

# **Understanding caregivers' experiences of disclosure to HIV- positive children**

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A short dissertation submitted in partial fulfillment of the  
requirements for the degree of:

**MASTERS IN PSYCHOLOGY IN HEALTH PROMOTION**

In the School of Applied Human Sciences, Discipline of Psychology

at the

University of KwaZulu-Natal, Howard College

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# Declaration

I, **Zinhle Sokhela** declare that this research thesis titled: *Understanding the effects of disclosure to HIV-positive children* is my original work except where otherwise stated. I declare that this thesis has not previously been submitted for any qualification at any other university. I have acknowledged all sources in the reference list.



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October 2016

## **Acknowledgements**

- I would like to express the highest gratitude to God for making this possible for me.
- I would like to thank my family for always being there for me and the constant support and motivation they provided me throughout my research.
- I would like to give a special thanks to my parents for always motivating me and supporting me throughout this journey.
- To my sisters Busisiwe, Gugulethu, and Zanele and my brother Thembinkosi - this is for you for the constant motivations, the support and the love, thank you so much.
- To Bonga Sibisi, thank you so much for the support, the wise words of encouragement and everything you greatly contributed in making this possible.
- I would like to thank my friends, Wanda Zulu, Amanda Tabo, Nkosikhona Memela and Simphiwe Sithole for all the motivation and support they gave to me while I was in the process of writing this research.
- I would like to give the biggest thanks to my supervisor, Professor Inge Petersen; I would have not done it without her. I thank you so much for your support, guidance and motivation and I will forever be grateful to you.
- I would like to extend my gratitude to the Vuka Program and Miss Sphindile Manyana for her utmost valued support and assistance.
- I would also like to express gratitude to my mentor from the Human Science Research Council, Professor Refilwe Nancy Phaswana-Mafuya.

## **ABSTRACT**

**Background:** South Africa has the highest burden of the HIV/AIDS epidemic in the world, with a large number of peri-natally infected children. With the advent of antiretroviral treatment, these children are now able to live into adolescence, adulthood and old age. With this longevity comes the responsibility of disclosing the child's HIV-positive status to them so that they can begin to take responsibility for their health and well-being, as well as protect others from possible HIV infection.

**Aim:** The research aimed to understand caregivers' views on the process of disclosure of a child's HIV status to the child, to develop an understanding of factors that promote disclosure, as well as the impact of disclosure on the child.

**Method:** This study used a qualitative design. Semi-structured qualitative interviews were held with ten participants who were caregivers to HIV-positive children. The participants were recruited through the Vuka Family Programme: Supporting Health and Behavior of South African HIV+ Youth. Inclusion criteria were that participants had to have disclosed their status to their HIV-positive children. Thematic analysis, specifically the framework approach, was used to analyse the data.

**Results:** Findings from this study show that disclosure is not an easy task to undertake, with caregivers needing help on how to disclose; however, it reportedly had benefits for the child, such as improved levels of adherence. Factors promoting disclosure included children questioning the medication that they were taking and pressure from clinicians to disclose. Factors hindering disclosure included fear of stigma and discrimination against the child, as well as shame, guilt and embarrassment among the biological caregivers.

**Conclusion:** The need for the introduction of HIV disclosure guidelines for clinicians and caregivers of children living with HIV is recommended, to assist in making the process of disclosure easier.

**Keywords:** PLWHA, HIV, Disclosure, Adolescents, Prenatal, ART

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## **Chapter One: Introduction to the study**

### **1.1 Introduction and background to the study**

The rate of peri-natally HIV-infected children has increased in the past three decades as part of the HIV/AIDS epidemic globally, with South Africa having the largest population of HIV-infected individuals in the world (Heeren, Jemmott, Sidloyi, & Ngwane, 2012). Increased survival into adolescence and beyond is an indication of a direction towards success in the battle against the disease that has claimed the lives of millions (Sohn & Hazra, 2013). Globally, HIV has infected approximately 70 million people and has claimed the lives of about 36 million individuals (World Health Organization [WHO], 2013). Worldwide, it was estimated that 35.3 million people were living with HIV in 2012. In 2014, approximately 6.1 million people were living with HIV in South Africa (UNAIDS, 2014).

In terms of children, by the end of 2011, approximately 3.4 million children were living with HIV globally, with sub-Saharan Africa making up the 91% of the population of infected children (WHO, 2013). South Africa is known to have the highest prevalence of HIV/AIDS among the world child population, with an estimated 280 000 infected children below 15 years old. There is a great need for treatment as, in the absence of treatment, approximately 75% of peri-natally infected children do not reach the age of five years (UNAIDS, 2013). In South Africa, approximately 61% of HIV-positive children are on antiretroviral therapy (UNAIDS, 2008). In 2006, an estimated 38 000 South African children acquired the virus through mother-to-child transmission (WHO, 2009). Unprotected heterosexual intercourse is the most frequent cause of HIV/AIDS infection among children between the ages of 15 and 18 years (UNAIDS, 2008).

A study conducted in South Africa on HIV infection in pregnant women shows that, in 2009, an estimated 29.4% of pregnant women between the ages of 15 and 49 were HIV positive, while another study estimated that 10.9% of people aged 20 and above were HIV positive (Department of Health , 2010). Furthermore, according to Shisana et al. (2005), approximately 11.9% of male and 5.1% of female children are reported to have their first sexual encounters at the age of 15 years.



With the increasing population of HIV-positive children comes the responsibility of disclosing the child's HIV-positive status to them by their caregivers. In a South African study conducted by Negese et al. (2012), out of the 428 children in the study, approximately 39.5% had been disclosed to and the mean age of disclosure was 10.7 years.

Evidence from developed countries indicates that informing children about their HIV status can result in positive psychosocial and clinical results, with little evidence of emotional or psychological impairment from disclosure (WHO, 2011). Furthermore, WHO (2011) adds that the emotional reactions that predictably transpire when disclosure first occurs disperse over time. Regardless of the positive value of disclosure, however, little is known about when, what and how HIV-infected children are made aware about their illness (Vaz et al., 2011). According to Vreeman, Gramelspacher, Gisore, Scanlon, and Nyandiko (2013), disclosure in this instance is used to refer to a child attaining knowledge of his/her HIV status. Understanding the issues associated with disclosure is therefore viewed as important in promoting disclosure, which in turn is associated with greater participation and active involvement in one's treatment (Vaz et al., 2011).

Adolescents living with HIV since birth experience stressors from ongoing medical treatment, hospitalisations, experience to pain and protected life experiences (Mellins & Malee, 2013). Behavioural health issues and psychiatric disorders and in children who are HIV positive can result to poor antiretroviral (ART) adherence, participating in risky behaviour, such as substance abuse, early sexual debut, risky sexual behaviour, and teenage pregnancy (Laughton, Cornell, Boivin, & VanRie, 2013).

Historically, when HIV was a deadly and untreatable disease, caregivers were not faced with the issues related to adolescent sexuality, disclosure and adherence to HIV treatment in HIV-positive children (Myer et al., 2006; Wiener, Mellins, Marhefka, & Battles, 2007). However, peri-natally HIV-infected children face health and social challenges that arise from having HIV. Such challenges include stigmatisation, need for adherence to a lifelong treatment and the impact this has on their social and sexual relationships, just to mention a few (Havens & Mellins, 2008). Failure to address these psychosocial factors in HIV-positive children may

lead to costly long-term consequences such as further transmission of HIV and also the risk of secondary transmissions due to unsafe sexual practises (Ledlie, 1999).

In a Romanian study, evidence on disclosure to children showed that the risk of death to children who had received disclosure was 50% lower than to those who had not (Vreeman et al., 2013). It is suggested that disclosure of the child's HIV status could be viewed as a tool to promote survival as it seems to be associated with an enhanced adherence to treatment amongst HIV-positive children (Krauss, Letteney, De Baets, Baggaley, & Okero, 2013).

The child's mental stability and age seem to be the key determinants of HIV-positive status disclosure to the child by the caregiver (Weiner et al., 2007; Lesch et al., 2007). A large number of parents suggested 10 years to be the appropriate minimum age for partial disclosure (Vreeman et al., 2013). This involves telling the child some details of their illness; however, the term 'HIV' is excluded from the details. Full disclosure, was thought to be the appropriate at 14 years; this involves the names and provision of HIV-related information (De Baets, Sifovo, Ross, & Pazvakavambwa, 2008). The present research endeavoured to understand the process of disclosure of their status to an HIV-positive child, to develop an understanding of factors that promote disclosure as well as the impact of disclosure on the child.

## **1.2 Problem statement**

Caregivers of an HIV-infected child are faced with the responsibility of having to disclose their child's status to them. There is a pool of literature that focuses on disclosure, but studies focusing specifically on the impacts of disclosure are limited; however, studies allude to the fact that caregivers need to be provided with guidelines on how to disclose, as they often lack knowledge and appropriate skills to disclose. It is not clear how disclosure has affected both the child and the caregiver psychologically, as evidence in this regard seems to be limited. The purpose of this study was to provide insight into the impacts of HIV/AIDS disclosure to the child. The findings could be useful for policy makers as well as programme developers working in the field of HIV/AIDS for developing and designing policies aimed at improving the level of disclosure, impact of disclosure and providing guidelines to disclosure across the country. It will also be a useful addition to the body of literature on HIV/AIDS disclosure.

### **1.3 The purpose of the study and research questions**

The main objective of the study was to explore the experiences of the caregivers of HIV-positive children regarding the process of disclosing their status to the HIV-positive child and to develop an understanding of factors that promote, hinder and impact on the child's overall well-being. The findings of this study could assist policy makers in addressing interventions aimed at assisting with HIV/AIDS disclosure to HIV-positive children. The key questions this research aimed to answer were:

- What are the levels of awareness of the child's HIV-positive status?
- What are the factors that promote HIV disclosure to a child?
- What are the factors that hinder HIV disclosure to a child?
- How does HIV disclosure impact on the child's psychosocial well-being

### **1.4 Structure of the dissertation**

This dissertation is divided into six chapters:

*Chapter One* introduces the study. It provides relevant background information, outlines the research problem, states the purpose and objectives of the research, and summarises the significance of the study.

*Chapter Two* reviews literature relevant to this study, presented according to the following themes: prevalence of HIV/AIDS, HIV challenges for mental and behavioural health, importance/benefits of disclosure, negative impacts of disclosure, and factors that promote disclosure. The theoretical framework used to inform this study, namely Ecological Systems Theory (EST) is then introduced. EST and how the theory has been applied in different fields are discussed, as well as how the levels of the theory have been applied in understanding the impact of HIV-positive status disclosure to a child by their caregiver.

*Chapter Three* outlines the study methodology. The study area, sample considerations and criteria, data collection method and analysis, and ethical considerations are presented.

*Chapter Four* presents the results from the study.

*Chapter Five* presents discussion of the results using the EST.

*Chapter Six* concludes this study by discussing considerations and recommendations for future endeavours in this area of research. The limitation of the study are also presented

## **Chapter Two: Literature review**

### **2.1 Introduction**

In the past three decades the rate of HIV peri-natally -infected children has increased as part of the HIV/AIDS epidemic globally; with South Africa having the largest proportion of HIV infected individuals in the world (Heeren et al., 2012). Survival into adolescence and beyond is a sign of the route towards success in the fight against the disease that has taken the lives of many (Sohn & Hazra, 2013). Findings from developed countries shows that telling HIV positive children about their status can consequently lead to positive clinical and psychosocial and outcomes, with little evidence of psychological or emotional harm from disclosure (WHO, 2011). Additionally, the emotional reactions that predictably occur post disclosure end over time. Irrespective of the significance and importance of disclosure, little is known about what, when and how HIV-infected children are informed about their HIV positive status (Vaz et al., 2011). According to Vreeman, Gramelspacher, Gisore, Scanlon and Nyandiko's (2013) definition, disclosure in this instance, is used to refer to a child attaining knowledge of his/her HIV status. Understanding the issues associated with disclosure is therefore viewed as important to promoting disclosure which is in turn associated with participation and active involvement in one's treatment (Vaz et al., 2011). This research therefore endeavoured towards understanding the process of disclosure of the status of an HIV-positive child, to develop an understanding of factors that promote awareness of the child's HIV positive status, the factors that promote disclosure, as well as the impact of disclosure on the child.

### **2.2 HIV prevalence**

HIV is a public health issue faced globally with approximately 70 million infected people and has taken the lives of about 36 million individuals (WHO, 2013). Worldwide, it is estimated that 35.3 million individuals were living with HIV in 2012. By the end of the year 2011, an estimated 3.4 million children were HIV positive globally, sub-Saharan Africa contributing up to 91% of the population of children living with HIV (WHO, 2013). In sub-Saharan Africa, approximately 300,000 children were newly infected with HIV/AIDS in 2011 (UNICEF, 2013). In sub-Saharan Africa approximately, one in four children receive antiretroviral treatment (ART) (Morsheimer, Dramowski, Rabie, & Cotton, 2014). In

developing countries, the number of children receiving ART has improved as in 2009, approximately 355 000 were on ART while an estimated number of 740 000 children were on ART in 2013 (WHO, 2015). South Africa is known to have the highest prevalence of HIV/AIDS epidemic among the child population in the world, with approximately 280 000 infected children below 15 years old.

In 2014, approximately 6.1 million people were living with HIV in South Africa (UNAIDS, 2014). There is a great need for treatment as approximately 25% of peri-natally infected children do not reach the age of 1 year while more than 50% die before the age of 2 years, in the absence of treatment (UNAIDS, 2013). In South Africa, there is approximately 40% ART coverage for children below the age of 15 years (UNAIDS, 2013). In South Africa the majority of HIV-infected children got the virus through mother-to-child transmission, with approximately 70.4% maternal deaths and 50% deaths of children below the age of 5 years in the year of 2011 related to HIV infection (WHO, 2012). In a South African study conducted by Mahloko and Madiba (2012) it was reported that more than half of HIV infected children were disclosed to between the age of 11 and 17 years

### **2.3 HIV challenges for mental and behavioural health**

Adolescents living with HIV since birth experience stressors and a multiple of unique issues associated to the psychosocial impact of HIV, a highly stigmatised and transmittable illness that may make transition through adolescence challenging (Mellins & Malee, 2013). The multitude of factors (such as treatment doses) which affect the child's daily functioning serve as a reminder of the existing illness within the child, and developmental delays (such as poor expressive and receptive language development and motor development skills) seem to be significantly associated with the heightened level of emotional distress (Lester et al., 2002). According to prior literature, there seems to be a higher adverse effect of discussing a highly stigmatised illness like HIV with children whose cognitive capacity is still in development as they may not be able to appropriately understand the information provided to them and may not be able to keep their status confidential (Deacon & Stephney, 2007). Neurocognitive deficits have been reported in peri-natally HIV-infected children to which disturb their autonomy, relationships and school achievements. Additionally, HIV may damage subcortical white matter and fronto-striatal systems which control behaviour and emotion which puts adolescents at risk of mental health problems (Mellins & Malee, 2013).

According to Laughton et al. (2013) behavioural health challenges and psychiatric disorders in children who are HIV positive can result to poor ART adherence, and unsafe sexual behaviour,. In the past, when HIV was a deadly and untreatable disease, caregivers were not faced with the issues related to adolescence sexuality, disclosure and adherence to HIV in HIV positive children (Myer et al., 2006; Wiener et al., 2000). Peri-natally HIV-infected children face health and social challenges that arise from living with HIV. Such challenges include stigmatisation, need for adherence to a lifelong treatment and the impact this has on their social and sexual relationships just to mention a few (Havens & Mellins, 2008). Inability to tackle these psychosocial factors in children living with HIV may result to costly long-term consequences such as further transmission of HIV and also the risk of secondary transmissions from unsafe sexual practises (Ledlie, 1999).

#### **2.4 Importance and benefits of disclosure**

Previous research focusing on disclosure of an HIV-positive status to children has shown positive outcomes (Negese et al., 2012). According to Woldemariam (2012), disclosure by the parent of a child's status seems to lead to positive results. This was also reported in a study by Arun, Singh, Lodha, and Kabra (2009) conducted in India among caregiver of 50 children living with HIV, where 42% of caregivers indicated parents as the most appropriate person for disclosing the child's HIV-positive status. In a South African qualitative study by Moodley, Myer, Micheals & Cotton (2006) among of 174 caregivers, it was evident that the majority of caregivers (83%) believe that it should be the parent or caregiver who is responsible for disclosing the child's HIV-positive status to them. Caregivers are more than willing to share the responsibility of adherence with the child after disclosure (Vreeman et al., 2013).

Delaying the process of initial disclosure may lead to undesirable results for the HIV-infected child. There may be issues with regard to treatment adherence as the child may not understand the reason behind the treatment they are taking and therefore not participate in taking treatment (Campbell et al., 2012). Learning about their HIV status is not only important for children's health but also for the protection of the people around the child. As the child grows and reaches the developmental stage of adolescence, they usually begin experimenting and engaging in risky behaviours. Therefore, knowledge about their status is

not only important for their own health maintenance but also for preventing the transmission of HIV to others (Vreeman et al., 2013).

In a study by Krauss et al. (2013), summarising 14 studies representing over 3 300 HIV-positive children from ten countries, the authors showed that children whose HIV status has been disclosed to them have greater health benefits and there was little to no evidence of psychological or emotional damage. Previous studies have contended that disclosure of the child's HIV status has a significant association with an improvement in trust, open family communication, better ART adherence and better health and emotional well-being in children (Negese et al., 2012). Furthermore, previous research indicates that the level of adherence to treatment improves in children who have their status disclosed to them, as they understand the reason for the continuous treatment they are taking and are more motivated to take the treatment (Vreeman et al., 2010). Improved adherence to treatment post disclosure was reported in four qualitative studies (Bikaako-Kajura, Luyirika, Purcell, Downing, Kaharuza, Mermin, Malamba, and Bunnell, R., 2006; Corneli, Vaz, Dulyx, Omba, Rennie, Behets, 2009; Hejoaka, 2009; Fetzer, Mupenda, Lusiana, Kitetele, Golin, Behets, 2011). In Burkina Faso, youths stated that disclosure encouraged them to proceed with taking their HIV treatment, and improved their ability to hide the status from others. One youth in the DRC had this to say about improved adherence, "Having heard explanations made it easy for me to take the medicines. I was told what medicines do in my body" (Vreeman et al., 2013).

Disclosure of a child's HIV status could be a difficult task for a parent but it has its advantages, as discussed above. In a study by Santamaria et al. (2011), the psychological and disclosure measurements showed that children who have received disclosure were found to report lower levels of anxiety compared to those who have not. In one study (Menon, Glazebrook, Campain, Ngoma, 2007), the psychological differences between 'disclosed children' (who have been told about their HIV-positive status) and 'non-disclosed children' (who have not been told about their HIV-positive status), in a study conducted in a total of 127 children it was reported that non-disclosed children were more than two times susceptible to experiencing higher levels of emotional challenges. In a South African qualitative study among 25 adolescents, nearly all participants reported disclosure to be emotionally challenging (Vreeman et al., 2013). According to these few studies, it seems as though discussions within the family, including detailed knowledge about the effects of

parental illness, emotional distress, death and other factors related to the disease, would be beneficial for the child's overall well-being and development.

Disclosure to others about the child's status is also helpful for accessing social support systems and other forms of support. In addition, caregivers and adolescents reported disclosure to teachers being beneficial as it resulted to better academic support, and the school being more understanding (Petersen et al., 2010). According to Lester et al., 2002, parental disclosure to children could result in improvement in the level of intimacy between a child and a parent, hence strengthening the parent-to-child relationships. Furthermore, withholding children's HIV status from them may also result in greater levels of psychological and behavioural issues, lower access to support services, and more difficulty dealing with bereavement (Lester et al., 2002).

Parents telling the child about their HIV status could assist in reducing harm to the child and those around them, and also reduce the level of anxiety from not knowing about their chronic health condition and its severity (Santamaria et al., 2010). According to Sherman, Bonanno, Wiener, and Battes (2000), disclosure of the child's status is a difficult task but it has enormous rewards for the child's health as it was found that children who were aware of their HIV status were more likely to have more regular CD4 check-ups. This is supported by a quantitative study in Zambia on paediatric ART adherence which found that among children who knew their HIV status the average number of missed ART days was 38% lower (Vreeman et al., 2013).

In a South African qualitative study on disclosure conducted by Heeren, Jemmott, Sidloyi, and Ngwane (2012), there are several positive outcome expectancies regarding disclosing. They said, "the child will no longer protest to take medication but understand that if it takes the medication it will stay healthy," "the child himself or herself will follow-up and take the medication itself and ask for healthy diet," and "increase their CD4" (Heeren et al., 2012, p. 50). In addition, in the context of Highly Active Antiretroviral Therapy (HAART), a child's knowledge of their own diagnosis is related with delayed disease progression, as the parent and child are more likely to work together to ensure adherence. Furthermore, the child may take better care of his or her health with the knowledge of behaviours they should not engage in. From the preliminary literature, it seems as though parents who are also HIV positive are more likely to disclose their children's status and are able to model positive behaviour



allowing children to cope with distress and also adopt a positive attitude (Petersen et al., 2010). Earlier research on HIV-infected children that investigated parents' emotional functioning after disclosure revealed that parents who have disclosed their child's HIV-positive status had significantly lower levels of depression and anxiety when compared to those who have not disclosed their child's HIV-positive status to them (Murphy, 2008). Furthermore, disclosure could lead to a release from stress on the side of the caregivers, as they no longer have to come up with different excuses why the child has to continually take medication and constantly needs to go to the clinic (Vreeman, et. al., 2010).

In a Romanian study, evidence on the disclosure to children presented that children who had been told of their HIV positive status had 50% lower susceptibility to death than those who had not been told of their HIV positive status (Vreeman et al., 2013). It is suggested that disclosure of the child's HIV positive status to them could be seen a tool for promotion of survival, as it seems to be associated with an improved adherence to treatment amongst HIV-positive children (Krauss et al., 2013).

According to the findings from the study by Lester et al. (2002), there seems to be an association between the child's age and higher levels of anxiety, which suggests that older children have a greater understanding of the potential implications the HIV/AIDS disease will have in their lives, as well as heightened contact with other stressors within the families.

There seems to be a need for disclosure as numerous studies have shown a variety of positive outcomes related to the disclosure of their HIV-positive status to the child. Some of the positive factors relating to the disclosure of their HIV-positive status to the child are promotion of trust between the child and the caregiver, open family communication (as there will be no secrets in the family which improves communication within the household), improved adherence to treatment (as the children now have knowledge of their HIV-positive status so they will work together with their parents or caregivers when it comes to taking treatment), and improvement in the child's well-being (Wiener et al., 2007).

## **2.5 Negative impacts of disclosure**

HIV-infected children experience a variety of social, psychological, physical and emotional issues (including disclosure of diagnosis) as they grow older, and this is an important part of their journey of development. There seems to be an unclear link on which factor causes the

other, whether disclosure leads to enhanced stresses within the family, or whether it is a stressful event within the family that leads to disclosure. Disclosure can possibly result in psychological harm, as children may not be prepared to deal with the implications of disclosure (Lesch et al., 2007).

Disclosure can also have negative consequences for the child as well as the parent. According to past studies by Kouyoumdajan, Meyers and Mtshizana (2005), Rwemisisi, Wolf, Coutinho, Grosskurth, and Witworth (2008), and Woldemariam (2012), the level of disclosure by parents to a child is very low because parents fear the child may tell other people and consequently experience the stigma and discrimination that comes with being infected. Discrimination in most cases is due to imagined danger which the person living with HIV is assumed to pose to others. A large number of South African societal contexts are ingrained with stigma, which perpetuates discrimination amongst those infected with HIV.

Hosegood et al. (2007) argue that manifestations of discrimination include being isolated and excluded, as infected people are seen as a threat to others. It can be concluded that stigma and discrimination are adverse conditions that people openly living with HIV/AIDS experience from their societies. In a study conducted in Ethiopia by Deribe, Woldemichael, Wondafrash, Haile, and Amberbir, (2008) the low rate of disclosure was associated with the existence of a greatly intensified stigma related to HIV. Therefore, caregivers and parents fear the stigma that exists around HIV and the discrimination which results from the highly prevalent stigma in both the family and community as a whole. Especially since most of the children are perinatally infected and the disclosure of the child's HIV status does not end there but also opens up other sensitive topics within the family, many caregivers choose to avoid disclosure which may possibly lead to more discrimination.

In addition, parents may not tell their children of their status because of the fear of the child's response and guilt for infecting the child (Vreeman et al. 2010). According to Lester et al. (2002), disclosure of diagnosis of the terminal illness leads to mixed outcomes, as parents indicated children had heightened experiences of anxiety after disclosure; this may, however, be due to other factors which were not controlled in the study, such as treatment doses and the child's age. Children's self-reports of depression and anxiety on the standardised

Behaviour Assessment Scale for Children (BASC) do not present with related heightened distress in association with HIV disclosure.

Telling the child about their status could lead to them telling other people, especially in cases when the child is still too young to understand all of the implications (Heeren et al., 2012). According to Heeren et al. (2012), the biggest barrier to disclosure is the fear of children revealing their diagnosis to other children or neighbours. Previous studies (Kallem, Renner, Ghebremichael, Paintsil., 2010; Biadgilign, Deribew, Amberbir, Deribe, 2009; Oberdorfer, Puthanakit, Louthrenoo, Charnsil, Sirisanthana, Sirisanthana, 2006) indicate that, regardless of the individual's context, the fear of disclosure and the decision to withhold the child's HIV status are related to the community's anticipated response and education regarding the HIV/AIDS infection. Individuals fear experiencing negative reactions from school, churches, and neighbours, as well as their relatives, and these fears are highly prevalent in a context where communities lack knowledge and necessary information about HIV/AIDS (Lester et al., 2002).

People knowing about the child's status could result in the child (and possibly the whole family) being discriminated against in the community and the child no longer having friends to play or engage with. In terms of internalised stigma, some adolescents indicated that they withdrew themselves from social activities and their friends when they found out their status. There was internalised stigma in more than 50% of the adolescents who felt uneasy when people were talking badly about HIV-infected individuals (Petersen et al., 2010).

Disclosure to the child about their life-threatening illness, as well as awareness about the meaning of death and sickness, could be viewed as something that needs to be a recurring process throughout the child's cognitive and emotional developmental stages (Lester et al., 2002). HIV differs from other life-threatening illnesses such as cancer, as social stigma and the experiences of those infected and affected by HIV differ from those with illnesses like cancer. This is supported by evidence from early research that 30% of parents who disclosed their HIV-positive children's status expressed that, after disclosure, they experienced greater difficulty in their lives (Lester et al., 2002).

## **2.6 Factors that affect disclosure**

The reaction of HIV-infected children after receiving disclosure is different depending on the child, and it is common for the family to have disagreements regarding the right time to disclose to the child. There are a variety of factors which need to be considered when disclosing or thinking about disclosing HIV-related information to the infected child; for example, it is emphasised that disclosure should be child centred, and consider the child's parent(s), family, household, and the community at large. Communication related to disclosure focusses around information regarding a possibly life-threatening, transmittable, and highly stigmatised disease, which is the reason a majority of caregivers are scared to disclose to their children, as they fear it would cause distress for the child.

A number of factors influence the decision by parents and caregivers to proceed with disclosure. For example, one of the factors which drive parents into disclosing the child's status is the child's constant questioning regarding the medication they are taking. Brown et al. (2011) found that the decision to disclose was based on the questioning by children regarding medication. Furthermore, the child's mental state and cognitive capacity to deal with the information are used as indicators by most parents as to whether it is the appropriate time for disclosure.

It is not advisable to disclose the status of a child who has not yet developed the cognitive ability to fully understand the implications of being HIV-positive or has mental impairment, as they may not understand completely. Often, early disclosure of the child's status is related to their developmental readiness to understand the multifaceted condition of an HIV diagnosis and prognosis. The child's cognitive development may be the indication of whether the child might be able to handle the consequences that come with knowing their HIV-positive status, as the results of disclosure could possibly be destructive for the individual child as well as their family. For children with increased delay in development and psychiatric impairments, this may be associated with decreased levels of impulse control and keeping their HIV status a secret could be more complicated (Lester et al., 2002).

The child's age seems to be a significant factor of whether a child has been disclosed to (Heeren et al., 2012); but clinical observations seem to indicate that family and community factors also play an important part in determining the occurrence of disclosure about the

extremely stigmatised HIV virus (Lester et al., 2002). In a study conducted by Lester et al. (2002), the mean ages of the children receiving disclosure were higher (10.5 years) than those who had not received disclosure (6.6 years). According to results from prior study conducted by Feinstein, Moultrie, Myers, Rie (2010) in South Africa, among children aged four- to six-year olds, only 3% knew their status, compared to 17% of children aged seven- to ten-year and 77% of those aged 11 years and older.

According to the American Academy of Pediatrics, there is great emphasis on the need for school-aged children to be told their HIV-positive status. However, in most countries, including South Africa, such recommendations and guidelines have not yet been put in place in regard to paediatric HIV, and disclosure of HIV-positive status to the child remains a greatly troubling issue for the caregivers and parent(s). Despite the existing policy in support of developmentally appropriate full status disclosure for HIV-positive children, previous research has indicated that status disclosure in these children is usually delayed well past school entrance age (Lester et al., 2002). Age as one of the key determinants of disclosure seems to be supported by the cognitive theories pertaining to the child's perception of disease. Furthermore, it is argued that from the age of 9 to 10 years, it is viewed the appropriate time for HIV-positive status disclosure to the child, as they will have a better understanding of the illness and the implications of having the disease.

Another barrier to disclosure communicated by the caregivers was the child's lack of emotional readiness; the caregivers believed the children are not yet emotionally mature enough to handle the implications of being infected with the HIV disease (Weiner et al., 2007). Additionally, the non-existence of recommendations and guidelines on how to disclose to the child, as they have never done this before and it is a very sensitive topic to discuss with the child, serves as a barrier to disclosure and leads to the low rates of disclosure.

A large number of parents suggested 10 years to be the appropriate minimum age for partial disclosure, where the child is told some details of their illness; however, the term 'HIV' is excluded from the details. Parents thought 14 years was the appropriate age for full disclosure, which involves the names and provision of HIV-related information (De Baets et al., 2008).

Results from the study by Negese et al. (2012) showed that most of children above the age of 10 years had knowledge about their HIV-positive status unlike those younger than 10 years who had participated in the study. Furthermore, children who had experiences of bereavement of a family member were twice as likely to have received disclosure of their HIV-positive status compared to their counterparts. In the studies conducted in New York (Kirstenbaum and Nevid, 2002; Negese et al. 2012; Mellins et al. 2002; Brown et al., 2011 and Biadgilign et al. 2011), the mean age of disclosure was 7 years; in Nigeria it was 8.7 years; Ghana 11.7 years; and in Ethiopia 10.7 years. South Africa was amongst those with the lower ages of disclosure as in one study, it was found to be at the average age of 9 years. Among the reported explanations for not disclosing the child's status to them in the study conducted in Ethiopia, the caregivers expressed that the child was not old enough to understand HIV and its implications; in addition, they feared the stigma surrounding HIV and the discrimination which is mainly perpetuated by the stigma around HIV disease.

According to research from prior studies, families that have disclosed their child's HIV-positive status at an earlier age are found to be more expressive; this emphasises the importance of assessment of communication in the family in order to identify families that may need more support with the process of disclosing their child's status (Lester et al., 2002). For some parents, disclosure is necessary when the child becomes too sick and is reluctant to take medication. They are then forced to disclose the child's status so that he/she continues taking the treatment and so that this motivates the child to get better.

According to Negese et al. (2012), biological parents are less likely to disclose their children's HIV status compared to the non-biological caregivers of the infected children. This could be because of a fear of being blamed by their children for infecting them and also the internal guilt carried by the parents for having infected their children and therefore, this makes it hard for them to tell their children about their HIV-positive status. According to Negese et al. (2012), in a study done in Ethiopia, there was correspondence with the results of the studies conducted in Thailand and Philadelphia: the caregivers who were not biological parents of the HIV-infected children had higher levels of disclosure than those who were the biological caregivers of the children. In these studies, it was found that the majority of children who had knowledge of their HIV-positive status were living with caregivers they were not related to while the majority of those who had not yet received disclosure were living with the biologically related caregivers.

In a study done by Lester et al. (2002), it was found that a child with a higher intelligence quotient (IQ), greater family expressiveness and inner-city family residence were greatly associated to earlier disclosure of the child's HIV-positive status, although there are other factors which were reported to be related with the disclosure of the child's HIV status such as CD4 count, number of lifetime hospitalisations, treatment intake and death of family member. It also seems as though the disclosure rate among high-income and low-income countries differs, as was evident in the study by Negese et al. (2012) conducted in Northwest Ethiopia where the disclosure rate was 39.5%, compared to 57% to 100% in the developed countries. For example, compared to families living within the inner-city San Francisco Bay Area, residence in a non-urban location, such as a small cities or rural areas within the middle valley of California, may be linked to a delay in disclosure of diagnosis (Lester et al., 2002).

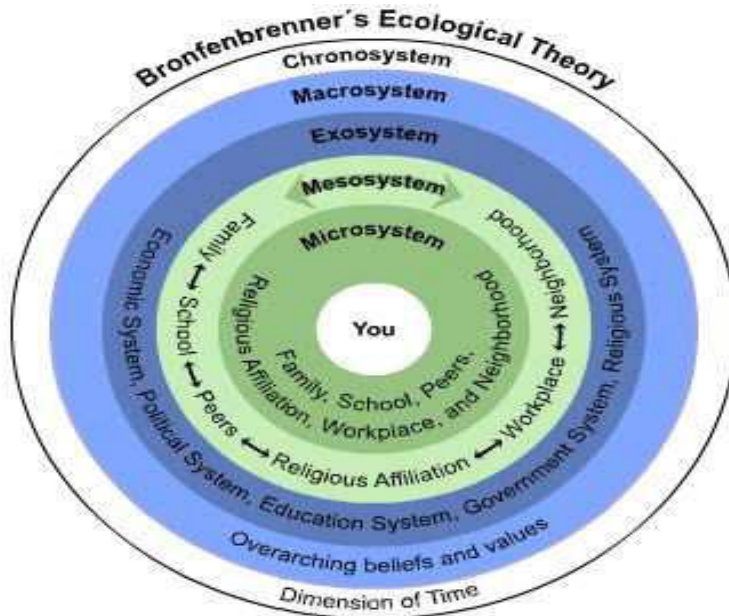
The study conducted in Northwest Ethiopia by Negese et al. (2012) on factors related to HIV-disclosure to children, found that in a population of 428 HIV-infected children, only 39.5% had knowledge about their HIV-positive status. Furthermore, among the population of learners who received disclosure, 40.8% of children were informed by their biological parents and the remaining 39.6% of infected children received disclosure from clinicians. The main reason for disclosure was related to the perceived maturity of the child, as well as the continuous questioning by the child.

There are multiple factors which seem to be associated with the caregiver or parent's decision to disclose and, among those factors, are the caregiver's relationship with the child and the child's age (Mandalazi et al., 2014). Additionally, there are factors which were associated with the caregiver which were found not to be significantly related to the decision of HIV disclosure to the child; these included the caregiver's sex, religion, HIV-positive status and educational background, sex of the child.

## **2.7 Theoretical approach**

This study will make use of the ecological systems approach which contains different levels and was developed in the 1970s by Urie Bronfenbrenner (Bronfenbrenner, 1994) (see Figure 1). A systems approach suggests that an individual can be impacted either negatively or positively by merely existing in an ongoing interaction with their networks and their environment (Wilder, 2009). By giving attention to both individual and environmental issues,

this approach highlights the necessity of looking at the interdependence and mutual influence of people and their social and physical environments (Coady & Lehmann, 2008). The ecological theory has not only been used to explain human development, but has also been applied in health promotion research, such as in the study of experiences of family caregivers taking care of aging adults (Wilder, 2009).



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**Figure 1: Bronfenbrenner's ecological theory**

The ecological model is useful for studying the impact of disclosure on the lives of HIV-positive children. A number of studies of youth have found that family, social, and contextual factors are greatly related with mental health, treatment adherence, and sexual and substance use behaviours (Mellins et al., 2002; Traube et al., 2011). The ecological perspective emphasises the relationship between the individual and their social environment, and the interdependence of factors within and across all levels of a health issue (Bronfenbrenner & Morris, 1998). It puts emphasis on individual's connections with their physical and sociocultural surroundings.

There are two primary factors in the ecological perspective that assist in the identification of the intervention points for promoting health amongst individuals. Firstly, it is argued that behaviour affects and is affected by numerous levels of influence. Secondly, individual



behaviour is influenced by and influences the social environment as there is reciprocal causation (Bronfenner & Morris, 1998). Therefore, the impacts of disclosure of the individual child's HIV-positive status will be greatly influenced by the society in which they are embedded. For example, if there is a great deal of stigma around HIV/AIDS and discrimination of infected individuals in the society, then learning and accepting their status will probably be difficult for a child receiving disclosure. On the other hand, a supportive society, well informed about the realities of HIV/AIDS, could result in a positive experience of disclosure for both the child and the parent.

When looking at the factors that influence the parent's decision about disclosing the child's status, this model could be used, together with the systems that structure it, to explain how these factors influence and impact on disclosure to the child. The ecological model contains a number of levels that can be used to explain the influences. In this study, the relevant levels are the microsystem, exosystem, mesosystem, macrosystem and chronosystem. It is important to recognise the intricacy of the influences, interactions and inter-relationships between the individual child and the other systems that are linked to the child. According to this model, the systems affect and are affected by other systems; therefore, the relationship between the systems is reciprocal.

The **microsystem** looks at the form of activities, roles and interactive relations experienced between individuals and the systems in which they actively engage in (Bronfenbrenner, 1994). The microsystem relationships that children have can have an effect on disclosure. The microsystem is characterised by those individuals and events near to one's life and require constant face-to-face interaction, with each individual mutually influencing the other. Disclosure could have either a positive or negative impact on the child in terms of his or her relationships with the parent, teacher or a friend. A parent having a positive relationship with their child could have an effect on disclosure as there is a need for warmth from the parent towards the child and this could positively impact on the disclosure experiences for both parties. As discussed previously, disclosure can lead to academic support from teachers, since they will be aware of the student's health condition and can also lead to strengthened child to parent relationships.

**Mesosystem** looks at the relationships that progress and happen among the microsystems. At this level, the family, school and peer group engage with one another, reciprocally

transforming each of the systems (Bronfenner & Morris, 1998). For instance, a child who has learned of their HIV status from an unsupportive caregiver may not receive the emotional support he/she requires, thus placing that child at risk of developing psychological problems or even leading to stress and non-adherence to treatment. However, the child may also have an attentive and caring teacher who is able to provide a positive environment, which with time, can boost the child's self-confidence and adherence to treatment. At the mesosystem level, the caregivers interact with the peers, family members and the neighbourhood (other parts of the child's microsystem).

The mesostemic level best explains how the caregiver's attitude and decision about disclosure are influenced by the social agent's or society's attitude towards HIV. For instance, in situations where there is a high level of stigmatisation and discrimination against HIV-positive individuals, the child's caregiver may be less likely to disclose their child's status to them. This has been seen in past studies from parents who have not disclosed, as a result of fear that they will experience discrimination if their child's status is known. On the contrary, there are communities where HIV-positive individuals are not stigmatised but are assisted with the necessary support in order to deal with HIV and live a positive life; hence, this environment is more favourable for disclosure.

**Exosystem** refers to the environment that the child is not involved in directly as an active participant but which may influence or be influenced by what occurs in the surroundings and relations which affect the child directly. It is known as the communal level (Bronfenbrenner & Morris, 1998). For example, if the caregiver is not able to disclose the child's HIV status with care, warmth and great caution as a result of their stressful conditions at work, this could result in the child being affected negatively in relation to their psychological well-being. This will be due to the caregiver's working environment that is stressful but in which the child is not involved directly. The healthcare system's failure to provide the parents with guidelines and ongoing counselling services on how to disclose HIV/AIDS status to the children leads to parents not being able to disclose their child's status earlier and properly.

**Macrosystem** refers to the beliefs, attitudes, ideologies and values that exist in the systems of a specific society and culture, which may have an impact on or be influenced by any of the above systems (Bronfenner & Morris, 1998). Furthermore, this system includes the policies that exist in the geographical location of the child that may have either negative or positive

effect on disclosure. The South African government, for instance, has put forward a policy of 'health for all' and this allows HIV-positive patients to have access to medication and has also provided grants for HIV-positive individuals allowing them to afford a healthy diet. However, there seem to be no counselling services for parents who want to learn how to disclose to their children in a way that will not have a negative impact on them.

The lack of knowledge about HIV/AIDS leads to the existence of stigma and discrimination in the community around individuals with HIV/AIDS and may negatively impact the child who has received disclosure. The child may also carry self-stigmatisation and have a low self-esteem as a result of the stigma embedded in their society.

**Chronosystem** refers to the major life changes, historical and environmental incidences that happened over the child's development (Bronfenner & Morris, 1998). This system is important given that the level of cognitive development can influence how well a child understands the implications of being HIV-positive. According to Childs and Cincotta (2006) disclosure should consider the child's perception of HIV in order for it to potentially influence positively on their health. Making use of Piaget's stages of cognitive development, where between the ages of 2-6 is the prelogical stage, ages 7-10 years is the concrete-logical stage and ages 11-upwards is the formal logical stage. It seems as though disclosure of the child's HIV positive status is highly influenced and centred on the child's cognitive developmental age although it is not always the same as their chronological age.

Adolescence is seen as a period of human development which happens after the childhood stage which is between the ages of 10 to 19 years (WHO, 2010). This study chose to focus on the adolescent developmental age of 10-14 years. Adolescence is characterised as the stage where there are physical and psychological changes; it is when children move to adulthood learn to take responsibility for their lives as well as their health (Moultrie, 2013).

As the child grows their understanding of HIV, the causes and consequences of living with HIV also increase. That is why it is important for the caregiver disclosing the child's HIV positive status to them explain HIV in a manner that would be easier for the child to understand taking into consideration their cognitive development. The high accessibility of ART and people who are infected with HIV living longer has led to HIV no longer being seen as a deadly disease but one of the chronic diseases (Moultrie, 2013). It is reported that by school age children have experience and would have an understanding of how the illness came about and how they are to take care of themselves (Moultrie, 2013).

These are the different systems that exist under the umbrella of the ecological model which assisted in the formulation of the questionnaire used in this study, as well as assisting in the formulation of the questions around the factors that influence the impact of disclosure in children. These will be discussed in the following chapter.

## **Chapter Three: Methodology of the study**

### **3.1 Introduction**

This chapter discusses the study design, study area, participants and sampling method used. The data collection procedure by means of qualitative semi-structured interviews with caregivers of HIV-infected children is described. Lastly, how the data was analysed using thematic analysis is discussed, including the role of the researcher and the ethical considerations covered.

### **3.2 Aims and objectives of the study**

The main aim of the study was to develop an understanding of caregivers' views on factors that promote HIV status disclosure as well as the impact of disclosure on the child living with HIV.

Research objectives:

- ✚ To understand levels of awareness of children's HIV-positive status.
- ✚ To understand factors that helped to promote HIV status disclosure to the infected child.
- ✚ To understand factors considered to hinder HIV status disclosure to the infected child.
- ✚ To understand the impact of HIV disclosure on the child's psychosocial well-being.

Research questions:

- ✚ What are the levels of awareness of the child's HIV-positive status?
- ✚ What are the factors that promote HIV disclosure to a child?
- ✚ What are the factors that inhibit HIV disclosure to a child?
- ✚ How does HIV disclosure impact on the child's psychosocial well-being

### **3.3 Research design**

The study made use of a qualitative methodology. This was the appropriate methodology for the research as it occurred in a natural setting which allowed for the use of interviews, documentation and observation (Patton, 2002). Furthermore, qualitative research seeks to understand a problem or issue being researched from the participants' own lived experience. In this instance, the study participants consisted of caregivers who had disclosed their child's HIV-positive status to them and the study was focused on understanding the impacts of

disclosure based on the participants' lived experiences. Qualitative methodology was appropriate as the study was exploratory in nature and allowed for an in-depth approach to the issues or situations concerned, for the purpose of attaining deeper understanding (Hennink, Hutter, & Bailey, 2011). In this instance, the study was concerned with understanding the impact of disclosure of an HIV-positive status and thus conducted face-to-face semi-structured interviews with caregivers of HIV-positive children between the ages of 9 and 14 years, who had disclosed their child's HIV-positive status to them.

### **3.4 Study site**

The study was conducted at the Prince Mshiyeni Hospital which is located in the township of Umlazi, V section, in the Durban metropolis, KwaZulu-Natal. The population served by this hospital is primarily made up of black Africans from a low socio-economic class and who are mainly isiZulu speaking. Durban is the largest city in the KwaZulu-Natal province of South Africa; this province has the highest number of HIV-infected people in the country, with approximately 40% of the South African HIV-positive population located here (Department of Health, 2010). The participants in the study were all isiZulu speakers and the researcher is fluent in the language and is also well versed in the culture. This assisted in attaining a thorough understanding of the participants' responses.

### **3.5 Recruitment description and sampling strategy**

The sampling methodology used for the study was a purposive non-probability sampling method used specifically by researchers interested in acquiring information on/from a specific population (Teddlie & Yu, 2007). Furthermore, purposive sampling allows for more in-depth information from studying a small number of carefully selected cases (Teddlie & Yu, 2007). Purposive sampling is the appropriate methodology as the study was interested in exploring caregivers of HIV-positive youth between the ages of 9 and 14 years receiving treatment at Prince Mshiyeni Memorial Hospital HIV treatment clinic who have informed the youth of their HIV positive status.

The participants were recruited from the Vuka Family Programme: Supporting Health and Behaviour of South African HIV+ Youth, which had already gained approval from the University of KwaZulu-Natal Biomedical Research Ethics Committee (BREC ref:BF429/13); see Appendice D). This programme was already operational at the Prince Mshiyeni Hospital and the study was able to obtain participants enrolled for this project, as the study was also

working under this project. Most of the participants were recruited during the Vuka project enrolment phase. The potential participants were recruited from the clinic waiting area. The Vuka project field workers would start by explaining to the potential participant the purpose of the Vuka project study, while they were attending the HIV clinic. Thereafter, the fieldworker explained further to the participants about the disclosure study operating under the Vuka project and formally invited them to also participate in the study. Following informed consent procedures, the potential participants were interviewed in a private space at the clinic.

### **3.6 Demographics of the sample**

The sample consisted of ten caregivers. As described above, the participants recruited for this research were already available as this research was working under the umbrella of the Vuka Family Programme: Supporting Health and Behaviour of South African HIV+ Youth. In addition, the following additional eligibility criteria were used for the study:

- ✚ Caregivers had at least one HIV-positive child to whom they had disclosed their HIV-positive status.
- ✚ The child was receiving treatment at Prince Mshiyeni Memorial Hospital HIV treatment clinic.
- ✚ The HIV-positive child was between the ages of 9 and 14 years.

All the participants met all of the eligibility criteria for the study. The youngest age at disclosure was 8 years and the oldest was 12 years. All the participants were black African, isiZulu-speaking females. Seven out of the ten caregivers were the child's biological parents and only three of the participants were non-biological caregivers. The participants came from a context which experiences high levels of poverty and unemployment.

### **3.7 Data collection**

In-depth semi-structured interviews were conducted by the researcher with the participants who were caregivers of HIV-infected children, guided by an interview guide with open-ended questions (see Appendice B). Interviews were conducted in a private room at the clinic in order to ensure confidentiality, to make the participant comfortable to express themselves and to protect their privacy. An interview guide was developed with the assistance of the existing questionnaire from the larger study of the Vuka Family Programme. The themes that were covered in the interview schedule were: HIV-positive status awareness, factors that promote

or hinder disclosure of HIV-positive status to the child and the benefits of the disclosure of HIV-positive status to the child. The interview questions were designed in English and translated into isiZulu.

Open-ended questions were used because they allowed the researcher to obtain data in greater detail by remaining conversational and situational (Ulin, Robinson, Tolley, & McNeill, 2002). Open-ended questions allowed a two-way interaction between the researcher and the participants which helped to provide a more intensive way of exploring themes of the study (Hennink et al., 2011). Following informed consent procedures (see Appendice C), the individual interviews were recorded in isiZulu using a tape recorder, with the participant's permission. The interviews were then transcribed and translated into English with back-translation checks done by an independent bilingual English-isiZulu speaking researcher.

### **3.8 Data analysis**

#### **3.8.1 The Interpretive Phenomenological Approach**

The research study made use of an Interpretive Phenomenological Approach (IPA). This approach accounted for the role of the researcher as an analyst in understanding the experiences of the participants of the study and focussed on attempting to interpret the meaning people attribute to their experiences (Smith, 2004). IPA assisted in exploring how the participants created meaning from their social experiences.

The researcher engaged in a close and in-depth reading of all the texts collected from the interviews in order to make sense of the data. This approach assisted the researcher to fully understand the impact of disclosure based on the participant's experiences and it guided the focus of emerging themes from the data. The researcher made notes of thoughts, observations and reflections on the information as she read the interview transcripts (Smith, Jarman, & Osborn, 1999).

#### **3.8.2 The analysis process**

The data was transcribed and translated (if necessary) into English with back-translation checks applied by an independent bilingual English/isiZulu-speaking researcher. Each interview transcript was subjected to a thematic analysis with the help of NVIVO 10 software. The method of thematic analysis assists in the identification, analysis, and reports of patterns (themes) within data (Braun & Clarke, 2006). The procedure of data analysis



involved immersion in the transcriptions. A thematic coding framework including the key codes rooted on the interview questions and new emergent codes was developed. This was followed by the coding and the analysis of the coded answers across the caregivers.

### **3.9 Reliability and validity**

According to Golafshani (2003), reliability in qualitative research is concerned with the replicability and consistency of the collected data. This is achieved when a different researcher is able to repeat the study following the same steps. Validity is concerned with how well the findings reflect the truth. There is much controversy regarding qualitative research and the applicability of the concepts of validity and reliability. However, there has been a development of concepts such as rigor and trustworthiness in order to fulfil the requirements for validity in qualitative research (Golafshani, 2003).

In order to achieve validity and reliability in qualitative research, there are four criteria to consider: credibility, transferability, dependability and confirmability (Shenton, 2004). These aspects provide trustworthiness to a study. Credibility is evident when the research findings from the interviews are accurate, adequately rich, rooted and backed up by literature (Ulin et al., 2002). According to Terre Blanche, Durrheim, and Painter (2006), credibility is also evident if the participant's views and answers to interview questions are accurately reflected in the findings of the study. This was accomplished as the researcher was an isiZulu speaker who is also familiar with the English language, which made the translation and transcribing of the participants' responses easy and accurate. Transferability is the level to which results in the qualitative research can be transferred or generalised. In the context of qualitative research it is the responsibility of the researcher. In this research, the population studied was described in detail which will allow the next person who wishes to transfer the results to a different context to make the necessary changes and consideration taking into account their setting (Terre Blanche et al. 2006).

The research process's consistency establishes its dependability (Ulin et al., 2002). The overall study research questions were considered to be clear and logically connected to the research design and objectives. In terms of the data collection process, the research questions were translated from English into isiZulu. The questions were asked in English/isiZulu during the interviews and later translated back into English, where necessary; however, this did not

negatively affect the consistency or dependability of the findings in this study. Confirmability refers to whether the study's findings and conclusions of the research are correct with regard to the objectives of the study and not influenced by the researcher's own biases and values (Terre Blanche et al., 2006).

### **3.10 Ethical considerations**

The permission and ethical clearance for conducting this study was granted by the University of KwaZulu-Natal Biomedical Research Ethics Committee (BREC ref: BE415/14) (Appendice A). Permission was obtained from the relevant gatekeepers of the Vuka Family Programme at Prince Mshiyeni Hospital (Appendice E) and the participants before conducting interviews. Ethical principles such as confidentiality, beneficence and the trustworthiness of the study through credibility, dependability, confirmability and transferability were covered in this research as part of the informed consent process. The ethical principle of trustworthiness is achieved by means of the credibility and validity of a qualitative research study (Burns & Grove, 2005). How the remaining principles were attained will be discussed below.

**3.10.1 Informed consent and confidentiality** since this study focused on participants who are caregivers to HIV-positive children and who might also be living with HIV, the researcher/interviewer took great caution when asking questions and the manner in which they asked, as there was a possibility that questions deemed as harmless could make the participant uncomfortable. Considering the study's sensitive nature, anonymity and confidentiality were maintained and ensured through use of pseudonyms to protect participants' identities and the storage of audio recordings in the researcher's locked and safe cabinet. Participants in the study were asked to sign the informed consent form (see Appendice C). It was communicated with the participants that their participation was on a voluntary basis and they could withdraw from the study at any time if they wanted. Moreover, they told that their withdrawal from the study would not affect their participation in the Vuka project or the healthcare they received from the Mshiyeni Hospital clinic. The researcher made sure that the participants were aware of what they were consenting to. This was achieved by sharing information about the study with the participants (including the risks and benefits) in a manner and language that they could fully understand. The study participants' consent was obtained before audio recording of the interviews. The researcher

ensured that benefits for all the participants were maximised while risks were minimised or at best eliminated.

### **3.10.2 Beneficence and non-maleficence**

The principles of beneficence and non-maleficence aim to affect participants positively and avoid any harm caused to the participants in the research study (Orb, Eisenhauer, & Wynaden, 2001). Participation on the study was on voluntary basis and participants were also told to contact the researcher and the supervisor at any time after their interviews if they wished to say or ask something related to the study. The participants were provided with a remuneration of R20 after their interview sessions which was compensation for their time spent during the interview and contribution to the study. In addition, they were informed that the findings of this research could assist policy makers in designing intervention programmes aimed at addressing issues related to the impact of disclosure of HIV-positive status.

## Chapter Four: Results

### 4.1 Introduction

This chapter focuses on the presentation of the study findings starting by describing the demographic characteristics of the research participants. Thereafter, the research findings are presented according to the major themes that emerged from the data analysis.

**Table 1: Demographic characteristics of caregivers and children**

Characteristic	Frequency
<b>Caregiver</b>	
<b>Gender</b>	
Male	0
Female	10
<b>Relationship to child</b>	
Biological parent	7
Non-biological parent	3
<b>HIV-positive child</b>	
<b>Gender</b>	
Female	8
Male	2
<b>Age</b>	
9 years	1
10 years	2
11 years	3
12 years	1
13 years	2
14 years	1
<b>Age of disclosure</b>	
8 years	1
9 years	2
10 years	4
12 years	2
13 years	1

### 4.2 Introduction of themes

This study was conducted on a total of ten female caregivers of children living with HIV. All participants were black African women, isiZulu speaking and resident in Kwazulu-Natal. The children's ages ranged between 9 and 14 years. The participants met the eligibility criteria of

being a caregiver to a child between the ages of 9 and 14 years, living with HIV and who had had their HIV-positive status disclosed to them.

Four overarching themes emerged from the study:

1. **Awareness of the child's HIV-positive status.** This theme focussed on the experiences of the caregivers. This included the subthemes of:
  - Family awareness
  - Institute/communal awareness
  - Child's own status awareness.
2. **Difficulties experienced in disclosure.** This theme included the different factors which hindered or made it difficult for caregivers to disclose their status to their HIV-infected children. This theme had the following sub-themes:
  - Internal stigma
  - External stigma
    - Stigma and discrimination at the institutional level
    - Stigma manifesting in interpersonal relationships
    - Stigma and discrimination on the community level
    - Stigma within the family.
  - Communication with child/difficulty in communicating sensitive issues
  - Developmental delays
  - Guilt, shame and embarrassment as a challenge in disclosure
3. **Factors promoting disclosure.** This theme focuses on the different factors that positively influence the caregiver's decision to disclose the child's HIV-positive status to them. The subthemes are:
  - Children questioning of medication
  - Clinicians pushing for disclosure
  - Government policies (focus on policies that encourage disclosure).
4. **Impact of disclosure (for the child and caregiver).** This had the following subthemes:
  - Caregiver relief
  - Improvement in adherence
  - Emphasis on secrecy.

### **4.3 Awareness of the child's HIV-positive status**

This theme will focus on both the biological and non-biological parents' experiences of how they came to have awareness of the child's status. Caregivers' first knowledge of their child's HIV status varied as some discovered a few months after the child was born and others only years later when the child became ill. Participants seemed to find out about their own status at the same time they found out about the child's status. The majority of the biological caregivers of the children living with HIV learnt about the child's status after birth and when the child started getting sick (n=6). Two of the three non-biological caregivers also learnt about the child's status when the child started getting sick, as explained below in the quotes from the participants.

#### **Biological caregivers**

Among the seven participants who were the biological caregivers, six reported to have learnt of their children's status when the child started getting sick. In as much as they were the biological caregivers of the HIV-positive child, they indicated that they did not learn of the child's HIV-positive status after birth at the hospital.

*Participant 4: I checked when I was pregnant in 2003, then they also checked him because he was sick and always had a headache, and then the Doctor Mohammed advised me to take him here at Mshiyeni so they check him and they checked him here at Mshiyeni and found that he's like this.*

Only one out of the seven biological caregivers expressed learning of the child's HIV-positive status in the hospital after giving birth. The participant said that the child was born sick and had to stay in the hospital for a long time. The participant also expressed already being aware of her own HIV-positive status before the diagnosis of the child.

*Participant 8: He was born sick and from birth stayed in the hospital after his birth, so he basically grew up in hospital. He was really sick and even his body is soft as his bones are not developing properly. It was bad that he even had a hole in his stomach where his bones were coming out and they only found out about his status when he was 4 years old. I already knew about my status at the time.*

Some of the participants expressed learning about their own HIV-positive status at the same time they learnt about the child's HIV-positive status (n=3). One of the participants expressed that her child had always been sick and got tested a couple of times at the hospital but she never learnt about the child's status or even received the child test results:

***Participant 7:** He was 3 years because I did not find out at birth, but ever since I had him, he's just been a person who is sick. Just that I don't know if it was carelessness or what in hospitals because he had been tested like three times before, but they would discharge him without giving us his results. And then it was as if he was a child with epilepsy and then one time a counsellor said he can't test the child without testing me. So we both took the test at the same time and that [was] when we found out what the child had and also at that time learned about myself.*

### **Non-biological caregivers**

The non-biological caregivers (n=3) indicated that they learned of the child's HIV-positive status when the child's biological parents got sick or passed on and/or when the child also started getting sick, and they became responsible for taking care of the child's health. As the following caregiver expressed:

***Participant 10:** What can I say? I'll explain, it [is] my sister's child and my sister stopped taking ARVs and I told her to go back to take her treatment but she would not listen and said she is a Christian, she is saved and God will save her. She then got meningitis and I had to take her to hospital and she stayed there as she was in a coma. So she spent three weeks in hospital and she was discharged and after that I was able to make her take the pills even when she did not want to. And her child, I could see is not well as he started having sores all over the body, so I was then also forced to take her child to the hospital. When I got to the hospital, they said that he needs to start ARVs and he started them and I asked his mom... So the time the mother got meningitis, it resulted to her losing her hearing and she can't hear any more so I was forced to be the one who takes care of things now. So she has her own house and I also have my own house (I am married), so I took the child here and they welcomed the child and started with ARVs.*

These two non-biological caregivers also reported that their children had experienced parental bereavement or a loss of their biological parents. One of the participants expressed that this was the reason that they had to postpone telling the child about their HIV-positive status as they were still scarred from the loss of the parents and the child was also not in good health at the time. As one of them expressed:

***Participant 9:** I told him last year and the reason I told him last year is because my sister who is his mother passed away and I first looked at his situation and saw that, if I was to tell him now, it would really affect him as I could see that he was really affected and even his health as he had TB. And then I saw that, no next year would be better as he is better now and realised that now I can sit down with him and tell him. He was 10 years old at the time.*

#### **4.3.1 Family awareness**

Among the ten participants interviewed, four reported that the whole family had knowledge of their child's HIV-positive status. It seems that these four caregivers had disclosed the child's status to all family members. For one of the four caregivers, making the whole family aware of their child's HIV-positive status was not by choice, but the child's psychological problems led to everyone in the family being aware of the child's status.

***Participant 1:** All of my family knows about my child's status.*

For another participant, the child's psychological development or mental capabilities make the child unable to keep a secret or unaware of what they should share or not share with other people. Therefore, disclosing to the child was indirectly disclosing to the rest of the family.

***Participant 10:** Everyone in the family knows because of his mother's condition. They know but what saddens me is that, when we talk to him about things, he goes and tells other people outside, which shows that his mind is not matured enough to understand that the things we talk about are just between the two of us.*

Four participants reported that there was only partial family knowledge of the child's HIV-positive status; the reason for this was that certain family members were too young to understand.

***Participant 3:** Yes, everyone knows, even his sisters. One is in Grade 6, and the other one is in Grade 7, and the other younger sister who's in Grade 2. I don't really think*



*she knows, even though she has seen him taking his pills, but we haven't told her because she is still young.*

While one of these four participants had disclosed to most of the family members, she nevertheless also suggested that family knowledge of the child's or the caregivers' HIV-positive status could lead to negative experiences for them. This participant expressed having experienced discrimination from her family members when they found out about her own HIV-positive status:

**Participant 8:** *Everyone except his 4-year-old sibling and it is okay but it just my family that did not take it well, as, when I told them about myself, they did not want anything that was associated with me. They would say they're scared because the mosquitos would bite me and then bite them. I would hear them talking about me in the room; they did not use the same dishes as me or even blankets. It was so bad that my sister even went to stay in the outside building and cook only for herself. My own mother and sister wanted nothing to do with me, [so] that when I slept in the hospital for three months when I had TB, they never came to visit me. I was really hurt and I do not wish for anyone to experience that. And [it] turns out my sister was also positive and scared to take pills because mom might see her and so I told mom that if my sister dies, it is on her.*

#### **4.3.2 Institution/community awareness**

Seven participants indicated disclosure to institutions within the community such as schools, and church, as well as community members such as neighbours. Four indicated that they had disclosed to the school:

**Participant 3:** *His teacher from last year knows and the principal, but this year I have not met with his teacher. I went there and she was not in school, as they say we must tell the teachers [before we come to visit]. So this year's teacher does not know, but the one from last year knew.*

Two of the participants reported choosing not to let the school know of the child's HIV-positive status as they feared that the child might be discriminated against or even not be accepted by the school, as expressed by one of these participants:

**Participant 10:** *I do not know because with these types of Indians... and maybe telling them could lead to the child being abused somehow. I don't know. You see, the time*

*he was taking treatment for TB, he had to stay at home for three weeks and we explained to them that he was sick, then took a letter from the clinic and sent it to the school. Okay, but I just have that fear of telling them that he is positive.*

The other participant who reported not disclosing to the school about the child's HIV-positive status explained that it was not necessary as she is now a stay-at-home mom and is able to take care of the child. The child is able to take their medication even before going to school and thus she saw no need of informing the school about the child's HIV-positive status:

***Participant 2:*** *At her school they don't know. Because she got really sick when she was a baby, I ended up leaving work so as to fully take care of her and give her the medication myself. Because when I wasn't around, sometimes my mom would forget to give her so I saw no need to tell them at school because she leaves at seven for school and that is right after taking her medication. But when I have to go to Mshiyeni, I do report and come back with the doctor's note as proof.*

For one of the participants, she chooses to keep the child's status a secret from the community in order to avoid gossip, as the participant expressed:

***Participant 2:*** *You know in my community, if they found out, I would be hurt because people are different. You may tell a person and they take it somehow and tell other people. Like in the past few days, there is a person who saw me here in Mshiyeni and then told other people that Lungelo is taking pills with her child, and this story went around and even reached the church. They called me in church and told me that they heard that I am taking pills and I have been complaining about gaining weight and it [is] because of these pills. And there was one lady who did not like these talks that were circulating about my name and asked to talk to me and said, just because you are taking pills, you don't have to tell everyone because now everyone is talking about you now. They were even saying [they] could look at the person all big, only to find out that they are taking these pills. And this did not sit right with me and because I had heard who these people who were talking about my name were, I went and asked them.*

### **4.3.3 Child's own status awareness**

Participant caregivers disclosed to their children at differing ages, with the age of disclosure ranging from 8 years to 13 years. Seven participants disclosed to the child between the ages of 8 and 10 years, and three of the participants disclosed between the ages of 12 and 13 years. Disclosure was reported to not be an easy process and was usually done with the assistance of someone close to them (caregivers) or a health worker (doctors/counsellors). Some, however, did do it on their own with their children.

*Participant 3: I think he learnt about his status during the counselling sessions that they usually have here at the hospital and even last year; he was here for counselling and they told him. So I think it was definitely last year, at the age of 10.*

### **4.4 Difficulties experienced in disclosing**

There were multiple reasons that prevented caregivers from disclosing and one of the reasons expressed by eight out of the ten caregivers was the fear of stigma and discrimination that the child might possibly experience or could be exposed to after disclosure.

#### **4.4.1 Internal stigma**

As discussed in the previous section, most of the participants expressed that they had difficulty in disclosing the child's HIV-positive status to others or their children as they feared that the child may be teased or discriminated against or stigmatised. They were also concerned that the child may internally stigmatise themselves and end up isolating themselves from their peers. One participant explained:

*Participant 7: You know, kids can tease each other when they are together, so as a parent you sometimes want to try and protect your child from all of that and it [is] not easy to disclose to the child like that. The child might also feel different from other kids and end up isolating themselves from other kids because they [are] thinking because they [are] sick and it [is] like this, you see. That is why, even when he goes to school, I sometimes go there so as to explain his condition to his teacher. Because sometimes we have to go for appointments and the teacher might start to worry why the child is missing school so much, then you need to tell the teacher not because you want to but you are scared that the child might somehow be bullied by other kids. So it hard to tell the child that is like this even though you do wish to tell the child; it just*

*that you don't want to hurt them and want to protect them, but then end up telling them.*

#### **4.4.2 External stigma and discrimination**

The majority of participants (n=7) indicated that the availability of and access to ARVs had reduced experiences of stigma and discrimination; the treatment had allowed for HIV to be seen as any other chronic disease that can be managed, and HIV-positive people no longer look different from other people as the treatment allows for individuals to look as healthy 'as the next person'. The introduction of ART has led to an increase in the number of people living with HIV and, although more people are still being affected and infected by HIV in the communities, it has become normal and the public is also more accepting.

***Participant 7:** Uhmmm... I can say that in my neighbourhood almost everyone has it and we talk about it and maybe one of my neighbours would come by my place and we would talk about the hospitals we go to and the treatment or check-ups that we do, then see if we [are] both getting the same treatment even though we [are] at different hospitals and then on our next appointments, we ask the doctors if there is something we want to know...so we really help each other. So, even though my kid is positive, he is treated just like the other kids in the community. I could say it not the same as before, so now people are comfortable and treated better... Hasn't had anything bad like that he has told me about being discriminated against or treated badly or teased at school...Before ARVs, people would say that he is sick and then isolate you from the rest; but now since the introduction of ARVs, people see it as just another illness and say you just need to go to the clinic and take your treatment and get better, and it [is] no longer like HIV kills now, so people don't have that in their heads as much as they used to because of the introduction of ARVs, which has given people some relief.*

His friends talkevertheless, as discussed in Section 3.4.2, three participants feared children experiencing stigma in the community or if institutions within the community such as schools, churches, etc., were to know about the child's HIV-positive status.

*Participant 4: his friends talk too much and mock each other they would not be quiet but they would tease him about it if he had talked about it because he was told not to do that I can see that his not doing it. Because I would ask him if he did like this and he would say no and I would tell him not to even say it to his friends at school as they would laugh at him and tease him about it. His friends are still his friends it might happen that other parents could see that ohh... this one is taking pills and maybe say no to play with that person.*

#### **4.4.3 Communication with child/ difficulty in communicating sensitive issues**

For most of the caregivers (n=8), it was difficult to communicate with their children and their children also seemed to not be comfortable to talk about sensitive issues with their parents and especially those issues related to their HIV status. One of the caregivers expressed having a difficult time communicating with the child about sensitive issues such as sex and this difficulty has led her to not communicating about sex-related issues with the child at all. The participant also said that initiating such conversation with the child sometimes makes the child feel as though the parent suspects that they are dating and the child may become offended and act out, making it hard to have such conversations with the child.

*Participant 2: I never talk about sex. It sometimes gets hard talking about those issues with a child; it [is] really hard. ... It [is] easy when it comes to non-sensitive topics but those that are tough and sensitive - it [is] really hard like when you [are] telling the child that they should not date and all of that, it [is] hard to talk about things like that with the child because you don't know how they are going to feel. At times, she shouts when I tell her and says, "Mom you acting as if I'm dating when I am not, and I won't do that". But I'm trying to give her direction and let her know [what] the results of starting dating at a young age are.*

One of the participants also expressed feeling awkward when communicating with the child about sensitive topics; nevertheless, she continues to talk to the child even though she expresses that this is not an easy task to undertake as a parent,

*Participant 4: Arhm... we talk, even though there's that awkwardness. But, yes, we talk.*

One of the participants expressed that communicating with their child about sensitive issues such as sex was hard in the beginning but that was before joining an HIV/AIDS programme called the Vuka Family Programme which assisted her in communicating with her child about HIV/AIDS and other health-related issues which may affect the child's overall well-being.

**Participant 7:** *At first it was not easy but now it is better, especially after joining the Vuka Programme last year; it has helped. We do talk at times as he told me that they asked him if he has had sex, do you drink alcohol and a lot of other things, and I asked what he said and he says I said no... I don't have a girlfriend. All the things that he was taught or questioned about during the Vuka sessions, he usually asks me for more detail when we get home. And even with his pills... he is way better now. He makes sure that he is taking them but in the beginning, he would not want to take them and sometimes pretended as though he had swallowed but then spit them out but ever since we started with the Vuka Programme, he knows that if you don't take your pills, he will get sick and he does not like getting sick. So now we have an alarm that we set so he knows that when [it] rings, he takes his pills and even mine as well and [he] gives me. So he is so much better now.*

On the other hand, some of the participants (n=3), indicated that it was relatively easy to communicate with their children about sensitive topics.

**Participant 3:** *Yes, we have no problem talking to him.*

One of the participants reported making use of creative methods in order to send or communicate health-specific messages on sensitive issues such as sex to her children. She made use of movies which focus on health-promoting behaviour such as safe sex practices. The video triggered discussion and made it easier to engage further with the children. As this participant expressed:

**Participant 9:** *It [is] me who usually talks to him even though my husband has accepted him as his own but it [is] just that he doesn't talk that much so it [is] me who usually talks to him. You know, I have movies and I can see that the movie is about the things that are not wanted. I call them, the both of them, even my own who does not have anything and tell them that "You see the cause of this and you see why this is not good for you?" and make them see what they are watching and you see with my own, I can see now that he is probably dating and I tell him to please use condoms. And you see with us, it was dark, we didn't know and I tell them to please get tested first if*

*you want to build a home with someone and not want to build a home with someone who might bring you closer to your death. If you love them, yes, you can continue with them but knowing exactly what is going on and not do something because you are in the dark... Tell them unsafe sex, my kids... even condoms, it [is] just that I'm just that type of person. I even buy condoms, even with the groceries. I show them and tell them, "You see what I use and it not because I'm stupid or because I don't want to get pregnant and besides HIV there are other infections you can get and when you also reach this stage that I am in of using this, whether you know the person or not, and you only know them when they are in front of you."*

#### **4.4.4 Developmental delays**

For some of the participants, the child's psychological development made it hard for the caregiver to communicate with them. They are not sure whether or not the child understands, as one of the participants said that the child seems to forget about their HIV-positive status and they need to continuously remind them. Thus, they felt their child's delayed psychological development hindered their ability to effectively communicate with the child as they easily forget or do not understand the significance of the information they are given regarding their health. As the following participant's explained:

***Participant 1:** Yes, it is easy because for me the only thing that was difficult is just that his mind; the only problem is his mind. What can I say? It gets difficult because he forgets. Even when you tell him something now and say it like this, but now I can see... it just that he's that child that doesn't like talking too much and doesn't like talking and hides things. He kept on trying to say something when he got back from school, saying there is something we talked about at school, asking me what protection is, and I would say just say it condoms. [Both laugh] So he is a boy and doesn't just talk, you know, and doesn't like talking.*

#### **4.4.5 Guilt, shame and embarrassment as a challenge in disclosure**

Most of the biological participants reported not being able to disclose their child's HIV-positive status to them as they blamed themselves for it. They also carried the guilt of infecting the child and feared the child's response or the questions that the child might have after finding out that they were positive because of their parent's behaviour.

***Participant 1:** The stress I would have was that maybe when this child is grown, they will blame me. I sometimes have that and say, "Ey, our children are paying for our*

*sins; what is he going to say when he is grown?” Or even when he gets a girlfriend or a wife, he would say, “I was born infected”, I sometimes have that in me. And I sometimes wish his mind was working fully like other kids, even though T is not crazy, you won’t see it sometimes; it [is] just that I see it as a parent that there is something that little wrong in his mind but he doesn’t have anything.*

Another of the participants expressed having the fear of disclosing to the child how the child got infected as they were scared of the questions that would come up after this. The parent said she would find it difficult to answer these. It would also show the child how careless she was when she fell pregnant, which is not the image she would like her child to have of her, as it is her duty to nurture and protect the child which she might have failed in doing:

***Participant 7:** What can I say?... It was me just being scared as the child would ask me how he got infected. So it would be difficult for the child and [he would] wonder why mom was so careless when she was pregnant, not able to take care of him and nurture him. So a child might look at you differently and wonder why you just let them get infected just like that and not protect them you see... but the thing is, at that time, things were different and now the clinics makes sure you get tested when pregnant. So [the] year 2004, that was not really serious and I did not see the need for it as me and his dad were not sick, and also just not being educated well. So it can be hard thinking of what thoughts your child is now going to have of you and how will they view me now as a mom.*

#### **4.5 Factors promoting disclosure**

This theme focuses on the different factors that influenced the caregiver’s decision about disclosing the child’s HIV-positive status to them. Although the process of disclosure is hard, all of the caregivers had managed to disclose the status of the children to them, with the assistance of either the clinic staff or a family member.

##### **4.5.1 Children questioning of medication**

Most of the participants responded that children questioning the ARV medication that they were taking were the reason for parents deciding on disclosing to the child. Below are the responses from different caregivers regarding children questioning of medication:

***Participant 7:** I would say at first he started asking why he was taking pills all the time and what were the pills for, because at first he was taking pills for TB and he*



*completed his treatment and then began asking why he is still taking pills, because the doctor had told him that he is now fine and so what are the pills that I am taking now for? Then I was forced to tell him because even his resistance to taking his pills was because he did not understand what the pills he kept taking were for now, and then I was forced to tell him what they were for then.*

Children also started questioning when they would stop having to take the medication and if they are ever going to get better. As they had previously suffered from HIV opportunistic infections such as TB and got better and no longer took medication for TB, they now wanted to understand when they would also stop taking the medication that they are taking now.

**Participant 5:** *He never asked me but he would ask me, “For how long am I going to be taking these pills? Aren’t I ever going to get better?” He used to take treatment for TB and he took it and finished it, so now he can see here that he keeps on taking and it does not stop and he asked me, until when?*

One of the caregivers expressed that it is not only the infected child that asks about the medications that they are taking but the child’s siblings also inquire about the medication that their brother is taking and why it is only him who takes it:

**Participant 4:** *Yes, he had started as he was always questioning what the pills that his [sibling is] always taking for? And his brothers would always ask, what are the pills that he’s always taking for? Because sometimes you have to give him his special meal and say, “Here eat here”, and then they ask, “Why, why only him?”*

#### **4.5.2 Clinicians pushing for disclosure**

Among the ten participating caregivers who had disclosed to their children, eight reported that they were encouraged by the clinic staff such as the doctors, nurses or counselors to disclose. Clinicians influenced the process of disclosure by asking the caregivers to disclose to their children or continually asking them when they would be ready to finally disclose to them.

**Participant 2:** *I saw that my daughter was growing and the doctor here was telling us that it is very important for the child to grow up knowing their status because these pills are being advertised on TV and they are taught about it at school. She learn at school and on TV and [she] get hurt and ask, “Why did you hide this from me?” and that is when I sat down with her and told her.*

One of the participants reported that HIV programmes which encourage disclosure influenced her decision to disclose to her child:

*Participant 8: I would say it was the people from Vuka who came here recruiting and when I wanted to join, I told them that I had not disclosed and so to join the programme, I had to disclose and I sat him down then and told him, though I did not think it was necessary as he has memory issues and it [is] just as though I did not tell him anything.*

#### **4.5.3 Government policies influencing disclosure**

There are South African policies in place which are aimed at the protection of children's rights and one of the participants reported that these policies also influenced her decision to disclose to her child:

*Participant 1: Don't you guys say that the law tells us to make our children aware of their HIV-positive status at the age of 9? But I said, no I can't, he is still too young and what if I tell him and he goes around telling other people here and maybe gets mentally abused? He just found out now; I could see he is ready now.*

#### **4.6 Impact of disclosure for the child and caregiver**

This theme focuses on the different results of disclosure. Most of the results were positive in regard to the child's health and their relationship with their caregivers. The caregiver expressed relief at having disclosed, and disclosure led to improved adherence and increased emphasis on secrecy, as discussed in the sections below.

##### **4.6.1 Caregiver relief**

All of the ten caregivers interviewed reported not having any regret after disclosing to the child about their HIV-positive status. Instead, disclosure had led to a relief and stress has been alleviated for the caregivers, as they are no longer carrying any secret and they are now honest with their children. They believe that the child also has the right to be aware of their status.

*Participant 1: I have no regret, as now I no longer have stress.*

*Participant 3: No, we don't regret. He deserves to know about his status.*

*Participant 8: No, I think I made the right decision. He deserves to know about his health.*

#### 4.6.2 Improvement in adherence

In response to questions focussing on the improvement in the ART adherence after disclosing and if there had been an improvement, half of the participants said their children did not want to take treatment before disclosure but after disclosure, the child's adherence levels increased, as the caregivers reported:

***Participant 2:** You see, before she found out, I won't lie, she did not want [to take the medication]. You see, there is this medication that she had to take back then when she was younger and it was really bitter. Then she would take the medication and not swallow it and spit it outside and when we get here, her results would not be good and then my father followed her and caught her. She hated these pills and when I say "T, come and take these pills", she would be grumpy. But after telling her, she makes sure that she takes them and says, "I don't want to end up dead or in hospital". You know after Rhythm City at seven, she knows it [is] time for the pills. And even when I am in the other house outside, she would come with water and pills for me to take as well. When I am away, she tells me that she took them in front of grandma. She has accepted it and is fine now.*

After being told about their HIV-positive status, another participant reported that her child became more motivated in taking his medication.

***Participant 7:** He had problems with taking his pills and he really did not want them at all... he really did not want them and started asking questions about them and I did not even know what to say and he would not swallow them. But ever since telling him what his pills were for and I told him that, "I am also taking these pills like you, as I am also sick". And, "Have you noticed that when you take yours, I also take mine?". And he said yes and that [was] when he got motivated in taking his medication. When the alarm rings, he takes his and my pills and we take them together. Because when the child knows why they are taking what they are taking and [you] tell them also of the impacts that come with not taking them, that if he does not take his pills, he will get sick and end up dead, this is not a nice or easy thing for a parent to tell their child, but you need to.*

For some of the participants (n=4), there were reportedly no changes in the way the child took his/her medication after disclosure, as they used to take them consistently prior to disclosure.

***Participant 9:** He would take them with no problem even before telling him and even now when he goes to play during weekends, he comes back and asks if it is not 6 o'clock yet and I tell him no but will call him when it is 6 o'clock.*

Only one participant reported that after disclosure, the child still cried, asking when would God heal them and they would not have to take their ART medication any more - the child was reportedly completely tired of taking the pills:

***Participant 4:** I said we are both sick as we are taking them together. He asked, "What do we have?" And then I told him we have a virus; they teach you at school about the virus like this and he said yes he knows from school. Then I told him we need to take them every day but then he sometimes cry and says Jesus must heal him now; he does want these pills anymore, "Jesus must heal me; when is he going to heal me?" And I tell him he's going to heal you but for now let's take them. It has been hard... it has been hard...he used really to cry and say he does not want them now...he says he does not want them, he does not want them anymore... he's tired of taking pills [unclear].*

#### **4.6.3 Emphasis on secrecy**

For most of the participants, even after disclosing to the child, there was still a need for secrecy. The child was given the responsibility of keeping their status a secret from those who were not aware of it and this could be at the school, friends, etc.

***Participant 2:** What can I say? I did not have problems because I had told her that it [is] just her secret and she does not have to tell her friends. There is no problem; they come by my place and visit [and] also take her along if there are trips and [she] comes back happy and explains to me what they got up to. She is fine and comfortable with her friends even now. It [is] only one friend that knows and it [is] the one that comes to here with her [at] Mshiyeni.*

## Chapter Five: Discussion and Conclusion

### 5.1 Introduction

The main objective of the study was to explore the experiences of the caregivers of HIV-positive children regarding the process of disclosing their HIV status to the child, and to develop an understanding of factors that promote or hinder disclosure and the impact of disclosure on the child's overall well-being. The findings of this study could assist policy makers in addressing interventions aimed at assisting with HIV/AIDS disclosure to HIV-positive children the key questions this research aimed to answer are:

- What are the levels of awareness of the child's HIV-positive status?
- What are the factors that promote HIV disclosure to a child?
- What are the factors that hinder HIV disclosure to a child?
- How does HIV disclosure impact on the child's psychosocial well-being

This chapter will discuss the findings of this study in relation to these four broad research questions and the literature.

### 5.2 Summary of themes

The themes outlined below were derived from the above-stated objectives of this study. These themes will be discussed in the subsequent sections.

#### 5.2.1 Awareness of the child's HIV-positive status.

This theme looks at awareness of status of the HIV-positive child, focusing on the family and community members' awareness of the child's status, as well as the child's own awareness of their status. There were three sub-themes:

***Family awareness.*** This theme focusses on whether or not the child's family members had knowledge of the child's HIV-positive status.

***Institution/community awareness.*** This theme focusses on understanding whether the community or the institutions in the community such as schools, churches, etc., had knowledge about the child's HIV-positive status.

***Child's own status awareness.*** This theme focusses on understanding when the child learnt of their HIV-positive status.

### **5.2.2 Difficulties experienced in disclosure**

This theme focusses on the difficulties that caregivers experience when they are faced with the task of disclosing.

*Internal stigma.* This theme focusses on the child's self-stigmatisation after having learnt of their HIV-positive status.

*Stigma and discrimination at the community level/institutional level (external stigma).* This theme focusses on ill-treatment of HIV-infected people or any stigma around the virus.

*Stigma within the family.* This theme focusses on stigma around HIV in the family.

*Communication with child/difficulty in communicating sensitive issues.* This theme focusses on communication between the child and the caregiver.

*Developmental delay.* This theme focusses on the child's psychological development and how it influences disclosure and communication.

*Guilt, shame and embarrassment as a challenge in disclosure.* This theme focusses on what caregivers experienced when they came to tell their children about their HIV-positive status.

### **5.2.3 Factors promoting disclosure**

This theme focusses on the different factors that influence the caregiver's decision to disclose the child's HIV-positive status to them.

*Children questioning of medication.* This theme focusses on the different questions that children had about their ART.

*Clinicians pushing for disclosure.* This theme looks at the role that clinicians play in the facilitation of disclosure of the child's HIV-positive status to them.

*Government policies.* This theme focusses on the governmental policies that encourage disclosure.

### **5.2.4 Impact of disclosure (for the child and caregiver)**

This theme focusses on the impact of having disclosed to the child.

*Caregiver relief.* This theme focusses on caregivers' feelings after having disclosed their child's HIV-positive status to them

*Improvement in adherence.* This theme is about changes in treatment adherence among children after they had received disclosure.

*Emphasis on secrecy.* This theme is about how, after having disclosed, parents and caregivers encourage children to keep their HIV-positive status a secret from others.

### **5.3 Awareness of child's HIV-positive status**

This theme looks at how participants came to be aware of their child's HIV-positive status and when the child became aware of their own HIV-positive status. It also looks at whether people and institutions around the child are aware of the child's HIV-positive status. This theme focusses on the family, the community and the institution's knowledge of the HIV-positive status, as well as the child's knowledge.

#### **5.3.1 Family awareness**

Almost half of the participants in this study reported that their whole family was aware of the child's HIV-positive status. The participants believed that this was appropriate as the family provided them with the support that they needed when it came to dealing with issues related to HIV and also in communicating with the child about the HIV-related issues. It has been reported in prior literature that disclosure to family or other people such as the school community, church, etc. assisted the caregivers and their children in getting the support that they needed for dealing with disclosure and living with HIV (Petersen et al., 2010). This goes to show the importance of the mesosystem in supporting the process of disclosure. People who make up a child's microsystems can provide support for disclosure.

Some participants needed to disclose to their family members in order for the family to assist in the child's medication adherence as the caregiver might not always be with the child and the family is helpful in assisting to make sure that the child was taking their medication. It seems as though the family having knowledge of the child's HIV-positive status leads to an improvement in the child's adherence as there are people around the child who assist in reminding the child about taking medication.

Moreover, participants also saw the need to disclose to the whole family because HIV is all over the media and HIV/AIDS messages are broadcast on TV shows and adverts. For the participants, disclosing to the child meant also having to disclose to the rest of the family in order for the family members not only to be supportive but also sensitive and always cautious of what they are say or comment on in relation to HIV. The caregivers saw the need to tell the whole family in order to encourage sensitivity and more education about HIV/AIDS. It has been reported in prior literature by Wiener et al. (2007) that some of the factors that influence

disclosure of their HIV-positive status to the child are promotion of trust between the child and the caregiver, and of open family communication within the household.

Families' awareness of the child's HIV-positive status was not necessarily by choice; instead, in some cases, the child was reported to have minor psychological issues and unable to completely understand, even when told that their HIV-positive status is their secret and they are not to share it with others. The child's lack of understanding of the significance of their status being a secret led to the child disclosing their status themselves to the family members, as they were not able to keep a secret.

For those participants who reported not disclosing the child's HIV-positive status to the whole family but only to some of the family members, the reasons given included that some members of the family were still too young to understand what it meant for their sibling to be HIV positive. This finding that some caregivers do not disclose the HIV-positive status of their child for fear that other family members may be too young to understand is supported by previous literature (Lester et al., 2002).

It seems as though most of the participants, who had disclosed to the whole family, began by disclosing to the family before disclosing to the child. It seems as though the family supported the process of disclosure and also supported the caregiver and the child in taking medication and also accompanying the child for their appointments. While most chose to disclose to the entire family, a few chose to disclose to only some family members who were seen to be reliable and who could be trusted with information regarding the child's HIV-positive status.

### **5.3.2 Institution/community awareness**

Most of the participants indicated not disclosing directly to the community but because they make use of the community clinic, they felt their neighbours were bound to find out about the child's HIV-positive status. It seems as though people having access to the same facilities prevents them from keeping the secret of the child's HIV-positive status. For example, it seems as though having a dedicated HIV clinic unintentionally leads to identification of HIV-positive patients in the community. Participants reported that the community members would question why they were constantly going to the clinic.



This is one of the issues which have been reported in previous studies (Visser, Makin, Vandormael, Sikkema, & Forsyth, 2009) as hindering people from going to the community clinics for treatment as the neighbours would find out this way and possibly discriminate against them. This aspect also triggered some of the participants to tell their child about their HIV-positive status for fear that they might hear it from other people. This raises questions on the need for integrated care which would be inclusive of HIV/AIDS services, as opposed to stand-alone HIV clinics.

Furthermore, there seems to be a need to make use of the integrated chronic disease model which can serve to empower individuals to take control of their own health, while at the same time intervening at a health services level to improve operational efficiency and quality of care. This model also provides intervention at the community level in order to have an informed population and attain optimal clinical outcomes for patients with chronic communicable and non-communicable diseases (Mahomed et al., 2014). This approach is similar to that of the ecological model, which looks at the different factors and the different levels of influence on the health of individuals and also considers those factors in order to improve individuals' quality of health (Mahomed et al., 2014). The integrated chronic disease model is inclusive of multiple levels of influence and is also participatory which leads to greater chances of successful health outcomes.

However, some participants did report that community knowledge of the child's HIV-positive status was not always bad, with some participants reporting that this led to support from the community such as reminding the child when it is time to go home for medication. This can be understood as a product of African culture which is historically collectivist and wherein a child is raised by the community. This is contrary to what individuals might believe would happen if the community was to find out the child's HIV-positive status. In this regard, one of the caregivers reported that they chose not to disclose their status to the community for fear that the community would gossip and express stigma towards them. Perceptions about HIV/AIDS are mostly negative and stigmatising (Hosegood et al., 2007).

Participants seemed to understand the importance of disclosing to the school as almost half of the participants reported having chosen to disclose the child's HIV-positive status to the school that their child attended. This was triggered by the need for the child to regularly attend clinic appointments for medication and medical check-ups or assessments. Therefore,

the caregivers saw the need for the teachers to be aware that the child would sometimes not be at school and for the teachers not to be worried if the child possibly acts differently or feels drowsy in class. They hoped the teachers would understand that it is the medication causing this and that the teachers would also provide the parents with feedback regarding the child.

Disclosing to the school and the child's teacher seemed to create a stronger teacher-parent relationship and also provided additional support for the child as the teacher's awareness of the child's health enabled them to provide more support and also be more sensitive towards the child. The participants also reported the schools being supportive in terms of providing food to the children which assists in the taking of the medication. Previous literature indicates that disclosure to others about the child's status is also helpful for accessing social support systems and other forms of support (Mitra, Gogolishvili, & Globerman, 2013). In addition, disclosure to the school and teachers has also been reported being beneficial to caregivers and adolescents it seems to result to better academic support, and the school being more understanding after disclosure (Petersen et al., 2010). This evidently shows that the school and the teachers who form part of a child's exosystem have a significant role to play in making the child living with HIV adjust better after learning about their HIV positive status.

Notwithstanding the above, there were participants who reported choosing not to disclose to the school for fear that the school might exclude the child from their institution. This is despite the fact that such behaviour is against South African law and there is legislation protecting people living with HIV/AIDS from stigma and discrimination (AVERT, 2016). Participants having expressed these views indicated that people living with HIV in South Africa still do not know their rights and it is important for the old and new generations living with HIV to be aware of what they are entitled to; one of those things is access to education regardless of their HIV-positive status. The Department of Education's (1999) National Policy on HIV/AIDS for Learners and Educators in Public Schools outlines some significant policy issues related children living with HIV/AIDS in schools, with the key aim of the policy being that HIVinfected learners should live as full a life as possible and should not be deprived of an opportunity to attain education that is in accordance with their capability.

### **5.3.3 Child's own status awareness**

It seems as though, for most of the participants in the study, the child's age was a significant factor in considering whether or not to disclose the child's HIV-positive status to them. Most of the participants saw the need to disclose to their child as they were growing older. In this study sample, the median age of disclosure of the child's HIV-positive status to them was 10 years old. The results from a prior study by Negese et al. (2012) showed that the majority of children above the age of 10 years had knowledge about their HIV-positive status, unlike those younger than 10 years who had participated in the study.

It seems as though disclosing to the child was also based on whether or not the caregivers see their child as being old enough to understand what it means to be HIV positive and the implications that come with being HIV positive. Although, some of the participants reported that although the child was chronologically older, they were still of the view that the child was too immature cognitively/psychologically to completely understand what it means to be HIV positive and the accompanying implications. This was what made some of the participants reluctant to disclose to their children earlier. Similar findings have been reported in previous studies, where the child's mental state and IQ level were found to be used as indicators by most parents on whether it was an appropriate time for disclosure. Often, early disclosure of the child's status is related to developmental readiness to understand the multifaceted and varying nature of an HIV diagnosis and prognosis (Brown et al., 2011 Lester et al., 2002). This highlights the importance of the chronosystem in influencing disclosure as caregivers make use of the child's cognitive ability and their development in order to assess whether they can disclose the child's HIV positive status to them, as well as if the child will be able to process the information that they are told and understand the implications that come with living with HIV/AIDS.

Another factor promoting disclosure was the child approaching the adolescent stage of development with the accompanying possibility of starting to date and consequently, engaging in sexual intercourse. According to Shisana et al. (2005), in South African children, approximately 11.9% of males and 5.1% of females have their first sexual encounter by 15 years of age. As has previously been suggested, it was deemed important that the child learn about their HIV status not only for their own health maintenance, but also to prevent the transmission of HIV from them to others (Vreeman et al., 2013).

Participants reported that disclosure was a difficult process, with the child taking a while to understand what being HIV positive means, and some of the participants reported repeatedly having to explain to the child that they are taking pills because of their HIV-positive status. This shows that disclosure is not a once-off process, but it is something that the parent or caregiver constantly needs to explain to the child as they grow and ask more questions (Lester et al., 2002). This concurs with previous literature that suggests that disclosure is not a once-off task that is undertaken by caregivers, but is a continuous process which is influenced by the child's age and their cognitive development, as well as their understanding of the meaning of sickness and death (Lester et al., 2002). Most of the participants reported that disclosure to the child was not an easy process to undertake. Participants indicated that they had either received assistance from family members or clinicians at the clinic. In as much as disclosure was not an easy process to undertake, the participants nevertheless reportedly did not regret choosing to disclose to their children as it led to positive results for the child, their health and also for themselves as caregivers. This will be discussed further later in this chapter.

Some of the participants who were non-biological caregivers saw the need to disclose the child's HIV-positive status after the death of the child's own biological parent. This provided an opportunity for the non-biological caregivers to take charge and work together with the child in attaining good health. Some of the non-biological caregivers reported that the child's biological parents were in denial about their HIV-positive status and were not taking treatment, and also not giving the child their treatment. Thus, the non-biological caregivers saw the need to be actively involved in improving the child's health and also assisting this by disclosing the child's HIV-positive status to them. According to Lester et al. (2002), children who had experiences of bereavement of a family member were twice as likely to have received disclosure compared to those who had not suffered bereavement.

#### **5.4 Barriers to disclosure**

There are multiple factors which serve as barriers to disclosure or contribute to making the process of disclosure more difficult than it is already for the caregivers of HIV-infected children. This is an overarching theme which includes subthemes such as internal stigma, external stigma and discrimination, communication issues, developmental delay, and guilt, shame and embarrassment. These will be discussed in more detail below.

**5.4.1 Internal stigma** Participants feared that disclosure would lead to stigma and discrimination from others as well as the child stigmatising themselves and seeing themselves as different from other children. The participants reported fearing that the child might feel inferior to other children and possibly isolate themselves from the rest of their peers and friends after learning of their HIV-positive status. This has been reported in prior studies where it was reported that some adolescents withdrew from their friends and social activities when they found out their status and felt uncomfortable when people spoke negatively about HIV-infected people (Petersen et al., 2010).

#### **5.4.2 External stigma and discrimination**

Participants also feared the possibility of the child experiencing stigma and discrimination from the community and the institutions within the community if they were to disclose the child's HIV-positive status to them. Hosegood et al. (2007) argue that manifestations of discrimination against an HIV-positive person include being isolated and excluded, as they are seen as a threat to others. In a study conducted in Ethiopia by Negese et al. (2012), the low rate of disclosure was associated with the existence of stigma related to HIV. This was intensified by the fact that the majority of children are peri-natally infected and the disclosure of the child's HIV status opens up other sensitive topics within the family such as parental HIV infection, which caregivers may choose to avoid.

Fear of stigma and discrimination thus seems to still persist even with the introduction of ART, which has removed the association of HIV/AIDS with death and has allowed for people living with HIV to live longer and healthier lives and to be seen to be like the rest of the population. This goes to show how society's perceptions and attitude towards HIV (factors in the macrosystem) influence the attitudes of caregivers and ultimately decisions about disclosure.

#### **5.4.3 Stigma within the family**

Notwithstanding the fear of stigma and discrimination discussed above, only a few participants actually reported having experienced stigma and discrimination after disclosing their child's HIV-positive status to their family members. Most participants had chosen to disclose their own status to their family members before disclosing their HIV-positive status to the infected child. For most of the participants, the family seemed to be accepting and

supportive, and they were willing to assist with some of the responsibilities of ensuring the child's overall well-being.

#### **5.4.4 Communication with child/difficulty in communicating sensitive issues**

Most of the caregivers who form part of childrens' microsystems reported experiencing difficulties communicating with their child about HIV/AIDS-related information as well as sensitive issues such as sexual intercourse, relationships, etc. They dealt with this challenge by coming up with creative methods which provoked discussions around these sensitive issues without directly personalising them. They made use of videos or movies which centred on health-promoting behaviour. For example, they found the Vuka Family Programme intervention very helpful in that it makes use of comic books to educate children about HIV/AIDS, allowing the children to identify with the characters but not necessarily talking directly about themselves.

This project is similar to that of the Amaqhawe Family Project which is the project of the Collaborative HIV/AIDS Adolescent Mental Health Programme in South Africa (CHAMP-SA). This project has adopted the CHAMP model focusing on community involvement at all stages of implementation of the intervention, in order for it to meet the needs of individuals infected or affected by HIV/AIDS (Petersen et al., 2006). The use of digital colour imaging in education and promoting healthy behaviour among children living with HIV/AIDS and their caregiver's assists in triggering the conscientisation process, provides positive role models who participate in health-promoting behaviour, and facilitates the provision of information to fathers, as they commonly do not participate in intervention. This was seen in this study, where only female caregivers participated (Petersen et al., 2006).

#### **5.4.5 Problem of developmental delays**

It was reported by some participants in the study that their child's delayed cognitive and psychological development made it hard to engage in progressive communication with them about their sexuality and risk behaviours. The caregivers mainly complained about the child forgetting information. This has been previously reported as a challenge in discussing a highly stigmatised illness, as HIV-positive children often experience developmental delays (Deacon & Stephney, 2007).

In dealing with HIV positive children it seems as though considering their cognitive development is an important factor to consider highlighting the importance of the chronosystem in decisions to disclose.

It is reported in the literature that some parents fear disclosing to their children, as they do not think the child has developed enough cognitively to understand the implications that come with having the virus, including the ability to keep one's status a secret in order to avoid potential stigma and discrimination. According to Heeren et al. (2012), it has been reported that telling the child about their status could lead to them telling other people, especially in cases when the child is still too young to understand. As has also been reported by Heeren et al. (2012), the biggest barrier to disclosure is the fear of children revealing their diagnosis to other children or neighbours.

#### **5.4.6 Guilt, shame and embarrassment as a challenge in disclosure**

All of the biological caregivers reported having experiences of guilt, shame and embarrassment in disclosing the child's HIV-positive status to them. This fear hindered the participants from disclosing to their children as they felt guilty, ashamed and embarrassed from having infected their child and, as a parent, they believed they had failed to do what they saw as every parent's number one responsibility which is to protect their child from any harm or danger. This finding concurs with previous studies which found that caregivers feared disclosing to their HIV-infected children as they believed they were guilty of having infected them and feared the child's reaction and the questions that the child might have (Vreeman et al., 2010).

Biological parents have been found to be less likely to disclose their children's HIV status compared to non-biological parents of the infected children (Mandalazi, Bandawe, & Umar, 2014). According to literature, the reason for this could be the fear of being blamed by their children for infecting them and also the internal guilt carried by the parents for having infected their children, which therefore makes it hard for them to tell their children about their HIV-positive status (Mandalazi et al., 2014).

In contrast with evidence that there is HIV testing and counselling for pregnant women offered at the South African clinics and hospitals, as well as prevention of mother-to-child HIV transmission, it seem from the results that most of the caregivers did not receive these

services. Most of the biological caregivers interviewed reported only learning of the child's HIV-positive status after birth and others reported learning when the child started getting sick. It seems as though the policies put in place for testing pregnant women are not being accurately followed or practiced. Alternatively, as much as the policies and services might be in place in support of testing, it is possible that they are not properly utilised.

## **5.5 Factors promoting disclosure**

This is an overarching theme which focusses on the different factors that influenced caregivers' decisions about disclosing the child's HIV-positive status to them. The process of disclosure is hard but all of the caregivers managed to disclose the status of the children to them with the assistance of either the clinical staff or a family member.

### **5.5.1 Children questioning their medication**

For most of the participants, children (and sometimes siblings) questioning their ARV medication was identified as a reason for deciding to disclose to the child. In this regard, children started asking when they would stop having to take their medication and if they were ever going to get better. Some had previously suffered from HIV opportunistic infections such as TB and recovered (and thus no longer took medication for TB) and now they wanted to understand when they would also stop taking the ARV medication. This finding concurs with previous studies that indicate that one of the factors which drive parents to disclosing the child's status is the child's constant questioning regarding the medication they are taking (Brown et al., 2011).

### **5.5.2 Clinicians pushing for disclosure**

Participants also reported being encouraged by the clinic staff such as the doctors, nurses or counsellors to disclose to their children. Clinic staff seems to play an important role in making the caregiver aware of the importance of disclosing to their children as some might have not seen the importance of disclosing at the time. Some were reported to also help and support the caregiver with disclosing to the child. This finding concurs with previous literature that suggests that clinic staff play an important role in assisting with disclosure to children (Klitzman et al., 2008).

In as much as the participants reported disclosure being a difficult task to undertake, it seems as though the clinicians assisted in making the process easier for most of the participants, as they reported the clinicians had encouraged them to disclose. This is also evident in prior literature as it was reported that most of the disclosure to a child by the caregiver is facilitated



by a clinician (either a nurse, doctor or counsellor), which was evident in the study. According to Klitzman et al. (2008), when disclosure-related disagreements happen, especially when a healthcare worker suggests the need for the child to receive disclosure of their HIV-positive status and the caregiver does not want to disclose, serious ethical matters emerge. Even when caregivers and healthcare workers agree that it is the right time to start talking about HIV with the child, questions can still come up as to how to disclose, for instance, in terms of what it is exactly should be communicated. Clinicians often need assistance with these challenges, and guidelines for both parents and caregiver can be b.

This shows that clinicians have a greater responsibility not only in telling the participants their status but also in assisting them with what comes after in terms of the child being aware of their status (Wiener et al., 2007). More research needs to be done in this area.

### **5.5.3 Government policies influencing disclosure**

Some of the participants reported that South African policies which protect children's rights were also influential in promoting disclosure, such as Chapter 11 in the National Policy of HIV/AIDS (Department of Education, 1999) and the child's right to health. The children's rights demand that children have the right to know about their health and HIV status. It is the South African rights of children that influenced some caregivers to disclose to their children, as they do not want to violate any of their children's rights or the South African Law. This goes to show that the policies which are at the macrosystem level have significant impact in the decision of the caregivers to disclose their children living with HIV.

## **5.6 Impact of disclosure**

There are different consequences to disclosure and, for the most part, the consequences are positive, specifically, regarding the child's health and their relationship with their caregivers. The caregivers reported experiencing relief, improved treatment adherence on the part of the child and greater emphasis on secrecy; these are discussed in detail below.

### **5.6.1 Caregiver relief**

All of the participants reported experiencing relief after disclosing to their children their HIV-positive status, as they were no longer hiding anything from their children and they could work together in maintaining positive health outcomes for the children and themselves. Previous studies also found that caregivers are more than willing to share the responsibility of

adherence with the child after disclosure (Vreeman et al., 2013). Furthermore, Vreeman et al. (2013) found that disclosure reduced stress and improved well-being in caregivers as they no longer had to come up with different excuses for why the child had to continually take medication and constantly needed to go to the clinic (Vreeman et al., 2010). Murphy (2008) also found that parents who had disclosed their child's HIV-positive status had significantly lower levels of depression and anxiety compared to those who had not disclosed to their child. Benefits to the child have also been reported in previous studies, with children who have received disclosure found to report lower levels of anxiety compared to those who had not received disclosure (Santamaria et al., 2011).

### **5.6.2 Improvement in adherence**

Most of the caregivers reported that disclosure not only led to children understanding their illness better, but also assisted in making the child more willing to take their pills, thus improving the child's ART adherence. Participants indicated that, after disclosure, the child also remembered their time for taking treatment and no longer needed to be reminded, which contributed positively to their adherence level. This finding concurs with previous studies which showed that the level of adherence to treatment improves in children who have their status disclosed to them, as they understand the reason for the continuous treatment they are taking and are more motivated to take the treatment (Krauss et al., Vas et al., 2011; Vreeman et al., 2010).

It is clear that delaying the process of initial disclosure may lead to an undesirable result for the HIV-infected child. There may be issues with regard to treatment adherence as the child may not understand the reason behind the treatment they are taking and therefore may not participate responsibly in taking treatment (Campbell et al., 2012).

Notwithstanding the above finding that is supported by the literature, not all of the participants reported that disclosure led to improved treatment adherence; one participant reported that, after disclosure, her child cried and continued to be uneasy about taking the medication.

### **5.6.3 Emphasis on secrecy**

In as much as most of the participants reported a reduction in stigma and discrimination in the community after disclosure, participants still seemed to emphasise the importance of

maintaining secrecy after disclosure to the HIV-infected children. In order to protect themselves from potential stigma and discrimination, the child was advised to keep their status a secret from those who were not aware of it; this could be the school, friends, etc. As discussed previously, stigma and discrimination were identified as a barrier to disclosure in this and other studies (Kouyoumdajan et al., 2005; Rwemisisi et al., 2008; Woldemariam, 2012). All of the caregivers reported informing the child of non-disclosure to other people, which is why most of the participants reported considering the child's age and their cognitive development when it came to choosing when to disclose to them.

This chapter discussed the findings of the study in relation to the literature. It also describes the study's limitations and provides recommendations which could be useful for policy makers as well as programme developers working in the field of HIV/AIDS. The aim would be to contribute to developing and designing policies aimed at improving the level as well as the impact of disclosure and providing national guidelines to disclosure. It also provides recommendations which will assist in future research on HIV/AIDS disclosure.

## 5.8 Conclusions

In as much as South Africa seems to be working hard and providing ART treatment to a large number of people infected with HIV and prolonging the lives of many, South Africa is still faced with many challenges, having the world's largest antiretroviral therapy (ART) programme, with approximately 3 million people on ART by 2015 (WHO, 2015). The country is currently faced with the new challenge of how to assist and support caregivers of peri-natally infected children with the process of disclosure. Although there are national policies in place for the protection of HIV-infected individuals, there are no policies which deal specifically with the issues of disclosure to HIV-infected children and also provide the caregiver of peri-natally infected children with a guide on how to disclose. This study was conducted in KwaZulu-Natal which is the area faced with the largest HIV infection rate in the country, with approximately 40% of the South African population living with HIV located in the province (AVERT, 2016).

The aim of this study was to explore the experiences of the caregivers of HIV-positive children regarding the process of disclosing their status to the HIV-positive child, and to develop an understanding of those factors that promote, hinder and impact on the child's overall well-being. This study provides information to support policy makers in addressing interventions aimed at assisting with HIV/AIDS disclosure to HIV-positive children. The key aspects this research aimed to answer were:

- To understand levels of awareness of children's HIV-positive status in the sample.
- To understand factors that helped to promote HIV status disclosure to the infected child.
- To understand factors considered to hinder HIV status disclosure to the infected child.
- To understand the impact of HIV disclosure on the child's psychosocial well-being.

For the participants, disclosure was not an easy process to undertake; it takes a great deal of thought and consideration of multiple factors before the decision to disclose is made. For the participants, disclosure was not a once-off task but was something that was ongoing and dependent on the child's cognitive and socio-emotional development.

Participants who were the biological caregivers reported learning of the child's HIV-positive status when the child started getting sick. This should not be the case given that, in South

Africa, pregnant women are offered HIV counselling and testing services while they are pregnant and the child is also tested when it is born. For the participants to report only attaining knowledge of their HIV-positive status and the child's HIV-positive status when the child started getting sick raises a number of questions. These include the hospital/clinic's capacity to follow guidelines and procedures in providing appropriate healthcare services to patients and in this case, specifically to pregnant women. In this regard, a participant reported being tested with their child multiple times but never receiving their HIV test results. It is recommended that clinic staff is provided with systematic refresher training and quality-improvement measures to ensure adherence to guidelines.

The participants reported different factors which assisted in promoting disclosure such as the child's age, child's questioning of medication/treatment, and clinicians encouraging disclosure. These factors are also identified by previous studies (Lester et al., 2002; Vreeman et al., 2013) to be the key influencers of disclosure. In particular, it seems that, for the majority of the participants, clinicians encouraging disclosure was a key driver of the participant's decision to disclose. This shows that the role of the clinic staff such as nurses and doctors goes beyond giving results and providing counselling, in that they also assist caregivers in the process of disclosure to the HIV-infected child. Therefore, it is recommended that the clinic staff be equipped with the necessary skills to provide caregivers of peri-natally infected children with accurate and correct assistance on how to go about disclosing to their HIV-infected child.

The second most reported factor which influenced disclosure was that of the child's age. Most of the participants reported needing to tell the child of their HIV-positive status because of the child's questioning, as well as the child entering the pre-adolescent phase of development. This stage is a precursor to adolescence, which is associated with dating and possible sexual intercourse. Caregivers were concerned that children of this age be aware of their HIV-positive status and know the precautions that they need to take. This also suggests the need for providing caregivers with guidelines on how to disclose to the child and talk about high-risk behaviours in accordance with the child's age and their psychological development, without them feeling uncomfortable or uncertain as to what they are doing.

In as much as there were multiple factors reported that served to promote disclosure, participants also reported multiple factors which hindered disclosure. These included the

guilt, shame and embarrassment of the caregiver; difficulties in communication; and stigma and discrimination. The two factors which came up most strongly as hindering disclosure were fear of stigma and discrimination and the guilt, shame and embarrassment of the caregiver.

Participant responses were, however, contradictory on the issue of stigma and discrimination as, while they reported having fear of stigma and discrimination, they also reported that the community was accepting of people living with HIV/AIDS. While stigma and discrimination may be slowly subsiding with the rollout of ART, it is, however; obviously still an issue, highlighting the importance of the need for the development and implementation of enduring and effective anti-stigma interventions (Kuhn et al., 1994; Norr et al., 2004; Pital et al., 2007).

From the participants' responses, it seems that disclosure leads to more positive than negative outcomes, as the caregivers expressed no regrets about their decision to disclose to their children. It also reportedly provided relief for them and promoted greater participation of the child in adhering to their treatment regime. Disclosure also seemed to provide the child with an insight into their health, empowering them to contribute actively to their well-being. These findings highlight the importance of developmentally appropriate disclosure and the need for policies and tools which support disclosure.

### **5.9 Limitations of the study**

1. A limitation of this study is that it does not include the views of the children themselves regarding their health, as only the children's caregivers were interviewed in this study.
2. It is important to mention that the participants in this study represent a small section of the population from a specific context and location, which does not allow for generalisability.

### **5.10 Recommendations for future research**

- With regard to disclosure having an impact on improved adherence, it would be interesting to explore this in a larger study, making use of quantitative methods, on whether adherence level improves after disclosure to the child and possibly looking at the child's medical records before and after disclosure.
- It would be worthwhile to provide caregivers with guidelines on HIV disclosure to infected children and evaluate the impact for both the caregiver and the child of making use of the guidelines.

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## Appendice A



20 November 2014

Miss Zinhle Sokhela  
J 2005 Umhazl  
Bophela Road  
[zinhlesokhela@gmail.com](mailto:zinhlesokhela@gmail.com)

Dear Miss Sokhela

**PROTOCOL: Understanding the effects of disclosure to HIV positive children: Degree Purpose (Masters). BREC REF: BE415/14.**

### EXPEDITED APPLICATION

A sub-committee of the Biomedical Research Ethics Committee has considered and noted your application received on 03 September 2014.

The study was provisionally approved pending appropriate responses to queries raised. Your responses received on 12 November 2014 to queries raised on 22 October 2014 have been noted by a sub-committee of the Biomedical Research Ethics Committee. The conditions have now been met and the study is given full ethics approval.

This approval is valid for one year from 20 November 2014. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2004), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

The sub-committee's decision will be **RATIFIED** by a full Committee at its meeting taking place on 09 December 2014.

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely

Professor D.R. Wassenaar  
Chair: Biomedical Research Ethics Committee

Biomedical Research Ethics Committee  
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## Appendice B

### Interview schedule

#### Interview schedule (VUKA members) - Caregiver (Questions of the Caregiver)

##### Section 1: Demographics

- 1.1. How old is your child?
1. 2. Where do you stay?
- 1.3. How many members live in your home? (Specify)

##### Section 2: background information

- 2.1. What is your relationship to the child?
- 2.2. At what age did you disclose your child's status to him/her?
- 2.3. Is it easy to communicate with your child?

##### Section 3: HIV positive status awareness

- 3.1. Are you the person who mostly talks to your child about their health?
- 3.2. How did you get to know your child's HIV+ status, and how old was the child?
- 3.3. Who else knows about your child's HIV status in the household?

##### Section 4: addresses issues related to factors that promote hinder and benefits of disclosure.

- 4.1 What factors helped you to decide to disclose to your child (age, others talking about it, child asking questions, etc.)

*Probe: How comfortable are you to talk to your child about HIV and other sensitive topics such as sex?*

*Is there acceptance of people with HIV/AIDS in the community / school level?*

*Is there better acceptance of HIV positive people as a result of Anti-retroviral treatment?*

- 4.2. What made it difficult to disclose? (Probe: Do you blame yourself – explore why (infected through mother)?

***Probe: Did your relationship with your child influence your experience of difficulty in disclosing?***

***Did the community's attitudes towards HIV make it difficult to disclose?***

***Was the lack of acceptance of HIV positive people even after the availability of ART influence in the difficulty of disclosing?***

***Does stigma surrounding HIV in the community made it hard for you to disclose to your child?***

**4.3. How did you prepare your child before disclosing? (like cooking your child's favourite foods, gifts, making sure that the child felt loved)**

***Probe: How did they react when you told them that they were HIV+?***

***What questions did they ask after disclosure?***

**4.4. Has disclosing benefited you, the child and/or the family? In what way?**

***Probe: How has disclosing benefited your relationship with your child?***

***How has disclosing benefited your relationship with your neighbours?***

***How has disclosing benefited the child's relationship with friends?***

***How has disclosing benefited the child in the school environment?***

**4.5. Do you have any regrets about disclosing?**

## **ZULU Version interview schedule**

### **Section 1: Demographics**

**1.1. Ineminyaka emingaki ingane yakho?**

**2.2. Uhlala kuphi nendawo?**

**2.3. Bangaki abantu enihlala nabo ekhaya?**

### **Section 2: background information**

**2.1. Ungubani wena kumntwana?**

**2.2. Ingane wayazisa nge status sayo ineminyaka emingaki?**

**2.3. Ngabe kulula ukuxoxisana nengane yakho?**

### **Section 3: HIV positive status awareness**

**3.1. Ngabe uwena umuntu ovame ukuxoxisana nengane yakho ngezinto ezimayelane ngempilo yakhe?**

**3.2. Wazi kanjani ukuthi ingane yakho inesifo sengculazi, ingane yona yayineminyaka emingaki?**

**3.3. Ngabe ubani omunye ekhaya enihlala nayo owazinyo ngestatus somntwana?**

**Section 4: izinto ezikwenza kube lula noma kube nzima ukutshela ingane ngeHIV+ status sayo.**

**4.1. Ngabe yini eyakusiza ukuthi utshela ingane yakho nge HIV positive status sayo (iminyaka, abantu babekhuluma ngakho, ingane eyeyinemibuzo, etc.)?**

**Probe: ukhululeke kangakanani ukukhukluma nengane yakho nge HIV kanye nezinye izindaba ezifana nezocansi?**

- **Ngabe bamukelekile yini emphakathini wenu kanye nasezikoleni abantu abane HIV/AIDS?**
- **Ngabe abantu sebamukeleka kalula njeba sekukhona amaARVS?**

**4.2. Ngabe yini eyakwenza kwaba nzima ukutshela ingane nge HIV+ status sayo? (Probe: ngabe uzisola wena- ngobani? Ngabe yayithola kumama)**

**Probe: ngabe ukuxhumana kwakho nengane yakho kwaba nomthelela ekwenzeni kube nzima ukuyitshela nge HIV+ status sayo?**

- **Ngabe indlela abantu abayiyo mayelana ne HIV/AIDS kwenze kwaba nzima ukuyitshela ingane nge status sayo?**
- **Ngabe abantu abane HIV/AIDs emphakathini abamukelekile ngisho kukhona ama ARVS, ngabe yikho lokhu okwenza kwaba nzima ukutshela ingane nge status sayo?**
- **Ngabe indlela abantu emphakathii abayibona ngayo IHIV/AIDS yenze kwaba nzima ukutshela ingane nge status sayo?**

**4.3. Ngabe wayilungiselela kanjani ingane yakho ngaphambi kokuba uyitshela nge status sayo? (ngabe wayiphekela ukudla ekuthandayo, wayithengela isipho, ngabe wayitshengisa uthando kakhulu)**

**Probe: wenzanjani umntwana ngenkathi umutshena ukuthi unegciwane lengculazi?**

- **Ngabe ingane yabuza miphi imibuzo usuyitshelile nge status sayo?**

**4.4. ngabe ukutshena ingane nge status sayo kube nomthelelo omuhle kuwena, enganeni kanye nasezindabeni? Kanjani?**

**Probe:Ngabe ukutshena ingane yakho nge status sayo kube nomthelelo omuhle kubudlelwane bakho nengane?**

- **Ngabe ukuphemela kube nomthelelo onjani kubudlelwane bakho nomakhelwane?**
- **Ngabe ukutshela ingane nge HIV+status sayo kube nomthelela muni kubudlelwane bengane nabangani bayo?**
- **Ngabe ukutshela ingane nge HIV+status sayo kube nomthelela muni kwingane endaweni yesikole?**

**5. Ngabe uyazisola ngokutshela umntwana ukuthu unesandulela ngculazi?**

## Appendice C

### Consent to Enrol

I, \_\_\_\_\_ agree to participate in the research study on the Impact of disclosure in Family. I have received and understood the study information sheet. I have discussed the advantages and disadvantages of participating in the study. In agreeing to participate I am aware that:

- I will be asked to answer a number of questions about my experiences of disclosing to my child.
- I will also be asked to participate in an audio-recorded interview about the impacts and assisting and inhibiting factors of disclosure.

I know I can leave the research study at any time without prejudice.

Signature: \_\_\_\_\_

Name: \_\_\_\_\_

Date: \_\_\_\_\_

#### Witness 1

Signature: \_\_\_\_\_

Name: \_\_\_\_\_

Date: \_\_\_\_\_

#### Witness 2

Signature: \_\_\_\_\_

Name: \_\_\_\_\_

Date: \_\_\_\_\_

You may keep one copy of this form. The other copy will remain in our study files.

### Permission for audio recording

#### Understanding the effects of disclosure to HIV positive children

The researcher conducting the study requests to record the interview for purposes of the study and also for reference while continuing with this study. The recording will only be done with permission from the participant. If you do grant permission to be recorded, you have the right to change your mind about being recorded at any time.

I hereby grant permission for the interview to be  recorded

I do not grant permission for recording

In the event that permission is not granted, the researcher will need to make written notes for the documentation of the interview

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**Signature of participant**  
**Appendice D**



24 February 2015

Prof A Bhana  
c/o Prof I Petersen  
School of Applied Human Sciences  
Howard College  
[peterseni@ukzn.ac.za](mailto:peterseni@ukzn.ac.za)

Dear Prof Bhana

PROTOCOL: YUKA family Programme: Supporting Health and Behaviour of South African  
HIV+ Youth: BREC REF NO.: BF429/13

**RECERTIFICATION APPLICATION APPROVAL NOTICE**

Approved: 24 December 2014  
Expiration of Ethical Approval: 23 December 2015

I wish to advise you that your application for Recertification dated 28 January 2015 for the above protocol has been noted and approved by the Biomedical Research Ethics Committee (BREC) at a meeting that took place on 10 February 2015 for another approval period. The start and end dates of this period are indicated above.

If any modifications or adverse events occur in the project before your next scheduled review, you must submit them to BREC for review. Except in emergency situations, no change to the protocol may be implemented until you have received written BREC approval for the change.

Yours sincerely

Mrs A Marimuthu  
Senior Administrator: Biomedical Research Ethics

## Appendice E



health

Department:  
Health  
PROVINCE OF KWAZULU-NATAL

Health Research & Knowledge Management sub-component  
10 – 103 Natalia Building, 330 Langalibelele Street  
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3200  
Tel: 033 – 3953189  
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Email : [hrkm@kznhealth.gov.za](mailto:hrkm@kznhealth.gov.za)  
[www.kznhealth.gov.za](http://www.kznhealth.gov.za)

Reference : HRKM 053/13  
Enquiries : Mr X Xaba  
Tel : 033 – 395 2805

Dear Drs A Bhana and M. McKay

**Subject: Approval of a Research Proposal**

1. The research proposal titled 'The VUKA Family Program' was reviewed by the KwaZulu-Natal Department of Health.

The proposal is hereby **approved** for research to be undertaken at RK Khan and Prince Mshiyeni Memorial Hospital. Two other clinics will be identified with the National Department of Health.

2. You are requested to take note of the following:
  - a. Make the necessary arrangement with the identified facility before commencing with your research project.
  - b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.
3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to [hrkm@kznhealth.gov.za](mailto:hrkm@kznhealth.gov.za)

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

**Dr E Lutge**

Chairperson, Health Research Committee

Date: 07/04/2013

uMnyango Wezempilo . Departement van Gesondheid

*Fighting Disease, Fighting Poverty, Giving Hope*

