MOTHERS' EXPERIENCES OF DISCLOSURE TO THEIR CHILDREN OF THEIR HIV-POSITIVE STATUS AT A LOCAL HOSPITAL IN THE WESTERN CAPE: A SOCIAL WORK PERSPECTIVE

UNIVERSITY *of the* **WESTERN CAPE**

Tembela Boyana

Student number: 2222687

Supervisor: Dr N. Henderson

05 December 2019

ACKNOWLEDGEMENTS

I am sincerely grateful to God. Thank you, Lord!

I would also like to extend my heartfelt gratitude to Dr Henderson despite me struggling to meet deadlines at times, you kept on motivating, supporting, and guiding me with critical thinking and structuring my work, which enabled me to successfully complete this study. Thank you for overlooking my disadvantaged educational background.

Prof. Mark Cotton, thank you for allowing me to study and to do my research at FAMCRU, and for financially supporting me throughout the writing of this thesis.

Thank you to all the participants of this research study who shared their experiences with me.

Many thanks go to my children, Onwaba, Akholwa and Liminathi my baby, I respect you with this work and with the hope of creating a legacy of tolerance, compassion and understanding of the study process.

Last but not least, a warm and heartfelt thanks to my dear husband, Luyanda Boyana, without whom this journey would not have been possible. Thank you for the love, support and encouragement you have given me, and for helping me achieve my goal.

ABSTRACT

Antiretroviral therapy (ART) is been researched and reported available worldwide and it has been reported to work; children on treatment live longer periods of life. Tygerberg Hospital (TBH) is one of the well-known academic healthcare institutions located in Parow, Western Cape, South Africa with several units including the paediatric unit. This research unit situated at TBH is focused on pharmaceutical trials and consists of approximately 500 children actively participating in the study, as well as approximately 300 pregnant mothers. This study aimed at exploring the experiences of mothers who have disclosed to children about their HIV-positive status, as well as exploring interventions to assist disclosure. The ethics of care is the theoretical framework utilised in the study. The population was mothers whose children are HIV-positive and the purposive sample included approximately four social workers and ten mothers who have been cognisant about disclosing to their children their HIV status. Key informants included social workers who dealt with these cases interviewed to triangulate the data. The interviews were conducted at the social worker's office located at TBH paediatrics unit. The study is qualitative with explorative and descriptive research design. Data was collected through in-depth semi-structured interviews transcribed verbatim. Data analysis was utilised to develop themes and sub-themes on the topic. Ethics considerations were adhered to. The findings highlighted challenges that mothers encountered during the process of disclosing, particularly a sense of shame and fear how their children and their communities will respond. There was a mixed response to how mothers felt about support from social workers and other care workers at the hospital, including the local clinics and there was a strong belief that training should be secured so that mothers can be empowered to do HIV disclosure to their HIV positive children.

KEW WORDS

HIV

Disclosure

Mothers

Children

Social work

Care

Family

Support

LIST OF ACRONYMS

HIV-Human Immunodeficiency Virus

AIDS-Acquired immunodeficiency syndrome

ART-Antiretroviral therapy

WHO-World Health Organization

TAC-Treatment Action Campaign

UNAIDS-Joint United Nations Programme on HIV/AIDS

DOE-Department of Health

HCT- HIV Counselling and Testing

NSP-National Strategic Plan for HIV & AIDS and STIs

NDH-National department of health

TABLE OF CONTENTS

Table of contents

Chapter three

Chapter four

Chapter five

List of tables

x

List of annexures

<div align="center">

CHAPTER ONE

INTRODUCTION

</div>

1.1. Background and rationale

Human Immunodeficiency Virus (HIV) is a worldwide problem. According to the World Health Organization (WHO) and Joint United Nations Programme on HIV/AIDS (UNAIDS), since the beginning of the epidemic, almost 60 million people have been infected with HIV, and about 25 million have died of acquired immunodeficiency syndrome (AIDS)-related diseases. The first report of AIDS in children worldwide was published in 1983, and it was concluded that they had acquired it before, during, after birth, or during breastfeeding – called mother-to-child transmission (MTCT) (Avert, 2005). HIV can be transmitted from an infected mother to her baby through the placenta during pregnancy, through blood contamination during childbirth and breastfeeding (Dyk, 2005). It is estimated that transmission occurs in utero as early as during the first trimester of pregnancy. A mother is more likely to infect her foetus during pregnancy if she is infected during or just before pregnancy. South Africa has been reported to be the largest antiretroviral treatment (ART) programme in the world and these efforts have been largely financed from its own domestic resources. Kaplan (2013) reported that there is a strong scientific evidence for use of antiretroviral (MTCT) evident that that ARV therapy essentially interrupts HIV transmission ,2008 ,the majority of about 430 000 new paediatric HIV infections were in sub-Saharan Africa ,where the is recent evidence that ARV can be used to decrease transmission, and the success of ART programme marked increases in national life expectancy, rising from 61.2 years in 2010 to 67.7 years in 2015.

HIV is the causative agent of AIDS and it has been reported that there are two types of HIV: HIV-1 (type one) is the dominant worldwide and HIV-2 (type two) is more applicable to West African countries. UNAIDS has declared Nigeria as the country with the third highest prevalence of HIV/AIDS in the world. South Africa has the greatest and highest profile rate of HIV epidemic in

the world, with an estimated 6.3 million people living with HIV. Furthermore, 3.2 million children worldwide are living with HIV and 91% of these reside in Sub-Saharan Africa (Avert May, 2015).

It was reported by Dyk (2005) that more than 60% of cases of transmission of HIV infection from a mother to her baby occurred during labour and delivery. The main reason for this is contact with the mother's blood and mucus in the birth canal during the birth process.

In 1994, a public health service in the United States of America (USA) recommended the use of zidovudine, also known as azidothymidine (AZT) to prevent MTCT of HIV, and this antiretroviral therapy is still in use today and reported to be working well. South Africa consists of nine provinces, and at least 25% of pregnant women are HIV-positive. The epidemic varies within South Africa. In KwaZulu-Natal, HIV prevalence among those who visit an antenatal clinic was approximately 37%, which is about three times higher than in the Western Cape –the province with the lowest prevalence (Dyk, 2005). The reason to give this background is to understand the importance of knowing.

The research was conducted at the Family Clinical Research Unit (FAMCRU) at Tygerberg Hospital in the Western Cape, South Africa, and works closely with the infectious clinical diseases team that provide ART to HIV-infected children and their respective parents through the state sector. The Paediatric is the focusing on pharmacokinetics to determine the correct medication dosages for young children and infants – currently starting from birth. FAMCRU has a multidisciplinary team consisting of doctors, nurses, pharmacists and other support staff like the social worker rendering psychosocial support for all the mothers infected with HIV and to prioritise the health and safety of children of these mothers. HIV disclosure is a subject with which some mothers at FAMCRU Paediatric Unit battles to address , the National department of health (2016) stated that the reason for poor disclosure to children is because parents fear the emotional impact of disclosure towards the child , Fear of the consequences of disclosure like the child would accidentally or un aware that they are disclosing to community

and family members that are not supposed to be aware of the child's HIV positive status and fear of being blamed and feeling guilty for infecting the child.

Due to slight different factors, ranging from psychological to cultural, that lead to non-disclosure. It has been reported by different authors (Lesch, 2007; Madiba, 2015) that little research has been conducted about disclosure especially in Sub-Saharan Africa. The fact that there is still stigma attached to HIV disclosure may negatively influence some of the mothers. This is particularly prevalent among the isiXhosa-speaking mothers who visit Tygerberg Hospital. It is not clear whether cultural factors impact their non-disclosure, but it would appear to have some connection to the problem. This study aims to discover from some of the mothers the reasons why they are reluctant to disclose to their children their HIV-positive status. Lesch *et al.* (2007) described disclosure as an act.

1.2 Problem statement

The availability of ART over the past few years has improved health radically for both adults and HIV positive children. However the challenges are still there, which is people living with HIV they have fear of stigmatized and once again it means that mothers are reluctant to disclose their HIV status, which has a knock-on effect with regards to disclosure to children. The researcher monitored mothers who had poor adherence with regards on enforcing their children's medication and who are attending at the FAMCRU infectious diseases clinic. Mothers reported that the children from the ages of seven-years-old and older refuse to drink their medication as they do not believe they are sick. National Department of Health (2016) reported that, a child that is unaware of their illness it cause's a negative effect on their body, like poor adherence leads to high viral loud and constant HL leads to resistance. Furthermore, rejection and blame is the most unbearable behaviour that mothers could not be able to control over their HIV positive children and that is the mother's responsibility

to protect their children against an emotional imbalance. Tartakovsky & Hamama (2011) mentioned that the School of Social Work researchers argue that, parents of children with a chronic medical condition are anxious for their child's well-being; they blame themselves for the child's illness, and suffer from their inability to help their child recover. Therefore, parents of children with a chronic medical condition may be more caring and providing. However, they have reported that the children have started asking questions about their treatment like, why they have to adhere to the treatment. This is what the FamCru paediatric unit experienced, children constantly asking questions about their treatment

The availability of ART has decreased mortality in children but there is a need to prepare and improve the emotional and psychological state of HIV-positive mothers in disclosing to their children. This will require engaging with mothers on strategies for disclosure. On the other hand, the role of the father, although not part of this research, could also be highlighted when looking at intervention tools.

1.3 Research question

The research question tends to be answered at the end of the study and is as follows: What were the experiences of mothers who disclosed to their HIV-positive children at Tygerberg Hospital, Western Cape, and what intervention tools would be suitable to enhance disclosure from a social work's perspective?

1.4 Aim

The aim of the study was to explore and describe mothers' experiences of disclosure of their children's HIV-positive status at Tygerberg Hospital, Western Cape and to determine intervention tools, strategies that will be suitable to strengthen the mothers on disclosing to their children's HIV

positive status and to explore the involvement and the availability of the social workers on assisting and equipping mothers to disclose to their HIV infected children.

1.5 Objectives

a) To explore the mothers' experiences of HIV disclosure to their HIV-positive children at Tygerberg Hospital in the Western Cape.

b) To explore and describe the role of the social workers facilitation on disclosure of children's HIV positive status at Tygerberg Hospital in the Western Cape.

1.6 Theoretical framework

In order to make sense of mothers' experiences of disclosure to their children about their HIV-positive status and from a social worker's perspective, the ethics of care was used as a theoretical framework to understand the morals and values. Tronto (2012) emphasises that 'care' within the political ethics of care framework is about commitment, 'caring about' is more general and impersonal, while 'caring for' is more specific and focused, requiring knowledge about context of care. Tronto (2012) emphasised the four ethical elements of care, which are the following:

1.6.1 Attentiveness (caring about) (Tronto, 2012): Crucial to the ethics of care because care requires recognition of others' needs in order to respond to them. It would be important for mothers to be attentive to the needs of their HIV-positive children. Tronto (2012) highlights that some fathers are often absent when it comes to recognising the needs of others.

1.6.1 Responsibility (caring for) (Tronto, 2012): In order to care, we must take it upon ourselves, thus termed, responsibility. Once the need is recognised, then a person or group of people need to take responsibility to ensure that people's needs are met. The mothers would need to take responsibility together with the support of the social workers to address the HIV-positive status of

the child. Tronto (2012) is critical of fathers within African-American families for rarely being available as a support, and this could link to patriarchal fathers within a South African setting. As indicated in this research, it is not often that we have seen fathers accompany the mothers to the clinic; at the antenatal visits, one would hardly see the presence of the father.

1.6.2 Competence (care-giving) (Tronto, 2012): Competence is not just a technical consideration, but also a moral quality. Competence also assumes that the person has the knowledge and resources to do good work. The mothers need to be empowered through an intervention tool to disclose to their child, or social workers must find another solution for the non-disclosure. Mothers in the rural areas of South Africa do not always have the knowledge to be competent in HIV disclosure.

1.6.3 Responsiveness (Care-receiving) (Tronto, 2012): Responsiveness signals an important moral problem within care; by nature, care is concerned with conditions of vulnerability and inequality. Responsiveness entails assessing whether care has been effective. Tronto (2012) requires the care-receiver to respond to the care-giver, and in this case the child would be able to understand the importance of taking the medication once disclosure has occurred.

Tronto (2012) states that care is often unpaid work and mostly carried out by women, which is at the heart of her argument as she believes that men should be prepared to share in the caring responsibilities of children. This would influence the kind of intervention tool required for mothers (and possibly fathers) to disclose to their HIV-positive children.

1.6 Outline of the thesis

1.6.1 Chapter 1: Introduction

Introduces the study and provides background aims and objectives of the study. This chapter is important because it clearly provides the reader with a direction of the project. Two things stand out

in this introduction: what the research is about and how the research is organised.

1.6.2 Chapter 2: Literature review

The literature review, among other things, highlights key debates about disclosing to HIV-positive children from a social work perspective. This chapter starts by highlighting t h e theoretical framework that serves as a base for this research. The framework provides a lens through which to guide the research project. This chapter is helpful because it provides explanations of concepts and phenomena through established theories. The chapter ends with a discussion around a social worker's perspective on assisting mothers in disclosing their children HIV-positive status.

1.6.3 Chapter 3: Research Methodology

This chapter highlights research design and methodology of this study, and outlines how to make use of the qualitative method, the gathering of in-depth interview data and observations. This chapter further details the account of who was interviewed and where the interviews took place. This chapter ends by providing the ethics that guided the research and the challenges this study faced.

1.6.4 Chapter 4: Study findings

This chapter presents the results of the research, analysis, and discussion of the findings. In this chapter, theories used in this project are considered in light of the findings. Not only does this chapter reveal results based on the realistic research conducted, but it a l s o makes sense of such results.

1.6.5 Chapter 5: Conclusion

This chapter concludes the study by providing a comprehensive summary and suggestions. This chapter is linked to the introduction, as it completes everything discussed and offers research based on suggestions to stakeholders, providing possible areas for further research and possible amendments on the children's policy.

CHAPTER TWO

Literature review

This section presents a comprehensive review of literature based on experiences of mothers' disclosure to their HIV-positive children from a social worker's perspective. During the literature review, the researcher identified a gap in the existing literature with regards to qualitative studies about the experiences of mother's disclosure to their HIV positive status. This chapter is divided into sections. Section one outlines the theoretical framework, HIV/AIDS treatment, HIV/AIDS disclosure, and section two examines literature on HIV disclosure and the social worker's perspective. The review of literature assisted the researcher to be acquainted with key debates and information (Mouton, 2001; Reid, 2000) in the field of social work and HIV disclosure. Ethics of care strengthens this study to explore the behaviour, principles and norms on experiences about HIV disclosure to children. It will outlined and provided the origins, historical background and the development, as well as the critiques of the theory. It further justifies a gap in the existing literature with regards to qualitative studies about the experiences of mothers' disclosure to their children about their HIV-positive status from a social worker's perspective.

2.2.1 Theoretical framework

In order to make sense of mothers' experiences of disclosure to their children about their HIV-positive status and from a social worker's perspective, the ethics of care was used as a theoretical framework to understand the morals and values. According to Van Wyk (2011), a theoretical framework provides the reader with an understanding of the researcher's perspective and the context in order to make sense of the entire study. Once again, a theory is a collection of rationally-organised laws, principles and morals that one might need to follow and apply to their everyday lives Christensen *et al.* (2014). Tronto (2012) emphasises that 'care' within the political ethics of care framework is about commitment, 'caring about' is more general and impersonal, while 'caring for'

is more specific and focused, requiring knowledge about context of care. Tronto (2012) emphasised the four ethical elements of care, which are the following:

2.1.1 Ethics of care

Ethics of care was started as a feminist theory and it was originally created by psychologist Carol Gilligan in 1989. Joan Tronto (1993) is a well-known professor who focused on a political argument on ethics of care and focused on woman studies (care and feminism). She views ethic of care in a personal, social, moral and political approach and she believes that all human beings need to receive care and provide care to others, especially to the vulnerable. The choice to apply the political ethics of care theory is related and relevant to the research that I am doing as the research is based on mothers caring for HIV-positive children and women in South Africa are mostly undermined on a political and social level. Ethics of care gives emphasis to the importance of response and in this case, disclosing HIV-positive status to anyone is an important act. Different theorists criticise the application of ethics of care because of common values as morally problematic while Gilligan (2008) recognises that men and women have tendencies to view morality in different ways.

Gilligan's (2008) theory continues to call for women to emphasise empathy and compassion over the notions of morality, while some feminists have criticised care based on ethics for emphasising traditional stereotypes of a "good woman." Gastmans (2006) describes ethics of care as a moral perspective otherwise orientation from which ethical theorising can take place; this can mean that ethics of care is more of a bearing. Nodding (1980) further contributed to the theory by focusing on the approach of intimate relationships; she felt it was necessary to differentiate between 'natural caring' and 'wanting to care,' and 'ethical caring' or 'needing to care.' Tronto (2012) continuously emphasises the following five notions on ethics of care, however for the focus of this study, only four notions will be highlighted below:

2.1.2 Caring about: Taking notice of people's needs, listening to what people are saying, and being observant of what they are not saying (attentiveness). Listening to the caregivers who are in need of assistance for their HIV-positive children's disclosure in order to avoid viral logical challenges. However, at the same time, promote a long life for children and ease the caregiver's conscience. It is essential for people to be self-reflexive about their own needs for care and to ensure that the self is not subsumed in the caring, which is important for mothers – especially those working and who have children with chronic diseases (Barnes, 2012).

2.1.2 Caring for: Taking on the duty of ensuring that people's needs are met (responsibility). Children being made aware of their HIV-positive status is essential to avoid unnecessary further sickness that would lead to hospitalisation and to avoid death. Being responsible means preventing the negative outcomes of not doing the right thing at the right time. The role as a caregiver and the extent to which social workers are recognised as professionals could impact responsibility within healthcare and how they are valued socially. Therefore, the issues of status and roles of healthcare professionals should, therefore, be understood in terms of influence relations between the care-receiver and caregiver, as well as the impact on the responsibility to care (Barnes, 2012).

2.1.3 Caregiving: The physical act of caring for people (competence). A social worker is a professional caregiver and doctors treat patients in fighting for their lives. Mothers are caregivers and are expected to be active in caring for their family's needs. Daily increased workload of social workers might lead to lack of attentiveness, likely in local day clinics, since competency in caring can be a challenge when caregivers see organisational requirements as hindrances, rather than support for care practices (Tronto, 2010).

2.1.4 Care-receiving: Reaction to the care that is provided by the caregiver (responsiveness). The caregivers also need care of their own at some point, and in this case, the unit social worker is able

to render the fourth phase of care to the mothers by assisting in disclosing the HIV-positive status of their children. As Engster (2005) stated, during the care-receiving phase, the caregiver engages with clients in order to conclude the nature of their need and to monitor their responses to the care. Tronto (2010) emphasised that care practices are well accomplished if all four of these elements are met appropriately.

2.2 Care

According to Tronto (2010), care for people with HIV-related illnesses can only be understood in terms of the support of people in their communities to care for one another. In this study, mostly close family members care for each other by showing support to the HIV-infected individuals. 'Taking care of' refers to responding to a need that has been identified. This study continues recognising 'caring about' as individually and culturally shaped – suggesting that some issues may be more important to address for some than for others (Tronto, 1993: p. 18).

The impact of caring for people with HIV is that it constructs a shift of caregiving due to the demand of care and responsibility towards health care workers, like the mothers who would like social workers to be more involved in their children's disclosure. Care for people with HIV illnesses often takes on the form of charity. Caring cannot be self-sacrificing, however, it should be a mutual relationship between caregiver and care recipient where caregivers and care recipients have different self-interests, and caregivers also need care – similar to the mothers from our clinic.

A study that was conducted in the Western Cape, South Africa revealed a feminist ethics of care perspective to understand the type and quality of care that disadvantaged people with HIV-related illness receive, and it focused on the economic and social value of women's caregiving. The study interrogates how gender boundaries play out in both opposite-sex and same-sex caregiving contexts

between care recipients. Different theories recognise caring as an ethically-relevant issue. Tronto (2012) further emphasises the association between care and "naturalness." Women recognises care as high priority in this study and that makes it relevant with the as mentioned by different theorist that socially and culturally gender roles where care is assumed to be the woman's role.

2.3 Feminism

Feminism has been viewed as a population of people who hate men and allow women to assert everything, while other theorists believe that men and women are equal. Women are reported to be the ones who face more inequality and are seen as less valuable or weaker than men.

Care-focused feminism is a branch of feminist thought, informed primarily by ethics of care, as the body of the theory is critical of how caring is socially engendered, being assigned to women and consequently devalued. Care-focused feminists regard women's capacity for care as a human strength, which can and should be taught to and expected of men as well as women (Gilligan, 2006).

The low socio-economic status of most women and their dependency on men for economic support places them in a vulnerable position for HIV infection, and may cause them to carry the blame for AIDS in South Africa (Madlala, 2002). The status of women and the wellbeing of children are deeply intertwined (UNICEF, 2007: p. 2). Child survival is dependent on the survival of women as women are, in majority of cases, the primary caregivers.

Chersich & Rees (2008) reported that unequal sexual power and economic disparities, women will, however, continue to have limited ability to negotiate protected sex and few alternatives to adopting practices that explicitly aim to satisfy men's sexual desires (often at great cost to their own health and wellbeing). This clearly highlights the power man has against woman. And Motherhood is the women's primary role, they had to raise children, care for the home and see to the needs of the family

for an example In African societies women were expected to undertake agricultural tasks as well to help feed the family. On this research as mentioned before that it was only woman who was always visible at the FamCru paediatric clinic.

2.5 Women and HIV

Woman that were interview for this study it was all black Xhosa woman, there was no man that a researcher could have used due to unavailability and invisible to the FamCru clinic. Qubuda (2012) reported that black women lack economic power and that they feel obliged to have sexual intercourse with their partners as they are a source of income; furthermore, it is the man who decides whether or not to use contraception. Once again, in the isiXhosa culture, it is the norm for a man to have multiple partners and this is similar in the Tanzanian culture where gender inequalities in societies prevent women, and young women in particular, from negotiating safer sexual practices including contraception use. In Swaziland and in KwaZulu-Natal in South Africa, there are established patriarchal societies which lead to high levels of gender inequality, as men constantly dictate a woman's reproductive and sexual health. These patriarchal beliefs could impact on disclosure as women feel disempowered to reveal their HIV status for economic reasons.

3. Review of literature

This section presents a comprehensive review of literature based on experiences of mothers' disclosure to their HIV-positive children from a social worker's perspective. During the literature review, the researcher identified a gap in the existing literature with regards to qualitative studies about the experiences of mother's disclosure to their HIV-positive children from a social worker's perspective. Mothers reported that they do not know when and how to disclose to their children and they always prefer the nurse or the doctor to do it. Their fear was to say it in a wrong manner that might cause more harm to the child. In the existing literature, mothers are not given the opportunity

to relate their own experiences, including challenges that they have encountered during the disclosure process and the views of how disclosure should be addressed to their children. children started asking questions like "why do I have to drink my medicine every day because I am not sick" mothers would think of something like Asthma and the child will continue asking questions like , but I am not coughing meaning my asthma is better now. One mother told her son that he drinking the medicine because he wet the bed and the child told the mother that, "well should I not wet my bed I won't drink the medicine because I don't remember wetting the bed for the last couple of months now". Mothers reported to be harsh on these children because as mothers they understood the importance of giving them medicine everyday never the less children did not see any importance and according to the children they have improved as they are not experiencing or feeling any of the problems that their mother I telling them that they have.Mandalazi, Bandawe & Umar They mentioned that mothers they don't disclose to their children because they feel like they are robbing their children of happiness ,fear of making their own status known to more people, and fear of confrontation or creating enmity with their children as impediments to disclosing their child's positive HIV status to him or her.

3.1.Disclosure

Makhlouf *et al.* (2010) explained disclosure as an approach to open up about the HIV epidemic and recognise its importance of being known. National health guidelines (2012) made it clear that "Disclosure should follow a plan or process, it does not have to be a once off or a rapidly-reached end point, therefore disclosure should be handled as a cyclical process", which gets repeated as new information is shared with the child. Which mothers could be part of this process and to be explained to them all the steps. WHO 2014 highlighted that disclosure creates a network (even if it is very limited) of people who can provide emotional and practical support, Health providers can help

adolescents decide who to disclose to, how, when and where; to weigh the advantages and disadvantages of disclosure; and to help them anticipate likely responses.

It distracts support from family and friends where HIV-positive individuals feel rejected by families or partners, which often leads to anger. One can think about a child who is trying to find his/her identity and would be informed about HIV that needs a lifelong treatment and t consider their level psychological ability.

Disclosure does not always lead to negative results; it can be beneficial to both the patient and his or her family. For instance, the infected individual might benefit from receiving support from family and friends and this reduces the stress of coping alone. Many caregivers have reported, as highlighted by Reda *et al.* (2012), that they are afraid to disclose owing to the following reasons: inability of the child to understand, fear of psychological disturbance of child, fear of blame, not knowing how to inform, fear that the child will share the information which might lead to him/her being discriminated against, creating distrust between the child and the caregiver, expending energy in protecting information, and resentment and bitterness from the child for not being informed earlier. Reda *et al.* (2012) highlighted the following as the benefits of disclosure

1. Relief from secrecy.

2. Empowers patient to participate in healthcare.

3. Allows child to talk openly about his/her feelings.

4. Less anxious feelings about accidental disclosure during medical appointment.

5. Communicates respect to the child.

6. Reflects child's individual rights.

7. Helps children understand illness and promotes willingness to adhere to treatment.

2.2 HIV-positive status disclosure to children – International

The American Academy of Paediatrics (AAP) recommended that all adolescents should be made aware of their HIV status and disclosure is considered appropriate for those of school-age. However, the AAP provided few concrete guidelines to support providers and families in the process of HIV disclosure, including *when* and *how* to inform, how to decide, and how to evaluate the psychosocial effects of disclosure. Robert Klitzman *et al.* (2008) and Myer *et al.* (2006) reported that in the USA, health providers may need to play a central role in supporting disclosure of HIV status to infected children. In Thailand, 50% of the interviewed mothers reported the need for assistance from health workers (Kowitt, Emmeling & Fisher, 2015).

2.3 HIV-positive status disclosure to children – Africa

Three research sites from Abidjan, Côte d'Ivoire (also known as the Ivory Coast) in Africa, had a team of psychologists providing psychological support to the HIV-positive children and their mothers, however it is not stated whether they used an intervention tool or not. O'Malley *et al.* (2014) reported that the Namibia Ministries of Health and Social Services developed and implemented a multipronged intervention tool to support health care workers (HCW) and mothers. This intervention was based on a cartoon book entitled, *WHY I TAKE MY MEDICINE*. The results showed that the book was the most valuable intervention tool on disclosure and HCW reported that it reduced mothers' resistance to disclose.

2.4 HIV-positive status disclosure to children – South Africa

Madiba *et al*. (2015) stated that disclosure is a major challenge for caregivers and healthcare professionals providing services to HIV-positive children. However, healthcare professionals and caregivers are reported to be struggling with the lack of policies and guidelines on how, whom to and when to disclose. The WHO (2011) developed disclosure guidelines, but the use of it does not

highlight an intervention tool that can be used to assist HCW in supporting mothers with disclosure. This a gap that this research hopes to address by exploring possible intervention options for mothers. Madiba (2012) and Moodley *et al*. (2006) reported that many mothers avoid disclosure because of fear that the child will resent the disease, and that this will adversely affect the mother-child relationship. On the other hand, Kouyoumdjian (2005) reported in a qualitative research study, that was conducted in Chris Hani Baragwaneth Hospital in Soweto (near Johannesburg) titled, *Barriers to disclosure to HIV children*, that healthcare and social services providers should facilitate disclosure to children.

3.5 International studies on mothers' experiences of disclosure of their children's HIV-positive status

The improvement of lifespan since the availability of treatment and the confirmation that it is working very well (UNAIDS, 2013). However, concentration needs to be informing the children about their HIV-positive status so that they can have an improved viral logical suppression. Ostro *et al.* (2006) reported that "women are concerned that their children might be unable to keep the diagnosis as a secret, resulting in stigmatisation and isolation for them." Ostro continued to emphasise that "there is limited empirical research regarding the impact of stigma on mothers' decision to disclose to their children." However, Ostro continues highlighting the study that was conducted on mothers suffering from several limitations when disclosing to their children.

Lara *et al*. (2010) reported a recent review of paediatric disclosure literature, from the United States, Canada and Europe, which revealed that 10-75% of HIV-infected children had been informed of their HIV status; there were limited details about when full disclosure occurred, what was discussed, and how often they spoke to the child about it. Makhlouf *et al.* (2010) reported that the implications about disclosure deserves special attention and given its consequences for communication, initiative

to support disclosure needs to be an ongoing process, rather than focusing on a single point in time, and counselling cannot be the same at all stages but should consider evolving motivations and consequences.

Makhlouf *et al*. (2010) emphasised that the main goal of the review was to assess the extent to which HCW facilitated disclosure, and they found that healthcare workers' facilitation of disclosure was limited by the potential for discrimination at health facilities, limited counselling abilities of many workers and their fears and concerns regarding HIV (Gachanja, 2016). The American Academy of Paediatrics recommends disclosure of HIV status to school-age children. Several guidelines exist to facilitate the disclosure, paediatric HIV disclosure is proposed to be a process-oriented framework and although disclosure guidelines about HIV-positive children is widely recommended, there are few specific frameworks to guide caregivers, families, and healthcare providers through the disclosure process (WHO, 2011).

Different writers proposed a process-oriented framework for the disclosure of HIV in children and adolescents. This educational framework incorporates Piaget's cognitive development theory in an attempt to disclose and assist children and adolescents in understanding their HIV status. The framework is organised into 10 sequential stages of disclosure and three assessment stages, during which healthcare providers discuss HIV health concepts with the child and caregiver, and the described framework can be easily replicated by healthcare providers to disclose disease status to children with HIV. It highlighted that parents who have disclosed the status to their children experience suffer from less depression than those who did not. Wasan *et al*. (2010) reported that in Asia, mothers believe that "availability of healthcare providers make prevention and control of paediatric HIV in Asia a realistic goal."

3.6 African studies on mothers' experiences of disclosure of their children's HIV-positive status

O'Malley *et al.* (2015) reported that "availability of antiretroviral therapy has significantly improved the length and quality of life for children living with HIV in Africa." O'Malley continued that caregivers often feel unprepared to disclose to children, fearing blame, negative judgement, resentment, stigma resulting from the child telling others, or that disclosure will psychologically harm the child and in most cases, caregivers often desire healthcare worker support for the disclosure process." This is why we at FAMCRU feel that caregivers need professional assistance in disclosure to children, as disclosure may have a long-term psychological effect on the child's future. Namibian Ministry of Health and Social Services, in collaboration with the International Training and Education Centre for Health, developed and implemented an empirical ground and theoretically-informed intervention tool – which was designed and implemented in Namibia and has been used by doctors, nurses and counsellors. The caregivers loved the book because it assisted their understanding of the virus. The experience of mothers disclosing to their children was made more positive because of the assistance they received.

Another study was conducted in Kenya about disclosure of HIV status at an antiretroviral therapy paediatric clinic, and Vreeman (2010) reported that "disclosure involves support of a network of helpers." The study recommends a need to train clinicians or counsellors in paediatric disclosure and standardised materials to guide paediatric disclosure, and this is what this study aims to expose, advance, and unleash – the importance of professional assistance.

A study was conducted at a paediatric clinic in the Democratic Republic of the Congo about disclosing to children. Vaz *et al* (2010) compared a study that was conducted in Zimbabwe, examining healthcare providers' and community members' perception of disclosure of HIV status to children; the outcome was that half of the community members would prefer healthcare workers to be involved in initiating disclosure and discussion about the disease with their children. Vaz *et al*

(2010) continued to analyse that healthcare services can provide more support to caregivers in multiple ways. A study was conducted in the Democratic Republic of the Congo about the involvement of healthcare providers, but it is not clear how the study was conducted, meaning there is no clear evidence of what intervention tools and skills were applied, and whether they worked.

Kajubi *et al.* (2014) conducted a study in Uganda, which argued that communication about and knowledge of HIV medicine among children with HIV is low, and that caregivers should be supported in communicating diagnosis and treatment to children with HIV by healthcare workers. No clear explanation was offered as to how they should be supported.

A study that was conducted in Namibia by Beima-Sefie *et al*. (2014) evaluated a nationally-implemented intervention tool to assist healthcare workers and caregivers with HIV disclosure to children. The study mentions a previous study about disclosure, in which there was a major concern surrounding healthcare workers lacking formal guidelines on child counseling, how to prepare and support caregivers in disclosure.

While Kiwanuka (2014) states that there is a need to "empower with practical skills to recognise opportunities to initiate the disclosure process early, as well as supported to manage it in a phased, developmentally appropriate manner and the potential role for peer counsellors in the disclosure process deserves further study," meaning the involvement of counsellors is very minimal and no positive feedback about it has been raised yet.

3.7 South African studies on mothers' experiences of disclosure of their children's HIV-positive status.

Madiba & Mkoena (2012) report that South Africa has made significant progress in rolling out ART and highlighted that children receiving ART have a longer lifespan. However, that brings new challenges and concerns about HIV disclosure becoming more significant because of the multiple benefits of disclosure for the children and their caregivers.

Madiba & Mokgatle (2015) report that there is a significant benefit of disclosure especially when healthcare professionals are involved, but do not specify nor provide guidelines on how said professionals can get involved, or at which stage of the disclosure process to become involved. Reppssi (2011) suggested that "development workers and NGOs (non-governmental organisations) working in the area of HIV have also struggled with issues of disclosure, and in particular how best to provide disclosure support for HIV-positive children."

The review found [that] there is broad evidence of the positive outcomes for children made aware of their status, including greater adherence to treatment. As a result, the WHO (2012) recommends "that children of school-age should be informed of their HIV status, and younger children should be told in a manner appropriate to their developmental stage." However, the review does not unpack how disclosure should take place and who should take the lead on the process. The WHO (2012) continues to mention that some guidance is available from the WHO on health workers and counselling training, but more investigation needs to be carried out to better identify models for NGOs looking for concrete tools to support parents in disclosing to children, the Wits Reproductive Health & HIV Institute conducted a pilot study in 2008 which investigated the efficacy of a 'talking book.' The book is an illustrated comic tool for counsellors and healthcare workers, which guides caregivers on how to disclose a child's HIV status. The book was reviewed in 2012 by Reppssi.

Heeren *et al.* (2012) conducted a focus group on: *Disclosure of HIV Diagnosis to HIV-Infected Children in South Africa: Focus Groups for Intervention Development*. In the focus group,

researchers cited that "there is a need to build an empirical foundation for strategies to appropriately inform infected children of their diagnosis, particularly in South Africa which has the largest number of HIV-positive people in the world." They discussed the "implications for developing interventions to help caregivers appropriately disclose HIV status to HIV-infected children and, more generally, communicate effectively with the children to improve their health outcomes."

A lack of necessary knowledge and skills to communicate effectively about HIV with their children, concern about the reactions of the children, and concern about the entrenched stigma that revolves around HIV are factors that result in the consequence of caregivers not being able to disclose. Research conducted by Jemmott III (2014) in the Eastern Cape, South Africa reveals that "interventions to increase paediatric HIV disclosure in South Africa should help caregivers enlist support for disclosure among important referents and improve communication with their HIV-infected children." Most researchers in the same or similar field have highlighted the same suggestion about intervention in order to improve the disclosure process.

Obermeyer *et al.* (2014) states that the influence of health services on disclosure has not been systematically examined, but we can piece together information on three interrelated questions:

- First, whether staff at health facilities contribute to reducing stigma and discrimination, thus normalizing HIV;
- Second, whether they encourage disclosure by HIV-positive persons and promote testing and referral of partners and family members; and
- Third, whether they are prepared to counsel and support those who are tested, to facilitate voluntary disclosure and support.

The extent to which health facilities promote disclosure depends in part on whether they provide a supportive context for the difficult experience of being HIV-positive. Evidence suggests that health

facilities sometimes fall short in this regard. Discrimination against HIV-positive individuals was reported to occur when healthcare workers treat them differently, use excessive precautions. Naidoo (2015) reports a study that was conducted at the Paediatric ART Clinic, Edendale Hospital, Pietermaritzburg, South Africa that one of the greatest psychosocial challenges that parents and caregivers of HIV-infected children face is disclosing HIV status to their children and enlisting the child's cooperation in treatment programmes.

The results of the study indicate that "the caregivers of the first 100 children who met the criteria and consented to participate were enrolled in the study. Of these children, disclosure had occurred in 27 patients, while 73 were unaware of their HIV status. HIV disclosure entails communication about a potentially life-threatening, stigmatised and transmissible illness, and many caregivers fear that such communication may create distress for the child". Naeem-Sheik and Gray (2010) reported that it has been suggested that disclosure of the diagnosis to the child is an integral part of providing comprehensive medical care to a child infected by HIV. Murnane *et al.* (2016) reports that between 2013 and 2014, 553 HIV-infected children between the ages of four- and nine-years-old were enrolled into a cohort study in Johannesburg, South Africa, during which time they assessed the extent of disclosure among these children and evaluated characteristics associated with disclosure. They concluded that caregivers and healthcare workers require additional support to address disclosure and a broader public health strategy. Integrating the disclosure process into paediatric HIV treatment programs were recommended.

Madiba (2016) reported a study that was conducted in Botswana and South Africa which revealed that the caregivers cited lack of disclosure skills but believed they were primarily responsible for disclosure to children. They further added that they require support from healthcare workers during the disclosure process. Caregivers believe that counselling on how to approach disclosure and

training on when and how to disclose will make the disclosure process easier. Madiba emphasised the purpose of the study that he conducted to answer the following questions:

1) What makes disclosure difficult for caregivers of perinatal infected children?

2) What would make disclosure easier?

He emphasised that it is important that the challenges caregivers face regarding disclosure are explored and understood in order to facilitate the development of context-specific and locally relevant disclosure guidelines and procedures.

3.8 Western Cape studies on mothers' experiences of disclosure of their children's HIV-positive status

Moodley *et al.* (2006) reported that after she conducted a study in the Western Cape on caregivers that "most caregivers said that doctors should also be involved in disclosing HIV infection to a child." She continues to emphasise that "greater attention to issues of disclosure of HIV status to infected children may contribute to the improved quality of long-term care for this vulnerable population." Involvement of any healthcare professional would make a significant difference in disclosure, and this study looks at social work contribution.

3.9 HIV/AIDS treatment in South Africa

An activist group made up of different community members in South Africa called the Treatment Action Campaign (TAC) was formed in December, 1998. It was launched because the poor and marginalised were dying from HIV/AIDS while ART was only available within the private sector. Furthermore, the ART provided through pharmaceutical companies was expensive, the African National Congress (ANC) government was not addressing the issue due to the allegations of denialism about the president at the time, Thabo Mbeki (Natrass, 2007). The TAC focused on improving health particularly among the poorer working class population, and it achieved its unique objectives; this could be perceived through the new governmental approach to HIV/AIDS in South Africa soon after Dr Nono Simelela was appointed as Chief Executive Officer (CEO) of the South African National AIDS Council (SANAC).

Madiba (2012) reported that South Africa has an increasing population of children accessing ART at the age where they should be aware of their HIV status and again, Madiba (2012) argues that ART prevents the HIV virus from multiplying and destroying the immune system. The implication of disclosing to these children at FAMCRU is the minimisation of the gap that is mentioned by Madiba (2015). UNAIDS announced on 13 May, 2016 that the South African government had announced a major policy shift that will move the country faster towards the set global 90–90–90 treatment target.

South African Minister of Health, Aaron Motsoaledi, announced in his Health Budget speech in 2016 that the country will implement a new evidence-based policy of offering HIV treatment to all people living with HIV by September 2016. This ground-breaking announcement brings South Africa, which already has the world's largest HIV treatment programme, in line with the latest WHO guidelines for HIV treatment. South Africa is amongst the first countries in Africa to formally adopt this policy.

3.9 Social worker's perspective

Cynthia and Walker (2010) emphasised that social workers "[ensure] needed services are intact, empower families and often act as the coordinator between medical and psychosocial care and [play] a role as monitors, as they are supporting adherence. A complete and consistent adherence is highly associated with improved health outcomes for infected children and social workers [are] often the best to relay the importance of adherence to children, adolescents their families." While the intervention requires trained psychologists and counsellors, who are likely to have a positive impact on the psychosocial wellbeing of children and their caregivers, they are often not feasible in resource-limited settings. Having full-time social workers confidently set up in clinics will have an optimistic impact for many families affected by HIV.

According to Amazel *et al.* (2013), although knowledge is increasing in approaches that address the psychosocial needs of vulnerable and HIV-infected children, there is still limited evidence demonstrating which interventions have positive effects on the wellbeing of HIV-infected children. Amazel *et al.* (2013) mentioned that healthcare providers must work closely with caregivers during the progressive disclosure process, particularly during the crucial period following diagnosis or disclosure. Johanna and Mahloko (2013) mention that doctors, nurses and social workers assisted in disclosure but they do not state how. They also mention that the increasing involvement of healthcare providers in disclosure, observed in this study, further demonstrate that discussion about HIV disclosure with HIV-infected children is increasingly becoming part of their comprehensive care structure in South Africa. WHO 2014 most adolescents, families remain the primary, trusted source of emotional, material and practical support. They have an important role to play in encouraging and supporting an adolescent to live positively with HIV, beginning with disclosure of the adolescent's HIV status if they have not yet done so. As children become adolescents, families and other caregivers are the key partners with health providers in supporting a child's transition from paediatric

to adult services. WHO 2014 and by involving the health care workers chances that the child will adhere to treatment. However, the potential benefits of family support can only be gained when an adolescent agrees for their family to be involved. Health care providers should assess family dynamics and, when appropriate, encourage adolescents to allow family members or other supportive adults to play a role in supporting their positive living.

3.10 HIV policy

According to the National HIV Counselling and Testing Policy guidelines (2015), "in order for HIV/AIDS prevention, treatment, care and support recommendations to be fully integrated into HIV/AIDS and reproductive health services and programs, they must be mainstreamed into polices, frameworks, guidelines, and plans for monitoring and evaluation." This outcome measures the success of advocacy efforts to increase HIV/AIDS awareness and education among policy makers leading to the adoption and formalisation of recommendations at national, provincial, and district levels. The South African Constitution on section 27 states that, everyone has the right to have access to health-care services, while section 28(1) states that children have the right to basic nutrition, basic health care services and social services (Republic of South Africa, 1996). HIV and AIDS is preventing these rights of children, hence there is a need for an immediate response in terms of policy and legislation.

International and national policies and the resulting programs addressing HIV/AIDS generally focus on four primary areas:

1) Prevention (For example, through PMTCT, IV drug use, male circumcision, pre- and post-exposure prophylaxis, contraception use, sexual and other risk reduction, testing and counselling, and targeting highest risk populations).

2) Support care for people living with HIV/AIDs, as well as orphaned and vulnerable children.

3) Treatment using ART, nutrition and related services.

4) Health system strengthening. For example, integration of HIV/AIDS services with maternal and child health, family planning, and related health programs is a growing collaborative effort that should be indicated in national-level policies (PEPFAR, 2009).

According to Republic of Namibia (2007), "The National Policy on HIV/AIDS has been developed to provide an overall reference framework for all HIV/AIDS-related policies, and to guide the national HIV/AIDS responses of all sectors in society. It aims to guide current and future health and multi-sectoral responses to HIV/AIDS in Namibia, to encourage all Namibian institutions to fulfil their obligations for responding to HIV/AIDS, and to serve as a guiding frame for a coherent and sustained approach enhancing political commitment and participation of civil leadership at all levels. This policy is very much similar to the South African HIV/AIDS policy because both focuses on current and future health implementations.

The HIV/AIDS policy announced by President Jacob Zuma on the World AIDS Day of 2009 shows how firm the South African Government to prevent the transmission of HIV from mother-to-child. Within the old policy, HIV positive pregnant women were entitled for treatment if their CD4 count was less than 200, whilst the new policy, which came into effect on 1st April 2010, states that all pregnant HIV positive women with a CD4 count of 350 or who merely show symptoms regardless of CD4 count, can access treatment. The policy also provides that all other HIV positive pregnant women who do not fall under this category can now access treatment at 14 weeks of pregnancy in order to protect the baby, instead of at the last term of pregnancy as per the old policy (Zuma,

2009).However, the fact that South Africa has implemented several policies and legislative instruments designed to respond to the HIV and AIDS epidemic demonstrates how great an opportunity it has to fight the epidemic. These developments are a result of a strong resolute Government to reduce the spread of HIV and AIDS.

The policy is a framework for supporting five broad strategies: the strengthening of an enabling environment so that people infected and affected with HIV/AIDS enjoy equal rights in a culture of acceptance, openness and compassion; prevention to reduce new infections of HIV and other sexually-transmitted infections (STI); access to cost-effective and high-quality treatment, care and support services for all people living with or affected by HIV/AIDS; strengthening and expanding the capacity for local responses to mitigate socio-economic impacts of HIV-integrated and co-ordinated programme management; and effective management structures and systems, optimal capacity and skills, and high-quality programme implementation at national, sectoral, regional and local level, and the goal of the national HIV/AIDS policy is to provide a supportive policy environment for the implementation of programmes to address HIV/AIDS that reduce new infections, improve care, treatment and support, and mitigate the impact of HIV/AIDS; this in turn will assist in achieving the 2030 vision.

HIV/AIDS is a development challenge, and more than just a public health issue. It is a complex, multifaceted problem affecting all aspects of society and impacting on development goals. Maureen Mswela (2009) is of the opinion that "customary institutions that discriminate against or which are harmful to women (by increasing their exposure to HIV) should be identified, and where possible, be developed in line with the constitutional objective of gender equality, without relinquishing the true and positive values that underlie a relevant custom."

The Department of Basic Education values the constructive comments of the public and wishes to encourage all stakeholders and interested parties to provide their written input and suggestions, ultimately, in order to strengthen the policy and its implementation. This approach led to the release of the Draft National Policy on HIV, STIs and TB for public comment on 5 May, 2015.

Implementation of HIV Counselling and Testing (HCT) programme within a legal and human rights framework is a key intervention tool towards the realisation of the goals of the National Strategic Plan for HIV & AIDS and STIs (NSP). HCT is the key entry point to a comprehensive continuum of care. It is central to HIV programs and requires close linkage with other health services. Through linkages with care, treatment and support programs, HCT contributes to lessening the impact of the HIV epidemic. The South African Government has embarked on a deliberate effort to scale up and strengthen the quality of HCT at all health facilities and non-health facilities.

In recent years, HCT has become increasingly available in South African public healthcare facilities. In accordance with the current local and international trends and recommendations, DOH emphasises that while certain core elements of HCT remain unchanged, like 5Cs (confidentiality, counselling and consent, correct test results, and linkage to care), DOH also introduces approaches to HCT that will reduce the number of missed opportunities such as provider-initiated counselling and testing (PICT), couple counselling and testing (CHCT), home-to-home HCT, and infant and children HCT.

3.11 Law and HIV

FAMCRU is a research clinic that follows the national health policy as it is reported that "all research related to HIV testing may only take place after having obtained ethical approval from research ethics committee."

The national counselling and testing HCT policy guidelines (May, 2015) highlight that HIV/AIDS counselling and testing seeks to create an enabling environment that promotes universal access to safe, effective and good-quality HCT services. It aims to provide a national framework and guidance for the provision of HIV counselling and testing services in the public and private sectors in South Africa, as well as provide a framework for conducting HIV counselling and testing among adults and children. The caregivers together with their children have been tested for HIV/AIDS following the policy that was implemented by the National Department of Health.

The national counselling and testing HCT policy guidelines (May, 2015) emphasised that disclosure of HIV status to a child is based on the need to protect the best interests of the child at all times, and disclosure is carried out in partnership with the family or caregiver with respect of their views and wishes in mind. The guidelines continue to highlight further steps such as the readiness of the child and the caregiver for disclosure. The children's act declares that every child has the right to confidentiality regarding their HIV status.

3.12 Cultural factors' impact on HIV disclosure

Mswela (2009) stated that "Section 30 of the constitution provides individuals with the right to culture, while section 31 summarises the right of persons belonging to a cultural, religious or linguistic community to enjoy their culture practise, religion and use their language, thus making the right an individual as well as a community entitlement."

Mswela (2009) reported that women in patriarchal societies have rationally been rendered to the same status as children; they too are vulnerable in respect of certain harmful cultural practices, such as the following:

3.12.1 Polygamy

Polygamy has two forms. Polygyny is practised in South Africa and refers to when one man has more than one wife and is often practised by the Zulu culture, SiSwati culture and is an additional traditional practise within the kingship and Xhosa cultural group. However, not all Xhosa groups practise this – only certain groups with a specific Xhosa clan practise polygamy. Polyandry refers to when a woman has more than one husband, but this is not practised in South Africa, although is common in India and China.

Polygamy contributes to the continued existence of the community, particularly the black communities like Xhosa's ethnic group, and the SiSwati and Zulu groups. Through a high fertility rate, it also enables a husband to marry a second wife if the first wife is infertile or has not delivered a son.

3.12.2. Levirate

Ukungena means levirate – a practised custom that dictates that when a man dies without a male heir, the widow will be expected to choose another husband from among the deceased man's younger brothers in order to bear male children for the deceased's house. This custom is practised to provide as maintenance of the widow and preserve the relationship between the families that was initiated in the original marriage. Mostly practised in the Zulu culture, the practice allows a male relative to marry his sister-in-law or the widow of his brother. Apart from exposing women to an increased risk

of contracting HIV, this practice is in conflict with the equality rights of women, as well as their human dignity and personal autonomy.

3.12.3. Early marriages and virginity testing

In a gerontocratic society, older men marry young girls and in most African countries, this practice is known as early marriages. In some cases, young girls have boyfriends who are older than them, while other young girls are involved in commercial sex work (prostitution), some of whom are having love affairs with married men/woman, placing both parties at high risk of contracting HIV. In South Africa, commonly in the province of KwaZulu-Natal, there has been a recent revival of the traditional practice of virginity testing, with reports of increasing activity in schools based in the Eastern Cape and in Mpumalanga. A higher value is traditionally placed on virgin brides, as evidenced in the higher amount of *lobola* (bride price) paid for them. However, supporters of virginity testing presently claim that it will assist in the reduction of HIV/AIDS and teenage pregnancy, as well as the detection and prevention of child sexual abuse.

In view of the current and traditional belief that intercourse with a virgin may cure or protect against AIDS and venereal diseases, public identification as a virgin may in fact increase the risk of sexual abuse and HIV-infection. Young girls may be less eager to report sexual abuse for fear of disclosing that they are no longer virgins. The Commission for Gender Equality has described the testing as discriminatory, invasive of privacy, unfair, intrusive of the dignity of young girls, and unconstitutional. Parliamentary and public hearings responding to the draft Children's Bill were extremely critical of female genital mutilation and virginity testing and highlighted them as examples of harmful cultural practices.

Female genital mutilation

Female genital mutilation (FGM) is predominantly practised in Sub-Saharan countries and in Egypt. The difference between male and female circumcision is that female circumcision is far more extensive and its consequences are physical, psychosomatic, violent and long-lasting. FGM involves a procedure in which parts of a girl's external genitals are expurgated without anaesthesia. The girls subjected to this procedure experience pain and trauma, and regularly experience severe physical consequences such as blood loss, infections or even death. FGM has turned out to be a health and human rights matter in Western countries such as Australia, Canada, England, France and the USA. Its physical harm has drawn worldwide attention. In 1996, the USA legislative body passed criminal law legislation prohibiting the ritual within the USA.

During a seminar on harmful traditional practice in March 2009, the Minister of Health at the time, Tshabalala-Msimang, remarked that FGM had been introduced to South Africa from other African countries through refugee migration. Some scholars submit that female circumcision is practised as an initiation process among most Xhosa cultural groups. From a human rights perspective, FGM constitutes an abuse of women's rights, including an impairment of women's sexual pleasure, physical health, and physiological health that is extremely invasive and unnecessary, whilst also placing them at risk of contracting HIV/AIDS.

Mswela (2009) highlights that a major concern resulting from polygamous marriages in South Africa is the problem of HIV/AIDS.

3.12.5 The practice of 'dry' sex

Literature on 'dry' sex suggests that it is widely practised by women. This practice entails the artificial drying of the vagina for the sexual gratification of males. James McIntyre (2011) explained

that practising of dry sex is about drying and tightening (and sometimes warming) of the vagina for more pleasurable sexual intercourse.

Despite the dangers of HIV transmission associated with this practice, people continue to practise dry sex. In an interview conducted among sex workers who practice dry sex, 33% of the interviewed women remarked that dry sex is a painful customary practice. In South Africa, KwaZulu-Natal is the province where dry sex is mostly practised. It is incidentally also the area with the highest prevalence of HIV/AIDS in South Africa.

3.12 .6 HIV/AIDS and women in South Africa – Gender

Amazel *et al.* (2013) states that gender norms and inequalities impact the psychosocial health and wellbeing of children. Socially- and culturally-constructed expectations of how women and men's behaviour play an important role in HIV risk and vulnerability and negativity impacts health outcomes. Harmful norms related to masculinity influence risk perception, risk-taking, and limit to access critical information. Gender norms for girls limit their ability to refuse unwanted intercourse.

Mswela (2009) reported that the HIV epidemic in South Africa is mainly regarded as a heterosexual type of epidemic with a strong link between factors such as low income, unemployment, violence against women, and poor education about HIV infection. Young black women, Xhosa and Zulu in particular, are disproportionably affected by the disease. Msewla (2009) continues to explain that customary practises and habits facilitate the spreading of the virus in South Africa – especially through examples such as resistance to use of contraception because of specific sexual and cultural norms, social norms such as allowing or promoting a high number of sexual partners, phenomenon of extended family household structure, preferences for male child, practise of polygamy, and the adherence to the culture of silence. According to Mswela (2009), some traditions, customs, practises

and religions entrench the subordinate position and exploitation of women in marriages and relationships, thereby increasing their vulnerability to HIV infection.

Van Niekerk & Kopelman (2012) reported that a HIV/AIDS adds another burden to the spectrum of difficulties that confront women in Africa as they already have many other things to deal with. The situation in Africa has shown that AIDS flourishes most demonstrably in a society where women are particularly vulnerable. In Africa, there were approximately two million more women than men infected by AIDS. The position of women in the current HIV epidemic landscape in South Africa is made to be more precarious through the severe forms of stigmatisation that people who acknowledge their HIV status currently have to face. In 1998, Gugu Dlamini, a young woman from KwaZulu-Natal, decided to reveal her HIV-positive status and started to campaign on her own, but was stoned to death in her neighbourhood.

Mswela (2009) reported that in "South Africa the universalist versus culturally relativist argument has been rendered marginal by the constitution, which is founded on a universalist human rights structure hence the drafters of the Children's Act were faced with the complex assignment of dealing with a very contentious issue in a way that values and promotes the rights and dignity of a girl, children and young woman, including a girl child's right not to be circumcised, while at the same time respecting traditional cultural customs and practices."

UNICEF (2012) recently made available figures that show that many African women are dangerously ignorant about HIV and its perils. Women's power over their sexual partners, the frequency of sexual intercourse and the use of contraception; it can be deduced that this is an area where there is urgent need for more research.

Summery on literature review

It seems to be slight literature with regards to studies that have been conducted to look at the children's disclosure by their parents who are well equipped to conduct disclosure to their children and with the assistance of a social worker's. However a number of researchers have reviewed the literature on disclosure, nonetheless it is not stating who should be conducting it. Once again not much literature that clarifies about the health professionals like social worker's on how they could play role on facilitating disclosure. Getting to understand the struggles and challenges that mothers experience will help to implement better support structures that will assist other mothers to cope better and successfully manage the virus.

CHAPTER THREE

Methodology

Introduction

The previous chapter reviewed literature pertaining to the mothers' experiences of disclosure of their children's HIV-positive status in a paediatric unit at Tygerberg Hospital: a social work's perspective. This chapter presents the methodology of this research study; which is the points and procedures engaged in this study. The following will be discussed: qualitative approach, study design, research setting, study population, sampling, data collection, pilot interviews, and data analysis. The research process for qualitative research is emergent, as the key behind qualitative research is to learn about the problem or issues from participants, and to explore the research to obtain the information (Creswell, 2013)

Qualitative research would be the most appropriate approach for this study as it supported the researcher to understand the insider's views (Christensen *et al.*, 2011: p. 53), and this simply means that participants have the opportunity to share their own views regarding the challenge affecting them. Research used to quantify the problem by generating numerical data or data that can be transformed into useable statistics to quantify attitudes, opinions and behaviours would not be suitable for this study. Quantitative methods generalise results from a larger sample population but for this study, it is appropriate to use a qualitative method in order to understand the insider's views.

According to Domegan & Fleming (2007: p. 65), "Qualitative research aims to explore and to discover issues about the problem on hand, because very little is known about the problem." There is usually uncertainty about dimensions and characteristics of the problem.

This chapter included the aims, objectives, data collection, data analysis, data verification,

trustworthiness and ethics considerations, as well as the participants' agreement to be part of this research process. The qualitative approach assisted the ideas and views of mothers whose children are HIV-positive and receiving ART. Data was collected after permission and approval was obtained from the Health Research Ethics Committee at the University of the Western Cape, FAMCRU, and Stellenbosch University.

3.2 Research question

What were the experiences of mothers who disclosed to their HIV-positive children at Tygerberg Hospital, Western Cape, and what intervention tools would be suitable to enhance disclosure from a social work's perspective?

3.3 Objectives

a) To explore and describe mothers' experiences of disclosure of their children's HIV-positive status at Tygerberg Hospital in the Western Cape.

b) To explore and describe intervention purposes of the social workers to facilitate disclosure of children's HIV status at Tygerberg Hospital in the Western Cape.

3.4 Research approach

A research methodology is a technique used to collect data (Bryama, 2001). The study applied qualitative research methodology and research design, which refers to the framework or a plan that stipulates how a researcher intends to conduct a research project (Babbie & Mouton, 2004). The qualitative method was chosen because it is challenging for researchers to explore, describe and capture an in-depth understanding of human experiences such as pain, grief, hope or caring to quantify the data. The design was chosen to maximise an in-depth understanding of the life experience of the participants. It was earlier revealed that qualitative methods were applied to this study because they are an appropriate and effective alternative and the goal of good, qualitative research is to provide understanding rather than explanation. It is important

for a researcher to understand the feelings of the mothers about disclosing to their HIV-positive children. Denzin *et al*. (2005) stated that qualitative researchers stress the socially-constructed nature of reality when interviewing HIV-positive mothers about disclosure and social workers working with these mothers that this is the actuality of what they face on a day-to-day basis. Furthermore, Babbie (2012) reported that quantitative methods are about converting data to a numerical format and involve converting social science data into a machine-readable format that can be read and manipulated by computers or similar technology used for quantitative methods.

Creswell (2014) explained the eight characteristics of qualitative approach, which have been applied from the start of this study, highlighted as follows:

3.4.1 Natural setting: For qualitative researchers, this is the first phase of collecting data through exploratory documents, observing behaviour, or interviewing participants. Researchers may use a protocol as an instrument for collecting data however, researchers are the ones who gather the information, and they do not tend to use or rely on questionnaires or instruments developed by other researchers (Creswell, 2014). All questions in this study were developed by me as the researcher.

3.4.2 Researchers as key instruments: According to Creswell (2014: p. 185), qualitative researchers collect data through examining documents, observing behaviour, or interviewing participants. In this case, as a researcher, I observed the behaviour first-hand and interviewed the mothers and the social workers using open-ended questions.

3.4.3 Multiple source of data: Audio-visual and voice-recording was not used because participants were not comfortable having their voices recorded due to the sensitive nature of the topic. Creswell (2014) emphasised that qualitative researchers gather multiple forms of data, such as interviews, observations, documents, and audio-visual information rather than

depending on a single data source. In this study, face-to-face interviews with patients were conducted, with notes also taken during interview sessions. After reading the data collected from the participants. The researcher reviews all of data, make sense of it, and organises it into themes that change across all of data sources.

3.4.4 Inductive and deductive data analysis: Creswell (2014) stated that it is during this stage that qualitative researchers build their patterns, categories, and themes from the bottom up by organising the data into increasingly more abstract units of information. The abovementioned was applied by assessing the different themes, with subthemes added during the reading of the data. Creswell (2014: p. 186) continues explaining that an "inductive process illustrates working back and forth between the themes and the database until the researchers have established a comprehensive set of themes." This helps to make sense of the data for analysis.

3.4.5 Emergent design: Qualitative researchers attain about the participant's challenges during data collection process, and it is necessary to understand the participant's experiments. Creswell (2014: p. 186) explained that the initial plan for research cannot be tightly arranged as some of the process may change, and if not, they might adjust after the researcher enters the field and begins to collect data. The themes of this study changed a few times.

3.4.6 Reflexivity in qualitative research: As a researcher, at times I had to position myself in light of cultural backgrounds and different experiences relating to the study. Wolcott (2010) stated that readers have the right to know about the researcher as well as the topic being investigated. The free-to-share and free response approach was adopted during questioning, and an understanding of the research, the interest in their lives, and an outline of who benefits from the investigation was provided. Creswell (2014) is also of the opinion that the researcher's role in the study and their personal backgrounds, culture, and experiences hold potential for

shaping their interpretations, such as the themes they advance and the meaning they ascribe to the data.

3.4.7 Holistic account: This is when a researcher attempts to understand the bigger picture of the research as researching is about identifying what can assist other people out of the outcomes, and for it to be applied by the next generation if not adopted at the time of publishing. According to Creswell (2014, p. 186), "qualitative researchers try to develop a complex picture of the problem or issue under study. This involves reporting multiple perspectives, identifying factors involved in a situation, and generally sketching the larger picture that emerges. A visual model of many facets of a process or a central phenomenon aids in establishing this holistic picture."

Creswell (2007) emphasised that qualitative research is a locater that observes the world and continues describing things like people's life experiences in their natural settings, attempting to make sense of what people experience in life. According to Sharan (2009), research is intended to inform decisions and to assist in deciding on a particular course and action.

This is not to say that qualitative data does not convert data to themes, as illustrated by Babbie (2012). Babbie (2012) explained that qualitative researchers pay special attention to understanding life as the participants view it, and this is what was observed in understanding the participants of this study, especially how they see and view disclosure of their HIV-positive status to their children. Choosing the qualitative research method allowed the asking of open-ended questions so that participants could provide detailed and in-depth descriptions of their experiences. This provided more access and opportunity to observe the participants' behaviour. The design of quantitative research allows data to be collected telephonically as it does not matter how the interviewer feels or expresses his or her feelings.

3.5 Research design

This is the part of research where a student had to uncover a plan about what she wanted to achieve at the end of the research. Babbie & Mouton (2001:74) explains research design is a plan or blueprint of how one intend to conduct his/her research project. The student had to focus on the end product about the research and making sure that it is what it was designed for. Structure rising of the research it consists of systematic, methodical and accurate execution of the design (Babbie & Mouton, 2001).

3.6 Explorative design

In order to gain a better understanding of a situation, which, in this study, is about the experiences of mothers' disclosure to their children who are HIV-positive, exploratory research was applied and is defined as the initial research into a hypothetical or theoretical idea where a researcher has an idea or has observed something and seeks to understand more about it (Ander, 2015). Mothers' experiences living with HIV and having to look after an HIV-positive baby can only be explored by them as they experience the consequences and the different emotions on a daily basis. Applying explorative design supports curiosity and a desire to listen to social workers who have been assisting HIV-positive mothers. The explorative design was chosen because there is little available research conducted on disclosure and the experiences of social workers. Explorative studies are valuable to social science research. Babbie (2010: p. 93) emphasised the importance of explorative studies in that they are occasionally definitive in themselves and they have to do with representativeness, which is the people. All open-ended questions were exploratory, so that when participants provide feedback, they are providing an opportunity to gain insights on topics that one may not have thought of before. Beyond this, when it comes to designing a survey and research plan, it is usually not best to stray from traditional or conventional

designs. All research strategies can benefit from reviewing similar studies taken and learning from their results.

3.7 Descriptive design

One purpose of qualitative research is to provide an accurate description of a particular phenomenon or situation and descriptive design is present to the degree that the account reported by the researcher is accurate. A descriptive design was chosen for this study because it enables the researcher to illuminate knowledge that was not known about mothers' experiences of disclosing to their HIV-positive children and the social worker's perspective. The interviews enabled the participants to share details about their experiences. Firstly, according to Sandelowski (2010), 'qualitative description' is a label used in research for studies that are descriptive in nature and is particularly common in qualitative studies of healthcare and nursing-related phenomena, including disclosing HIV-positive status to someone needs a health professional's attention. Secondly, this research design was applied because it is described as less theory-driven than other designs.

3.8 Research setting

The research was conducted at FAMCRU, a pharmaceutical infectious disease research unit based at Tygerberg Hospital, situated in Parow, Cape Town, Western Cape. The research unit consists of a number of pharmaceutical studies, meaning the clinic specialises in medical research and researchers are constantly looking for new and improved ways to treat HIV/AIDS. Soon after the participants arrived at the waiting room, they were called one at a time to the social worker's office. On the way to the office, I would greet them, ask them how they are and offer them a seat. I explained to them the purpose of the interview (Information sheet, Appendix A and B), why they were selected to participate, and the expected duration of the interview. I asked for permission to record the interview, however all participants declined owing to the

sensitive nature of the topic. They were anxious about the safety of the recordings even though the security measures were explained and asked that notes rather be taken. This is challenging for a researcher as the interaction in the process is not always fully documented.

The FAMCRU facility accommodates patients ranging from infants to adults. This research clinic is under the paediatrics department of Stellenbosch University, based at Tygerberg Hospital, as it is an academic hospital. Mothers who come to this clinic are referred by local clinics doctors who are well-informed about the services of the infectious diseases unit.

3.9 Population and sampling

This section was about the population that the student had studied about. The study sample consisted of 14 mothers, who agreed on participating on the student's research. It was mothers whose children are HIV-positive and attending in the paediatric clinic and four Social workers as key informants. These mothers repetitively took their children for follow-ups at the same clinic as they have signed consent for treatment for their children. And the four social workers they are the employees of Tygerberg Hospital not working for the FamCru clinic, however they are based on the same hospital premises with the student.

3.10 Population

A study population is a term that sets boundaries for the study units (Denzin & Lincoln, 2005). It is also known as a well-defined collection of individuals or objects known to have similar and/or specific characteristics (Taylor, 2015). A population is defined as "the aggregate or totality of those conforming to a set of specification," according to Polit & Beck (2014). Population is also viewed as the set of individuals that researchers would like to attract and understand, and from which to draw conclusions (Babbie, 2010).

The researcher needed to have reasonable access to this population and, for the purpose

of this research, the accessible population was the mothers visiting the FAMCRU clinic at Tygerberg Hospital and the social workers who are based at Tygerberg hospital working closely with HIV positive mothers.

A study population is a group of objects, events or individuals, with common characteristics that the researcher is interested in studying. In this research, the study population is HIV-positive mothers who gave birth to HIV-positive children and are receiving ART. Mothers take their medication at their local clinics and are seen by their local doctors, however, their HIV-positive children are strictly seen by our sub-investigators (doctors) as they cannot combine the Department of Health medication with the research medication.

This clinic strictly treats children who were born with the HIV virus and who have not received any other treatment. The age group of these children is between 11- and 15-years-old. The population group is also filtered to include children whose HIV-positive status has not yet been disclosed by their mothers, and children who are compliant or non-compliant with their medication. It is impossible to interview the entire research population, and only a small portion of the research population has been selected for inclusion.

A participant information leaflet was used to explain the research study, and all selected participants were asked to sign a consent form before the study commenced. Interview protocol was used to collect relevant information. Four key informants were also interviewed; these were social workers questioned in order to triangulate the data and to add necessary insight into the research topic.

3.11 Purposive sampling

A purposive sampling strategy was selected as it fits the intention of the study. Purposive sampling "selects information diverting cases for in-depth study," according to Patton (1990: p. 182). It was important to be specific and selective of what was sought for this study,

especially identifying the category of HIV-positive mothers and not HIV-negative mothers. According to Patton (1990:p.169), sample size is identified according to what the researcher needs to know, the purpose of the inquiry, what is at stake, and what will be useful, in addition to what can be done with the available time and resources to be able to continue with the research.

Purposive sampling was applied when selecting the social workers because of their everyday interaction with HIV-positive mothers and to understand the role played by social workers on assisting the mothers with disclosure. Social workers operating in the health sector and specifically those working with HIV-positive mothers were selected. Babbie *et al.* (2010) emphasised that in the sampling, the type of suitable participants becomes clear and certain types of subjects seemed more central to understanding than others. Purposive sampling is appropriate to "select the unique cases that are especially informative," according to Neuman (2006: p. 22).

This is a widely-used sampling method in qualitative research, especially for the identification and selection of information-rich cases that are related to the phenomenon of interest. Palinkas *et al*. (2015) described it as a sampling method that involves identifying and selecting individuals who are especially knowledgeable about or experienced with a phenomenon of interest. For example, the mothers were chosen because they gave birth to HIV positive children and they are the same people who always brought the same HIV-positive children for follow-up appointments at the same clinic. On the other hand, fathers could not be selected as they do not conventionally bring the children for follow-up appointments and some fathers have not been seen by the student at the clinic. This could be due to cultural factors or that the father is not involved in the children's lives. In some cases, the father would be working and would not be able to be present. However, absent fathers is a known phenomenon in the Western Cape and it would be considered abnormal if fathers did attend.

Mothers were suitable for this study because they are the ones who make sure that their HIV-positive children receive their medication at home twice daily. As mentioned, this process is not traditionally carried out by the father, particularly within patriarchal societies. Norman *et al*. (2000) mentioned that mothers are born to nurture, not the fathers – a notion that has been critiqued by the ethics of care. Tronto (1995) argues that men can be irresponsible when it comes to day-to-day activities involving children; she adds that this privileged irresponsibility is contributory to women's disempowerment.

Reddy (2014) highlighted the absence of fathers who support HIV-positive mothers in the research that was conducted in the Eastern Cape on families caring for HIV-positive children. Finally, purposive sampling is based on the judgement of an expert in selecting cases with a specific purpose in mind and they require the researcher to exercise his or her own judgement in identifying the respondents who would be useful for the research. In my case, the mothers and the social workers were the relevant sample that needed to be explored so as to gather information and data that was trustworthy.

3.12 Data collection

The data was collected for the purpose of this research, through the use of semi structured interviews. Greef (2002: p. 302) stated that "semi-structured interviews can be used to gain a detailed picture of a participants' beliefs, or perceptions of a particular topic while giving the researcher and the participants much flexibility." An interview is the process whereby the researcher reads the questions directly to the participants and records their response (Dejong *et al.*, 1998: p. 182). Semi-structured interviews in this research were adopted as it involves direct personal contact with the interviews conducted at the research unit, FAMCRU; a private office was used to conduct interviews to ensure confidentiality.

To triangulate the data, semi-structured interviews were conducted with key informants, who were the social workers who are working for Tygerberg hospital. According to Creswell (2010: p. 189), "one needs to establish the protocol for recording information." All interviewees asked that the researcher not record the interviews but rather to take notes while asking the questions. As stated earlier, it is challenging to take full notes and fully engage with the participant. The semi-structured interviews were conducted in English and isiXhosa as most of the participants were isiXhosa-speaking. Translation of the isiXhosa interviews proceeded timeously after the engagement so that no information was lost.

Three out of four social workers interviews were conducted in English as they were Afrikaans-speaking and were happy to communicate in English. During each interview, the researcher prepared the space so that participants felt comfortable and would be willing to open up about disclosure or their thoughts about disclosure. As the researcher, I was fully aware of the sensitive nature of the topic particularly because some of the questions could trigger the mother's fears about the HIV disclosure or bring back memories of when they first found out about their HIV status. I observed a similar trend in the non-verbal communication amongst the participants; their energy levels were down when I asked them about how they dealt with being told about their HIV-positive status. This was observed when they were taking long pauses when responding to the questions and their facial expressions and emotional demeanor highlighted the challenges of speaking about the topic. As more questions were posed, they became more relaxed and seemed curious about the next question around disclosure.

According to Shneiderma & Plaisant (2005), interviews can be very productive since the interviewer can pursue specific issues of concern that may lead to focussed and constructive suggestions. The main advantages of the interview method of data collection are direct contact with the users which often leads to specific, constructive answers. In addition, the interviews

obtained detailed information from the participants on their challenges around disclosure despite the lack of audio-recording.

3.13 Pilot interviews

A pilot study can be defined as a trial run of the study, using questions and participants similar to those in the final study (Landman, 1998). The first two interviews with the mothers and the social workers were used as pilot interviews to address the logistical issues such as testing the interview schedule to check if the questions were suitable and to ensure that it will be able to obtain sufficient data. Importantly, the purpose of the pilot interviews was to test the ability of the researcher in conducting an accurate semi-structured interview.

No changes were made to the interview guide questions after the pilot interviews as the questions were valid and participants provided in-depth answers. The amount of information that was obtained from the two pilot interviews was enough to provide an indication that sufficient data would be obtained from the questions asked. The two pilot interviews formed part of the actual study.

The challenges that I experienced is that at the research clinic I had more appointments of pregnant mothers who were HIV-negative and therefore I had to wait for four weeks for the new circle of HIV-positive mothers' appointments for their children's medical check-up. I could not conduct appointments alone, as I had to rely on the clinic schedule. Other mothers were very happy to talk about their past and about their children's disclosure. The two people interviewed during the pilot were honest about the quality of the questions and gave in-depth answers.

3.14 Instrument strategies

Data collection is a series of interrelated activities aimed at gathering good information to answer emerging research questions (Creswell, 2010). Semi-structured interviews were utilised to gain in-depth answers from participants.

The use of an interview schedule ensured the limited interview time was used constructively. Larry & Turner (2015) emphasised that qualitative data observations yield detailed, thick descriptions; inquiry in-depth interviews that capture direct quotations about people's personal perspectives and experiences. Norman *et al.* (2000) stated that every researcher depends on the interview as a source of information, with the assumptions that interviewing results are true and accurate reflections of respondents' views. Interviews were noted down as much as they took time to complete. Darlington & Scott (2002) stated that in most qualitative research, transcription and note-taking at a general level of detail would include emotions and humour, which happened while interviewing my participants.

3.15 Process of interviews

Permission to conduct the study was obtained from the Ethics Department of Stellenbosch University as well as at UWC. The mothers were first approached soon after the ethics committee acceptance and permission. At the waiting room, I introduced myself as the unit social worker and called each participant to my office and explained the study. The second contact was through a telephonic conversation after I went through the clinic diary and took note of all the dates of the HIV-positive mothers; I reminded them about the interview date that was on the same date as the doctor's appointment at the clinic. The day the participants came to the clinic, all participants were asked to sign an informed letter of consent which satisfied all the above-mentioned criteria.

Interviews were recorded in a form of note-taking as described. All interviews with the social workers went according to schedule, with the only change being that interviews were not always started on time due to the hospital's busy schedule.

3.16 Interview skills

Conducting an interview, entered into a dialogue with the participant. This dialogue, in turn, involves asking for access to participant's space and information. It was important for me not to probe too much when the participants were uncomfortable about opening up. When conducting the interviews for the purpose of the study, I made sure that I respected the participants at all times and that I did not overstep boundaries or probe if it appeared that the participants were uncomfortable. The purpose of the study was explained at the beginning of every interview, written consent was obtained from each participant to continue with privacy and confidentiality was ensured.

I practised good communication skills by maintaining eye contact, nodding when appropriate and clarification was used to encourage the participants to talk. The setting was suitable as there was no disruption. The space was in a quiet room at the hospital and I ensured that there was no disturbance. Therefore, privacy was ensured at all times to allow the participants the opportunity to speak freely without fear of being overheard. Notes were analysed immediately after the interview to gain a sense of the emerging themes in order for the researcher to have a clear understanding of the analysis process of qualitative data.

3.17 Data analysis

Data analysis in qualitative studies involves an examination of text rather than numbers, which are considered in quantitative studies. Chilla *et al.* (2012) reported that data in qualitative research is non-numerical, and usually in the form of written words. Creswell (2007) stated

that qualitative data analysis will proceed through two levels: the first being the more general procedure in analysing the data, and the second being analysis steps within specific qualitative designs.

The written notes taken during the interviews were then organised into piles, ordered from the first interview at the top to the last interview at the bottom. While reading through the notes, I started jotting down emerging thoughts in the margin of the transcript paper to assist in finding meaning from the information read. This process was repeated until all the notes were meaningfully read and interpreted.

A list of all topics that emerged from the information in the note-taking was compiled and similar topics were clustered together. The topics were formulated into a list of columns and taken back to the notations. The topics were then abbreviated as codes, which were written next to the segment of the text. This was completed by the researcher in order to explore the new categories and themes that might emerge from the data. It was challenging to identify the themes that fit within the theoretical framework, namely the ethics of care. However, it was necessary to re-read the notes several times and highlight the most repeated ones in order to determine the themes. Once the themes and sub-themes were identified, I engaged in literature control, where quotes from participants were linked to suitable literature. The theoretical framework was embedded into the main themes and sub-themes.

3.18.1 Trustworthiness

Assessing the accuracy of qualitative findings is challenging. However, there are several possible strategies and criteria that can be used to enhance the trustworthiness of qualitative research findings. D'Cruz & Jones (2004) mention that there are four criteria to be used to measure the trustworthiness of the data, namely:

3.18.2 Credibility

Data collection of this study took place over three months. The researcher made use of bracketing to ensure credibility of the research findings. Credibility is accomplished using tactics, which help to ensure honesty from informants when contributing data (Cox, 2015). By employing this strategy, the researcher prolonged engagement with participants. Each participant approached was allowed the opportunity to refuse to participate in the study in order to ensure that data collection sessions involved only those who were genuinely willing to participate. Participants were encouraged to be honest with the researcher from the start of each session, while establishing a rapport in the opening moments. Credibility ensures that there is consistency between participants' views and the researcher's interpretation of their views (Coughlan *et al.*, 2007; Brink *et al.*, 2012: p. 172) state that credibility reflects the truthfulness and accuracy of the data collected. Again, credibility in this study was obtained by returning notes to the participants soon after data collection was completed; they were each given a copy of the notes to verify whether their words were captured accurately. Consequently, this allowed for rich data collection and for me to gain adequate understanding of the experiences of the participants, as well as establish a relationship of credibility between the participant and myself.

3.18.3 Dependability

Dependability is concerned with whether similar results would be obtained with similar participants in a similar context. Hilla *et al.* (2012) describe dependability as the ability to apply the findings to other contexts or to other participants. Dependability was ensured through an in-depth chronology of research activities and processes, as well as influences on the data collection and analysis, emerging themes, classifications, or models and analytic memos (Mellis *et al.*, 2014).

3.18.4 Confirmability

The transcripts were read multiple times and copies were provided to the participants to verify that the information was captured correctly; this was completed in the month of February, 2018. Brink *et al.* (2012) describe confirmability as a guarantee that the findings, conclusions, and recommendations are supported by the data and reinforce the internal agreement between the investigator's interpretation and the actual evidence.

3.18.5 Transferability

Transferability is the data that is collected in a study and is applicable in another context or to other participants in another study (Shenton, 2004), and Rayan *et al.* (2007) refer to transferability as the findings that can be applied outside of the original study context. The findings of this study can be applicable to similar participants. The researcher interacted with the participants to the point of data saturation, and because of the sensitive nature of the topic, transferability would have been challenging. As the researcher, I struggled to retain deeper descriptions because of the time spent on capturing notes, which could impact transferability.

3.18.6 Reflexivity

Reflexivity is the process of becoming self-aware. Researchers make regular efforts to consider their own thoughts and actions in light of different contexts. Reflexivity allowed the researcher to be critical about what was heard, written and later interpreted. During the research process, we often find ourselves ruminating the ways in which our own aspirations, characters, values, philosophies, experiences, belief systems, political commitments, and social identities have shaped the researcher (Cox, 2015). As a social worker working at this paediatric clinic, I have observed many mothers who are HIV-positive.

I have witnessed the suffering of the mothers and the struggle of children who do not know

about their HIV status, as well as continuous feedback from the mothers that the children ask questions that the mothers do not know how to answer. As the researcher, I had to put myself in the shoes of the mothers and show empathy for their situation. I applied mutual collaboration social critiques in order to understand the participant during the interview. Social work has demonstrated its importance as a profession, although it can be associated with limited power.

Reflexivity is loosely defined as providing a full and honest appraisal about the research process – in particular, clarifying the position of the researcher in relation to the research. As the researcher, I have experienced the importance of conveying ideas from those who have direct experience about HIV disclosure to those who can render action in response to HIV disclosure (Reay, 2007).

3.19 Ethics consideration

Ethics approval to conduct this study was requested and granted by the Human Sciences Research Ethics Committee of Stellenbosch University, and the Senate Higher Degrees Committee of the University of the Western Cape. A clear statement of the purpose, procedures, risks, and benefits of the research project, as well as the obligations and commitments of both the participants and the researcher were discussed and contained in the consent form. Voluntary, informed, written consent was obtained from individual participants, ensuring confidentiality. The WHO (2017) encourages ethics consciousness enriched by the exchange of ideas and supported by a careful awareness of the needs and understandings of people, communities, and cultures. The expectations of people and communities participating in research as well as the impact of the research on those people and communities should be taken seriously. All of this explanation is about emphasising that researchers must adhere to ethical standards in order for the public to support and believe in the research. It was explained

to the participants that the data would be stored in a locked cupboard at FAMCRU's offices and is only accessible to the researcher and supervisor, as it is the intellectual property of Stellenbosch University and the University of the Western Cape.

3.20 Informed consent

All participants (mothers and social workers) were informed of the purpose of the study, which is to provide an individual narrative of the experiences of mothers who had not disclosed HIV-positive status to children, and to find out about the motives of not disclosing to their HIV-positive children. Participants were informed in writing about the aims and processes, and the final use of the outcomes was also detailed in the participant information letter. Participants were advised that they could withdraw at any time from the study, however, they would be required to sign a consent form before the commencement of the research. When results are available, they will be shared with participants and the paediatric unit at FAMCRU.

It was not necessary to refer any of the mothers for professional therapy as none of the participants were traumatised by the interview. Debriefing is necessary to remove any harmful effects or misconceptions about participation (Strauss & Corbin, 2014). All participants were given an outline of what the researcher was investigating, and their role in the research was also fully explained. The participants were asked if they had any questions and to those who did, they were fully and honestly answered.

Each participant was provided with a unique code to protect their identity, to ensure anonymity, and to allow the researcher to share the results without revealing their identities. Participants were not forced to answer all the questions. They were continuously reminded that they could omit questions should they feel that it was too emotionally difficult to answer.

3.21 Voluntary participation

All participants were informed that the agreement to participate was voluntary, and if they felt uncomfortable, they had the right to withdraw at any stage. According to the National Housing

Census and National Planning Commission (2010), the respect for human dignity supports the rights of participants' self-determination, and the right to decide whether to participate in the study or not. None of the participants withdrew from the study.

3.22 Privacy and confidentiality

The researcher ensured that the information shared by the participants is kept in a safe place and can only be accessed by the researcher, which allowed for privacy and confidentiality. According to Norman (2012: p. 140), "codes of ethics insist on safeguards to protect people's identities and those of the research location," and he continues to emphasise that confidentiality must be assured as the primary safeguard against unwanted exposure. The results of the study will only be made available once the study has been completed. The researcher's reflective notes will be retained for five years, after which they will be disposed.

3.23 Limitations

The limitations of the study are the characteristics of design, methodology or results that impact or influence the interpretation of the research findings. The limitations are the constraints on generalisability, applications to practice, and the utility of findings that are the result of the ways in which one initially chooses to design the study and/or the method used to establish internal and external validity (Onwuegbuzie & Johnson, 2014). The topic under investigation is sensitive, and some of the mothers who had indicated that they would take part in the study were not able to participate, resulting in the researcher replacing them with new HIV-positive participants. This created time delays as new participants had to be recruited. Again, this study only focused on HIV-positive mothers and their HIV-positive children who still needed to be informed about their HIV-positive status. The infected fathers were excluded from the study, together with the HIV-negative mothers who have HIV-positive siblings requiring HIV disclosure.

3.24 Conclusion

This chapter presented the research methodology as applied in conducting this research by discussing and explaining the actual procedures and measures adopted during the course of data collection and analysis. The researcher made use of the qualitative approach with an explorative and descriptive type to explore the experiences of the participants. Semi-structured interviews were used to allow participants the opportunity to share their experiences.

Ethical considerations that enabled the smooth flow of the data collection process were discussed. Data verification was applied in trustworthiness, and the criteria used to enhance the data were credibility, conformability, dependability and transferability. Despite the limitations previously indicated, I was successful in accessing participants who met the selection criteria, and further managed to interview 14 of them until data saturation occurred. In the next chapter, full details of the research results with appropriate literature discussion is provided.

CHAPTER FOUR

Findings of the study

4.1 Introduction

This chapter presents analysis and interpretation of data that was collected through interviews in order to address the aim of the study: to explore and describe mothers' experiences of disclosure of their children's HIV-positive status at Tygerberg Hospital, Western Cape from a social work's perspective. In this chapter, themes were identified which reflect different meanings. The ethics of care was used as theoretical framework. Themes and sub-themes were achieved by carefully analysing the descriptive responses provided by the participants in order to understand the meaning. Identified themes became the basis for analysing the text of semi-structured interviews.

After identifying the themes, the researcher examined the notes taken during the interviews and classified them according to theme. Codes were assigned to the main themes by counting the number of times the theme was mentioned in an interview. After analysing the themes that emerged, they were grouped to align with the literature and theoretical framework. The ethics of care approach was embedded into the main themes, which were identified as 1) mothers discovering their HIV-positive status, 2) mothers' acceptance of their HIV-positive status, 3) mothers' disclosure of their HIV-positive status, and 4) strategies to enhance mothers' disclosure to children of their positive status.

Reddy *et al.* (2012) suggests that different authors have addressed the impact on professional caregivers of caring for people with HIV-related illnesses. Furthermore, social workers are one of the professional caregivers who were chosen by the researcher because social work practice and ethics of care are relevant to each other (Lloyd, 2006).

In the table below are the biographical details of the ten mothers and four social workers. This section will provide a description of the caregivers and the social workers. The caregivers who were interviewed were all female and isiXhosa-speaking. Their ages ranged between 30- and 50-years-old. All the caregivers were the biological mothers of the children. The four social workers were between the ages of 38- and 55-years-old. All participants were Christian in religion. The children were between the ages of 9- and 12-years-old.

4.2 The following demographic information was attained by the researcher:

Age	Gender	Education level	Religion	Occupation	Marital status	Child's age
30	Female	Grade 12	Christian	Teller	Married	11
32	Female	Grade 10	Christian	Unemployed	Unmarried	12
35	Female	Grade 12	Christian	Unemployed	Unmarried	12
45	Female	Grade 5	Christian	Self-employed	Unmarried	11
50	Female	Grade 11	Christian	Unemployed	Unmarried	10
34	Female	Grade 10	Christian	Student	Unmarried	11
32	Female	Grade 12	Christian	Chef	Unmarried	9
30	Female	Grade 10	Christian	Retail shop worker	Unmarried	12
33	Female	Grade 10	Christian	Security	Unmarried	11

30	Female	Grade 8	Christian	Housekeeper	Unmarried	10
38	Female	Degree	Christian	Social worker	N/A	N/A
45	Female	Degree	Christian	Social worker	N/A	N/A
52	Female	Degree	Christian	Social worker	N/A	N/A
32	Female	Degree	Christian	Social worker	N/A	N/A

4.2.1 Gender

The characteristics of mothers and social workers are summarised below. HIV is usually associated with women, and HIV-positive mothers are faced with stigma, discrimination, economic insecurity, and a lack of access to information and resources, as well as insufficient opportunities for training and support. Since 1995 and after the implementation of national guidelines of prevention of mother-to-child transmission (PMTC) in South Africa, it is recommended that all pregnant mothers be tested for HIV as a preventative measure, and this leads to women being tested for HIV instead of men. However, there are other barriers to testing men as they assume that the clinic is for women. Recent research has shown that men are often reluctant to be tested, as they see health facilities as being a 'women's place,' and they feel that testing for HIV is non-masculine and might be perceived as weak (UNAIDS, 2012).

Men report worrying that queueing outside a testing facility will be an indication that they are living with HIV, and they also talk of avoiding testing because they fear a positive result. DiCarlo (2015) stated that encouraging men to test for HIV has been recognised as a major challenge in HIV prevention; however, men's health-seeking behaviours are still poorly understood. The WHO (2013) revealed that gender has been conceptualised as "socially-constructed roles, behaviour, and activities," and also points out that not all society consider testing appropriate for men and women, and because of that, women handle confirmation of HIV-positive results better than men. Squire (2007: p. 15) stated that in South Africa, "women's vulnerability to HIV, alongside their strategies for addressing it, are recurring issues." This is highlighted in women not men, and it was reported that men do participate in HIV research, but not as much as women, making it difficult to address HIV the same way as it is addressed for women (Squire, 2007). Researchers would like to prioritise HIV in men. This would align with the ethics of care, which argues that women are more likely to be the carers in a relationship and that men are among the 'cared for.' This research is about women because there are few visible men who come to the clinic.

4.2.2 Age

Mothers who visited clinic were aged between 30- and 50-years-old, and all four of the interviewed social workers were between 30- and 52-years-old. The age of the participants indicates that they started having children at a normative stage in their lives.

4.2.3 Educational and cultural backgrounds

All social workers who participated in this research obtained their degrees at different institutions. Only three mothers completed grade 12 whereas some mothers attended school up to grade 10 and one of them received up to primary school education. Education has benefits for women in that it allows them to gain better knowledge about HIV and their sexual

behaviours as well as lifestyle; it lowers exposure to violent intimate partners and increases the likelihood of becoming financially secure and independent (Donna, 2009).

Educational levels with regards to the mothers could reflect as cultural, as women in a patriarchal isiXhosa society would not have been encouraged to study as they were expected to marry, carry out home tasks, and look after children. Some of the mothers are working because they are the primary breadwinners, as a result of majority of fathers being absent. As Avert (2015) reported, HIV affects more women because of their unequal cultural, social and economic status in society, and these inequalities are more severe for marginalised women. Cultural and social norms, meaning the girls in families affected by HIV, are usually the ones who drop out of school to care for sick parents or start working to generate income for the family.

4.2.4 Marital status of mothers

HIV is often associated with the practice of having multiple sexual partners. However, this is not always the case as there are assumptions from the broader society that all women and men who are HIV-positive have had multiple sexual partners. HIV stigmatism appears to be associated more with women because of the belief that men can have multiple partners whereas women are expected to be monogamous. Only one out of the ten HIV-positive mothers were married, which could reflect that the others were promiscuous, and this potentially contributed to an HIV-positive status.

4.3. Presentation and discussion of data

Data presentation includes the description of the data collected into a form of explanation, understanding, or interpretation of the people and situations under investigation. This involves turning and modelling the data from the interviews into findings, which provide useful

information, suggestions, conclusions and supporting decision-making (Anyon, 2009). The main themes and sub-themes are set out in a table below.

4.3.1 Themes and sub-themes

Theme 1 Mothers discovering their HIV-positive status.	**Subtheme** Impact of trauma on HIV disclosure.
Theme 2 Mothers' acceptance of their HIV-positive status and impact on disclosure.	**Sub-theme** • Non-acceptance of status by their children due to stigma • Male partners' irresponsibility
Theme 3 Mother's disclosure of HIV-positive status to children.	**Sub-theme** • Challenges with responsibility of disclosure • Lack of social work competence towards disclosure • Trauma and HIV disclosure
Theme 4 Strategies to enhance mothers' disclosure to children of their positive status.	**Sub-theme** • Support systems to mothers • Professional support through disclosure

4.4 Mothers discovering their HIV-positive status

All mothers reported that they confirmed their HIV-positive status during antenatal clinical visits. Four out of ten mothers reported that they did not display symptoms of HIV and that they found out 24 weeks post-pregnancy during their routine clinic visit, whereas the other six mothers reported that they were displaying symptoms of sickness and weight loss. Due to the need of antenatal clinics, MTCT prevention was implemented for mothers to avoid

progression of the HIV. Availability of ART during that time was not as accessible as it is now, and the policy that was implemented in 2014, that every HIV-positive mother should receive ART, was not yet implemented (UNAIDS, 2010).

4.4.1 Impact of trauma on HIV disclosure

Trauma generally refers to a deeply disturbing or distressing experience, and can result from a situation, event, or a series of events that anyone can experience (Guess, 2018). Mothers expressed different emotions soon after they were informed of their HIV-positive status, and some reported that they were terrified, upset, confused and traumatised about the HIV-positive results. The following quotes highlight their feelings:

Mother 3: "When I found out about my HIV-positive status, I was shocked and did not know how I was going to handle my family and my child. I never expected to be HIV-positive because I only focused on one boyfriend at a time."

Mother 5: "Men are really not innocent. After I found out about my status, and I was innocent with my boyfriend. I was angry at him for not being honest with me. He is not even in the picture now."

Mother 6: "I cried because I was shocked about the results, but I got better after some time because I knew that taking medication will be the only way for me to live longer and I told myself that my child will take medication like me."

One mother stated that she was not shocked about the HIV-positive results for the reason that her late husband had multiple sexual partners, and because of this, she expected to be HIV-positive. The reaction of this mother is an indication of resilience as she continued reporting that she was infected with HIV by her husband. Some mothers did not express any blaming of their sexual partners. They displayed positive attitudes, despite mentioning that they

experienced trauma. They stated that what was important to them was not neglecting their children's health, and not allowing the traumatic discovery to take over their lives.

The Well Project (2012) discovered that trauma has negative effects on women's overall health and for women living with HIV. A history of trauma or post-traumatic stress disorder (PTSD) can lead to higher rates of non-adherence to HIV medication and consequent treatment failure, higher rates of death, and poorer quality of life. The interviewed social workers highlighted that trauma and depression is caused by fear for the unknown, especially when the caregivers do not have sufficient information about the chronic diseases being disclosed to them. It is important to take note that the fear associated with HIV has a general pattern. This fear and anxiety is caused by the stigma and discrimination people have experienced when they test HIV-positive. For example:

Social worker: "All mothers go through a period of trauma and depression soon after they find out about their HIV-positive status, made even worse when they find out that their baby or child is also HIV-positive. They only get better when they have someone to communicate their feelings, emotions. In most cases they have anger towards their sexual partners."

Social worker: "Caregivers, soon after they find out about their HIV-positive status, go through a state of shutting down everything in their mind and become fearful of the unknown. Death is the first thing that comes to their mind."

4.5. Factors influencing mothers' disclosure: Stigma and male partners' irresponsibility

All mothers reported that they not only have one HIV-positive child, but that they have other children as well who need attention and care. However, they continued to emphasise that they had to accept their HIV-positive status first to be able to have strength to care for others. Considering the five values of the ethics of care (Tronto, 1993), 'caring for' is the most appropriate act as mothers mentioned that they recognised the responsibility of caring for their

HIV-positive children even though they were emotionally traumatised by their HIV-positive results.

Mothers' main concerns were potential stigma and discrimination against their HIV-positive children. Edwards *et al.* (2007) stated that stigma in the context of HIV is not a "constant," and can be affected by the broader environment. Interventions that serve to reduce community-wide stigma of HIV need to be explored as they may improve the quality of life of HIV-affected families and promote prevention of transmission and persons disclosing without fear of rejection. Furthermore, more awareness education is needed so that people can perceive HIV-positive people as having a chronic disease, and by exposing the stigma, it will reduce the discrimination and rejection felt by HIV-positive individuals. UNAIDS and the WHO (2015) highlighted that fear of stigma and discrimination is the main reason why people are reluctant to be tested, disclose their HIV status, and receive ART.

Mothers highlighted how fathers were not prepared to take responsibility to care for their children, and how this has impacted their ability to disclose to their children. This was another factor that contributed to non-disclosure.

4.5.1 Non-acceptance of their children due to stigma

All mothers had a very important concern about their children's rejection from the communities in which they reside because of the stigma that exists around HIV and AIDS. Participants stated that society will mistreat their HIV-positive children if they found out about their children's status. Mothers accepted their HIV-positive status however, the only fear was for their children – of how they would be treated by the community regarding their HIV-positive status. This thinking is reflected below:

Mother 5: *"I am worried that my child will tell other people. I do not mind people who can talk about my HIV-positive status but not to gossip about my child. My worry is what could happen to her when she finds out from other people."*

Mother 7 *"I was very stressed when I found out that my child was HIV-positive. It took time for me to understand that he is going to be fine and my main worry was the people and his friends when he plays with them."*

Madiba *et al.* (2015) stated that disclosure is a major challenge for caregivers and healthcare professionals providing services to HIV-positive people, including children. Health professionals and caregivers are hampered by problematic policies and guidelines on how, whom to, and when to disclose.

According to Tronto (1993), responsibility for caring depends on a number of factors, including the extent to which an individual accepts that responsibility rests upon them while Bozalek *et al.* (2014) stated that carers have to be attentive as well as take responsibility for caring. This suggests that mothers have to take responsibility for informing their child.

Mothers raised concerns that their children might be stigmatised by the broader society. Moodley (2011) described stigma as something that is related to HIV/AIDS since it was discovered in the early 1980s. She continues to state that the origin of stigma has been traced back to society and culture, specifically the oversimplified conceptualisation of human sexuality and behaviours. Mothers are protective when it comes to their children, and having to share with their child that they are HIV-positive is a daunting task. Participants assumed that by not disclosing to their children their HIV-positive status, they are acting responsibly as they want to protect their child. However, this is not the case as there are serious implications if a child is not informed about the ART they have to take as a result of being HIV-positive. Mothers' fears are reflected in the quotes below:

Mother 3: "I don't want my child to feel isolated from other children. What if other children will hurt him and tease him, let alone not want to play with him because of his HIV-positive status?"

Mother 6: "I don't know if my child will take it well when she finds out and I do not know who can tell my child, or who will be able to make him understand everything."

Madiba (2012) and Moodley *et al.* (2006) reported that many mothers avoid disclosure in fear that the child will blame them for the disease and that this will adversely affect the mother-child relationship. Mothers were all under the impression that their children do not have to be informed about their HIV-positive status at this stage, and would prefer to wait until the child is older. It is clear that mothers take the blame for their HIV status and ignore the fact that the father is also likely to be blamed for their HIV-positive status.

4.5.2. Male partners' irresponsibility

Participants in the research are primarily single-parent women, with one married woman, due to the abandonment and unavailability of the fathers of their children. Fathers are welcome to attend the clinic with the mothers however, only three percent of patients' partners accompany their wives according to FAMCRU records. Married mothers spoke about their husbands not being aware of their HIV-positive status nor the status of the child. Tronto (2013) categorised responsibility as one of personal responsibilities to care and that men and women have the same opportunity to care for their children. She adds that if one does not embrace these opportunities, it is because they have not taken them seriously. Tronto (2013) argued that personal responsibility embodies moral values and that values and ethics are bound with responsibility. Fathers in this research were reported as irresponsible by the mothers as they are reluctant to come to the clinic to be tested or to involve themselves with the disclosure to their children as they do not see it as their responsibility. Patriarchy within some sectors of South African

society continues to be dominant, and men often do not take on the responsibility to care. This is illustrated below:

Mother 4: *"I do not know where the father of my child is and I do not care because he left me while I was still pregnant with this child. I want nothing to do with him; I am fine and am doing well without him."*

Mother 6: *"There is nothing I can do or change to have my child's father come here with me. He will ask me who will bring money if he comes to the hospital, so I do not even bother because I know his answer."*

Mother 7: *"When I informed my husband about the child appointment at Tygerberg Hospital, he only gives me money for transport. He does not ask questions when I return from the clinic. He does not bother to ask about the visit or outcome."*

However, mothers reported that they prefer to bring a family member with them to the hospital, such as their own biological mother. These are the maternal grandmothers to the children. Other family members include sisters (maternal aunts to the child). This is usually for emotional support as women are able to contribute to the caregiving role and, in the typical case of grandmothers, are sometimes left with the responsibility of the children when the parents pass away. Eddy (2014) suggested that critical men's studies' research challenge the idea that hegemonic masculinity and healthy positive behaviour are always incompatible in contrast to gender policy guidelines. The Department of Health (2002) reported that it mistakenly suggested that the reproductive health needs of women are at the expense of men.

The unavailability of the fathers to support the mothers is due to male gender norms, such as is evident in the isiXhosa culture. It is considered taboo for a man to be seen next to a woman all the time, so taking children to the clinic is perceived to be a woman's duty. isiXhosa men believe that their responsibility is to provide for their families financially. Tronto (2013)

highlighted that although men can and do care, "the image persists that what it means to be a man is not to care, or, at least, not to care well." This suggests that some men do care, it is more a case of that they do not care as well as a woman might. A study by Cable (2017) on single fathers argued that some men can take on caring responsibilities when they are forced to do so, such as when a woman is absent or neglectful. Cable reported that the men took on nurturing roles. Dominant constructions of masculinity and patriarchy contribute to the notion that men are not able to care (Tronto, 2013). In this study, isiXhosa men fall into the stereotype of privileged irresponsibility, where they use their masculinity to 'reject' a more caring role. Mothers may also be responsible for not insisting that these absent men take on more responsibility. They could also be reverting to stereotypes in their response. For example:

Mother 2: "The father of my child does not really care about us. All he does is deposit money at Shoprite and he does that only when I phone him. If I do not call him, he would not deposit the money because he does not know that the child should eat."

Mother 4: "I do not see my child's father often. However, when I see him he does not even ask how the child is. All he knows is to buy food for us, electricity and pays the child's school fees."

Social worker 1: "At the HIV paediatric clinic, we do not see fathers. It is very rare that they come to the clinic and we emphasised to the mothers to come with their partners, but for some reason they do not come with them. It is very important for us to speak to both father and mother of the child about the medication, as well as to find out about their coping mechanisms, so that if there is any emotional support they need, we could render that to them."

Gender refers to socially-defined and learned male and female behaviours that shape the opportunities that one is offered in life, the roles one may play, and the kinds of relationships that form. Masculinity norms can also pressure men into having multiple sexual partners, which contradicts HIV/AIDS prevention messages about fidelity, delaying onset of sexual activity in

young people, or reducing the number of sexual partners. This statement was also emphasised by Barrington *et al*. (2016) that men's sexual behaviours are theorised to play an integral part of constructing their masculine identity.

The power imbalance between men and women also translate to economic dependency for women. In most societies, men have greater control and access to productive resources (UNAIDS, 2001). Researchers, policy-makers, and programmers have long recognised that gender plays a role in vulnerability to HIV/AIDS and its impact in every region in the world. Reddy (2014) reported that some men wish to be good fathers however, they often conceptualise this as being able to provide financially for their loved ones. Responsibility is not only about finances. As Tronto (2013) argues, fathers must be more involved in caring for their children as an ethical responsibility.

4.6 Mothers' disclosure of HIV-positive status to children

None of the mothers in the study have disclosed to their children about their status as HIV-positive mothers, nor have the mothers disclosed to their children that they are HIV-positive. Mothers explain that they only informed their children of the importance of taking medication, without explaining the reason they have to do so. Through all the challenges they have undergone in taking care of their children, they followed the doctor's recommendations with regards to their children's medication and, as the children got older, they continued administering the medication to their children to avoid hospitalisation and death. However, disclosure was reported as a major stumbling block.

4.6.1 Challenges with responsibility of disclosure

The first challenge all mothers reported was that disclosing to their children about their HIV-positive status is daunting. They explain that it is difficult and that they do not know how they to do it. They stated that they would like their children to be aware of their HIV-positive status, but they were unsure when or how to disclose the information to their children. For example:

Mother 1: *"I would like my child to know what is wrong with him, but I do not know how to start speaking to him about HIV. I am afraid. I think it will be better to get some help from someone who knows how to speak to children."*

Mother 3: *"I do not know how to tell my child that he is HIV-positive, and I know that she needs to know what is wrong with her. I am afraid that she will blame me for being infected. I do not know if she will understand what is wrong with her."*

These are some of their concerns and their first question was how to disclose the child's HIV-positive status.

Mother 4: *"How do I disclose to my child? How do I start talking about HIV? How do I explain how she got it, and what do I do if my child is upset about having HIV? How do I know my child understands the disease?"*

Mother 7: *"As a mother, how do you tell a child about a disease that does not have a [cure]? That is my concern and the first question I ask myself. All we knew is that the child needs to drink medication every day. How do you explain to a child that she or he is sick with a disease that is stigmatised? How do you tell a child about a disease that is highly-associated with sex, and lastly how do you explain to a child about sickness that she or he does not even see or feel?"*

According to Moodley (2011: p. 243), "disclosure of HIV status to the child is an area of care that is fraught with ethical concerns." However, mothers must take responsibility so that children can be aware of the importance of the medication. All the participants mentioned that talking to a stranger about their HIV-positive status helped them.

Mother 8: *"Coming here and talking to the counsellors and you as a social worker, I felt like someone has lifted a heavy load off my shoulders, and I told the other mothers at the waiting*

room that it is good to speak out about how they feel so that they can get help. Keeping secrets is not good – I know it [for myself]. I am very happy with how things are done here."

The third phase in the ethics of care is caregiving. Competency may be viewed as caring, not only physically, but also by going through the emotions of attending to someone. Engster (2005) and Tronto (1998) proposed that caregiving requires individuals and organisations to perform the necessary caring tasks, as well as have the necessary understanding about how to care. Being competent means that anyone can have the knowledge and resources to do a good work. Competency does not only have to be based on professionals. In this research, mothers were not educated, but they appreciated and accepted support from other people who willingly supported them. Mothers are desperate to be competent, but this is coupled with fears of unknown. Lloyd (2006) stated that competency includes individual skills and knowledge to point out the necessity of adequate resources. Mothers who came to the institution lack the resources to facilitate disclosure as they are carrying the burden of having infected their child. Social workers are well-positioned to play a role in the disclosure and mothers expect the professional social worker to undertake this task to free them of the discomfort that the disclosure is anticipated to bring. The following response was expressed by the social worker:

Social worker 3: *"The load of work we have does not allow us to spend much time with caregivers, as much as we would love to render more support for HIV-positive patients."*

Some mothers felt that professionals should play a role in assisting disclosure as highlighted below:

Mother 5: *"A doctor should tell my child about the disease as he or she is the one who knows [more] about it. Social workers are supposed to tell the children what is wrong with them because they are trained to deal with it and to be caring for our children."*

Mother 7: "A social worker is the right person to tell my child because of how they talk to people and how they care for the children, and because they are trained to work with the emotions of people."

The ethics of care encourages a view of care as an activity interpreted, viewed and enacted through particular people negotiating caring in specific socio-cultural contexts, during which they are exploring the right thing to do for themselves and for their relationships (Tronto, 2010). It is in this sense that care is seen as a dynamic relationship formed between those helping and those needing help. In this case, it is mothers seeking help from professionals as they are unable or unwilling to tell their children as it is too difficult to do so. The ethics of care emphasises the everyday nature of a caring relationship in all lives, where everyone needs care and highlights reciprocity. Williams (2012), discusses care to be valued for the social good. In order to succeed in care, the suggestion would be finding different care networks or teams to be involved like social workers or nurses. The care that is provided and received within networks may include both paid and unpaid caregivers, such as family members, friends, and care workers, particularly as these networks are positioned in the townships from where most of the participants hail.

4.6.2 Lack of social work competence towards disclosure

All social workers in this research are based at a tertiary hospital and are recognised as helpers or as part of a care network, bringing solutions to the needy, and are perceived as people who can be trusted with other people's secrets. Social work is one of the professions that is focused on service delivery to the poor. Some social workers have specialities in different fields, such as social workers specialising in health challenges like HIV/AIDS. Social workers are equipped with special skills, values and ethics that can assist disclosure. These attributes are expected of social workers however, it is not always possible for social workers to respond to

the needs of their clients if guidelines are not clear. Moodley (2011: p. 143) refers to social work as a publicly-declared "dedication, promise and commitment." The role of the social worker in the field of HIV/AIDS, which has been primarily associated with loss and grief, has fundamentally changed with the introduction of ART (Skidmore *et al.,* 1994). Some social workers felt that it is the mother's role to disclose to their children their status as described below:

Social worker 3: "Disclosure is not an easy thing to do. If mothers can do it by themselves, it will be great, but they will need very intense training. It will be really good for the child to get the news from their mothers, as they are the one who care for them, in order to promote relationships as well."

However, there are others who feel that social workers should take on that role as described below:

Social worker 1: "Social workers should be the ones to disclose to children because they are well-trained to handle reaction of the child, and it should be stated on the policy of the Department of Health to have more social workers at local clinics to assist many more caregivers, because some children are not staying with their biological mothers and they need to be equipped or get assistance."

Social worker 2: "Social workers should be the ones to disclose to the children to assist families more and [act] as a psychosocial supporter. Social work assistance will have a great impact on many families as some are uneducated would be unable to [carry out the] disclosure process to their children, which might harm other children who will turn to bitterness."

There was a mixed response from one social worker who felt that both the social worker and the family should be involved during the process of disclosing the HIV-positive status to the child:

Social worker 4: "Social workers do not have enough time to do disclosure, as much as it is very important for us to do it. I am doing it at our clinic because families are very nervous about telling their children about their HIV-positive status. I think it will be better to have more social workers at the health facilities who will be trained or focus only on HIV disclosure for children to assist families. It does not have to be done all the time by social workers; families need to be involved in a unique manner."

It is clear from these findings that there are challenges regarding disclosure as some social workers do not mind the disclosure process, while others were unsure. Competence of social workers was then compromised and mothers feelings of disappointment. It is clear that a strategy needs to be developed to enhance disclosure so that the rights of the children are enhanced.

4.7 Strategies to enhance mothers' disclosure to children of their HIV status

The mothers' greatest wish is for their children to be aware of their HIV-positive status. However, they need professional assistance as they cannot do it themselves. They argued that they are not well-equipped and also lack the necessary confidence. Bozalek *et al.* (2014) stated that caregivers should pay attention to the responses of the care receivers. In this case, social workers should be able to pay attention to caregivers who require their assistance. Mothers have already given attention to their children who need love, guidance and care. It is clear from their responses that mothers do provide care but, on the other hand, they also deserve to be cared for. Responsiveness thus represents a different way of understanding the needs of others (Tronto, 1993). It is clear from this research that HIV-positive mothers need support to ensure that disclosure is correctly handled.

4.7.1 Support systems to mothers

Mothers reported that they feel comfortable to share their challenges with their family and social workers because they trust them with their emotions and they feel less burdened through revealing the information. Communities from where these mothers come, particularly in the townships, can be discriminatory towards HIV-positive individuals. The fourth value highlighted by Tronto (1993) is that responsiveness requires support for the one needing care – achievable by taking steps further than empathy (Lloyd, 2006). Responsiveness is when a person who is being cared for responds positively to the care that is provided. It enables the voice of the service user to be heard and, in this research, mothers have shared their challenges with the social workers about needing support for disclosing to their children.

Research conducted in the Eastern Cape, South Africa revealed that care is often characterised by strong emotional connections between the people who are living with HIV and those who care for them. Barnes (2015) suggested that caring involves emotional dimensions and such emotional connection within caring relationships helps to ensure that care is reciprocal. Social workers are emotionally connected to the mothers as some are mothers themselves or empathise with their situation, and so are in a relatable position to provide support to the mothers, which could lead to positive responsiveness.

Responsiveness might be perceived as a form of negotiation with others to recognise the specific nature of their needs as well as monitor the response towards care. Tronto (1993) describes responsiveness as an important moral problem within care, and that in a "core of its nature, there are conditions of vulnerability and inequality of which vulnerability has serious moral consequences." This is because people go through challenges and Tronto (1993: p. 135) argues about the "dependence and independence and it is thus a myth to regard ourselves as 'always autonomous, and potentially equal citizens." As an example of responsiveness, participants described their families as supportive during medication time:

Mother 6: *"I told my sister and she was very supportive. My family is supportive and [so is] my husband. I only told them about me, not about the child, however, they are supportive towards me."*

Mother 7: *"Support from my family surprised me because I thought they were going to have an attitude towards me, but not even one of them had. They are always reminding me about my medication and the child's medication, with information on how to live a positive life and what to eat."*

Mothers reported that on no occasion did they experience discrimination or neglect from their families. Lee *et al.* (2009) postulated that family is the first central shared institution and families are regarded as the cornerstone of society. Family guide and mould the child in a way that he or she is expected to be, most of which is steered in a positive manner. This following are examples of how mothers expressed the support from their families:

Mother 2: *"They are very supportive – always asking about my child to find out if she is doing well. My family always advise me to look [after myself] well after informing me about new information about HIV."*

Mother 5: *"My family support is very helpful, especially when I am not around the house. They know how to give medication to my child."*

Social worker: *"It makes our work very easy as social workers when the family is working with us to support the caregiver and to supervise the child's medication. In having someone mothers can rely on, we can also see the positive adherence of medication."*

One social worker expressed how mothers respond to her support:

Social worker: *"Mothers without a family support – we struggle with them. However, we do render support and immediately when we have formed a relationship with them, they become*

very [eager] to share and communicate about anything with us after they have developed trust."

4.7.2 Professional support through disclosure

Mothers mentioned that social workers are a significant support when it comes to HIV disclosure because they understand the caregiver's feelings without being judged. During the interviews, mothers highlighted that it will be valuable to have all the clinics equipped with social workers, like FAMCRU is, to support them through the phases of disclosure. They said that it will have a positive impact on their HIV-positive children and it will make their lives much easier than having to be anxious about how and when to disclose to their children.

South Africa is known for legislating formal provision for prioritising care for people and that is offered by the Department of Health and the Department of Social Development. The democratic government emphasised the need for preventative and primary healthcare promotion, and it is this care that underlines the role of community health centres. The local clinics and district health system were introduced for the delivery of healthcare services to the marginalised population (Reddy, 2014). Social welfare was introduced by the white paper date for financial and human resource constraints that present a context of mass poverty and HIV/AIDS. It emphasises participation in development, partnerships between states, private and non-profit sectors, as well as between families and communities.

UNAIDS (2005: p. 3) further stated that care and support for people living with HIV can help to protect the health of the public at large by putting preventative measures in place to be more effective. Social support can assist infected individuals in coping more effectively with each stage of the infection and enhancing quality of life. The WHO (2008: p. 8) reported that HIV affects all dimensions of a person's life – including their physical, psychological, and spiritual life; support from families can assist these people in coping with their illness. Participants confirmed that receiving support from their families or being accepted by their families keeps

them strong**.** However, there was a mixed response from the mothers about the professional support. Some stated that they were supported, whereas others felt that were not. This highlights the dilemma disclosure poses, for example:

Mother 6: "At the clinic where I took my ART, they are very friendly and supportive, asking about my family and how I feel, but it is the counsellors there who always laugh at the people. At some point, I do not really trust them because of the way they are so friendly with people. Social workers or nurses are always serious even though they can be nice. To me, I prefer serious people."

Mother 8: "I do not trust the counsellors in that clinic. They do things I do not like. They asked me about my child and told me I must disclose to my child about his status, but they do not ask me if am ready or not. I feel like they are forcing people and they do not care about how the child is going to react. At least the doctor or a social worker will have a way of explaining to us how to do this."

Mother 10: "A social worker should be able to guide disclosing to our children because they are good at advising people about their lives, like here at the hospital. I remember when I was very anxious about my child and a social worker from the ward where my child was admitted helped me to understand, how to start talking about HIV, how to handle my child's questions about HIV. I think I will be able to disclose to my child by myself. For now I do not need any professional assistance. However, should I get stuck, I will contact a health professional.

The Department of Health needs to train social workers and other carers to be competent in either helping mothers to disclose or to disclose to the children themselves if the mother is not able to do so. The right of the child to know their status is important, and when and how

to disclose could have a major impact on the child's future. Caregiving is often fraught with vulnerability and inequality, as highlighted by Tronto (1993). Social workers can play a major role in ensuring that caregiving is handled properly.

4.4 Conclusion

This chapter presents and discusses the findings about the experiences of mothers' disclosure to their HIV-positive children. The first part presents the demographical aspects about the participants. Data from semi-structured interviews was written down in order to identify themes and sub-themes. Quotes were used to substantiate the themes and, with integration of literature, were applicable. Themes emerged which highlighted the challenges within the ethics of care in a hospital setting. This chapter revealed that mothers with HIV-positive children need assistance from professionals to assist them in disclosing to their children.

Mothers demonstrated that family support is of paramount importance when one is in need; it also reflected the importance of disclosure and maintaining a good relationship with families in order to be able to deal with the diagnosis. Social workers highlighted and suggested that service providers at the ART clinic have a positive effect on decision-making when it comes to disclosure to children, and they emphasised the importance of professional involvement in disclosing to children. Gender has been repeatedly highlighted in the sense that there in an imbalance when it comes to supporting and caring for their family due to men's masculine insecurities. The conclusion and recommendations of the study will be presented in the next chapter.

Chapter five

Conclusion

5.1. Introduction

This chapter will present a summary of the study, conclusions of the findings and recommendations for future research. Literature and theory were used to substantiate, justify and contrast the findings of this study. The data was analysed and four main themes emerged which will be summarised in this chapter. A brief summary on each of the previous chapters, as well as conclusions and recommendations from the findings, will be presented.

5.2 Summary of the aims and objectives of the study

The aim of the study was to explore and describe mothers' experiences of disclosure of their child's HIV-positive status at a tertiary hospital in the Western Cape to determine what intervention tools might assist the disclosure. The objectives were, firstly, to explore and describe mothers' experiences of disclosure of their child's HIV-positive status at a tertiary hospital in the Western Cape, and secondly, to explore and describe intervention tools that can be used by social workers to facilitate disclosure of children's HIV status at a tertiary hospital in the Western Cape. A qualitative research approach was applied to the study. Explorative and descriptive design within a qualitative approach was selected because it suited the study's aim. The population was HIV-positive mothers who have HIV-positive children, and social workers working at tertiary hospitals were also interviewed to triangulate the data. The data was collected through live, face-to-face interviews. Note-taking was utilised as participants did not consent to audio-recording. The objectives were achieved as mothers spoke about their challenges when dealing with disclosure, highlighting the lack of support from their male partners. Mothers argued a need for more support from social workers. They emphasised a lack of resources at local clinics, which could contribute to positive disclosure.

5.3 Summary of the literature review

The research presented a comprehensive review of literature, which mainly unpacked global HIV-positive disclosure to children, as well as cultural and gender roles. Studies conducted in Africa and South Africa were also perused. Literature that explored social work interventions and perspectives on HIV disclosure was reviewed. The ethics of care was examined as the theoretical framework. This was deemed appropriate as care of HIV-positive mothers, and children was the main focus of the research.

5.4 Demographics of participants

The demographic information of the fourteen participants in the study were ten HIV-positive mothers and four social workers. Twelve of the participants were isiXhosa speaking and the other two were English speaking. The ages of the participants were between 30- and 50-years-old. Educational levels of the mothers were up to grade 12. All social workers had degrees from different universities.

5.5 Overview of the main themes

The following four themes emerged in the study: 1) Mothers discovering their HIV-positive status; 2) factors influencing mothers' disclosure, including stigma and male partners' irresponsibility; 3) mothers' disclosure of HIV-positive status to children; and 4) strategies to enhance mothers' disclosure to children of their positive status. Findings were presented in the form of the above-mentioned themes and in the sub-themes that were generated from the in-depth interviews which were carried out. The following is the in-depth summary of the sub-themes.

5.6 Mothers discovering their HIV-positive status

Impact of trauma on HIV disclosure

Mothers struggled to come to accept the fact that they are HIV-positive. A range of emotions were highlighted such as shock, anger and disbelief. Others stated that it was not surprising

as their husbands had had multiple partners. The social workers who were interviewed identified that mothers experience trauma with related depression as they fear the unknown.

5.7 Factors influencing mothers' disclosure: Stigma and male partner's irresponsibility

Rejection by their children due to stigma

Most mothers revealed that they feared for their children's safety if their HIV-positive status was disclosed. They revealed that they were anxious that their children would speak to other children and inadvertently reveal their status, which could lead to stigmatism, rejection and discrimination. Mothers felt that they were being responsible by not disclosing to their children due to the stigma in the society however, they did not appear cognisant of the ramifications of not revealing. There was also concern expressed by the mothers that their children will blame them for infecting them.

Male partners' irresponsibility

Mothers were critical of fathers not taking responsibility with regards to disclosing to their children. Some had been abandoned by their husbands whereas other fathers were reluctant to come to the clinic as they felt it was the mother's duty to handle the children. This is in line with patriarchy and privileged irresponsibility where fathers believe that their main duty is to be the financial provider. Fathers, according to the mothers, were also not willing to be tested for HIV, and so were not receiving any medication to prevent further transmission. This is, again, a lack of responsibility on their part. Mothers reported that their extended family (mothers, grandmothers, sisters or aunts) accompanied them at the clinic. Male stereotyping contributes to the fathers' irresponsibility as laws that should be enforcing parental responsibility on fathers are not functioning. The mothers are often dependent on the fathers for financial support and therefore will not report them to child maintenance court.

5.8 Mother's disclosure of HIV-positive status to children

Challenges with responsibility of disclosure

The study revealed that all the mothers interviewed have not disclosed to their children their own status, as well as the status of the children, because they find it too daunting. One interviewee spoke about feeling afraid while another said she felt her child would blame her. The process of disclosure was also highlighted by a mother who stated that the child would need explanations about sexual intercourse and other related matters. Mothers struggle with competency within the ethics of care as it is too traumatic for them to share with their children. They believe that a professional (such as a social worker) is more competent in disclosing to their children.

Lack of social work competence towards disclosure

Social workers have the skills to carry out the disclosure on behalf of the mothers, but they report that they do not always have time nor do they feel that mothers should take on the responsibility. Some social workers also spoke about the need to train the mothers and/or fellow social workers about how to disclose to children effectively. This mixed response from social workers impacts on competence as they are not clear on what process should be followed. This feedback would be concerning for the mothers as they are already traumatised by the irresponsibility of the fathers and stigma regarding HIV and AIDS within the broader community.

5.9 Strategies to enhance mothers' disclosure to children of their positive status

Support systems to mothers

Mothers report that their extended families are very supportive in terms of disclosing their HIV status, but are in need of more support when the time comes to disclose to their children. Responsiveness within the ethics of care is crucial as mothers should be able to reflect positively on the support they are receiving at the hospital and at home. Families also share

new information on HIV with the mothers, which contributes to their support network.

Professional support through disclosure

Some of the mothers highlighted social workers as a source of support, but they felt that more social workers should be employed at clinics so that the support is more widespread. The challenges being experienced within the health sector in South Africa is compromising the kind of support that is needed for HIV-positive mothers. Local health clinics are often unable to cope with the workload due to insufficient resources. Some mothers were more complimentary about the tertiary hospital who appeared to respond appropriately to their needs.

5.7 Limitations of the study

All the participants in the study were HIV-positive, isiXhosa-speaking women. Men were not included to contribute their views. Different racial groups could have been approached as well. The research study was conducted at one tertiary healthcare facility. Therefore, the findings cannot be generalized and are only applicable to this study setting. Older children who are already conscious of their HIV-positive status were not included to share their experiences of how, why, and if there were any intervention tools used or applied to them during the disclosure process.

5.8 Recommendations and suggestions

- Social workers are thought of as life-guiders and are trusted by most mothers. Therefore, the study recommends more social workers to assist families in disclosure.

- Every local clinic should have a Social workers that would be specializing on assisting families and their adolescents about their HIV status.

- The general guidelines on disclosure should specify who should perform or assist the disclosure.

- Training should be provided for mothers on disclosure to their children and how to handle children's questions about their medication. More education regarding stigma

associated with HIV and AIDS should be made available through websites, social media as well as local television and radio stations.

- Family involvement can be further strengthened so that disclosure to children can be instilled and effects of stigma and rejection are taught and avoided.

- The department of health should have HIV disclosure programme in place for a definite age, for example it should be stated on the clinic guideline that, a child at a specific age should be aware of his/her status with the help of the social worker.

- Handing out booklets like magazines with images for the parents/care givers to assist them to disclose to their children at their own comfort homes , so that children can relate when one speaks about HIV,CD 4 counts and the High viral loud. .

- Due to resource limitation if there is any, health care providers can refer HIV positive children to peer support groups that already exist in the community or associate with community-based organizations that support such activities. In developing such partnerships, reporting and referral mechanisms need to be established to handle sensitive or urgent issues. Health services can also develop innovative approaches to providing peer support despite tight budgets and space limitations.

5.8 Recommendations for policy makers

- To enforce the Children's Act 38 of 2005, chapter 2, section 13 so that the process of disclosing to the child should start at the age of eight-years-old so that mothers can be assisted.

- To apply the Children's Act 38 of 2005, chapter 2, section 7 in the best interest of the child so that HIV-positive children can benefit.

- To apply the Children's Act 38 of 2005, chapter 2, section 13, which promotes access to health information and confidentiality in everyday life.

- To advocate that the Children's Act 38 of 2005, chapter 2, section 13 (b), where persons have access to information regarding his or her health status, be recommended.

5.9 Suggestions for further research

- Research on tools to be used to assist mothers and their families in disclosure ,like the use of video's ,like looking at the time of accessibility of phones and children these days they looked advanced when it comes playing games on their phones . Disclosure to be in a format of a game that will be educational for the HIV positive child.

- Research on different racial groups of HIV-positive mothers. The other race might not be struggling like the race the student wrote about and others can learn from the others on how to handle disclosure for their children.

- Improved involvement of fathers towards HIV-positive children. There is not much the student researched about the fathers, except that they less involvement on their children's upbringing or not even aware of their children's HIV positive status.

- Cultural influences on children's disclosure. This could again assist to find out about different cultural practises about disclosure and how mothers/care givers handling it for their children.

- Research to the local clinics to find out what equipment's and assistance they need to assist on disclosure, like do they need a friendly adolescent zone at their clinics and less waiting hours for the adolescent.

- Research on HIV positive adolescent support group like adolescent mentorship under the guidance and supervision of a social worker.

5.10 Conclusion

This last chapter of the study provided the reader with a summary and conclusion of the proceeding chapters, from the introduction, literature review, theoretical framework, applied methodology and the presentations of the research findings. Recommendations were made regarding how to improve the situation with disclosure to HIV-positive children and to assist the mothers who are traumatised by the responsibility. The Children's Policy is written in legislation, however, not practised at times. The researcher made suggestions for future research. In conclusion, the study is expected to add new understanding to limited research on HIV children's disclosure.

References

Abby L. DiCarlo, Joanne E. Mantell, Robert H. Remien, Allison Zerbe, Danielle Morris, Blanche Pitt, Elaine J. Abrams & Wafaa M. El-Sadr (2014) 'Men usually say that HIV testing is for women': **gender dynamics and perceptions of HIV testing in Lesotho**, Culture, Health & Sexuality, 16:8, 867-882, DOI: 10.1080/13691058.2014.913812

Anyon, J. (2009). *Theory and Educational research toward critical social explanation.* London: Sage Publications.

Barnes, M. Brannelly, T. Ward, L. and Ward, N. (2001) **Ethics of care:** Oxford University

Babbie, E. & Mouton, J. (2001). **The Practice of Social Research** (South African Edition). Oxford: Oxford University Press.

Babbie, E.R. (2007). *The practice of Social Research, 11^{the} Edition.* California: Wadsworth

Bozalek. & Leibowitz, B. (2010) **An Evaluative Framework for Social Justice in Higher Education Teaching and learning** .44(2):107-120

Brink, C .Van der Walt. &Van Ransburg. (2012) **Fundamentals of research Methodology for Healthcare Professionals:** (3rd Ed) Claremont, Cape Town. South Africa.

Carla Makhlouf Obermeyer, DSC, parijat Baijal, MA and Elisabeth Pegurri MSc. **Facilitating HIV disclosure across diverse setting.** Public health journal 101(6):1011-1023.Accesded 04 April 2017

Creswell, J. W. (2010). *Research design: Qualitative, quantitative, and mixed methods approach*. Sage publications.

Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approach*. Sage publications.

Babbie, E. & Mouton, J. (2014). *The practice of social research.* Cape Town. Oxford University Press.

Chilemba E, Phiri C (2015) **Benefits and Risks of Disclosing Human Immunodeficiency Virus Diagnosis to Perinatally Infected Children**. Journal of Nursing Care 4:260. doi:10.4172/2167-1168.1000260:Accesed 23 March 2017

De Vos, A., Strydom, H., Fouche, C. & Delport, C. (2007). **Research at Grass Roots for the social sciences and Human Service Professions.** (3rd Ed) Pretoria: Van Schaik Publishers.

De Vos, E., Strydom, H., Fouche, C., & Delport, C. (2016). *Research methods at Grass roots.* Oxford: Oxford University press.

D'Cruz, H. & Jones, M. (2004). **Social work research Ethical and political contexts**: London, UK.

Depoy, E. & Laura, N. (2011).**Introduction to Research** (4th Ed). Philadelphia: Pennsylvania John, B., Jemmott, III. G. Heeren, K. Sidloyi, L.Marange, C. & Ngwane, Z. Caregivers intentions to disclose HIV diagnosis to children living with HIV: South Africa (2014) *Aids Journal*.10.1007/s10461-013-0672-0.Accesed June 2017

Darlington, Y. & Scott, D. (2002). **Qualitative research in Practice** .Mc Grew-Hill education.

Denzin, N., & Lincoln, Y. (2005). Introduction: the discipline and practice of qualitative research. Thousand Oaks, CA: Sage.

Eugene Tartakovsky & Liat Hamama (2010) *Mothers' Acceptance-Rejection of Their Children Infected With HIV: The Role of the Mothers' Social Axioms, Psychological Distress, and Relationships,* School of Social Work, Tel Aviv University.

Gilligan C. *In a different voice: psychological theory and women's development*. Boston, MA. Harvard University Press, 1982.

James Mcintyre ,T Mags E Beksinska, Helen V Rees, Immo Kleinschmidt. **The practice and prevalence of dry sex among men and women in South Africa Reproductive Health Research** Unit, Department of Obstetrics and Gynaecology, Chris Hani Baragwanath Hospital, PO Bertsham 2013, South Africa. http://dx.doi.org/10.1136/sti.75.3.178

 Mandalazi, Bandawe,& Umar

Joint United Nations Programme on HIV/AIDS (2012)

Jamieson, L &Lake, L (2013) **Children's act guide for Health Professionals** fifth edition: University of Cape Town.

Kiwanuka, J. Mulogo, E. & Haberer, JE. (2014). **Caregiver perceptions and motivation for disclosing or concealing the diagnosis of HIV infection to children Receiving HIV care in Mbarara,** Uganda: accessed on 16 March, 2016 9(3):e93276

Kouyoumdjian. (2005) Family health Centre: *Paediatrics Journal* 51(5): 285-287. Accessed on 09 June 2016 at http://tropej.oxfordjournals.org/content/51/5/285.abstract

Lara M.E. Vaz, Ph.D., S.M.,[1] Eugenia Eng, D.Ph., M.P.H.,[2] Suzanne Maman, M.H.S., Ph.D.,[2] Tomi Tshikandu, M.D.,[3] and Frieda Behets, Ph.D., M.P.H. *Family Health International, 4401 Wilson Boulevard, Suite 700, Arlington, VA 22203.*

AIDS Patient Care STDS. 2010 Apr; 24(4): 247–256.

Lesch, A., Swartz, L., Kagee, A., Moodley, K., Kafaar, Z., Myer, L. & Cotton, M. (2007). **Paediatric HIV/AIDS disclosure: towards a developmental and process-oriented approach. PubMed journals** .accessed 2015 October 2015:19(6):811-6 Stellenbosch University.

Mabaso R (2006) **Theoretical frameworks in qualitative research.**7:7 DOI 10, 2202/1940-1639, 1246 .Volume VII No7. Accessed September 2018.

UNICEF (2012)

Madiba, S. (2012). **Disclosing HIV to infected children in South Africa in the Era of HAART.** *Journal of AIDS, 2.319-329.*Accesed 08 June 2016

Madiba, S. (2012). **Disclosing HIV to infected children in South Africa in the Era of HAART.** *Journal of AIDS, 2.319-329.* Accessed 16 July 2017

Madiba, S and Mokgatle, M (2015) **Health care workers' perspectives about disclosure to HIV-infected children**; cross-sectional survey of health facilities in Gauteng and Mpumalanga provinces, South Africa. Journal of PubMed 25893147. Accessed 25 May 2017

Madiba (2016) **Caregivers Lack of Disclosure Skills Delays Disclosure to Children with Perinatal HIV in Resource-Limited Communities**: Multicentre Qualitative Data from South Africa and Botswana: Nursing Journal

Maureen Mswela. LLM. Lecturer, Department of Jurisprudence, **Cultural practices and HIV/Aids in South Africa: A legal perspective**" School of Law, Unisa A medico-legal analysis" 2010 (4) *Medicine and Law Journal* 523-536 accessed 12 February 2019.

Mc coy, Malow, Edwards, Thurland, Rosenberg (2017)

https://doi.org/10.1080/15504263.2011.620429

Mouton, J. & Babbie, E. (2001). The practice of social research. (9th Ed). Cape Town:

Moodley K (2014) **Medical ethics, law and human rights**: a South African perspective

Mswela (2009).**Cultural practices and HIV in South Africa**: a legal perspective VOLUME 12 No 4, ISSN 1727 -3781 accessed 23 August 2018

Myer, L. Moodley, k. Hendricks, F. &Cotton, M. (2006) **health provider's perspective on discussing HIV status with infected children.** 52(4):293-5 accessed March 2016

Matthew F. Chersich & Helen V. Rees (2008) **Vulnerability of women in southern Africa to infection with HIV: biological determinants and priority health sector interventions.** Accessed 29 November 2019 4:S27-40. Doi: 10.1097/01.aids.0000341775.94123.75

National department of health South Africa (2016) accessed 14 Juley 2018

National HIV counselling and testing policy guidelines May (2015): accessed 8 June 2017.

Natrass, N. (2007). Mortal Combat: **Aids denialism and style antiretrovals in South Africa**, Scottsville, South Africa: University of KwaZulu Natal.

Nostlinger .C, Colebunders, R. (2006).**Informing children of their HIV**: status HGH McMaster University Canada. , issue 9534, 5-11.

Noddings N. *Caring: a feminine approach to ethics and moral education*. Berkeley, CA. University of California Press, 1984.

O'Malley ,G. Beima-sofie ,K. Ferris, L. Shepered Perry ,M. Hamunime ,N. Stewart, G. Tjituka ,F. and Brandt,L.Medical Journal. Volume 68, number 1. "If I take my medicine I will be strong:"1;68(1):e1-7available 1 January 2015 http://www.ncbi.nlm.nih.gov/pubmed/25296096

O'Malley ,G. Beima-sofie ,K. Ferris, L. Shepered Perry ,M. Hamunime ,N. Stewart, G. Tjituka ,F. and Brandt,L.Medical Journal. Volume 68, number 1. "**If I take my medicine I will be strong:**"

Pamela M. Murnane, Stacy-Lee Sigamoney, Francoise Pinillos, Stephanie Shiau, Renate Strehlau, Faeezah Patel, Afaaf Liberty, Elaine J. Abrams, Stephen Arpadi, Ashraf Coovadia, Avy Violari & Louise Kuhn(2016). Extent of disclosure: **What prenatally HIV-infected children have been told about their own HIV status** Journals: AIDS care. http://dx.doi.org/10.1080/09540121.2016.1224310 Accessed 28 March 2017

Patton. (1990). **Qualitative Evaluation & Research methods** (4th Ed).USA: McNauhtin&Gunn Inc. Republic of South Africa. (1996).

People Living with HIV- 2014 South Africa

Reda, A. & Biadgilign, S. (2012). **Determinants of Adherence to Antiretroviral Therapy among HIV- infected Patients in Africa**. Aids Research Treatment volume 2012.   Ethiopia DRachel C.Vreeman,M.D.,M.S. Winstone M. Nyandiko, MBChB, MMED,Samwel O. Ayaya, MBChB, MMED, Eunice G. Walumbe, M.P.H.,David G. Marrero, Ph.D. and Thomas S. Inui, Sc.M., M.D. **The Perceived Impact of Disclosure of Paediatric HIV Status on Paediatric Antiretroviral Therapy Adherence, Child Well-Being, and Social Relationships in a Resource-Limited Setting** (2010) *1020410 West 10th Street, Indianapolis* oi: 10.1155/2012/574656

Reddy, V., Meyer, S., & Shefer, T. (2014). *Care in Context: Transnational Gender Perspectives*. T. Meyiwa (Ed.). Cape Town: HSRC Press.

.

Strauss, A., & Corbin, J. (2014). **Basics of qualitative research**: Grounded theory procedures and techniques. Newbury Park, CA: Sage Publications.

Tronto, J.C. (2012). **Ethics and Social Welfare***: Gender Justice* 303–316. New York: Routledge.

Tronto, J 1993, Moral Boundaries: **A Political Argument for an Ethic of Care**, Routledge, New York.

Tronto, J. (2010). *Creating Caring institutions: politics, Plurality, and Purpose.* Ethics & Social Welfare, 4 (2): 158-171.

Van Niekerk .c. & Kopelman. N. (2012) **Ethics &aids in Africa**. Cape Town publication**.**

Walker, S. (2010). '**Paediatric HIV Social Workers:** Sage Journals. 10(4):415-433, accessed on 16 July (2016) http://qsw.sagepub.com/content/10/4/415.short

Wasana Prasitsuebsai, M.D.,Asha C. Bowen, B.A., M.B.B.S., Joselyn Pang, M.A., Cees Hesp, M.A., Azar Kariminia, Ph.D., and Annette H. Sohn, M.D.Pediatric **HIV Clinical care Resources and management Practices in Asia. AIDS patient** care journal, 24(2):127-131: accessed 17 April 2017

Well Project (2012) disclosing to adolescent

World health organization (2015) Guidelines **on HIV Disclosure Counselling for Children up to 12 Years of Age.**

http://dx.doi.org/10.1155/2016/9637587.Accesed 15 April 2016

World Health Organization (2011) **Guidelines on HIV Disclosure Counselling for Children up to 12 Years of Age.**

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-938 4548/ Fax: 021-9592845
E-mail: mgini@sun.ac.za
INFORMATION SHEET

Project Title: Mothers experiences of disclosure of their children's HIV positive status in a paediatric unit at Tygerberg Hospital: a social work perspective

What is this study about?

The purpose of this research project is to explore and describe the experiences of mothers who have disclosed to their HIV positive children. And to find strategic interventions so that can be shared with other mothers who have not disclosed.

What will I be asked to do if I agree to participate?

You will be asked to sign a consent form which will be used as evidence that you have given your permission to be interviewed in English to be audio recorded. If you agree to all the requirements on the consent form then the researcher will arrange for an interview with you.

Would my participation in this study be kept confidential?

To ensure your confidentiality and anonymity in the study, the study will be conducted in a way that does not infringe on your rights as the participant. To ensure your anonymity, your real name would not be used and it will be replaced with a number to protect your identity. In ensuring confidentiality all audio recorded interviews, documents or files that might contain personal information will be locked in a safe space

What are the risks of this research?

There may be some risks from participating in this research study. You may be asked to talk about your specific experiences about HIV and its treatment. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention. However, referrals will be done in respect of your right to self-determination and the respect of legal right to only engage in intervention sessions at your own discretion.

What are the benefits of this research?

The benefits of the research will be that it is a chance for the participants to express their concerns as a way to find out what could be one to improve their experiences. The results may help the investigator learn more about experiences of mothers who disclosed to their children and might help other professionals to adopt their strategy. This will be shared with the participants and will be written up in the thesis to be published and presented at conferences at a later stage.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized.

Audio recordings

This research project involves making audio recordings of you. The recordings will be used to write the verbatim transcripts which will be used to analyse the interview information. The student researcher and his supervisor will have access to these recordings and they will be stored in a safe space. Furthermore, the data will be saved on a computer that is password secure.

What if I have questions?

This research is being conducted by Tembela Boyana who is a Master's Research student at the University of the Western Cape. If you have any questions about the research study itself, please contact Tembela Boyana at The University of the Western Cape, Department of Social work Private Bag X17 Bellville 7535. Telephone number of supervisor: + 27 21 959 2843 student researchers email address: mgini@sun.ac.za

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

 Prof Catherine Schenck

Head of Department

University of the Western Cape

Private Bag X17

Bellville 7535

cschenck@uwc.ac.za

Prof José Frantz

Dean of the Faculty of Community and Health Sciences

University of the Western Cape

Private Bag X17

Bellville 7535

chs-deansoffice@uwc.ac.za

   This research has been approved by the University of the Western Cape's Humanities and Social Sciences Research Ethics Committee

REFERENCE NUMBER:

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2843 Fax: 27 21-959 2845

E-mail:nhenderson@uwc.ac.za
Ingcazelo ngoluphando

Isihloko soluphando:Omama abasebacazele abantwana babao abanesifo sika gawulayo kwi ziko lempilo elijongene nabantwana kwisibedle sase Tygerberg.yabantwan ngesifo sika gawulayo:ngokwezimvo zikanontlalontle.

lumalunga ngantoni oluvavanyo?

Isizathu sokwendza oluphando kungoba ndifuna ingaciso ephangaleleyo ngokuva ngamava wo mama abasebazisile abantwana babao ngesifo sika gawulayo, abahamb kwi kliniki yabantwa ese Tygerberg Hospital.

Zintoni izinto ezilindelekileyo kum ubangaba ndingavuma ukuthatha ingxagxeba?

uzakucelwa uba utyikitye kwisivumelwno le izakusetyendziswa njengobunqina ukuba wena unikezele ngemvume yokubuzwa kuvavanyo ngo lwimi oluthethayo.uba uyavuma umphathi uzakwendza ixesha lovavanyo nawe.

ukuthatha kwam ingxaxeba koluvavanyo luzakugcinwa luyimfihlo.

Ukuqinisekiso ngemfihlo nokungakucazi koluphando luzakwendiza ngendlela apho singanakalisi amalungelo akho njengomthathingxaxeba. Ukuqinisekisa ngokungacazwa kwakho asizukulisebendzisa igama lakho endaweni yalo sizakusebendzisa inani ukukhusela isazisi sakho. Ukuqinisekisa ngemfihlelo zonke I ingxogxo ezendziwe ngokushicilelwa ngonomathotholo woshicilela okanye impepha ezinencukaca ngawe zizakuvalelwa kwindawo ekhuselekileyo.

luthini ungcipheko loluphando?

Lungakhona ungcipheko ngokuthatha ingxaxeba koluphando.kuzakufunaka uncokole nomphandi ngendlela ozivangayo ngesio sika gawulayo nangokusacela umtana wakho. Umphandi uzakuzama kangangoko ukuhlisa uncipheko oluthe luvele xa ungaziva kakuhle ngokwase mphefumleni.uba kuthe kwavela ukudandatheka uqithiso kubantu abafundele ukuthetha nabantu abdandatheke empefumlweni luzakwendziwa.

uthini umvuzo woluphando?

Umvuzo woluphando ingaba kukubalisa komthathingxagxeba ngendlela ayihambileyo ngoku xelela umtwana wakhe. Iziohumo zoluphando zizakumceda umphandi ngokunceda abanye onontlalontle nabanye omama abasafuna ukucazela abantwana babau ngesisifo. Wonke lomsebendzi uzakwabelwana nabathathingxaxgeba noba uzabulwalwa waziswe kwilizwe lonke.

Kunyandzelelkile ndibe koluvavanyo noba ndingayeka ukuthatha ingxaxgeba naninina?

Ukuthatha kwakho ingxaxeba koluvavanyo yintando yakho qwaba. Ungayeka wakuziva ufuna.ungaketha ukungaqalisi kwa ukuqalisa. Uba uyaqubekeka uthatha ingxagxeba koluvavanyo okanye uvele uyeke , awoseze wohlwaywe ngalonto.

ushicilelo ngonomathotholo

oluvavanyo luqulathe nokushicilela wena ngonomathotholo.This research project involves making audio recordings of you. Ushicilelo luzakusetyendziswa xa kukutshelwa ushicileleo lubalwa phantsi encwadini. Umfundi lo uphandayo nomphathi wakhe bazakufikeleleka kululonke olushicilelo ngoba luzabe luvalelwe kwimfihlakalo. Ngaphezulu olunye ushicileleo luzakuhlaliswa kwi computa lufakwe amamnani emfihlelo.

Uba ndinombuzo

oluvavanyo lwendziwa ngu Tembela Boyana owendza izifundo zophandondzulu kwi ziko lemfundo ephakamileyo iyunivesitu yase Ntshona koloni. Ubanawo nawuphina umbuzo malunga noluphando cela uqagamishelane no Tembela Boyana kwi univesiti yasentshona koloni kwisebe lonontlalontle Private Bag X17 Bellville 7535. Amanani emfonomfono ngala xa ufuna ukugxebela umphathi wakhe: + 27 21 959 2843 I dilesi yelixesha yomfundi lo uphandayo : 2222687@myuwc.ac.za

uba unemibuzo ngoluphando malunga namalungelo akho ngokuthatha ingxaxeba koluvavanyo okanye uba unqwenela ukucaza ingxaki othe wavelanana nazo olungxulumene ngoluphando sicela udibane naba:

 Prof CatherineSchenck

Intloko yesebe lonontlalontle

Univesiti yentshonakoloni

Private Bag X17

Bellville 7535

cschenck@uwc.ac.za

Prof José Frantz

Dean of the Faculty of Community and Health Sciences

University of the Western Cape

Private Bag X17

Bellville 7535

chs-deansoffice@uwc.ac.za

oluphando luphunyezwe yi imvundo ephakamileyo yentshona koloni nail qumrku lezabantu lezokuhlala ngedlela eyiyo efanelekileyo isiqeba. REFERENCE NUMBER:

Annexure -B

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 786320247Fax: 27 21-959 2845

E-mail: mgini@sun.ac.za

CONSENT FORM

Title of Research Project: Mothers experiences of disclosure of their children's HIV

positive status in a paediatric unit at Tygerberg Hospital: a social work perspective

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name………………………..

Participant's signature……………………………….

Date………………………

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 786320247Fax: 27 21-959 2845

E-mail: mgini@sun.ac.za

Imvume

isihloko sovavanyo :   Omama abakhe bacazela abantwana babo ngesifo sentsholongwane ka Galwayo kwizikolempilo labantwana isibedlele esiyi Tygerbeg : ngezimvo zikanontlalontlo.

Oluvavanyo lucacisiwe kum ngolwimi endilivayo. Imibuzo yam ngoluvavanyo iphendulekile .ndiyaqonda ngokuthatha kwam ingxaxeba noba ndiyavuma ngokunganyandzelwanga ngokuzithtandela. Ndiyaqonda uba inkgcukaca zam azizukucazwa nakubanina. Ndiyaqonda uba ndinga yeka naninina ukuthatha ingxaxgepba koluvavanyo ngaphandle kokunika isizathu noba ngaphandle kokoyika iziphumelo ezingetlanaga ngam.

Igama lomthathingxaxeba………………………..

Utyikityo lomthathingxaxeba …………………………….

Umhla………………………

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 786320247Fax: 27 21-959 2845

Interview schedule with mothers

This interview plan is to address the following research question: What are the experiences of mothers who disclose their child's HIV positive experience at Tygerberg Hospital, Western Cape and what intervention tools would be suitable to enhance disclosure?

'*Title:* "Mothers experiences of disclosure of their children's HIV positive status in a paediatric unit at Tygerberg Hospital: a social work perspective".

A consent form has to be signed before you start participating on this interview.

Date of interview: ……………… Pseudonym: ………..Race…………. Age………………

Annexure D

Interview Guide

Introduction
The researcher introduces herself and thanks the participant for coming to the interview!

Profile of the participant

- Name and surname

- Age

- Race

- Level of education

- Marital status

About HIV

- How do you feel about being HIV positive?

- When did you find out about your HIV status?

- How much information do you know about HIV?

- How much information do you have about the HIV treatment

- How did you respond when you first find out about your child's HIV positive status

- Is your family aware about your HIV status and your child's status if yes please explain their response?

- How is the support system within your family?

About medication

- How is he/she responding when you give medication?

- How do you respond to your child's questioning about daily medication?

- How are you keeping the medication where you are staying?

- Are you the only one giving the child medication and if so why is that?

- What is your view on medication accuracy (adherence)? About the correct dosage and time of medication.

- Have you disclosed to your child about his/her HIV status? ,

- If no, what is the reason for not disclosing?

- When do you think will be the right time to disclose?

- What age do you think is suitable to disclose to your child? And why?

- If yes, what was your reason for disclosing to your child?

- How did you disclose? Please share?

- Did you use a book or any other tool to disclose to your child? If yes what was the tool and how did it go?

- Who in your view is the right person to tell a child's status to him/her? And why?

Interview questions for Social workers at Tygerberg hospital

Profile of the participant

- Name and surname

- Age

- Race

- Level of education

- ■ Marital status

- ■ Employment and company

- ■ Duties

- ■ How do mothers respond when you give them feedback of adherence report?

- ■ How do they respond to you when you ask about their children's behaviour about medication?

- ■ Do they share to you on how they keep their children's medication?

- ■ How do you assist the mothers on medication accuracy (adherence)? About the correct dosage and time of medication?

- ■ Do you ask the mothers if they have disclosed to their children and how do they respond?

- ■ Do you advice the mothers of when to disclose and how to disclose to their children? If yes, what could be the reason for you to do that?

- ■ Do you only speak to mothers about disclosing to their children, what about fathers?

- ■ Who in your view is the right person to disclose the children's HIV status? And why?

Annexure-D

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2843 Fax: 27 21-959 2845

E-mail: nhenderson@uwc.ac.za

Uvavanyo nomama

Oluvavavanyo lumalunga nokuva izimvo zomama abasele bebezale abantwana babao ngesifo sika gawulayo esizokwendzelwa kwisibedle sase tygereberg. Ukufumna ezinye indle zokwendzela nabanye o mama.

Isihloko : omama abasebebacazele abantwana babao ngesifo sika gawulayo abanaso abahamba kwi zikolempilo labantwana elikwisibedlele sase Tygerberg : ngokwezimvo zikanontlalontle.

Imvumelwano kufuneka ityikityiwe ngulowo uthatha ingxaxgeba

umhla: ……………… imvihlo: ………..uhlanga ………….iminyaka………………

Ingcazelo

Umphandi uzakuzazisa nomphathi ngxagxeba uzakuzazisa

Ngo mthathi ngxagxeba

- ▪ Igama nefani

▪ Iminyaka
▪ uhlanga
▪ imfundo
▪ Uthsatile

Ngesifi sika Gawulayo

▪   Uzivanjani ngesifo sika gawulayo?
▪   Wazizinini ukuba unesifo sika gawulayo
▪   Unolwazi ulungakanani ngesifo sika gawulayo
▪ statuswazivanjani mhla uxelelwa ngesifo sika gawulayo
▪ abazali nezihlobo bathini xa ubaxelela ngesisifo sika gawulayo? Kawundicacisele.
▪ Ilunga lakho liyakuxhasa phofu kwaye kanjani?

Malunga namayeza

▪ umtwana wakho wendzanjani xa umpha amayeza
▪ How do you respond to your child's questioning about daily medication?wena umphendula kanjani umtwana wakho xa ekubuza ngamayeza la awaselayo?
▪ Amayeza apho uhlala khona uwabeka phi ?
▪ Are you the only one giving the child medication and if so why is that?nguwe wedwa opha umtwana wakho amayeza ? uba kunjalo kutheni?
▪ medication.zithini izimvo zakho ngokubalwa nangendlela ekuphiwa ngayo umtwana amayeza wakhe?
▪ Have you disclosed to your child about his/her HIV status? , wawukhe wamxelela umtwana wakho ngesifo anaso sentsholongwane ka gawulayo? Uba awukamxgelelei ,kutheni?
▪ ucinga linini ixesha lokumcazela?

- kwiminyaka emungaphi ocinga umtwana anagxelelwa ngesifo anaso? Noba kutheni ucinga njalo

- khandibalisele wamcazelanjani umtwana wakho ngesigulo anso?

- Did you use a book or any other tool to disclose to your child? If yes what was the tool and how did it go?wasebenzisa incwadi ngoku wawumcazela ?ukuba kunjalo yasebendza njani?

- Kwimbono okanye kwingcinga zakho ngubani ocingba ulungile ukucazela umtwana ngesifo anaso.

OFFICE OF THE DIRECTOR: RESEARCH

RESEARCH AND INNOVATION DIVISION

Private Bag X17, Bellville 7535
South Africa
T: +27 21 959 2988/2948
F: +27 21 959 3170
E: research-ethics@uwc.ac
.za www.uwc.ac.za

Annexure -E

08 May 2017

Mrs T Boyana
Social Work
Faculty of Community and Health Sciences

Ethics Reference Number: BM17/2/6

Project Title: Mothers experiences of disclosure to their children their HIV positive status at a local hospital in the Western Cape: A social work perspective.

Approval Period: 05 May 2017 – 05 May 2018

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

PROVISIONAL REC NUMBER -130416-050