

**Dealing with a positive HIV diagnosis**

**A qualitative study exploring the lives of five people living with HIV in a rural Eastern  
Cape setting**

**By**

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## Declaration

I declare that, unless specifically indicated to the contrary, this dissertation is the result of my own work. It is being submitted in partial fulfilment of the requirements for the Degree of Masters of Social Sciences - Research Psychology in the Discipline of Psychology; University of KwaZulu-Natal, Pietermaritzburg. It has not been submitted before for any degree or examination in this or any other university.

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## Dedications

I would like to dedicate this thesis to The Most High God whom, through His Son Jesus Christ has enabled me to complete this work. I am where I am because of You Lord; You inspire me to be great. Father I am grateful.

**“What is impossible with man is possible with God” Luke 18: 27**

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## Abstract

Receiving an HIV diagnosis is a complex reality facing individuals. It alters life and its meaning for the infected individual, their family and the community. This study explored the experiences of five people infected with the Human Immunodeficiency Virus (HIV) in a rural South African community. The aim was to understand the challenges faced by those living with HIV and the role their environment played in the management of the virus. The focus was on uncovering the meaning that the individuals attach to being diagnosed with HIV and how they perceived themselves in relation to their community.

A qualitative study that paid attention to the participant's subjective experiences was implemented. In-depth interviews were conducted with five participants (two men and three women) who had self-reported living with HIV. Questions relating to management of the virus were posed to the participants, for example: why they decided to take an HIV test, the process they went through in accepting the diagnosis, their experience around disclosure, and around treatment. The interviews were transcribed and translated from *isiXhosa* to English by the researcher. Thematic analysis was used to analyse the transcribed data. The results of this study showed that participants experienced feelings of despair and helplessness upon diagnosis. The future of their children in the event of their inevitable death was a concern for the women in the study. While these fears were constantly present, the support of family members and close acquaintances helped the participants to accept their diagnosis. Disclosing their HIV status was a key decision for participants. Deciding to whom to disclose, and how to disclose was important. It was easier for the participants to disclose to females i.e. mothers, sisters or female friends. Disclosing to a sexual partner was difficult for those participants who were in relationships and in most of the relationships condom usage changed with the disclosure of the status. The participants experienced lack of acceptance within their community. Interventions to optimize perceptions of social support and community acceptance are needed.

# Chapter 1 Introduction

## 1.1 Epidemiology of HIV in rural South Africa

A steady increase of HIV infections has been evident in South Africa in recent years; the country has to date one of the highest HIV infection rates in the world (Shisana, Rehle, Simbayi, Zuma, Jooste & Zungu, 2014). Various interventions from government as well as the private sector have been made in an attempt to combat the epidemic, yet the number of new infections continues to rise (Shisana et al., 2014). It was a rise in the number of HIV/AIDS related deaths that was a public health concern and Antiretroviral Therapy (ART) was introduced in response to the high number of these deaths (Cloete, Strebel, Simbayi, van Wyk, Henda & Nqeketo, 2010). According to Shisana et al., 2014, the increase in the survival time of people living with HIV as a result of the treatment increases the likelihood of new infections, thus further increasing the number of people living with the virus (Shisana et al., 2014). The rise in new HIV infections is thus attributed to the introduction of ART to the South African population.

There is higher HIV prevalence in rural areas than in urban areas (Shisana et al., 2014). Life in the rural areas is characterised by unique challenges. Factors such as poverty, unemployment and limited access to resources and information have been cited as some of the causes of higher prevalence of HIV in rural areas (Drimie, 2002; Sowell, Lowenstein, Moneyham, Demi, Mizuno & Seals, 1997). Poverty is a pivotal factor in HIV transmission and can affect people in such a way that can lead to an increase in the epidemic itself (Drimie, 2002). For example, people living with HIV might lose employment as a result of deteriorated health (Leclerc-Madlala, Simbayi & Cloete 2009). These socioeconomic dimensions make people and households more at risk of, or vulnerable to, the epidemic (Drimie, 2002; Brandt, 2006).

According to Drimie (2002), poor people with HIV/AIDS are more likely to become sick and die faster than wealthier people since they are likely to be malnourished, weak, and lacking medical attention and drugs. The dietary requirements for maintaining health when one is on ART may potentially have negative implications for someone who is unemployed and is dependent on social grants. Other challenges in rural areas include: difficult access to health

care, lack of personal and public transportation where people live far from health facilities and having to attend health facilities with limited resources (Heleba, 2012).

To counter the challenges of people having to travel long distances to access health care and to progress toward improving health, the South African government has built health care facilities in the most remote parts of the country (Benatar, 2004). This process was not without challenges. Although hospitals have been built, the services provided there are not of the same standard as those in urban areas. As a study by Benatar stated “new tertiary care hospitals are being built in the Eastern Cape and KwaZulu-Natal provinces, but a shortage of specialized personnel frustrates the delivery of services” (Benatar, 2004, p.82).

Additionally, services rendered at these facilities are free and can be accessed by anyone needing them. Although this is the case, people often avoid taking up these services, especially those related to HIV/AIDS, because of social stigma (Obermeyer & Osborn, 2007; Petros et. al., 2006). People living with HIV have admitted to avoiding seeking health care in their local communities for fear of being recognised by others while at a health care facility (Lee, Kochman & Sikkema, 2002). The close knit familial environments in rural areas, where community members are aware of the events in each other’s lives, often impact on people’s responses to their health care needs.

Also characteristic of rural living is the lack of privacy in health care relationships. According to Townsend (2009), the intimacy of rural living is a key factor to many aspects of rural health care. The close-knit nature may also imply familial relationships between health care providers and their patients. A positive HIV diagnosis may potentially be difficult to manage in such environments where one would have to seek care from someone one knows or someone who has personal information about one. Such environments may impact negatively on an individual’s capacity to cope with a positive HIV diagnosis. Understanding the relationship between HIV and the rural area is thus central to understanding the impact of the epidemic on people in rural areas (Drimie, 2002). The question that directed this research study was: “what are the experiences of those living with HIV in a rural community?”

As mentioned above, maintaining privacy and confidentiality in a rural community can be challenging. Disclosure and speaking openly about HIV can be difficult in such an environment. Thus other questions that guided this study were “what challenges are the

people living with HIV facing in this context?” and “in what ways does the context facilitate or impede people living with HIV?”

The literature review of this study will be presented in Chapter 2; it will be in four sections (1) a background to HIV/AIDS, (2) HIV diagnosis and the effects of living with HIV, (3) HIV treatment, and lastly (4) living with HIV in the rural context. The aims and rationale of the study form part of Chapter 2 with the methodology section following in Chapter 3. The results will be presented in Chapter 5 and these will be discussed in Chapter 6. Chapter 7 is the conclusion, along with the study limitations and recommendations.

## **Chapter 2 Literature review**

### **2.1 Introduction**

The literature review discusses living with HIV and how contextual factors play a role in this. It focuses on how HIV affects the lives of individuals and the experiences they go through in managing their status within their community. It explores the negative aspects underlying a positive HIV diagnosis. It explores the effects of a rural context on the infected, as well as how relationships are affected by a sero-positive diagnosis.

Persons living with HIV/AIDS who live in rural areas face distinctive challenges. At the personal level, rural residents are less likely to have health insurance and may feel less able to conceal their HIV status within small communities (Townsend, 2009). At the community level, problems include distance from care, lack of health care facilities and health care providers with HIV/AIDS expertise, limited availability of supportive or ancillary services, stigma and discrimination and limited educational and economic infrastructure.

Social barriers such as stigma and discrimination continue to hinder access to testing. As a consequence people test or present late for HIV treatment, usually once their health is deteriorating, which reduces the benefits of ART (WHO, 2013).

### **2.2 Taking the HIV test**

The experience of living with HIV begins with the decision by an individual to get tested for the virus. HIV testing, also known as HIV counselling and testing (HCT) is an important precursor to determining people's HIV status. The moral responsibility placed on individuals with regards to HIV testing is that when one knows one's HIV status, one is able to protect others and oneself from infection or re-infection, to access appropriate care, treatment and support, and to plan for the future (Bell, Mthembu, O'Sullivan, & Moody, 2007). Testing for HIV therefore has been identified as a priority intervention in combatting HIV/AIDS (WHO, 2013). In practice, HIV testing is multifaceted. It is often characterised by avoidance, fear and uncertainty, which usually means that people delay testing.

Stigma and discrimination are identified as a major barrier to HIV testing and HIV management as a whole (Skinner & Mfecane, 2004; Pettifor, Rees, Kleinschmidt, Steffeson, MacPhilia, Hlongwa-Madikizela, & Padian, 2005). These social factors make it difficult for people living with HIV to access testing, treatment, care and counselling or even to act on a diagnosis, for fear of being judged (Bell et al., 2007). Stigma also introduces a desire not to know one's own status, thus delaying testing and accessing treatment, which increases people's vulnerability to infection (Skinner & Mfecane, 2004). The reluctance to test and access treatment poses a great challenge to HIV/AIDS control and prevention.

Along with stigma and discrimination, marital status has been reported as having an influence on the decision to test. According to Day, Miyamura, Grant, Leeuw, Munsamy, Baggaley and Churchyard (2003), when a married person takes an HIV test this is interpreted as mistrust between the partners in the relationship (Rhodes & Cusick, 2000). For people unmarried people in relationships, taking the test indicates a partner's trustworthiness and commitment to the relationship (Day et al., 2003).

According to D'Cruz (2004), to be HIV positive is to learn that you are carrying a transmittable, lethal virus. Even though you may not already be sick, you are dangerous to yourself and to others (D'Cruz, 2004). Discovering that one is HIV positive is experienced as traumatic; this is described by Stevens and Tighe Doerr as a perceived threat to one's life (Stevens & Tighe Doerr, 1997). As a result of these factors and meanings attached to HIV testing it has been discovered that people delay taking the test. These dynamics (Krefting, 1991) play an important role in decisions about testing and seeking health care provision thereafter.

The public health sector shifted the testing procedure from Voluntary Counselling and Testing (VCT) to HIV counselling and testing (HCT). This meant a "routine offer of HIV testing" to all who visit public health care facilities (South African National Department of Health HCT Guidelines, 2010). This was done to increase the number of people taking the HIV test. Patients are now offered routine tests at the public clinics and hospitals irrespective of their reasons for seeking health care at these facilities (South African National Department of Health HCT Guidelines, 2010).

In addition to HCT, the South African government implemented the Preventing Mother to Child Transmission (PMTCT) programme in 2010 (Department of Health HCT Guidelines,

2010). This was aimed at preventing the transmission of HIV from a pregnant mother to an unborn child (Doherty, McCoy, & Donohue, 2007). Women attending the clinic for antenatal visits are routinely screened for HIV. This is how the majority of women who test positive come to know of their status in South Africa today (Leclerc-Madlala et al., 2009).

A study conducted in the Eastern Cape province on HIV testing indicated that men often delay taking an HIV test until they show symptoms of illness, while women are commonly referred for an HIV test by an antenatal health care professional (Hutchinson & Mahlalela, 2006). If a significant number of cases of HIV testing are health worker referred cases, then people may receive news about their HIV status when they are unprepared, which can result in the discovery being a traumatic experience.

The benefits of this approach to testing can be criticized because research indicates that it is easier to accept a positive diagnosis when you anticipate that you might be HIV positive (Majumdar & Mazaleni, 2010). Those who take the HIV test when they are under the impression that they are HIV negative are usually “shocked” by the positive result and take time to come to terms with the diagnosis (Majumdar & Mazaleni, 2010). Upon implementation of these interventions, it was not foreseen how the “involuntary” voluntary testing would affect those taking the HIV test.

HIV test results can be classified as an epiphany, a confirmation or a calamity for the recipient (Stevens & Tighe Doerr, 1997). The results are considered an epiphany when they are perceived as life changing and a confirmation when the individual had been suspecting that they could be HIV positive, either from experiencing symptoms of illness or if an individual had been exposed to risk. Someone who experiences the discovery of their status as a calamity would experience shock, fear, and anguish and possibly be suicidal (Stevens & TigheDoerr, 1997). In such instances the individual may be vulnerable and may be in need of follow up and further interventions (such as counselling), which are not always available in rural contexts (Drimie, 2002).

One could suggest that taking the HIV test should be a voluntary exercise, considering the negative effects of HIV seropositivity on those infected. This suggestion is an ideal however, because as discussed above, people avoid testing for various reasons.



### **2.3 The decision to disclose HIV status to others**

One of the goals outlined in the Department of Health HCT guidelines (2010) with regards to disclosure is that every testing and counselling programme should encourage and support the voluntary disclosure of HIV status. It is anticipated that through disclosure the client will gain emotional support from others as well as assistance with healthy lifestyle choices that include the active prevention of the spread of HIV.

Factors that have been identified as barriers to disclosure include; the fear of rejection and isolation, and the perception that HIV is as a result of promiscuity and a low moral character (Leclerc-Madlala, Simbayi, & Cloete, 2009). By implication, a person disclosing their status would indirectly be admitting to promiscuity or deviant behaviour, which is why people do not readily accept or disclose their HIV status. In support of this, Petros, Airhihenbuwa, Simbayi, Ramlagan, and Brown have noted that that people who are infected often hide their status from others (Petros et al., 2006). This denial results in the HIV positive individual being unable to accurately assess their personal risk and vulnerability to infection and thus failing to manage their condition.

Another facet of disclosure outlined in the Department of Health policy guidelines on HIV testing is that no persons may disclose the status of another individual without their permission or in the case where the disclosure is to a medical professional, and the disclosure is done in the interest of the participant (Department of Health, 2010).

Considering that the discovery of a positive HIV status is potentially traumatic, having to disclose that information to others may be even more so because HIV is seen as a threat to one's life. In their study, Stevens and Galvao (2007) also found that women will engage in unprotected sexual intercourse at the insistence of their partners although they would have attempted to initiate condom use. This may result in them experiencing a perceived responsibility for the death, or the infection of others (Stevens & Galvao, 2007).

### **2.4 How stigma affects those living with HIV**

HIV/AIDS is consistently associated with stigma due to its initial association with "risk groups" such as homosexuals and drug users, its sexual mode of transmission, as well as its infectious and incurable nature (D'Cruz, 2004). Living with the virus carries with it the

element of discrimination; where people who are HIV positive experience or expect stigma and discrimination from others (Peltzer & Phaswana-Mafuya, 2008).

In South Africa, the connection between stigma and HIV to historical racism and sexism has developed into a particular form of discrimination. Blame is often assigned to black people or women where HIV is concerned; men blame women for infecting them and spreading the virus (Leclerc-Madlala, 2002), and HIV is seen as the black people's disease (Ndinda, Chimbwete, McGrath & Pool, 2007; Skinner & Mfecane, 2004). Goffman (1963, as cited in Alonzo & Reynolds, 1995) says that stigma occurs because of a person's failure to meet social expectations of desirability and normalcy, and thus being perceived as immoral or deviant in some way. People who are infected are 'othered', and perceived as deviant or promiscuous, in order to make those who are not infected, or those who believe that they are not infected, feel free from risk (Sowell et al., 1997).

Stigma is a well-recognized barrier to HIV testing, disclosure, and adherence to treatment (Gilbert & Walker, 2010; Mahalan et al., 2008; Sowell et al., 1997). Gilbert and Walker (2010) found that individuals who are eligible for treatment usually delay taking appropriate treatment because they fear this will result in their status being discovered by others. To avoid being recognised by people who know them and their families, some people who are taking the ARV treatment travel long distances outside their local communities in order to get medication (Sowell et al., 1997).

An extreme example is of a woman interviewed at a Johannesburg clinic who reported that she travels from Port Elizabeth to Johannesburg for her treatment, for fear of being identified and stigmatized by others in her home city (Gilbert & Walker, 2010). Although extreme, this case shows how stigma affects access to treatment.

Fear of discrimination also limits the possibility of disclosure for those living with the virus, even to potential important sources of support such as family and friends. Stigma has also brought to light issues such as the importance of confidentiality in dealing with HIV in communities and privacy within communities and health care facilities (Skinner & Mfecane, 2004). This needs to be explored to understand the extent to which the participants are affected by stigma and discrimination in their communities.

## **2. 5 Contextual factors that affect people living with HIV**

### **2.5.1 The rural setting**

Rural areas are by definition those that are outside of towns or cities and are characterized by limited access to drinking water, underdeveloped infrastructure, low income levels and poor access to health facilities (Heleba, 2012). They are home to one third of the South African population. People in rural areas generally rely on neighbouring towns for public services (Fobosi, 2013). The population is, in most cases, black, relatively poor, and poorly educated (Pettifor et al., 2005). These characteristics vary from place to place, although they have commonalities (Sowell et al., 1997). For example, most rural areas are impoverished, have limited access to health care and have limited privacy around health care access (Sowell et al., 1997). The reason for selecting this type of setting is that research shows that rural areas have a higher HIV prevalence when compared with urban formal settings (Shisana et al., 2014). It is thus important to investigate the lives of rural inhabitants to find out how their context affects them as they manage their HIV status.

Heckman, Somlai, Peters, Walker, Otto-Salaj, Galdabini, and Kelly (1998a) conducted research in the USA on barriers to care among people living with HIV/AIDS in urban and rural areas. This study found that individuals in rural areas had difficulty obtaining specialist health care and travelled long distances to access health care (Heckman et al., 1998a). These people faced geographical, medical and psychological challenges related to a lack of adequately trained personnel and medics who were willing to provide services to people living with HIV (Heckman et al., 1998a). The authors also reported that stigma was a challenge faced by their participants within their small communities (Heckman et al., 1998a). While rural people living with HIV may share similarities with people living with HIV in urban areas, there are important differences between them. These differences can impact healthcare access and outcomes.

Lower perceptions of social support from family members and friends, more community stigma, and a heightened personal fear that their HIV status would be learned by others was reported in another study by Heckman and other authors (Heckman, Somlai, Kalichman, Franzoi & Kelly, 1998b).

Kelly, Ntlabati, Oyosi, van der Riet, and Parker (2002) comment that in well-resourced environments, where services and support mechanisms are established, individuals may be sufficiently empowered to make conscious shifts in their behaviours and practices. However in under-resourced contexts individuals are disempowered in relation to choices about their present and future (Kelly et al., 2002). It is therefore important for researchers to take into account the community and social contexts that surround the individual.

With regards to rural areas, people living with HIV might also lack privacy in health care relationships due to overlapping relationships and familiarity between health care providers, patients and communities. Privacy and confidentiality within the patient-provider relationship change when friends, neighbours, or acquaintances, rather than strangers, are involved (Townsend, 2009). As a result of the close knit environment, health care workers know the patients, and have details of their personal lives (Townsend, 2009).

This distinction is fundamental to many of the differences between urban and rural health care. Trusting relationships in rural health care are enhanced by the familiarity common in rural living. In rural communities, residents know many of the details of each other's lives, which can lead to confidentiality issues (Townsend, 2009). Maintaining confidentiality may be challenging solely because residents are aware of each other's activities and lives. These factors need to be considered in determining how context may affect individuals living with HIV.

### **2.5.2 Poverty and HIV**

HIV can impoverish people in such a way that can lead to an upsurge in the epidemic itself (Drimie, 2002). For example, people with HIV might lose employment as a result of deteriorated health. The death of breadwinners who are HIV positive also negatively affects the household. HIV can thus deepen poverty, reverse human development, aggravate gender inequalities and deprive families, communities and entire nations of their young and productive people (Leclerc-Madlala, Simbayi & Cloete 2009). These socioeconomic dimensions in turn make people and households even more at risk of, or vulnerable to the epidemic (Brandt, 2006; Drimie, 2002).

A tension also exists between the needs of people living with HIV and the economic and social realities in many developing countries, where health care services for the entire

population are under resourced (Bell et al., 2007). The virus is regarded as a unique illness when compared to other chronic illnesses due to its influence on the patient (Cameron, 2005; Drimie, 2002). An understanding of the relationship between HIV and poverty is central to understanding of the impact of the epidemic on rural livelihoods (Drimie, 2002).

Peltzer and Phaswana-Mafuya (2008) found that people living with HIV used the social disability grant to meet basic household and health care needs. It is not surprising that this was the case because more than half of people in rural areas are unemployed and looking for work; they rely on the government disability grant (Kelly et al., 2002). The disability and other social grants are a source of health and welfare for respondents in the sample and this may be true for most who are HIV infected in the Eastern Cape as the province has the highest unemployment rate in the country (Shisana et al., 2014).

## **2.6 Social support for people living with HIV**

The family as a unit is a facilitator of positive health behaviours for people living with HIV. Those people who have family support report better adherence to treatment, more disclosure and psychosocial wellbeing (Heckman et al., 1998b). People in rural areas have reported lower perceptions of family support when compared to people in urban areas (Heckman et al., 1998a). These perceptions may have adverse effects on treatment adherence, disclosure and psychosocial wellbeing.

Participants in a study by Ndinda et al., (2007) in a rural South African setting, stressed that families should treat HIV/AIDS positive people well and support them. They further stated that it is within the family unit that the emotional, material and spiritual needs of those living with HIV should be met (Ndinda et.al, 2007). These findings show that negative family attitudes towards people living with HIV/AIDS should change with time. The family could be considered as a unit of intervention for people living with HIV/AIDS. One way of reducing stigma is by involving family members in the treatment plan. This is where a relative or close friend accompanies the person living with HIV to the clinic to initiate treatment (Petros et al., 2006).

The person attends adherence counselling with the person living with HIV in order to help them adhere to their treatment. This model may help reduce stigma associated with living with HIV, it may also create an environment where family members are more aware of the

nature of the disease and are therefore able to help the HIV positive persons efficiently. The family as a unit can be regarded as enhancing individual wellbeing, by helping people living with HIV to accept and live with their status. People who receive support from their families report better adherence to treatment; this means they are managing their status more effectively.

Community norms and structures are among the factors cited as influencing the response to an HIV diagnosis and subsequent health seeking behaviour. It is assumed in this study that the meaning that individuals attach to situations (HIV diagnosis in this instance) would have an influence on certain decisions and ultimately their behaviour. The participants were asked the impact of HIV on their lives, HIV risk behaviours, and relationships both prior to and since diagnosis. The way in which the participants coped with the diagnosis within their context was also explored.

## **2.7 Summation**

In the literature there are paradoxes about living with HIV. ARV treatment was seen as a medical breakthrough, yet now, due to its life preserving nature, more and more people are at risk of contracting HIV. From the medical perspective there is the hope - medical knowledge and technology has finally provided useful workable solutions to HIV. People who live with HIV monitor and manage their viral loads and control them by adhering to treatment. Thus on the surface it seems as though HIV is less of a problem than it was, because of this breakthrough; those infected can now live 'normal' lives. However this is continuously undercut by uncertainties, failures and the appearance of new problems. Often, because of the efficacy of the ARVs, participants' social and economic needs become undermined in favour of the medical breakthroughs of HIV treatment. Therefore the optimism around HIV and ARVs is accompanied by other difficulties that HIV positive people face. HIV is often described as a chronic disease, like any other, but it can be particularly hard to live with. HIV puts the responsibility and blame on the HIV infected person. It becomes a matter of management, adherence, and control. The control of the virus becomes a matter of individual responsibility; this individual responsibility may be especially difficult to deal with in the absence of appropriate psychosocial support, especially in a rural setting like *Ematjholweni*, where the research was conducted.

HIV/AIDS has brought about a new situation where risk of illness, uncertainty and imminent death is constantly present (D’Cruz, 2004). In his book, titled *A Witness to AIDS*, Edwin Cameron describes the different reactions he experienced in living with HIV. Cameron mentions the “shock” of his diagnosis, living with the virus in “muteness and secrecy” for years, internal struggles with stigma and the fear that his flesh will eventually fail him. In the end the author states that he is aware he has AIDS, even if he wanted to forget that reality he could not because ‘remembering is in him like blood’ (Cameron, 2005, p.214).

Cameron’s experiences summarize the struggles and challenges that people infected with HIV are faced with. They may come to an acceptance of their status; however, contracting the virus forms part of their identity. It becomes engraved in them like an imprint. The virus is thus regarded as a unique illness when compared to other chronic illnesses due to the social, psychological and medical implications for the infected (Cameron, 2005; Drimie, 2002). This study thus aims to explore these experiences for people whose environment can be considered challenging in and of its own.

## **2.8 Aims and rationale**

This study aimed to understand the impact of the HIV diagnosis on men and women living in a rural community. It explored the experiences of men and women who self-identify as living with HIV/AIDS in *Ematjholweni*. Gaining access to the life experiences of individuals living with HIV may assist in developing intervention strategies related to the needs of this population.

The geographical area was of particular interest for the purposes of this study because it is a setting that may pose difficulties for people living in this kind of environment because of the unique contextual challenges discussed in the literature review above. The aim of this study was to explore the experiences of those living with HIV, both socially and geographically. The study explored how HIV positive participants experience their lives in a rural Eastern Cape setting. The aim was to investigate whether living in a rural context impacts on the participants in a particular way. The assumption was that, since living with HIV is a challenge that makes it different from other chronic illnesses, people living with HIV in a resource constrained environment may experience additional challenges.

If this is the case, then the question was whether people living with HIV in this area faced any challenges, and if they did, what these challenges were. The study explored the reasons that led to the participants' decisions to take an HIV test. Studies on HIV testing have found that there are various reasons that lead people to the decision to take an HIV test and various reasons why people delay taking the test (Day et al., 2003; Gilbert & Walker, 2010; Hutchinson & Mahlalela, 2006). Literature indicates that when people are on antiretroviral therapy, they are 40% less likely to infect their sexual partners with the virus (Shisana et al., 2014). However, this is possible when the HIV positive individual uses the treatment as required. It may thus be beneficial for people to get tested because when they get tested they will be put on treatment if and when it is necessary. Having those living with HIV on treatment will lessen the likelihood of their sexual partners being infected and thus lessen the rate of new infections and thus the spread of the virus.

Additionally, the study aimed to explore the disclosure patterns of the participants, as previous studies show that people living with HIV disclose first to close family members and, with time, to more people. Disclosure is an important factor for People Living with HIV/AIDS (PLWH) because they stand the risk of being supported or rejected by others should they disclose. Many individuals living with HIV report that the family is the basis for support; this means that how one manages your HIV status after disclosure may be largely influenced by how the family has received you (Pettifor et al., 2005).

This study further investigated whether there were any significant changes in the participants' lives, in terms of lifestyle, family life, and treatment by others as a result of disclosure of their HIV status. This study will potentially contribute to understanding and addressing the challenges faced by people living with HIV - psychosocial needs, for example. Finding out about testing and disclosure patterns will lead to better understanding of the barriers to testing and disclosure which can be addressed in assisting those living with HIV in this community. In addition, study results could be used to inform health policy so that strategies can be developed to address the barriers to testing and the stigma that can arise from disclosure.

Living with HIV in a rural area adds a burden to individuals living with the virus and the community context needs to be considered when dealing with people living with HIV. This study aimed to therefore further explore how people living with HIV in a rural setting manage their status. It also aimed to identify conditions that are unique to this kind of environment that may provide additional burdens for those living with HIV. Investigating the



life experiences of people living with HIV may broaden the understanding of those in position of influence.

## **2.9 Research questions**

The following research questions were identified as pertinent to this study:

- What is the experience of living with HIV in a rural community?
- What are the support structures available to people living with HIV within the community?
- How do people living with HIV manage the disclosure of their HIV status?
- What role does stigma and discrimination play in the lives of people living with HIV in a rural area?

## Chapter 3 Methodology

### 3.1 Introduction

This study drew on data collected as part of a National Research Fund (NRF) Thuthuka funded study entitled ‘Activity theory and behaviour change’ in a rural area in the Eastern Cape Province of South Africa. The NRF study focused on people’s responses to HIV/AIDS and sexual risk behaviour. The five participants selected for this study were individuals who had self-identified as living with HIV during their involvement in various data collection activities conducted by the broader NRF study. The broader study used interviews and focus group discussions as a form of data collection. The pseudonym *Ematyholweni* was given to the research site to protect the community and the research participants. It is important to note that due to practical constraints related to the distance of the research site and the cost involved in going there I was not directly involved in recruitment or sampling the research participants, or in conducting the research data collection.

### 3.2 Research design

The study used a qualitative research approach which, according to Babbie and Mouton (2005), is an approach that covers several forms of research inquiry that assist in explaining and understanding social phenomena. Through this approach, the researcher sought to establish the meaning of a phenomenon from the views of the participants. In-depth interviews were used to explore how HIV positive participants experienced life after a positive diagnosis in a rural Eastern Cape setting.

Qualitative research allows the researcher and participants to be able to study events as they occur in their natural environments (Babbie & Mouton, 2005). This type of research can be both descriptive and interpretative in nature (Leedy & Ormrod, 2005) thus using this strategy allowed the researcher to access rich, descriptive information about the participants’ experiences of living with HIV. The researcher’s interest in conducting the study was about understanding the meaning that people attach to their world and their experiences. An interpretive qualitative approach was used in order to illuminate these experiences and to identify the phenomenon of living with HIV through how it is perceived by the actors in the situation.

In order to understand the challenges and concerns of the participants the researcher needed to probe into the experiences of the participants of taking the HIV test, their reactions after their diagnosis, disclosure patterns, how they manage their symptoms and also their concerns about living with HIV. According to Neuman (2005), an interpretive researcher wants to learn what is meaningful or relevant to the people being studied, or how the individuals experience daily life.

### **3.3 Site**

*Ematyholweni* is made up of 14 villages that are governed by a traditional authority, located in the main village. The villages are traditional, with a strong kinship system, a history of migrant labour and are resource constrained. *Ematyholweni* is 25km of dirt road away from the nearest town; it is served by one Primary Health Care (PHC) facility and one referral hospital situated in the nearest town. For the purposes of the larger project, people from all of the 14 villages were sampled to map the impact of geographic proximity to resources, such as the school and the clinic, on responses to HIV and AIDS (Msweli, 2014). Each village has a Residents Association and a chairperson. As part of the broader study, a letter was sent to the chief asking for his permission to conduct the project in the area (see Appendix 1A) and (see Appendix 1B) for the *isiXhosa* version of the letter. A meeting with the chief was held, the study objectives were explained to him and he agreed that the study could take place.

In his description of *Ematyholweni*, Msweli (2014, p.35) writes “*Ematyholweni* is rural with very little development. There is a lack of access to resources for residents. It also has very high levels of unemployment. The author further states: “local residents of *Ematyholweni* usually have to find sources of income in surrounding towns and far-away cities” (Msweli, 2014, p.35). Both young and old people were faced with the problem of HIV/AIDS, which is not only unique to their research site, but extends to other rural areas in South Africa (Shisana et al., 2014). It was therefore significant to conduct this study in an area with potentially high levels of HIV infection (Shisana et al., 2014), limited knowledge about HIV/AIDS (Kelly et al., 2002) and high levels of sexually risky behaviour (Msweli, 2014).

### **3.4 The research process**

Below I explain the steps taken by the research team during the process of conducting the interviews. There is one chief for the 14 villages of *Ematyholweni*, each village has a

chairman. The chief was informed of the study and permission was obtained from him by the principal investigator, Dr Mary van der Riet.

### **3.4.1 Sample**

#### **3.4.1.1 The relationship between this study and the broader NRF research project**

This study sampled participants through the broader NRF project. It is necessary to provide a brief explanation of the recruitment and sampling procedure of the broader study, because I drew on data from that study. The broader NRF project had worked with people who were HIV positive and had interviewed some of these people in 2012. Additional data was also collected in 2013.

For the data collection in 2012, although *Ematyholweni* is under the leadership of the chief the researchers had to gain access to participants through the residents' association chairpersons in each village (Msweli, 2014). A key informant who helped with the recruitment of participants was identified by the study coordinator - Dr Mary van der Riet - with the help of her research team. The key informant was well known across all the 14 villages and had a good knowledge of the setting (Msweli, 2014). The residents' association chairpersons were then informed about the study and permission was asked for recruitment in the villages. The chairpersons acted as gatekeepers and, with the key informant, helped with identifying some of the participants that were required for the broader NRF study. When potential participants had been identified, the researchers went to their homes, and informed them about the study.

The researchers then asked potential participants if they would be willing to participate in the study. Other recruitment strategies that were used by the researchers included attending a local soccer tournament where many of the young people of the different villages would be gathered. Potential participants were informed about the study and if they were interested in participating, their contact details were recorded. Other community gatherings were also used as sites for recruitment, for example, choir practice sessions (Msweli, 2014).

Given the sensitivity of this research topic, the 2013 recruitment process was different from that of 2012. While in 2012 most members of the community were invited to participate in the activities led by the research team, in the case of this study, more purposive sampling techniques had to be followed. Purposive sampling refers to the selection of research

participants based on specific criteria which are relevant to answering the research questions (Creswell, 1998). It is the most commonly used sampling method in qualitative research because qualitative studies aim to depict central, important or decisive aspects of the investigated phenomenon and this sampling technique assures that these are covered (Creswell, 1998). Thus purposive sampling was deemed appropriate to use in sampling for the research study. The selection criteria were people who were living in the research site, with a positive HIV status.

In addition to the purposive sampling strategy, convenience sampling was also employed to gain access to the research participants. Convenience sampling is actively selecting cases that are available at the time the research is being conducted (Babbie & Mouton, 2005). This refers to a researcher using participants who are available and willing to participate in a research study (Babbie & Mouton, 2005; Neuman, 2011). In the 2013 data collection phase, participants who had self-identified as living with HIV in the research process in 2012, or through contact with the research team, were approached by the research team and asked if they would be willing to answer questions related to them living with HIV.

The self-identified HIV positive participants were also asked if they knew other people who were living with HIV in the area who were willing to be interviewed. Those who knew people were asked to ask them to participate in the study, so a snowballing technique was also employed to get to the study participants (Green & Browne, 2005). It is worth noting that two of the participants in the study were living openly with HIV during the time of the interviews while the other three were not living openly with the virus. Those living openly with HIV were the ones who were asked to approach others that they knew to be living with the virus.

The participants who took part in the study were between the ages of 30 to 56 years, they were married or living together with their partner. They reported living with a HIV diagnosis for five years and more. At the time of the interviews the participants reported that they were currently sexually active. All the participants had no form of employment and some indicated that they were looking for work. Some reported having completed secondary school. Each participant interviewed had been living in *Ematyholweni* for at least five years at the time of the data collection.

Five participants were interviewed for this study between the ages of 30 and 56 living with HIV in the research site. The respondents resided in different villages in *Ematsholweni*. The demographic information for the participants in this study is presented in the following table.

<b>Pseudonym</b>	<b>NRF project data base codes</b>	<b>Age</b>	<b>Gender</b>
<b>Nozuko</b>	20130529_H_F1(1)_OJ_S 20130606_H_F1(2)_OJ_S	46	Female
<b>Xoliswa</b>	20130525_H_F2(1)_OJ_R 20130604_H_F2(2)_OJ_R	42	Female
<b>Zodwa</b>	20120615_HPP_F_OJ_V_(E)(1)	30	Female (interview conducted in 2012)
<b>Dlamini</b>	20130529_H_M2(1)_OJ_V 20130604_H_M2(2)_OJ_V	56	Male
<b>Bongani</b>	20130523_H_M1(1)_OJ_V 20130630_H_M1(2)_OJ_V	39	Male

**Table 1 : Study participants**

With this being a qualitative study the focus was on the quality of responses rather than the quantity of respondents. Durrheim and Painter (2006, p.95) state that “qualitative researchers typically work with and actually prefer small, non-random samples of information with rich cases that they can study in depth”. Thus this study focused on a small sample that could be studied in depth.

### **3.4.2 Data collection**

Data collection includes collecting information through structured or semi-structured observations and interviews, setting boundaries for the study as well as establishing protocol for recording information (Creswell, 2006). This study used the qualitative approach of interviewing in collecting the data. Qualitative in-depth interviews are more like conversations than formal structured interviews (Creswell, 2006). The semi-structured interviewing technique was employed in this study because it allowed the research inquiry to be flexible and to be adapted to the problem discussed and each individual’s particular

experiences. This in turn afforded the participants an opportunity to elaborate on their accounts without any restrictions. This data collection technique requires much skill and mastery of the language on the part of the researcher in order to encourage concrete responses from the respondents (Leedy & Ormrod, 2005). The in-depth interviews were used to gain more detail about the participants' experiences of living with HIV. Due to the sensitive nature of the topic, this was the best method of data collection as there is more privacy in a one on one interview than, for example, a focus group.

The recruitment and interviewing for this study was done in two phases. One interview was sampled from NRF data which was collected in 2012, while the rest of the interviews were conducted in 2013. The interview from the 2012 data was selected after transcripts generated in 2012 for the broader NRF study were reviewed. The 2012 data corpus in the form of transcriptions of interviews was made available to me by the study coordinator and her research team. Interviews from this data corpus were analysed and one interview was found where the participant recounts how she found out that she was living with HIV. The participant was a 30 year old female, her interview revealed information about her experience as an HIV positive individual living in *Ematylholweni*. Although the questions asked during the 2012 data collection process were not directly related to living with HIV and were more about HIV knowledge and information, the responses of this one participant were relevant to the current study and thus this interview transcript was included in this study. When the 2013 interviews were conducted, the participants were asked similar questions to those that were asked in 2012, although the 2013 questionnaire was more in-depth (the 2012 interview schedule can be seen in appendix 5A and 5B and the one from 2013 can be seen in appendix 6A and 6B).

The 2013 data collection drew on Seidman's (2005) three stage-interview series. The three stage interview series includes three separate interviews with each participant. The stages involved in the series are: a) a focus on life history, b) the details of experience and c) a reflection on meaning (Seidman, 2005). This study combined the first two stages of Seidman's three stage-interview series: the first questionnaire combined stage a) and b) where the questions asked focused on a person's life history and details of their experiences about living with HIV. The second questionnaire had questions detailing facilitating a reflection on the meaning of the diagnosis for the participants. This resulted in two interviews being conducted with each study participant as opposed to the proposed three (Seidman,

2005). Combining the first two stages of the three stage series helped deal with the challenge of spending a long time at the research site. Due to time and money constraints, it was not feasible for the research team to spend a long time in the field, as is required by the three stage series (Seidman, 2005).

This type of interviewing was adopted as it allows for rich detailed information about the participant's experiences on the subject under study (Seidman, 2005). It also allows for a process of reflection on the data collection process with the interview participant, as more than one interview is conducted. It is important to clarify that the one interview that was conducted in 2012 did not use this staged approach. Only one interview was conducted with this participant. The staged approach was used for the four interviews conducted in 2013, thus two interviews were conducted with each participant. The interviews were conducted in either the participants' homes or in vacant preschool buildings.

The research process was explained to each participant, prior to interviewing. Participants were given an information sheet (Appendix 2A & 2B) and a consent form (Appendix 3A & 3B) that informed them about the voluntary nature of the interview process. This information allowed them room to withdraw from the interview if they felt they did not want to continue, and also informed them that they did not have to answer any questions that they felt uncomfortable answering. Written consent to be part of the research process and to be interviewed was thus obtained. All the study participants were allowed time to ask questions when they did not have clarity on a matter and all were treated with respect. The interviews were conducted in *isiXhosa* and were audio recorded using digital recorders to ensure that the researcher captured the exact words of the participants. Written consent to be audio-recorded was obtained from the participants (see Appendix 4A & 4B).

Recording an interview in this way allows for the researcher to have access to the participants' responses at all times. The audio-recorded interviews were transcribed and translated from *isiXhosa* to English. Recording the interviews was also useful during the transcribing and analysis of data as I was able to move back and forth in a recording. This enables the researcher to engage better with the data.

As previously mentioned I was not directly involved in the collection of data for this study. The interviews (in 2012 and 2013) were conducted by a research assistant on the project. The 2012 data was transcribed and translated by the research team working on the NRF project. I



was responsible for the translation and transcribing of the 2013 in-depth interviews. The interviews were transcribed verbatim; the procedures that were followed included listening to the taped recordings and then transcribing the participants' responses and translating them into English during the transcribing. I was responsible for transcribing and translating the eight interviews from the 2013 data. The transcription notation conventions used were an adaptation of the notation symbols in conversation analysis (see Appendix 8).

To further ensure that the participants' identities were protected, codes were used on the transcribed interviews. The codes were used during the interviewing process, for the recorded data, as well as on the transcripts, e.g. 20120613\_26-34\_F\_DZ\_T\_ (E). From this code, the researcher is able to tell the date of the interview, the age group of the participant, their gender as well as the initials of the researcher who conducted the interview. Pseudonyms are used for participants in this report. The name of the study location was also changed to *Ematyholweni*. There is therefore no identifying information that links the interview transcript to a participant. The list of transcripts used in this study, and how it relates to the extracts used in the discussion section is available in Appendix 7, it is labelled "extract codes".

In this study a process of back translation was employed to ensure the validity of all the research instruments. This involved translating *isiXhosa* interview schedules, consent forms, information sheets and transcripts into English. Back-translation is a method that involves two independent translators (Brislin, 1970). Translator One translates the original version of the transcript into the target language (Chen & Boore, 2009). The second translator then translates it back into the original language. This is done so that the researcher can consult with the translators to determine discrepancies (Chen & Boore, 2009). This process aids in ensuring that all data is precisely captured (Brislin, 1970). Two colleagues were involved in the back translation. One colleague had completed his Masters in Research Psychology and was working as a research assistant on the broader project. The other one had completed her course work component of the Masters Research Psychology degree and was working as a research intern and assistant on the broader project.

### **3.4.3 The interview schedule**

The interview schedules used to guide for the 2013 data collection process were in English and *isiXhosa*, (see Appendix 6A & 6B), the interview schedule used in 2012 can be found in

Appendix 5A and 5B. According to Babbie and Mouton, (2005) an interview schedule should be used as a guide that keeps the researcher on track rather than a tool used to rigidly define the data collection process. This is especially true when one wants to know the subjective accounts of individuals. The researcher allows the participants to narrate their stories and personal experiences of a social phenomenon (Silverman & Marvasti, 2008). The interview guide consisted of questions on the participants' background as well as probing, open-ended qualitative questions, to allow an in-depth understanding of the subject's experience.

#### **3.4.4 The pilot interview**

As part of strengthening the reliability, dependability and auditability of a qualitative study, Miles, Miles, & Huberman (1994) suggest peer or colleague reviews during the research planning. The interview schedule used in 2013 was piloted with a woman living in Pietermaritzburg who is living openly with HIV. This pilot interview was to determine whether the research questions were clear and whether the data that would emerge from them would be congruent to the study design (Green & Browne, 2005).

Consent to interview the participant was obtained by the study coordinator, Dr van der Riet, before interviewing commenced. One researcher from the NRF project (who was ultimately going to be involved in the data collection for the study) and I conducted the pilot interview. This participant gave important feedback on the schedule and in the interview process. She provided input on how to best ask the interview question as well as advising the researchers on the most appropriate questions to ask a person living with HIV.

The subject matter of this study was sensitive and getting advice on how one should conduct oneself when interviewing people living with HIV proved to be valuable for the researchers who collected the data. The pilot interview allowed for an insider perspective about living with HIV before going to the the research site. Some of the interview questions were changed according to this pilot interview process.

After the pilot interview, the interview guides were finalised and reviewed by the research team member who collected the study data. The process of back translation as described above was followed.

### **3.4.5 Language of the data collection**

All data collection was done in *isiXhosa*, by members of the NRF research team, who are fluent in *isiXhosa*. The information sheets and consent forms were translated from English into *isiXhosa*, so that participants could understand what was being asked and so that they could answer without any language barrier.

### **3.4.6 Data analysis**

Data analysis is one of the most important phases in qualitative research, if done thoroughly it increases the reliability of information gathered and its relevance to the subject at hand. The analysis of qualitative data is a process of making sense of findings, making a structure from the data and giving this significance for ourselves and any relevant audiences (Babbie & Mouton, 2005). Thematic content analysis was used to analyze the data in this study.

#### **3.4.6.1 Thematic Analysis**

One of the advantages of thematic analysis is its flexibility (Braun & Clarke, 2006). It is a method of analysis which allows for rich, detailed data. The interview transcripts served as entry points to identifying common themes that individuals face living with HIV in a rural area. A detailed line by line approach was adopted, where every sentence was studied to determine what it says about the experience as suggested by van Manen as cited in D’Cruz (2004).

I looked for patterns of living and patterns of behaviour of the study participants. The first pattern of experience that was listed was the process of taking an HIV test, the different explanations from the participants and how each of them came to the decision to take the test. The second pattern of experience identified was how the participants felt after they received their diagnosis. From there the pattern of disclosure was identified. This process of identifying themes and patterns continued until I had all the themes that are presented in the results section of this report. Thematic analysis requires that one build an argument for choosing the themes or patterns of experience, this is done by relating the study findings to literature (Aronson, 1995). The patterns of experience were then put together to form a picture of the collective whole. This approach required that these experiences be discussed in

great detail in order to gain an understanding of the phenomenon in question (Braun & Clarke, 2006).

Braun and Clarke (2006) explain that thematic analysis is a method for identifying, analysing and reporting patterns within data. It organises and describes the data set in rich detail. Step 1 in the method provided by Braun and Clark is familiarising yourself with the data. This included reading and re-reading the transcripts and noting initial ideas about the data. The next step (step 2) was to generate initial codes; this involved coding interesting features of the data, such as identifying instances where participants mentioned the words such as “fear”, or “death”. This was done systematically across the 9 individual interviews whilst simultaneously identifying data that was relevant to each code. Step 3 is searching for themes; it involved grouping codes such as: “not wanting to be seen going to the clinic” and “fear of stigma”. This step then involved gathering all data relevant to each potential theme. Step 4 is reviewing themes. This included checking if the themes work in relation to the coded extracts and the entire data set and generating a thematic ‘map’ of the analysis. Step 5 is defining and naming themes. This was an on-going analysis to improve the details of each theme, and the story emerging from the analysis. This was to generate clear definitions and names for each theme. Finally, Step 6 - producing the report - which Braun and Clarke (2006) argue is the final opportunity for analysis.

According to D’Cruz (2004), to be able to interpret lived experience at all, the researcher must have some understanding of the phenomenon in question. Wanting to understand what rural life is like for people living with HIV formed the basis of this research. The initial expectations I had were that living with HIV in a rural context would be inherently different from living with HIV in an urban area. Secondly the expectation was that participants would mention challenges such as inadequate health care and limited access to important resources such as water and food, which are features that commonly characterize rural areas. Thus I expected that the participants would express contextual challenges. Thirdly I assumed that living with HIV in a rural area would be burdensome due to socio-economic factors as well as the geographical setting. The findings of the study yielded information that differed slightly from these initial expectations and interpretations of living with HIV in a rural context. When reading through the interview transcripts, it was evident that there were discrepancies between the researcher’s initial interpretation and the way living with HIV was described by the participants. Based on the first reading, the researcher formulated a new

interpretation and read the transcripts a second time. This process continued until I experienced an agreement between my presumed interpretation of living with HIV and the way the individuals' conveyed their experiences of living with HIV.

### **3.5 Ethical considerations**

#### **3.5.1 Ethical approval**

The research protocol for this study was approved by the University of KwaZulu-Natal Humanities and Social Sciences Research Ethics Committee (REF: HSS/0369/013M), see Appendix 9. As mentioned earlier, this study formed part of a broader NRF project, led by Dr Mary van der Riet, which has conducted HIV related research in *Ematyholweni*.

#### **3.5.2 Autonomy, beneficence and justice**

Research ethics requires that participants be protected from harm (Orb, Eisenhauer, & Wynaden, 2001). To ensure that the participants' in this study were protected from harm, participants were informed of their right to participate in the study and to withdraw from the study should they wish to do so., Participants exercised their right to accept or refuse to participate in the study. The participants were not in any way treated unfairly or exploited. The benefit of the study was that its findings would provide insight into the participants' perspectives of the HIV positive diagnosis and its consequences and identify gaps which previous research had not covered concerning this population.

Furthermore, pseudonyms were used in place of the participants' real names. The name of the research site was also changed in an effort to conceal the identity of the participants as well as to keep their information confidential. The research site is far from the university where the results of the study will be kept therefore the participants cannot be easily identifiable or linked to the study.

#### **3.5.3 Psychosocial support and referral**

Before the data collection at the research site commenced, the nursing sisters at the local clinic were informed of the study. They were also made aware that the study participants might require ongoing support in dealing with distress and education and debriefing after participating in our study. An agreement was reached that the study participants would be

referred to the clinic should such needs arise. The nurse in charge of the HIV/AIDS department at the clinic received basic government training on HIV/AIDS counseling. Contact details were provided to the participants for the health care facility. The contact details of the clinic were provided in the information sheets (Appendix 2A and 2B).

In addition to this, the person responsible for HIV testing and counseling at the Health Care Centre in the neighbouring town was also made aware that the study would be taking place in *Ematyholweni* and that some of the participants might require her services after the interviews. She had received Life Line training in HIV/AIDS counseling. The participants were given this information on the information sheet and furnished with details of the person to contact should they want to utilize the health care facility in town instead of the one in their village. There were transport costs in getting to the health care Centre outside of *Ematyholweni*.

#### **3.5.4 Data usage, dissemination and storage**

Data obtained from this study was used for this thesis for the purposes of obtaining a Master's Degree. The results of the study may be used to produce research articles and may be presented at conferences so that other people may learn from the experiences of those living with HIV. As mentioned above, no names of participants and research site will be used in these publications and presentations. The project data will be confidentially stored by the supervisor of this project Dr Mary van der Riet for a period of five years. Upon completion and submission of this thesis the transcripts and information available to me will be deleted. This information was provided to the participants in the information sheet that was translated in both English and *isiXhosa* (Appendix 2A & 2B). A contract was signed between the study coordinator, Dr Mary van der Riet and myself, where we stated that the data was the property of the NRF, that I will only have access to the data for the duration of my thesis, and upon its completion I would delete all information that I had access to.

#### **3.6 Credibility, dependability and transferability**

Qualitative research is concerned with ensuring that the research process is done in a credible way that is dependable, transferable and trustworthy (Babbie & Mouton, 2005). The concept of credibility deals with the question "how congruent are the findings with reality?" (Shenton, 2003, p.64). Ensuring credibility of a study is important in establishing its trustworthiness

Lincoln and Guba (1985). The principle of credibility requires adequate submersion by the researcher in the research setting so that recurrent patterns can be identified and verified (Krefting, 1991). So what is important is for the researcher to spend substantial time with participants. The researcher is exposed to the participants' perspectives, while the participants get acquainted to the researcher. The familiarity is said to enhance research findings as well as finding hidden fact. The subject matter of this study necessitated that the participants be comfortable enough to talk to the researcher about sensitive information about their experiences. The individuals who conducted the interviews were familiar with the participants as they had conducted research in the study area before, thus it was assumed that the participants had been in contact with the researchers prior to these interviews taking place. Another strategy that was employed to ensure the credibility of this research study was back translation. The *isiXhosa* versions of the interview schedule, information sheet and consent form were given to an independent researcher to translate back into English to verify the translation.

Credibility is threatened when participants provide socially desirable responses (Krefting, 1991) rather than personal experiences. Social desirability is the tendency by respondents to respond in a manner which is socially appealing without a true reflection of their characteristics (Crowne & Marlowe, 1960). As this study depended on the subjective experiences of people living with HIV, it was important to stress the importance of answering honestly on the participants' part in order for the results to be usable. Another threat would be if the researcher fails to separate his/her own experiences from those of the participants. This was not a threat in the case of this study as I did not personally conduct the interviews. I was able to interpret the findings without any experiences of being involved with the research participants.

In this study I presented deviant cases where they were available, to avoid anecdotalism. Anecdotalism in qualitative research occurs when research findings depend only on well-chosen examples that support the argument the researcher is wants to make (Silverman & Marvasti, 2008). This further ensured the credibility of this research study.

Dependability has also been enhanced by describing the research site and the research processes followed, in such a way that another researcher can follow the decision trail of this study. For the research process to be dependable, it must be able to yield similar results when used on a similar study with participants similar to those used in this study (Babbie &

Mouton, 2005). Another way that dependability was heightened was through the assistance of colleagues and my supervisor to review and assess the research plan and implementation.

It is said that if one wants transferability of their research findings it is important to provide rich background information about the research setting, and participants in order for others to be able to assess the transferability of the research findings (Krefting, 1991). The aim of this study was not to make generalizations about the research subject; but rather to highlight the perspectives people living with an HIV.



## Chapter 4 Results

### 4.1 Introduction

The results section presents the analysis of the transcribed data recorded in the individual interviews. The study explored the experiences of people living with HIV in a rural context. The following issues will be presented in the results section: perceptions about HIV testing prior to diagnosis, taking the HIV test and finding out that the test results were positive, managing disclosure of status, how the use of condoms is negotiated by those in intimate relationships, stigma and discrimination associated with being HIV positive and accessing treatment in a rural community after positive diagnosis. Examining these issues provides a clearer understanding of what it means to live with HIV in a rural setting. Extracts from the data are taken from the transcripts of the interviews with the five participants and will be presented in italics. For example '(Nozuko; female 46)' indicates the pseudonym, age and gender of the participant. The line numbers present on the extracts refer to the line numbers of the original transcript documents.

### 4.2 Perceptions about HIV testing prior to diagnosis

Prior to diagnosis, the participants had negative perceptions about HIV which affected their testing decisions. When asked about their testing patterns prior to diagnosis, the participants indicated an avoidance of testing for HIV. One female participant explains how she felt about HIV testing prior to diagnosis

Extract 1

*236 Interviewer: Oh (.) I hear you (.) otherwise you were not a person who liked testing?*

*237 Participant: NO (.) I did not like it*

(Xoliswa; female 42)

When asked to give a reason for not liking testing, she explained that it was the fear of dying that kept her from taking an HIV test until the eighth month of pregnancy. Her account is presented below:

Extract 2

238 Interviewer: □wh()y did you not like it?

239 Participant: *(laughing)* No I did not like to (.) no (.) no (.3) □it was fear at that time

240 Interviewer: oh so you were afraid of □yhu what people would say

241 Participant: *(laughing)* Ye()s it was just fear

242 Interviewer: Ok then no I hear you (.) but then □wait were you afraid of what people

243 were going to say or were you afraid of death?

244 Participant: I was afraid of dying

245 Interviewer: oh you were afraid of dying

246 Participant: And also of how I would be treated *(clears throat)*

(Xoliswa; female 42)

According to the participant's response, associating the virus with death resulted in her fear of taking an HIV test thus delaying her diagnosis. In addition to that it was the fear of how she would be treated after testing. This is an indication of how stigma and discrimination can affect testing behaviours in people. The participant states that she did not like taking the HIV test because she feared being stigmatised. Nozuko spoke of her own fears about HIV testing. Below she narrates what she had heard from people concerning HIV illness.

Extract 3

275 Participant: *people would say, 'I had a sister'; you know those things, back in those*

276 *days. They would say that flesh would fall off; there was no treatment at that time.*

277 *Their feet would fall off, or they would become so thin they would be bones. Then,*

278 *I would also have that fear of 'hey- but then as soon as they said that there is now*

279 *ARVs and they are now at least helping people, in the end if you have gone. You*

280 *have to go and test before you get sick, there would be that thing of 'I do wish to*

281 *test' but then there would be that thing of fear. If it is an illness, it means that I*

282 *with it forever, you see*

283 *Interviewer: because it is incurable [*

284 *Participant: It is incurable] so I would have that fear, I would usually say that 'I*

285 *go but I would be scared. I would feel that I wish I could be brave just once and*

286 *test but I am scared before I get ill.*

(Nozuko; female 46)

Another misconception from the participants was that a person diagnosed with HIV would not live long.

Extract 4

173 *Participant: I used to think that when you are HIV positive, you do not live long*

174 *Interviewer: Mmh, so that's what you thought. What made you think that way?*

175 *Participant: It's because I heard that you cannot cure it you see*

*177 Because I heard that there is no (.) that it is inside your blood so I thought that it would*

*178 take a person two weeks three weeks to die*

(Dlamini; male 56)

Dlamini also mentioned that if he were to wish for anything it would be a cure for the virus.

Extract 5

*299 Interviewer: Or maybe I should first ask (.) do you need help as someone living with HIV?*

*300 Participant: If maybe there would be help of another form*

*301 Interviewer: (laughing) what kind maybe?*

*302 Participant: (.3) maybe if a person can say No (.) I can help you with this particular*

*303 medication maybe so that I can be able to cure it (HIV) (.) you see*

(Dlamini; male 56)

The fear of dying and being discriminated against, misinformation about HIV symptoms as well as the fact that the HIV cannot be cured were reasons given by the participants when asked about their perceptions on testing. They mentioned that these factors resulted in their reluctance to undertake HIV testing.

### 4.3 Taking the HIV test

From the accounts of the participants above, it is clear that the decisions to test for HIV are not neutral but can be very complex. This is because testing is related to the nature of the disease and the meaning attached to it. There was a clear indication from the participants that testing for HIV was something they had avoided prior to their diagnosis. Both male and female participants delayed taking the HIV test. The men took the HIV test after presenting with symptoms of illness, while the women were referred for testing by an antenatal health care professional during an antenatal visit. Four of the five participants were referred for testing by health care professionals while one participant went specifically for HIV testing after finding out that he could get tested for free. Thus four out of the five participants were 'health worker referred cases' as their testing was suggested during a clinical interaction about something else.

Not all the participants deliberately and voluntarily decided to get an HIV test. The women were all tested as part of antenatal care recommendations by a health care worker. This was not, therefore, a "voluntary" test, but one that was related to pregnancy where patients are advised to test in order to protect the life of the unborn child in the event of the mother being HIV positive. This dynamic is evident in the extracts below.

#### Extract 6

*202 Interviewer: Ok ke sisi, how long have you lived with °HIV? ° How many years have you 203 lived with it*

*204 Participant: Well since I say that I don't know when I became infected () I say that I*

*205 tested in [2008*

*206 Interviewer: 2008]*

*207 Participant: I found out that I was positive at that time () ↑so then I'm not sure where*

*208 it started, because I wasn't sick even then when I found out. Even when I had gone to*

*209 the clinic () I had not gone to test- I was tested only because I was pregnant, understand?*

(Nozuko; female 46)

Xoliswa was pregnant also when she found out about her HIV status.

Extract 7

*72 Interviewer: Ooh ok alright then (.8) and then how long have you been living with HIV?*

*73 Participant: I found out that I was HIV positive in 2005*

*74 Interviewer: Mmh*

*75 Participant: I was pregnant*

(Xoliswa; female 42)

Zodwa mentions that she was pregnant when found out about her HIV status, she further explains her reaction to the diagnosis.

Extract 8

*6 Interviewer: Ok so the first question that I would like to ask you is, how did you find out that you had the HI virus?*

*7 Participant: I was very upset because I was not expecting it.*

*8 Interviewer: Ok, but then how did you find out?*

*10 Participant: I was pregnant in 2004 and I found out in the clinic here at that time*

*11 when I kept going to check for pregnancy. And even at that time when the sister told*

*12 me, I found that I was quite hurt for that second the sister told me but I told myself*

*13 that there is nothing that I am going to do,*

(Zodwa; female 30)

While the female participants took the HIV test during their pregnancies, the male participants presented at the clinic with HIV related symptoms. This was when they were offered the HIV tests.

#### Extract 9

*153 Interviewer: Things like that, mmh I hear you. So now (.) no, I'm still going to ask (this question) I am in a hurry to ask. O () ok, what made you decide to go and get tested*

*155 Participant: I used to have certain symptoms you see, then I started suspecting and decided to go*

(Bongani; male 39)

Bongani says he was suspicious of his symptoms and decided to go and test. Dlamini tested when he heard on the radio that testing was offered for free at the clinic

#### Extract 10

*127 Interviewer: Ok (.) so now and then (.) how long have you been living with HIV?*

*128 Participant: I started knowing (.) uhm after listening to the radio in 2005 I decided to go and get tested*

*129 because a person does not pay money, I heard that you get tested for free so I decided to go*

(Dlamini; male 56)

Different reactions were evident as the participants related how they received their diagnosis. Although they were all able to eventually accept their diagnosis, the initial reactions varied.

#### 4.4 Reactions to HIV diagnosis

There were notable differences in how the men and women reacted to the news about their positive status. The men's narratives seemed less emotional than those of the women who were using words such as "shocked", "hurt" and "upset" when describing how they felt when they were diagnosed HIV positive.

Extract 11

*12 And even at that time when the sister told me, I found that I was quite hurt for that*

*13 second the sister told me but I told myself that there is nothing that I am going to do, if*

*14 I have it*

(Zodwa; female 30)

Another female participant provided accounts of their own reactions when they were told about their status:

Extract 12

*93 Participant: So she said I must come to the clinic (.) when I got there she sat me down and*

*94 told me that ' your results are saying this this and that (HIV positive)'*

*95 Interviewer: Mmh*

*96 Participant: ↑I ↑was ↑shocked (.) but I did not show the nurse that .hh this thing is a shock to me*

(Xoliswa; female 42)

The men's reactions that followed after the positive diagnosis are described below. For example Bongani commented:



Extract 13

690 Interviewer: *So then (.) but did you ever (.) like immediately after (.) not necessarily on the*

691 *day you tested but (.) did you not think about it a lot (.) and then you did not feel well (.) did*

692 *you not have that?*

693 Participant: *I do not want to lie to you (.) I did not have anything*

694 Interviewer: *Mmh*

695 Participant: *None of it troubled me at all*

(Bongani; male 39)

The participant comes across as having accepted his status upon diagnosis; he mentions that none of the information about his result troubled him. This reaction could be related to the fact that the participant already suspected that he was HIV positive. Bongani states that he suspected he could be HIV positive because of the symptom that he was experiencing. In contrast to this, the women state that they were unsuspecting of their positive status because they were not sick when they presented at the clinic. This could have led to the more emotional reactions of the women. In the following extract Nozuko describes her experience while her test was being taken.

Extract 14

229 *(in-breath) I was () have you ever seen () I was thinking () firstly, my going there,*

230 *even when the sister [nurse] is testing me there () I have that certainty, I didn't even know anything () I*

231 *weren't even concerned about it ()*

(Nozuko; female 46)

She describes what was going on in her mind during the test and moves on to explain that when she was getting tested she was certain that her status was negative and she was therefore not worried about taking the test. The participant was also unaware of what the testing procedure would be as she states below:

Extract 15

*239 I didn't realise that I would be told at that instant and even when she is doing that,*

*240 I'm not even worried; I'm thinking that 'maybe I'll be worried tomorrow when I have to*

*241 come and fetch the results', but while she is doing all these things I am not worried.*

*242 Then, as soon as she, when she said 'no, we are done' and then told me, then she told*

*243 me that I am, that the results indicate that I am positive*

(Nozuko; female 46)

As a result of this, the participant was dissatisfied about the way her test was taken. She added that counselling was not provided and that the testing procedure was not explained to her. She describes her experience in this way:

Extract 16

*232 ....Even when the sister was <testing me>, she didn't even do that thing ↓ what is it*

*233 called?*

*234 Interviewer: pre-counselling*

*235 Participant: counselling. She just <tested me> and even when she drew the blood, I'm*

*236 still thinking it is still going to move, that she is still going to leave and then the results*

*237 would come back, have you seen, those tests that are like that*

(Nozuko; female 46)

Both of these female participants were not aware that they would be told their results immediately after the test was done. This may suggest that they were not appropriately informed of the testing procedure.

#### **4.5 Concerns over children related to being HIV positive**

Children had a significant impact in how the participants perceived their HIV diagnosis. The women had different concerns about the implications of the virus on their children. One woman worried about her unborn child becoming infected with the virus, another with older children worried about employment and the other worried about death. Although the diagnosis resulted in negative emotions, in some instances thinking about their children empowered the participants. Nozuko commented on how thoughts about her children changed the way she responded

Extract 17

*260 Interviewer: When you are sitting alone, thinking about it [*

*261 Participant: (when) thinking about it] that is when I cried, at that time. In the end, I was 262 used to hearing it, people saying this and that about it [HIV]. I decided to be strong for 264 my children, understand*

(Nozuko; female 46)

Speaking of her unborn child, Zodwa stated that she wanted her child to be protected from infection. The words “At least” in this extract suggest that the woman felt that even if there is nothing that can be done for her, her child should get help

Extract 18

*14 I just told myself that if there is a way, my child should be protected so that they*

*15 don't get it. Then I was told that there is a way, then I asked that that they at least*

*16 aid my child, because that was my first child.*

(Zodwa; female 30)

Xoliswa received advice to accept her status for the benefit of her children.

Extract 19

*105 Participant: but there was no problem (.) and my sister was still alive (.) she said  
no its 106 not the end of the world you cannot cry to the extent where you want to take  
your life.*

*107 Interviewer: Mmh*

*108 Participant: No*

*109 Interviewer: It is not that big a problem*

*110 Participant: No (.) you must accept that you are HIV positive (.) you must just  
raise your*

*111 child*

(Xoliswa; female 42)

Her reaction changed from thoughts of taking her life to accepting her status and thinking of her children.

Extract 20

*138 Interviewer: So before you knew that you had HIV (.3) what would you think  
about*

139 *[during conversations] about HIV?*

140 *Participant: There was nothing that I was thinking of besides killing myself*

141 *Interviewer: (laughing) Ok I hear you; you thought that (“killing myself”) after being told*

142 *that you are – (HIV positive)*

143 *Participant: Yes of course*

(Xoliswa, female 42)

Xoliswa stated how her positive HIV status was preventing her from providing for her children. She painted a scenario where she found work as a domestic worker and how she would be treated in that household, knowing that she was HIV positive.

Extract 21

381 *Interviewer: How much more now that you are living with HIV (.) do you have any*

382 *worries that arise because you think (.) oh I cannot do this and that and that?*

383 *Participant: Mmh (.) Yes (.) you do get worried (.) you have some worries because you*

384 *can think (.) hey I wish I can get a job*

385 *Interviewer: Mh*

386 *Participant: But you think that (.) this job (.) at that house (.) some people have this*

387 *thing that when you drink with the same cup that someone else used*

(Xoliswa; female 42)

Nozuko mentioned that she worried about what would happen to her children should she die as a result of her being positive:

Extract 22

377 Interviewer: *EY, ok, I hear you. (0.2) ((sigh)) and then how does it – er- how does being*

378 *HIV positive affect your role as a parent or does your role as a parent get affected*

379 Participant: *() YES↑ () it's that thing that I was saying – that- you – you are – anxious- 380 you are anxious that you will die, so what will your children do?*

(Nozuko; female 46)

The reactions from the men seemed to be different when referring to their children. Bongani felt that the diagnosis was not a problem for him. When asked about his reaction when he was told about his status, he says that he thought “no stress”. He felt that what he needed to do was to tell his family (sisters and cousins) about his status

Extract 23

638 Interviewer: *and so you were like that even after hearing about the results? Hearing that 639 no this is the [situatuion]*

640 Participant: *No I walked out thinking (.) no stress (.) whatever*

641 Interviewer: *What made you accept so easily (.) maybe just repeat that?*

642 Participant: *It's about (.) I did not know my status you see (.9) and I realised that the*

643 *one thing that was going to cause [stress was that I'd always be thinking about this*

644 *thing you see (.9) but I told myself that (.) no man (.) what is important is telling my*

*645 family*

(Bongani; male 39)

The two male participants spoke of a different reaction to those of the female participants with regards to accepting their HIV status. These differences may be linked to the nature of testing, where both males had gone to the clinic in response to physical symptoms of illness and the women had been tested “unexpectedly” during antenatal interventions. After coming to terms with the diagnosis, the participants needed to transition to the issue of disclosure.

#### **4.6 Disclosure**

It seemed that disclosure was a complex issue for the participants as it was with testing for HIV. Disclosure patterns were different for each of the study participants. An issue that was clear from participants was that they wanted to control their disclosure, they were selective about whom they disclosed to and provided reasons for their preferences. Some of the participants disclosed only to family members, while others managed to disclose to people outside of their families as well. Some of the initial thoughts about disclosure were fear of being judged or labelled promiscuous, rejection and stigmatization.

##### **4.6.1 Disclosing to family members**

Disclosing of HIV status was influenced by what the participants perceived as important reasons for disclosure. Some participants disclosed their status with the knowledge that they would need support from their family members. Many families in the research site consisted of extended families. Therefore what the participants referred to as “my family” was usually a mother, sisters or female relatives. Participants did not mention fathers and brothers when talking about family members. Although the participants acknowledged their need for disclosure, it was difficult for some. Xoliswa describes the thoughts she had about her disclosure and how these affected her.

Extract 24

*99 Participant: Then I came back and told the people here at home (.) when I arrived here I just collapsed*

*101 Interviewer: You were thinking a lot?*

*102 Participant: Yes (.) it was difficult (.2) I was thinking of the people here at home (.) I was*

*103 afraid of their reactions when having to explain my HIV status*

(Xoliswa; female 42)

Her emotional state made it difficult for her to verbally disclose to her mother and sister, in the following extract she says:

Extract 25

*263 Interviewer: Did you tell her?*

*264 Participant: I did not tell her (.) it wasn't easy to (.) I just cried- then she asked what the*

*265 matter was (.) I then gave her the paper that had the results*

(Xoliswa; female 42)

Her feelings of anxiety were exacerbated by what she feared would be her family members' perceptions of how she contracted the virus.

Extract 26

*280 Interviewer: when you gave them the results and they were still going to read them (.)*

*281 what were you thinking?*

*282 Participant: I was thinking that they would (.) they would shout at me and say that I*

*283 have been promiscuous (.8)*

(Xoliswa; female 42)

Dlamini worried about whether his family would accept the news about his diagnosis:



Extract 27

232 Interviewer: *that's the truth, BUT how did you feel [having to disclose]*

233 Participant: *I was not alright (.3) because I did not know how my family would accept*

234 *what I was going to bring to them you see, because I had let them know first and tell*

235 *them that it's like this and this and this [HIV positive] (0.9)*

(Dlamini; male 56)

Bongani's family consisted of two sisters and a female cousin. He said he felt that his family should know about it rather than it being something that only he knew. The extract below suggests that he wanted to alleviate the burden of knowing his status.

Extract 28

728 Interviewer: *So what made you decide to tell your (.) to tell these three people*

729 Participant: *The reason I told them was that like (.7) this thing will bother me (.) do you*

730 *understand-*

731 Interviewer: *Mmh*

732 Participant: *-If I do not tell them (.) do you understand*

733 Interviewer: *Mmh*

734 Participant: *Just knowing it on my own*

735 Interviewer: *Mmh if it becomes your*

*736 Participant: then I saw that I will not be able to keep this secret (.) there must be others*

*737 who know about it (.) you see (.) yes and then I said no guys come and then I told them*

(Bongani; male 39)

Bongani explained that keeping his status from his family would have bothered him. This participant was the only one who did not comment on an overt emotional reaction when having to disclose his status to his family.

#### **4.6.2 The relationship between support and disclosure**

Reasons for disclosure were linked to what the participants perceived as benefits of the disclosure. The need for support emerged as one of the factors that led to the participants disclosing their HIV status. The perceived value in disclosing trumped the costs associated with disclosure. Xoliswa stated that she needed to disclose to her family members because she would need financial assistance from them. She had an infant whom she could not breast feed, so she needed financial help from her mother and sister to buy formula. Thus she had no choice but to disclose her status:

Extract 29

*289 Interviewer: were you*

*290 planning to tell them or was this something you were planning to keep as a secret?*

*291 Participant: I told myself that I should not hide it [status] because I am not allowed to*

*292 breast feed the child (.) she has to be on formula (.) then if I ran out of formula and the*

*293 child needs to be fed*

(Xoliswa; female 42)

Nozuko decided to disclose to her neighbour, below she describes how and why she chose a neighbour to disclose her status to. The participant defined a relationship with her neighbour of mutual trust and confidence. It is this relationship that enabled the participant to confide in her neighbour when she found out that she was living with the virus. It created a foundation for the participant to be able to disclose her own status to her neighbour:

Extract 30

*369 Participant: .hh I told my neighbour.*

*370 Interviewer: neighbour? Why her specifically*

*371 Participant: Well, the reason why I told my neighbour is because, she would tell me*

*372 about her sister who died because of HIV. Even in our discussions when we*

*373 spoke about it, she would tell me about her sister () I was also not aware of my status*

*374 at that time. She told me that her sister died as a result of HIV and AIDS. So then, I told*

*375 her because I thought she might give me () she might- she would encourage me (.)*

(Nozuko; female 46)

The participant expected to be encouraged by her neighbour therefore the disclosure was done with the perception that it would be of benefit. In the following extract Dlamini's family reassured him that he would receive support from them should he need it. He recalls their response to his disclosure below:

Extract 31

*239 Participant: They also encouraged me and said that if you went to the clinic and you*

*240 found out that you are positive (.) there's no problem (.2) it's not the end of your life*

*241 (.3) we'll support you (.) should there be anything that you are in need of, we'll be able*

*242 to support you*

(Dlamini; male 56)

Nozuko preferred to disclose to her husband and not to her parents. She was uncertain about the reactions of other family members and chose not to disclose to them. Below she gives her account:

Extract 32

*340 Participant: = and I was afraid of going to tell a parent, because I don't know how a*

*341 parent will react, how they will take it and at least when you know (.) with the husband*

*342 that you are in the <together> and most certainly, he also <has it [HIV]> so there is no*

*343 one who will criticise the other*

(Nozuko; female 46)

Despite the initial fears, anxieties and challenges mentioned above, the ultimate outcome from their disclosure was support from their families and other people to whom they had disclosed. Participants expressed relief when their families accepted them as people living with HIV. In the following extract the participant sums up the role of family in a context where people living with HIV may be exposed to stigmatisation and discrimination.

Extract 33

*890 Interviewer: Ok (.) so how can this happen (.) when you think about it*

891 Participant: *It can happen in such a way that your whole family should know and*

892 *accept that you are like this (.) you see*

893 Interviewer: *Mmh*

894 Participant: *Then maybe there will be (.) maybe someone from outside might disclose your status*

895 Interviewer: *Mmh*

896 Participant: *then your family will say (.) look do not think about everything because we 897 have accepted you (.) you see and what you are living with (.) what we will do is to go 898 to the person who was talking about you*

899 Interviewer: *Mmh*

900 Participant: *and tell them not to do what they are doing (.) because as a family we*

901 *have accepted this person (.) it is not as though we do not know his situation (.) the*

902 *situation is not for you to make fun of either*

903 Interviewer: *Mmh mh*

904 Participant: *You see things like that*

(Bongani; male 39)

The above extract from Bongani stated the importance of family support for individuals living with HIV in a context such as *Ematyholweni*. He emphasised the role that the family can play in protecting an individual living with HIV in the event where community members disclose that person's status. In the following section, the role of family support will be explored.

Bongani explains below why the diagnosis did not trouble him:

Extract 34

*259 Interviewer: But how did you feel for yourself (.) for your own life*

*260 Participant: No I thought that= because the sister had told me that it's not the end of*

*261 life (.) she also told me that if I have a certain problem I can go to her and she will give*

*262 me advice if I am not satisfied with the treatment, she told me that I can request for a*

*263 doctor and they would be able to call the doctor. So I saw that no, this is not the end of*

*264 my life, there are people who are able to support me*

(Bongani; male 39)

#### **4.6.3 The effects of support upon disclosure**

Although the participants experienced emotions of fear and reluctance about disclosing their HIV status to family members, the reactions that they received after disclosing were positive. This section describes the participants' views concerning the support they received after disclosure. The participants had to indicate the person/s that they disclosed to when they first found out about their HIV status.

The support received reassured the participants that they could still live even after being diagnosed with HIV. Some were able to change their own negative perceptions about the diagnosis as a result of the way the family responded to them after disclosing their status. This is echoed in the following extract:

Extract 35

352 Interviewer: *oh ok (.) so what made you like that (.) because you said (.) you had*

353 *suicidal thoughts because you [felt hopeless] (.2) [what changed that (.) making you*

354 *feel that you know what (.) this is not a big problem?*

355 Participant: *It was the way my family treated me*

356 Interviewer: *Mmh*

357 Participant: *They did not treat me negatively*

(Xoliswa; female 42)

Xoliswa had reported thoughts of committing suicide before she disclosed to her family. The change that is referred to in the extract was with regards to killing herself. In the extract below she explains how her sister helped her to see her situation differently:

Extract 36

300 Interviewer: *ok so how did that [the support] make you feel?*

301 Participant: *I felt better (.) I did not have stress for long (.) I did not have stress for a*

303 *long time*

(Xoliswa; female 42)

It was also important for this participant that her family heard about her status from her and no one else

Extract 37

286 Interviewer: *Mmh Mmh I hear you, I hear you, so now (.) .hh this is difficult if you have*

*287 to come in and tell your mother (.) but I think what helped is that (.) she was not shocked*

*288 Participant: and also that she did not hear about it from other people*

(Xoliswa; female 42)

Other participants also received positive feedback after disclosing their status to family members, with some being encouraged and offered support. Dlamini says:

Extract 38

*237 When I got home and told them (.) I was with my siblings*

*238 Interviewer: Mmh*

*239 Participant: They also encouraged me and said that if you went to the clinic and you*

*240 found out that you are positive (.) there's no problem (.2) it's not the end of your life*

*240 (.3) we'll support you (.) should there be anything that you are in need of, we'll be able 241 to support you*

*242 Interviewer: Mmh (.) So when you came back you told your mother*

*243 Participants: Yes*

*244 Interviewer: And who else?*

*245 Participant: And my siblings*

(Dlamini; male 56)

The participant was offered support and told that the family would help him with whatever he would have a need for from that point going forward. He in turn responded positively to the



support that was being offered by his family, describing how he felt after disclosing and the family offering support:

Extract 39

*278 Participant: I got encouraged because I got tremendous support [*

*279 Interviewer: ... how did their support make you feel?*

*280 Participant: Their support really strengthened me, I felt accepted*

(Dlamini; male 56)

He explained that although his family members supported him, their initial reaction was shock when he disclosed his status. Below he explains how the radio had played a role in informing his family about how a person living with HIV should be treated. He says:

Extract 40

*272 Participant: Yes they were shocked (.3) but they already knew about it [HIV] because*

*273 we always listen to the radio and on the radio programmes they get told that when*

*274 someone is HIV positive they must not mistreat them (.3)*

(Dlamini; male 56)

Radio broadcasts on HIV seemed to have played an important role in Dlamini's HIV journey. He went for an HIV test after hearing HIV symptoms on the radio and that the test was offered at the clinics for free. Bongani's family did not change the way they treat him after he disclosed his status, which made him feel accepted and supported. He felt that when people are living with HIV they are sometimes not allowed to cook in their homes because people are afraid that the food will be contaminated or people will feel sorry for them. Below the participant explains the experiences he had while living in his sister's house:

Extract 41

550 Participant: *There is one thing that I liked about my sister (.)*

552 Participant: *she did not treat me as someone like (.) feel sorry for me [you see things like that]*

555 Interviewer: *Mmh*

556 Participant: *Yaah and then now (.) what happened was (clearing throat) there are*

557 *some other families (.2) where you'll find that they'll say no we cannot eat food cooked*

558 *by you*

559 Interviewer: *Ok*

560 Participant: *or whatever (.) you see things like that (.) I did not have that problem*

563 Participant: *My sister would say (.) my brother (.) cook (.) you see things like that*

(Bongani; male 39)

Bongani felt accepted because his role within the family did not change. He was still expected to be part of family activities such as cooking. The support and acceptance received from family members after disclosure was a source of encouragement for some of the participants.

#### **4.6.4 Disclosing to children**

With regards to children and the positive diagnosis, the male participants related different reactions to those of the female participants. The two male participants mentioned that they

have children but they did not refer to an emotional concern for their children, the men did not refer to emotional concern for their children. Below Bongani mentions how and why he disclosed his status to his 11 year old son. The son lives in a nearby town and visits his father in *Ematyholweni* during school holidays

Extract 42

*982 Participant: what happens is that (.) I like sleeping with him [the son] when he is here 983 for the holidays (.) I do not want him to (.) I did not want him to be asking questions*

*984 when I take my medication (.)*

*985 Interviewer: Mmh*

*986 Participant: because the children these days ask a lot of questions*

*987 Interviewer: Mmh (.) they want to know everything*

*988 Participant: You see*

(Bongani; male 39)

Dlamini hoped that his young children received talks on HIV at school and discussed it at school, as he had disclosed his status to them and the disclosure had not affected his role as their father

Extract 43

*458 Interviewer: Mmh I remember (.) ok (.) and then how does living with HIV affect your*

*459 role as a parent?*

*460 Participant: It does not affect it because my children are still young but even the older*

*461 ones (.) understand (.) you see*

462 Interviewer: *[Mmh*

463 Participant: *[When I tell them [*

464 Interviewer: *Mmh Mmh*

465 Participant: *But even the young ones (.) my hope is that they talk about this at schools;*

466 *they get taught about it so they know about it you see*

(Dlamini; male 56)

Nozuko was concerned about how her HIV status would affect her children; neither of her interviews clarified whether or not she had disclosed her status to them however.

Extract 44

362 Participant: *and then you have that thing of 'oh my children, when they hear this thing,*

363 *it will have a negative effect on them' so if it affects them negatively, surely it will not*

364 *affect you positively. So in the end, children are affected by that thing, that our parents*

365 *were killed by this, they were HIV positive.*

(Nozuko; female 46)

Although disclosing to family members and children did not seem to have negative outcomes for the participants, challenges were encountered when disclosing to partners. Some of the partners did not believe that the participants were telling the truth when they disclosed to them. In the section below we will illustrate some of the partner responses to disclosure.

#### 4.6.5 Disclosing to a partner

Disclosing to a partner was challenging for the study participants. The partners were not readily supportive and accepting of the diagnosis. Two female participants indicated that their partners did not believe the news when they disclosed. In these two incidences disbelief the participants were disclosing to a husband or a male partner. Xoliswa indicated that she disclosed to her boyfriend at the beginning of their relationship but the man did not seem to think that she was telling the truth about being HIV positive. His denial of her status made it difficult for Xoliswa to convince him to use protection during sexual intercourse.

Extract 45

*121 Interviewer: Oh Ok I see and then how has your living with HIV changed the way you*

*122 use condoms?*

*123 Participant: Yes (.) because now you have to use a condom all the time*

*124 Interviewer: So that*

*125 Participant: But my partner has times where he will say (.) I do not want a condom let*

*126 us sleep without a condom (.) you understand (.) it is things like that*

*127 Interviewer: Mmh and what do you say when he says that?*

*128 Participant: It becomes a fight in the house*

*129 Participant: (laughing) (.) .hh it becomes a fight here in the house (laughing)*

(Xoliswa; female 42)

Negotiating condom use often resulted in conflict between the participant and her partner. Perhaps the partner knew about his own positive status and was therefore not worried about contracting the virus. Xoliswa further explains why her partner does not want to use

condoms. Below she gives what she thought were the reasons for her partner's refusal to use protection

Extract 46

*139 Interviewer: What makes him not believe?*

*140 Participant: Because he has not seen me (.) maybe stressed (.) maybe*

*140 that is why when I*

*141 think about it (.) he has not seen me stressed or having lost weight*

*142 Interviewer: Mmh mh*

*143 Participant: Because I have been like this ever since*

*144 Interviewer: Mmh (.) you do not appear as someone who is-*

*145 Participant: =Sick*

(Xoliswa; female 42)

Nozuko's partner also reacted with disbelief when she disclosed her status to him; she states the following about her husband's response to her disclosure:

Extract 47

*245 I said 'ey I am positive' because he had not tested. He said ()*

*246 in fact his response was 'don't talk nonsense'. I said I would never joke like that.*

*247 The results came back, they showed that I am positive, I am HIV positive*

(Nozuko; female 46)

However he soon accepted and was able to support his partner. According to Nozuko he also got tested and found out that he was HIV positive as well. He became a source of support to her, even when it came to taking treatment:

Extract 48

*90 Participant: NO↑ Just as I was explaining that we just accepted it, there were*

*91 no things- to the point where none of us looked at the other for causing this () since I told you*

*92 that I went to test first, my husband supported me. I mean even when it came*

*93 taking my treatment he would even remind me, that treatment*

(Nozuko; female 46)

Some participants found that disclosing their HIV status to a new partner was a challenge. Dlamini was unable to disclose his status in the beginning of a new relationship. Below he explains how his partner got to know about his status as he had failed to disclose.

Extract 49

*86 Interviewer: O:k (.3) I am trying to understand that (2.0) Does she (partner) does she know (about status) though*

*87 Participant: Yes*

*88 Interviewer: How did she come to know?*

*89 Participant: (.3) found out one day when I was going to get my medication*

*90 Interviewer: from the clinic*

*91 Participant: Yes*

*92 Interviewer: Oo:h so you explained to her*

*93 Participant: Yes*

94 Interviewer: *What did she say when you told her?*

95 Participant: *She (used) to say that she will go for a test and things like that you see*

96 Interviewer: *Mmh*

97 Participant: *Then she went (.) and came back saying she's positive*

98 Interviewer: *Oo:h But what made you keep it from her from (.) from the beginning?*

99 Participant: *(.3) I did not have the courage to tell her*

(Dlamini; male 56)

Dlamini had not disclosed his status at the beginning of his relationship. He only disclosed after this partner saw him going to the clinic to get his medication. In the extract below, the participant explains why he could not disclose his status:

Extract 50

100 Interviewer: *Oo:h (.) were you afraid perhaps*

101 Participant: *Yes*

102 Interviewer: *What were you afraid would happ()en*

103 Participant: *(laughing) I was thinking that it would affect our relationship negatively*

104 *or things like that*

105 Interviewer: *Oo:h*

(Dlamini; male 56)



The participant feared that disclosing his status would result in the break-up of his relationship. He protected his relationship and not his partner - when she went to test she found out that she was infected.

#### **4.6.6 Condom use after disclosing to a partner**

For some of the participants condom use patterns changed after discovering that they were living with HIV. Disclosure of HIV status to a sexual partner seemed to have an impact on condom use - participants used condoms regularly before disclosing their status and used them less frequently after disclosure.

Extract 51

*120 Interviewer: Mh (.) ok (2.0) alright (.5) and then has living with HIV changed the how*

*121 you use condoms (.3) you and your partner?*

*122 Participant: No it has not changed*

*123 Interviewer: It has not changed (.) in what way maybe?*

*124 Participant: Because when we are going to have sex we (.9) but now we do not use it*

*125 we used to use it before [*

*126 Interviewer: [Oo:h you used it before?*

*127 Participant: Yes*

*128 Interviewer: And then you are saying now you do not use it? Why don't you use it now?*

*129 Participant: .hh*

*130 Interviewer: I'm ask(h)ing a l(h)ot (laughing)*

*131 Participant: No I wouldn't know what happened*

*132 Interviewer: Mmh*

*133 Participant: Mh*

*134 Interviewer: .hh but what made you use them in the beginning*

*135 Participant: (.3) it was during the time when I had not disclosed my status*

*136 Interviewer: Oo:h (.3) so you are saying you stopped using them since you now knew that –*

*137 Participant: She's also positive*

(Dlamini; male 56)

Nozuko said they had not been using condoms with her husband for a long time in their relationship so that did not change even after finding out that they were both living with HIV. She felt that introducing condom use after a long time of sexual intercourse would bring frustration to both her and her partner. Her other rationale is that using a condom will not reverse the already positive HIV status, so she did not perceive value in using condoms. What is also important in the participant's narrative is the issue of being faithful, or using a condom when sleeping with other partners. She felt that using condoms would not change their already positive status. She describes her thoughts in the following extract:

Extract 52

*61 Interviewer: °Ok, no I hear you (sisi name of participant) so has knowing your status,*

*62 changed how you use condoms?*

*63 Participant: No, it hasn't*

*64 Interviewer: Or how do you do? °I should have asked it like that°*

*65 Participant: If do we use it?*

66 Interviewer: °yes°

67 Participant: °no we don't use it°

68 ((laughter))

69 Interviewer: *What are you laughing at?*

70 Participant: *No, we, we, we don't use it, yes, like, I had said at first, being the first person*

71 *to know that I am positive, I told him that we have to at the clinic I was told that we*

72 *have to use condoms. I was also not serious about it because I told myself that come*

73 *on, I already have it. He also has it; we have not been using condoms for a very long*

74 *time. We didn't start dating this year and marry the next, understand. So all that time*

75 *if some damage has occurred, it has happened already. I told myself that I mustn't keep*

76 *frustrating this person, or us frustrating ourselves because ...it is frustrating oneself*

77 *because you will not be told that you will be healed if you use it. If it were said that if you*

78 *use it, you are restored to health and that thing is treated we would have long been*

79 *using it but now but it knowing in the end it is like that now. Now it was up to the*

*80 individual to ensure that they do (use condoms) when they are stealing on the side (outside the marriage), especially*

*81 with men, you know that with a man they don't, don't () you are not always with him*

*82 twenty four hours, so I told him that, what is important is that you stick to your partner*

(Nozuko; female 46)

Although Nozuko is not using condoms with her partner, her response indicates an acceptance of the partner's infidelity and she tells him of the importance of safe sex outside the relationship. The risk of reinfection was not considered by many of the participants. The majority of them seemed to stop using condoms once they had disclosed to their partners and knew that the partners were also HIV positive. Participants seemed to think that mutual HIV positive status was not a risk.

After disclosing to family members and sexual partners, the participants had to deal with how their disclosure would be handled. Some participants desired to keep their status known only to the family member they had disclosed to, however this did not happen as they would be seen going to the clinic regularly. Others felt that there was a lot of gossiping within the village so the people to whom they disclosed could easily tell someone else and their status would be known eventually by many.

#### **4.6.7 Controlling HIV status after disclosure**

According to the participant below, she could not trust people in her community to support her with regards to her HIV status. The participant seemed to believe that her status could be disclosed to others by those whom she disclosed to. She refers to it in this way:

Extract 54

*284 Participant: You perhaps you want that stress to leave you-[and] you tell that person- 285 they will act as if they sympathise with you until you leave and then they will go and*

*286 talk to somebody about it. Then they go to a neighbour's house and say 'I met up with 287 so and so and they told me, it's true, it's like that'. There is still a lot of gossiping going 288 on, there isn't that sense of support, and it's just gossip*

(Nozuko; female 46)

In addition to the gossiping that was experienced by the participants was the lack of confidentiality at the local clinic. The participants expressed their views about the HIV related services at the clinic based on their experiences. Most of the participants indicated that the members of staff at their local clinic directly and indirectly disclosed the status of those living with HIV. The following extract provided an example of how nursing staff in a clinic in a neighbouring town discussed patients with other non-medical people:

Extract 55

*299 Interviewer: SO, SO DO women and men disclose to others that they have the HI Virus?*

*300 Participant: No I have not heard anyone disclosing*

*301 Interviewer: But are there others who are HIV positive in this village*

*302 Participant: There are (.) because when I was going to the clinic at (nearby town) you*

*303 would hear a nurse (saying) that we want so and so to come and test ((coughing))*

(Dlamini; male 56)

In the extract above, nurses would call people to come to the clinic to collect their HIV results. There was concern about perceived privacy and confidentiality at the local health care facility among participants. There are reports of incidents where clinic staff disclosed the status of the participant without the patient's knowledge and authorisation. Bongani shares his views on how the information gets out of the clinic:

Extract 56

362 Interviewer: *So now are there any challenges with taking treatment from here (local clinic)?*

367 Participant: *because as I told you (.) that there you can find the nurse alone in the room*

368 Interviewer: *Mmh*

369 Participant: *But there are those ladies who are assistants there*

370 Interviewer: *Mmh*

371 Participant: *You find that they want to know the reasons you are there*

372 Interviewer: *Mmh*

373 Participant: *That is what they want to know*

374 Interviewer: *Mmh*

375 Participant: *Do you understand that*

376 Interviewer: *Mmh mh*

377 Participant: *So that is whereby they come out with inside information*

378 Interviewer: *Mmh*

379 Participant: *From the hospital*

380 Interviewer: *Mmh*

381 Participant: *So then (.) they end up disclosing you*

(Bongani; male 39)

The clinic staff members were also indirectly disclosing the participants' status by sending members of the community to enquire about the participants' well-being when they had missed clinic visits. Zodwa's extract below implies this:

Extract 57

*236 Participant: Ey sisi, here in my village we do have HIV positive people, but I don't know*

*237 whether they are scared or, their names are there in the clinic and they have been sent*

*238 for a number of times, they are wanted there in the clinic*

(Zodwa; female 30)

Below a male participant attests to what the participant above said about the clinic staff sending people to an HIV positive person who missed a clinic appointment.

Extract 58

*473 Participant: And then you'll find that someone will be sent to check up on you*

(Bongani; male 39)

Below the rural context will be discussed and how it impacted on: the participants' experiences of living with HIV, access to treatment and community stigma.

#### 4.7 The rural context

There was a general concern among the participants about the familiarity of the rural context. Individuals with HIV are identifiable in the community and there were assumptions about who is positive or who is negative. Those living with HIV in this community become easily identifiable as they visited the clinic to collect their ARV treatment on a monthly basis. The participants indicated that community members deduce from their monthly visits to the clinic that they (participants) are living with HIV.

Extract 59

*427 the clinic, people have that thing that maybe you are going to get treatment. Once you*

*428 are seen going to the clinic regularly, <going to clinic again and again>) they have that*

*429 thing that you must be going to fetch treatment. And then of the treatments the one*

*430 that most people go to get is this one for HIV. If they see you about three times, four*

*431 times, that person who sees you, then it becomes known that you are positive*

(Nozuko; female 46)

As they were seen going to the clinic regularly some of the participants were confronted by community members questioning them about the frequent clinic visits. In the following extract, Bongani was confronted by the grandmother of his ex-girlfriend. The elderly lady wanted to know the reason for his clinic visits, as people had been talking about him.

Extract 60

*379 Interviewer: Mmh*



380 Participant: you understand (.) yaah (.) then her grandmother (.1) asked me that  
(.) hey 381 <it was the time that we were starting sort of like a support group you  
see>

382 Interviewer: oh ok

383 Participant: YAAH you understand (.) she said that people are talking about me  
things

384 like that

385 Interviewer: this was said by the grandmother

386 Participant: yaah the grandmother (.) [You understand

387 Interviewer: [Mmh

388 Participant: How does the grandmother know this (.) you see?

389 Interviewer: Mmh

390 Participant: where does that information come from

(Bongani; male 39)

Weight loss was another reason why people were spoken of behind their backs. Nozuko relates an incident that occurred when she visited a house not far from her own:

Extract 61

434 Participant: I was fat but then my weight dropped-

435 Interviewer: uhm

436 Participant: But I wasn't feeling anything and I had accepted it, I wasn't feeling

437 anything painful there wasn't anything. I see that they deduced from my regular  
clinic

438 visits and my weight loss. I remember one time going to the house just above this one,

439 and the man from there- I hadn't seen him in a long time () when I entered that house,

440 he [exclaimed and] said () ↑ tyhini ((Nozuko)) there is no truth to what was being said

441 about you. I asked him what is that <what had been said>, he explained to me- he's

442 one of these men that drink a lot, he said that he was told that 'it was said that you are

443 emaciated, [you are] thin. I don't want to lie, I left feeling very hurt because () in the end () even if () I mean () I am not sick

444 Interviewer: uhm

445 Participant: I asked him 'Why they had been speaking about that?' 'Where were you

446 gathered?'

447 Interviewer: uhm

448 Participant: He said 'no, it's because they saw your weight dropping'. I thought a lot of

449 things; I must have been stressed by the business because there are a lot of things

450 because I have never been ill till now to the point of me thinking that it must be

451 this – that thing (HIV). I don't even get the regular flu. Understand?

(Nozuko; female 46)

From her weight loss and regular visits to the clinic, members of her community concluded that she was HIV positive. The extract shows how the participant was affected when she heard that she had been discussed by some members of her community.

#### **4.7.1 Community attitudes regarding HIV**

Stigma and discrimination were one of the challenges that people living with HIV experienced within this community. Accessing treatment, keeping their HIV status secret and maintaining relations with others within the village appeared to be problematic. One of the dominant themes in this study was the extent to which the fear of stigma and discrimination remained a central concern for people living with HIV. The participants indicated that people in the community had not yet accepted those living with HIV. They spoke of how community members spoke negatively about HIV, those living with HIV and about those whom they suspected to be living with HIV. Because of this, both male and female participants preferred to keep their newly discovered status a secret from the community because they expected the worst reactions from them. This is from the way that HIV and testing are viewed in the community. Nozuko talks about community attitudes towards HIV and how these affected her.

Extract 62

*291 Interviewer: = the way it was spoken of=*

*292 Participant: The way it was spoken about, in such a bad way, and really even when it*

*293 was, first came it was said that you got it from being promiscuous, they have only just*

*294 recently said that you are able to get it even if you have been conducting yourself well,*

*295 like helping someone who - maybe they are now adjusting it. However in the end,*

*296 elderly people, people still have that impression that it is because of promiscuity,*

*297 understand? So that is what I was scared of (going to the clinic)*

(Nozuko; female 46)

The main mode of HIV transmission is sexual intercourse, and due to this a moral judgement is made about the behaviour of people who are HIV positive. The following responses from some of the participants reflected this:

Extract 63

*488 Interviewer: Ok, so what about the other people, people who don't know that you are*

*489 HIV positive, how do they speak about it, when you hear them talking about HIV.*

*490 Participant: They usually criticise it (), they still criticize it because of that thing, as I said*

*491 of criticising it. SHE HAS THIS THING, it becomes this thing and you find that a person is*

*492 sneering upon it. It has not really been accepted, not really accepted, properly. And*

*493 they still have that thing of- that someone who has it was all over the place,*

*494 understand?*

(Nozuko; female 46)

The moral judgement is seen in relation to the use of the words 'criticise', 'sneer'. The lack of acceptance of HIV is seen in the community members use of the words 'this thing' that is, being unable to actually use the words HIV. The suggestion that someone was 'all over the place' is a reference to promiscuity. In the extract below Xoliswa gave her view of

discrimination and stigma related to HIV. This discrimination was in the form of gossip, laughing, pointing fingers, saying negative things about HIV positive people, which had a negative influence on the participants' testing behaviours:

Extract 64

*147 Interviewer: Mmh (.) how did you see HIV?*

*148 Participant: HIV arrived during the time when people were gossiping about each other a lot*

*149 Interviewer: Mmhh*

*150 Participant: people would laugh and point fingers saying hey that one has AIDS (.)*

*151 people would talk behind other people's backs and point fingers at others saying negative things*

*152 Interviewer: Mm*

*153 Participant: So now I was afraid thinking that if I get tested (.) people will know about it*

*154 without me disclosing it (.) because people have a way of knowing things without you 155 saying anything about it*

(Xoliswa; female 42)

In addition to the gossiping and pointing fingers Xoliswa believes that the community attributes HIV infection to promiscuity. However, in the last few words of this extract, she argues that it is not promiscuity that results in an HIV positive status:

Extract 65

*378 Interviewer: To people (.) <yes to people> (.) >so now< (.) aah what do people (.) who 379 do not know that you have HIV (.) >say when they talk about HIV< like when they are 380 just talking about it (.) what do they say?*

*381 Participant: like when they are just talking?*

*382 Interviewer: Mmh*

*383 Participant: Mmh you get that (.) some people will be critical and say (.) we heard that 384 so and so has HIV*

*385 Interviewer: Mmh*

*386 Participant: So and so is promiscuous (.) and it's not promiscuity that leads to one*

*387 contracting HIV*

(Xoliswa; female 42)

The following response from Dlamini indicated that he himself associated HIV infection with promiscuity. He responds to a question about the changes he had made in his relationship since contracting HIV:

Extract 66

*172 Interviewer: Mmhh ok, what about relationships (.3) have you changed the way you*

*173 maybe before you were someone who used to beat your partner perhaps*

*174 Participant: It has changed (.) because now I'm not supposed to be promiscuous (.) I*

*175 must only have one person now (.)*

(Dlamini; male 56)

This means that the participant also associates HIV with promiscuity and believes that he needs to change his behaviour now that he has contracted HIV. The participants report that community members talk negatively about the virus, regarding it as something dirty and associated with promiscuity. As a result of these negative attitudes there is a lot of gossip

when people are known or suspected to be living with HIV. These experiences were common among all the participants in the study.

Extract 67

*251 Interviewer: Oh! I hear you. What are the challenges faced by a person who is living*

*252 HIV here in your village?*

*253 Participant: .hh ( ) well it is those that I mentioned earlier of gossiping mongers. You*

*254 find that even when you are just going about your business, 'she lives with it' is written*

*255 on you. In the end you just have to deal with the fact that a person says what they say,*

*256 in that place they say in- people don't speak nicely about an HIV positive person () who*

*257 lives with it-ehe*

(Nozuko; female 46)

Nozuko illustrates a situation where a person who is known to be living with HIV is treated, it seems as though one cannot run away from or hide the fact that they are HIV positive. She says ultimately one has to deal with the fact that people talk about others no matter what. Participants mentioned that they talked to people of the same status about HIV or someone who had a relative who was living with HIV. Bongani explains who he talks to about his status.

Extract 68

*738 Interviewer: ok I hear you were you telling people in general or is it something you did*

739 *not want people to know?*

740 *Participant: No (.) people (.) as I am saying to you (.) I talk to people whom I know are*

741 *of the same status as me (.) do you understand*

742 *Interviewer: Alright*

743 *Participant: Yah (.) you see (.) yes I talk to people (.) whom I know have the same status*

744 *as me (.) I have conversations with them*

745 *Interviewer: here in the village*

746 *Participant: Yes here in the village (.)*

(Bongani; male 39)

Below the participant explains why he prefers to talk with people who are also HIV positive:

Extract 69

755 *Participant: Yahh*

756 *Interviewer: The rest (.) what makes you unable to talk to them (.) (you say it as*

757 *though) people know that you are living with HIV in the village*

758 *Participant: The rest like I don't (.) I don't (.) you can tell a person [about your status]*

759 *(.2) but they end up making fun of the situation (.) that is why I*

760 *Interviewer: Ooh ok*

761 *Participant: That is why I do not like to (.) to talk about it to others*



(Bongani; male 39)

The participant in the following extract opened up to someone whose father was also HIV infected.

Extract 70

*330 Interviewer: ok and (.) do people know that you have HIV?*

*331 Participant: Yes*

*332 Interviewer: Did you tell them?*

*333 Participant: No (.) they just know*

*334 Interviewer: Who told them?*

*335 Participant: I told them*

*336 Interviewer: (laughing)*

*337 Participant: I to()ld them (.) by chatting-*

*338 Interviewer: What did they say when you tell them?*

*339 Participant: No they do not have a problem (.) you see the owner of that house-*

*340 Interviewer: the one I am facing?*

*341 Participant: yes*

*342 Interviewer: That white one?*

*343 Participant: No the green one- you see there*

*344 Interviewer: there at the green house*

*345 Participant: -her husband is my cousin s:o we talk*

346 Interviewer: *Mmh Mmh*

347 Participant: *I usually talk to her (.) her father was also affected by HIV*

348 Interviewer: *Oh the lady's father?*

349 Participant: *Yes*

350 Interviewer: *O::oh so you talk and talk*

351 Participant: *Yes*

(Xoliswa; female 42)

#### **4.8 Thoughts about death and dying**

Death came up frequently from the data, in some instances the participants regarded it as their eventual destination, in the following extract Xoliswa gave her thoughts on HIV and how she related it to death.

Extract 71

160 Interviewer: *ok but then (.) how would you talk about it (.) did you see it as something*

161 *that one could live with or did you see it as the end of one's life?*

162 Participant: *It seemed like the end of the world because a person would just get sick*

163 *you would see a person getting sick and then they would die*

164 Interviewer: *mmh (.) quickly*

165 Participant: *So it would seem like the end of life (.) a person must just give up their life*

(Xoliswa; female 42)

In the extract below Nozuko pointed out that one of the major concerns about living with HIV, was the reality that the virus is incurable. As a person living with HIV, she felt that in the end death from the virus is inevitable.

Extract 72

*18 Interviewer: The first one is: what is it that worries you the most as a result of being*

*19 diagnosed with >HIV<° (0.3 ) what do you think ?*

*20 Participant t: (0.2) It is knowing that HIV is incurable and that in the end I will die () I think*

*21 of that (), I do understand that a person dies anytime and anyhow [*

*22 Interviewer: uhm*

*23 Participant: but () I mean () it is something that you understand that in the end, when it*

*24 is like his, you are like this, there is only one that thing that you are being led to and*

*25 that is death]*

(Nozuko; female 46)

Nozuko uses the words “being led to” meaning that she feels that she has no control over what her positive diagnosis will eventually lead to. The same participant mentioned that it was still peoples’ perceptions and attitudes that made it difficult to live with HIV. Deaths of young people within the community were said to be as a result of HIV related causes.

Extract 73

*297 Interviewer: You were scared of people talking?*

*298 Participant: And what I looked at, whenever a person died, people would say-*

299 *so and so died of-[HIV]*

300 *((Interruption))*

301 *Interviewer: ((giggles))*

302 *Participant: Tyhini↑ people would say that so and so's boyfriend died. There isn't*

303 *anything else that kills a person especially when they are still young-*

304 *Interviewer: uhm*

305 *Participant: So what I would do was () I would observe my ex-boyfriends to see if any*

306 *died and unfortunately I didn't have any ex-boyfriend who got ill or died, until I got*

307 *married*

(Nozuko; female 46)

Bongani pointed that if he were to die, people in the community would say he had died of HIV related causes.

Extract 74

315 *Participant: YAAH (.) It's the same as if I do not wake up-*

316 *Interviewer: Mmh*

317 *Participant: -today=*

318 *Interviewer: Mmh*

319 *Participant: =they would say no he was killed by such and such [HIV]*

320 *Interviewer: Mmh*

(Bongani; male 39)

Concerns about death and dying were also mentioned in relation to children. The participants worried that they would die and leave their children motherless. This participant mentioned that she would not have fallen pregnant had she known that she was HIV positive. This was a consequence of thoughts that HIV is incurable. This following extract sums up what the concerns and worries that the participants expressed.

Extract 75

*25 Interviewer: uh::m ° so that is how you think?*

*26 Participant: yes I do, that's what I think about and you have that thing of thinking that*

*27 you will die, you will leave these kids while they are still young for instance, understand,*

*28 what will they do?*

*389 Participant: So you as a parent have that thing. For instance with me, I sometimes have*

*390 that thing of wishing that if I had known before I had had a child. I would never have*

*391 had one. I would never have made a child, understand?*

(Nozuko; female 46)

Although death seemed to be an omnipresent reality for the participants, it appeared that they had found ways of dealing and managing the anxieties that resulted from thoughts about death, and death was seen as an eventuality that awaited everyone.

Extract 76

*400 it is not much of a problem'. Even if I was crying, I would think that 'in the end there is*

*401 nobody who will not die' because everybody is made to die, no matter what their cause*

*402 of death is*

(Nozuko; female 46)

The participant abates her fears by referring to death as inevitable for everyone.

#### **4.9 Coping with the HIV Diagnosis**

The participants expressed that they face intrapersonal, interpersonal as well as societal challenges on a day to day basis. From the initial shock of the diagnosis, disclosure and dealing with other people's reactions to their diagnosis, the participant also had to come to terms with the knowledge that they were faced with a chronic illness. The mechanisms that some participants applied in coming to terms with being diagnosed with HIV are discussed below. Normalising the virus was identified as one way the participants made sense of living with the virus. In the following extract, HIV was compared to Diabetes and it appeared less life threatening according to Xoliswa:

Extract 77

*306 Participant: Mmh yes it helped me (.) it really helped me because they explained to me*

*307 that HIV is not worse than Diabetes (.) because a person with Diabetes can have low*

*308 sugar levels and die unexpectedly whereas a person with HIV is able to live a long life*

(Xoliswa; female 42)

This comparison helped get the participant to a level of acceptance of their HIV status. For other participants too, normalising the virus appeared to be a way of accepting it. After overcoming the initial shock of the diagnosis, Nozuko narrates below how she manages the emotional reactions that she sometimes has.

Extract 78

*382 Participant: So it comes afterwards that- it is just to console yourself when you say*

*383 that - well in the end, everyone will die. You strengthen yourself and say that 'no I take*

*384 treatment*

(Nozuko; female 46)

Nozuko mentions that the thought that she is taking HIV treatment helps her to deal with thoughts that may cause her to lose strength in living with her diagnosis. This was also seen in Dlamini's response when he mentioned that whenever he thinks that about his status, he tells himself that his life will not end quickly because he was taking treatment.

Extract 79

*434 Interviewer: I hear you (.) but beside::s beside::s being sick (.) you see (.) what about*

*435 do you ever have stress (.) when you think about living with HIV?*

*436 Participant: No (.) I do not have it*

*437 Interviewer: You do not have it (.) but do you ever have it?*

*438 Participant: No (.) I think about it randomly (.) I tell myself that since I am using the pills*

*439 then it is not going to be (.9) my life will not end too quickly*

(Dlamini; male 56)

From what the participant states in the above extract, the knowledge that there is ART treatment available helped the participant to accept his status and not think negatively about

his diagnosis. Bongani who was a 39 year old male at the time that the interviews were conducted mentioned that after finding out about his status, nothing changed for him.

Extract 80

*260 Participant: -yaah I just remained as I am*

*261 Interviewer: Ok (.) but what can you say helped you to be that way*

*262 Participant: Come again?*

*263 Interviewer: what helped you be that way (.) because other people (.) hey hey*

*264 Participant: I started to (.) I started by supporting myself (.) that's the first thing I did*

*265 I was just the person I usually am*

*266 Interviewer: Mmh*

*267 Participant: I told myself that no (.) my life has not ended*

(Bongani; male 39)

For this participant it was neither the ARVs nor normalising talk that helped him to deal with his status he stated that he remained the same after diagnosis.

#### **4.10 Summary of findings**

In the results of this study participants were found to have different trajectories in dealing with the diagnosis. The participants' perceptions highlighted the association of HIV with sexual immorality as potentially driving stigma within their community. HIV infection was associated with sexual immorality. This resulted in moral judgements being made about the participants; this led to reluctance to undergo HIV counselling and testing (HCT) and a fear of utilising HIV care and treatment services.

The stigma and discrimination experienced by the participants was not overt but was implied in community members' remarks when speaking to the participants. As a result of the



negative attitudes, the study participants stated that they would have preferred their HIV status to be known by close relatives or only the people to whom they had disclosed.

The HIV diagnosis had different meanings for the individual participants: some feared their imminent death and the negative impact dying would have on family subsistence. Some experienced sadness about their prognosis in relation to their children. Amidst the feelings of despair, and dealing with community stigma, the participants managed to enter into care in an effort to maintain their physical health. Below is a discussion of the findings of this study.

## Chapter 5 Discussion

### 5.1 Introduction

The main aim of this study was to explore the lives of people living in a rural community in an attempt to understand their subjective experiences of living with HIV. To achieve this, a qualitative method was utilised to guide this research. The study aimed to capture and report on the personal experiences of people living with HIV in a rural community. The study aimed to explore challenges faced by people living with HIV and to explore how their context supported or inhibited their livelihoods. It further sought to find out how the participants coped with their diagnosis, for example, how they coped with disclosure, or fears that arose from living with a chronic illness. Chapter 6 will discuss the answers to the question ‘how do the participants deal with an HIV positive diagnosis in *Ematyholweni*’.

This chapter will discuss the findings of the study presented in the previous chapter. This chapter will attempt to show the experiences of the participants from a subjective point of view. The participants’ experiences are documented using the HIV continuum which begins with testing for HIV, disclosing the HIV status and living with HIV. Chapter 6 will be divided three into parts. Part 1 will focus on participants’ experiences in relation to the individual, by looking at how the HIV diagnosis affected them at as an individual. Part 2 will focus on participants’ experiences in relation to other people, by looking at disclosure, interpersonal interactions such as condom use and family support. Part 3 will discuss the context related experiences, by considering interactions with health service providers and community members after diagnosis.

### 5.2 Part 1

The precursor to knowing one’s HIV status is HIV testing. When learning about a positive HIV status, numerous personal and social stresses may arise. This section will begin by looking at how the participants came to know their status; it will focus on HIV test taking, how the revelation of their status affected them and what their reactions were.

### 5.2.1 Taking the HIV test

Literature indicates that people have different reasons for taking an HIV test and will usually delay taking the test for various reasons (Majumdar & Mazaleni, 2010). The current study had similar findings; it found that the majority of participants were tested for HIV when they had visited the clinic for other health problems besides HIV. The women were tested during their antenatal visits while one man had consulted at the clinic because he was ill. Only one participant had visited the local clinic with the intention of taking an HIV test. This participant had been experiencing HIV related symptoms and heard on the radio that HIV testing was being offered for free at local clinics.

According to Majumdar and Mazaleni, (2010) it is more difficult and will take an individual longer to come to terms with their HIV status if the test was taken when the person did not suspect their status and that it is easier to accept a positive HIV diagnosis when the decision to take the test was deliberate. The present study showed that testing deliberately or being tested when unsuspecting of your status has an impact on accepting a positive diagnosis. The participant who had gone to the clinic specifically for HIV testing mentioned that after speaking to the nurse he realized that HIV was not a death sentence; he can live with as long as he takes care of himself. His response to the diagnosis displayed acceptance. Another participant whose response showed easy acceptance of the HIV status was the participant who had gone to the clinic because they had physical symptoms of illness. This participant mentioned that he had “no stress” about his status. This participant might have been suspecting his HIV status because the symptoms he described were those related to HIV. He had diarrhea and night sweats for a while before deciding to go to the clinic.

The participants who got offered HIV testing during routine antenatal visit were not prepared for the test. They mentioned that they were in a state of shock when they found out about their results. One of the participants even mentioned that she fainted when she was told that she was HIV positive. These different reactions are supported by Drimie (2002), who stated that when tested without suspecting they are HIV positive, participants experience more intense reactions to their status than someone who had consulted a health facility specifically to test for HIV. It was evident from the participants’ responses that being HIV positive brought emotional turmoil, and being tested when unaware of their HIV status created additional stress for them. As important as taking a test and knowing one’s status is, it is equally important that consideration be made for the individual who will be receiving the test

result. From the study findings it appears as though the participants were not prepared for what their test results revealed.

Some of the participants in this study mentioned that they were not aware that they would be receiving their test results immediately after the test and that no counselling was provided before and after the test was taken. The reality that the HIV continuum does not end at just testing has to be considered when people are offered HIV testing at clinics. Once an individual is diagnosed with HIV, it opens up other important dynamics that are involved in dealing with the diagnosis. In remote villages such as *Ematyholweni* which are serviced by one clinic, patients are left on their own to deal with issues that arise upon taking an HIV test, they are lucky if they get the basic pre- and post-test counseling when taking an HIV test. This has negative implications for testing attitudes and reactions after HIV diagnosis. In this next session the participants' reactions and thoughts about being HIV positive will be discussed.

### **5.2.2 Reactions to HIV diagnosis**

The fear of death and dying was prominent in the participants' responses. This theme occurred when participants were asked the question "what is your main concern about living with HIV". The participants mentioned that although there is treatment for HIV, the fact that it is not curable was terrifying for them. Participants were concerned that the virus cannot be cured, with one participant mentioning that the only help he needs is for someone to come up with medication that can cure HIV. For the participants having just the HIV treatment was not enough as it just "slows" the virus and does not cure it. Given these perceptions, some of the participants viewed death as inevitable, stating that ultimately they are being "led" to their deaths because they have HIV.

Edwin Cameron alluded to this in his book, *A Witness to AIDS* when he stated that he feared that his flesh would ultimately fail him (Cameron, 2005). It seemed as though the participants viewed being HIV positive in a negative light, although they were taking their treatment they still felt that their prognosis was grim. The knowledge that one is HIV positive seems to be omnipresent, to the point where even if one can try to forget the memory is there. Cameron also talks about not being able to forget that he is living with AIDS and that remembering is a part of him, like blood (Cameron, 2005).

As reported in the section about disclosure to children, living with HIV and having children was a challenge for the study participants. They were not able to disclose to children who were of school going age. The women particularly feared that they would die and leave their children motherless. They wanted to be able to live long enough until their children could take care of themselves independently. They therefore had the fear of dying and leaving their children whilst they are still young. One woman mentioned that even dying of HIV would impact her children negatively because they would know that their parents were “killed by this thing”. The women’s fears of dying and leaving children young are founded on truth because in the past the country has seen many child-headed households due to HIV/AIDS related deaths (Meintjes, Hall, Marera & Boulle, 2010).

Participants used various mechanisms to deal with the thoughts of death and dying. Some participants were able to counter these by telling themselves that death was an inevitable reality for everyone, and not just to people living with HIV. In other instances participants compared the virus to other chronic illnesses, stating that if managed well, HIV becomes less life threatening when compared to other chronic illnesses. The support they received from their family served as a way to protect the participants from negative effects of their diagnosis, leading them to interpret HIV as similar to other chronic illnesses.

### **5.2.3 Unemployment**

HIV literature indicates that unemployment negatively affects individuals living with HIV (Drimie, 2002; Leclerc-Madlala, Simbayi & Cloete, 2009). Although the study participants were unemployed their employment status did not seem to have an adverse effect on them managing their status. Participants mentioned that they were able to maintain themselves through government supported social grants as well as by growing vegetable gardens. Being unemployed also did not play a role in accessing treatment as no transport was required to get to the clinic, it was within walking distance for all of the participants.

## **5.3 Part 2**

Disclosure may be a challenge for some people when they have not yet come to terms with their HIV positive status. Study participants were afraid to disclose to family members, anticipating that their reactions would be negative or judgemental. They feared that family

members would think that they had been promiscuous. This section will look at disclosure and the challenges that participants faced when disclosing their HIV status.

### **5.3.1 Disclosure**

Disclosure is one of the key elements in HIV literature and in coping with an HIV diagnosis (Lee et al., 2002; Sowell et al., 1997). Apart from it being an important element, it is also a requirement according to HCT Guidelines (2010) that a person discloses their status to someone after testing HIV positive. One of the goals outlined in the HCT Guidelines (2010) with regards to disclosure is that every testing and counselling programme should encourage and support the voluntary disclosure of HIV status. The study participants mentioned that they did not face any challenges when disclosing their status to family members, only one participant found it challenging. She could not even tell her mother about her status, she only managed to show her the paper with her test results. The rest of the participants felt that they were able to tell selected members of their families about their status.

In encouraging disclosure the government anticipates that through disclosure the HIV positive individuals will gain emotional support from others as well as assistance with healthy lifestyle choices that include the active prevention of the spread of HIV (Department of Health HCT guidelines, 2010). The study participants stated that upon disclose they experienced support from family members and close relatives. The challenge that they had was having the people they had disclosed to, keep their status a secret because they did not want it to be known by everyone that they were HIV positive.

This fear of uncontrolled disclosure was linked to the stigmatisation of the status of having HIV. They feared rejection and being isolated by others should community members know about their status. According to a study by Leclerc-Madlala et al. (2009) the fear of rejection and isolation, stems from the stigma in the community is related to seeing HIV transmission as being linked to ‘bad’ behaviour such as promiscuity a perception that HIV is a result of promiscuity and a low moral character (Leclerc-Madlala et. al., 2009 ). It is therefore the fear of being seen as having behaved ‘badly’, being sexually promiscuous, that the participants were afraid of.

### **5.3.2 Disclosing to a sexual partner**

Disclosing to a sexual partner appeared to be a complex issue for the majority of the study participants; one even reported having unprotected sexual intercourse without disclosing his

positive HIV status to his partner. It is only one married female (Nozuko) who preferred to disclose to her husband before disclosing to other people.

The use of condoms with sexual partners fell away completely when the participants knew their partners' HIV status. Results showed that participants used knowledge about their partners' HIV status as justification for not using a condom. When they had established that the partners were also HIV positive it was easier to view their partners in a positive light and therefore be less concerned about using a condom. Even in situations where condoms were used previously, having knowledge about their partners status resulted in participants engaging in sex without using a condom, and this was done to maintain a good relationship with their partners.

Stevens and Galvao (2007) found that women in relationships would discontinue the use of condoms if a partner refuses to use a condom. The women in this current study stated that it becomes a fight when they bring up the subject of condom use in their relationships and because they did not want to frustrate their partners or themselves they agreed to intercourse without a condom. A woman in this study stated that her partner refused to get tested for HIV yet he insisted on intercourse without a condom. This he did despite him knowing that she was HIV positive.

### **5.4 Part 3**

Part three will focus on community related experiences. As the participants managed to overcome fears related to families and close friends, there were the community members to deal with when it came to their diagnosis.

#### **5.4.1 Disclosure in relation to the community and local health facility**

Alonzo and Reynolds (1995) asserted that individuals with HIV and AIDS are stigmatised because their illness is associated with deviant behaviour. Miller (1987) suggests that such public responses generate the feeling of being unclean or dirty, such that people may avoid discussing their diagnosis with others. The perception that HIV is as a result of deviant behaviour becomes a barrier to disclosing HIV status because when the people disclose, they feel that they are indirectly admitting to promiscuity and or a low moral character. The study participants felt that the virus was associated with promiscuity in their community which made them not want to live openly with HIV.



Collecting treatment at the local clinic was another challenge to the participants. Participants acknowledged that they were getting adequate HIV related health education as well as encouragement from clinic personnel. What became a challenge for them was that they did not trust the nurses; they felt that their information is not kept confidential. A facet of disclosure as outlined in the Department of Health Policy guidelines on HIV testing is that no persons may disclose the status of another individual without their permission or in the case where the disclosure is to a medical professional, and the disclosure is done in the interest of the participant (Department of Health, 2010). Participants argued that some health providers released their information to other members of the community.

They felt that their test results were disclosed by people who work at the clinic to other people in the community without the participants giving permission for their test results to be disclosed. Community health workers who worked at the clinic were also not confidential about the participants' clinic visits. Two participants experienced incidences where members of the community approached them either asking whether the rumours (regarding their HIV status) were true or not. This resulted in participants not trusting the health care providers and being reluctant to go to the clinic for help. This phenomenon was found by Townsend (2009) in his study on privacy and confidentiality in rural health. His study states that privacy and confidentiality within the patient-provider relationship change when friends, neighbours, or acquaintances, rather than strangers are involved (Townsend, 2009).

#### **5.4.2 Confidentiality in the community**

Along with rumours from clinic staff, the participants were publicly seen going to the clinic for their treatment. Participants mentioned that when they were seen going to the clinic or losing weight the members of their community assumed that they were HIV positive. The regular visits to the clinic became visible signs that the participants were on HIV medication and community members deduced that the participants were going to the clinic for HIV treatment. That was how their HIV status was indirectly disclosed to others because they are seen going to the clinic. Parker, Colvin and Birdsall (2006) found that people living with HIV leave clinics in their local communities for clinics in neighbouring towns for fear of being identified by people who know them in their communities. Although none of the participants suggested a preference for clinics outside their communities, being seen going to the clinic regularly was one of the main concerns for them. A place where participants felt confident about disclosing their HIV status was within their families.

The stigma and discrimination that was experienced by participants in their community was not overt but implied in people's comments and remarks when they spoke to the participants. The participants indicated that they preferred to talk about things related to their status with other HIV positive people to avoid discrimination. They further stated that people were not open about their HIV status in the community; they would only know other people living with HIV because they collect treatment from the same clinic.

#### **5.4.3 Family support**

An important factor that led participants to disclose to their families was that they needed support from their families. The participants felt that they were receiving adequate support from the people to whom they disclosed. According to the participants, the support was in the way the family members received the news of their status and also in the way that the family members treated them as individuals living with HIV after disclosure.

The participants used words such as "strengthened" and "encouraged" to describe how they felt after disclosing their status and being accepted by their family members. There was no gender difference in how the participants perceived family support; the men and women in the study acknowledged that they valued the support they received from their families when they disclosed their status. This finding was contrary to that of Heckman et al. (1998a) whose study found that people in rural areas reported lower perceptions of family support when compared to people in urban areas. This was significant because the participants perceived the family as a safe environment where they would be protected from negative community attitudes.

The HIV diagnosis had different connotations, some participants experienced sadness about their prognosis and what it meant for the future of their children. Amidst the feelings of despair, and dealing with stigma and discrimination, however, participants managed to enter into care with the intention to restore their health.

There are many challenges that the participants in this study faced in dealing with their HIV positive diagnosis. Many of which were related to the context in which they found themselves in. Indirect stigma played a role in how they defined their diagnosis as well as how they perceived themselves as HIV positive individuals. In most instances they preferred to limit their interactions to close friends and family as well as other HIV positive

individuals. The family played a significant role in providing the individuals with psychosocial support. Participants also indicated that the family was a source of security, financially and physically where they felt that they could be protected by family members in situations related to discrimination.

## Chapter 6 Conclusion

### 6.1 Introduction

The study sampled and interviewed men and women infected with HIV in *Ematyholweni*. The aim was to understand the impact of the HIV diagnosis on the participants' lives. It thus explored the subjective experiences men and women living with HIV in this community. The study used interview data to help gain an understanding of living with HIV in a rural area that might shed light into the barriers and mediators to living positively with HIV. A thematic analysis of the data was used to better understand the phenomenon under investigation. In reviewing literature for this study it was evident that a lot of information is available in HIV literature; however there was lack of research available on the experiences of people in a rural setting within the South African context.

This study had four research questions. The first question looked at the experiences of the participants living with HIV. The results of this study suggest that people living with HIV experienced fear of death, despite the fact that they were all on ARV treatment. Most of this fear is perceived as resulting from the knowledge that the virus is incurable. Women particularly feared dying early and leaving their children motherless. Mentioning that when they discovered they were positive, what mattered most was protecting their unborn children.

The second research question was whether there were support structures available to people living with HIV in *Ematyholweni*. There were no structures such as support groups in the area of *Ematyholweni*. People relied on family members or friends for psychosocial support.

The third question investigated how people managed disclosing their HIV status to others. It was evident from the data that there were factors that influenced the participants' disclosure. The findings of the study indicate that participants disclosed to family members and some to friends. Trust was used as a basis to judge who the participants disclosed to. Participants also had a preference of talking about their status or HIV in general, with others who were HIV positive as well. The need to talk to someone about their diagnosis was another factor that led some participants to disclose their status. Multiple tensions arose when participants disclosed their status. They received support from family members but they feared that the people they

had told reveal their status to other people. This was problematic as participants had wished that their status remain a secret. As much as participants did not want the burden of knowing about their status alone, they had the fear that information about their status might not be kept confidential.

The fourth research question looked at role of stigma and discrimination in HIV management for the participants, which has been understood as a barrier to many HIV intervention strategies. Context played a role in how the participants accepted and managed their HIV diagnosis. People in the communities of *Ematyholweni* still experience stigma where HIV is concerned, participants reported experiencing stigma and discrimination from others who knew or suspected that they were HIV positive. The environment thus affects the way that people deal with their diagnosis. Negative attitudes of community members affected the participants' experiences within their community. Open dialogue about HIV and the impact of stigma on HIV positive individuals within communities may be a way of fighting community stigma. Secondly, talking openly about HIV at schools may also aid in lessening the stigma surrounding the virus.

Disclosing to various members of their families was difficult for the participants but proved beneficial as they received support and acceptance from the people to whom they disclosed. Family support is thus valuable and is necessary for those living with HIV in order for them to have a positive experience about themselves and their condition. There were internal conflicts in dealing with living with HIV as the participants were faced with thoughts of death and the fear of dying. These thoughts resulted from labeling the virus as incurable.

The participants attended the clinic, took their treatment without openly disclosing their HIV status. They told close friends and family members about their status and left the rest of the community to speculate whether they were HIV positive or not. With family support and the support of close friend, however, the participants were able to accept and live with their diagnoses.

It is important to note that the findings of this study reveal that some of the participants' experiences were not unique to people living with HIV in a rural area but were experiences common to people living with HIV in general. A unique finding of the study which pointed to the rural community was that given the size of the population, people knew each other in *Ematyholweni*. A person living with HIV could be identified through their regular visits to

the clinic; weight loss was also used by community members to distinguish those living with HIV and those who were not. These issues made it difficult for the study participants to be free about their status.

Another finding which was unique to the rural context was the lack of privacy and confidentiality at the local clinic. Participants felt that information about their HIV status was not protected at the clinic as health care providers were people from the community. These health care providers also did not seem discrete about people's medical information as it was mentioned by participants that they can send a community member to you should you not collect your treatment when you were supposed to. This resulted in participants being reluctant to attend their local clinic and feeling vulnerable to discrimination from others in their community. Participants attended their clinic however, stating that it was the only one that was easy to access.

The findings of the study show that dealing with HIV is a complex process that is affected by various factors; a multidisciplinary approach is needed to assist individuals living with HIV in rural communities. The experiences that emerged from the interviewed participants were insightful however the findings of this qualitative study should not be generalized. Due to the small, purposive sample, experiences of these participants cannot be taken to represent the experiences of all HIV infected individuals living in rural areas. The sample of participants used in this study cannot represent the breadth of experiences that HIV-infected people in rural areas may have. The knowledge gained from this study might be transferable to other contexts involving people in similar situations.

## **6.2 Limitations and strengths of the study**

Given the sensitive nature of the subject matter of this study, one of the limitations was finding people to participate in this study. The researchers relied on participants who had self-identified to be HIV positive and this limited the number of people who were willing to take part in it. Another limitation of this study was that the participants were not interviewed as couples, and many couple dynamics and interactions arose within the data and there was no opportunity to conduct follow up interviews regarding these dynamics.

What can be considered as one of the strengths in this study is language fluency; the interviewers, participants as well as persons responsible for transcribing and translation were

native *isiXhosa* speakers. The interviewers were able to question and probe in *isiXhosa* while participants were able to express themselves in their own language.

The study relied on self-reported experiences and the sample of the study was small, this could have negatively affected the credibility of the research findings as self-report research is at risk of bias through social desirable responding. Transferability of findings is possible to sites similar to the research site as the description around the characteristics of the research site, methodology and data analysis process was provided.

### **6.3 Recommendations for further studies**

It was the finding of this study that the participants did not receive counselling that met their expectations. They felt that their results were not explained to them adequately, and also that they were not made aware about the time it would take for their results to be available. The recommendation of this study is that people are given adequate counselling prior to testing and that the testing procedure be explained thoroughly.

Considering how unexpected testing affects people it is important that there be measures in place to assist patients with further management beyond testing. For example, someone who has visited the clinic specifically for the HIV test should not be treated the same as someone who is tested when they are at the clinic for other health reasons. Measures such as intensive counselling before and continued counselling after the test could be made available should a person be tested when they had visited the clinic for other health problems and they receive a positive HIV diagnosis

Studies focusing on the quality of health communication between the patient and provider may help in highlighting the gaps in the way that tests and counselling are done at the clinics in order for participants/patients to be adequately prepared for a positive HIV diagnosis. Couple-focused interventions to reduce HIV transmission and retransmission risk could be researched and implemented in community settings. The study participants were either married or in long term relationships where they were sexually active and they had challenges with the issue of condom use post diagnosis.

Research is needed that will focus on rural health and the effects of the context on people living with chronic illnesses, in this case HIV.

The recommendations of this study are offered with the hope that that they might provide insight about the lives of those living with HIV in rural areas and might assist in improving conditions for individuals living with HIV in these contexts. Gaining access to the life experiences of individuals living with HIV may assist in developing intervention strategies relevant to the needs of this population.



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## Appendices

### Appendix 1A Letter to the chief

8 December 2011

Dear Chief

I have worked in the *Ematyholweni* with various research projects since 1990. In 2000-2003 we conducted research about HIV/AIDS, youth, relationships and sexual health. I would like to consult with you, and seek your permission to continue the research in the *Ematyholweni*, over the next few years.

The focus of the research would be on seeing how responses to HIV and AIDS have changed in *Ematyholweni*. It would look at what people know about HIV and AIDS, what they think about it and how they are responding to it. The team of people working on the project is from the University of KwaZulu-Natal, in Pietermaritzburg, and also staff and students from Fort Hare University.

The research would involve interviews and focus groups with young people, parents, church groups, traditional leaders, traditional educators, traditional healers, and the clinic staff. It would also involve workshops at which information collected in interviews and focus groups will be presented and discussed. The process of the research project is meant to include the residents of the *Ematyholweni* in understanding and analysing this information. It might happen that because we are all discussing the research process and the information together, changes will come out of the workshop process.

We would like to work in a few villages in the *Ematyholweni*. Unfortunately because of time constraints it will not be possible to work in all of the villages.

The project data collection would start in 2012, and might continue until the end of 2013. The interviews and focus groups will be recorded so that the researchers can accurately capture what it is that people have said, and translate it into English. The workshop process will be filmed using a video camera, also to accurately record what people discuss.

This information will then be transcribed (or written down) from the video recording. The names of all of the people who participate in the interviews and focus groups will be kept

confidential and known only by the research team. Each participant will be given a code number so that their views will remain private. The information collected in the research process will also be used to write research articles, and to present at conferences so that other people may learn from the experience of our research. Some of the students and lecturers conducting the research will be using the research project to study for their degrees.

I will be happy to answer any questions that you have about the project.

Yours sincerely

Dr Mary van der Riet

Senior Lecturer, Psychology, UKZN



## Appendix 1B Letter to the chief *isiXhosa* version

8 December 2011

Nkosi Ethandekayo

Ndike ndasebenza *Ematyholweni* ndisenza iinkqubo zophando ezininzi ukusukela ngo 1990. Ngo 2000-2003 senza uphando ngentsholongwane nesifo sikagawulayo, ulutsha, ezobudlelwane kunye nempilo ekwabelaneni ngesondo. Ndingathanda ukuba sidibane, ukuzo cela imvume yakho yokuba siqhubeke noluphando *Ematyholweni* kuleminyaka embalwa elandelayo.

Ingqwalasela yoluphando kukubona ukuba iimpendulo malungelana nesifo sikagawulayo sezatshintsha na *Ematyholweni*. Oluphando lizakujonga ulwazi labantu ngentsholongwane nesifo sikagaqulayo, iingcinga zabantu ngesisifo kunye nokuba bapendula/bayibona kanjani lemeko. Iqela labantu abasebenza koluphando basuka e Yunivesithi yaKwaZulu-Natal, eMgungundlovu (Pietermaritzburg), kunye nabasebenzi, nabafundi abasukae Yunivesithi yaseFort Hare.

Oluphando luquka, udliwano-ndlebe kunye nengxoxiswano nolutsha, abazali, amabandla, inkokheli zesintu, iingcibi, abanyangi/izangoma kunye nabasebenzi base kliniki. Oluphando luzoquka/bandakanya iimfundiso/imihlangano apho ulwazi oluqokelelwe kudliwano-ndlebe nakwiingxoxiswano, lizokwandlalwa khona. Lenkqubo yoluphando yenzelwe ukuba abahlali base *Ematyholweni* babe nesabelo ekuqondeni nasekucalucaleni olulwazi. Kungezeka ukuba ngenxa yokuba sixoxisana sisonke kulenkqubo yophando kunye nakwi ncukacha, utshintsho lungavela emhlanganweni.

Singathanda ukuqhuba oluphando kwiilali ezimbalwa zase *Ematyholweni*. Kodwa ngenxa yokuba ixesha esinalo lufutshane, asizukwazi ukuba sisebenze kuzo zonke iilali. Uqokelelo-lwazi loluphando luzokuqala ngonyaka ka 2012 futhi lungaqhubeka kude kuyophela unyaka ka 2013.

Iindliwano-ndlebe kunye nengxoxiswano zizoshicilelwa ukwenzela ukuba abaphandi babambe ngononophelo oko abantu abakuthethileyo, bakutolikele kwisingesi. Inkqubo yemfundiso/yomhlangano izoshicilelwa kusetyenziswa i-video camera, kushicilelwe

nyanisekileyo oko abantu abakuxoxileyo. Olulwazi luzokubhalwa phantsi lusuka/lusukela kushicilelo lwe-video.

Onke amagama abantu abazobe behlomla/bethatha ingxaxheba kudliwano-dlebe nakwi ngxoxiswano azogcinwa efihlakele azokwaziwa liqela lophando kuphela. Wonke umntu ezoba ehlomla uzonikwa inombolo ukuze izimvo zabo zihlale zifihlakele.

Ezi nkcukacha ziqokelelwe kule nkqubo yophando zisosetyenziswa ukubhala amanqaku azokwaziswa/bhengezwa kwi nkonfa ukwenzela ukuba abantu bafunde kumava oluphando. Abanye babafundi nabafundisi-ntsapho abaqhuba oluphando bazokusebenzisa lenkqubo yophando ukufezekisa/ukugqibezela izifundo zabo. Ndingathanda ukuphendula yonke imibuzo mayelana noluphando.

Ozithobileyo

Dr Mary van der Riet

Senior Lecturer, Psychology, UKZN

## Appendix 2A Information sheet

Dear Participant

We are doing research in *Ematyholweni* about HIV and AIDS; we would like to do an interview with you. In this interview we will ask questions about your experiences as a person living with HIV here in *Ematyholweni*. In this interview we will ask you some questions about relationships, sexual health and the risk of HIV and AIDS. We would like to find out what your experience is, and what you think about these things. We would also like to find out what it is like to live with HIV in *Ematyholweni*. We would like to do more than one interview with you so that you can have time to reflect on the discussion and we can have time to reflect on the first interview together. Each interview will be about an hour long and we would like to record each interview so that we can have an accurate record of what you say.

The information gathered from these interviews with you will be used to write up a thesis for the purposes of obtaining my Master's Degree. It may also be used to produce research articles and papers to present at conferences so that other people may learn from the experiences of our research. Your views will help us gain a deeper understanding of the problem of HIV/AIDS. We assure you that your name will not be revealed in any part of the research process as we will be using codes instead of names for the purpose of this research study. The information we gather from you will also be used by other students at the University for their Research Studies, after which it will be stored by the supervisor of this project Dr Mary van der Riet and in the NRF database.

Should you need further counselling and support after our interviews, we have spoken to counselling staff members at the nearest Health Care Centre, to provide some support to you. The staff members have been made aware about the study that will be conducted and that you may require her services after the interviews.

As an alternative to the above mentioned Health Care Centre, we also spoke to the staff members at the local clinic. Be free to contact them as well for assistance. The nursing sisters at the clinic are aware of the study that will be conducted in the area and they are willing to assist with counselling should you need it.

If you agree to participate, but then later feel that you wish to withdraw from the interview and not participate anymore, that is fine. You can say so and we will stop the interview. If you have any questions then please let us know, you can talk directly to us or you can call the following people:

Mary van der Riet: (Supervisor of the Research)

Nasiphi Mqedlana: (Masters Student)

If you have any concerns about the ethics of this study you can contact the Humanities and Social Sciences Research Ethics committee.

## **Appendix 2B Information sheet isiXhosa version**

Ucwecwe lwemvume yengxoxiswano

Kule ngxoxiswano sifuna ukukbuza imibuzo ngentlalo yakho njengomntu ophila nesifo sika gawulayo. Sifuna ukwazi ukuba kukho umntu osele umxelele na ngesimo sakho sokuphila nogawulayo, ukuba ukhona, sifuna ukwazi uye waphathwa kanjani emveni kokuba uzixelile

Ingxoxiswano yethu izakwenziwa izihlandlo ezintathu, ezi zihlandlo zintathu zizothatha ixesha elingande yure isihlandlo ngasinye. Emva kodliwano ndlebe nengxoxiswano sizothatha incukacha sizenze imfihlo. Uzonikwa inombolo eyiyi kodi ukuba igama lakho lingaveli, kwaye nezinto ozithethileyo.

Sifuna ukusebenzisa ezincukacha eziqokelwe kule nqubo kwezinye ingxoxiswano, phambi kwabanye abantu. Kule nqubo kwezinye ingxoxiswano kulapho esingathetha khona, sive ukuba abanye abantu bacinga ntoni ngokuphila nesifo ugawulayo, ucalucalulo lwabantu abaphila nayo.

Incukacha eziqokelelwe kule nqubo zizosetyenziswa ngabafundi, ukubhala amaphepha wabo weresearch nokufumana iidigri zabo. Futhi zizo bhengezwa kwikomfa phambi kwabanye abantu ukubazisa ngalenqubo yolu phando.

Ukuba uthe wakuthatha inxaxheba koluphando ze waziva udinga ukuthetha thethana nomntu mayelana nezinto ezikukhathazileyo, sicele abantu base Sibehdlela esikufutshane nawe ukuba ze bancedise nge-counselling. Ungaya khona emva kokuba sihambile thina. Kanti ungaya nakule klinikhi yalapha kulenginqi yenu. Nakhona sibaxelele ooNesi ngoluphando silwenzayo. Ukuba uthabatha inxaxheba kule ngxoxiswano esiyibambayo, amava akho azosinceda ukuba sibe nemibona ngale ngxaki ye HIV ne AIDS.

Ukuba uyavuma ukuba lilunga lenqubo, kodwa mhlawumbi emva kwexesha uphinde uzive ufuna ukurhoxisa inxaxheba yakho, kulungile. Kufuneka usixelele, sizorhoxisa.

Ukuba unemibuzo ofuna ukuyibuza, ungatsalela umnxeba kwaba bantu balandelayo

Mary van der Riet: (Umphathi wenqubo)

Nasiphi Mqedlana: (Ofundela ukuba ngumphandi)

Ukuba unemibuzo ngemvume yoluphando ndicela uqhakamshelane iHumanities and Social Sciences Research Ethics.

### **Appendix 3A Consent form for individual interview**

- I agree to participate in this research.
- I have had an opportunity to read and understand the information sheet given to me.
- The purpose of the study has been explained to me. I understand what is expected of me in terms of my participation in this study and the time commitment I am making to participate in this study.
- I understand that my participation is voluntary and I know that I may withdraw from the study at any point, without negative consequences.
- I understand that the information collected in this interview will be kept safe
- I understand that my identity will remain confidential
- I understand that the information collected may be used for student studies, for future research, for conference presentations and for journal articles. I understand that in all of this my name will not be mentioned and my participation in this research will be completely confidential. I understand that no identifying information about me will be published.
- I have the contact details of the researcher should I have any questions about the research.

Signature of Participant----- Date -----

### **Appendix 3B Consent form for individual interview *isiXhosa* version**

- Ndiyavuma ukuthabatha inxaxheba kulenqubo
- Ndilifumene ithuba lokufunda ucwecwe lencukacha zale nqubofuthi ndiyaziqonda
- Ndiyichazelwe intloso yale nqubo. Ndinalo ulwazi lokuba kulindelwe ntoni kum, ndiyazibophelela ukuba ndenze zonke ezi zinto zicelwe kum
- Ndiyaqonda ukuba akunyanzelekanga ukuba ndithabathe inxaxheba kule nqubo, futhi ndingayeka nanini na apho ndithande ukuyeka khona.
- Ndiyaqonda ukuba zonke incukacha eziqokelelwe kule nqubo zizogcinwa ziyimfihlo
- Ndiyaqonda futhi ukuba mna ndizogcinakala ndikhuselekile kule nqubo
- Ndiyaqonda ukuba inchukacha ezivela kwezingxoxo esizozibambazizokusetyenziawa ekubhaleni amaphepha azobhengezwa kwikomfa naphambi kwabanye abantu nabaphandi. Abanye abafundi bazosebenzisa lenqubo ukuze bafumane idigri zabo. Ndiyaqonda ukuba kuyo yonke lenqubo igama lam lizohlala likhuselekile.
- Ndinazo incukacha zabaphandi kule nqubo kwaye ndingabatsalela umnxeba nanini ukuze ndicaciselwe ngemibuzo endinayo nangezinto endingaziqondi.

Isityikityo----- Umhla -----



## **Appendix 4A Consent for audio recording**

In order to be able to understand clearly what you have said in this interview, and to remember it, we would like to record the discussion on this small digital recorder. We will then listen to the recording and write it down (transcribe it). It will also be translated into English. After we have written the information down, we will then delete the recording on the digital recorder.

We assure you that your name will not be linked to the recording or the written information from the recording. We will give you a code name using numbers, for example Nozuko\_Interview 3.

Do you agree that we can record this discussion?

If yes, then please sign here \_\_\_\_\_ Date \_\_\_\_\_

## **Appendix 4B Consent for audio recording *isiXhosa* version**

Ucwecwe lwemvume yokuqopha udliwanondlebe.

Ukuze siqonde kakuhle futhi sikhumbule okuxoxwe apha sifuna ukuteypha ingxoxo yethu ngerekoda.

Sizophinda siyimamele le ngxoxo kulerekoda sibhale phantsi incukacha zale ngxoxo. Ingxoxo izotolikwa ukuze iviwe ngabanye abaphandi. Ukugqiba kwethu ukwenza lonto, sizokuyicima yonke into ekwi rekoda. Siyakuthembisa ukuba igama lakho alizukavela kwi recorder nakwizinto ezibhaliwe e phepheni. Igama lakho sizokuligcina liyimfihlo ngokulinika inomboro.

Ingaba uyavuma ukuba siyiqophe ingxoxo?

Ukuba uyavuma, Ndicela utyikitye apha \_\_\_\_\_ umhla ka \_\_\_\_\_

## **Appendix 5A 2012 Interview schedule 18+, parents, married people**

### **Process**

Introduction of the research process

Sign consent documents

Obtain permission for audio-recording

Complete demographic information sheet

### **Relationships**

1. How long have you been married?
2. Tell me a bit about how you met your husband/wife?
3. Do you have children?
  - a. What are their ages?
4. Do you talk to your children about sex?
  - a. If yes, at what age did you/do you talk to them? Can you tell me briefly what you say?
  - b. Do you talk to them about the risks in sex?
5. What kinds of risks?
  - a. What can they do about these risks?
  - b. If no, why do you not talk to them?
6. Have you been in a relationship before?

## **Health risks**

6. As married people, have you discussed the risks of sex? Why/why not?

a. If yes, what risks have you discussed? Who raised the question of the risks?

b. What was said in the discussion?

c. Did anything change because of the discussion?

7. Do you think it is important to worry about safe sex in your marriage? Why/why not

a. Do you think it is important to practice safe sex in your marriage? Why/why not?

8. Have you discussed with your wife/husband how to prevent getting a sexually transmitted infection?

a. Please tell me briefly about that discussion (why did it come up? What was the worry/concern? Who raised it? ) If no, why have you not discussed this?

9. Can you discuss sex freely with your partner? Why, why not?

## **Condom use**

10. Have you ever used a condom in your marriage?

a. If yes, can you explain when and why? Do you always use a condom? If no, why not?

b. How do you feel about getting a condom? Why? Where would you get a condom? Are there problems with getting condoms? Elaborate

11. Are there other ways of practicing safe sex without using a condom? Please explain.

12. Can you freely suggest using a condom to your husband/wife? Why/why not?

a. What would his/her reaction be if you suggested using a condom? How would you feel if your husband/wife suggested using a condom?

13. Do you carry a condom with you? Why/why not?

a. What do you think about a woman carrying a condom around with her? What do you think about a man carrying a condom around with him?

14. The last time you had sex, did you and your husband/wife talk about condom use? Can you tell me what happened?

15. The last time you had sex did you use a condom? Can you tell me what happened?

## **HIV questions**

16. Can you tell me briefly what you know about HIV/AIDS (Please note I do not want to know your status, you do not have to tell me anything about whether you are positive or negative).

17. Have you ever talked to anyone about HIV and AIDS?

a. If yes, please elaborate?

b. If no, why not? What stops you from talking about HIV?

18. Is there anything you would like to know about HIV? Do you know anyone in *Ematyholweni* who is HIV positive? (Please do NOT tell me their names)

a. How do you know they are HIV positive?

19. If someone is HIV positive should they tell others? Why/why not

a. Do you know of anyone who is HIV positive? How people who are HIV positive are treated in *Ematyholweni*? Should this change? Why/why not

## **Testing**

20. What do you know about HIV testing?

a. What do you think about it? Is it a good/bad thing? Why?

21. Do you know your own HIV status? (PLEASE DON'T TELL ME YOUR STATUS, ONLY WHETHER OR NOT YOU KNOW YOUR STATUS) Did you check your husband/wife's HIV status before getting married? Why/why not? Have you ever been for an HIV test?

a. If yes,

i. Why did you go?

ii. What did you feel about going for the test? Where did you go?

iii. What was it like? Have you been again? How often do you go?

iv. Would you go again? Why/why not?

b. If no, why have you not gone?

i. What would need to change for you to go? (under what conditions would you go for a test?)

22. If you have a husband/wife do you know his or her HIV status?

a. If yes, how did you find out? (Did your partner tell you? Did you go for a test?) If no, why not?

i. Do you want to know?

23. Have you discussed going for a test with your husband/wife? Why/ Why not?

### **Treatment**

24. Can HIV be treated?

a. If yes, how?

b. If no, why not?

c. If you had HIV, how would you treat it?

d. Where would you go in *Ematyholweni* for treatment?

25. What do you know about anti-retroviral treatment (ARV's)? (What is it, what does it look like, how does it work?)

26. Would you take ARV's if you needed to? Why/why not?

a. If yes, where would you go to get them?

b. If no, what would stop you from taking them.

## **General**

27. What can be done about HIV and AIDS in *Ematyholweni*? What can YOU personally do about HIV and AIDS in *Ematyholweni*?



## **Appendix 5B 2012 Interview schedule 18+ parents, married people isiXhosa version**

### **Process:**

Introduction of the research process

Sign consent documents

Obtain permission for audio-recording

Complete demographic information sheet

### **Relationships**

1. Lingakani ixesha seleutshatile?
2. Bendicela undichazele kancinci ukuba nadibana kanjani nomyeni wakho/nonkosikazi wakho?
3. Unabo na abantwana?
  - a. Mingaphi iminyaka yabo?
4. Uyathetha na nabo ngokuthandana nentlobano zesini?
  - a. Waqala nini ukuthetha nabo ngezizinto?
  - b. Bendicela undixelele kancinci ukuba uthini kubo?
  - c. Uyathetha na nabo ngeengozi zentlobano zesini?
    - i. Uthetha ngeziziphi iintlobo zenengozi?
    - ii. Yintoni abanokuyenza bona ngezizingozi?
  - d. Ukuba awuthethi nabo, kutheni ungathethi nabo?
5. Wena wake wanaye Umntu othandana naye?

## **Health risks**

6. Njengabantu abatshatile, niyaxoxa na ngengozi zeentlobano zesisni?
  - a. Ukuba kunjalo, zeziphi iingozi enizixoxayo?
  - b. Ngubani owavusa lombandela wezizingozi?
  - c. Kwathiwani kulengxoxo?
  - d. Khona uthsintsho owalibona ngenxayalengxoxo phakathi kwenu?
7. Xa ucinga, kubalulekile ukuba kuthethwe ngokulalana okukhuselekile emthsatweni?
  - a. Xa ucinga, kubalulekile ukuba nizikhusele xanilala emthsatweni wenu?
8. Wakewaxoxa nomkakho/nomyeni wakho ngezifo ezigqithiselwa ngokulala?
  - a. Bendicela undichazele kancinci ngalengxoxo?
  - b. Ukuba akunjalo, kutheni?
9. Uyaxoxa ngokukhuleka ngentlobano zesini nomyeni/nomkakho?

## **Condom use**

10. Niyazisebenzisa na iicondom emthsatweni wenu?
  - a. Ukuba kunjalo Bendicela undixelel ukuba wazisebenzisa nini, kutheni?
  - b. Niyisebenzisa njalo na icondom?
  - c. Ukuba akunjalonga, kungoba kutheni?
  - d. Uziva kanjani xakufuneka uyofumana icondom? Ngoba?
  - e. Uyfumanaphi icondom, zikhona ingxaki ojamelana nazo xaufuna icondom? Bendicela uchaze

11. Zikhona na ezinye iindlela zokuzikusela ungayisebenzisanga icondom? Ndicela undichazele

12. Uyakwazi na ukumcela umyeni wakho/umkakho ukuba manisebenzise icondom ukhululekile?

a. Uye athini xa usenza esisicelo?

b. Ungaziva kanjani ukuba umkakho/umnyeni wakho angakucela ukuba nisebenzise icondom?

13. Uyayiphatha na wena icondom? Ngoba?

a. Ucinga ntoni ngabafazi abaphatha iicondom?

b. Ucinga ntoni ngendoda ehamba iphethe icondom?

14. Nathetha na ngokusebenzisa icondom? Bendicela undichazele ukuba kwenzeka ntoni?

15. Ukugqibela kwakho ukulala nomntu wakho, nayisebenzisa na icondom?

### **HIV questions**

16. Bendicela undixelele kancinci ngolwazi onalo ngentsholongwane ka gawulayo? Andifuni kwazi ukuba upositive na

17. Ukhona umntu owake wathetha naye nge AIDS

a. Bendicela undichazele

b. Ukuba akekho, kutheni engekho?

18. Kukhona na into oralela ukuyazi ngesisifo?

19. Kukhona na Umntu apha e*Ematyholweni* omaziyo ukuba upositive?

a. Wazikanjani ukuba upositive lomntu?

20. Ukuba Umntu uneHIV okanye iAIDS, kufanele na abazise abanye abantu? Ngoba?

- a. Ukhona na Umntu omaziyo oHIV positive?
- b. Baphathwa kanjani abantu abanentsholongwane apha e*Ematyholweni*?
- c. Kufuneka itshintshe na lento?

### **Testing**

- 21. Loluphi ulwazi onalo ngokuhlolwa kwentsholongwane kagawulayo?
  - a. Ucinga ntoni ngayo, yinto entle okanye ayintlanga? Ngoba?
- 22. isimo sakho seHIV uyasazi na? ndicela ungandixeleli ukuba sithini
- 23. Umyeni wakho, umkakho wamhlola na intsholongwane ngaphambilokuba nitshate?
- 24. Wena wake wayihlolwa iHIV?
  - a. Ukuba kunjalo
    - i. Kwakutheni uzeuye
    - ii. Wawuziva kanjani ngelixeshauyohlolwa?
    - iii. Wahlolwa phi
    - iv. Kwakunjani?
    - v. Selekewaphinda, kangaphi?
    - vi. Ungaphinda futhi uyohlolwa? Ngoba?
  - b. Ukuba zange uphinde, kutheni?
    - i. yintoni ekunofuneka itshintshe ukuze uphinde?
- 25. Ukuba unaye umfazi/inkosikazi, uyasazi na isimo seHIV sakhe?
  - a. ukuba uyasazi, usazi kanjani?

b. Ukuba awusazi, kutheni ungasazi?

i. Uyafuna na ukusazi?

26. Nakenaxoxan nomkakho/nomyeni wakho ngokuyohlolwa?

### **Treatment**

27. Iyatritwa na iHIV?

a. Ukuba kunjalo, kanjani?

b. Ukuba akunjalongo, kanjani?

c. Ukuba uneHIV uyitrita kanjani?

d. Ungayaphi e*Ematyholweni* xaufuna itritment

28. Uyazazi iARVs?

29. Ungazithatha na xakunesidingo sokuba uzithathe? ngoba?

a. Ungayozithatha phi?

b. Yintoni enokunqanda ukuba ungazithathi?

### **General**

30. Yintoni enokwenziwa ngeHIV e*Ematyholweni*?

31. Yintoni onokuyenza ngeHIV wena apha e*Ematyholweni*?

## **Appendix 6A 2013 Interview schedule (1) First interview**

**Ucwecwe Lwemibuzo Yengxoxiswano Yabantu abaphila nentshologwane ugawulayo**

**Ibibuzo Yengxoxiswano yokuqala (1):**

1. I would like to find out about you and your life. Can you tell me your life story?

**1. Ndithanda ukwazi ka banzi ngawe nobomi bakho. Ndicela undixelele ibali lobomi bakho**

2. Where were you born?

**2. Wazalelwa phi?**

3. When did you come to *Ematyholweni*?

**3. Uze nini apha *Ematyholweni*?**

4. Are you married?

**4. Utshatile?**

If yes,

Ukuba ewe,

**5. How long have been married for?**

5. Unexesha elingakanani utshatile?

**6. Do you have children?**

6. Unabo abantwana?

**7. How many children do you have?**

7. Bangaphi abantwana bakho?

**8. Where do they stay?**

8. Bahlala phi?

**9. Tell me about your life before finding out that you are HIV positive**

9. Ndicela undixelele ngobomi bakho phambi kokuba ube nentholongwane ugawulayo

**10. Before being diagnosed with the virus, what were your thoughts about it? What were your thoughts about people living with HIV?**

10. Ngaphambi kokuba uzazi ukuba unalentsholongwane, wawucinga ntoni ngokuba nentsholongwane? Wawucinga ntoni ngabantu abaphila nale ntsholongwane?

**11. How long have you been living with HIV?**

11. Unexesha elingakanani uphila nentsholongwane kagawulayo?

12. How did you find out that you are HIV positive?

**12. Wazazi kanjani ukuba unentsholongwane ugawulayo?**

If through testing:

Ukuba waTesta:

**12.1 Tell me about the experience of testing?**

12.1 Ndicela undixelele ukuba waziva njani xa utesta

**12.2 What were the conditions that made you go and test**

12.2 Ngezphi izizathu ezenza ukuba uhambe uyotesta?

12.3 How did you feel upon hearing about your results?

**12.3 Waziva njani xa wawuxelelwa iziphumo zetest?**

13. What happened after you found out about your status? (How did you feel? Can you please explain?)

**13. Wenza ntoni usofumana iziphumo zetest?**

14. Did you tell anyone about your status?

**14. Ingaba kukho umntu owamxelelayo?**

15. Who did you tell?

**15. Ngubani lomntu owamxelelayo?**

16. Why did you tell this person?

**16. Kwakutheni ze uxelele yena lomntu?**

17. What was that person's reaction?

**17. Wathini lo mntu akuva iziphumo zakho?**

18. In your view, how are women living with HIV treated by others in *Ematyholweni*?

**18. Ngokokubona kwakho, umphakathi walapha uwaphatha kanjani amakhosikazi abaphila nentsholongwane iHIV?**

19. In your view, are women living with HIV are treated the same way as men living with HIV?

**19. Ngokokubona kwakho, ungathi amakhosikazi anale ntsholongwane aphathwa ngohlobo olufanayo namadoda anale ntshologwane?**

20. How are you treated by those who know that you are HIV positive?

**20. Bakuphatha kanjani abantu abayaziyo ukuba uphila nentsholongwane ugawulayo?**



## **Appendix 6B 2013 Interview Schedule (2) Second interview**

### **Imibuzo Yengxoxiswano Yesibini**

1. Are there any issues you would like to discuss with me from the last interview?

**1. Ingaba kukhona izinto ofuna sithethe ngazo eziye zavuka emva kwengxoxiswano yethu yokuqala?**

2. Did the last interview make you think about any issues? If yes, please elaborate.

**2. Kukho izinto ocinge ngazo emva kwe ngxoxiswano yethu? Ukuba ewe, ndicela uchaze.**

3. How has being HIV positive affected your marriage/relationship?

**3. Ubundixelele ukuba utshatile. Ndicela undixelele ukuba intsholongwane le iwuchaphazele kanjani umtshato wakho?**

4. What areas of the relationship have been affected? (Can you give examples?)

**4. Ngeziphi iindawo ezichaphazelekileyo kubudlelwane benu? (ndicela undinike imizekelo)**

5. Has your status changed condom use in your relationship? (Can you tell me how?)

**5. Ingaba ukuphila nale ntsholongwane kuyithsintshile indlela enisebenzisa ngayo icondom? (Kuyitshintshe kanjani).**

6. Which aspects of your life have been affected the most in living with HIV?

**6. Ngeziphi iindawo zobomi bakho ezitshintshileyo ngenxa yokuphila nentsholongwane iHIV?**

7. Are you on ARV treatment?

**7. Uyazisebenzisa ipilisi iARVs?**

If yes, tell me about the treatment you are taking?

**Ukuba ewe, ndicela undixelele ngepilisi zakho.**

7.1 Where do you go to get your treatment?

**7.1 Uzifumana phi ezi pilisi?**

7.2 Are there any challenges with getting treatment?

**7.2 Zikhona ingxaki ohlangabezana nazo ngendaba yepilisi?**

7.3 Have you had any side effects from the treatment?

**7.3 Ingaba xa uziselile ezipilisi kukhona izigulo oba nazo?**

If yes, please tell me about them

**Ukuba ewe, ndicela undixelele ngazo**

7.4 I understand that some people face challenges with adhering to treatment, has this been your experience?

If yes, please explain

**7.4 Ndiyayiqonda ukuba abantu abanintsi bahlangabezana nengxaki xa kufuneka bethathe ipilisi ngexesha, ingaba ukhe wahlangabezana nayo lengxaki?**

**Ukuba kunjalo, ndicela undichazele kabanzi ngezo ngxaki**

8. Do you get support as an HIV positive person?

**8. Uyalufumana uncedo njengomntu ophila nentsholongwane ugawulayo?**

8.1 Where or from whom does your support come?

**8.1 Ulufumana phi okanye kubani oluncedo?**

8.2 What are the challenges have you faced in getting support?

**8.2 Ngeziphi ingxaki ohlangabezana nazo ekufumaneni uncedo?**

8.3 Where do you think you should get help from?

**8.3 Ucinga ukuba kufanele ulufumane phi oluncedo?**

8.4 How can this happen?

**8.4 Ingenzeka njani lonto?**

8.5 How does receiving support benefit you as a woman living with HIV?

**8.5 Yintoni oyizuzayo xa abantu beku supporta njengo nkosikazi ophila nogawulayo?**

9. What are the challenges you face with as someone living with HIV here in *Ematyholweni*

**9. Zintoni izinto ohlangabezana nazo apha *Ematyholweni* njengomntu ophila nentsholongwane ugawulayo?**

10. What is your greatest concern about being diagnosed with HIV?

**10. Yintoni eyona nto ikukhathazayo ngokuphila nentsholongwane ugawulayo?**

11. How does living with HIV affect your role as a wife and a mother?

**11. Ukuphila nentsholongwane kagawulayo kuyichaphazela kanjani indima yakho njengo Nkosikazi nanjengomzali?**

12. How do you feel when people talk about HIV/AIDS?

**12. Uziva njani xa abantu bethetha ngentsholongwane ugawulayo?**

13. In your view, how do you think people perceive HIV positive women?

**13. Ngokokubona kwakho, abantu bambona njani umntu oyinkosikazi ophila nentsholongwane ugawulayo?**

## Appendix 7 Extract Codes

<b>Extract number</b>	<b>Interview code</b>
Extract 1	20130525_H_F2(1)_OJ_R
Extract 2	20130525_H_F2(1)_OJ_R
Extract 3	20130529_H_F1(1)_OJ_S
Extract 4	20130529_H_M2(1)_OJ_V
Extract 5	20130529_H_M2(1)_OJ_V
Extract 6	20130529_H_F1(1)_OJ_S
Extract 7	20130525_H_F2(1)_OJ_R
Extract 8	20120615_HPP_F_OJ_V_(E)(1)
Extract 9	20130523_H_M1(1)_OJ_V
Extract 10	20130529_H_M2(1)_OJ_V
Extract 11	20120615_HPP_F_OJ_V_(E)(1)
Extract 12	20130525_H_F2(1)_OJ_R
Extract 13	20130523_H_M1(1)_OJ_V
Extract 14	20130529_H_F1(1)_OJ_S
Extract 15	20130529_H_F1(1)_OJ_S
Extract 16	20130529_H_F1(1)_OJ_S
Extract 17	20130529_H_F1(1)_OJ_S
Extract 18	20120615_HPP_F_OJ_V_(E)(1)
Extract 19	20130525_H_F2(1)_OJ_R
Extract 20	20130525_H_F2(1)_OJ_R
Extract 21	20130604_H_F2(2)_OJ_R
Extract 22	20130606_H_F1(2)_OJ_S
Extract 23	20130523_H_M1(1)_OJ_V
Extract 24	20130525_H_F2(1)_OJ_R
Extract 25	20130525_H_F2(1)_OJ_R
Extract 26	20130525_H_F2(1)_OJ_R
Extract 27	20130529_H_M2(1)_OJ_V
Extract 28	20130523_H_M1(1)_OJ_V
Extract 29	20130525_H_F2(1)_OJ_R
Extract 30	20130529_H_F1(1)_OJ_S

Extract 31	20130529_H_M2(1)_OJ_V
Extract 32	20130529_H_F1(1)_OJ_S
Extract 33	20130630_H_M1(2)_OJ_V
Extract 34	20130529_H_M2(1)_OJ_V
Extract 35	20130525_H_F2(1)_OJ_R
Extract 36	20130525_H_F2(1)_OJ_R
Extract 37	20130525_H_F2(1)_OJ_R
Extract 38	20130529_H_M2(1)_OJ_V
Extract 39	20130529_H_M2(1)_OJ_V
Extract 40	20130529_H_M2(1)_OJ_V
Extract 41	20130523_H_M1(1)_OJ_V
Extract 42	20130630_H_M1(2)_OJ_V
Extract 43	20130604_H_M2(2)_OJ_V
Extract 44	20130606_H_F1(2)_OJ_S
Extract 45	20130606_H_F1(2)_OJ_S
Extract 46	20130606_H_F1(2)_OJ_S
Extract 47	20130529_H_F1(1)_OJ_S
Extract 48	20130529_H_F1(1)_OJ_S
Extract 49	20130529_H_M2(1)_OJ_V
Extract 50	20130529_H_M2(1)_OJ_V
Extract 51	20130529_H_M2(1)_OJ_V
Extract 52	20130606_H_F1(2)_OJ_S
Extract 53	20130525_H_F2(1)_OJ_R
Extract 54	20130606_H_F1(2)_OJ_S
Extract 55	20130523_H_M1(1)_OJ_V
Extract 56	20130630_H_M1(2)_OJ_V
Extract 57	20120615_HPP_F_OJ_V_(E)(1)
Extract 58	20130630_H_M1(2)_OJ_V
Extract 59	20130529_H_F1(1)_OJ_S
Extract 60	20130523_H_M1(1)_OJ_V
Extract 61	20130529_H_F1(1)_OJ_S
Extract 62	20130529_H_F1(1)_OJ_S

Extract 63	20130529_H_F1(1)_OJ_S
Extract 64	20130525_H_F2(1)_OJ_R
Extract 65	20130525_H_F2(1)_OJ_R
Extract 66	20130604_H_M2(2)_OJ_V
Extract 67	20130606_H_F1(2)_OJ_S
Extract 68	20130523_H_M1(1)_OJ_V
Extract 69	20130523_H_M1(1)_OJ_V
Extract 70	20130525_H_F2(1)_OJ_R
Extract 71	20130525_H_F2(1)_OJ_R
Extract 72	20130606_H_F1(2)_OJ_S
Extract 73	20130529_H_F1(1)_OJ_S
Extract 74	20130523_H_M1(1)_OJ_V
Extract 75	20130606_H_F1(2)_OJ_S
Extract 76	20130529_H_F1(1)_OJ_S
Extract 77	20130525_H_F2(1)_OJ_R
Extract 78	20130606_H_F1(2)_OJ_S
Extract 79	20130604_H_M2(2)_OJ_V
Extract 80	20130523_H_M1(1)_OJ_V

## Appendix 8 Transcription notation conventions

(.)	<b>Just noticeable pause</b>
(.3), (2.6)	Examples of timed pauses
↑word, ↓word	Onset of noticeable pitch rise or fall ( <i>can be difficult to use reliably</i> )
A: word [word B: [word	Square brackets aligned across adjacent lines denote the start of overlapping talk. Some transcribers also use "]" brackets to show where the overlap stops
.hh, hh	in-breath (note the preceding fullstop) and out-breath respectively.
wo(h)rd	(h) is a try at showing that the word has "laughter" bubbling within it
wor-	A dash shows a sharp cut-off
wo:rd	Colons show that the speaker has stretched the preceding sound.
(words)	A guess at what might have been said if unclear
( )	Unclear talk. Some transcribers like to represent each syllable of unclear talk with a dash
A: word= B: =word	The equals sign shows that there is no discernible pause between two speakers' turns or, if put between two sounds within a single speaker's turn, shows that they run together
<u>word</u> , WORD	Underlined sounds are louder, capitals louder still
°word°	material between "degree signs" is quiet
>word word<<word word>	Inwards arrows show faster speech, outward slower
→	Analyst's signal of a significant line
((sniff))	Transcriber's effort at representing something hard, or impossible, to write phonetically

## Appendix 9 Ethical clearance letter for this study



21 November 2013

Ms N Mqedlana Z13569760  
School of Applied Human Sciences  
Pietermaritzburg Campus

Protocol Reference Number: HSS/0369/013M  
Project title: Women Living with HIV in the rural Eastern Cape HIV

Dear Ms Mqedlana

### Full approval notification – Committee reviewed protocol

With regards to our letter dated 01 August 2013 and your response thereof. This letter serves to notify you that your application in connection with the above study has now been granted full approval.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach/Methods must be reviewed and approved through an amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

Best wishes for the successful completion of your research protocol.

Yours faithfully

Dr Shenuka Singh (Chair)

/ms

cc Supervisor: Dr Mary van der Riet  
cc Academic Leader Research: Professor D McCracken  
cc School Administrator: Mr Sbonelo Duma

Humanities & Social Sciences Research Ethics Committee

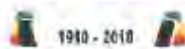
Dr Shenuka Singh (Chair)

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## Appendix 10 Approval notification (Change in title) for this study



13 March 2015

**Ms Nasiphi Mqedlana (213569760)**  
School of Applied Human Sciences  
Pietermaritzburg Campus

Dear Ms Mqedlana,

Protocol reference number: HSS/0369/013M

Project title: Dealing with a positive HIV diagnosis ; A qualitative study exploring the lives of five people living with HIV in a rural Eastern Cape setting

### Approval Notification – Amendment

This letter serves to notify you that your request for an amendment received on 09 March 2015 has now been approved as follows:

- Change in Title

Any alterations to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form: Title of the Project, Location of the Study must be reviewed and approved through an amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number.

**PLEASE NOTE:** Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

Best wishes for the successful completion of your research protocol.

Yours faithfully

Dr Shenuka Singh (Chair)

/ms

cc Supervisor: Dr Mary van der Riet  
cc Academic Leader Research: Professor D McCracken  
cc School Administrator: Mr Sbonelo Duma

Humanities & Social Sciences Research Ethics Committee

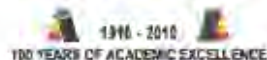
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