other relationships, do you have a boyfriend?

P: Ok, there is this other guy, I used to like him a lot but I could not go out with him, I was held back because I knew I was like this. Because if you are in a relationship with someone, you have to be honest, so what is the point of having a relationship when you know that you have a secret that you are hiding from him? I was like you know.. I am still young, I will still find someone that will love me for who I am. Even in my support group, my granny thinks I may find somebody, Eh but then I worry about my granny and then this thing is here... I can handle this thing. I even practice in the mirror and change the voice practising to tell somebody. So I did not date anyone because I am worried that if he finds out, then he would leave, thinking that I would infect him, he would go like that. I said maybe I would wait; good things come to those who wait. I worry about what granny would say though.

I: Is there anyone that you like at the moment?

P: I used to like the guy from,but I noticed that he was not the good guy, he likes me but he likes high status. There is this other new guy in the group, everybody likes him. I went to him and I greeted, when I started to talk to him, he open up and we started to share a lot of things together. He asked me whether I could love someone like him, I thought if I tell him yes, he would take advantage of that. To be honest I was lying to him and to myself.

- I: He thinks that you do not like him?
- P: Yes, but I do not know, I also thought that he needed my help but if he realises that I have feelings for me, he would not open up, so I lied (laughing). We go out and sit and talk, we go out during the day and he would talk to me about what is happening. He told me about his girlfriend, I was a little disappointed but then I said common yeah, I advised him to play his cards right. We talk a lot.
- I: How has your church helped you?
- P: In my church I sing, I say poems; I am active in my church. I am very involved as a result I do not have time to think about all the negative things
- I: Do you think about death?
- P: I do... I do (laughing), lots of times. Sometimes I would sit in my room, watch myself, I would ask myself what if I die before doing this or I have not told someone things. I asked myself what if I die without telling someone that I love him, I kept quiet, I called him. I think about death and how I would die and. ...It does not worry me
- I: Does it come to your mind that you can die from AIDS
- P: Yes, I worry about that when I am travelling if it is cold and that my body would react I would have flu and cold sore, however I do not allow that to disturb me. I enjoy to the fullest because I still have time. I go to youth camp and I carry all my medicine when I am travelling in case I get sick
- I: Does it worry you when other young people start medication and they are not doing well on medication as you are?
- P: I do, I do besides those that have started medication, I worry about those who are younger than me dating older than me. I pray a lot and I worship the Lord. I sing what is a pray to me. I sing everywhere. I watch Christian radio station. I love gospel and I was raised by my mother who was a Christian.
- I: You have not told me much about your dad
- My dad passed away before I was born, he died in September and I was born in October. So I stayed with my paternal granny. I think my maternal granny is late. I am not sure because when I visited home (*maternal relatives*) I was told that my father is a Jali and I asked them what about this dad and granny that I live with, is she not my real granny? They said she is not my real granny but she does not know that. The one that died said that he was going to marry my mother in spite of being pregnant with the child that was not his, but they were going to hide this from granny, so I am not

sure. There is nothing I can say. I have never asked my granny because I do not know how she would react

I: If you continued to stay with that family, how do you think your life would have been?

P: I always tell my granny that if I stayed in that family (*maternal relatives*) I would have died by now, I had sores in my whole body, food was scarce and I would go to school without food. My uncle would leave pocket money but she (*uncle's wife*) would not give me. I still visit them. My uncle loved me but his wife did not love me at all. Just because of his wife, I was not treated well. I have forgiveness. I have been baptised, I know where I am going. Jesus forgave me so I always forgive

I: Do you have any regrets?

P: No I love myself, I love my talents. I do not regret that I am HIV. It opened my eyes and it does not mean my dreams have stopped. I think my life is gonna be great. After my first public speaking, I went to talk with teenagers in children's homes. It is hard to have a child and no future. Retain your dreams. Learn from your mistakes. I have goals, my house my car and my wonderful husband.

I: Mhh thank you for sharing your experiences with me and for your time.