

**EXPERIENCES OF HEALTHCARE PROVIDERS  
REGARDING MANAGING CHILDREN DIAGNOSED  
WITH HIV AND AIDS IN A PUBLIC HOSPITAL IN  
GAUTENG**

by

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“Every challenge you encounter in life is a fork in the road. You have the choice to choose which way to go, backward, forward breakdown or breakthrough.-  
Ifeanyi Enoch Onuoha.”

## DECLARATION

Student number: 27491898

I Mercy Thandiwe Ndacayisaba, hereby declare that this research study entitled **Experiences of healthcare providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng** is my own work and that all sources consulted or quoted have been indicated and acknowledged by means of complete references. I further declare that this work has not been submitted for any other degree at any other institution.

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Mercy T Ndacayisaba

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Date

## DEDICATION

This study is dedicated to the following important people in my life:

- My mother **Monica Nkosi** who worked so hard to give me the education she could afford.
- My grandmother **Faniswako Qwabe** who passed away just before I completed this study. I know **Mnguni** you would have been proud of me. May your soul rest in peace.
- My husband Thomas for being always supportive throughout the study.
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## ABSTRACT

The aim of the study was to explore and describe the experiences of health care providers regarding managing children hospitalised with HIV and AIDS in a public hospital in Gauteng province. A qualitative, explorative, descriptive and contextual design was used to conduct the study. The population consisted of all health care providers who provided care to children diagnosed with HIV and AIDS in a public hospital in Gauteng. The participants included nurses, doctors, physiotherapist, social workers, clinical psychologist and dieticians. Purposive sampling was used to select the participants who provided care to children diagnosed with HIV and AIDS for at least a year. Three focus group interviews were used to collect data. Data was analysed using Tesch's method. An independent co-coder was also used.

Two themes was developed from the study which was: factors affecting disclosure of positive HIV status in children and outcomes of non-disclosure of HIV status. It was recommended that further research be conducted with other public hospitals of different levels on the same topic. It was also suggested that further research be done to develop guidelines that can be implemented in the pediatric sector by health care professionals for the disclosure of HIV status to infected children. The hospital where the study was done is hoped to take it as a matter of concern and put the suggested recommendations into place.



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HIV:	Human Immunodeficiency Virus	
AIDS:	Acquired Immunodeficiency Syndrome	
UNAIDS:	Joint United Nations prevention on HIV/AIDS	
P.M.T.C.T:	Prevention of mother to child transmission of HIV	
R.N.A:	Ribonucleic Acid	
HPCSA:	Health professions council of South Africa	
SANC:	South African nursing council	
CEO:	Chief Executive Officer	



DOH: Department of health	
ARV: Antiretroviral	
FTT: Failure to thrive	
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## 1. OVERVIEW OF THE STUDY

### 1.1 INTRODUCTION AND BACKGROUND

Globally, by the end of 2014 an estimated 3.2 million children were living with HIV and AIDS of which an estimated 91% of these children were in Sub-Saharan Africa (UNAIDS, 2015:1-2). In South Africa, about 340,000 of the 6.8 million of the population living with HIV and AIDS were children aged 0 to 14 years in 2014 (UNAIDS, 2015:1-2; UNAIDS South Africa, 2016:1). Children mostly contract HIV through vertical transmission due to non-adherence to prevention of mother to child transmission (PMTCT) principles during delivery or breastfeeding, which accounts for more than 90% of HIV infections (Ngwende, Gombe, Midzi, Tshimanga, Shambira & Chadambuka, 2013:1; Wiysonge, Shey, Kongnyung, Sterne & Brocklehurst, 2011:5). Another mode of transmission is horizontal whereby children get infected as a result of high risk behaviours related to sexual abuse, early sexual debut and drug abuse, which accounts for less than 10% of HIV and AIDS infections (Awotidebe, Phillips & Lens, 2014:11806; Hockenberry & Wilson, 2009:939; Rudolph, Rudolph, Lister & Gershon, 2011:1164). Some of the children, especially those with vertical transmission, grow up without the knowledge that they are HIV positive, until they make deductions based on opportunistic infections they suffer from or repeated hospitalisation.

Two general patterns of HIV and AIDS progression have been observed among perinatal acquired HIV infections: there are those children who are fast progressors and slow progressors. The fast progressors are estimated to be 25% of all perinatal acquired HIV infections who develop manifestations of AIDS in their first year of life and become severely ill during infancy. Slow progressors are children who may not develop manifestations of AIDS until the age of school entry (6 to 10 years) or even puberty or adolescence, between the ages of 11 up to 17 years (Rimawi, Rimawi, Micallef, Pinckney, Fowler & Dixon, 2014:1; Davis, 2013:692; Khakshour, Moghadam, Kiani, Saedi & Zarif, 2014:146). These slow progressors, usually children of 10-17 years, access health care and sometimes become admitted to hospital with opportunistic infections. Most children are not told by their guardians or parents that they are HIV positive. The children are usually admitted for the following conditions: failure to thrive where the patient is severely emaciated and reluctant to eat, severe diarrhoea, chest infections like tuberculosis and pneumonia, multi-organ



failure and liver diseases (Department of Health, 2013:9.2). Various diagnostic procedures are carried out and medicines administered routinely during hospitalisation as part of the management of AIDS. The procedures carried out on children lead these children to ask their health care providers during hospitalisation about their diagnosis, the reasons for procedures conducted on them, and the medicines administered (Fair & Walker, 2012:420-421; McCleary-Sills, Kanesathasan, Brakash, Vujovick, Dlamini, Namisango, Nasaba, Fritz, Wong & Bowsky, 2013:53-56). The health care providers that are faced with such questions posed by the children include nursing staff who attend to the physical needs of the children during hospitalisation. Among the tasks performed are lowering temperature, ensuring intake of nutritious food, hygiene and taking of medication to ensure recovery according to the scope of practice (South African Nursing Council, 1984:2). Doctors, physiotherapists, occupational therapists, dieticians, and social workers are also involved in the provision of care according to their scope of practice (Allied Health Professions Act no 63 of 1982; Health Professions Act no 56 of 1974). Not all health care providers' scope of practice permits them to disclose a diagnosis to patients.

Providing an explanation regarding patients' condition would be the first step in ensuring the child complies with treatment, lives a positive life and enjoys improved psychological well-being (Mahloko & Madiba, 2012:5). However, some categories of health care providers in South Africa are not able to disclose the diagnosis and explain the condition to patients due to ethical and legal provisions (Le Roux-Kemp, 2013:226-228). Disclosing an HIV and AIDS diagnosis to children as patients by any member of the multidisciplinary team (including the doctors) is even more difficult as it should be done with the parents or guardians' permission (Heeren, Jemmott, Sidloyi, Ngwane & Tyler, 2012:47; Hamadache, Donaghy, Connan et al, 2014:5). Croskery (2012:50) indicated that according to a medical-legal standpoint the explanation of a diagnosis to a patient is the physician's duty. Doctors find that the development of the cognitive level of children makes it difficult for them to explain the diagnosis to children even though the Child Care Act (Act No. 38 of 2005: Section 130) permits that children who are 12 years and above have the right to consent to HIV testing. The explanation of results to a 12 year old becomes a problem as they do not have sufficient cognitive maturity to understand the benefits, risks and social implications related to the diagnosis. This is the reason why parents or guardians need to give consent and be present when the doctor discloses the HIV and AIDS diagnosis to the child (Le Roux-Kemp,



2013:226-228). Without the parents or guardians' permission, no healthcare provider would disclose an HIV and AIDS diagnosis to a child.

Health care providers are challenged continuously to answer questions raised by children regarding their diagnosis as at an adolescent age children transit from concrete to operational thinking, according to Piaget's theory (MacIntosh, Helms & Smyth 2003:1726). The theorist explained that the concrete thinking that is in place among children of 7-10 years means that the child thinks in observable terms. When the child reaches operational thinking at the age of 11-13 years, the child thinks in more abstract terms and this means that a child thinks about possibilities and through hypothesis (MacIntosh, Helms & Smyth, 2003:1726). Piaget's theory of cognitive development confirms that a child who is at an adolescent age and receiving a chronic diagnosis will start enquiring about his or her diagnosis, the causes, treatment, prognosis and future implications. Children diagnosed with HIV and AIDS request health care providers to explain their diagnosis, treatment and prognosis, hence this becomes a challenge as to how to manage these children's questions, if the parents or guardians did not consent to it.

It has been recommended that disclosure of a positive HIV status to children should be done with caution and as a process rather than a once-off intervention to avoid psychological trauma to the children (Brown, Oladokun, Onesinusi, Ochigho, Adewole & Kanki, 2011:1057; Heeren et al; 2012:52). Cantrell, Patel, Mandrell and Grissom (2013:304) and Vreeman, Gramelspacher, Gisore, Scanlon and Nyandiko (2013:18466) contend that in the United States of America there is no clear legal mandate concerning most HIV disclosure dilemmas to children who are HIV positive, when the parents or guardians have consented to testing but decided not to disclose the HIV and AIDS diagnosis. If the parents decided to keep the diagnosis a secret from the child, the US federal and state laws are not explicit regarding how disclosure of HIV positive status to children should be done. Similarly, Le Roux-Kemp (2013:226-228) explains that the legal system of South Africa also does not include any clear guidelines about the disclosure of positive HIV status to children. It is recommended that there should be consideration of the cognitive, emotional and social development, clinical state and psychosocial ability of the child and parents to adjust if disclosure is considered. In South Africa the silence regarding disclosure of HIV and AIDS status to children is dependent on whether parents or guardians will give consent. As such the parents' or guardians' consent is to date the only mandate to permit the doctor to disclose the diagnosis to the children. Health care providers are therefore confronted with questions



they cannot provide answers to due to legal and ethical guidelines as most parents do not consent to the disclosure of positive HIV status to children.

This study therefore will explore and describe the experiences of health care providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng.

## 1.2 PROBLEM STATEMENT

The researcher is a paediatric nurse who observed that some children in early adolescence are admitted to the hospital diagnosed with opportunistic infections, although they are not aware of their positive HIV status as their parents or guardians did not disclose the diagnosis to them. As such children sometimes request explanations from the health care providers as to why they have been admitted or must take medications. Some of the children diagnosed with HIV and AIDS have to take treatment twice daily without knowing what the medication is being taken for.

As children above 11 years have enquiring minds they may search for information on the administered medicines. Indications for medicine use might provide a clue as to their diagnosis and children may ask more questions (MacIntosh, Helms & Smyth 2003:1726). On the other hand when children confront health care providers regarding their medicines it becomes difficult to tell the children what the diagnosis is as disclosure of HIV and AIDS status can only be done by the medical doctor after informed consent and in the presence of parents or guardians (Hereen et al., 2012:47).

Research studies have reported that there is continued non-disclosure of positive HIV diagnoses by parents and guardians to children of an adolescent age. The children enquire from the health care providers to know what their diagnoses are during medical provision (Krauss, Letteney, DeBaets, Baggaley & Okero, 2013:1; Siu, Bokeera-Kitaka, Kennedy, Dhabangi & Kambugu, 2012:606). Health care providers are not allowed to disclose the diagnoses due to legal constraints (Le Roux-Kemp, 2013:226-228), resulting in stress-related health problems among the health care providers (Stanley & Matchet, 2014:139; Sheraz, Wajid, Sajid, Qureshi & Rizwan, 2014:205). There is a scarcity in the literature which deals with experiences of health care providers regarding managing children diagnosed with HIV and AIDS during the provision of health care. This brought about the need for the



researcher to explore this phenomenon of experiences of health care providers regarding managing children diagnosed with HIV and AIDS during the provision of care. The findings of the study may raise awareness of the needs and support required by children diagnosed with HIV and AIDS.

### **1.3 SIGNIFICANCE OF THE PROPOSED STUDY**

The study will raise awareness among health care providers regarding the need to disclose the HIV positive status to children of ages above 11 years. The health care providers will in addition have a platform to communicate and share their concerns regarding parents who do not disclose the diagnosis to their children. It is also expected that health care providers will be assisted to encourage and support parents/guardians to consent to disclosure of the diagnosis to their children by engaging in dialogue with them to consider this option.

The study has the following significance for clinical practice: health care providers, including nurses, will be made aware of the need to disclose positive HIV status to children by motivating the parents to agree to disclosure. The health care providers will be able to navigate the means to disclose to the children. The study has significance for the education of health care providers, as the topic under discussion could be included in the curriculum. The educators need to be made aware of the findings of the study. Furthermore, the study has significance for health care research. More studies may be conducted to inform strategies to be developed to encourage the disclosure of HIV positive diagnoses to children.

### **1.4 RESEARCH QUESTION**

The research question guiding the study was:

What are the experiences of health care providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng?



## 1.5 AIM AND OBJECTIVES

### 1.5.1 Research aim

The aim of this study was to explore and describe the experiences of health care providers regarding managing children hospitalised with HIV and AIDS. This information can then be used to develop strategies to promote efficient and quality care to the patients and their parents and guardians.

### 1.5.2 Research objective

The objective of the study was:

To explore and describe the experiences of health care providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng.

## 1.6 CONCEPT CLARIFICATION

The following concepts will be clarified for the reader:

- **Human Immunodeficiency Virus (HIV)**

HIV is a human retrovirus. A retrovirus contains Ribonucleic acid (RNA) as its genetic material as well as the enzyme reverse transcriptase required to translate Ribonucleic acid to Deoxyribonucleic acid within the human host cell. Once HIV's RNA is transcribed into human Deoxyribonucleic acid, it becomes a functional virus capable of producing a profound immune deficiency leading to the development of opportunistic infections and to AIDS (Van Dyke, 2012:28-36). In this study HIV will refer to children who are infected with this virus, although most of them are not aware of that.

- **Acquired Immunodeficiency Syndrome (AIDS)**

HIV is said to be acquired because the virus is not inherited as it enters the body from outside. Immunity is the body's natural ability to defend itself against infection and disease. Deficiency is the weakening of the immune system, so that it can no longer defend itself against passing infections. Syndrome is a medical term for a collection of specific signs and symptoms that occur together and that are characteristic of a particular condition (Van Dyke 2012:1). In this study AIDS refers to the state of illness which the children suffer from





because of severe weaknesses in their immunity caused by the HIV virus. The children are admitted into hospital wards suffering from HIV/AIDS related conditions including failure to thrive, severe diarrhoea, chest infections like pneumonia and tuberculosis, and cardiac and liver diseases.

- **Child**

According to the Children's Act no 38 of 2005, a child means a person under the age of 18 years (Republic of South Africa 2006: section 1). In this research study the focus is on children aged 11 to 13 years old, who are hospitalised and who question their health care providers about their hospitalisation and diagnosis. The paediatric wards admit children only up to 13 years of age.

- **Health care providers**

According to the National Health Act no 61 of 2003, this means a person providing health services in terms of any law, including the Allied Health Professions Act no 63 of 1982, Health Professions Act no 56 of 1974, and Nursing Act no 33 of 2005. All the health care providers covered under these Acts (excluding the Nursing Act no 33 of 2005) are registered with the Health Professions Council of South Africa (HPCSA). Health care providers include doctors, physiotherapists, occupational therapists, dieticians and social workers. Nurses on the other hand are covered by Nursing Act no 33 of 2005 and they include professional nurses, enrolled nurses and nursing auxiliaries; they register under the South African Nursing Council (Republic of South Africa, 2004: volume 469; Republic of South Africa, 2006: section 30). All the health care providers mentioned here work with children diagnosed with HIV and AIDS.

- **Professional Nurse**

According to the Nursing Act no 33 of 2005, this is a person qualified and competent to independently practise comprehensive nursing in the manner and to the level prescribed and who is capable of assuming responsibility and accountability for such practice. The performance of the professional nurse is based on physical, chemical, psychological, social, educational and technological means applicable to health care practice ( Republic of South Africa, 2005: section 30; SANC, R2598:2).



- **Enrolled Nurse**

According to the Nursing Act no 33 of 2005, this is a person educated to practise basic nursing in the manner prescribed. The enrolled nurse follows acts and procedures as part of a nursing regimen planned and initiated by a registered nurse and carried out under supervision (Republic of South Africa, 2005: section 30; SANC, R2598:4).

- **Nursing Auxiliary**

According to the Nursing Act no 33 of 2005, this is a person educated to practise elementary nursing care in the manner and to the level prescribed. The nursing auxiliary follows acts and procedures as part of a nursing regimen planned and initiated by a registered nurse and carried out under supervision ( Republic of South Africa, 2005: section 30; SANC, R2598:5).

- **Parents/ Guardians and Caregivers**

According to Children’s Act no 38 of 2005, a parent or guardian is a person who has parental/ guardianship rights and responsibilities stated in section a18 of the Act and who has specific or full responsibility in respect of the child. The responsibilities include safeguarding the child and maintaining the child, and the parent/guardian is involved in legal matters which concern the child (Republic of South Africa Government Gazette, 2006: section 1). The term includes adoptive parents but excludes biological fathers of a child conceived through rape or a person who is biologically related to the child by reason of being a gamete donor for the purposes of fertilisation, or a parent whose responsibility and rights have been terminated. In this study the parents/ guardians and caregivers are all the people who take care of the children admitted into the hospital diagnosed with HIV and AIDS maintaining and making decisions in all areas of the child’s life.

- **Disclosure**

According to Vreeman et al. (2013:18466) disclosure refers to a child gaining knowledge of his or her own HIV status by being informed by another person. In this study, the children’s HIV status is not disclosed to them by their parents or guardians when coming for hospitalisation.



- **Experiences**

These are an individual's subjective evaluation (i.e. affective, cognitive, and behavioural) of events related to his/her activities which begin before, during, and after an event (Wing Sung Tung & Ritchie, 2011:1369). In this study, experiences will mean what the health care providers have observed and noticed while managing children hospitalised with conditions relating to HIV and AIDS.

- **Manage**

This is the process whereby, human, financial, physical and information resources are employed in order to reach goals. It includes the following sequence of events: what needs to be done, how it should be done, who should do it and finally checking if it was carried out (Algahtani, 2014:74). In this study, the term 'manage' will refer to the general and specific care given to children during hospitalisation, including the responses and answers the health care providers give the children who enquire about their diagnosis and medication.

## **1.7 ASSUMPTIONS OF THE STUDY**

Assumptions are statements that are taken for granted or are considered true, even though they have not been scientifically tested. In studies assumptions are embedded in the study design, and interpretation of findings (Burns, Grove & Gray, 2013: 41-42). The assumptions used in the study were as follows: ontological, epistemological, theoretical and methodological.

### **1.7.1 Paradigm**

According to Polit and Beck (2012:11), a paradigm is a world view, a general perspective on the complexities of the real world. The naturalistic paradigm was used in this study. According to Polit and Beck (2012:12-13) the naturalistic paradigm assumes that the knowledge in a research inquiry can be obtained through close researcher and participant interaction. The researcher becomes part of the enquiry as he or she listen to participants' experiences to obtain the facts. This study was also context bound and the naturalistic paradigm also supports contextualised studies. This researcher chose this paradigm as it fits the study design very well and further details will be explained under each assumption.



### **1.7.2 Ontological assumptions**

This paradigm is based on the belief that reality is multiple and subjective and mentally constructed by individuals (Polit & Beck, 2012:11-16.). In this study the assumption was that during the empirical enquiry multiple truths will emerge as participants communicate their lived experiences regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng.

### **1.7.3 Methodological assumptions**

According to (Polit & Beck, 2012:13.) methodological assumptions refer to how the researcher will obtain information. In this study the researcher interacted with participants by posing the main questions and then allowing the participants to relate their views on the topic under discussion, which was experiences of health care providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng. The researcher also used extra probing questions to verify information or to direct the conversation until the data reached saturation.

### **1.7.4 Epistemological assumptions**

According to Burns, Grove and Gray (2013: 693), epistemology is a view of knowing and knowledge. It is about the relationship between the researcher and the participants. It is believed that the researcher will interact with those taking part in the study in order to generate knowledge (Polit & Beck, 2012:11-16). This paradigm suits this study well because the researcher and moderator interacted with the participants during data collection to create new information on the experiences of health care providers regarding managing children diagnosed with HIV and AIDS.

### **1.7.5 Theoretical assumptions**

The study was based on Oral Robert's theory of the "whole person" as it focuses on the promotion of health while managing physical, social and emotional well-being. A person has a mind, body and soul or spiritual according to Oral Roberts University, Anna Vaughn College of Nursing (2015-2016:8) and this make a man an integrated bio-psychosocial being. These components that make up a person relate to the following meaning, emotional or mental, body or physical and soul or spiritual social wellbeing. The children hospitalised with HIV and AIDS have a condition that is physical, but they should be cared for as a whole



as they have enquiring minds that require answers from health care providers. The physical, social, and mental wellbeing of the children according to the theory refers to:

- Physical/body According to Oral Roberts University, Anna Vaughn college of nursing (2015-2016:8) the body includes those processes that are physiological (biological) in nature. In this study children are diagnosed with HIV and AIDS as they are admitted with different illnesses which leads to destabilisations of their physical wellbeing.
- Mind/Emotional/intellectual: According to Oral Roberts University, Anna Vaughn college of nursing (2015-2016:8), the mind includes those processes that can be described as emotional, volitional, and intellectual. In this study non-disclosure of positive HIV status to children mentally affected the health care providers, parents and guardians including the children.
- Spirit/soul According to Oral Roberts University, Anna Vaughn college of nursing (2015-2016:8) the concept spirit refers to the part of the person that is in communion with God. Communion is the sharing or exchanging of intimate thoughts and feelings, especially when the exchange is on a mental or spiritual level. In this study communication as a means of sharing emerged between the health care providers, parents and children. The spiritual component of communicating with God was not communicated by participants.

To attain this, the researcher established a dialogue with health care providers to create awareness on the questions the children are asking regarding being hospitalised, so that the children are managed as whole people and not only in terms of the symptoms and signs they are presenting with.

## 1.8 RESEARCH METHODOLOGY

A qualitative research design was used to explore and describe the research question, i.e. the experiences of health care providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng. An explorative, descriptive, and contextual design was followed as the best approach for this study. The qualitative design was followed as it fits the study well as it uses a systematic, interactive approach to describe life experiences and give meaning to the experiences (De Vos et al., 2011:308; Polit & Beck, 2012:723; Burns & Grove, 2009:6). Purposive sampling was chosen, which is a non-probability



sampling technique whereby the researcher selected participants based on personal judgment about which ones will be most informed on the phenomenon that is being researched (Polit & Beck, 2012:739).

In this research study, focus group interviews were the method used to collect data as it was considered the best way to explore the phenomenon of experiences of health care providers in managing children diagnosed with HIV and AIDS in a public hospital in Gauteng. Three focus group interviews were conducted consisting of six to eight people per group. Data collection involved three phases which included preparation for the interview, interviewing and the post-interview phase. For more information see chapter two. Tesch's method of qualitative data analysis was used, as explained well in Cresswell (2003:192). Details will be explained as well in chapter 2.

## 1.9 ETHICAL CONSIDERATIONS

According to De Vos, Strydom, Fouche and Delport (2011:114) and Polit and Beck (2012:727) ethics is the system of moral values that is concerned with the degree to which research procedures adhere to professional, legal and social obligations to the study participants.

Permission to conduct the study was obtained from the University of Pretoria's Ethics Committee and the chief executive officer of the tertiary hospital where the study was conducted. The ethical principles adhered to were beneficence, respect for human dignity and justice (Polit & Beck, 2012:152-155). A psychologist was also provided.

### 1.9.1 Beneficence

According to Polit and Beck (2012:720) this ethical principle imposes a duty on researchers to minimise harm and maximise benefits to study participants as either individuals or society as a whole.

- **Right to be free from harm and discomfort**

This principle was ensured by doing the following: Permission to conduct the study was obtained from the University of Pretoria's Ethics Committee and the chief executive officer (CEO) of the tertiary hospital where the study was conducted. The participants were not



subjected to unnecessary risk or harm or discomfort. Since this study did not deal with physical intervention, caution was taken during interview session not to evoke stress or unnecessary grief or emotion. The moderator was very thoughtful and considerate when using wording and probing strategies. The moderator avoided pressing the participants to talk when they showed signs of emotional disturbance, but in any case the participants did not show signs of emotional disturbance during the discussions. Furthermore the moderator made sure that participants did not use words that would hurt others who may have children or family members who are living with HIV and AIDS. Steps were taken during probing not to evoke the participants' deep-seated fears and anxieties which might make the participants very uncomfortable (Wood & Harber, 2010:253; Polit & Beck, 2012:152-153).

- **Right to protection from exploitation**

The participants were reassured that their participation and the information they provide will not be used against them in any way. The participants were asked for consent and were informed about the discussion time which was estimated to be 35 to 45 minutes but the interview concluded after around 55 minutes. The researcher took steps not to exploit the participants but to keep in a relationship of a researcher-participant role. The focus group interview was conducted for the study purposes only (Polit & Beck, 2012:153; De Vos et al., 2011:117).

### **1.9.2 Respect for human dignity**

According to Wood and Harber (2010:253) and Polit and Beck (2012:154), this ethical principle includes the right to self-determination and the right to full disclosure.

- **Self determination**

Self-determination means that prospective participants have the right to decide voluntarily whether to participate in a study without penalties or prejudicial treatment. The participants were informed that it was their right to ask questions, to withdraw from the study and to refuse to give information. No participants were coerced to take part (Polit & Beck, 2012:154).

- **Full disclosure**

Here the researcher has to fully describe the nature of the study, the person's right to refuse participation and the researcher's responsibility, and likely risk and benefits. The participants were fully informed that they were not coerced, and participation was voluntary (Polit & Beck, 2012:154).



### 1.9.3 Justice

According to De Vos et al. (2011:253) and Polit and Beck (2012:155), this ethical principle includes participants' right to fair treatment and their right to privacy.

- **Right to fair treatment**

This principle was assured in this research study by doing the following: The participants were informed about the criteria used to sample the prospective participants. The participants were informed about the benefits of the research, i.e. that it will help in generating information to help health care providers in similar situations to manage children diagnosed with HIV and AIDS. Participants were informed that if they declined to participate in the study they will not be subject to unfair treatment or any kind of ridicule. Participants were respected all the time (Polit & Beck, 2012:155).

- **Right to privacy**

Participants' privacy was respected through out the study. The participants were informed that the data provided would be kept in strictest confidence. No names were used that identified the participants. The recorded data was identified as focus group 1, 2, 3 and participants were also assigned numbers (Polit & Beck, 2012:155).

## 1.10 ORGANISATION OF CHAPTERS

CHAPTER ONE: Overview of the study

CHAPTER TWO: Research design and methodology

CHAPTER THREE: Discussion of results and literature control

CHAPTER FOUR: Conclusions, recommendations and limitations of the study

## 1.11 CONCLUSIONS

Chapter 1 provided an overview of the research, an introduction and background, and significance of the study. In brief the research design was outlined with research aims and objectives. The ethics of research and its application in the study was outlined. The study was conducted using a qualitative, explorative, descriptive and contextual design to address the experiences of health care providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng. A detailed discussion on the methodology used will be provided in chapter 2.





## 2. RESEARCH DESIGN AND METHODOLOGY

### 2.1 INTRODUCTION

Chapter 1 provided an overview of the research study. Chapter 2 describes the research design which was used to conduct the study on experiences of health care providers regarding managing children diagnosed with HIV and AIDS. A qualitative design was used to conduct this study. According to Burns, Grove and Gray (2013:23) qualitative research is an interpretive methodological approach that is thought to produce more subjective data than quantitative study. This qualitative study contextualised the phenomenon, which means the researcher interacted with participants to search for answers to the research questions within their social settings (Burns, Grove & Gray 2013:23). The research answered the following question and attained the following objectives as stated in 2.2 and 2.3.

### 2.2 RESEARCH QUESTION

The research question guiding the study was:

What are the experiences of health care providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng?

### 2.3 AIM AND OBJECTIVES

#### 2.3.1 Research aim

The aim of this study was to explore and describe the experiences of health care providers regarding managing children hospitalised with HIV and AIDS. This information can then be used to develop strategies to promote more efficient and quality care to the patients and their parents and guardians.

#### 2.3.2 Research objective

The objective of the study was:

To explore and describe the experiences of health care providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng.

## **2.4 RESEARCH DESIGN**

According to Polit and Beck (2012:741) and De Vos, Strydom, Fouche and Delport (2011:142) study design is the overall plan for addressing a research question, including specifications for enhancing the study's integrity. In this study a qualitative, explorative, descriptive, contextual research design was used.

### **2.4.1 Qualitative design**

According to Burns, Grove and Gray (2013:705) and De Vos et al. (2011:308) a qualitative design is the systematic, interactive approach used to describe life experiences and give meaning to those experiences. This approach was chosen by the researcher as it was considered the best method to explore and describe the experiences of health care providers regarding managing children diagnosed with HIV and AIDS.

### **2.4.2 Explorative design**

An explorative design is conducted to explore human experiences (Polit & Beck, 2012:723). In this study an explorative design was used to explore the phenomenon of the experiences of health care providers regarding managing children diagnosed with HIV and AIDS.

### **2.4.3 Descriptive design**

This design provides an accurate portrayal or account of characteristics of a particular phenomenon in real life situations for the purpose of discovering new meaning, describing what exists, and categorising information (Burns, Grove & Gray, 2013:692; De Vos et al., 2011:96). The descriptive design suited this study as it enabled the description of the experiences of health care providers regarding managing children diagnosed with HIV and AIDS.

### **2.4.4 Contextual design**

According to Burns and Grove (2009:693) a contextual design is a qualitative study which takes into consideration the setting, the situation and concerns unique to each person within which a person can be understood. The study was conducted in a tertiary referral hospital in Gauteng province. In this hospital there are two paediatric medical wards (30 beds each), one surgical ward (30 beds), one orthopaedic ward (13 beds) and one paediatric intensive

care unit (7 beds). In all the wards mentioned there were a total of about 69 registered nurses, 32 enrolled nurses and 22 enrolled nursing assistants, about 40 doctors, which included paediatricians and registrars, three physiotherapists, three social workers and two dieticians.

The children are admitted in different states of illness and conditions in these wards. A number of these children were HIV positive. In the medical wards, the children are commonly admitted with the following problems/conditions: failure to thrive, where the patient is severely emaciated and reluctant to eat; some have severe diarrhoea, chest infections like tuberculosis and pneumonia, multi-organ failure, liver diseases, or cardiac, renal and other conditions. In the surgical and orthopaedic wards, the patients are mostly admitted with surgical and orthopaedic diagnoses, and they are often HIV positive. The hospital further has paediatric outpatient clinics with the following services: follow-up surgical, orthopaedic and medical patients including investigations done (e.g. CD4 count and viral load). Some of the older children (ages 11-13 years) are admitted without disclosure of their HIV positive diagnoses, thus coming for follow-up visits raises some questions as to what their diagnoses are.

## **2.5 RESEARCH METHODS**

To describe the research methods, attention will be paid to the population, sample, sampling, data collection and data analysis.

### **2.5.1 Population**

Population is the entire aggregation of cases in which a researcher is interested. The cases include individuals, objects, events or substances that meet the sample criteria for inclusion in the study (Polit & Beck, 2012:738; Burns, Grove & Gray, 2013:703). In this research study the population was all health care providers who provided care to children diagnosed with HIV and AIDS. The health care providers included doctors (paediatricians, registrars and medical interns), nurses of all categories (which included registered nurses, enrolled nurses and nursing auxiliaries), physiotherapists, occupational therapists, dieticians and social workers. All of these health care providers were working in the paediatric units where the children diagnosed with HIV/AIDS were admitted and managed.



## 2.5.2 SAMPLE AND SAMPLING

A sample is a sub-set of the population selected to participate in a study. Sampling is the process of selecting a portion of the target population to represent the entire population (Polit & Beck, 2012:742). In this study, the sample was all health care providers providing care to children diagnosed with HIV and AIDS in the five paediatric wards where the children are admitted in the public hospital.

Purposive sampling was chosen, which is a non-probability sampling technique whereby the researcher selects participants based on personal judgment based on the fact that the ones selected will be most informed on the phenomenon that is being researched (Polit & Beck, 2012:739; De Vos et al., 2011:232). According to Burns, Grove and Gray (2013:275) purposive sampling is the most applicable method for a focus group discussion because the researcher will be able to choose health care providers based on personal judgment concerning their possession of the correct information level on the phenomenon to be studied. In this study, the sample consisted of all health care providers providing care to children diagnosed with HIV and AIDS and who agreed to participate in the study. Interviews were conducted in three focus groups.

The total sample for these three groups was 21 participants. Each focus group sample of participants was set up as follows: focus group 1=8, group 2=7 and group 3=6. There were 2 doctors, 2 social workers, 1 clinical psychologist, 2 dieticians, 1 physiotherapist, 8 professional nurses, 2 enrolled nurses, and 3 enrolled nursing assistants.

- ***Inclusion criteria***

Inclusion criteria refer to the sampling criteria identified by the researcher that must be considered for the participants to be included in the sample (Burns, Grove & Gray, 2013: 696). In this research study, each participant from among the health care providers needed to have at least a year of experience providing care to children diagnosed with HIV and AIDS in the selected public hospital, had to agree to participate in the study, and had to be above 18 years old.

- **Exclusion criteria**

Sampling requirements identified by the researcher are those that eliminate or exclude participants from being included in a sample (Burns, Grove & Gray, 2013:694; Polit & Beck, 2012:727). Health care providers who had less than a year of experience and those who did not provide care to children diagnosed with HIV and AIDS were excluded.

## **2.6 DATA COLLECTION**

This is precise, systematic gathering of information relevant to the research purpose or specific objectives or questions for a study (Burns, Grove & Gray, 2013:691; Polit & Beck, 2012:725). In this research study, specific information on the experiences of health care providers regarding providing care to children diagnosed with HIV and AIDS was explored using focus group interviews. A focus group interview is a discussion carefully planned between the researcher and a group of individuals who experienced the same phenomena and are assembled to answer questions on a given topic (Polit & Beck, 2012:728). A focus group should be fairly homogenous to promote comfort and group dynamics (De Vos et al., 2011:365). According to Polit and Beck (2012:537), the group should consist of five to twelve people. Focus group interviews were conducted until data saturation occurred. Participants in this study were homogenous and included health care providers who provided care to children diagnosed with HIV and AIDS in a selected hospital. One main question was used to initiate conversations during data collection and probing strategies were then used. See annexure A for the interview schedule which was used during focus group discussions. The main question was:

- What are the experiences of health care providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng?

In this study the participants were considered a homogenous group in that they were health care providers of different categories who provided care to children diagnosed with HIV and AIDS in the public hospital. The main reason for mixing the categories of health care providers was to collect in depth data from them as they experienced the phenomena in a multidisciplinary level. Power imbalance was not observed by the researcher as all the participants engaged in open dialogue and no category was observed to overpower others.

It was however noted that narratives from some categories, for example enrolled nurses and nurse assistants did not form the identified themes and categories.

### **2.6.1 Pilot study**

A pilot study was done prior to conducting focus group interviews. A pilot study is a smaller version of a proposed study conducted to develop or refine the methodology, such as the data collection instrument or data collection process (Burns & Grove, 2009:713; De Vos et al., 2011:370). In this research study, one focus group interview was conducted before the main study in order to enable the researcher to see if the questions were understood by participants and how follow-up questions could be structured. This enabled the researcher to make needed changes to the question and probing methods. Findings from the pilot study were not included in the main study.

Data collection followed three phases, which were preparation for the interviews, the interviewing phase and the post-interview phase.

### **2.6.2 Preparation for the interviews**

The interviews were prepared as follows:

- **Negotiating entry**

After getting permission from the ethics committee of the University of Pretoria, from the Provincial Hospital Chief Executive Officer and the Assistant Director of the department of paediatrics the researcher introduced herself and the purpose of the study to the potential study participants. The introduction included the research topic, the reason it was being conducted, who was eligible to participate and how the results would be used. The assistant director informed operational managers of the study in a paediatric sectional meeting.

- **Recruiting**

After introduction of the research study during the sectional meeting by the assistant director the researcher made individual appointments with the ward managers so that she would be allowed to come and address staff of all levels about the research. The researcher addressed questions and gave answers to the participants' enquiries (De Vos et al., 2011:365). The researcher also informed participants that she would be accompanied by a

moderator who would conduct interviews, and that an audio recorder would be used and notes written.

The researcher secured appointments for the focus group interviews based on the availability of participants who volunteered to participate. Then the researcher took the phone numbers and email addresses of the prospective participants in order to contact the participants a week before the actual focus group interview to remind them of the appointment. Furthermore, two days before the interview the researcher contacted the participants in order to confirm their availability. On the day of the focus interview the researcher made follow-up phone calls to every participant before arriving at the secured venue (De Vos et al., 2011:366; Terreblache, Durrheim & Painter, 2009:304). Agreement on the time for the focus group discussion was arranged with the hospital clinical teaching department manager and ward manager, to determine the most appropriate time to release participants from their duties. The participants who came for the focus group interviews did not in any way compromise patient care as the lunch hour and personnel relief system were used. The interviews took about 55 minutes to 60 minutes. Those participants who had to come for a focus interview in their lunch hours were informed that refreshments were available. It was in the researcher's plan that, if it was not possible to get enough participants together for focus group interviews, additional individual interviews were to be scheduled with healthcare providers at a time that suited them best and did not interrupt health care provision. In this study, a sufficient number of participants turned up and focus groups comprised of 6-8 participants each.

- **Preparation for the venue**

The researcher needed the assistance of the sectional manager to secure a venue in the hospital, but as already stated it was secured by the clinical teaching department. The venue was conducive for the meeting as it was free from disturbances of any kind (De Vos et al., 2011:365). The venue was booked earlier and participants were informed where exactly the venue was and it was easy for them to attend as it was located at the hospital (Gerrish & Lacy, 2010:362).

- **Preparation of equipment**

A high quality audio recorder to record focus group interviews was purchased. Pens and pencils, highlighters and papers for writing field notes were available.

- **Moderator**

The moderator was a skilled interviewer for a focus group interview and guided the interview according to a written set of questions (Polit & Beck, 2012:538). She had a Master's degree and experience in interviewing focus groups. She was given the proposal prior to the interview in order to familiarise herself with the phenomenon to be studied.

- **The researcher's role**

The researcher has worked in the paediatric wards where the research was conducted. The researcher was not actively involved in the discussions of the focus group interviews so as to enhance the credibility of the study. The researcher was active in organising the interviews and taking field notes.

### **2.6.3 Interviewing phase**

The researcher greeted the participants and let participants sign the consent form before the discussion. Some participants signed the consent form before the day of the focus group interview. The researcher gave a brief overview of the study to the group, introduced the moderator and then the focus group interview commenced. The moderator took over and used her interview skills to allow the participants to relax. The moderator posed the first research question, and used probing strategies and follow-up questions as per annexure A. The tape recorder was switched on and the researcher observed and recorded field notes until participants confirmed that they had no more information on experiences to share. The researcher and moderator finally thanked the participants and assured them of their anonymity (Gerrish & Lacy, 2010:363). Focus interviews were conducted until no new information emerged.

### **2.6.4 Post interview phase**

The researcher thanked the participants and made them aware that she may come back for verification of data after transcription (Gerrish & Lacy, 2010:363). After each focus group interview the researcher and the moderator discussed the interview's success and saw what



needed to be improved with the next interview. The researcher did verbatim transcription of the audio recorded data and field notes after each focus group interview so as to identify the data that needed to be probed.

## 2.7 DATA ANALYSIS

This is the systematic organisation and synthesis of research data (Polit & Beck, 2012:725). In this study, data analysis started by verbatim transcribing of the audio taped interviews and field notes. Transcription means to write down notes that reflect the interview experience. Tesch's method of qualitative data analysis was used, as explained in Cresswell (2003:192), to analyse the data for this research study. The following steps were used:

- The first thing to be done in data analysis process is verbatim transcription of the audio recorded interviews (Polit & Beck, 2012:557), and this was done after every focus group interview. The researcher read the transcripts to get a sense of the whole, read each transcript carefully with ideas coming to mind, and in the process she jotted notes down on the margin of the transcripts.
- After completing the task of reading the transcripts from the three focus interviews, and listening to the audio tape several times a list of topics was made. This was done to assist the researcher to gain access to parts of the data without having to repeatedly reread the data set in its entirety. Similar topics were clustered together accordingly. This was done by writing notes in the margins of transcribed data on A4 paper.
- Notes were written next to the data to explain what it means. After getting a sense of the data and what it means the researcher classified it into categories and sub-categories by grouping it accordingly. Similar categories were grouped together to themes, which is the major findings standing for a group of categories.
- Thereafter the verbatim transcripts were taken to an external coder and she conducted independent data analysis. The external coder was a researcher, experienced in coding research and involved in qualitative data analysis. After the independent external coder has finished doing the data analysis, the researchers met again and compared the findings and reached a consensus (Polit & Beck, 2012:559).



- A final decision was made after repeated refining and naming of the main themes, categories and sub-categories. Data was arranged in tables to provide reference during discussion of the data.

## 2.8 TRUSTWORTHINESS

According to Polit and Beck (2012:745) and De Vos et al. (2011:365) trustworthiness is the degree of confidence qualitative researchers have in the data. It is assessed using the following criteria, namely, credibility, dependability, confirmability, transferability and authenticity. In this study, the researcher ensured that these criteria were met. Lincoln and Guba (1985) explain the criteria as cited in Polit and Beck (2012:584). Strategies to enhance trustworthiness included the following:

- **Credibility** refers to the level of confidence in the truth of data and interpretations (Polit & Beck, 2012:585; De Vos et al., 2011:365). Strategies used included prolonged engagement with the data. This was done by listening intensively for about an hour during focus group interviews and probing for more information where necessary. The researcher works in the paediatric unit and has been engaging with the phenomenon for some years. Data collection was triangulated as the researcher and moderator together collected data and the experienced supervisors went through the collected data again. Three focus group interviews were conducted using an audio recorder and field notes based on non-verbal communication cues were documented. Member checking was done by the researcher before leaving the field by engaging the participants in order to verify the accurateness of information.
- **Dependability** refers to the stability of data over time and conditions. Strategies to enhance this criterion included tape recording of each focus group interview with a high quality audio recorder to catch all conversation thoroughly. Transcription of the audio recorded interviews was done after repeatedly listening to the tape recorder for the three focus groups (De Vos et al., 2011:585). The process of development of themes and categories was followed through the supervisor's expertise.

- **Confirmability** refers to the objective and potential of congruence between two or more independent people about the data's accuracy and relevance for meaning (Polit & Beck, 2012:585; De Vos et al., 2011:585). To enhance confirmability, the researcher's objectivity was maintained by remaining objective by avoiding imposing her own ideas. The supervisor's guidance and monitoring of the study was kept as evidence in records for the purpose of scrutiny. An experienced moderator was used in data collection for the confirmability of data. The independent coder was given the research data and thereafter conclusions were reached based on consensus on the sub-categories and themes. The findings were illustrated with quotations in participants' own words to present evidence of the information provided.
- **Transferability** refers to the extent to which the findings can be transferred to or have applicability in other setting or group (De Vos et al., 2011:419). In this study the researcher explained the study context in detail so that the readers can see what transpires in those settings and be able to determine transferability to another setting.
- **Authenticity** refers to the extent to which a research will fully and further show a range of different realities (Polit & Beck, 2012:585). Authenticity emerges in a report when it conveys the feelings and tone of participants' lives as they live them. The researcher ensured that she captured the true feel of the participants through the use of an experienced moderator to conduct the discussions. While the moderator focused on conversation, the researcher observed thoroughly the emotions the group felt and captured all the non-verbal language and documented it carefully so that the readers could have a feeling of what transpired in the interview process. Quotations in participants' own words to present evidence of the information were provided so that the readers can understand and have a sense of what exactly the participants said. Data triangulation methods used were made as clear as possible during data collection and data analysis as already explained in the other criteria already described in this chapter.



## 2.9 CONCLUSIONS

In this chapter the research design and methodology used was discussed in detail. The specific sampling method used was discussed. Details of data collection were included from preparation for the interview up to the post-interview phase, including details of the proceedings of the focus group interviews. The data analysis process was outlined. Measures to enhance trustworthiness during the study was outlined. Chapter three will concentrate on discussion of the results and literature control.

## 3. DISCUSSION OF THE RESULTS AND LITERATURE

### 3.1. INTRODUCTION

Chapter two described the research design and methodology used for the study. Chapter three focuses on a discussion of the findings in order to derive meaning from the participants' (health care providers') experiences regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng. The data emanating from the experiences of the participants in this chapter was arranged into themes, categories and sub-categories after data analysis. Literature is also used to confirm the findings in this study.

### 3.2 OPERATIONALISING THE FIELD RESEARCH

A total of three focus group interviews were conducted at one provincial hospital in Gauteng. Each focus group consisted of six to eight health care providers who had been managing children diagnosed with HIV and AIDS for a period of one year or more. The numbers of focus groups one, two and three participants were: eight, seven and six, totalling to 21 participants. The participants consisted of doctors (2), all categories of nurses namely, professional nurses, enrolled nurses and nursing assistance (13), social workers (2), a clinical psychologist (1), dieticians (2) and a physiotherapist (1). The participants consisted of one male and twenty females. There were both black and white participants but the black participants dominated the group in numbers. The ages of the participants ranged between late twenties to late fifties. Working experience of the participants with children ranged from above one year to above twenty. The educational qualification ranged from certificate, diploma, degree and masters. Among the doctors and the nurses there those who have speciality in child care.

### 3.3 PROCESS OF DATA ANALYSIS

The focus group discussions were audio recorded and transcribed verbatim by the researcher. Data analysis was done using Tesch's method of qualitative data analysis as described in chapter two. The themes, categories and sub-categories that emerged from data analysis are presented in table 3.1.

**TABLE 3.1: TABLE OF THEMES, CATEGORIES AND SUB-CATEGORIES:**

THEMES	CATEGORIES	SUB-CATEGORIES
3.2.1. Factors affecting disclosure of positive HIV status in children	3.2.1.1. Dilemma on who should initiate disclosure to children	<ul style="list-style-type: none"> <li>• Interdisciplinary boundaries not in place</li> <li>• Early involvement of all multidisciplinary team members in disclosing results</li> </ul>
	3.2.1.2 Difficulty in determining the right age for disclosing to children	<ul style="list-style-type: none"> <li>• Lack of clarity on appropriate age of disclosure</li> <li>• Legal and ethical issues</li> </ul>
	3.2.1.3 Knowledge of children, parents or guardians and health care providers on HIV	<ul style="list-style-type: none"> <li>• Lack of information by children diagnosed with positive HIV status</li> <li>• Lack of knowledge of parents and guardians on HIV and its management</li> <li>• Health care providers' knowledge and competences on HIV</li> </ul>
3.3.1 Outcomes of non-disclosure of HIV status	3.3.1.1 Accidental disclosure to the child	<ul style="list-style-type: none"> <li>• Overhearing the diagnosis</li> <li>• Suspicion regarding the diagnosis</li> </ul>
	3.3.1.2 Effects of non-disclosure on the health care provider	<ul style="list-style-type: none"> <li>• Difficult situation</li> <li>• Powerlessness</li> </ul>
	3.3.1.3 Secrecy between parents and family members	<ul style="list-style-type: none"> <li>• communication break down</li> <li>• Medication compliance is affected</li> </ul>

The data emerged with themes that were aligned to the 'Whole Person theory'. It was evident that the children diagnosed with HIV were cared for considering their physical, social and mental/ emotional wellbeing. However, the spiritual aspect of wellbeing part of the whole person theory did not emerge during data collection. Integration of the theory will be done with the findings during the discussion. The discussion of results will be done with the literature control. Two themes emerged from the data collected from the focus group discussions, namely: factors affecting disclosure of positive HIV status in children and outcomes of non-disclosure of HIV status.

In this study the reporting of results will refer to the focus group indicating the number as (FG1) and the category of the participants such as professional nurse (P/N), enrolled nurse (E/N), nurse auxiliary (N/A), doctor (DR), social worker (SW), clinical psychologist (PC), physiotherapist (PT), dietician (DT), or researcher (R).

### **3.4 FACTORS AFFECTING DISCLOSURE OF POSITIVE HIV STATUS IN CHILDREN**

The first theme that emerged during data analysis was factors affecting the disclosure of positive HIV status to children. Three categories emerged from this theme and these are: dilemma on who should initiate disclosure to children; difficulty in determining the right age of disclosing to children and knowledge of children, parents or guardians and health care providers on HIV.

#### **3.4.1 Category 1.1. Dilemma on who should initiate disclosure to children**

The dilemma on who should initiate disclosure to children is the first category that emerged from the theme factors affecting disclosure of positive HIV status to children. This category has two sub-categories namely: interdisciplinary boundaries not in place and early involvement of all multidisciplinary team members in disclosing of results. This category was aligned with the social component of Whole Person theory. The health care providers had difficulty communicating the diagnoses to the children due to challenges related to the social context at their work place. The health care provider's social context affected the wellbeing of the children diagnosed with HIV and AIDS as there were no clear line of communication for managing the children.

- **Interdisciplinary boundaries not in place**

Evidence from the study shows that it was not clear among health care providers as to whose role it was to disclose the diagnoses of positive HIV and AIDS status to children. The boundaries for working in a team were not clear as to how to handle the process to disclose a positive HIV status to the child among health care teams. Routinely, doctors are the ones who disclose such a diagnosis to patients. However, regarding disclosure of positive HIV status of older children, doctors reported that it was the multidisciplinary team's work. Among the doctors, some reported that they were not even considering initiating the disclosure of positive HIV status to children at all. The nurses were clear that it is not within the boundaries of their scope of practice to disclose the diagnoses of positive HIV status to the children. Some participants said:

FG1 (DT): *"It is not your place but it's the doctor's place to say you are HIV positive, but we are not allowed to tell her (child) you are HIV positive."*

FG1 (P/N): *"It's not the policy but that's how it's been done all along. So that's why for us it's difficult for us to be the ones breaking the news to the child. The doctor should break the news then we support and then we come with our counselling after. That's why with us nurses most of the time we don't say first unless the doctor say it then we come after."*

The findings indicate that some doctors seem not to accept their roles. This is what the doctors had to say in response to a question of who is responsible to disclose the diagnosis of positive HIV status to a child:

FG3 (DR): *"Everyone that is working with the patient, but there should be principal ... I mean the doctor should be also, but I'm saying at the end of the day we should ... it's a team work."*

In addition the other doctor reported as follows:

FG2 (DR): *"That is a bit difficult, there is not, there is no written protocol about that. What we do is if I need to test a child, it's a minor I take the consent from the parent or the health care or the caregiver and then when results come out, I give them to the parent. We usually do not even ask at the moment whether the child would like to know or whether the parent would like us to tell the child."*



Among the multidisciplinary team members the physiotherapists and the social workers needed clarity regarding team members' responsibilities regarding disclosing a positive HIV status to the child. In response to questions posed by the researcher on the procedure for the disclosure of a diagnosis of positive HIV status to the child, the participants reported:

FG2 (PT): *"Well, I don't know from the nursing side because we (physiotherapists) don't disclose."*

For further clarification the social worker wanted to know the role of the nurses regarding disclosing a positive status to the child. The participant said:

FG1 (SW): *"Sorry, you ask one question, you said, what is the primary role of the nurse in counselling? I am interested to know myself."*

The lack of clarity of the boundaries for disclosing positive HIV status to children seems to be consistent among the multidisciplinary team members. There is a need for guidelines as reported in a study by Croskery (2012:50) as the author explains that according to a medical-legal stand point, diagnosis and the disclosure thereof is largely a doctor's responsibility. Disclosing of the diagnosis of a patient is part of the doctor's clinical responsibilities, as confirmed by Tsoussis, Papadogiorgaki, Markodimitraki, et al. (2013: 516) however, the focus of this study was international. In the South African context there is no specific literature in this regard but the same rule applies to the doctor. This means that in a health care team in general the doctor is legally bound to disclose the patient's diagnosis. In this study participants indicated that it is the doctor who should disclose the diagnosis to the patient, but some doctors indicated that it is the multi-disciplinary team's responsibility.

According to Le Roux-Kemp (2013:226-228) the main challenge for health care providers is to disclose a positive HIV status to a minor, for which to date there are no guidelines. The disclosure of a positive HIV status to children is multi-layered as it includes disclosure of information to the child, the parents of the child, and other siblings or family members. It is further anticipated that the child will have to disclose this information to friends, family and his or her community. While disclosure of the positive HIV status of an adult has received considerable attention in research and guidance documents, the paediatric disclosure of a positive HIV and AIDS diagnosis in South Africa is still a challenge as there are no clear guidelines. The findings in a study by Le Roux-Kemp (2013:226-228) concur with the

findings of this study as the doctors find themselves challenged by the situation of making a positive HIV status disclosure to children. They do not take full responsibility to disclose the diagnosis of a positive HIV status as with other medical conditions.

The nature of stigma attached to a positive HIV status, unlike other medical conditions, complicates the disclosure procedure to children. When it comes to HIV testing and disclosure the parent or guardian is involved throughout the process. This means that health care providers will not disclose a positive HIV status to the child without the parent's involvement and permission. Heeren et al. (2012:49) are of the opinion that it should be the parents who disclose a positive HIV status to the child rather than the health care providers. This finding appears to be supported by this study as the health care providers could not take a stand and decide who should disclose the diagnosis of a positive HIV status to the children as in other medical conditions.

- **Early involvement of all multidisciplinary team members in disclosing results**

The health care providers in this study were concerned about the present process for HIV testing as it does not involve all multidisciplinary team members. They felt that there was no clarity as to when some members such as the psychologist are integrated in diagnosing and disclosing the process of the positive HIV status to the child. The social worker experienced that they are called in to solve issues with problematic children related to being HIV positive. This is what the participants reported:

FG1(SW): *“So it’s also important because if you open a can (start something) and then you ask me after you open that can, then you give me a problem how am I going to start now because you already opened a can of worms.”*

FG2 (PC): *“But I also feel at times they call us at the point where it is already late. If you call me to come and disclose, why didn’t you call me for the pre-counselling so I can prepare my own ground for the disclosure. So that’s where I feel you know if we could fix that point. It’s you know like making a big mess first and try...come clean up. If we could be called for pre-counselling, then it’s already half-done for the post-counselling.”*

FG3 (PN): *“And sometimes you find that you were not there when they took the test and then now you have to disclose something that you not even sure about.”*

It emerged that it is important to integrate the psychologist and social workers at the phase of pre-counselling for HIV testing. They find it very challenging to be called to undo the management problems created by other team members which they compared to a “big mess” that they are called in to clean up. Early multidisciplinary team involvement might create an environment for parents and doctors to disclose the positive HIV status to older children. The process of disclosure of HIV to children needs proper planning and involvement of the multidisciplinary team throughout the process.

Boon-yasidhi, Chokephaibkit, McConnell et al. (2013:757,758) demonstrated how the multidisciplinary team functioned in the disclosure process to children in their study on the ‘Development of a diagnosis model for perinatally HIV-infected children in Thailand’. The counsellors, who were nurses, psychologists, and social workers, were involved throughout the disclosure process which starts from assessment before disclosure, during disclosure and after disclosure. Such an arrangement might be a suitable solution in the present study. According to Cantrell, Patel, Mandrell and Grissom (2013:304-305) following the Thailand model could mean that the child would have a consistent designated facilitator who should be a child life specialist or social worker. The health care providers and the child specialist should be involved during initial assessment with the child and the caregiver/parent to ensure stability with issues of timing and readiness to disclose the positive HIV diagnoses.

However, in a study conducted by Madiba and Mokgahle (2014:6, 7) in South Africa health care providers reported that there were no guidelines to help them in the process of disclosure so they did not know how to handle it. Without guidelines in place interdisciplinary integration in HIV testing is not possible and the roles to be played by the health care providers will not be clear. This information complements the findings of this study.

The social component of Whole Person theory is covered under the category of the dilemma on who should initiate disclosure to the children. It is evident that the children with HIV was negatively impacted by the fact that health care providers did not inform them about the HIV diagnosis.

### 3.4.2. Category 1.2: Difficulty in determining the right age for disclosing to children

The difficulty in determining the right age for disclosing to children, is the second category that emerged from the theme: factors affecting the disclosure of positive HIV status to children. This category has two sub-categories namely: lack of clarity on appropriate age of disclosure, and legal and ethical issues. This category merged well with the mental component of 'Whole Person theory. The children intellectual development as determined by their age was reported to be used as criteria regarding when to disclose the positive HIV status. The health care providers could not disclose a positive HIV status as age, legal and ethical issues presented a problem to them.

- **Lack of clarity on appropriate age of disclosure**

The age at which to disclose a positive HIV status to the child emerged as a problem as children's intellectual capacity develops differently. However, the age of 12 years was mentioned in this study as the age that children may be informed depending on their level of intellectual development. One participant even mentioned that some eight and ten year old children may also understand when disclosure is done. This was expressed as follows:

FG3 (DR): *"No, I won't say but at least you must, there is no definition but I think it depends on an individual. I mean you can have a twelve year old who doesn't understand a thing, you can have a twelve year old who does understand things. So it depends on an individual person. I cannot pin down and say no by this age you must, but depending on your patient."*

FG2 (PC): *"You know I say it depends largely on the emotional intelligence of the child, because you'll find a ten year old or a twelve year old but you also in the pre-counselling that's where you see how the child handled previous adverse circumstances. But you can also have an eight year old that you can from the mind or stage of an eight year old disclose HIV and tell him in your picture form using diagrams and to explain to this child what is HIV."*

Health care providers, parents and guardians in this study did not really know the exact age to suggest for disclosure of HIV status to HIV infected children. In a study conducted by Madiba and Mokgahle (2015:4) on health care providers' opinion on the age of disclosure, young ages to eight years were mentioned by some participants while others suggested eight to ten years, eleven to fourteen years, and fifteen to eighteen years. Contrary to the early age for disclosing an HIV positive diagnosis, parents and guardians felt the children



should be informed a little later to delay the disclosure. The parents' and guardians' opinions about the age of disclosure ranged from nine to fifteen years (Chew, Beng & Mun, 2012:13; Brown, Oladokun, Osinusi, Ochigbo, Adewole & Kanki, 2011:1056).

The studies share similar findings with this study and concur with the fact that when it comes to children, there is no exact cut-off age on HIV disclosure as there are other factors to be considered. It is just not about the age but the intellectual development need to be considered. At eleven to thirteen, children's thinking develops to an operational stage. The operational stage of thinking is where the child begins to think in abstract terms, which means that the child thinks about possibilities and through hypothesis. The child's reasoning is now at the higher level according to Piaget's theory (cited in MacIntosh, Helms & Smyth, 2003:1726). In an eleven to thirteen old sick child this will mean the child will start to enquire about the diagnosis, the causes, and the importance of treatment, prognosis and future plans in relation to the illness.

- **Legal and ethical issues**

The previous sub-category described the view of health care providers on the appropriate ages for disclosure while this sub-category explores their views on age of disclosure based on legal and ethical frameworks and guidelines. Ethical and legal guidelines influence the health care provider's decision regarding age of disclosure of a positive HIV status to a child. The health care providers acknowledged the fact that legally certain ages are recommended for disclosure, even though they were not sure of the exact age for HIV testing. The age of twelve to fourteen years was suggested as the right age for disclosing the results of an HIV test without the parents' involvement.

This is what the participants related:

FG3 (DR): *"The current practice, we involve the parents, ja (yes) because it's still I think age is now, is it fourteen years for medical consent, we follow the current guidelines in terms of going to get a consent for a child for medical or for surgical issues, I mean it's a medical thing, so we follow that. We normally if it's less than fourteen years you can still use the parents. So if you are dealing with talking about ten year old, definitely for consent to test the HIV, with the parent."*

FG2 (DR): *“The Child Care Act says twelve years but they also stipulate and say that it depends on the maturity of the child. If there are some twelve year olds that are now mature enough to know their statuses and there are some ten year olds that you can explain to and or maybe even eight years that you can explain to them and tell them what’s happening, but it must be at the level of that child.”*

Legally, it is stated in the Child Care Act (Act no 38 of 2005: Section 130) that a child can consent to HIV testing at the age of 12 years or above, or under 12 years if the child should have sufficient cognitive maturity to understand the benefits, risks and social implications of such a test. Where the child is under 12 years and is not possessing the cognitive maturity to understand the benefits, risks, and social implications, the child’s parent/caregiver or other legally appointed people should give consent; in the absence of the parent, the head of social development or superintendent can give consent (Child Care Act no 38 of 2005: section 130; DOH, 2012:20; Le Roux-Kemp, 2013:226-228). Even though the ages are stated legally it still a challenge when it comes to disclosure of the diagnosis of a positive HIV status to children.

In terms of the category of difficulty of determining the right age for disclosing to children, it appears that this category relates to the mental component of the ‘Whole Person theory’. The uncertainty of the health care providers with regard to the appropriate age of disclosure and legal ethical issues further discouraged the health care providers from disclosing positive HIV diagnoses to the child. As a result, the child remains uninformed which has negative consequences as the child stays with unanswered questions affecting mental wellbeing.

### **3.4.3. Category 1.3 Knowledge of children, parents or guardians and health care providers of HIV**

This category fits the social component of the ‘Whole Person theory’. The children remained uninformed of their diagnosis. Knowledge deficit on the diagnosis led to parents not to disclose. In addition, the health care providers’ knowledge and competence on HIV and AIDS is a problem as they cannot empower the parents with knowledge.

The third category that emerged from the theme: factors affecting the disclosure of positive HIV status in children, is the knowledge of children, parents or guardians and health care

providers of HIV. This category has three sub-categories, namely: lack of information by children diagnosed with positive HIV status; lack of knowledge of parents and guardians of HIV and its management; and health care providers' knowledge and competence on HIV.

- **Lack of information by children diagnosed with positive HIV status**

Participants experienced that children diagnosed with HIV and AIDS do not understand their diagnoses, management or their treatment. Meanwhile children diagnosed with other less stigmatised diseases like diabetes tend to be informed and to understand their condition and treatment and participate in their own care. One participant even compared a positive HIV status to diabetes mellitus and reported that by the age of seven and eight, children diagnosed with diabetes mellitus are clear about their treatments and condition as compared to children diagnosed with HIV and AIDS. This is what the participants said:

FG3 (PN): *“And then it comes up whereby you will find the child now at the age of seven years, the child him or herself doesn't understand the disease. Why I am saying this is because I have just taken this disease like a diabetic children whereby I have noticed that with the diabetes we encourage the parents both of them or whoever relatives that are staying with the child isn't it to take treatment to know how to inject, how to use the pen, taking treatments and all those things. But with HIV I have seen no child that can know/understand themselves.”*

FG3 (PN): *“With the diabetic they know also that before they can go for breakfast they must take their treatment. They want those pen to inject. You come with the needle as you are like, for example I'm from the off duties, I don't know that this child was in the ward for some time already had been seen outside by the diabetic clinic, pen has been issued. Then when I come with the needle and the profane or whatever Atrofil, then the child will tell me that I must use the pen. The pen is better pain than the needles. So with this little one (with HIV diagnoses) you'll find the child as little as seven/eight does not know this treatment, doesn't even know the difference.”*

According to Heeren, Jemmot, Sidloyi, Ngwane and Tyler (2012:51) children who were diagnosed with positive HIV did not know their diagnosis as their caretakers did not disclose it to them. Therefore the children diagnosed with HIV and AIDS will start nagging their guardians about why they are taking treatments and when they will stop taking the



treatments. Lorenz, Grant, Muyindike et al. (2016:8) indicated that often children infected with HIV will be given information on chronic illnesses in general or told that they have malaria instead of being told the truth and they are told not to worry. Motshome and Madiba (2014:132) stated that the parents tend to protect the children and resist disclosure to children, saying it's not the right time. The parents and guardians attribute the need for medical care to less stigmatised conditions like asthma and cancer.

The studies cited correlate with the current study by showing that children with HIV diagnoses will be denied the truth about the disease at all costs and that parents or guardians might even lie in order for them not to know. This will usually lead to a child not having any insight into the disease when compared to other children with less stigmatised diseases like diabetes mellitus.

- **Lack of knowledge of parents and guardians of HIV and its management**

The participants related that some parents/guardians seem to have a knowledge deficit in regard to HIV, the disease and its management. This lack of knowledge affects how they manage the day to day care of the child diagnosed with positive HIV. Actions displayed by the parents as reported by participants clearly show that there was a knowledge deficit about positive HIV/ AIDS management. Some caretakers hid medication, making compliance difficult for the child; in case they are not there, no one will administer the medication. Health care providers were worried that parents and guardians do not even give medication to the children as required. Parents who avert disclosure go around pretending not to know about their child's diagnosis. Some grandparents also appeared to lack knowledge of HIV and AIDS.

FG2 (PN): *"This mum knew about the status of the child... Then they (health care providers) took the mom bloods. The mom was positive. She went all the shopping around trying to find out whether it's true or not and then she came to our hospital, they asked about all this status she said no. And by that time it's about three months she knew about the status the child is not on medication, she's not on medication... We had those mothers."*

FG1 (EN): *"It depends who they live with at home. Some are living with the grandmothers, which they don't know nothing."*





Parents in this study were reported to be lacking knowledge of the implications of vertical mother to child transmission. Lack of knowledge on how the child got infected and how management should be implemented to an extent affected compliance. According to Mahloko and Madiba (2012:4) caregivers often lack knowledge, skill and guidance on how to approach HIV diagnoses and their disclosure to children. Heeren et al. (2012:49) and Madiba and Mokgahle (2014:5) further stated that caregivers lack knowledge of HIV, its symptoms, transmission and treatment, which leads to parents not complying with the proper management. The findings of the studies done are in line with this study's findings, as reported by participants, that some parents or guardians lack knowledge of HIV, affecting how they care for the sick children.

- **Health care providers' knowledge and competences on HIV**

The participants in all three focus groups stated that they themselves lacked information on HIV and counselling. They voiced that this is a concern as they are not really able to handle counselling issues for children, or for their parents and guardians. The participants voiced their need for training. This was stated as follows:

FG1 (PN): *"I think the first thing is knowledge, I think if we don't have sufficient knowledge about HIV ourselves and the counselling part of it, and how to talk to mothers and everything it's gonna be wrong information given to the patients which we are dealing... The information about HIV you might think that everybody knows but you go to families' funerals and what they ask you about HIV, sometimes I don't know, you know I don't know. Sometimes I don't even know what is 3TC and Lamivudine and what. So I think the first thing if we can be always be empowered about the HIV."*

FG3 (PN): *"Me, I haven't gone under counselling doing this training counselling as such. It's only through experience since this HIV thing has started, then I have worked a lot with adults and with children. But not yet, I must also start with that counselling."*

FG1 (ENA): *"Full training about the disease at our level of education, we are not well-trained about it."*

Health care providers felt that they lacked accurate information that can equip them to counsel children and parents or guardians on HIV testing. Similar to the findings in this study,

it was confirmed by Woldermarian (2012:58-59) and Ramasopo-Oleja, Bagenda and Ekirapa-Kiracho (2015: 348) that health care providers lack counselling skills for children. Madiba and Mokgahle (2014:6) stated that social workers need special training to equip them for children's counselling and the disclosure of HIV and AIDS diagnosis issues. The participants suggested that the development of guidelines would be highly useful to train health workers on how to address issues of disclosure to parents and guardians, as well as children, in their communities. The cited information shares similar findings with this study. In this study participants experienced difficulties regarding counselling children diagnosed with HIV and AIDS due to a lack of knowledge and they felt they needed to be trained on HIV and counselling.

The category knowledge of children, parents or guardians and health care providers of HIV concurs with the social component of the 'Whole Person theory'. It is evident that the health care providers' incompetence with regard to HIV knowledge and counselling results in parents or guardians lack of knowledge on the diagnosis. On the other hand, if parents are not empowered they cannot comply with the treatment regime and will not be able to disclose the status to children with a positive HIV status.

### **3.5. OUTCOMES OF NON-DISCLOSURE OF HIV STATUS**

The second theme that emerged during data analysis was outcomes of non-disclosure of HIV status and three categories emerged from this theme, namely: accidental disclosure to the child, effects of non-disclosure on the health care provider, and secrecy between parents and family members.

#### **3.5.1. Category 3.1 Accidental disclosure to the child**

Accidental disclosure to the child is the first category that emerged from the theme, outcomes of non-disclosure of HIV status. This category has two subcategories, namely: overhearing the diagnosis and suspicion regarding diagnosis. Children diagnosed with HIV and AIDS used their intellectual capability to reason out diagnosis based on suspicion. In addition communication between the health care providers led to accidental disclosure where children overheard their diagnosis being mentioned.



- **Overhearing the diagnosis**

The participants mentioned that sometimes the children get to know of their HIV positive diagnosis through overhearing health care providers' conversations during ward rounds. Since the child overheard the discussion he or she will wait for an explanation about what he/she heard, which never happens. This was expressed as follows:

FG2 (PT): *"Maybe it's a ward round. Maybe they are talking there and then this child will overhear. And the next thing they come in they (health care providers) not saying anything to the child, especially the one who will come with the stroke. And now they want to find the primary cause of this. They are standing there talking and then the next thing they are quiet. And you can see that this, the model C (the clever children that have a higher level of understanding) they can hear most of the things you saying. And now if mummy comes in, mummy doesn't say anything. The next thing they call mummy to them (health care providers), and already the child heard that okay, this is what is happening even he didn't get full details..."*

FG2 (PN): *"Sometimes it happens when let's say maybe you didn't know that the child is positive, and then you want to do something then you just go on the file the patient to just gather information. Then when we give report then will start saying you'll give this child the treatment 7 o'clock then it will be like what treatment, and if the doctors or whoever is responsible to write all those things didn't inform us as nurses it becomes difficult for us because when we give report we just tell. And they are there sitting there listening. So we must when the report is there, we must be informed, don't disclose before  
Because you will just give report. I'll just tell please guys this child is getting treatment of ARVs of 8 o'clock innocently. But at the end of the day I've disclosed and they don't know. Then it will it's going to be a problem. I'll be, it'll be difficult to go and look at them again during the day if they tell me they don't know. So it will be a bad way disclosing. So we need to be informed also".*

It becomes a problem as parents and guardians avoid disclosing the positive HIV status to the children at a time when they need to know. The same findings emerged as reported by Brown, Oladukun, Osinusi et al. (2011:1055) and Woldermarian (2012:22) that the children at times accidentally discover their diagnosis through conversation between health care

providers and their parents/guardians. This observation was further supported by Moyer, Igonya, Both et al. (2013:68) by indicating that patients find it easy to overhear the diagnosis even if health care providers use codes instead of the diagnosis itself during case presentations and handover in the wards. The child will accidentally discover the diagnosis which can lead to negative psychological outcomes as the proper steps were not taken (Moyer, Igonya & Both et al (2013:68).

- **Suspicion regarding the diagnosis**

It was mentioned by the participants that children who are in teens age or puberty expected more information about their illness, begin to pose questions based on medication and procedures performed on them. The children eventually search for answers through suspicion and deducing the diagnosis based on medication and the procedures they undergo. This was expressed as follows:

FG3 (SW): *“The children are not stupid. I had some that we started telling and they said, ja I thought I had it (HIV) because of the test, I saw this and I see this. Some of them will say I am glad I know because I was wondering...”*

FG2 (PN) *The children talk, even that one with the granny. He knew them (medication) after the other ones (sick children) were talking and said Haa this one is taking same as mine, and then he started asking what is this... ooh the ARVs they are same as mine. Then it went my ear said something is not right and then I went and started talking to the granny. Does the child know? She said no. so it's when then I took the matters something must be done now not later than today.*

Non-disclosure of HIV status to children who are at the operational stage of thinking brings on the need for the child to enquire about the reason that they are sick and the reason they have to take medication. At this stage of their life, unlike when they were younger, with whatever is being discussed around the child regarding their condition, they make deductions, looking at similar situations or looking at the likely reason for that illness (Mumbiri & Bernadus 2014:18). Mahloko and Madiba (2012:345) and Negese, Addis, Awoke et al. (2012:4) stated that the reason parents sometimes decided to disclose the HIV status

to infected children was that the children persistently wanted to know the reason for their medications and to understand the diagnoses as they were becoming more suspicious.

The category of accidental disclosure to the child fits with the psychosocial component of the 'Whole Person theory'. Accidental disclosure is not good for a child with an HIV positive diagnosis as it happens in an unplanned manner and may leave the child with several unanswered questions. This affects children mental and social wellbeing.

### 3.5.2 Category 3.2 Effects of non-disclosure on the health care provider

The effect of non-disclosure on the health care provider is the second category that emerged from the theme, outcomes of non-disclosure of HIV status. This category has two subcategories namely: Difficult situation and powerlessness. This category also fits into the mental element of the 'Whole Person theory'. While managing the children with an HIV diagnosis, health care providers experience a lot of emotional challenges as the situation is difficult to work in.

- **Difficult situation**

The health care providers stated that providing care to children diagnosed with HIV and AIDS is frustrating and creates a difficult working environment, and especially for nurses. The dietician stated that sometimes feelings of anger also manifest. This is what the participants had to say:

FG2 (PN): *"it's very frustrating because you are in the middle of it all. You don't know what to do. It's difficult as one said, if you disclose or if you intervene at random like that then you are going to break other people's weddings also. And how are you going to feel if you are part of this. It's very difficult."*

FG3 (DT) *"It was difficult some of the moms just don't, they just don't want to disclose to their families so it impacts on the child. So personally I get quite angry but I'm not allowed to say anything so now."*

It is evident that the health care providers had challenges while providing care to children who were in the dark regarding their positive HIV status. The difficult situation is surrounding the issue of HIV disclosure to the child. The findings of the studies conducted by Woldermarian (2012:28-30), Water Meyer (2013:594) and Madiba and Mokgahle (2015:7)

support the findings of this study, which indicated that health care professionals report difficulties when it comes to HIV disclosure to children. The challenge include parents/guardians fear, social stigma, and negative emotional reaction to the child. Sariah, Rugemalila, Somba et al (2016:4-7) further asserted that health care providers were very uncomfortable handling disclosure of HIV status to children.

- **Powerlessness**

The health care providers stated that while working with children who have a diagnosis of HIV and who does not know the status lead to situations where they felt powerless. They voiced that this inability to do anything because they did not have power to do so, brought about emotional stress which at times they have to take it home. This is how they put it:

FG2 (PN): *“It was a child, I’m in Paediatrics, I was just giving medication and I was just something said to me where is your parents because mostly we are getting referrals from Limpopo, Venda, you know far away, then she said my parents – it was a Tsonga child that said my parents died. Then from there I felt that I can’t say anything you know, I can’t say anything I want to say something but I just I think I just held that child’s hand I said I’m very sorry. Then you know you work with that thing emotionally, psychologically affected thinking that you wish you want to know does she know that they passed away because of HIV, they passed away because of this.”*

FG3 (PN): *“That’s difficult. It’s difficult and that’s why I say sometimes you take it with you home. You don’t know how can we help or what to do because you got where we must end.”*

Mametja (2013:34-35) and Mavangira and Raniga (2015:430) asserted that health care providers caring for HIV positive patients sometimes feel so helpless and undergo emotional strain due to the nature of the disease and issues around it. They further stated that health care providers become so powerless when it comes to child hood disclosure issues as they do not know how it can be approached and the topic become untouchable. Health care providers in this study felt they cannot say anything they become dumb sometimes. Water Meyer (2013:594) stated that health care providers who were involved in HIV status disclosure to children voiced not to be happy or sure if they did well after each session. They felt somehow helpless and inadequate when dealing with children disclosure.

The category effects of non-disclosure on the health care provider also relates to the psychosocial component. The health care providers' inability to come up with solutions with regard to HIV disclosure issues has made them enjoy their work less, which can eventually result in negative consequences for the work environment and indirectly for the sick children themselves.

### **3.5.3 Category 3.3 Secrecy between parents, and family members**

Secrecy between parents and family members is the third category that emerged from the theme outcomes of non-disclosure of HIV status. This category has two sub-categories, namely: communication breakdown and medication compliance. This category concurs with the physical and social element of the 'Whole Person Theory'. Keeping the positive HIV diagnoses a secret between parents and family members indirectly leads to physical problems for the child manifesting with opportunistic infections. Furthermore the communication between parent or family members because they keep quiet until child is symptomatic.

- **Communication breakdown**

The participants related that the parents of a child diagnosed with HIV and AIDS, mostly the mothers, tend to keep the diagnosis a secret from one another. The mothers are mostly the ones who discover first. Nevertheless, both the father and the mother will keep the diagnosis from one another for fear of being blamed as the one who brought it home. The parent, including the fathers, who knows the child's positive HIV status will wait until the child gets very sick, where HIV counselling and testing will be offered to parents together in case the father has accompanied the sick child to hospital. In this case the child's positive HIV status will not be disclosed to him/her as both parents agree to keep it a secret and hide the child's diagnosis. The participants said:

FG2 (ENA): *"The mom will be highly afraid to disclose to the dad. They are normally afraid to tell the fathers at home what happened because they know it will be carried by them the mother's self."*

FG2 (ENA): *"And when the father comes, the doctor is done by the time, sometimes the mother will ask you, please don't ask the doctor to come now I'll sort it out at home. So if it's*

*like that, you can't just break it out between the two if there is no agreement because you will be breaking someone's marriage."*

FG2 (PC): *"I think the general view is the one who reports the status first, you are bringing it (HIV) into the family. If the wife says it first, then she is the one who brought it home. If it's the man, he's the one who brought it home. So they will either wait until a child is very sick or something drastic happens before they both consent that they can go and test."*

Parents are afraid of being blamed for the child becoming HIV positive, hence they try to keep the diagnosis a secret. The findings of the study are supported by research conducted in other parts of Africa, which shows evidence of mothers' fear of disclosing the positive HIV status of their children to their spouses. Wachira, Middlestadt and Braitstein (2012:23) found that the reasons for keeping the diagnosis a secret included a fear of physical/emotional abuse and lack of support from the spouse. On the other hand, Sendo, Cherie and Erku (2013:6) reported that there was a fear of abandonment, divorce, violence, loss of confidentiality and accusations of infidelity. Another reason stated by Madiba and Letsoalo (2013:6) was the fear of stigmatisation, abandonment and discrimination.

- **Medication compliance is affected**

Some participants related that children who did not know about their diagnoses and did not have insight into the nature of their illness seemed not to cooperate with issues concerning their care, specifically compliance on medication. The children are said to refuse to take medication, at times even to open their mouths, as they do not think they are sick. This leads to a problem of non-compliance as it is difficult to administer medication by force without explaining the reason. The participants related it this way:

FG3 (PN1): *"They are defaulters and then you can see personally that the child has not been looked after well... The child will refuse, won't want. Others they don't even open up their mouth as I say that I just started to realise with the bigger ones as I say 7 upwards, I'm looking that she must be the one that is helpful like the diabetic..."*

FG2 (PN5): *"Yes, this one. The information has not been disclosed and then the child started defaulting. Said I don't want to drink this because I don't know why I am drinking this. For the child to come into the hospital it's because the child defaulted. And then the child*



*was admitted, it's where we got the whole story that the child doesn't know anything. So I waited for the granny and ask, granny why is the child defaulting. She told me that the child doesn't know why she's taking ARVs. She's asking me, granny I'm okay why am I supposed to take this every day? Because I'm not sick."*

The results of non-disclosure of positive HIV status to children were reported to affect compliance with medication in this study. Some of the children who are diagnosed with positive HIV status and AIDS refused to take their medication. The reasons for refusal to take medication are related to parents and guardians not giving information about the disease to the children. A child who has developed operational thinking cannot be left clueless regarding reasons to take medication every day. The outcome of the knowledge deficit by children regarding their diagnosis is non-compliance with medication. Mandalazi, Bandawe and Umar (2014:102) and Kallem, Renner, Ghebremichaell and Paintsi (2011: 5) agreed that children refused to take ARVs due to lack of knowledge of their positive HIV status. The need to provide children with information on their diagnoses is supported by Motshome (2011:62) who warned that until children gain insight into their diagnoses, there will be no compliance with medication such as HIV and AIDS medication.

The category secrecy between parents and family members relates to the physical and social component of the 'Whole Person theory'. It is a problem if parents keep the diagnoses a secret or there is communication breakdown because the other parent will not know how to manage in the absence of the one who is informed. This will result in defaulting treatments thereby allowing the illness to progress and delaying the recovery of the sick child. Another problem is that due to secrecy the child may not comply with the treatment regime as he or she does not have insight into the reason for treatment. The end result will be a deterioration in the physical condition of the child and further breakdown in communication.

### **3.6. DISCUSSION OF FIELD NOTES**

The field notes are notes taken by the researcher to record what was seen, heard and experienced and what she thought about it in the course of the interview (De Vos, Strydom, Fouche & Delport, 2011: 359). In this study the researcher made all the logistical arrangements, which included arrangement of the venue, and organising the participants until focus group interviews were conducted. The researcher ensured that audiotapes were

in a functional status and that note pads for writing notes and pens were available. The moderator was used to conduct the focus group interviews and the researcher recorded field notes during the focus group interviews. The moderator was the one asking questions from the participants, listening to their experiences and comments, and also probing for more information on the experiences of health care providers regarding managing children diagnosed with HIV and AIDS. The researcher observed the non-verbal responses and expressions as the participants were responding to the questions. In this study the field notes included personal notes, observational notes and methodological notes.

### **3.6.1 Personal notes**

Personal notes are the researcher's notes about his/her feelings during the interview process pertaining to what was observed (Polit & Beck, 2012:737).

During the interview sessions I came to realise the importance of the decision taken in my protocol not to be the one interviewing the participants. While the interview was progressing, I felt like some participants should be putting their experiences in a certain way since I had also experienced the phenomena myself as I was working with them. It felt so good seeing some of the participants bringing the root of the problem up which made me conduct the study. Using someone to conduct the interviews was a good thing as it ensured trustworthiness. I felt so good seeing people responding spontaneously and really enjoying the discussions.

### **3.6.2. Observational notes**

Observational notes are the researcher's in-depth description of events and conversations observed in a naturalistic setting (Polit & Beck, 2012:736).

During the interviews it was observed that there was very active participation from almost all participants. Most of the participants discussed their experiences at length, showing a lot of insight into and excitement about the topic discussed. In the third focus group the conversation of one participant took up to 11 minutes with some probing in between. The conversations just came naturally. The participants exchanged conversations among themselves, giving one another answers to questions and asking one another questions at times until the moderator intervened to direct them. There was so much enthusiasm on this topic. Participants followed one another in the background with verbal cues like, hmmm and yes...yes..., and sometimes all laughing at the same time. At times they would talk at

the same time until one outstanding participant finishes up. Non-verbal language was observed like frowning when relating some challenges with regard to HIV disclosure issues to children.

### **3.6.3 Methodological notes**

Methodological notes are defined as the researcher's notes pertaining to his/her reflections about the strategies and methods used in the observations (Polit & Beck, 2012:733). The researcher (moderator) did not call the participants by names for the sake of confidentiality. No strategy was planned to address them by names. The moderator posed the question and welcomed anyone to start. She did however address some participants as sister or doctor without calling them by name if she was sure which discipline that particular participant they belonged to. For the sake of transcription the participants were referred to as P1, P2, and P3 etc. depending on the number. If the participants were 8 it will be up to 8.

## **3.7 CONCLUSION**

Chapter 3 has focused on discussion of the findings from participants, namely a description of their experiences regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng. The findings were then linked to the theory of the whole person.

Two themes were developed from data collected from three focus group discussions. The two main themes developed were: factors affecting disclosure of positive HIV status to children and outcomes of non-disclosure of HIV status. Each theme was divided into categories and sub-categories, and relevant studies from the literature were cited to support the findings. See table 3.1 for a summary and details. The following chapter will address the conclusion of the study and recommendations.



## 4. CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

### 4.1 INTRODUCTION

Chapter three focused on discussion of the findings of the study and the literature control. This chapter discusses the conclusions, limitations and recommendations of the study. During the three focus group interviews, a number of themes, categories and sub-categories were identified, discussed and supported with literature. In this chapter, conclusions, limitations and recommendations will be outlined.

### 4.2 CONCLUSIONS

The objective as stated in chapter one and two was attained, namely:

To explore and describe the experiences of health care providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng.

The following findings attest to the fact that the objective for this study was attained.

Findings from the study on the experiences of health care providers regarding managing children diagnosed with HIV and AIDS were divided into two main themes that emerged. The two main themes were: factors affecting the disclosure of positive HIV status in children, and the outcomes of non-disclosure of HIV status.

#### 4.2.1 Theme 1: Factors affecting disclosure of positive HIV status in children

Three categories were developed from the theme, factors affecting disclosure of positive HIV status in children, which were: dilemma on who should initiate disclosure to children, difficulty in determining the right age for disclosing to children, and knowledge of children, parents or guardians and health care providers on HIV.

##### Category 1.1 Dilemma on who should initiate disclosure to children

In this study, there were two sub-categories that were identified as the reason for the dilemma on who should initiate disclosure to children diagnosed with HIV and AIDS, and these were: interdisciplinary boundaries not in place, and early involvement of all multidisciplinary team members in disclosing results.



Findings from the study were that among the health care providers there was confusion on who exactly should disclose a positive HIV diagnosis to the child, as there were no guidelines or clear boundaries regarding who was responsible among the multidisciplinary team. Some participants mentioned that the responsibility to disclose the positive HIV diagnosis belongs to doctors. On the other hand, the doctors thought it was a multidisciplinary team's duty while one doctor stated that he never initiated disclosure to the child at all. Disclosure of an HIV positive diagnosis remains a grey area in the research and clinical setting.

The other concern that the health care providers mentioned was that, as part of a multidisciplinary team, they did not know when to be involved during the disclosure process. Some health care providers felt that the present process of HIV counselling and testing did not involve all disciplines. Some disciplines, like social workers and psychologists, felt that they were called only when there were problems, instead of being called during pre-counselling so as to prepare themselves for the disclosure intervention.

### **Category 1.2 Difficulty in determining the right age for disclosing to children**

Findings from the study emerged with two sub-categories which support the difficulty of determining the right age for disclosing to children, which were: lack of clarity on the appropriate age of disclosure, and legal and ethical issues.

Health care providers in this study were not sure exactly of the right age at which to disclose a positive HIV diagnosis. Health care providers mentioned different ages and they were not certain when the appropriate age for disclosing the positive HIV diagnosis was, as children develop differently intellectually and emotionally. The health care providers were however aware that when it comes to the age of disclosure of a positive HIV diagnosis there were ethical and legal guidelines. However, there was uncertainty as to which age is legally suitable to disclose a positive HIV diagnosis as both 12 and 14 years were mentioned.

### **Category 1.3 Knowledge of children, parents or guardians and health care providers on HIV**

Findings from the study revealed that there are three sub-categories that directly affect the knowledge of children, parents or guardians, and health care providers. These sub-categories were lack of information by children diagnosed with positive HIV status, lack of



knowledge of parents or guardians of HIV and its management, and health care providers' knowledge and competences on HIV.

The participants brought forward the fact that many children who are diagnosed with HIV and AIDS were not aware of their own diagnoses. They even compared this to children who were admitted with other conditions like diabetes, as they reported that these children know the diagnosis early and learn about the appropriate management. Another concern voiced was that the parents seemed to lack information on HIV and AIDS which further compounded the problem as it negatively affected how they care for their children. Some parents or guardians were said to not disclose a positive HIV diagnosis, while others even keep the treatments a secret and never involve other family members in the medication. Then, compliance becomes a problem and as a result some children are admitted to hospital repeatedly for follow-up treatment.

Health care providers were concerned about their own lack of knowledge and competence with regard to counselling children diagnosed with HIV and AIDS. Some health care providers felt they needed training or to be guided on how counselling children and their parents and guardians for HIV testing should be done.

#### **4.2.2 Theme 2: Outcomes of non-disclosure of HIV status**

There were three categories that were identified under the theme, outcomes of non-disclosure of HIV status, which were: accidental disclosure to the child, effects of non-disclosure on the health care provider, and secrecy between parents and family members

##### **Category 2.1.: Accidental disclosure to the child**

Findings from the study emerged with two subcategories which support accidental disclosure to the child which were: overhearing the diagnosis and suspicion regarding the diagnosis. Non-disclosure was identified as having negative effects on the child. Children who were old enough to understand the diagnoses of their illness were not informed, so the children kept on wondering what was wrong with them. They remained with unanswered questions and started to have suspicions and make their own deductions about the nature of illness. They started to follow certain cues and routines so as to make conclusions on the diagnosis. During hospitalisation, the children may overhear health care providers discussing their diagnosis during their routine work in the ward or in institutions such as

orphanages. Children wait with the expectation of receiving explanations of their diagnoses from health care providers, which does not always happen.

**Category: 2.2 Effects of non-disclosure on the health care provider**

Findings from the study emerged with two subcategories which support the category effects of non-disclosure to health care provider, which were difficult situation and powerlessness. Health care providers in turn stated in the study that providing care to children diagnosed with HIV and AIDS is frustrating and creates a difficult working environment mostly due to the fact that they were managing children who did not know their diagnoses. The health care providers also voiced that they felt powerless for the fact that they did not have power to do anything about the situation. They were emotionally affected by the situation and felt useless, not knowing what to do. They stated that they feel very frustrated and this made them not enjoy their work.

**Category: 2.3 Secrecy between parents and family members**

Findings in this study show that secrecy between parents and family members could lead to two problems, which are: Communication breakdown and medication compliance. Participants pointed out that mothers are mostly affected by the fact that they are the ones who take the children to the hospital, rather than fathers. When the HIV diagnosis is revealed, it is in the presence of the mother who took the child to the hospital. The mother may keep the diagnosis a secret from the father because she wants to avoid being blamed as the one who brought the disease home. Mothers thus may pretend not to know about the diagnosis, and sometimes wait for an opportunity when the child gets very ill and counselling and testing is offered to both parents. At times, they still agree to keep the diagnosis a secret from the child.

Another serious problem resulting from secrecy was that the sick child may not comply with the treatment plan. The child could practically rebel and he or she sometimes refuses to open his or her mouth as she or he does not know the reason for taking daily medication.

**4.3. RECOMMENDATIONS**

Considering the findings from this study, the researcher realised that health care providers face some challenges while managing children who do not know that they are diagnosed

with HIV and AIDS. The researcher is therefore putting forward the following recommendations and draft guidelines, based on the findings, to be implemented in clinical practice, education and research.

#### **4.3.1 Clinical practice**

This study recommends the development of practice guidelines which specifically address the disclosure of positive HIV and AIDS statuses to HIV infected children. The guidelines need to address all the challenges raised by the health care providers who participated in this study, which include the following:

- Boundaries should be clear within the multidisciplinary teams as to the various roles and responsibilities regarding the disclosure of an HIV positive diagnosis to children.
- All disciplines like social workers and psychologists should be included from pre-counselling for HIV testing.
- The exact age of initiating disclosure should be well known to the health care providers.
- The guidelines should include details of procedures to be followed during the disclosure process.
- The guidelines should take into consideration the role of parents and guardians in the disclosure process.
- In-service education needs to be conducted regularly by the hospital to ensure all health care providers are following the guidelines.
- A task team need to be formulated consisting of the multidisciplinary members to do monthly audits and solve disclosure challenges among children in the hospital.
- Health care providers need to collect history on HIV disclosure on initial assessment and history taking from family, parents and guardians.

#### **4.3.2. Education**

The disclosure of HIV status to infected children should be added to the knowledge base of health care professionals through the following measures:

- After the guidelines mentioned above are developed, they need to be added to the teaching curriculum so that students learn and are prepared early to deal with disclosure issues to children.



- The guidelines should be added to hospital newsletters, or nursing and medical journals, and be used for study purposes among health care professionals.
- The guidelines can also be presented in seminars, locally and nationally, to promote knowledge.

#### **4.3.3. Research**

- Further research is suggested in future in order to develop guidelines that can be implemented in the paediatric sector by health care professionals for the disclosure of HIV status to infected children.
- Further research needs to be conducted not only in this one public hospital, but should be extended to other public hospitals of different levels, on health care providers' experiences in managing children diagnosed with HIV and AIDS.

#### **4.4. LIMITATIONS OF THE STUDY**

The following limitations were found in the study:

- The results of the study are only limited to one provincial hospital in Gauteng province in the department of paediatrics, although the literature was used to support the findings.
- There could have been inherent power imbalance due to difference in scope of practice that led to voices of other health care providers not to be +heard in this study. Further research can concentrate on individual participants from a category of health care providers.
- The study was contextualised and therefore for it to be generalised to other settings, further research is necessary.

#### **4.5 SIGNIFICANCE OF THE STUDY**

The public hospital where this study was done houses a very ill paediatric population in Gauteng. The hospital management and its staff have a great deal of passion and provide high quality care to the sick children. The researcher was positive about the fact that if she does this study on the experiences of health care providers in managing children diagnosed

with HIV and AIDS, it would be a valuable contribution in improving the quality of care at the hospital.

Even though the recommendations were developed based on one public hospital, the researcher believes the findings are useful and can be used in other hospitals and clinics.

#### **4.6. CONCLUSION**

The purpose of the study was to explore and describe the experiences of health care providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng, and this aim was achieved. The health care providers related a wide range of challenges which they face while caring for sick children mostly stemming from non-disclosure of HIV status to the infected sick child. The challenges affected health care providers, the children and the parents or guardians.

Based on the findings of the study, it is concluded that the aim and objectives of the study have been achieved. The researcher has made recommendations to improve the current practice. It is hoped that the public hospital will take it as a matter of concern to put in place the recommendations to promote quality care to our children.

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**ANNEXURE A**

**INTERVIEW SCHEDULE**

## ANNEXURE A

### Interview schedule

#### Research question

- What are the experiences of healthcare providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng?

#### Follow up question

- What are the common questions children ask regarding their diagnosis?
- What are the common questions children ask regarding the prescribed medication?
  
- What do you think should be done?
- Probing strategies will be used.

## **ANNEXURE B**

**Participant's information leaflet and informed consent form for non-intervention study.**



**ANNEXURE B**

**Participant’s information leaflet and informed consent form for non-intervention study.**

**Title of the study:**

- Experiences of healthcare providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng.

Dear Mr. / Mrs. ....Date ...../...../.....

**Introduction**

You are invited to participate in a research study. This information leaflet is to assist you to decide if you would like to participate in the study. Before you agree to participate in this study, you should fully understand what is expected of you. If you have any questions, which are not fully explained in this leaflet, please do not hesitate to ask the person who is conducting the study. You should not agree to participate unless you are completely satisfied upon receiving full information on the research study proposed.

**The nature and purpose of this study**

You are invited to participate in this research study. The aim of this study is to explore and describe experiences of healthcare providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng. This study will be of value because the recommendations and strategies proposed from the study will be used to support healthcare providers in managing children diagnosed with HIV and AIDS. With the guidelines in place in management of children diagnosed with HIV and AIDS, a better environment will be promoted in the units so that healthcare providers render quality care to the patients and to their parents and guardians.

### **Explanation of procedures to be followed**

The researcher will arrange a 30-45 minutes focus group interview, session whereby the main question will be asked followed by other small questions to get clarification or to confirm facts. What you need to do, is to respond to the question asked, by telling the researcher about your experience regarding managing children diagnosed with HIV and AIDS.

### **Emotional discomfort or physical harm**

There is no physical harm expected or any emotional discomfort because there will be a discussion between the researcher and a group of health workers. The number of health workers will be about 6-8. As a participant in the group discussion you have a right of not responding to a question if you feel uncomfortable.

### **Possible benefits of this study**

Although you will not benefit directly from the study, the research will enable us to develop solutions to assist all health workers. This study will be of value because the recommendations and strategies proposed from the study will be used to support healthcare providers in managing children diagnosed with HIV and AIDS. With the guidelines in place in management of children diagnosed with HIV and AIDS.

### **What are your rights as a participant?**

Your participation in this study is entirely out of free will. You can refuse to participate or stop anytime during the interview without giving any reason.

### **Has the study received ethical approval?**

This study has received written approval from the research ethics committee of the Faculty of Health Sciences at the University of Pretoria and the referral Hospital. Copies of the approval letter are available if you wish to have one.

### **Information and contact person**



The contact person for the study is Mercy Ndacayisaba. My supervisor is Mrs. M. Mataboge. If you have any questions about the study contact my cell number on 082 504 6662 and the supervisor's cell number is 082 418 2865.

**Compensation**

Your participation is out of free will, no payment for being in the study.

**Confidentiality**

All information that you give will be kept very safe from people, only the researcher can have access to it and the supervisor/s. Once we have processed the information, no-one will be able to identify you. Research reports and articles in scientific journals will not include any information that may identify you or your clinic/hospital. The names of the participants will not be revealed in the study reports it will be kept confidential.



**CONSENT TO PARTICIPATE IN THIS STUDY**

I confirm that the person asking my consent to take part in this study has told me about nature, process, risks, discomforts and benefits of the study. I have also received, read and understood the above written information (Information Leaflet and Informed Consent) regarding the study. I am aware that the results of the study, including personal details, will be made without showing my name before it is processed into research reports. I am participating willingly. I have had time to ask questions and have no objection to participate in the study. I understand that there is not a punishment should I wish to discontinue with the study and my withdrawal will not affect any treatment/access to ..... / marks / ..... In any way.

I have received a signed copy of this informed consent agreement.

Participant's name.....

(Please print)

Participant's signature ..... Date.....

Investigator's name .....

(Please print)

Investigator's signature ..... Date .....

Witness's name.....

(Please print)

Witness's signature .....



## ANNEXURE C

### Letter of request for permission to conduct a research study

## **ANNEXURE C**

### **Letter of request for permission to conduct a research study.**

#### **The chief executive officer.**

Request to conduct the study on experiences of healthcare providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng.

#### **Title of the study**

Experiences of healthcare providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng.

#### **Introduction**

I am currently registered with the Pretoria University undertaking my final year of the Master's Degree in Paediatric Nursing (Mcur Clinical). One of the requirements to be awarded with the above mentioned degree is to conduct a full dissertation pertaining to paediatric nursing (clinical issues). Gauteng province is one of the provinces whereby hospitals accommodate children who are in early adolescent diagnosed with HIV and AIDS. Most of the HIV infected children, especially those infected through vertical transmission, may not know their HIV positive status as parents or guardians did not disclose the positive Human Immunodeficiency Virus (HIV) status to them. Some children make deductions based on signs and symptoms when acquired immunodeficiency syndrome (AIDS) sets in and they are hospitalised. At this age children start reaching for answers and ask the healthcare providers reasons for admission. As such healthcare providers experience challenges regarding how to manage the children diagnosed with HIV and AIDS during hospitalisation.

#### **The nature of the study**

Experiences of healthcare providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng. With the guidelines in place in management of children diagnosed with HIV and AIDS, a better environment will be promoted in the units so that healthcare providers will be able to encourage and support parents/guardians to consent for disclosure of the diagnosis to the children by engaging in dialogue with them to consider this option.

### **Explanation of the procedure**

The study is a semi-structured interview whereby the participants will be asked to answer some questions in focus group discussions. That information will be recorded, transcribed and data analysis performed using research process.

### **Risk and discomfort involved**

No risk involved, this will be a conversation between the researcher and the participants. The participants will be reassured about that if such a feeling comes they are free to refuse answering the question without any victimization involved to their child they care for.

### **Possible benefits**

The research will enable us to develop solutions to assist all healthcare providers to be able to manage children diagnosed with HIV and AIDS effectively.

### **Recommendations**

Recommendations will be submitted to the management of the hospital where the study will be conducted for possible implementation. The recommendations will also be useful as evidence whereby health professions can utilize it to develop guidelines and policies to manage children diagnosed with HIV and AIDS effectively.

### **Confidentiality**

All information. Obtained during this study will be regarded as confidential. The result will be published or presented in such a way that participants remain unidentified.

### **Consent to participate**

Participants will be requested to give informed consent and sign the consent form.

Yours faithfully

Mercy. T. Ndacayisaba

## **ANNEXURE D**

### **Permission to conduct a research study from the provincial hospital**



**GAUTENG PROVINCE**  
HEALTH  
REPUBLIC OF SOUTH AFRICA

████████████████████ HOSPITAL

Enquiries: ██████████  
Tel: ██████████  
Fax: ██████████  
E-mail: ██████████

████████████████████  
PRIVATE BAG ██████████  
2014 -08- 15  
PRETORIA 0001  
████████████████████ HOSPITAL

Ms. M.T. Ndacayisaba  
████████████████████  
████████████████████  
████████████████████  
████████████████████

RE :- APPLICATION – RESEARCH AT ██████████ HOSPITAL

“Experiences of healthcare providers regarding managing children diagnosed with HIV/AIDS in a public hospital in Gauteng”

Your letter regarding the above-mentioned refers.

1. The Chief Executive Officer hereby grants permission for the above-mentioned research to be done at ██████████ Hospital.
2. Distribution, completion and collection of questionnaires may only take place with the knowledge of the Assistant Manager of the Area, and should not interfere with patient care or any ward activities.
3. Please provide one copy of the final results of your study to Mrs. ██████████, Personnel Development.

Good luck with the proposed project.

████████████████████  
████████████████████  
████████████████████

MRS. ██████████  
ASSISTANT DIRECTOR  
2014-08-15



Permission to do the research study at this hospital and to access the information as requested is hereby approved.

Chief Executive Officer

[Redacted] Hospital  
[Redacted]

[Redacted]  
[Redacted] CHIEF EXECUTIVE OFFICER  
[Redacted] HOSPITAL  
[Redacted] of the CEO

12/8/2014

Hospital Official Stamp

[Redacted]  
PRIVATE BAG [Redacted]  
2014 -08- 12  
PRETORIA 0001  
[Redacted]

## **ANNEXURE E**

**Letter of approval from the Research Ethics Committee, Faculty of  
Health Sciences, University of Pretoria**



The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- FWA 00002567, Approved dd 22 May 2002 and Expires 20 Oct 2016.
- IRB 0000 2235 IORG0001762 Approved dd 22/04/2014 and Expires 22/04/2017.



UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences Research Ethics Committee

26/06/2014

**Approval Certificate  
New Application**

**Ethics Reference No.: 202/2014**

**Title:** Experiences of healthcare providers regarding managing children diagnosed with HIV and AIDS in a public hospital in Gauteng

Dear Ms MT Ndacayisabal

The **New Application** as supported by documents specified in your cover letter for your research received on the 30/05/2014, was approved, by the Faculty of Health Sciences Research Ethics Committee on the 25/06/2014.

Please note the following about your ethics approval:

- Ethics Approval is valid for 1 year
- Please remember to use your protocol number (**202/2014**) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, or monitor the conduct of your research.

**Ethics approval is subject to the following:**

- The ethics approval is conditional on the receipt of 6 monthly written Progress Reports, and
- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research.

Yours sincerely

**Dr. R. Sommers**; MBChB; MMed (Int); MPharMed.  
Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

*The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).*

◆ Tel:012-3541330      ◆ Fax:012-3541367 Fax2Email: 0866515924      ◆ E-Mail: [fhsethics@up.ac.za](mailto:fhsethics@up.ac.za)  
◆ Web: [www.healthethics-up.co.za](http://www.healthethics-up.co.za)      ◆ H W Snyman Bld (South) Level 2-34      ◆ Private Bag x 323, Arcadia, Pta, S.A., 0007



## **ANNEXURE F**

### **Verbatim transcript of focus group interview**

## ANNEXURE F

### RESEARCH DATA TRANSCRIPTION FOR FOCUS GROUP -2

**R** – Thank you. Eh ladies, tell me what have been your experiences in managing children who are HIV infected? Anyone can start.

**P1** – I've observed that especially amongst African people, opening up about the condition is still very difficult despite the fact that there is an awareness every annually that is held all over the world for people to speak about HIV. But with our African people, most of the time instead of just saying that the patient is HIV positive, they'd rather say it's just lung problems you know just to diminish the condition. That's one of the reasons that I don't understand kuri why up to 2014 people should not be, are not able to say its HIV. They don't admit it is the condition.

**R** – What is it that they do?

**P1** – Like if let's say someone is bringing the child to the clinic neee, and then you just ask what's wrong with the child? The parent, the person who is bringing the child will just say she is coughing you know. Okay coughing, what did the doctor say what's wrong with the child? No they just said the child is coughing. And then if you ask, are you staying 100% with the child, yes. Who brings the child regularly to the clinic? It's me. When you go to the doctor what is the doctor saying? Doctor says she is coughing. But when you look at all the records from maybe when the time from the time of birth, when this condition was diagnosed, you see that the child is HIV positive. But just to verbalize is difficult.

**R** – Have you had a chance maybe to ask any of those?

**P1** – Yaaaaa.

**R** – Why? What is their reason?

**P1** – Yaaaa. they'll just. We are health providers Neee. I think I will want them to be open to us but they'll just tell us that, other people do not take the child; they do not accept the child because they are afraid that the child will infect their children.

**R** – Okay

**P1** – Yes

**R** – Other people?

**P1** – Let me also answer that one.

**P1** – in the community

**R** – Oh in the community?

**P1** – Yes, in the community, yes.

**P2** – The other thing why they are afraid maybe the mother is with a child most of the time you find that it is the mothers who are accompany the kids.

**R** – Yes

**P2** – So if the child is diagnosed during the company of the mom, the mom will be highly afraid to disclose to the dad. They are normally afraid to tell the fathers at home what happened because they know it will be carried by them the mothers self. It becomes a secret

**R** – Okay in that situation, what have you done? What is it that transpired? Where a mother did not want, was the father present?

**P2** – Normally the father is not present. But he will come after the diagnosed is being said by the doctor. And when the father comes, the doctor is done by that time, away. And sometimes the mother will ask you please don't ask the doctor to come now I'll sort it out at home. So if it's like that, you can't just break it out between them two if there is no agreement because you will be breaking someone's marriage.

**R**- Okay.

**P3** – I think the general view is that the one who reports the status first you are bringing it into the family. If the wife says it first then it's, she's the one who brought it home. If it's the man, he's the one who brought it home. So they will either wait until a child is very sick or something drastic happens before they both consent that they can go and test. Another reason that I find mostly for non-disclosure, its families. You know it must stay in this nuclear family. The aunts and uncles must not know, they will think you know we are bad mothers and fathers. You know they fear how they will treat the child, how the child will be treated in the other family. And also at school, they are afraid maybe the teachers will isolate. That's the reasons they give. Isolate the children.

**R** – Who, sorry, who's that?

**P3** – The mom.

**R** – The mother?

**P3** – Yes, the mother will say I'm afraid if they know at school because it's you know, I don't know how they will treat the child. Will they isolate this child? Will they not give the necessary care when teaching? Or the other kids will just isolate him, he won't have friends to play with. Or and if my colleagues also know and maybe I'm bringing the child to work or so. They will just you know stay far. Make the child feel unwelcome. So mostly it's a societal pressure that I find that pushes the people away from disclosing the status.

**P3** – Another reason I've heard also the mother said the child is too young to be told.

**R** – How old was the child?

**P3** – It was ten.

**R** – Ten

**P3** – Yes. But the eagerness of the child to take the medication will usually use other reasons like you are suffering from tonsillitis. You have to take this one two three four tablets to make you well. They use another disease to motivate the child to take the ARV treatments.

**R** – and what about the mothers? Are they or the caregivers, are they motivated to take the medication?

**P3** – Ya, many that I find

**P4** – Especially the grannies.

**P** – Yes

**P4** – They are they are very committed.

**R** – They are very committed?

**P4** – Yaaa and they become very overprotective. That's why sometimes it's difficult for them to tell the child. So they would rather lose anything and everything, but not

**P3** – The real thing

**P4** – To tell them the truth.

**P5** – We have a case of the child I think it was ten years or twelve years, that boy the parents died and then the child is staying with the granny. And the granny was saying to the child, no, because granny is taking the high blood medication to be well so take this medication you are going to be strong and you know, you'll grow strong. And then at the end, the child came into the ward in that cubicle most of them they are taking the same ARVs that the child has taken. And then the other ones are informed that these are the ARVs. And the child,

**R** – They know?

**P5** – Yes, this one. The information has not been disclosed and then the child started defaulting. Said I don't want to drink this because I don't know why I am drinking this. For the child to come into the hospital it's because the child defaulted. And then the child was admitted, it's where we got the whole story that the child doesn't know anything. So I wait for the granny and ask, granny why is the child defaulting. She told me that the child doesn't know why she's taking ARVs. She's asking me granny I'm okay why am I supposed to take this every day? Because I'm not sick. So we had to intervene and call the granny and she told us please don't tell this child that I know. When you come and talk about this, talk to me as if it's the first time for me even for me. So it was a little bit of chaos. So we had to call the social worker and the doctors to come and clarify this to the child.

**R** – So what did the, how did, how was the disclosure? How was the child disclosed to? Who disclosed?

**P5** – it's the doctors. They did disclose. They told her about the parents died because of HIV. HIV you can control it but it's not, there is no cure. So the child was taken step by step with the doctors. Then it was not a daily, a one day thing. They took the step by step every day. I think about a week.

**R** – And how did that child react? How did he handle this?

**P5** – He was quiet all along. He didn't say anything. They would say, do you understand? I understand. So because she thinks granny doesn't know, I think that's the point with us. That if granny because the granny told us if this child knew that I know, it's going to be a problem.

**R** – How old was the child?

**P5** – Ten, between ten and twelve. So the way we disclosed to the child or hiding the information until that age it's very dangerous. Because for that child at that time defaulting to her was a normal thing because he doesn't understand why he's taking ARVs and he didn't even know that these are ARVs.

**R** – Okay. And tell me, what is the procedure of disclosing in your clinical?

**P5** – to a child?

**R** – Isn't it you are dealing with children, you are talking about children? How do you disclose? Have you had a child who was asking like, she was saying the child was asking why am I taking treatment? What is the procedure?

**P4** – You know, there's a thing that happened I think I had two cases where the doctors would be talking about this child

**R** – in the presence of the child?

**P4** – Maybe it's a ward round. Maybe they are talking there and then this child will overhear. And the next thing they come in they not saying anything to the child, especially these ones who will come with the stroke. And now they want to find the primary of this, they are standing there talking talking and then the next thing they are quiet. And you can see that this, the model C they can hear most of the things you saying. And now if mummy comes in, mummy doesn't say anything. The next thing they call mummy to them, and already the child heard that okay, this is what is happening even if they didn't get full details. But they...

**R** – What did the child do? With that experience, what did the child do?

**P4** – No, they just looked there. Because they are waiting in expectation that maybe someone call me and tell me something.

**R** – Okay, but what is the procedure there?

**P4** – Well, I don't know from the nursing side because we don't disclose.

**R** – Nurses don't disclose?

**P4** – Physios. I don't know

**P6** – that is a bit difficult, there is not, there is no written protocol about that. What we do is if I need to test a child, it's a minor I take the consent from the parent or the healthcare or the caregiver. And then when the results come out, I give them to the parent. We usually do not even ask at that moment whether the child would like to know or whether the parent would like us to tell the child.

**R** – But these are the child's results?

**P6** – Yes.

**P3** – And I think...

**R** – How old is that child?

**P6** – No, even twelve year olds. We give the results to the parents. We don't even ask the parent if we should give, we should say something to the child or tell the child at that moment. No. we just give the results to the mother and then we tell them okay, we going to start treatment. We don't even **P6** – so that comes about when, that comes about telling the child usually is when the child will start asking questions at home or at school

**R** – What are the questions that they ask?

**P6** – Why am I taking medication? Why am I taking this medication every day? That's what they usually ask. And then the parent or the caregiver will come back and then.....Most of the time they don't even tell us. It's not a primary problem that they come with. The child might ask, but they won't come to the hospital to ask a healthcare worker what to do in this situation.

**R** – But if the child is in the ward, you have done the tests, the child is positive. You say you say you wait for the parent or the caregiver?

**P6** – Yes

**R** – but what about the child?

**P3** – I think if I can...

**P6**– We don't consider that to be honest

**P5** – I think most of the times it's because by that time the kids are babies. Then they grow up being HIV positive then knowing about these pills when they are old. Because medications are not the same for the small ones and the bigger ones. For the smaller ones, most of the times it's the syrups. But with the grownups, its tablets and the very big ones that they are supposed to take in. its where they become aware why am I taking these big big medication. So it's not about studying now they are HIV positive now, it's because they've been grown up being babies and then this is the situation in being HIV positive.

**R** – Have you had a situation of children who or teenagers who come being infected? Not from birth?  
Any

**P3** – I've had I think the problem starts with the pre-counseling because when you get, when you going to test the child let's say ten year olds twelve year olds. In your pre-counseling test, that's where you should be talking to the other also. You know these are the possibilities, what if they come back like this would you like me to do this? Who else would you like me to include? I think the pre-counseling plays a very important role. It stops the confusion after the test results are there. Because if you set your things right there, then there is no confusion on what to do after the results.

**P3** – Yaaaaa

**R** – But what I was interested in is to know what is the right thing that we do for the children especially the ones who are older, the ones who are now asking questions? You just...

**P3** – ya I think for, in my case cause most of the doctors would refer the children to me and say you know here the status this child doesn't know. And the parents we don't know how to start them.

Whom to start. Then what I usually do is that the parents, the primary caregivers must first if they are, if they are at ease with the situation with the disease, if they know how to handle it, if their strengthened then they can provide a lot of holding for the child when they are going to disclose.

**R** – Who strengthens them? Who assists them to be strong?

**P3** – As a psychologist, I play that role.

**R** – Okay

**P3** – I play the supportive role to provide a lot of holding for them so they can in turn support the child in the home. You know, and I've got also specific ways of disclosing with the children. When the couple or the primary caregiver agrees that this child must now know I'm ready, because the mother will say I can't even look at this child. I'm always crying. Now if she herself is not strong enough, how can she carry over that support to the child? So I'd first start with the primary caregivers, then make a day and date and time of disclosure. They will come and then either the mom will say I will tell or the dad will say no I can't do it, please do it on our behalf because we trust that you can do it in a better way. And then from there if it needs follow up sessions we book them for you know. How is this child coping with the medication? Is there peers at school, whose family members until a child is firm enough or strong enough to you know, face life squarely on the face on a day to day basis.

**R** – Okay. From the, your experiences, those that you have disclosed to, how have they reacted?

**P3** – I think it also depends on how you prepare the child. Mostly, the ones that I was involved in disclosure, they will own the responsibility. Take up the responsibility for their own health because I was with the child somewhere this week, whilst I was seeing the mother, the child heard, the ten year old child whilst I was busy with the mother the child phoned to say Ma it's time for my ARVs just during, so so you could see that the child takes responsibility. So I said to the mom oh this is good it means things are going well. We stopped then and then she went out and she took the water, the tablets. This child swallowed, she didn't even look around who's looking. No it felt like it's my health. I will stay healthy if I'm drinking this. And the outcome for me is good. It will be good.

**P7** – I think to add on that, it also depends on how we pre-counsel the patient because

**P3** – Yes, pre-counseling is the main thing.

**P7** - HIV initially it was over-commercialized. So a lot of, in fact all of us will so were scared of victimization even today and discrimination. So for the parents to disclose, it's even to a child, thinking that what are the peers are going to say about this child of mine having this HIV. I'd rather not tell him or her until at the certain age. But that age when it comes, especially adolescents they are at a critical age where there's this confusion and now there is medication, there's all of those things. So it becomes difficult for them that that's where they end up defaulting the treatment because of now what if people will say about me. In my case I have a sister-in-law who she and her kids, two kids, are HIV positive. Because of this discrimination she thinks we don't know because you know if

she tells one sister the other sister will tell the other that you know what. But there is you know and it's terrible and painful because of sometimes you can't advise. What advice can you give if you don't, she thinks you don't know. You see, you become in a dilemma in that whenever the child is sick, you say take this child to the hospital. Just for treatment. So it's really, it's a very difficult situation that you're having these days with this HIV.

R – So what do you think is the, it's as nurses, as nursing professionals what is your role in counseling especially around HIV and AIDS?

P7 – I think like...

R – Do you do any form of counselling?

P7 – We don't but you know sometimes when you discuss certain things, that's when you see you are you have to be involved. As a health professional, that's why we are advocates at some stages, they say nurses are advocates to patients. So we have to be involved rightfully.

R – But presently are you, are you involved in any counselling?

P7 – No, not really. Not really unless there is a problem and then we just touch there and there but not like...

R – Who does the counselling?

P – Usually we call the social worker, or the doctors.

R – So it is their responsibility the social workers and the psychologist?

P 3- But I also feel at times they call us at the point where it's already late. If you call me to come and disclose, why didn't you call me for the pre-counselling so I can prepare my own ground for the disclosure. So that's where I feel you know if we could fix that point. It's you know it's like making a big mess first, and then try...

P7 - Somebody to come and clean it up

P3 – Come clean up ya. If we could be called for pre-counselling then it's already half done for the post-counselling.

P2 – What if had to cause, we do call the social workers being called every time for pre-counselling

P3 – Ah that's good

P2 – And then before the doctor can do anything and thereafter they can take blood and after bloods, the results will be told to the parents by the doctor and the social worker will also be inclusive.

R – To whom is a pre-counselling done?

P2 – to the parents

R – to the parents?

P2 – Because we normally work with babies. As sister now said that we working with babies but as they grow up because they do grow up now, some are twelve years and are taking these things. So that's why I said this thing needs a serious motivation by us the health workers because we've been doing it all along. We've been giving counselling to the parents so I think they need a lot of motivation.



It's a pity you can't go with them at home, but just to tell them what to do at home. You don't know if they are seriously going to do it or so. So...

**P4** – And another thing you know with these kids staying in orphanage homes.

**R** – Oh yes

**P4** – the caregivers there will just first and say okay this one is HIV and you not supposed to do one, two three and then all of a sudden the child is dropping at school because its frustrated and you can't ask now my aunt you said were you talking to me or were talking about me that I am HIV positive because now they have fifty kids. So maybe one caregiver is assigned to five kids and then as they are talking, you know we talk things.

**R** – It has happened, is that?

**P4** – It does hurt them

**P3** – Yes it does. We're seeing about 5 children's homes, its true what you saying

**P4** – They will just hear from the caregiver that oh okay this is what's happening. And then only the teacher at school will say uh uh but there is something wrong with this child. And then when they come to the hospital, already the child is demotivated already wanting to default because now they don't understand why is all this happening. And

**R** – And the child was on treatment?

**P4** – Uhhmm

**P 3**– Not knowing about it

**P4** – And now this is not even the immediate family, so it's the caregiver now you thinking my parents died, granny is staying far, can't look after me now. This one is there and she is talking about me she is not even saying anything to me and then the only close person you have is the teacher at school. And caregivers are not trained at all

**R** – Are not trained. They don't even counsel us

**P4** – If the, well-established community then they do have social workers going there but I don't know the program I don't know how they deal

**P3** – Actually they are requesting from us to give them training programs. But I'm one for the whole hospital, it is not always practical.

**R**– its not possible.

**P 3**– Ya.

**P1** – I just want to say if this issue of HIV was attacked by many stakeholders like for example, the community needs in the clinics if they were running, rubbing this HIV story in and the teachers at school when they are teaching in their programs then it would be very easy for the nurses and the doctors at the hospitals to continue with this. Because as the children are growing, they are being taken to the clinics for whatever and then there at the clinics if there are maybe people who are just talking, talking talking about HIV, that thing will just become normal like a pulmonary TB. And at

school also when the teachers just teach about HIV because it's something that will never go away. So if all of us were just join together everything was going to be easy at our level but it's not like done like that.

**R** – What do you think are the other needs for HIV for caring for HIV? She has said one

**P7** – I think the other need is maybe we should identify I don't know, maybe the age or the maturity of the child to disclose to the child. Because if you wait for the child to know from the streets that I'm HIV positive, drinking ARVs, it really kills the child. So I don't know it's like when I adopted the child, I don't know when can I tell the child that I'm not your biological mother you understand what I'm trying to say?

**R** – Yes, I understand

**P7** – And then the neighbour will just say ah this is not your mother. So it's like HIV is like that. The child is drinking this medication not knowing what it is and then at the end of the day, somebody tells him or her that you are HIV positive that's why are drinking this. So we must identify the age and the maturity of the child to say now it's the time to explain to this child. The caregiver or the mother can just take the child to the hospital maybe for a certain check-up and then there we can call the child, do the pre-counselling first. Do you know about this? Do you know the effects? Do you know what causes this? And then because some of the schools at least they are teaching them such certain things and...

**P4** – Life orientations

**P7** – Yes life orientation. This level this this, it's good. So they can tell them that okay, so you know up to this far, then this is what's happening. Do you know why you don't have a mother today? It's because of this and this and this. That's why we are preventing this to you to have such problems

**R** – May I ask from your experience, at what age do you think it's...

**P3** – You know I say it depends largely on the emotional intelligence of the child. Because you'll find a ten year old or twelve old but you also in the pre-counselling that's where you see how the child handled previous adverse circumstances. But you can also have an eight year old that you can from the mind or stage of an eight year old disclose HIV and telling in your picture form using diagrams and what to explain to this child what this HIV is. How does it work in the body? It's like little soldiers, these tablets are going to fight you know where the. You know to explain at the level of the child. And you find that these children they take it upon themselves to keep themselves healthy. Even at the tender age even of five or six or what a child will actually tell the mother, mum I need the little soldiers to keep my soldiers awake. You know referring to the tablets. As the child grows or at every progress if a child makes progress, let's say he or she goes for the CD4 count it's good to inform the child that your CD4 count is this or that. And the interpretation it means this. So if the child is being, it's like giving a child a pat on the back. You know the CD4 count is good, is rising, it means I'm doing

something well therefore I keep it up. If it's going down it means there is something I'm not guarding taking well, I must increase B and C and D. you know the feedback works very well with children.

**P6** – The child care act says at twelve years.

**P3** – Yes

**P6** – But they also stipulate and say that it depends on the maturity of the child. If there are some twelve year olds that are not mature enough to know their statuses and they are some ten year olds that you can explain to and or maybe even an eight years that you can explain to them and tell them what's happening but it must be at the level of that child.

**P3** – that is why it we first assess the emotional intelligence of the child and it's not always a chronological age that says it's done now.

**R** – Okay, have you been in a situation where you had a child in the ward admitted for some other disease other than HIV? In that case, has anyone has had that experience? The child is admitted, she's suffering from something else say cardiac or something else but she has maybe she's taking ARVs she has HIV. In that case has anyone?

**P6** – 9.5 is most of them

**P4** – We have a lot of them especially on that age.

**R** – Which age?

**P5** – above ten.

**P5** – Yes

**P5** – We had the other one girl, it's a girl. She know that the parents are not there, she's left with the aunt. But at the same time the aunt is not treating the child well. So the child for her to default, its because she wants to die cause the parents are not there. So the state that they are in its emotional. It counters a lot.

**R** – What are the emotional?

**P5** – That I don't have a mother and then this one I'm staying with is not taking care of me. At school they you know the environment at school she doesn't have friends because they are afraid of her that she is HIV positive.

**R** – Do they know? Do other kids know?

**P5** – I don't know who told them

**P4** – You never know

**P5** – She told us that they know that she is positive, I don't know who told them and then she doesn't have friends because they think she will infect them and whatever. I think they disclosed at school or what I'm not sure about that one. But at the end of the day they default because there is nobody supporting the child. There is no support at all from home, so the child every time she'll go after 2 weeks she is back. After 2 weeks she is back. Why are you here? It's not nice at home. It's nice here in hospital. So the support

**P1** – I think the problem

**P5** – I think the support from the family

**P1** – Support system

**P 5**– Like they said even at school the child needs support.

**R** – You wanted...

**P2** – I think with us the problem with us Africans is this kind of thing comes mostly in the disadvantaged areas and families where there is a lack of education, where people mostly people are feel so much oppressed that they can't even open up to neighbours or to friends. So if you can't open up to neighbours, friends; how are you going to open up to the child that you are raising?

**P5** – Even open up to other members of the family

**P2** – Yes

**P5** – The aunties and the other ones. It ends here.

**P2** – Ya

**P5** – it's me and my children. But outside the other ones they won't know. Then the painful comes when the parents dies. Then they have to take care of this child. Then it becomes a problem, they don't accept the child easily or the child is not well-supported with the other families.

**R** – My earlier question, I don't know if I did not phrase it well but you tried to answer it. Which when I said the child comes she has some other disease and also she's also on ARVs. What happens, she stays in the hospital for a week, but HIV is not the main problem, do you also entertain the HIV part?

**P5** – Normally the doctors when they take bloods they will do all the tests. But if they can't find anything let's say everything is positive or negative, negative, it's only the lungs or it's only the bronchiolitis or something, they will prescribe. But if the child doesn't get better, I think they do take bloods. They sign the consent form for blood to take bloods to test or the HIVs and some thing.

**R** – but they

**P6** – We know is on ARVs and they come for something else

**P 5**– Yes

**R** – Oh if they know?

**P2** – If she comes with the pills

**P6** – They come with their medication and we just incorporate them into the treatment that we going to give and if its not the main problem at that time, usually we just check that they are on treatment their last CD4 is this and they are taking treatment this and then we leave it there.

**R** – What Are?

**P5** – Sorry, to add on that, we had another mum. This mum knew about the status of the child, the mum went to the clinic in Kimberly they told her the status. She I think was in denial, she came back

she went to Joburg Gen. they gave her the very same results. In that period, she didn't even give the child Neverapine or whatever.

**R** – It was the child's status?

**P5** – The child's status and then they took the mom bloods. The mom was positive. She went all the shopping around trying to find out whether it's true or not and then she came to our hospital, they asked about all this status she said no. and by that time it's about three months she knew about the status the child is not on medication she's not on medication. They ask her the status she said everything is fine. And the child is FTT (failure to thrive). Two months baby but still small. Then they took the bloods everything, when they came to tell her about the results she said yes I knew. So why didn't you tell us? I wanted you to do your job.

**P5** – So we don't know whether its denial or what. We don't know. And then if the child doesn't want to drink medication, said so what must I do the child doesn't want to drink. She doesn't care. We had those mothers. So

**P3** – I think the mother first needs to be to have some form of therapy. She has we know problems that she needs to work through. Because if when she's okay then I think she'll better accept and react better to her newly found status.

**P5** – So if they didn't get that pre-counselling the information is very difficult for them. It's very difficult

**P7** – And it does happen you'll find the doctor calling a parent over the phone wanting to get permission consent over the phone. How can you do such a thing over the phone? You can't do pre-counseling over the phone.

**P5** – You can't

**P7** – You can't. But I don't know

**P7** – But they do orientate you guys from first year level about this

**R** – Parents, but parents do they do come

**P6** – Yes. Most of them do come

**R** – But why does anyone has to do it over the phone?

**P4** – Some situations will push them because they can't get

**P3**– The child has been in the ward for two weeks

**P4** – There is no transport. Because sometimes you have to

**P6** – for example a patient who stays in Mpumalanga they take, when you discharge the child, you must just put the child on the transport I'll meet the child in the hospital. They won't come because they don't have money and you need to test the child. But it's not ideal.

**R** – And have you had a situation where you did not get any consent at all from...

**P6** – Not really. It's either they will refuse to test but usually if you ask them to test most of them do test.

**R** – No I mean for the children where you did not get consent from the caregiver or the parent.

**P6** – Where they will not give it or where cannot get it?

**R** – You cannot get hold ya

**P6** – Not really. There's usually if there are no parents there's usually a grandmother or someone who brought the child in

**R** – And has there been a situation where parents did not, refuse like the one who said don't tell the child that I knew? Have you had...?

**P6** – Where they refused to test

**R** – Where they refused to give consent for the child to be tested.

**P6** – It used to happen before. But these days not so much.

**P6** – Not so much.

**R** – And in that case what do you do? Would you leave the test?

**P6** – Well if they refuse, we can't test. You can only advice and counsel them but if they refuse we don't force them

**P3** – Okay but that chapter to the constitution says the child has the right to have so it will be a long procedure but if you follow it ultimately this child can be tested.

**P6** – if I ask now and the parent doesn't want to test I won't force matters and go and test because then if I do that we won't have cooperation from the parents.

**R** – after the results

**P6** – after that. Even if I want to start the child treatment, its either they will not start treatment, they will not give it they will so it should be a relationship for trust. If they don't want to do it I'll give them time. Give them options to go and think about it and then come back or to go somewhere else because if you force them you will just wasting you time and their time. They might just not even come back for the results you forced them.

**P3** – and the treatment

**P6** – And the treatment also

**R** – And tell me, the issue, let's go back to the issue of disclosure. How does it impact on you as health providers?

**P1** – it's very frustrating

**R** – it's frustrating

**P1**– it's frustrating because you are in the middle of it all. You don't know what to do. It's difficult as one said, if you disclose or if you intervene at random like that then you are going to break other people's weddings also. And how are you going to feel if you are part of this. It's very very difficult.

**P5** – Sometimes it happens when let's say maybe you didn't know that the child is positive, and then you want to do something then you just go on the file the patient to just gather information. Then when we give report then will start saying you'll give this child the treatment 7 o'clock then it will be like what treatment, and if the doctors or whoever is responsible to write all those things didn't inform

us as nurses it becomes difficult for us because when we give report we just tell. And they are there sitting there listening. So we must when the report is there, we must be informed, don't disclose before

**R** – Oh yes

**P5** – Because you will just give report. I'll just tell please guys this child is getting treatment of ARVs of 8 o'clock innocently. But at the end of the day I've disclosed and they don't know. Then it will it's going to be a problem. I'll be, it'll be difficult to go and look at them again during the day if they tell me they don't know. So it will be a bad way disclosing. So we need to be informed also

**R** – I've just remembered something, now with these kids, do you make sure that they are disclosed to maybe earlier in the admission?

**P4**– Hmm earlier maybe they are too sick they won't even

**R** – I'm just thinking of what she said if you giving report, she hasn't been told yet, she has just been admitted a few hours ago or maybe a day.

**P4** – no. that's too much.

**P** – It was introduced one time at AIDS day that when you are diagnosed and come collect your you take treatment and come and collect every time you must have a buddy. You not supposed to come alone. So I think the person who realized this thought it would work much better because this buddy will help with the counselling and everything to this person

**R**– A buddy should also be HIV positive?

**P2** – No

**P2** – Not necessary

**P2** – Not necessarily. But just to remind always and support

**R** – So I just want to follow up what sister has said, so there is a chance that something can be said around the diagnosis when the child has not been told yet

**P2** – Hmmm

**P4** – And they won't ask questions. But sometimes when they come to us maybe for therapy, they'll keep asking why I am doing this. And now you want to send them to the special school because they need to be accommodated then most of the times grannies. So now how am I supposed to tell this child that she doesn't qualify for this school all because Thando is attending there and now she must go to another school? Then we also don't know how to tell that child. Because they'll ask you how long am I gonna be coming here. Will I be able to walk at least and go join Thando?

**R** – And how have you handled that? So far

**P4**– We just stay positive.

**R** – You just leave the child?

**P4** – Because if the family said not yet, so I can't say anything. I just continue with my therapy. And one other thing, the things they understand. So you just send them to this special school just for their

physique and now attend they get to the school and they see other kids are actually worse and now they come back they think they gonna be the same.

**R** – So what other impacts? Did we exhaust all the impacts on how providers they do experience?

**P1**- rather I've observed in the past, well because while I'm no longer working I used to work in an admission ward where either the child is very sick and with some doctors they pre-counselling is I don't know whether to say its pre-counselling or what but when they speak to the parents maybe they suspect that this child may be HIV positive, they won't give some privacy to the mother. You know, like maybe someone is busy with them back then the doctor will just say eh mummy have you heard HIV? I want to take your child for blood HIV. Some such things.

**R** – So there is lack or privacy?

**P1** – Privacy eh

**R** – Okay, is there anything else that you want to add? Yes

**P3** – I just want to add, lack of privacy thing. I think it's also a question of resources. If this doctor had you know social worker who's on call, a few social workers, he will if he suspects HIV you just say mummy daddy please go to that room somebody is going to talk to you about something without saying in the hall full of people. So the social worker will be able to close the door and behind closed doors start to disclose, so question of resources is also very necessary.

**P4** – And social workers are working seven. Say maybe its at night, sometimes the child is too sick they don't have time to call this one. They want to do this thing now. So there is no time to phone mummy and mummy is too stressed sitting outside. Some situations are impossible

**P2** – I think what they doing now at the local clinics is much better cause they now. The pregnant moms they test them before they can deliver. They get enough counselling and they get tested also. So they know their results before they can go and deliver.

**P3** – But with children it becomes difficult

**R** – Is there any addition that you want to add?

**P5** – I think the last thing I can say it's this, especially these children that big from age ten upwards. Sometimes when they are admitted, let's say they know each other I know that some will me and who and who when the other one comes very sick being on that last stage, then there is saw that child there'll be very sick. It affects them in a way that they just see themselves like that means you are going to die.

**R** – They also get sick?

**P5** – Yes

**R** – Yo

**P5** – I don't know because someone is psychologically or somehow but immediately if they can hear so and so died, then

**P7** – That partner they know



**P5** – That partner they know that that one was drinking the ARVs together, it affects them a lot. Its really affecting them.

**R** – And tell me, I've just remembered something, when they are in the ward, do they get to know that even that one is also positive.

**P5** – They talk

**R** – Oh they talk among themselves?

**P5** – They talk. Some other they talking, even that one with the granny. He knew them after the other ones were talking. Haa this one is taking same as mine, and then he started asking what is this. No the ARVs they are same as mine. Then it went my ear said something is not right and then I went and started talking to the granny. Does the child know? She said no. so it's when then I took the matters something must be done now not later than today.

**R** – Maybe there should be a support group of like

**P5** – I think so

**P3** – Actually it's a condition similar to the oncology ward for children. You know it's the same condition as they die, it's like the remaining ones it's like a sympathetic condition they also just become more ill falling to the whole depressive state. It's like if one passes away, support for the rest but staffing is also a problem. It warrants getting people

**P5** – They even defaulted. They eventually I'm going to die so what. So if so and so died, then that means I'm going to die also. You give the tablets then he'll just hide them under the pillow

**R** – And how do you handle that?

**P5** – We have to sit down and explain to them if you don't drink you medication you make the matter worse. Said okay sister. So we'll just wait there, say drink and you observe. Did you drink? Ah No. kids. Did you swallow? Yes. You don't just give and put the tablets and leave it there. They won't drink. You must wait, observe them to drink and then they will drink them.

**R** – Okay. No, thank you so much people for your information. I think it is going to help us and help other people who are HIV positive. Thank you so much

## **ANNEXURE G**

### **Acknowledgement of language editing**



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To whom it may concern:

This letter confirms that I have professionally edited the Master's dissertation prepared by Mercy Ndacayisaba for the University of Pretoria.

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