

**DISLOSURE OF HIV STATUS TO INFECTED CHILDREN IN SWAZILAND**

by

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submitted in accordance with the requirements

for the degree of

**MASTER OF ARTS**

in

**NURSING SCIENCE**

at the

**UNIVERSITY OF SOUTH AFRICA**

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NOVEMBER 2016

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### DECLARATION

I declare that **DISCLOSURE OF HIV STATUS TO INFECTED CHILDREN IN SWAZILAND** is my own work and that all sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.



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## **DISCLOSURE OF HIV STATUS TO INFECTED CHILDREN IN SWAZILAND**

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### **ABSTRACT**

The purpose of this study was to develop support guidelines to assist with disclosure of HIV status to HIV infected children by their parents and caregivers in Swaziland. The study explored parents' and caregivers' experiences with disclosure, and described the pattern of disclosure for HIV status to infected children. A qualitative descriptive research was conducted. Data were collected through semi-structured with thirteen (13) parents and caregivers who were purposively selected to participate in the study. Data analysis was done using qualitative content analysis. Three themes emerged which were understanding the general concept of disclosure, the pattern followed by parents and caregivers on disclosure of HIV status to infected children and the experiences of parents and caregivers on HIV status disclosure to their children. Based on the findings, support guidelines were formulated to assist parents and caregivers with disclosure of HIV status to their infected children. The outcome of this study is the description of a clear pattern of when, how and what to be disclosed to HIV infected children; as described by the parents and caregivers of the HIV positive children.

### **KEY CONCEPTS**

Caregiver; child; disclosure of HIV status; experience of disclosure; parent; pattern of disclosure.

## **ACKNOWLEDGEMENTS**

I am humbled by the grace of the Almighty God, who granted me and the strength to do this work. Thank you Lord.

I wish to express my sincere gratitude to the following people for making this study a success:

- My supervisor, Professor MC Matlakala, who patiently and dedicatedly worked with me to produce this study. Her guidance and tolerance will ever be appreciated.
- The hospital authorities, who granted me permission to interview their clients.
- My family and friends for the love, support, and encouragement they gave to me during this journey of my research.
- My two children, Nosisa and Sabusiswa, for the support and understanding when I was too busy for them.

## *Dedication*

*I humbly dedicate this work to the Almighty God for the good health, and a sound mind He granted me in order for this work to be completed.*

*In memory of my late husband who encouraged me to pursue my studies against all odds.*

*To my beloved children, Nosisa and Sabusiswa, for their love, support and understanding when I had less time with them.*

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**LIST OF ABBREVIATIONS**

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-retroviral therapy
HCW	Health Care Workers
HIV	Human Immunodeficiency Virus
MTCT	Mother-to-Child Transmission of HIV
NARTIS	Nurse-led ART initiation strategy
PMTCT	Prevention of Mother-to-Child Transmission of HIV
PIHTC	Provider initiated HIV testing and counselling
SDHS	Swaziland Demographic Health Survey
UNAIDS	United Nations Joint Program for HIV/AIDS
WHO	World Health Organization

# CHAPTER 1

## ORIENTATION OF THE STUDY

### 1.1 INTRODUCTION

Human Immunodeficiency Virus (HIV) infection in Swaziland was identified for the first time in 1986 and the first Acquired Immune Deficiency Syndrome (AIDS) case in 1987 UNAIDS (2014). Since that time, the number of persons living with HIV and AIDS has increased rapidly throughout the population. Data from the National HIV Sentinel Surveys of women attending antenatal clinics are currently used to provide estimates of HIV prevalence and trends. Swaziland has the highest HIV prevalence in the world, with 27% of their population living with HIV. In 2013, 11,000 people were newly infected with HIV and just over 4,500 people died of an AIDS-related illness. According to UNAIDS (2014) in Swaziland women are disproportionately affected by the HIV epidemic whereby of the 200,000 people living with HIV, 110,000 are women.

According to the Swaziland integrated HIV management guideline (WHO 2015), Swaziland is at a tipping point with regards to turning the tide against HIV epidemic. This is due to successful implementation of the 2010 HIV guidelines, which focused on extensive decentralisation of HIV services especially antiretroviral therapy (ART). This has been made possible by the implementation of Nurse-led ART initiation (NARTIS), provider initiated testing and counselling (PIHTC), and the prevention of mother-to-child transmission (PMTCT) of HIV. It is evident that antiretroviral therapy has been identified as one of the interventions that can help lower the risk of HIV transmission from one person to another. This is true with pregnant women in reducing the risk of perinatal HIV transmission to infants.

HIV disclosure may be perceived as simply the process of revealing a person's HIV status, whether positive or negative. HIV status is usually disclosed voluntarily by the index person, but it can also be revealed by others with or without the other person's consent (Xiaming, De Wit, Qiao & Sherr 2015:S2). In the case of children who are HIV positive, the researcher believes that disclosure decisions lie with the parent or caregiver in collaboration with the health care workers. According to the Swaziland

Ministry of Health (MOH) (2015), integrated HIV guidelines disclosure is paramount in the management and care of HIV. It is a worldwide fact from statistics that HIV affects both adults and children because of its mode of transmission, Swaziland inclusive. Disclosure is not only important for children but even adults are encouraged to disclose their HIV status to significant others especially their families and partners. In Swaziland the practise is that prior to initiation of antiretroviral therapy (ART) the client should bring with a treatment supporter to the clinic. This treatment supporter should be someone trusted by the client and should be aware of the HIV status of the concerned client (MOH 2015).

## **1.2 BACKGROUND TO THE RESEARCH PROBLEM**

Swaziland is divided into four administrative regions, namely, Hhohho, where the capital city Mbabane and Government ministries are located; Manzini which contains the largest industrial site in the country; Lubombo, where most of the agricultural plantations are found and the region where this research study was conducted; lastly, Shiselweni which is the least developed region. The country is further subdivided into 55 constituencies for political purposes. Swaziland is a kingdom observing Christianity as the main religion and culture is preserved. According to the Swaziland demographic Health Survey (SDHS) (2007), Hhohho region has the highest prevalence of HIV at 29% among the population between 15-49 years. The second highest is the Lubombo region at 26%, followed by Manzini region with a prevalence of 25%. Shiselweni region has a least HIV prevalence at 23%. The SHDS (2007) further states that HIV prevalence in Swaziland is higher in urban areas than rural areas at 31% and 24 % respectively.

In Swaziland, there is the culture of reed cutting for the youth girls and boys who do not have children whereby they sleep together in the tents and bath together. There is totally no privacy in such occasions, and children who are on HIV medication without their knowledge may feel embarrassed to be told by other children that the medication they are taking is antiretroviral therapy (ART).

In this case, disclosure may take place in an inappropriate manner and by the wrong person. This may negatively affect the child psychologically, emotionally, and socially. The problem is that, peer pressure has no exceptions on HIV status. HIV infected adolescents may engage in unprotected sexual encounters during these cultural

ceremonies and infect their partners. The adolescent's knowledge of his or her HIV status may reduce the spread since protection is most likely to be used if one is HIV infected. Disclosure is crucial based on the cognitive level of development (Cantrell, Patel, Mandrell & Grissom 2013:302) There is paucity of information on how parents and caregivers disclose the HIV status to their HIV infected children and their experiences on disclosure in Swaziland.

Informing children of their HIV status is an important aspect of long-term disease management. Disclosure poses challenges to the health care workers (HCWs) and the parents or caregivers of HIV-infected children (John-Stewart, Wariuna, Beima-Sofie, Richardson, Farquhar, Maleche-Obimbo, Mbori-Ngacha & Wamalwa 2013:1067). The argument based on this background is that, despite the emerging evidence of the benefits of disclosure, when and how to disclose the status to infected children by their parents or caregivers remains a dilemma. According to Zamberia and Mabundza (2014:124); and Vreeman, Nyandiko, Ayaya, Walumbe and Inui (2013:466) disclosure increases the child's adherence to medication and access to social support. Kimani-Murage, Manderson, Norris and Kahn (2013:744) point to the challenges facing caregivers with the complicated decision of disclosure to children. This includes; stigma behaviours associated with transmission routes, parents or caregiver's feelings of shame and their fear of inadvertent disclosure of family sickness. The above mentioned reasons make most HIV infected individuals to keep their HIV status their little secret. Children on the other hand may not have the capacity to handle this as adults may be in similar situations (Kimani-Murage et al 2013:744).

### **1.3 STATEMENT OF THE RESEARCH PROBLEM**

A study conducted in Northwest Ethiopia on HIV positive status disclosure and associated factors among children shows that one of the most difficult issues that families with HIV-infected children face is when and how to talk about HIV to their children (Cantrell et al 2013:302). The authors further state that disclosure should take place in a supportive environment with collaboration and cooperation among caregivers and health care providers; and that disclosure is contingent on the caregiver's knowledge of the illness, the readiness to disclose, and the child's cognitive skills and emotional maturity (Cantrell et al 2013:310). In another study on patterns of HIV-status disclosure to infected children conducted in a Sub-Saharan Africa, Democratic Republic

of Congo, Ishikawa, Ishigaki, Ghidinelli, Ikeda, Honda, Miyamoto, Kakimoto and Oka (2011:413) state that adult caregivers provide children living with HIV varying amounts and types of information about their health status that may affect their coping and health care behaviours.

In Swaziland, there are no support guidelines that are in the cultural context of Swazis on HIV status disclosure to infected children by their parents or caregivers. The use of antiretroviral therapy has become widely available in developing countries including Swaziland. This increases the numbers of HIV infected children surviving into adolescence and beyond. As they grow older, they need to know the facts about the disease and the treatment. Adolescents start engaging in sexual practises and infect others without knowing it, thus spreading the disease in the country. HIV disclosure entails communication about a potentially life-threatening, stigmatised, and transmissible illness. Generally, parents and caregivers tend to give vague information to the infected child on the disease and treatment; hence adherence to treatment is affected. Some parents lack competency on disclosure as to when, how and what information to give to the infected child. There is limited research studies that have been done in Swaziland to explore the parents and caregivers' experiences with disclosure of HIV to their infected children.

#### **1.4 RESEARCH PURPOSE**

The purpose of this study was to develop support guidelines that will assist with disclosure to HIV infected children by their parents or caregivers in Swaziland.

#### **1.5 RESEARCH OBJECTIVES**

A research objective is a concrete, measurable end towards which effort or ambition is directed (Brink, Van der Walt & Van Rensburg 2014:85). The objectives of this study were to

- explore the concept of disclosure of HIV status to infected children in Swaziland
- describe the pattern of disclosure of HIV status to infected children and adolescents in Swaziland

- explore the experiences of parents and caregivers regarding disclosure of HIV status to their children

### **1.5.1 Research questions**

The research questions were based on the objectives of the study and were as follows:

- What is the meaning of the concept of disclosure of HIV status to infected children?
- How do parents and caregivers disclose the HIV positive status to their children in Swaziland?
- What are the experiences of parents and caregivers on disclosure of HIV status to their infected children in Swaziland?

### **1.6 SIGNIFICANCE OF THE STUDY**

Disclosure of HIV positive status to children is an important aspect of paediatric HIV/AIDS treatment and support; and the parent or caregiver is the most important person in the disclosure process. Therefore it is crucial that the parent or caregiver must know when, how, and what to disclose to the infected child. It is believed that disclosure has more benefits than disadvantages to the client, family and health care workers. The significance of this study was to find a clear pattern on when, how and what should be disclosed to infected children and adolescents on their HIV status. The experiences of parents and caregivers regarding disclosure of HIV status to their infected children were noted and guidelines to assist them on disclosure of HIV status to infected children were formulated.

The guidelines may give an insight on how to help parents or caregivers with disclosure in the near future. The reality of HIV disclosure to the infected child or adolescent was established as parents and caregivers shared their experiences with disclosure in a real situation. Benefits of disclosure were stated and the barriers. Support guidelines which are congruent were formulated to specifically address the issue of disclosure of HIV status.



## **1.7 DEFINITIONS OF KEY CONCEPTS**

According to Grove, Burns and Gray (2013:689), a concept is a term that abstractly describes and names an object or phenomenon, thus providing it with a separate identity or meaning. The researcher believes that concepts are important terms that forms the major aspect of the research study. It is important to define concepts so that their right meaning in the study is clearly understood. One concept may have different meanings hence defining them gives the reader a clear understanding in the context. The following concepts are defined in the context of this study.

### **1.7.1 Caregiver**

A caregiver is someone who takes care of a person who is young, old, or sick (*Cambridge Online Dictionary* 2008). In this study the caregiver refers to a person formally dedicated to caring of the HIV positive child in the absence of a biological father or mother.

### **1.7.2 Disclosure of HIV status**

Disclosure refers to a fact that is made known (*Paperback Oxford English Dictionary* 2012:201). In this study, disclosure of HIV status means that the fact that is made known refers to the HIV status of an HIV positive child.

### **1.7.3 Experience of disclosure**

Experience refers to having undergone or been affected by a situation (*Paperback Oxford English Dictionary* 2012:249). The experience of disclosure in this study refers to the situation that is undergone by parents or caregivers during disclosure of the HIV status to their children.

### **1.7.4 Parent**

A parent in this study refers to a biological father or mother (*Paperback Oxford English Dictionary* 2012:521).

### **1.7.5 Pattern of HIV disclosure**

Pattern is a regular form or order in which a series of things occur (*Paperback Oxford English Dictionary* 2012:526). In this study pattern of HIV disclosure refers to the procedure or way in which information is imparted from parents to children who are HIV positive or the way in which children who are HIV positive are informed of their HIV status.

### **1.7.6 Prevalence of HIV**

Prevalence is the proportion of a population having a particular condition at a given point in time (Polit & Beck 2014:388). In this study the condition refers to HIV disease; thus the prevalence of HIV.

## **1.8 THEORETICAL FRAMEWORK**

A framework is an abstract, logical structure of meaning that guides the development of the study and links the findings of the body of knowledge (Grove et al 2013:116). Polit and Beck (2014:146) define a framework as the conceptual underpinning of a study, including an overall rationale and conceptual definitions of key concepts. A process-oriented framework for the disclosure of HIV status to infected children was used in this study. This framework incorporates Piaget's cognitive development theory in an attempt to disclose and assist children and adolescent in understanding their HIV status. This disclosure framework states that disclosure is based on the child and adolescent's developmental level to allow periods of integration of HIV/AIDS concepts. This framework stresses the importance of the ongoing education process leading to the disclosure of diagnosis and promoting adjustment. The framework is discussed further with the findings and guidelines in chapters 4 and 5.

## **1.9 THEORETICAL FOUNDATIONS OF THE STUDY**

The theoretical foundations of this study were based on the assumptions underlying the study. An assumption is a principle that is accepted as being true based on logic or reason, without proof (Polit & Beck 2014:374). The assumption underlying the study was that, parents and caregivers experience challenges with disclosure of HIV status to

their infected children in Swaziland due to lack of knowledge on when, how, and what to disclose. Other assumptions were as follows:

### **1.9.1 Ontological assumptions**

According to Polit and Beck (2014:14), ontological assumption refers to the basic philosophical questions of what the nature of reality is. The ontological assumption of this study was the nature of knowledge of parents and caregivers regarding disclosure of HIV status to their infected children. This study followed a realistic ontology in which the physical world of the researcher assumed the existence of the lived experience of parents and caregivers on HIV disclosure. Reality was that it is not easy to disclose information if one does not understand the concept of disclosure.

### **1.9.2 Meta-theoretical assumption**

The term 'meta-theory' refers to critical reflection on the nature of scientific inquiry. Meta-theoretical reflection typically addresses issues such as the nature and the structure of scientific theories, the nature of scientific growth, the meaning of truth, explanations and objectivity (Babbie & Mouton 2009:20). Meta-theoretical assumptions are interrelated sets of concepts, beliefs, commitments and propositions that constitute the study. Their origin is philosophical in nature, and therefore not meant to be tested. They denote commitment to the truth of the theories and laws of a particular paradigm. Creswell (2013:11) postulates that qualitative research focuses on the process occurring as well as the product. The assumptions that were made about disclosure of HIV status to children were that parents and caregivers do not know when and how to disclose the HIV status to their infected children.

### **1.9.3 Methodological assumptions**

Methodological assumptions refer to, how evidence is best obtained (Polit & Beck 2008:14). The methodological assumption of this study was based on the approach that would be followed to understand how parents and caregivers disclose the HIV status to their infected children in Swaziland. Qualitative research methodology was found to be relevant as it encompasses verbal and written conversations with the participants.

## **1.10 INTRODUCTION TO RESEARCH METHODOLOGY**

According to Polit and Beck (2014:390), research methods are the techniques used to structure a study and to gather and analyse information in a systematic fashion.

A qualitative approach was used and it provided an opportunity for the researcher to have an in-depth and holistic understanding about the phenomenon, by collecting rich narrative data. The researcher is able to probe during the interview; hence interpretation was enhanced (Polit & Beck 2014:270). In this study the phenomenon under investigation was disclosure of HIV status to infected children.

### **1.10.1 Research design**

A research design is the blue print for conducting a study. It maximises control over factors that could interfere with the validity of the study findings (Grove et al 2013:195). An exploratory and interpretive design was followed for this study. The goal of interpretivism was to identify the essence of human experience about the phenomenon as described by the participants. This design also focused on “lived meaning” of the phenomenon it investigated (Streubert & Carpenter 2011:84). In this study the researcher made sense of the experiences of parents and caregivers regarding disclosure of HIV status to their infected children.

### **1.10.2 Setting and population**

The study setting refers to the specific place or places where the data are collected (Brink et al 2014:59). The setting for this study was one referral hospital offering comprehensive HIV/AIDS care in the Lubombo region of Swaziland. This hospital is servicing over ten clinics in the region. It was the most ideal site for this study since the parents and caregivers were interviewed during theirs and their children’s monthly refills HIV medication.

According to Grove et al (2013:703), population refers to all individuals who meet the sample criteria for inclusion in a study. Polit and Beck (2014:387) describe population as the entire set of individuals or objects having some common characteristics. The population for this study comprised of parents and caregivers of HIV infected children

aged between 6 and 15 years who had disclosed or not yet disclosed the status to their children. Non probability purposive sampling was used to select the participants. More information on this is presented in chapter 3.

### **1.10.3 Data collection**

Data were collected through semi-structured individual interviews. The questions were designed in English, and then translated to SiSwati which is a local language in Swaziland with the help of a qualified language teacher. Probing was done by the researcher to get the desired information and focus was kept on the research topic and objectives. Respect for privacy and confidentiality was observed since the interviews were conducted with each individual with the researcher only in a private consultation room.

### **1.10.4 Data analysis**

According to Polit and Beck (2014:378), data analysis is the systematic organisation and synthesis of research data. Data analysis is conducted to reduce, organise, and give meaning to data (Grove et al 2013:691). Data analysis was done using qualitative content analysis to identify prominent themes and patterns among themes (Polit & Beck 2014:517).

## **1.11 ETHICAL CONSIDERATION**

The ethical principles of autonomy, beneficence, and non-maleficence were observed throughout the study. Ethical clearance was sought and obtained from the Higher Degrees Committee of the Department of Health Studies, Unisa (Annexure 1). Permission to conduct the study was sought from the hospital in writing (Annexure 2). After permission was granted (Annexure 5), the researcher got the names of the eligible participants through the assistance of the health care workers in the HIV/AIDS clinic. The participants were explained to about the purpose of the study and their expectations. The goals of the study were stated and how the data would be used. They were told about the type of data to be collected and the procedure to be followed. The estimated time for the interview was stated.

The participants were told that the study was for academic purposes and therefore, no incentives for participation. It was explained to them how they were selected from the legible population. They were assured that there would be no physical risk in this study; but that emotions may be triggered and psychological trauma which would be cared for by a dedicated psychologist. The participants were assured that confidentiality would be maintained with all data and complete anonymity was guaranteed. Their privacy was respected throughout. It was explained that participation was strictly voluntary and that they had the right to withdraw from the study anytime or to refuse to provide any specific information. The participants were provided with information of the researcher with information of the researcher to contact should they have any questions or comments.

### **1.12 MEASURES TO ENSURE TRUSTWORTHINESS**

Trustworthiness is the degrees of confidence qualitative researchers have in their data and is assessed using the criteria of: credibility, dependability, confirmability and transferability, and authenticity (Polit & Beck 2014:394). These five criteria were adopted in developing trustworthiness in this study and are discussed further in chapter 3.

### **1.13 ORGANISATION OF CHAPTERS**

The structure of the dissertation is as follows:

Chapter 1: Orientation to the study

Chapter 2: Literature review

Chapter 3: Research design and methods

Chapter 4: Analysis, presentation, and description of the research findings

Chapter 5: Conclusion and recommendations

### **1.14 CONCLUSION**

In this chapter, the introduction and background of the research problem was explained. The statement of the research problem, purpose, objectives, and research questions were stated. The significant of the study was explained and key concepts for this study were defined. The process-oriented framework for the disclosure of HIV status to

infected children or adolescents was introduced. The theoretical foundations of the study were explained and the methodology which was used. Ethical considerations which were followed in this study were introduced. The criteria for trustworthiness of this study were also introduced. The next chapter discussed literature review.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

In this chapter the literature review for this study is presented. According to Polit and Beck (2014:384), a literature review is a critical summary of research on a topic; often prepared to put a research problem in context or to summarise existing evidence. The purpose of the review is to generate a picture of what is known and not known about the research problem (Brink et al 2014:54). Literature review was conducted in order to locate existing similar or related studies on HIV disclosure to infected children. The literature served as a basis for this current study, and helped the researcher to develop a theoretical framework and appropriate study methods to use. This chapter aimed at determining what was identified by other researchers on disclosure of HIV status to infected children and adolescents internationally, regionally and locally. The discussion is on the empirical literature on HIV disclosure and the theoretical framework underpinning disclosure.

#### **2.2 HIV STATUS DISCLOSURE IN CHILDREN**

In the recent past years of HIV epidemic, the survival time of perinatally infected infants and children was short. Disclosure of their HIV positive status was not given close attention (Hazra, Siberry & Mofenson 2010:170). Disclosure to children is beneficial to their self-esteem, develop a sense of autonomy and empowerment, and help them to participate in their own medical treatment (WHO 2015:136).

#### **2.3 GLOBAL ISSUES ON HIV STATUS DISCLOSURE TO CHILDREN**

In a study conducted by Kennedy, Cowgill, Bogart, Corona, Ryan, Murphy, Nguyen and Schuster (2010:1101) in the United States of America on parents' disclosure of their HIV infection status to their children in the context of the family, the findings were that HIV positive parents were not always able to disclose to their children according to a plan. Instead, children often learnt about their parents' HIV status accidentally or through their



own observation. Ishikawa et al (2011:414) in a study on paediatric HIV and elimination of mother-to-child transmission of HIV in the Association of South East Asian Nations (ASEAN) region indicated that the challenges on paediatric HIV care, support and treatment were disclosure, adherence to treatment to the infected individual who is still a child. Sexual and reproductive health was a possible problem as and when infected children grow and develop into adolescents and into adulthood.

John-Stewart et al (2013:1069) in a study conducted in Kenya on prevalence, perception and correlates of paediatric HIV disclosure in an HIV treatment program, indicate that caregivers believed that children should know their HIV status. However, the prevalence of disclosure to the child was relatively low. This meant that even though they believed in disclosure, implementing it was a challenge. The common reasons for non-disclosure stated were similar for developed and developing countries, and were not limited to; cognitive development of the child, fear of the child disclosing to others, fear of discrimination, fear of the child experiencing depression, being blamed by the child, and not knowing how to disclose. The study further revealed that disclosure was done mostly by careworkers and parents or caregivers in some cases. Furthermore, disclosure was either complete or partial (John-Stewart et al 2013:1069).

A study conducted in Ghana by Kallem, Renner, Ghebremichael and Paintsil (2011:1124) on prevalence and pattern of disclosure of HIV status in HIV infected children showed that the disclosure rate was very low at 21%. According to Kallem et al (2011:1124), this disclosure rate was consistent with reported rates of disclosure from Thailand, Zambia and Uganda.

According to Madiba (2012a:325), in a study on the process, reasons and outcomes of disclosure of HIV infected children in South Africa there is a relatively low disclosure rate. Madiba (2012a:325) further revealed that non biological parents do not have to deal with most of the fears that biological parents have to first deal with on the issue of disclosure.

## **2.4 DISCLOSURE OF HIV STATUS IN SWAZILAND**

There is scarcity of information on disclosure of some illnesses including HIV in Swaziland. A study conducted by Root (2009:300) on religious participation and HIV-disclosure rationales among people living with HIV/AIDS in rural Swaziland showed that disclosure needs a variety of support systems to be done effectively. The church and their leaders were identified as important people in the community on disclosure of HIV status. However, nothing was mentioned on how they are prepared to professionally assist people living with HIV including children on disclosure (Root 2009:300).

The importance of disclosure in the management and care of HIV/AIDS in Swaziland was indicated in a study by Zamberia and Mabundza (2014:123) on the role of family members in HIV-positive status disclosure and antiretroviral therapy uptake in Swaziland. The authors found that people living with HIV assess the possibility of disclosure by considering how they would be viewed by members of their families, consider the fact that family members are the ones who ultimately have to care for them hence disclosure becomes necessary. Furthermore, a positive or negative evaluation of the outcome of the disclosure led to failure to disclose or being able to disclose (Zamberia & Mabundza 2014:131).

## **2.5 PERSPECTIVES ON DISCLOSURE OF HIV STATUS TO CHILDREN**

HIV status disclosure from parent to child is complex and challenging. This is seen in a study conducted by Gachanga Burkholder and Ferraro (2014:19) on HIV positive parents, HIV positive children, and HIV negative children's perspective on disclosure of a parent's and child's illness in Kenya. The purpose of this study was to understand the lived experiences of HIV positive parents and their children during the disclosure process in Kenya. Disclosure of HIV status to children is important for HIV positive parents but many are challenged by the disclosure process. The findings of this study showed that HIV disclosure is a process that moves a child from a state of nondisclosure to partial, and then full disclosure of illness (Gachanga et al 2014:20).

The findings of the study showed that, disclosure is a child's right and parent's decision. The parent needs to decide and be ready to fully disclose the HIV status to the child. HIV positive children were against being lied to about the illness by their parents

because it betrayed their trust. Disclosure is a process, and parents expressed that full disclosure to a child should be performed as a process and in stages. Parents preferred full disclosure of all illnesses in the family to older children. However, they stated that full disclosure of many family members' illnesses at the same time may be traumatic for children, worst with HIV/AIDS.

This study further showed that, even without full disclosure children may be aware of the disease and able to guess the nature of the illness. Since children develop and mature differently, the decision to fully disclose should be assessed individually. Young children would not understand the meaning of the HIV illness. They further stated that young children may not be able to keep the information a secret thereby exposing the family to stigma. Another challenge was who should perform disclosure to the infected child (Gachanga et al 2014:28).

## **2.6 HIV STATUS DISCLOSURE PREPARATION**

There is paucity of information on how parents and caregivers prepare for disclosure of HIV status to their children worldwide. In a study conducted by Gachanja, Burkholder and Ferraro (2014:24) on HIV positive parent account on disclosure preparation activities in Kenya, the four-phased model of HIV disclosure was used as a conceptual framework. The mentioned authors proposed that HIV parents go through four phases when preparing for full disclosure of illness to their children. The four phases are secrecy phase, exploratory phase, readiness phase, and full disclosure phase.

*Secrecy phase:* In this phase the parent needs to first accept their own diagnosis before they can tell it to their children. In the study, parents verbalised that full disclosure was a challenge hence; they needed to first contemplate, understand and accept the nature of their illness before disclosure to anyone including their children

*Exploratory Phase:* This is when parents have accepted their illness, they begin to explore how would fully disclose to their children. They make disclosure plans, considering family dynamics, and read information to teach children about the disease. Family dynamics requires a lead person during disclosure.

*Readiness Phase:* This is when parents perceive themselves as being ready to fully disclose and they judged their children as being receptive to the news. At this level they actively seek activities that would assist them to deliver the news.

*Full disclosure phase:* In this phase, the parent is ready to give full disclosure to the child after good preparation. Questions asked are answered truthfully and misconceptions about the disease are corrected (Gachanja et al 2014:25-28).

## **2.7 PATTERNS OF HIV STATUS DISCLOSURE TO CHILDREN**

A study conducted by Vaz, Mamam, Eng, Barbarin, Tshikandu and Behets (2011:310) on patterns of disclosure of HIV status to infected children in a Sub-Saharan Africa setting in Democratic Republic of Congo showed that there are various patterns of disclosure. These patterns of disclosure range from no information provided, deflecting information provided, partial information provided and full information provided.

*No information provided:* In this pattern nothing about the HIV illness or health status of the child is given even if questions are asked. General information is given to the child and questions are ignored.

*Deflecting information provided:* This is said to be whereby untrue information is given to the child and to be retracted later in order to provide HIV information. This is usually done intentionally by the parent.

*Partial information provided:* This is when information provides some insight on the HIV status even though HIV was not mentioned. For instance, statements encouraging the child to take medication or else they would die.

*Full information:* This is when the child is provided explicitly with the name of the illness he/she is suffering from. The path physiology, mode of transmission, and the importance of taking medication are fully explained. All questions asked are truthfully answered and support given (Vaz et al 2011:310-311).

## **2.8 BARRIERS TO HIV STATUS DISCLOSURE TO CHILDREN**

The reasons that parents and caregivers state for not disclosing the HIV status to the infected child clearly show the barriers to disclosure. Five of the commonly given reasons for non-disclosure were age too young, guilt, fear of emotional distress, stigma and discrimination, and lack of knowledge (Kallem et al 2011:1125; Jemmott, Heeren, Sidloyi, Mmarange, Tyler & Ngwane 2014:1028; Heeren, Jemmott, Sidloyi & Ngwane 2012:49).

One of the reasons parents and caregivers give for non-disclosure is that the child is too young, and so will not be able to understand the whole concept of HIV/AIDS. The mode of transmission of HIV from mother-to-child is the most route that 90% of children get infected (UNAIDS 2014). This makes the parent to be guilty of having infected an innocent child, hence disclosure becomes a challenge. Moreover, parents fear that the children will experience depression upon hearing their diagnosis and may lose their will to live. However, beyond the direct effects on children's neuro-cognitive and psychological functioning, HIV infection may disrupt many of the social support systems that children depend on for optimal development (Kennedy et al 2010:1101).

According to Kennedy et al (2010:1102) parents and caregivers have fear of social rejection and isolation, and fear of being judged as being promiscuous. Furthermore there is fear that the disclosure to the child will lead to inadvertent disclosure of their own status, leading to discrimination against the child and the whole family. Although many parents realised that the child has to be told, they felt helpless since they did not know how to do this in the least painful way possible (Kennedy et al 2010:1101-1102).

## **2.9 A PROCESS-ORIENTED DISCLOSURE FRAMEWORK**

This study used a process-oriented framework on paediatric HIV disclosure by Cantrell et al (2013:306). This framework incorporates Piaget's cognitive development theory in an attempt to disclose and assist children and adolescents in understanding their HIV status. This educational framework states that disclosure is based on the child and adolescent's developmental level to allow periods of integration of HIV/AIDS concepts. It stresses the importance of the ongoing education process leading to the disclosure of

diagnosis and promoting adjustment. HIV disclosure evolves as an ongoing dialogue across developmental stages with increasing details.

### **2.9.1 Disclosure and development**

According to Cantrell et al (2013:303), there is evidence that caregivers resist disclosure because of concerns about children's developmental readiness, inability to understand disease status and inability to understand the concept of chronic illness. Children's comprehension of their chronic disease status increases with age as they reframe illness information according to their cognitive development.

The World Health Organization (WHO) (2011) guidelines on HIV disclosure counselling for children up to 12 years of age recommends that, health care providers and caregivers should be proactive in creating an open and accepting environment for the child during initial stage of disclosure. The guidelines further indicate that it is important that the disclosure process proceed on a developmentally appropriate progression from childhood, through adolescence, and into adulthood. Full disclosure can be a successful experience if it is accurately mapped to the child's cognitive and emotional development, and seen as an ongoing process that evolves as the child develops psychological and spiritual awareness of illness and death (WHO 2011:27).

### **2.9.2 Development of children's concepts of illness based on Piagetian theory**

This theory comprises of three stages of development namely; the pre-operational stage, concrete operational stage and formal operational stage.

*Preoperational stage:* This is between 2 to 6 years of age. Piaget characterised this stage by pre-logical thinking, when children are unable to reason beyond their own environment. Because of this, at this stage, children may not be able to understand illness causation or conceptualise internal parts of the human body.

*Concrete operational stage:* This is between 7 and 10 years of age. Piaget characterised the concrete operational stage by concrete-logical reasoning, where children are able to make multiple connections of causation to a single phenomenon and can understand hierarchies. Children are able to identify an external cause as the

source of their illness identifying it as something 'bad'. At this stage, children are in a better position to understand illness.

*Formal Operational stage:* This is from age 11 years and above. Piaget characterised this stage by formal-logical thinking, where children begin to think hypothetically and abstractly. They can correlate multiple causations to illness, including external and internal factors related to their health (Cantrell et al 2013:307; WHO 2011:28).

## **2.10 DISCLOSURE AS A PROCESS RATHER THAN AN EVENT**

According to the WHO (2011:16) guidelines on HIV disclosure counselling for children up to 12 years of age, disclosure leads to extended discussions as the implications of having HIV in the family unfold. The guidelines state that such discussions do not occur as a discreet, one-time event, but they occur over time (WHO 2011:16). According to the guidelines, children have questions and worry about what will happen to them in the course of their own disease; and also worry about who will take care of them if their parent or caregiver is ill or dies. The guidelines further states that children get concerned on how HIV is transmitted so as to how they really got infected. Based on Piaget theory of cognitive development, children on the concrete and formal operational stages may be confronted by stigma, discrimination or bereavement on their HIV status. Disclosure is a process of many conversations over time and may call for information, reassurance and planning (WHO 2011:16).

## **2.11 CONCERNS ABOUT HIV STATUS DISCLOSURE PROCESS IN CHILDREN**

According to Cantrell et al (2013:304) the paediatric HIV disclosure process-oriented framework indicates that the main concerns on disclosure of HIV status to children are; the appropriate age for disclosure, who should disclose and how to disclose.

### ***2.11.1 Appropriate age for HIV status disclosure***

The paediatric HIV disclosure process-oriented framework Cantrell et al (2013:304) propose disclosure of HIV infection status to school-age children and recommends that adolescents should know their HIV status. According to the framework, child age is

significantly associated with disclosure; with older children being more likely to have been disclosed to.

### **2.11.2 Who should disclose**

The WHO (2011:13) indicates that a health care provider is needed to help parents and caregivers to tell their children about their status (WHO 2011:33). In a study conducted in India to determine the perception of HIV disclosure to children Arun (2009:805) indicates caregivers as appropriate to reveal the infection status. Another study conducted in Thailand indicates that the caregivers reported they prefer to be the ones to disclose the HIV/AIDS status to the child.

### **2.11.3 How to disclose**

According to the WHO (2011:16) disclosure needs to be a process rather than a single event that takes place over a period of time taking into account different phases of the child's life and ongoing communication with families. The WHO further indicates that the process may even last several years, depending on the cognitive development of the child. Therefore the importance of respect for family needs, wishes and expectations as well as community norms needs to be taken into consideration (WHO 2011:17).

## **2.12 CONCLUSION**

This chapter presented literature reviewed on disclosure of HIV status to infected children. The global issues on HIV disclosure, including of Swaziland were discussed. Perspectives, HIV disclosure preparations, patterns and barriers of HIV disclosure were also discussed. This chapter further discussed the process- oriented disclosure framework and presented disclosure as a process rather than an event. The concerns of HIV status disclosure in children were briefly discussed. The next chapter presents the research design and methods.



## **CHAPTER 3**

### **RESEARCH DESIGN AND METHOD**

#### **3.1 INTRODUCTION**

This chapter describes the methodology used in the study. Methodology refers to the steps, procedures and strategies for gathering and analysing data in a study (Polit & Beck 2014:385). Furthermore, the research design and methods followed which include the research population and sampling, data collection, management and analysis are explained. The ethical considerations and trustworthiness in the context of both the study design and methods to be used are discussed.

#### **3.2 RESEARCH DESIGN**

A research design is the blue print for conducting a study. The research design maximises control over factors that could interfere with the validity of the study findings (Grove et al 2013:195). An exploratory and interpretive design was followed for this study. The goal of interpretivism is to identify the essence of human experience about a phenomenon as described by the participants. Interpretivism also focuses on “lived meaning” of the phenomenon it investigates (Streubert & Carpenter 2011:84). In this study the researcher made sense of the experiences of parents and caregivers with disclosure of HIV status to their infected children.

#### **3.3 RESEARCH METHODS**

According to Polit and Beck (2014:390), research method refers to the techniques used to structure a study and to gather and analyse information in a systematic fashion.

#### **3.4 SETTING OF THE STUDY**

The study setting refers to the specific place or places where the data are collected (Brink et al 2014:59). For qualitative studies the researcher mostly collect data in a natural setting (Polit & Beck 2014:267). Natural settings are uncontrolled real life

settings where studies are conducted (Grove et al 2013:373). This study was conducted in one hospital, which is the only major referral hospital offering comprehensive HIV/AIDS care in the Lubombo region of Swaziland. This hospital is serving over ten clinics in the region. It was the most ideal site for this study since the parents and caregivers were interviewed during their visit for monthly refills of the children's HIV medication.

### **3.4.1 Population of the study**

Population is the entire set of individuals who have common characteristics (Polit & Beck 2014:387). According to Grove et al (2013:703), population refers to all elements that meet the sample criteria for inclusion in a study. In this study the population comprised of all parents and caregivers of HIV infected children between the ages of 6 and 15 years who have disclosed and not yet disclosed the HIV status to the child.

### **3.4.2 Sample and sampling method**

A sample is a subset of the population that is selected for a study (Grove et al 2013:708). According to Polit and Beck (2014:391), sampling refers to the process of selecting a portion of the population to represent the entire population. Purposive sampling method was used to underpin the selection of participants. Purposive sampling is a non-probability sampling method in which the researcher selects participants based on personal judgement about who will be most informative (Polit & Beck 2014:389).

The advantage of purposive sampling is that it allows the researcher to select the sample based on knowledge of the phenomena, hence gets sample of experts. In this study, the researcher did not include any parent with a HIV infected child but those who met the eligibility criteria for inclusion; also based on their knowledge of disclosure of HIV status.

Eligibility criteria refer to the criteria designating the specific attributes of the target population by which people are selected for inclusion in a study (Polit & Beck 2014:379). For the participants to be included in this study, they had to be a parent or caregiver to a HIV positive child aged between 6 and 15 years. Twenty eligible

participants were recruited for this study. However, the sample size was not predetermined; rather it was dependent on the extent to which no new information was gathered during data collection. This meant that data saturation was reached.

### **3.4.3 Data collection**

Grove et al (2013:691) define data collection as the precise, systematic gathering of information relevant to the research purpose or the specific objectives, questions, or hypothesis of a study.

A semi-structured face to face individual interview was used to collect data. An interview schedule was used to guide data collection. The questions were open-ended to avoid leading the participants or channelling the participants' responses. The open ended questions were not based on preconceived answers and they provided richer and more diverse data. The semi-structured face to face interview method was conventional and interactive to enable participants to give deep, rich and detailed information. This method was relevant for this study because the parents and caregivers of the HIV infected children were able to share their experiences on disclosure.

Data collection was conducted only on Wednesdays which were set for the comprehensive care of HIV infected children at one hospital. Parents and caregivers usually brought their children for refill of medication in the hospital on Wednesdays. It is this reason that they were purposively selected for interview. Each selected participant was informed about the purpose of the research and the ethical considerations which were followed. The interview lasted between twenty to thirty minutes.

The data collection tool was developed by the researcher (Annexure 3) and was initially used on one (1) participant in a pre-test phase to elicit its ease of use and to identify any aspect that needed modification. The result of the pre-test helped to researcher to identify the relevancy, appropriateness and quality of the data collection tool. A conclusion was reached that the tool was ready for the research questions; and therefore no changes were made on the tool.

At the beginning of data collection, the researcher welcomed each participant on entering the room, introduced herself then briefly explained the participant's eligibility

criteria to clarify to participants as to why they were handpicked to participate in the study. The purpose of the study was explained; both ethics clearance and hospital permission letters to collect data were shown to participants. The researcher also explained the process of data gathering and management including the ethical considerations in maintaining anonymity, privacy, confidentiality and the right and freedom to withdraw from the study at any time.

After the participants showed interest and verbally agreed to participate, the researcher further explained the importance of obtaining an informed written consent from the participant as a means that an agreement that he or she was willing to participate. After signing the written consent forms (Annexure 4), the participants were made aware that the conversation would be recorded and sometimes the researcher would be taking notes during the conversation. The researcher used an interview guide for follow-up and probing questions. Non-verbal communication was noted as the participants gave detailed explanations. Further probing questions were asked to the participants for clarity and additional information (Annexure 3).

The researcher believed that utilising the face-to-face interview method would enable taking the advantage of social cues such as voice, intonation, body language and mannerisms of participants. These provided the interviewer with extra information that was used for follow-up on the verbal responses of the interviewee to a specific question asked. Data collection was done over a period of one month. The researcher continued data collection until she reached a point where the interview process gave almost same information; that is, there was no new information obtained and redundancy was obtained. Data saturation was reached on the thirteenth participant therefore confirming the sample size of thirteen (13) participants. According to Brink et al (2014:153), there are advantages and disadvantages of individual face to face interviews. The researcher noted the following advantages and disadvantages of interviews in the context of this study:

#### ***3.4.3.1 Advantages of face to face interviews***

- Responses were obtained from definite participants.
- The participants did not need to be able to read and write as the interview took the form of a verbal conversation.

- Non-verbal behaviour and mannerism were observed.
- The researcher was able to clarify questions on the spot if they were misunderstood.

### ***3.4.3.2 Disadvantages of face to face interviews***

- The interviews were time consuming; especially because the participants had predetermined times to stay at the hospital following their refill of medications.
- Some participants were a bit anxious because the interviews were audio recorded.
- Other participants were shy to express themselves on HIV issues.

## **3.5 ETHICAL CONSIDERATION**

According to Polit and Beck (2014:380), ethical considerations are systems of moral values concerned with the degree to which research procedures adhere to professional, legal and social obligations to study participants. The following measures were taken to comply with the expected ethical considerations. The ethical principles of voluntary participation and protecting the participants from harm were formalised in the concept of informed. Various ethical issues were observed which included permission from relevant authorities, participants' information and informed consent from participants. Ethical principles observed were; autonomy, beneficence and confidentiality.

*Ethical clearance and permission to conduct the study:* Since the researcher received ethical clearance from the University of South Africa, the fundamental element when conducting this type of research was obtaining permission from the relevant authorities. This was an agreement for conducting a study sought from relevant authorities. The gate keeper's permission was sought from the Ministry of Health research ethics board in Swaziland and the authorities of the hospital in which data were collected in the Lubombo region.

*Informed consent from the participants:* Consent refers to a written agreement signed by a study participant and a researcher concerning the terms and conditions of voluntary participation in a study (Polit & Beck 2014:377). In this study, the participants were given all the relevant information regarding the study such as voluntary participation,

purpose of study, benefits of participating and also the risks related to participating in the study. A choice to participate was made without coercion. They were given the choice to freely withdraw from the study should they feel uncomfortable to continue. Participants were requested to sign a consent form (Annexure 4). However, the participants were explained to that since the interviews were audio recorded, it would be difficult to withdraw from the audio records.

*Autonomy.* Respect for persons as autonomous beings and having the right to self-determination was observed. This implied that individuals had the right to decide whether or not to participate in a study, without the risk of penalty or prejudicial treatment (Brink et al 2014:35). They were free to withdraw from the study without any form of victimisation or threat.

The researcher first had information giving session with every parent or caregiver who met the criteria. The potential participants were given information about the purpose of the study and ethical aspect which the researcher would adhere to. This session helped in preparing the participants for the actual interview as they managed to ask for clarification on any question that they had about the study. The participants were considered to have the legal capacity to give consent as they were above 18 years with good mental health status. The consent form provided the free power of choice to participate without any elements of coercion (Annexure 4). The possible risk of psychological discomfort was highlighted as HIV and AIDS issue is a very sensitive topic. The participants were assured that should any emotions get triggered, counselling was arranged with a dedicated psychologist, available for them at the time of need.

*Beneficence and non-maleficence:* Beneficence refers to a fundamental ethical principle that seeks to minimise harm and maximise benefits for the study participants (Polit & Beck 2014:83). The researcher avoided any questions which could deliberately harm the participants emotionally. The participants would benefit from the research study results in future when HIV disclosure policy guidelines are formulated.

*Privacy and confidentiality:* According to Grove et al (2013:169), privacy refers to an individual's right to determine the time, extent, and general circumstances under which personal information will be shared with or withheld from others. Confidentiality refers to the protection of study participants so that data provided are never publicly divulged

(Polit & Beck 2014:377). In this study there was use of code names to protect participants' identity. The participants were coded as participant #1 to #13 instead of names. Recorded interviews were stored under locked safe cabinet. Transcribed interviews were accessed by the researcher and supervisor only. Respect for privacy and confidentiality was observed since the interviews were conducted with each individual with the researcher only in a private consultation room.

### **3.6 DATA MANAGEMENT AND ANALYSIS**

According to Polit and Beck (2014:378), data analysis is the systematic organisation and synthesis of research data. Data analysis is conducted to reduce, organise, and give meaning to data (Grove et al 2013:691). Data analysis was done using qualitative content analysis to identify prominent themes and patterns among themes (Polit & Beck 2008:517).

Data analysis began as soon as data were collected. Top quality recording equipment was used for verbatim transcriptions of the recordings. This helped to increase the accuracy of data management. Handwritten notes were made during the interviews which assisted with reaching the most comprehensive and accurate description, and were to be used as a backup in case the recording device failed. The recordings were listened at immediately after the interview, and transcribing was done for verbatim. The recorded information was also compared with the field notes taken on the same day to identify any common important relationships that could be considered in developing units, codes and themes.

Data were analysed using qualitative content analysis. According to Polit and Beck (2008:518), content analysis involves the analysis of the content of narrative data to identify prominent themes and patterns among themes. Data were broken down into smaller units, coding and naming the units according to the content they represented and grouping materials based on shared concepts. The entire sets of transcripts were read in order to get a sense of the whole and discriminate irrelevant units from the participant's description of the experience under study. Data were coded for common themes, and the coding involved combining data for themes, categories, and making similar passages of text with a code label. Analysis involved identifying emerging themes and ideas from the data. All meanings attributed to by the participants were

interpreted into consistent statements regarding the participants' experiences on disclosure of HIV status to their infected children. More information on this is described in Chapter 4 of this study.

### **3.7 MEASURES TO ENSURE TRUSTWORTHINESS**

Scientific rigour was maintained following Lincoln and Guba's framework of quality criteria described in Polit and Beck (2014:323). Trustworthiness is the degrees of confidence qualitative researchers have in their data and was assessed using the criteria of: credibility, dependability, confirmability, and transferability and authenticity (Polit & Beck 2014:394). These five criteria were adopted in developing trustworthiness in this study.

*Credibility:* This refers to the confidence in the truth of the data and the interpretation thereof (Polit & Beck 2014:323). In this study the participants were purposively selected and provided rich data on HIV disclosure to their infected children. They had lived experiences with HIV disclosure, hence made this data credible. Prolonged engagement was achieved during initial sessions of recruitment with the participants where rapport was established during explanation of the purpose of the study.

*Dependability:* This refers to the stability of data over time and over conditions (Polit & Beck 2014:323). In this study dependability was achieved by using a recording device during the interview. This ensured that data is kept real as it was directly presented by the participants. Parents and caregivers with HIV infected children presented their experiences and that was recorded. This ensured that there could be no way the data could be altered.

*Transferability:* This refers to the extent to which qualitative findings can be transferred to other settings or groups (Polit & Beck 2014:323). This was achieved by purposive sampling of participants, who had good knowledge of HIV disclosure. The researcher carefully selected a proper site and participants sampling method and technique which represented the entire setting and population. The researcher gave detailed explanation of both site and participants of the study so that findings could be relevant to the settings and participants involved in this study.



*Confirmability:* This refers to objectivity, that is, the potential for congruence between two or more independent people about the data's accuracy, relevance, or meaning (Polit & Beck 2014:323). To ensure that no bias influences the results, tape recordings and field notes were utilised and these were kept for further auditing. This process allowed the truthful perceptions of the participants to be reflected accurately. All the interview transcripts were reviewed by the researcher's supervisor to confirm the actual process of data collection, analysis up to conclusions and recommendations. Printed transcripts with all data related to interviews were kept safe and secured to be access by any legal individual willing to confirm the study findings.

*Authenticity:* This refers to the extent to which researchers fairly and faithfully show a range of different realities (Polit & Beck 2014:323). Verbatim codes from the interviews were used to show authenticity of this study.

### **3.8 CONCLUSION**

This chapter presented an overview of the research design and methods. The next chapter presents analysis and description of the research findings.

## **CHAPTER 4**

### **ANALYSIS, PRESENTATION AND DESCRIPTION OF THE RESEARCH FINDINGS**

#### **4.1 INTRODUCTION**

This chapter presents the analysis and findings of this study. The chapter begins with the description of the data collection and analysis process; and the final section presents the participants' characteristics, followed by the themes and categories which emerged from analysis of the interview data. The findings are discussed with reference to the research objectives. The purpose of this study was to develop support guidelines to assist with disclosure of HIV status to infected children by their parents or caregivers in Swaziland. The objectives were to explore the understanding of the concept of disclosure of HIV status to infected children, describe the pattern of disclosure of HIV status to infected children in Swaziland, and to explore the experiences of parents and caregivers regarding disclosure of HIV status to their children.

#### **4.2 DATA COLLECTION**

Data were collected by the researcher using individual semi-structured interviews. Thirteen face-to-face interviews were held with participants who met the eligibility criteria as explained in chapters 1 and 3 of this study. The participants were parents and caregivers of HIV infected children who do the monthly refills of Anti-retro viral therapy (ART) at the selected hospital. The interviews took place at the ART clinic department in the hospital. A consultation room was availed by the department senior sister on arranged Wednesdays, which are the only days for refills for children.

Each interview began with a brief introduction given by the researcher stating the purpose and objectives of the study. The participants were asked if an audio recorder could be used to record the interviews and all the participants agreed to be put on record. Written consent to participate in the study was provided by the participants. The form was prepared by the researcher before the study and the contents were read to the participants to seek their consent. As part of seeking consent for the study, the

researcher informed the participants that they were free to withdraw their participation at any time of the interview since participation was voluntary. In all cases, interview codes were used in the form of the number, unit and gender; in order to promote confidentiality and anonymity. During each interview, the researcher also took notes.

### **4.3 DATA MANAGEMENT**

The interviews were audio recorded with the permission of the participants. Each audio recorded interview was saved on the computer using a code and pseudo-names, same with the notes taken were coded to represent the participants. All written notes, signed consent forms and computer with audio recordings ready for analysis were kept in a safe lockable cupboard. Each audio recorded interview was listened to and written down by the researcher in the form of a verbatim transcript which was later analysed. The interview schedule was in English and Siswati version which was done with the help of a language teacher prior to the interview. The verbatim reports were transcribed the same day following each interview, and the written notes were added to the relevant sections of the transcripts to support the data collected. The translation from SiSwati to English was done following transcription in order to prevent loss of meaning during analysis.

#### **4.3.1 Interview schedule**

A prepared interview schedule was used and probes were made based on the participants' response. The questions that were used to direct the interview are attached as (Annexure 3) in this study.

#### **4.3.2 Challenges encountered during interviews**

The following challenges were encountered during the interviews:

- Some parents came with young babies, so there were some interruptions from the noise from the babies, and often the parents or caregivers had to divert their attention to the babies, thus making the interview a bit lengthy.
- There was no total control of cell phones since they were requested to put them on silent modes so the vibrations disturbed the recording.

#### **4.4 DATA ANALYSIS**

Data analysis was started immediately after data collection from each participant. The researcher used a computer word processor to manage data. All audio recorded and English translated interviews were typed into a word document and transcribed verbatim. The researcher read the entire sets of transcripts to get a sense of the whole from the participant's description of disclosure of HIV status to their infected children. All significant statements were extracted from the transcripts and analysed to identify the participants' explanations of descriptions under study.

Qualitative content analysis was followed for data analysis. The analysis involved breaking down data into smaller units, coding and naming the units, according to the content they represent, and grouping coded material based on shared concepts (Polit & Beck 2014:306). Data were broken down into smaller units coded and named units according to content they represented. Meaningful units were derived from transcribed materials as narratives, the researcher verified the narrative material and aligned them with established categories, and where needed these categories were redefined. Then similar categories were clustered into broad themes.

Below is an illustration of how the researcher started by obtaining significant statements from transcripts; formulated meanings and then finally identified themes which had different categories.

“Eish sister ..., I do want to tell the child but it is difficult to do it. He can see we come to the clinic to get our medication, but I have not told him exactly about the medication. And I don't even know how I can tell him, though he sometimes talks about HIV.” (Participant #1, parent to 7 years old boy).

**Table 4.1 Sample significant statement**

<b>Significant statement</b>	<b>Formulated meaning</b>	<b>Theme</b>	<b>Category</b>
"I do want to tell the child but it is difficult to do it."	The parents have difficulty with telling the children about HIV status	The experiences of parents and caregivers on disclosure of HIV status to their children	Challenges with disclosure of HIV status
"I have not told him exactly about the medication."	The child was not told about the reason for taking the specific medication		Challenges with disclosure of medications

The researcher formulated more general statements or meanings for each significant statement from the transcripts. Formulated meanings were developed for all significant statements followed by the researcher then the formulated meanings were arranged into themes clusters.

#### **4.5 RESEARCH FINDINGS**

The presentation of the findings begins with the characteristics of the participants followed by the participant’s narratives.

##### **4.5.1 Characteristics of the participants**

The purpose of providing the characteristics of the participants was for the reader to understand the sources of the information. It is used in qualitative data as a means of ensuring transferability, as participants characteristics are described to allow for comparability of findings in the settings similar to the one studied (Bryman, Bell, Hirschsohn, Dos Santos, Du Toit, Masenge, Van Aardt & Wagner 2014:45).

There were thirteen (13) participants who met the inclusion criteria and all of them participated in the interviews. They were interviewed on an individual basis in a private room. The characteristics of the participants are described according to gender, age and relationship with the child. The participants were all adults aged of 26-70 years, related to the children infected with HIV as parents or caregivers. There were only two males and eleven females. Only two participants had not disclosed the HIV status to their

children but had done so to significant others. See Table 4.2 for additional information related to the characteristics of the participants.

**Table 4.2 Demographic profile of the study participants**

<b>Participant number</b>	<b>Gender</b>	<b>Age of parent or caregiver</b>	<b>Relationship with child</b>	<b>Age of child</b>	<b>Age at disclosure</b>
Participant #1	Female	48	Mother	7	-
Participant #2	Male	70	Grandfather	7	-
Participant #3	Male	42	Father	9	8
Participant #4	Female	47	Mother	15	14
Participant # 5	Female	68	Grandmother	11	10
Participant #6	Female	26	Sister	8	6
Participant#7	Female	41	Mother	15	11
Participant #8	Female	46	Mother	8	7
Participant #9	Female	63	Grandmother	9	8
Participant #10	Female	42	Mother	6	6
Participant #11	Female	40	Mother	7	6
Participant #12	Female	41	Mother	7.5	7
Participant #13	Female	38	Mother	11	10
<b>Total=13</b>	<b>Gender</b> Male=2 Female=1	<b>Age (years)</b> 26-29=1 30-39=1 40-49=8 60-70=3	<b>Parent or caregiver</b> Parent=9 Caregiver=4	<b>Disclosure</b> Children disclosed to=11 Non-disclosed to=2	

#### 4.5.2 Participants' narrative findings

The participants' narratives were grouped into themes and categories, supported by meaning units. Table 4.3 presents the themes and categories together with their meaning units accordingly. Three (3) themes with individual categories emerged from the narrative findings.

**Table 4.3 Themes, categories and meaning units**

<b>Themes</b>	<b>Categories</b>	<b>Meaning units</b>
<p><b>Theme 1</b> Understanding the general concept of disclosure</p>	<p><b>Category 1.1</b> Disclosure of HIV status as a process rather than an event</p> <p><b>Category 1.2</b> Disclosure of HIV status to the child and other person</p>	<p>Disclosure is not a once off event</p> <p>Telling the infected child or other about his/her HIV status</p>
<p><b>Theme 2</b> The pattern followed on disclosure of HIV status to infected children</p>	<p><b>Category 2.1</b> The proposed person to disclose the HIV status to the child</p> <p><b>Category 2.2</b> The appropriate age to disclose HIV status to a child</p> <p><b>Category 2.3</b> The type and amount of information to give in relation to the HIV status</p>	<p>The reasons stated on the issue of disclosure</p> <p>When to disclose the HIV status to the child</p> <p>What to explain about the medication taken</p>
<p><b>Theme 3</b> The experiences of parents and caregivers on disclosure of HIV status to their children and adolescents</p>	<p><b>Category 3.1</b> Reasons for disclosure</p> <p><b>Category 3.2</b> Reasons for non-disclosure</p>	<p>The reasons stated on the issue of disclosure</p> <p>The children were told about the HIV status and the medication taken</p>

#### **4.6 DESCRIPTION OF DATA**

The data were described according to the formulated themes and categories, supported by narrative extracts from the transcripts and literature. The WHO (2011) guidelines were used to support the findings as evidence for preparation for the development of guidelines for this study.

##### **Theme 1: Understanding the general concept of disclosure**

Understanding the general concept of disclosure emerged as a theme in relation to the categories of disclosure of HIV status as a process rather than an event and disclosure

of HIV status to the child and other person. The findings indicate that the participants had a general understanding of the concept of disclosure. This is supported by the fact that the participants mentioned that they believed children should be told about their HIV status while they are still young even though some of them had not told their children. The participants said the following:

“I believe that a child should be told while still young about his HIV status.”(Participant # 3, parent to 9 years old child girl).

“It is important that we tell our children about their status and be truthful how they got infected. As they grow they will understand how HIV can be transmitted.”  
(Participant # 8, parent to 8 years old boy).

### **Category 1.1: Disclosure of HIV status as a process rather than an event**

The participants mentioned that disclosure is a process that should be ongoing as the child grows from childhood to adolescence and adulthood. The participants further indicated that when the child is still young she or he cannot understand the concept of HIV and therefore it may not be beneficial to give detailed information on the disease. The participants were of a similar view that the child should be told in stages and according to the age. The participants mentioned the following:

“I can say that it is important to tell the child at least around the age of 10 years. This should be done in stages and see the child’s reaction.” (Participant #7, parent to 15 years old boy).

“I think at the age of 8 years, she will be in a position to understand about HIV.”  
(Participant # 11, parent to 7 years old girl).

“I think it is important for the child to know in a simple manner, laughter ..., a child may be confused as to what are you talking about being HIV positive.”  
(Participant # 6, caregiver to 8 years old girl).

“I will keep on telling her as she grows because she cannot understand much about HIV now.” (Participant # 12, parent to 7.5 years old girl).



The findings concur with the WHO (2011:16) guidelines on HIV disclosure counselling for children up to 12 years of age, which state that disclosure leads to extended discussions as the implications of having HIV in the family unfold. The guidelines further state that, such discussions do not occur as a discreet, one-time event, but they occur over time (WHO 2011:16).

### **Category 1.2: Disclosure of HIV status to the child and other person**

This category emerged when the participants indicated that they had disclosed the HIV status to the child or significant other, other than the child. It was revealed that even if parents had not fully disclosed the HIV status to the infected child, they had disclosed it to the family members or trusted people in the community like the rural health motivators and pastors. This signified clearly that disclosure is important in HIV management and care. Some participants had disclosed to both the HIV infected child and significant others. The participants mentioned the following:

“My condition is not a secret to the family and community members. I also disclosed to all of them about the status of the child. Even at school the head teacher and other teachers are aware that this child is on HIV medication.” (Participant # 7, parent to 15 years old boy).

“The family members and other community members are aware. Even some of the church members know about our HIV status.” (Participant # 13, parent to 11 years old boy).

“My family knows about my HIV status and that of the child. The rural health motivators and few church members including our pastor are aware of our HIV status. It is not a secret to the people close to me.” (Participant # 12, parent to 7.5 years old girl).

“My family knows especially my mother and my siblings. Some community members know about it and I am the one who told them.” (Participant #10, parent to 6 years old girl).

The findings of this study concur with the WHO (2011:36) guidelines which state that “social disclosure” may assist in dealing with HIV-related issues. Social disclosure has

been defined as disclosure that a person is HIV positive or that a family is HIV affected to a larger circle of family, friends and others in social networks (WHO 2011:36). This was revealed in this study by the participants who had disclosed their HIV status and that of their children to the family, community and church members.

## **Theme 2: The pattern followed on disclosure of HIV status to infected children**

The findings in this study indicate that disclosure occurred in various patterns. This theme emerged with three categories, namely, the proposed person to disclose the HIV status to the infected child, the appropriate age to disclose the HIV status to a child and the type and amount of information to give in relation to the HIV status. The findings revealed the proposed procedure or way in which information was imparted from parents and caregivers to children with HIV.

### **Category 2.1: The proposed person to disclose the HIV status to the child**

The participants, including those who had not disclosed the HIV status to their children indicated that they preferred to personally tell the children about their HIV positive status. The participants mentioned the following:

“It is important that we tell our children about their status and be truthful how they got infected. As they grow they will understand how HIV can be transmitted.” (Participant # 8, parent to 8 years old boy).

“I think I can be brave to tell her myself my child.” (Participant # 5, caregiver to 11 years old girl).

“Laughter ..., I think I can definitely tell him sister.” (Participant # 8, parent to 8 years old boy).

“I just felt I should do it on my own because I wanted her to understand why she has to take the medication.” (Participant #3, parent to 9 years old girl).

Interestingly, when asked who else would be appropriate to disclose or help to disclose the HIV status to the child, another participant indicated the need for a counselor to tell the child about his or her HIV status. This was gathered from the statement below:

“I think the counselor can help me since I am afraid on my own.” (Participant #1, parent to 7 years old boy).

## **Category 2.2: The appropriate age to disclose HIV status to a child**

The issue of when to disclose had many variations based on different reasons perceived by each participant on to disclose or not to disclose the HIV status to the infected child. The findings indicated no definite age but suggested that it was done according to various reasons and situations encountered by each participant.

The cognitive level of the child was another factor that was indicated in the findings. The findings revealed that some of the participants were of an opinion that the children did not have a good understanding of HIV when young; and rarely question the medication that they were taking. This was in relation to a revelation by the participants when the children questioned the medication and the parents or caregivers had to disclose prematurely. That is, before the parents or caregivers were ready for disclosure. The participants mentioned the following:

“When she was around 6 years old, she asked about the medication and my mother told her that her blood was unclean and she should take her medication.” (Participant #6, caregiver to 8 years old girl).

“It is important that the child should know about her status but it is a difficult task. I also told her last year at the age of 6 years.” (Participant # 11, parent to 7 years old girl).

“This child is clever sister; he was asking more questions about the medication he was taking every day. He even asked why he was the only one among the children who was taking the medication.” (Participant #9, caregiver to 9 years old boy).

These findings relate with the paediatric HIV disclosure process-oriented framework (2013:304) which encourages disclosure of HIV infection status to school-age children and recommends that adolescents should know their HIV status. Children generally

start primary school at the age of six (6). Parents of adolescents in this study had disclosed their status to them in full. A participant said:

“I have told him that if he has a girlfriend he should use a condom so that he cannot infect his partner as he is living with HIV.” (Participant # 7, parent to 15 years old boy).

### **Category 2.3: The type and amount of information to give in relation to the HIV status**

This category referred to which information should be imparted from parents to children who are HIV positive. The participants had different views on the information and whether to tell their children about their HIV status. Although the participants commonly believed it was important to disclose, the type of information they disclosed was different. The findings revealed that some participants had not given any information about HIV or the medication to their children. On the other hand, the other participants had given partial information without actually naming the disease. The participants indicated the following:

“I have told her that she is sick and should take her medication for the rest of her life, but I did not openly tell her that she has HIV.” (Participant #12, parent to 7.5 years old girl).

“I have not openly told him that he is HIV positive; but just told him that the medication he is taking is important that he takes it every day of his life. I even told him that I am also taking the same medication.” (Participant #8, parent to 8 years old boy).

“I only told her that her blood is not clean, so that is why she should take the medication.” (Participant # 5, caregiver to 11 years old girl).

“No I have not openly told her that she has HIV, but one nurse told her that she was taking the medication because she is sick. She does not know about the sickness.” (Participant #10, parent to 6 years old girl).

The findings indicate that the parents and caregivers did not give full disclosure to their children. Full disclosure is when the child is provided explicitly with the name of the illness he or she is suffering from. The pathophysiology, mode of transmission and the importance of taking medication are fully explained. Additionally all questions asked are truthfully answered and support is given (Vaz et al 2011:314). With regard to full disclosure the participants indicated the following:

“I started by talking about HIV as a sickness and how it is transmitted. I asked if they have learnt anything at school about HIV and she agreed. I also told her that I also have HIV that is why I am taking the medication. I told her that the medication she is also taking is for HIV, which she got from me as it is transmitted through blood. I explained that she got it through breast milk.” (Participant #11, parent to 7 years old girl).

“I called her one day and explained why his father’s children were sick and eventually died. I then explained how HIV can be transmitted in different ways. I noticed that she understood as she was quiet and listening to me. I told her that the medication we were both taking every day was for HIV, which we got from her dead father.” (Participant # 4, parent to 15 years old girl).

The findings concur with those of a study cited by Madiba (2012b:212) and conducted by Vaz, Eng, Mamam, Tshikandu & Behets (2010:248) on patterns of disclosure of HIV status to infected children in a Sub-Saharan Africa, which indicated that there are various patterns of disclosure; ranging from no information provided, deflecting information provided, partial information provided and full information provided.

### **Theme 3: The experiences of parents and caregivers on disclosure of HIV status to their children and adolescents**

The experiences were shared with regards to before, during and after disclosure of the child’s HIV status by parent of caregiver. The findings revealed that the participants, whether having done partial or full disclosure shared similar experiences before telling the children about their HIV status. The findings indicated that disclosure of HIV status to a child was a heavy task and an unpleasant experience. The participants used different words to describe how they felt such pain, difficulty, worry and fear as indicated in the following statements:

“It was a difficult and painful thing sister. During the time of medication it worried me that the child was taking this medication even though she had not complained about anything and does not feel any sickness in her body.” (Participant #11, parent to 7 years old girl).

“Eish sister, it worries me a lot now that at school they learn about HIV. I am afraid that he is going to ask me straight about it. He might speculate that the medication he takes daily is for HIV as I told him that he should not stop it in his life.” (Participant # 8, parent to 8 years old boy).

“It was troubling me a lot because my interest was for her to know about her HIV status and why she is taking the medication.” (Participant # 3, parent to 9 years old girl).

The findings revealed that during disclosure, parents experienced confidence and bravery to be able to tell their children openly about their HIV status and naming the disease. The participants who were parents also revealed to their children that they too were HIV positive and on treatment. The parents further explained to their children how HIV was transmitted from them as parents to their children. This suggests that the children got to know about their HIV status and that of their parents collectively. The participants said:

“I told her that I also have HIV that is why I am taking the medication. I told her that the medication she is also taking is for HIV, which she got it from me as it is transmitted through blood.” (Participant # 11, parent to 7 years old girl).

“I decided to tell him one day when we were from the hospital to get our medication. Along the way I told him that the medication he was taking was for HIV and that I was also taking the same medication as I am also HIV positive.” (Participant # 13, parent to 11 years old boy).

The findings indicate that during disclosure even the caregivers had the courage to mention to the child how they got infected with HIV. A participant mentioned the following:

“I told him the truth about the medication and made him aware that he had HIV. I think it helped me that he was aware that his mother died while he was a child. I managed to openly tell him that, even your mother had HIV and she passed away when you were still very young.” (Participant # 9 caregiver to 9 years old boy).

The participants verbalised relief and happiness following disclosure of the HIV status to their infected children. This was revealed by both parents and caregivers. They expressed this in different words such as feeling happy, good and relieved as indicated in their verbatim narratives below:

“I felt so relieved sister but was watching her closely.” (Participant # 11, parent to 7 years old girl).

“I felt good in my heart and relieved that I had broken the news a bit. This was important to me.” (Participant # 12, parent to 7.5 years old girl).

“I felt so relieved after telling the child about his status.” (Participant #7, parent to 15 years old boy).

“Eish ... I felt so happy and it was like a big rock has been rolled off my shoulders.” (Participant # 9, caregiver to 9 years old boy).

These findings revealed that after disclosure parents and caregivers said they were relieved and verbalised that their children did not show any negative behaviour but improved medication adherence and responsibility for their health from the children was observed. The findings of this study concur with those of a study conducted by Kennedy et al (2010:1101) on parents' disclosure of their HIV infection to their children in the context of the family. Kennedy et al (2010:1101) indicated that parents felt relieved after telling their children about their HIV positive status; and the findings of the study further showed that the children did not display any serious negative reactions as feared by their parents. Interestingly, the children were said to instead be supportive; which was a positive reaction to disclosure of HIV status (Kennedy et al 2010:1101).

### **Category 3.1: Reasons for disclosure**

The reasons for disclosure were found to be similar amongst the parents and caregivers who participated in this study. The common reasons for disclosure stated were medication adherence, fear of infecting others and children asking about the medication.

- **Medication adherence**

The issue of medication adherence was deemed the priority reason for disclosure by the participants. This was seen in statements made by the participants as follows:

“I believe it is important for a child to know her HIV status. This is because she has to understand why she is taking the medication.” (Participant #4, parent to 15 years old girl).

“I wanted her to understand the reason she should take the medication every day.” (Participant # 5, caregiver to 11 years old girl).

“I believe so much that he should know his HIV status as he grows so that he does not stop taking the medication.” (Participant # 2, caregiver to 7 years old boy).

“I find it very important that she knows about her HIV status; because as she is taking the medication, she should know because she might stop if she does not know why she is taking the medication.” (Participant # 3, parent to 9 years old girl).

The participants mentioned that disclosure of the HIV status to their children yielded good results in terms of medication adherence. It was revealed that once the children got to know about their HIV status, they were able to take responsibility of their health. This was related in the statements made by the participants as follows:



“I can say that she is very punctual on the time of taking her medication. Even if she goes for youth camps and reed dance cutting, she packs her medication without being told. She is the one who reminds me on our refill dates now.” (Participant #4, parent to 15 years old girl).

“In the past she used to take medication but at times will refuse if I am not at home. Now ever since I explained to her about the medication, she takes it correctly because each time I bring her to the hospital the pill count shows that she is taking them correctly”.( Participant # 3, parent to 9 years old girl).

“Oh ... There is good change; he is now able to take his medication correctly at the same time without being reminded.” (Participant #7, parent to 15 years old boy).

“She became more responsible for her medication. She always asks us the time and can take the medication on her own. Laughter..... Even this morning I had forgotten and she is the one who reminded me.” (Participant #6, caregiver of an 8 years old girl).

- **Obtaining support from others**

The findings indicate that the participants were able to get support from relatives and other health care partners in their communities. This help was in terms of health advice and material things like food parcels. According to the findings, this support was only received by those whose HIV status was known. The findings further revealed that if the parent had not disclosed the school would not had known and registered the child for available and relevant support. The participants mentioned the following:

“We get support from care centers. These HIV positive children are registered at school and they would get counseling from the centers, they are being assisted in their studies and even provide some food parcels.” (Participant # 6, caregiver to 8 years old girl).

“At church they do assist us on food and the local non-government organisations like Save Our Souls (SOS) do give us food parcels and money to go to the hospital for refill.” (Participant # 13, parent to 13 years old boy).

“The rural health motivators visit us and check our cards if we refill correctly on the said dates.” (Participant #11, parent to 7 years old girl).

“My parents and siblings support us a lot especially when the child is sick. They encourage me to take care of him and also say that he should eventually know about his status so that he understands why he takes the medication every day and often visits the hospital.” (Participant # 8, parent to 8 years old boy).

- **Fear of infecting others**

The findings indicate that the parents and caregivers of adolescents disclosed because they wanted their children to know their HIV status, so that they may not infect others as they grow. The participants understood the mode of transmission of HIV. The participants said the following:

“In my case sister, she is now fifteen years old; she might have a boyfriend and engage in sexual relationships and can infect the other person without her knowledge.” (Participant # 4, parent to 15 years old girl).

“When you grow old, never you meet with another person without a condom. When you want a baby you will need to visit the clinic for doctors to help you on what you are supposed to do in order to have a child in your condition.” (Participant # 2, caregiver to 7 years old boy).

The findings of this study concur with those of a study conducted by Madiba (2012a:320) which revealed that disclosure increases knowledge and understanding of HIV and decreases risky behaviours. Among the adolescents risky behaviours may include having unprotected sexual intercourse and infecting the partner unintentionally. A study conducted by Jemmott et al (2014:1028) also revealed that when people are told about their HIV status they can take steps in making other behavioural changes to protect their health and reduce the likelihood that they could transmit the virus to others (Madiba 2012a:320, Jemmott et al 2014:1028).

- **Children asking about the medication**

The findings revealed that the parents and caregivers were of a common view that the children were not comfortable taking medication every day at stipulated times when they were actually not feeling sick. The indication was that the children questioned the medication and in some instances refused to take the medication. This act gave some parents no choice but to disclose. The participants shared the following statements:

“This child is clever sister; he was asking me more about the medication he was taking. He even asked why he was the only one among the other children who was taking the medication. I then thought it was high time I tell him the truth about the medication and make him aware that he has HIV.” (Participant # 9, caregiver to 9 years old boy).

“Now that she knows, she takes her medication well. She was resisting to take them saying that how come her elder brother does not take the medication.” (Participant #10, parent to 6 years old girl).

“When she was around 6 years old, she asked about the medication and my mom told her that her blood was unclean and she should take her medication.” (Participant #6, caregiver to 8 years old girl).

The findings in this study are in line with a study conducted by Madiba (2012a:323) on disclosing HIV to infected children in South Africa in the era of HAART. Madiba’s (2012a) study focussed on the process, reasons and outcomes of disclosure; and found that caregivers reported that the disclosure event was influenced by their children’s asking questions about why they had to continuously take medication. The study further indicates that some of the caregivers disclosed the HIV diagnosis to the child because of the child’s refusal to continue taking medication (Madiba 2012a:324).

### **Category 3.2: Reasons for non-disclosure**

The findings of this study revealed three classical reasons for non-disclosure which the participants stated. These were age and cognitive development of the child, lack of knowledge on disclosure and the child’s reaction to the news.

- **Age of the child and cognitive development**

One of the reasons parents and caregivers gave for non-disclosure in this study was that the child was too young, and so would not understand the whole concept of HIV. Furthermore, the participants were of an opinion that the child could not keep it secretly to themselves and might end up sharing this confidential information with others. This was gathered from the participants who said:

“Sister, I feel he is still young and might tell other people about it; yet this is a family issue. I will tell him though when he is around ten years old and can understand more about the condition and keeping it a family thing.”(Participant # 8, parent to 8 years old boy).

“Eish sister, I am scared that the child may go on and talk about his HIV status anyhow. That is the main problem.” (Participant # 1, parent to 7 years old boy).

The findings of this study are in line with those of a study conducted by Jemmott et al (2014:1028) which stated that one of the common reasons parents cited for non-disclosure of HIV status to children was fear that children might inappropriately tell others, who would occasionally gossip, stigmatise, and discriminate towards them and the family (Jemmott et al 2014:1028).

- **Lack of knowledge on disclosure**

The participants verbalised having knowledge deficit on disclosure of HIV status to their infected children. They indicated that they were being encouraged by health workers to disclose, but they were not clearly educated how to do it. The participants said the following:

“Let me say as far as I can remember, they have not told me how I am going to tell the child about his HIV status. The only thing that they told me about is that the child should take his medication correctly, at the same time and do not miss a dose.” (Participant # 2, caregiver to 7 years old boy).

“I can say I have not yet received any help on child disclosure. I still need to be educated on how to disclose the HIV status to my child.” (Participant # 1, parent to 7 years old boy).

“From the hospital I do get help on the medication part because it is where she gets her medication, but nothing on the issue of disclosure.” (Participant # 3 parent to 9 years old girl).

According to Punpanich (2009:52), whilst parents realised that the children need to be told, they felt helpless since they did not know how to disclose in the least painful way possible. Therefore, the parents were inclined to postpone this as long as possible.

- **Child’s reaction to the news**

The findings revealed that parents and caregivers understood that children have feelings and can react differently towards a diagnosis. This could be heard among the participants who were afraid to tell their children about their HIV status for fear of the unknown reaction. The participants mentioned the following:

“I was scared to tell her because I thought she was going to be very angry. I did not know how I was going to explain how she got infected.” (Participant # 4, parent to 15 years old girl).

“It worried me as to how I was going to tell the child about his HIV status. I knew that he needed to know as they tell me at the hospital. The biggest worry was how he was going to take it.” (Participant # 9, caregiver to 9 years old boy).

“At first he was a bit upset but later he was just ok after seeing other children in the community who have HIV and attending the teenage club.” (Participant # 13, parent to 11 years old boy).

The findings of this study concur with those of a study conducted by Madiba (2012a:324) which revealed that prior to disclosure most caregivers were fearful of the children’s reaction to the HIV disclosure.

## **4.7 DISCUSSION OF THE RESULTS**

### **Theme 1: Understanding the general concept of disclosure**

The study revealed that parents and caregiver had a clear understanding of the concept of disclosure. They appreciated the importance and benefits of disclosure in the management and care of HIV. This was seen as the parents and caregivers had not disclosed, had done partial disclosure and others had fully disclosed. Disclosure of HIV status to children infected was perceived as a process rather than an event by the participants in this study. In a study conducted in Kenya by John-Stewart et al (2013:1069) on the prevalence, perception and correlates of paediatric HIV disclosure in an HIV treatment program, the findings indicated that caregivers believed that children should know their HIV status, especially those who were on medication.

It was interesting to note that even if parents and caregivers had not fully disclosed the HIV status to the infected child, they had disclosed it to the family members, health workers and trusted people in the community like the rural health motivators and pastors. This suggested that the participants believed that disclosure was paramount. According to Zamberia and Mabundza (2014:123) in a study on the role of family members in HIV-positive status disclosure and antiretroviral therapy uptake in Swaziland, people living with HIV assess the possibility of disclosure by considering how they would be viewed by members of their families. Furthermore, the fact those family members are the ones who ultimately have to care for HIV positive children make disclosure become necessary (Zamberia & Mabundza 2014:123). This was true with the findings of this study when the participants admitted that they did get support from family members and significant others whom they had disclosed the HIV status of the child to

### **Theme 2: The pattern followed on disclosure of HIV status to infected children**

The findings in this study indicated that disclosure occurred in various patterns. This refers to the procedure or way in which information was imparted from parents to children who are positive with HIV.

The parents and caregivers preferred to be the relevant people to disclose the HIV status to their children. There was nothing that showed preparation by parents and caregivers on disclosure in this study. However, the four-phased model of disclosure framework used by Gachanja et al (2014:24) on HIV positive parent account on disclosure preparation activities in Kenya was followed in this study. This model included the secrecy phase, exploratory phase, readiness phase and full disclosure phase.

It seems the participants in this study also underwent the secrecy phase. In this phase, the parents and caregivers needed to first accept their own diagnosis before they could tell it to their children. This was achieved in line to when the parents and caregivers explained that they were also taking medication. Exploratory phase was achieved when the participants indicated that they had to accept their illness; and then began to explore how they would fully disclose to their children. The findings did not show though if they made disclosure plans considering family dynamics or reading information to teach children about the disease. The parents and caregivers further stated that they needed to be supported by counsellors and health care workers such as nurses on disclosure of HIV status to their children.

The participants in this study did not indicate if they reached the readiness phase. Interestingly, others were rather pushed by circumstances to disclose. According to Gachanja et al (2014:28) this is when parents perceive themselves as being ready to fully disclose and they judged their children as being receptive to the news. At this level they actively seek activities that would assist them to deliver the news. Full disclosure delivery was done when the participants openly told their children they had HIV, questions asked by their children were answered truthfully.

The pattern of disclosure observed from this study was from non-disclosure, partial disclosure and finally full disclosure. The appropriate time for disclosure varied based on individual situations among the participants and their children. However, the findings showed that Piaget's theory of cognitive development (1936) was incorporated in this study. Some parents and caregivers from this study mentioned that they disclosed the HIV status to their children at the age of six years. According to Piaget's theory, children at the preoperational stage are characterised by pre-logical thinking; and unable to reason beyond their own environment.

The parents and caregivers in this study disclosed the HIV status of their children at the concrete operational stage which is between 7-10 years of age. Piaget characterised the concrete operational stage by concrete-logical reasoning, where children are able to make multiple connections of causation to a single phenomenon and can understand hierarchies. Children are able to identify an external cause as the source of their illness, identifying it as something 'bad'. At this stage, children are in a better position to understand illness. The findings of this study were slightly indifferent from Piaget's theory of development since some parents had disclosed the HIV status to their children at the age of 6 years. According to Piaget's theory the formal operational stage is from age 11 years and above. Piaget characterised this stage by formal-logical thinking, where children begin to think hypothetically and abstractly; when they can correlate multiple causations to illness, including external and internal factors related to their health. The parents and caregivers of children at this stage had done full disclosure.

### **Theme 3: The experiences of parents and caregivers on disclosure of HIV status to their children and adolescents**

The findings of this study revealed reasons for disclosure and that of non-disclosure. The reasons for disclosure mentioned were medication adherence, fear of infecting others, children asking about the medication, and fear of reaction from children. Parents and caregivers were concerned that their children should take the medication as they believed it prolongs life. This was stated by the parents and caregivers who had disclosed partially and fully. The parents and caregivers of the HIV positive children mentioned that they feared that their children may engage in sexual relationships and infect others without their knowledge. They believed these children should know about their HIV status to avoid spreading the disease.

It was revealed that in some cases, children questioned taking the medication and threatened to abandon it since not everyone in the family was taking it. This circumstance gave parents and caregivers no choice but to disclose. The readiness phase would not be met but full disclosure was compelled. According to John-Stewart et al (2013:1069) in their study on caregiver perceptions regarding disclosure, caregivers who believed disclosure was important cited reasons why they deemed important to



disclose HIV status to the child. Amongst the reasons cited was that they wanted the child to understand reasons for taking the medication.

The study revealed the reasons cited by some parents and caregivers for non-disclosure which are in support of literature were age and cognitive development of the child, lack of knowledge on disclosure, and child reaction to the news.(Kallem et al 2011:1125; Jemmott et al 2014:1028. These Parents and caregivers were not comfortable disclosing to young children as they may not be able to keep the status confidential. Another factor that came out from this study was that some participant verbalised having knowledge deficit with disclosure of HIV status to their infected child. They stated that they were not well educated even from health facilities on disclosure of HIV status to a child. The parents and caregivers admitted that they were being encouraged by health workers to disclose, but they were not clearly educated how to do it. it seems that the parents and caregivers did not disclose because they feared the children's reaction to the news.

Parents and caregivers understood that children have feelings and could react differently towards a diagnosis. This could be seen among the adolescents who had a better understanding of HIV including the mode of transmission.

#### **4.8 CONCLUSION**

In this chapter data were analysed, presented and described with literature. The findings of this study as presented in this chapter are used as evidence to design the guidelines to assist with disclosure of HIV status to affected children by parents and caregivers which is the purpose of this study. The next chapter will present the guidelines, conclusion and recommendations for this study.

## **CHAPTER 5**

### **CONCLUSIONS AND RECOMMENDATIONS**

#### **5.1 INTRODUCTION**

The objective of this chapter is to provide the study conclusions, limitations and recommendations. The purpose of this study was to develop guidelines for disclosure of HIV infected status to children in Swaziland.

#### **5.2 RESEARCH DESIGN AND METHOD**

Individual semi-structured interviews were conducted from purposively selected parents and caregivers who had a child who was HIV positive. A qualitative, exploratory and interpretive design was followed in this study. It aimed at determining the experiences of parents and caregivers with disclosure of HIV status to their infected children. Data were analysed following qualitative content analysis. The findings indicated that parents and caregivers had challenges in disclosing the HIV status to their infected children. Finally the findings were used as evidence to develop the guidelines to assist parents and caregivers on disclosure of HIV status to infected children.

#### **5.3 SUMMARY AND INTERPRETATION OF THE RESEARCH FINDINGS**

The research findings were as follows:

##### **5.3.1 Understanding the general concept of disclosure**

The general concept of disclosure emerged as a theme with regard to, disclosure as a process rather than an event and disclosure of HIV status to the child and other person as categories. Parents and caregivers showed understanding of the importance of disclosure to the infected child. The participants mentioned that disclosure is a process that should be ongoing as the child grows from childhood to adolescence, and adulthood. They further indicated that when the child is still young she or he cannot understand the concept of HIV and therefore it may not be beneficial to give detailed

information on the disease. The participants were of a common view that the child should be told in stages and according to the age. This was seen when most parents gave minimal information on HIV during disclosure. Parents with adolescents showed concern on issues of sexual relationships. This showed that the level of information on HIV disclosure increased with the age of the child. This is in line with the WHO (2011:36) guidelines in counselling of children under the age of 12 years on HIV disclosure.

Disclosure of HIV status to the child and other person was another category that was revealed under this theme. All the participants verbalised that they had disclosed the HIV status of their children to someone else, even if they had not disclosed to their infected children. The parents and caregivers found disclosure of their children's HIV status to family and significant others beneficial. The conclusion in this study is that they get support in caring for their children and even assistance on food parcels. Disclosure generally helps to reduce the stigma attached to HIV. However, the issue of confidentiality and respect for the right of the child was not observed. The parents and caregivers had no guarantee that the person whom they disclosed to would keep that information in confidence. This is in contrast with the Children's Protection and Welfare Act (Act 6 of 2012) contained in the Swaziland Government Gazette (2012:11).

The Act says that no person may disclose the fact that a child is HIV positive without the consent given under subsection (2) of the Act. The Act further states that children above the age of 12 years may give consent to have their HIV status disclosed to others. The Children Act (Act 38 of 2005) contained in the constitution, (section 28) of the Bill of rights also contrasts with this (South Africa 2006:25). The Act says that children are also entitled to confidentiality regarding their health status, providing it in the best interest of the child to keep the information confidential (Mellish, Oosthuizen & Paton 2010:172). Moreover, there could be danger of inadvertent disclosure to the child by the other person. This could create problems for the parent and the child's relationship especially adolescents who understand the mode of transmission of HIV.

### **5.3.2 Pattern followed on disclosure**

This referred to the procedure or way in which information was imparted to the child on his or her HIV status. Accordingly disclosure occurred in various patterns in this study. The pattern followed on disclosure emerged in relation to the appropriate person to disclose the HIV status to the infected child, the appropriate age to disclose, and the type and amount of information to give regarding HIV status to the infected child. The parents and caregivers mentioned that they were encouraged at the health facilities to be the ones to disclose the HIV status to their infected children. However, they stated that they were not educated on how, when and what to disclose to the infected children. This is the reason other parents and caregivers revealed they needed to be assisted by a counselor to disclose the HIV status to their children.

The appropriate age to disclose was not clear. The findings revealed that some parents had disclosed when their children were six (6) years old. A child who is six (6) years old is still in the pre-operational stage. According to Jean Piaget's theory of cognitive development (1936), at this stage the child cannot understand disease process and causation. It was not clear whether the children whose HIV statuses were disclosed at this early age did understand the concept of HIV.

The parents' and caregivers' opinions were in line with Piaget's theory of cognitive development which said that children understand the meaning of illness at the concrete and formal operational stage. Concrete operational stage is between 7-10 years of age. Piaget characterised the concrete operational stage by concrete-logical reasoning, where children are able to make multiple connections of causation to a single phenomenon and can understand hierarchies. Children are able to identify an external cause as the source of their illness. This was seen as the parents and caregivers had either done partial or full disclosure from the age of eight (8) to eleven (11) years. Formal Operational stage is from age 11 years and above.

Piaget characterised this stage by formal-logical thinking, where children begin to think hypothetically and abstractly. They can correlate multiple causations to illness, including external and internal factors related to their health. In this study, all the children who were above eleven years had been disclosed to. It was gathered that the pattern of disclosure in this study ranged from non- disclosure, partial and full disclosure. Partial

disclosure could pose serious problems as the child may not understand the dangers of the disease she or he suffered since it was not named as HIV. This could be even worse for those children who had not been disclosed to their treatment yet. The children may even default the medication since they would not know or had a clear understanding about it. The spread of the disease could be easy among the teenagers when they had started engaging in sexual relationships, as they would infect the partner unintentionally.

### **5.3.3 Experiences of parents and caregivers on disclosure of HIV to their children**

Parents and caregivers had some reasons for disclosure and non-disclosure. Those who had disclosed were rather compelled by certain circumstances as opposed to respecting the right of a child to know. This was revealed in the reasons they stated such as they wanted the child to understand why she or he had to take the medication, fear of infecting others as they grow into adolescents and adulthood, wanting support from others and children questioning the medication. It seems that disclosure of the HIV status to their children and adolescents yielded good results in terms of medication adherence. Once the children got to know about their HIV status, they were able to take responsibility of their health. The parents and caregivers who had done partial disclosure basically disclosed the medication as something important for the child to take rather than the disease the child had. Disclosing the HIV status to others showed that parents and caregivers were able to get support in caring for their HIV infected children.

The parents and caregivers feared that their adolescents would infect others during a sexual encounter if they were not aware of their HIV status. This meant that parents and caregivers were considerate that HIV should not be spread in the country. Another reason stated by the parents and caregivers was that children questioned their medication. Essentially, it becomes awkward to individuals to take medication when not feeling any pain or sickness in their bodies. This could be the reason why the children questioned the medication. Thus parents and caregivers were compelled to disclose the HIV status to the children and adolescents. According to the four phased model disclosure framework, the exploratory and readiness phases were missed out and

disclosure phase done. This could interfere with the type and amount of information given to the children

The reasons stated by parents and caregivers for non-disclosure of HIV status to their infected children included age and cognitive development was the most stated reason. It seems the parents and caregivers felt HIV information was complex for some children. The issue of children not in a position to keep their HIV status confidential was a concern. This showed that there was still stigma attached to HIV. It was interesting to note though that parents and caregivers did disclose the HIV status of their children to others whom they believed were trusted.

Lack of knowledge on disclosure was also a serious concern among the participants including those who had disclosed. Some parents and caregivers verbalised that they were not knowledgeable of the issue of disclosure. It can be deduced that the parents and caregivers did not get sufficient help from health facilities on disclosure. This made it difficult for them to do it as each parent did it in his or her own way. Fear of the child's reaction to the 'bad news' was another reason mentioned for non-disclosure. The parents and caregivers, who had disclosed, verbalised that their children and adolescents never had serious negative reactions after disclosure. It was not clear if this was because of the amount of information given during disclosure or the age and cognitive development of the children at the time of disclosure.

#### **5.4 CONCLUSIONS**

The findings of this study call for evidence based and practical guidelines to assist parents and caregivers with disclosure of HIV status to their infected children. The gaps identified on HIV disclosure to children, experiences of parents and caregivers regarding disclosure of HIV status and the challenges were used to formulate the guidelines. Each guideline is formulated based on an identified problem or challenge; and rationale to each guideline is presented. These guidelines will be referred to the Ministry of Health, Swaziland Nursing Council, hospital management, and supervisors in the anti-retro viral therapy (ART) clinic (actual setting for this study) upon completion of this study.

## **GUIDELINES TO ASSIST PARENTS AND CAREGIVERS ON DISCLOSURE OF HIV STATUS TO INFECTED CHILDREN**

### **5.4.1 Understanding the general concept of disclosure**

*Guideline 1: Educate parents and caregivers on the issue of disclosure of HIV status to infected children.*

- Design and distribute pamphlets with essential information to include disclosure of HIV status.
- Develop lesson plans to educate parents and caregivers on disclosure of HIV status to infected children.
- Capacitate nurses and counselors to assist parents and caregivers with relevant information to include on disclosure of HIV status to infected children.
- Schedule time to educate the public on the issue of HIV disclosure, such as at gatherings such as funerals, stokvels, etc.
- Create a friendly environment for parents and caregivers to ask freely whenever they need help on disclosure of HIV status to children.

Rationale: To ensure that all parents and caregivers understand the general concept of disclosure.

### **5.4.2 Pattern followed on disclosure**

*Guideline 2: Ensure a standard pattern is followed on disclosure of HIV status to infected children*

- Develop a standard disclosure plan in the health facility.
- Group HIV infected children according to age in the health facility.
- Assist parents and caregivers to disclose age appropriate information to infected children by indicating the amount and type of information to be shared.
- Allow parents and caregivers to verbalise their concerns and challenges on disclosure of HIV status to infected children.

Rationale: to enable parents and caregivers to follow an age and developmentally appropriate disclosure pattern.

### **5.4.3 Experiences of parents and caregivers on disclosure of HIV to their children**

*Guideline 3: Establish the experiences of parents and caregivers on disclosure of HIV status to their infected children*

- Consider family and community dynamics on disclosure of HIV status to infected children.
- Seek the support of a psychologist, social worker or counselor to prepare parents and caregivers psychologically prior to disclosure of HIV status to their infected children.
- Encourage parents and caregivers to share their fears and achievements on disclosure of HIV status to their infected children.
- Arrange debriefing sessions for parents and caregivers before, during and following disclosure of HIV status to their infected children.
- Acknowledge individuality among parents and caregivers on disclosure of HIV status to their infected children.
- Observe and respect cultural influences on disclosure of HIV status to infected children.

Rationale: To make the HIV disclosure process to infected children easier and appreciated by parents and caregivers.

## **5.5 RECOMMENDATIONS**

The recommendations are for health care practice and further research.

### **5.5.1 Recommendations for health care practice**

- Develop standard HIV disclosure protocol for children in hospitals offering comprehensive HIV management and care.



- Provide nurses and counselors with training and adequate time to competently assist parents and caregivers on disclosure of HIV status to infected children.
- Put in place initiatives to enforce privacy and protection of institution policy and norms that prevent discrimination and promote acceptance of people living with HIV.
- Disclose to children of school age their HIV status incrementally to accommodate their cognitive level and emotional maturity.

### **5.5.2 Recommendations for further research**

Further research is needed on the following:

- The experiences of children and adolescents on disclosure of their HIV status.
- Evaluation of nurses and counselors knowledge on assisting parents and caregivers with disclosure of HIV status to their infected children.

## **5.6 CONTRIBUTION OF THE STUDY**

The guidelines are designed to provide the hospital management, supervisors and nurses in the ART department a direction in terms of assisting parents and caregivers to disclose HIV status to their infected children.

The study adds value to the understanding of disclosure process by the parents and caregivers. Parents and caregivers will understand when, how and what to disclose to HIV infected children. Children may also understand why disclosure of their HIV status is important. Moreover, the community will understand their role in assisting parents and caregivers with disclosure of HIV status to infected children. Health care practices on the other hand will establish appropriate disclosure protocols.

## **5.7 LIMITATIONS OF THE STUDY**

Limitations are weaknesses or restrictions in the study (Brink et al 2014:8). There is still a stigma attached to HIV/AIDS so some people preferred to say less about it even if they have fully accepted their status. The participants might have withheld of the

information as it might expose their ignorance regarding the care and support rendered to their infected children.

The limitations of this study were that it was conducted in one hospital in the Lubombo region of Swaziland which has four regions, and therefore the findings cannot be generalised to all the hospitals and communities or for the country, Swaziland. Only caregivers and parents were included in the study. Including children who are HIV positive could provide a bigger sample and more comprehensive results. Time and finance were other limitations which was why the research was conducted in one referral hospital in the country with six major hospitals.

## **5.8 CONCLUDING REMARKS**

The findings of this study revealed a need of standard guidelines to assist parents and caregivers with disclosure of HIV status to their infected children. It was noted that parents and caregivers lacked knowledge on the appropriate age to disclose the HIV status to their infected children and adolescents, and the type and amount of information to give is not known.

This was the main reason this study was conducted. Policy guidelines are needed to assist parents and caregivers, and health workers on disclosure of HIV status to children. There is a need for health care workers on the other hand need training and guidance on the issue of disclosure. The findings of this study make a valuable contribution to the body of knowledge on disclosure in the context of HIV. The implication for this study is strengthening the education on disclosure to both the children, parents, caregivers as well as the communities at large.

## **5.9 COMMUNICATING THE FINDINGS**

Communicating the findings involves the development and distribution or giving out of a research report to appropriate audiences (Brink et al 2014:50). The researcher will communicate the results of the study to others who may find it useful.

The findings of the study will be communicated through the research report which will be sent to the Ministry of Health Research Board in Swaziland and the hospital where the study was conducted. Also dissemination of the findings will be done through publication of the research in scientific journal or even presentation at relevant for such as workshops, conferences, congresses and updates.

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## **ANNEXURES**

**ANNEXURE 1**

**Ethical clearance certificate**



**UNIVERSITY OF SOUTH AFRICA  
Health Studies Higher Degrees Committee  
College of Human Sciences  
ETHICAL CLEARANCE CERTIFICATE**

**REC-012714-039**

**HS HDC/434/2015**

Date: 9 September 2015 Student No: 4195-053-4  
Project Title: Disclosure of infected children's HIV status.  
Researcher: Cebisile Precious  
Degree: MA in Nursing Science Code: MPCHS94  
Supervisor: Prof MC Matlakala  
Qualification: D Litt et Phil  
Joint Supervisor: -

**DECISION OF COMMITTEE**

Approved

Conditionally Approved

**Prof L Roets  
CHAIRPERSON: HEALTH STUDIES HIGHER DEGREES COMMITTEE**

**Prof MM Moleki  
ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES**

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES

## ANNEXURE 2

### Letter seeking consent from hospital institution

P.O.BOX 144

Simunye

14 May 2016

The Community Health Matron

Good Shepherd Hospital

P.O.BOX 2

Siteki

Dear Matron

**RE: REQUEST TO COLLECT DATA IN THE HOSPITAL FOR ACADEMIC PURPOSESES.**

I kindly request for permission to collect data for an academic research study in the hospital ART clinic department. My research study has been approved by the Swaziland Scientific and Ethics Committee in the ministry of health.

I am currently registered with the University of South Africa (UNISA) for Masters in Nursing Science (MA NSC). I submitted my research proposal which was approved by the Research Ethics Review Committee of UNISA; hence an ethical clearance certificate was issued. The title of my research study is: ***Disclosure of HIV status to infected children in Swaziland***. My supervisor is **Professor MC Matlakala** from the above said University in the department of Health studies.

Your positive response to my request will be highly appreciated.

Yours Sincerely



Precious Dlamini

## **ANNEXURE 3**

### **Interview guide**

- How old is your child now?
- When did you learn about the HIV status of your child?
- What do you understand by disclosure of HIV status?
- How do you feel about telling the status of HIV to your infected child?
- Have you told anyone about the HIV status of your child?
- Please share with me your experience as a parents and/or care giver regarding disclosure of HIV status to your child
- Please share with me the way in which you or a parent/caregiver should go about (when, where, how, with whom, why, etc) to tell their child about HIV status to infected children and adolescents
- Is there any support you get from significant others on disclosure of HIV status to your child?
- What can you say to a parent with an HIV infected child on disclosure?

## **ANNEXURE 4**

### **Consent form and participant information leaflet**

I hereby agree to participate in an in-depth interview related to the study on the disclosure of HIV status to infected children and adolescents by their parents or caregivers in Lubombo Region of Swaziland. I understand that my interview will be audio-taped. I understand that only the researchers will have access to this audio recording. The audio tapes will be destroyed after five years of completion of the study.

I understand that I am participating freely and without being forced in any way to do so. I also understand that although I am participating at any point should I not want to continue I can stop and that this decision will not in any way affect me negatively.

I understand that this is a study whose purpose is not necessarily to benefit me personally in the immediate or short term. I understand that my participation will remain confidential. I hereby agree to the audio tape-recording of my participation in the study.

Signature of participant ..... Date.....

### **Participant Information Sheet**

#### **Introduction**

My name is Precious C Dlamini. I am currently conducting my Master's dissertation in the School of Health Studies University of South Africa. I am conducting a research on the disclosure of HIV status to infected children and adolescents by their parents or caregivers in Lubombo Region of Swaziland. This research will make an important contribution to our understanding of disclosure and issues that surround pediatric disclosure of HIV. This will assist stake holders in formulation of policies regarding HIV disclosure and prevention.

#### **Purpose of the study**

You are being asked to participate in a research study on disclosure of HIV status to infected children/adolescents. The purpose of this study is to develop support guidelines

that will assist with disclosure to HIV infected children by their parents or care givers. HIV disclosure is very critical in the prevention and management of HIV and AIDS. Since parents are very crucial in the management and prevention efforts, it becomes imperative that their understanding and perception in this subject matter be explored.

### **Procedures and Duration**

If you decide to participate in this study, you will be engaged in an in-depth interview on issues relating to HIV disclosure. Your experience and knowledge in this matter will be explored. The interview will be audio taped and it may take between 30 minutes to 1 hour to complete. You are free to ask for clarification on any questions that you do not understand at any point or during the interview. If you have questions about the study, you may ask at any time. After the study you will be asked to come for the feedback of the results.

### **Risks and Discomforts**

Some of the questions that will be asked are of a personal nature that relates to life style issues and so you may feel embarrassed to respond to them. The answers you will provide will be kept private and confidential. In a situation that you feel very uncomfortable about any question, you will be free to decline answering any question(s) that you do not want to answer.

### **Benefits and/or Compensation**

There are no direct benefits/compensation that will come from participating in this study. The results will empower help in formulation of HIV prevention policies that will benefit the nation as a whole

### **Confidentiality**

If you indicate your willingness to participate in this study, your participation will be on a voluntary basis. You are free to withdraw from the study at any point. Information collected about you and your responses will be treated with utmost confidentiality. The interview guide to be used during the interview will be identified by a coded number and

a pseudonym shall be used instead of your name. This consent form will be separated from the coded interview guide and stored in a secure place.

**Additional Costs**

You will not incur any expenses from participating in this study.

**Offer to Answer Questions**

If you have any questions on any aspects that are not clear to you about this study, please feel free to ask me before you sign this form. You are free to take as much time as you can to think about it.

**Authorization**

By signing this form, it means that you have read and understood the information provided above, had all your questions answered, and decided to participate voluntarily without being coerced. You authorize me, field, and academic supervisors to access the information that you will have provided. The information you provide will only be used for the purpose of this study.

Signature of Respondent..... Date.....

Signature of Researcher..... Date.....

For any further information pertaining to this study, please feel free to contact me at:

PO Box 144, Simunye  
Cell: 76131941  
E-mail: [cebshlophe@yahoo.com](mailto:cebshlophe@yahoo.com)

## **YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP**

If you have any questions concerning this study or consent form beyond those answered by the investigator, including questions about the research, your rights as a research subject or research-related injuries: or if you feel that you have been treated unfairly and would like to talk to someone other than a member of the research team, please feel free to contact.

### **Research and Ethics Committee, Ministry of Health**

Mbabane Swaziland; Telephone: 76054727 OR

### **My supervisor, Professor MC Matlakala**

University of South Africa; Telephone: 012 429 6770; Email: matlamc@unisa.ac.za

### **The Psychologist, Mr Thokozani Zwane**

Good Shepherd Hospital; Telephone: 00268 782 150 20



## **SISWATI VERSION OF THE CONSENT FORM**

Ngiyavuma kungenela lolucwaningo lelu lapha eLumbonjenin mayalana nekwatisa umntfwana kutsi uphila neligciwane leHIV engatini yakhe. Ngiyacondza kutsi lokucocisana kutawutsejtulwa.Ngiyacondza kutsi lenkhulumo letsejtuliwe itawu sentjetiswa batsebuli kuphela,nabo batawu yigcina iminyaka lesihlanu nje kuphela emuva kwalelucwaningo.

Ngiyacondza kutsi ngilungenela ngitivumela mine kungenela lolucwaningo ngaphe kwekuphocenelelwa ngumuntfu.Ngiyacondza futsi nekutsi noma ngivumile kulungenela lolucwaningo,nangabe angisafisi kucubeka nalo ngivumelekile keyekela. Loko kungeke kungitsikamete ngalutfo.

Ngiyacondzisisa kutsi lolucwaningo alunakungikhokhela ngalutfo mine ngekulungenela.Ngiyacondza kutsi kulungenela kwami kutawugcinwa kuyimfihlo kanye naloko lengitakukhuluma.

Sayina..... Lusuku .....

Ngiyavuma kutsi inkhulumo yami kulelucwaningo itsetjulwe.

Sayina..... lusuku .....

### **Participant Information Sheet – S iSwati version**

#### **Singeniso**

Ligama lami ngingu Precious ngiwaka Dlamini.Ngingu nesi lochubeka nemfundvo yakhe enyuvesi yase sikhwahlande. Ngenta lucwaningo kubatali labane bantfwana labaphila neligciwane le HIV ngekubatisa ngesimo samo.Lelucwaningo litawusita ngekwati kabanti mayelana nekwatisa bantfwana ngesimo samo sabo se HIV. Loko kutawusita tishaya mtsetfo ekwakheni imigomo letsite mayalana nekwatisa bantfwana labaphila neligciwane le-HIV eSwatini.

## **Injongo yalelucwaingo**

Uyacelwa kutsi ungenele lucwaningo mayelana nekwatisa bantfwana labaphila neligciwane le HIV ngesimo sabo. Inhloso yalo lucwaningo kutsi kwakhiwe imigomo yelive letawusita batali kancono mayelana nekwatisa bantfwana ngesimo sabo sengati. Kwati ngesimo sakho sengati kubaluleke kakhulu ekuvikeleni kwandza kweligciwane le- HIV eveni. Batali ngibo lababaluleke kakhulu ekuvikeleni kwandza kweligciwane kubantfwana, ingako nje imivo yabo itawubukwa kulelucwaningo.

## **Incubo ne sikhatsi**

Uma uvuma kulungenela lolucwaningo, utawubutwa kabanti mayelana nekwatisa umntfwana kutsi uphila neligciwane le-HIV. Lwati lwakho ngaloku lutawuhloliswa ngalokujulile. Loko kucocisana kutawutsejula, kutawutsatsa imizuzu lengemashumi lamatsafu kuya e-aweni linye. Uvumelekile kubuta lapho ungevisisi kahle khona kusachubeka lokucocisana. Uma unemibuto ngalolucwaningo, ungabuta noma nini. Emuva kwalolucwaningo, utawunikwa imiphumela yalo.

## **Bungoti ne nekungakhululeki kahle emoyeni**

Leminye yalemibuto imayelana nendlela lophila ngayo kungenteka utivele ungakakhululeki kuyiphendvula. Letimpendvulo lotatinika titawugcinwa tiyimfihlo yalolucwaningo. Uma utivela ungakhululeki ngaleminye imibuto, uvumelekile kungayiphendvuli leyo mibuto.

## **Inzuzo noma sincephetelo.**

Lolucwaningo alunayo inzuzo noma sincephetelo kumuntu ngamunye lotalungenela. Lemiphumela itawusita ekwakheni imigomo yelive mayelane nekuvikela kwandza kweligciwane le HIV eveni.

## **Kugcinwa kwetimpendvulo**

Uma uvuma kulungenela lolucwaningo, loko utakwenta ngekutikhetsela wena. Uvumelekile kuphuma uma ungasatsandzi. Yonkhe inkhulumo ngawe

netimphendvulo takho titawugcinwa tiyimfihlo. Kungeke kusenjtetiswe libito lakho sibibili lulucwaningo.

### **Kungeteka kwetindleko**

Kute tindleko lotatkipha mawungenela lolucwaningo.

### **Kuvuma kuphendvula imibuto.**

Uma unemibuto ngalolucwaningo uvumelekile kungibuta ungaka sayini,uvumelekile kutsatsa sikhatsi sakho kucabangisisa ngaloku.

### **Kugunyatwa ngumtsetfo.**

Ngekusayina lemaphepha lawa kusho kutsi uyifundzile wayicondzisisa yonkhe lemininingwane yalolucwaningo. Imibuto yakho iphendvulekile wase uyavuma kulungenela lolucwaningo ngaphandle kwekuphocenelelwa.Uyabavumela bahloli,kanye nalabo lababasitako kutsi basebentise leyo mininingwane loyinetile kulokucocisana. Leminingwane yakho itawusentjetiswa kulelicwaningo kuphela.

Sayina lophendvulako..... Lusuku.....

Sayina umhloli ..... lusuku.....

Uma ufuna kuva kabanti mayalana nalolucwaningo,Ungangitsintsa kule tinombolo leti ngentansi.

PO Box 144 Simunye

Cell: 76131941

E-mail: [cebshlophe@yahoo.com](mailto:cebshlophe@yahoo.com)

Uma unalenywe imibuto mayalana nalolucwaningo ngetulu kwaleyo lephendvulwe ngulomhloli, noma utivela uphatseke kabi kusakhulungiswana kulolucwaningo, uvumelekile kuchumana nelihhovisi letemacwaningo etiko letemphilo kangwane kuletinombolo letingentansi.

**Research and Ethics Committee, Ministry of Health**

Mbabane Swaziland; Telephone: 2404 7245; Cell 76054727

**My supervisor, Professor MC Matlakala**

University of South Africa; Telephone: 012 429 6770; email: [matlamc@unisa.ac.za](mailto:matlamc@unisa.ac.za)

## ANNEXURE 5

### Ethical clearance from Swaziland Ministry of Health

Telegrams:  
Telex:  
Telephone: (+268 404 2431)  
Fax: (+268 404 2092)



**MINISTRY OF HEALTH**  
P.O. BOX 5  
MBABANE  
SWAZILAND

THE KINGDOM OF SWAZILAND

8<sup>th</sup> June, 2016

Precious C. Dlamini  
Principal Investigator  
STUDENT  
MBABANE

REF: MH/599C/FWA 000 15267/ IRB 000 9688

Dear Ms. Dlamini,

**RE: DISCLOSURE OF HIV STATUS TO INFECTED CHILDREN BY THEIR PARENTS IN SWAZILAND.**

The committee thanks you for your submission to the Swaziland Scientific and Ethics Committee, an expedited review was conducted.

In view of the importance of the study and the fact that the study is in accordance with ethical and scientific standards, the committee grants you authority to conduct the study. You are requested to adhere to the specific topic and inform the committee through the chairperson of any changes that might occur in the duration of the study which are not in this present arrangement.

The committee requests that you ensure that you submit the findings of this study (**Electronic and hard copy**) and the data set to the Secretariat of the SEC committee.

*The committee further requests that you add the SEC secretariat as a point of contact if there are any questions about the study on 24040865/24044905.*

Yours Sincerely,

  
**RUDOLPH T.D. MAZIYA**  
THE CHAIRMAN, SEC  
cc: SEC members

