Understanding The Provision And Implementation Of Psychosocial Support Services For Children Receiving HIV Care In Ethekwini Municipality Clinic, Kwazulu-Natal.

By

Samukelisiwe Ndaba

218085686

Supervisor: Dr. Maud Mthembu

Dissertation submitted in partial fulfillment of the academic requirements

For the degree of Master in Social Work.

School of Applied Human Science,

University of KwaZulu-Natal,

Howard College Campus, Durban.

October 2020

DECLARATION

I, Samukelisiwe Ndaba declare that:

1. The research reported in this dissertation, except where otherwise specified, is my original research.
2. This dissertation has not been submitted for any other degree or examination at any other university.
3. This dissertation does not contain other persons' data, figures, tables or other information, unless specifically acknowledged as being sourced from other persons.
4. This dissertation does not contain other persons' writing unless specifically acknowledged as being sourced from other researchers. Where other written sources have been quoted, then:
    a. Their words have been rephrased, but the general information ascribed to them has been referenced.
    b. Where their exact words have been used, then their writing has been placed inside quotation marks and referenced.
5. This dissertation does not contain text, illustrations or tables copied and pasted from the Internet, unless specifically acknowledged, and the source being detailed in the dissertation and the references sections.

…………………………………….

Samukelisiwe Ndaba (218085686)

…………………………………….

Date

…………………………………….

Place

ABSTRACT

Human Immunodeficiency Virus (HIV) continues to be a global problem, with about 36.9 million people living with HIV globally, 35.1 million of whom are adults, and 1.8 million being children under the age of 15 (UNAIDS, 2019). According to UNAIDS (2019) South Africa recorded the largest number of HIV burden in 2016, with an estimated 7.1 million people living with HIV. Additionally, 320,000 of the 7.1 million HIV-infected people were children under the age of 15. Providing HIV care and therapy is crucial in helping people deal successfully with HIV pandemic, this also improves the quality of their lives. Given the possible difficulties that HIV infected children may face, it was important to examine the provision and implementation of psychosocial support services in one of the EThekwini Municipal Clinic situated in Pinetown.

The study employed a purposive and snowball sampling strategies to select fifteen participants which comprise of seven healthcare workers and eight caregivers who live and cater for children living with HIV. These selected participants were interviewed using face to face in-depth interview techniques. This study was conducted in one of the ETkwenini Municipal clinic in Durban, KwaZulu-Natal, because it is a public primary healthcare facility that provides HIV treatments and supports services to the community of eThekwini and surrounding municipalities. The findings of the study established that EThekwini Municipal Clinic renderes psychosocial interventions for children living with HIV through Indivdual Counselling and Support Groups. The psychosocial support groups deal with issues around HIV care, which includes HIV testing, counseling and treatment programs, with the aim of both capacitating children with knowledge about HIV and equally addressing the psychosocial needs of children. The study further revealed that the facility under question also employs communication tools such as “Papa Noah” which assists and facilitates communication of healthcare workers and children in a child-friendly manner and aged-appropriate style.

The study concluded that psychological support services to children in HIV care at EThekwini Municipal Clinic have a potential to improve the children's quality of life and reduce mortality. The study also learnt that healthcare workers are playing a major role in the provision and implementation of the healthcare services; however, they are subjected to poor working conditions with long working hours, which often has a negative impact on both their drive and productivity.

Key terms: Psychosocial, Children living with HIV, Healthcare workers, Caregiver, South Africa

DEDICATION

In loving memory, I dedicate this dissertation to my late lovely mother, Miss Gugulethu Precious Ndlovu. Your death has taught me to persevere and prepared me to face all the challenges with faith and humility. Although she is not here to give me strength and support, I always felt her presence that earnestly and persistently persuaded me to strive and achieve my goals. Thank you so much for your love and protection, you are highly treasured and most loved.

ACKNOWLEDGMENTS

Without the following individuals, I would not have made it to this far:

- Jeremiah 29:11 " For I know the plans I have for you," declares the Lord, "plans to prosper you and not to harm you, plans to give you hope and a future.". My journey was arduous, I thank Lord for giving me the strength, knowledge, ability and opportunity to undertake this study.
- My sincere gratitude to my supervisor Dr. Maud Mthembu, thanks for your remarkable advises and persistence in guiding me.
- To our post-graduate administrator Miss Ayanda Ntuli, thanks for your support and for persistently installing so much hope and faith in me. You are highly appreciated.
- Gratitude to my loving grandmother, Doris Ndlovu, who has helped me to become the person that I am. Her words of encouragement and push for tenacity ring in my ears always.
- To my amazing uncle, Sithembiso Ndlovu, you have never left my side. I thank you endlessly for instilling both spirit and culture of faith and perseverance in me.
- To the Ngcobo family, thank you for your love and support. I am happy to have you in my life.
- My heartfelt gratitude to my siblings for their support, love and prayers. The journey was not so rosy, thank you for your unwavering support. I am absolutely blessed to have sisters and brothers of your kind.
- To my son, Siphuthando Khumalo, thank you for being the reason why I still smile.
- The moral support of my friends is sincerely appreciated. Special thanks goes to Siphesihle Kunene, Zakhele Thobela, Sethenjwa Nduli and Glen Mahlangu, in you, I have found a family away from home. You have certainly made this journey bearable. I would also like to express my gratitude and appreciation to all those who contributed to the completion of this dissertation.

ACRONYMS

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral treatment
HIV	Human immunodeficiency virus
HSSREC	Humanities and Social Sciences Research Ethics Committee
NIMART	Nurse Initiated Management of Antiretroviral Therapy
PEPFAR	The U.S. President's Emergency Plan for AIDS Relief
PMTCT	Prevention of mother-to-child transmission
SA	South Africa
UNICEF	United Nations Children's Fund
UNAIDS	Joint United Nations Programme on HIV/AIDS
UN	United Nation
WHO	World Health Organization

LIST OF TABLES

TABLE OF CONTENTS

CHAPTER 1 – INTRODUCTION

CHAPTER 2 - LITERATURE REVIEW

CHAPTER 3 - RESEARCH METHODOLOGY

CHAPTER 4 - PRESENTATION OF FINDINGS

CHAPTER 5 - CONCLUSION AND RECOMMENDATIONS

CHAPTER 1 - INTRODUCTION

1.1. Introduction

Commitment to improving HIV treatment facilities and access to the antiretroviral medication has greatly improved the survival of people living with HIV. Consequently, HIV is no longer a lethal disease but a chronic condition requiring lifelong treatment and support. According to Li, Betancourt, Eustache, Oswald, Louis, Mukherjee and Fawzi (2015) emphasises that treatment should also concentrate not only on treating the clinical symptoms of HIV but also on the psychosocial needs of people living with HIV and their families. For that reason, this research examined the psycho-social support services given to children living with HIV by healthcare workers and receiving HIV diagnosis and care at the Pinetown Municipal Clinic. This chapter offers an overview of the study's context and reasoning, the research issue statement, the purpose and the study goals. The theoretical framework which directed the study is also discussed in this chapter. Breifly, this chapter will explain the framework of the study as a whole.

1.2. Background to the study

HIV continues to be a global concern. Globally, approximately 36.9 million people live with HIV; 35.1 million are adults, and 1.8 million are children under the age of 15 years (UNAIDS & PEPFAR, 2018). In 2016, South Africa was reported to carry the highest burden of HIV, with 7.1 million South Africans estimated to be living with HIV. Furthermore, 320 000 of the 7.1 million people infected with HIV are children under the age of 15 years (WHO, 2016). As a result of this high HIV burden, South Africa has the most extensive antiretroviral treatment (ART) program in the world, and with the implementation of the ‘test and treat’ program, the ART program has increased exponentially. Despite this success in the fight against HIV, the global figures are not yet promising. Out of the prevailing rate of HIV infection globally, only 59% have access to ART (UNAIDS & PEPFAR, 2018). This shows that a significant portion of the population cannot access ART.

Mehta, Ekstrand, Heylen, Sanjeeva, and Shet (2016) emphasized that adherence to antiretroviral treatment is an essential aspect in the health of HIV infected children; it has been found to reduce the virus, increase CD4 counts, decrease the occurrence of opportunistic infections and improve the growth and development of children. However, adherence to treatment is a challenge for most people who take chronic treatment (Mehta et al., 2016). Ngarina, Popenoe, Kilewo, Biberfeld, and

Ekstrom (2013) argued that lack of motivation, poverty and the stigma attached to being HIV-infected makes it more difficult for people to adhere to antiretroviral treatment. There is a myriad of problems faced by children living with HIV in South Africa. Stigma and discrimination are some of the issues that children living with HIV experience, and this affects their psychosocial well-being (Amzel, Toska, Lovich, Widyono, Patel, Foti, and Mark (2013). Myths and misinformation regarding HIV/AIDS have increased HIV-related stigma and discrimination. Liechty and Bangsberg (2003) refer to HIV-related stigma and discrimination as prejudice, negative attitudes, and abuse directed to people living with HIV. Srithanaviboonchai et al. (2017) argued that due to HIV-related stigma and discrimination, people who are at risk or in doubt of HIV infection fear to undergo HIV testing. This further reiterates the impact of HIV-related stigma and discrimination on the process of HIV care. Correspondingly, Chan and Tsai (2017) also noted that generally, HIV-related stigma hampers treatment and prevention efforts, given its association with reduced uptake of voluntary counseling and testing, as well as, poor antiretroviral adherence. These stigmas, stereotypes and discrimination all impact accessing healthcare services for those living with HIV.

Holistically, inadequate psychosocial support is one of the eight priority challenges for children who are living with HIV (UNAIDS, 2013). The provision of HIV counseling and support is important in helping people cope effectively with the infection, which also enhances their quality of life. Psychosocial support services include a continuum of psychological, social, educational and spiritual support that is offered to children and their families. These services help children to live, cope with life and its stressors, and subsequently help to build resilience and can only be offered when children and their families become part of the HIV care program (Hankins, 2015).

Children who live with HIV may need a comprehensive psycho-social support intervention, as well as nurturing and a responsive relationship for optimal growth and well-being. Kose, Mandiracioglu, Mermut, Kaptan, and Ozbel (2012) argued that health care workers play a significant role in providing education, counseling, and support needs to HIV infected children and their families for them to be able to cope with HIV. Zenzano, Allan, Bigley, Bushardt, Garr, Johnson, and Shannon (2011) defined healthcare workers as people who provide health services, including doctors, nurses, dentists, pharmacists, and medical specialists. For this study, a healthcare worker is defined as a person that is involved in the provision of health services to a user. These include psycho-social services professionals such as social workers, psychologists and HIV counselors.

1.3. The rationale for the study

Many HIV infected children experience severe life events that could affect their psychosocial wellbeing, such as shock about their HIV status, losing parents to HIV/AIDS-related death, and not understanding the importance of adhering treatment. Vranda and Mothi (2013) mentioned that emotional challenges, poor mental health, non-adherence to treatment, disclosure to HIV are among the challenges that HIV infected children may experience, and psycho-social support intervention for children and families is a great need to improve the coping mechanisms of those affected and infected by HIV. It was further explained that the chronic treatment conditions of children living with HIV pose a variety of possible psychosocial challenges not only to children but also to family members and healthcare workers. Amzel et al. (2013) noted that the psychosocial well-being of HIV infected children is fundamental to establishing and maintaining successful treatment outcomes and overall quality of life. With the increased rollout of antiretroviral treatment throughout the world, HIV infection is shifting from life-threatening to chronic disease. Considering the above-noted challenges that HIV infected children may potentially experience and the importance of psychosocial support services, the researcher finds it significant to conduct a study to explore the provision and implementation of psychosocial support services for children receiving HIV care in Pinetown Municipal Clinic.

Several studies have explored the negative effect of interrelated HIV specific factors on the psychological well-being of HIV infected children. Despite the improvement made in accessing HIV care and treatment, Amzel et al. (2013) revealed that HIV can still be overwhelming due to the collaboration of complex factors, particularly HIV-related stigma and discriminating, disclosure and bereavement. For this reason, Collins, Jourdain, Hansudewechakul, Kanjanavanit, Hongsiriwon, Ngampiyasakul and Duong (2010) noted that providing early and progressive age-appropriate psychosocial support intervention is needed to increase self-reliance and self-acceptance in HIV infected children and their caregivers to promote appropriate health-seeking behaviors. Moving beyond the focus of other researchers, this study will identify different types of psychosocial support services using the ecological model to assess individual-centered programs, family-centered intervention and community intervention for HIV infected children.

Additionally, this study will also reflect on programs that support or train healthcare workers to provide effective HIV care services to children enrolled for HIV care and treatment.

Providing HIV care services, particularly disclosing HIV positive status to a child, is an emotional issue for both the healthcare worker and parents/caregivers (Kidia, Mupambireyi, Cluver, Ndhlovu, Borok and Ferrand, 2014). To illustrate, Rujumba, Mbasaalaki-Mwaka, and Ndeezi (2010) reported that providing HIV care services such as HIV testing, counseling, and disclosure of HIV status to children is a challenging task for healthcare workers because they lack counseling skills and therefore find it challenging facilitating the process of disclosure. This is further compounded by caregiver's refusal to disclose the HIV status of their children. In clinics with pediatric HIV care, it is important to explore the kind of support that children living with HIV receive and how it is provided to help children cope and understand HIV better. Considering the role language play in helping children understand things, it is, therefore, important to examine/explore how health care workers communicate with children.

1.4. Research problem statement

Amzel et al., (2013) mentioned that psychosocial support services should be included in all aspects of HIV care services including treatment, care and management of all patients living with HIV in order to minimize the negative effects of HIV, through adequate healthcare provision. Therefore, it is significant to conduct a study that aims to understand the provision and implementation of psychosocial support services for children receiving HIV care services. Various researches identified a range of psycho-social encountered by children who are living with HIV. Included in these challenges are poverty, parental loss and poor mental health. Vranda and Mothi (2013) affirmed that HIV is a universal threat of implication to child and adolescent evolving as a biological, psychological and social problem.

Children enrolled in HIV treatment programs have a unique opportunity to be seen by a multidisciplinary team of healthcare workers regularly, but the question posed by this study is if they enjoy this help and the question of its efficiency. The team may consist of counselors, nurses and social workers who may conduct assessments and screening to provide a range of psycho-social support programs to support the children and their families. The . The use of child- friendly tools is important to engage with children using the language they can understand and connect with more nature. However, little is known about the psycho-social services children with HIV receive from healthcare workers and how these services are provided to children, as well as tools and strategies which are used during child counseling within the study location. This study, therefore, seeks to explore the kind of psycho-social support services provided to children and their families. The study is also on the lookout for the strategies and tools health care workers use when communicating with children in Pinetown, Durban South Africa.

1.5. Research aim and objectives

This study aims to understand the provision and implementation of psychosocial support services for children receiving HIV care from Pinetown Municipal Clinic.

Objectives;

1. To identify the types of psychosocial support services provided by healthcare workers to children in HIV care,

2. To detect challenges experienced by healthcare workers when providing psychosocial support services to children in HIV care,

3. To understand the perspectives of caregivers about the impact and quality of psychosocial support services they receive with their children in HIV care,

4. To identify the tools and strategies that healthcare workers use to communicate with children in HIV care, and

5. To determine how healthcare workers are trained and prepared to communicate with children in HIV care.

Research questions;

1. What type of psychosocial support services is provided by healthcare workers to children in HIV care?

2. What are the challenges experienced by healthcare workers when providing psychosocial support services to children in HIV care?

3. What is the caregiver's perspective on HIV care services provided by the healthcare workers to them and their children?

4. What tools and strategies do healthcare workers use to communicate with children in HIV care?

5. How are healthcare workers trained and prepared to communicate with children in HIV care?

1.6. Theoretical framework

This section presents a detailed discussion of the theory adopted by this study. The link between the aim of the study and theoretical framework is also critically presented.

1.6.1. Ecological System Theory

Ecological systems theory is also known as the ecosystem theory. The term ecology is derived from biological science and refers to the interrelations between organisms and their environments. This theory was formulated by an American psychologist, Urie Bronfenbrenner, in 1979 to explain how the inherent qualities of children and their environment interact to influence how they grow and develop (Bronfenbrenner, 1979). This theory emphasizes the importance of studying children in multiple environments in an attempt to understand their development (Kail & Cavanaugh, 2010). The researcher believes that the ecological system theory provides one approach to understand how children living with HIV access care within their immediate environment. Bronfenbrenner (1979) noted that ecosystem theory examines the complex interactions and relationships between an individual and his/her multiple social and physical surroundings during adolescent development. The interactions that individuals have with others and with these various environments are seen as key to human development. This highlights that a person's development and behavior is affected by everything in their surrounding environment. Bronfenbrenner (1979) categorized four ecological systems, namely: micro-system, meso-system, exo-system, and macro-system. These categorizations will be explored further in this study.

In outlining what ecological system theory is, Berkowitz, Ford, and Brewer (2005) specified that the ecology of human development is the scientific study of the progressive, mutual accommodation throughout the life course between an active, growing human being and the changing properties of the immediate settings in which the developing person lives. HIV can affect the emotional, psychological and spiritual well-being of children who are living with HIV. Although anyone can have mental health problems, people who are living with HIV have a higher risk of mental health conditions than people who do not have HIV. Mental health refers to a person's overall emotional, psychological and social well-being. Good mental health helps people to make healthy choices, reach personal goals, develop healthy relationships and cope with stress. Therefore, it is important for children who are HIV infected to be taken care of since mental health conditions can be treatable.

Bronfenbrenner's ecological theory applies to this study as it is appealing as a conceptual tool for guiding public mental health interventions (Bronfenbrenner, 1979). An ecological perspective offers a way to simultaneously emphasize both individual and contextual systems and the interdependent relations between these two systems, and thus offers a variety of conceptual and methodological tools for organizing and evaluating health-promotion interventions (Stokols, Allen, & Bellingham, 1996). Ecological theories emanate from many disciplines, but health research has mainly been influenced by psychology, including community and developmental psychology (Richard, Sato, Nakayama, Takahashi, & Ding, 2011). Thus, the researcher believes that the use of ecological theory is potentially useful for guiding public mental health interventions since this study will be focusing on the provision of psychosocial support services provided to children in HIV care. The researcher will get an understanding of how healthcare workers go about in promoting the psychosocial well-being of children in HIV care. This theory is applicable in this study as it has the appropriate conceptual tools to analyse the effect of health-related and external context (environment) on the wellbeing and care process of children living with HIV.

Three ecological system models are relevant for this study, namely: microsystem, mesosystem, and macrosystem, to fully understand the provision and implementation of psychosocial support services to children receiving HIV care.

(a) Microsystem

The microsystem is the system closest to the person and the one in which they have direct contact with, for example, family, school, friends. Fundamentally, the microsystem is the immediate environment in which a person is operating. The first contact for children living with HIV or any child is their family environment; this includes interactions with parents and siblings. Family is viewed as the basic institution for a society (Mturi, 2012). A microsystemic change takes place as soon as caregivers discover that their child is HIV infected. Issues of HIV disclosure to the child and the whole change in the child's lifestyle, including taking a daily dose, are likely to have an impact on all other subsystems. At the individual and familial level, the presence of HIV often indicates financial frustration, which has devastating effects on the financial position of the family. In Limpopo province, Mafune, Lebese, and Nemathaga (2017) found that caregivers of children on antiretroviral treatment experience financial burdens because of transport costs needed to comply with follow-up date; insufficient money for food and clothing; pocket money for lunch boxes during school hours; and time lost while waiting for consultations.

(b) Mesosystem

When microsystems interact, a mesosystem is formed and encompasses the relationship between two or more settings, for example, the relationship between school and friends. The mesosystem is where a person's microsystems do not function independently but are interconnected and assert influence upon one another. These interactions have an indirect impact on the individual. Urdang (2006) refers to the mesosystem to the community, which contributes extremely in the acting out of leading HIV/AIDS issues. Living with HIV openly is still an offensive issue in many communities in South Africa, particularly. In such a way that people who are living with HIV experience stigma and discrimination from their family members or community. A study in Limpopo Province showed that caregivers indicated that fear of stigmatization and prejudice made them delay seeking HIV-related healthcare for their children (Ahonsi et al., 2014). However, some caregivers may receive support from their relatives, neighbours and community at large. It is, therefore, important to understand how HIV positive children's involvement at a mesosystem contributes towards their adjustment or maladjustment to their diagnoses.

(c) Macro-system

The final ecological system identified by Bronfenbrenner (1979) is that of the macro-system. The macro-system consists of larger societal structures and values, for example, social, cultural, political, religious etc. Macro-system doesnot directly impact the life of an individual HIV infected child, but rather society as a whole. Illness, disability, and death associated with the HIV/AIDS epidemic affect populations at multiple levels and in multiple ways. Besides, with the burden of caring for the sick and dying, family social and economic resources become strained. Businesses, schools, hospitals, and other institutions lose valuable personnel, and absenteeism decreases productivity. Food security is threatened, the result of effects on the production of food and the ability of households to afford a nutritious diet. School enrolments decline, and high death rates undercut the payoffs to investments in education among young adults. The economic costs of addressing HIV and its effects, both in the health sector and in other sectors of the economy, divert resources from other important needs and investments critical to economic development. The demographic structure of the population is affected, challenging systems for supporting dependent populations such as children and the elderly. In many cases, the impact of the HIV/AIDS epidemic on families, communities, and countries has concomitant effects that influence the course of the epidemic, for example, poverty and the breakdown of social and economic systems impair community systems that could help curb the spread of infection. The inclusion of ecosystems theory safeguarded that systemic influences were taken into consideration during the research process.

1.7. Research Methodology

This study employed a qualitative research method, Fortune, Reid, and Smith (1999) describes the qualitative approach as the excellent method that researchers can use to gain a first-hand, comprehensive understanding of phenomena of interest utilizing a flexible strategy of data collection as the study proceeds. This study was qualitative because it aimed to study human-beings in their health settings. This study was conducted in Pinetown Municipal clinic in Durban, KwaZulu-Natal, because it is a public primary healthcare facility that provides HIV and TB related treatment, care and support services to the communities of eThekwini and its surrounding municipalities which also has a large cohort of children enrolled for HIV care services. To answer the key research questions of this study, a qualitative research approach informed by interpretive paradigm was used. Interpretivism calls for the exploration and understanding of phenomena by interacting with the participants (Ritchie, Lewis, Nicholls, & Ormston, 2013).

For this study, purposive sampling and snowball sampling strategies were used to select fifteen (15) participants- seven healthcare workers and eight caregivers were selected and individually interviewed. According to Palinkas, Horwitz, Green, Wisdom, Duan and Hoagwood (2015), purposive sampling is a non-probability sample that is selected based on the characteristics of a population and the objective of the study. The researcher used purposive sampling to select healthcare workers who provide HIV care services for children aged 6 to 18 years. Utilizing a purposive sampling strategy was convenient for this study as it helped the researcher in ensuring that participants who were selected were likely to provide meaningful and relevant information based on their characteristics. In the recruitment of healthcare workers, the researcher also made use of snowball sampling. Palinkas et al. (2015) defined snowball sampling as a non-probability technique in which the samples have traits that are rare to find. Pinetown municipal clinic is a large clinic with many healthcare workers who provide different services, including HIV care for the different age groups. So in the recruitment of healthcare workers, those the researcher approached first made referrals to other healthcare workers that they work within providing HIV care services to children. Using snowball sampling was beneficial to the researcher; referrals made it easy for the researcher to find participants who meet the selection criteria.

In the recruitment of caregivers, the researcher used a purposive sampling strategy. Caregivers of children aged 6 to 18 years receiving HIV care services were selected, particularly those who have been providing care for the same child for at least a year or more were typically selected to understand their perspectives about the impact and quality of the psychosocial services they receive as well as the support provided to their children in HIV care. Snowball sampling was also used in recruiting caregivers, as the researcher asked for help from healthcare workers in the identification of caregivers of children age 6 to 18 years. The usage of these two sampling strategies made things much easier for the researcher to recruit, and it saved time as the researcher was approaching participants who she knew already met the criteria.

Gatekeeper permission was obtained from eThekwini Municipality Health Units and from the KwaZulu-Natal Department of Health to conduct the study. Ethical clearance for the study was obtained from the Humanities and Social Sciences Research Ethics Committee (HSSREC) at the University of KwaZulu-Natal. Informed consent was obtained appropriately from participants. Qualitative data were collected using semi-structured individual interviews, where narrative interviewing techniques were engaged to explore the 'life stories' of healthcare workers and caregivers. Interviews were conducted at the clinic offices, and the space participants considered convenient and private. The interviews were conducted in IsiZulu and English, and in selecting the appropriate language, participants’ choices informed the choice of language. To obtain a clear account of the narratives, extensive notes were taken due to healthcare workers' and caregivers’ unwillingness to have the interview sessions tape-recorded. Upon completion, the interviewing notes were transcribed, shown and discussed with the participants for accuracy and completion. This process was repeated before conducting the next interview. Then for data analysis, the data collected was translated and transcribed accordingly. The researcher made use of thematic analysis. Braun and Clarke (2006) describe thematic data analysis as a method for identifying, analyzing, and reporting patterns of themes within data. Furthermore, thematic analysis helps to identify themes that are recurrent within the narrative of participants. Through the usage of the thematic analysis method, the researcher was able to summarise all the views that have been collected from the participants.

1.8. The significance of the study

There are few research studies carried out on the provision of psychosocial support services for HIV infected children enrolled for HIV care services clinics. The provision of HIV care services includes HIV testing, counseling, disclosure, adherence to antiretroviral treatment and preparing children for transitioning into adult care, mental health support etc. As a result, little is known about how healthcare workers go about in providing HIV care services, and few studies have focused on the availability of communication or strategies that healthcare workers use to communicate such information effectively. Madiba and Mokwena (2012) argued that there is uncertainty between health care workers and caregivers on who is the 'best person' to reveal the HIV status to the child. Madiba and Mokwena (2012) noted that caregivers often do not have the skills to initiate HIV communication with children. Therefore, the results of this study will give clarity in terms of psychosocial support services available for HIV infected children, their caregiver and how disclosure is being handled. Moreover, gaps that could potentially exist will be identified to strengthen the provision of psycho-social support services and other needs for families affected by HIV.

1.9. Potentail limitations of the study

According to De Vos, Delport, Fouché, and Strydom (2011), limitations exist in all research studies even when the research is carefully planned; due to this, they need to be stated clearly. The limitation of this study is that healthcare workers might have hesitated to participate because they thought the researcher wants to evaluate if they are doing their job or not. However, during the recruitment process, the researcher kept potential participants aware of the main aim of the study. Due to high caseloads, healthcare workers did not have much time to participate. The researcher tried by all means to conduct an interview session that was not longer than an hour. Due to transportation costs, caregivers noted that they could not come for interviews at any day. The researcher then allowed caregivers to choose suitable dates for interviews, and the dates chosen were the ones where caregivers had clinic appointments for collecting HIV treatment for their children.

1.10. Operational Definitions

(a) Healthcare workers

Zenzano et al. (2011) define Healthcare workers as people who provide health services in terms of any law, including the doctors, nurses, dentists, pharmacists, and medical specialists. For the study, a Healthcare worker is defined as a person that is involved in the provision of HIV care services and psychosocial support services to children who are enrolled in health institutions for HIV care.

(b) Caregiver

A caregiver is a person who takes primary responsibility for someone who cannot take full care of himself or herself, which may be a family member, a trained professional or another individual (Legal, 2012). For this study, a caregiver is someone who is taking care of a child who has a chronic illness, who helps with managing medication and talks to the healthcare workers on behalf of the child who is ill.

(c) Children

According to the Constitution of the Republic of South Africa (1996), the term 'Children' refers to persons under the age of 18. For this study, a child is seen as an individual under the age of 12 years old, while an adolescent is someone older than 12 years (Tyabazayo, 2009).

(d) HIV

HIV stands for 'Human Immunodeficiency Virus' and refers to the virus that attacks the immune system, negatively affecting its ability to fight infections. People can live with HIV for years without feeling sick. A person will be said to be HIV positive when HIV antibodies are found in their blood (Alan & Sunter, 2000).

(e) AIDS

AIDS stands for 'Acquired Immuno-Deficiency Syndrome' and is caused by HIV. AIDS presents itself as several serious illnesses that the infected individual will eventually struggle with, as a result of the destruction of their immune system (Dyk & C, 2010). The diagnosis of HIV changes to a diagnosis of AIDS when the individual's CD4 count drops below 200 (Alan & Sunter, 2000).

(f) HIV care

Kaplan et al. (2015) refer to HIV care as a non-antiretroviral therapy clinical services, prevention and treatment of HIV-related infections. The non-clinical services that are in combination with antiretroviral therapy contribute towards the reduction of the rates of ill health and HIV-related deaths and increase the well-being of people who are living with HIV. Care and support to HIV infected children are important to facilitate immediate access to treatment when a child is diagnosed with HIV; to support adherence to treatment to attain viral suppression for children living with HIV. This is important for the sake of their health and to prevent infecting other people with HIV; to enhance the prevention and management of HIV-related infections and; to enhance coping with the challenges of living with HIV.

(g) Psychosocial support

The Psychosocial Framework of 2005–2007 of the International Federation defines psychosocial support as "a process of facilitating resilience within individuals, families and communities by respecting the independence, dignity and coping mechanisms of individuals and communities. Psychosocial support promotes the restoration of social cohesion and infrastructure" (Botton, 2008;95). Hilary (2003) enlightened that psychosocial support services can include mental health counseling, education, spiritual support, group support, and many other such services.

1.11. Structure of the Thesis

This thesis comprise of five chapters, which are summarized as below:

Chapter 1 – Introduction: This chapter presents an introduction to the study, including background and rationale, the main aim and the definitions of key concepts. It also highlights the theoretical framework and methodology employed to carry out the study as well as its rationale

Chapter 2- Literature Review: This chapter presents the contemporary argument about HIV care. Furthermore, the gaps existing in the literature were presented and debated to justify the reason for conducting the current research.

Chapter 3 – Methodology: The chapter outlines the research methodology employed in this study, which includes research design, sampling techniques, data collection techniques, issues of reliability and validity, data analysis and interpretation, ethical considerations, value and limitation of the study.

Chapter 4 - Data Analysis and Interpretation: In this chapter, collected data is presented, discussed and interpreted using verbatim quotations from the study participants. Findings were also presented based on the identified themes.

Chapter 5 - Recommendations and Conclusion: This chapter presents the summary and conclusion for the study, as well as recommendations for future research.

1.12. Conclusion

This chapter presented the background and rationale of the study, outlined the study aim, objectives and research questions. The problem statement was elaborated; the applicable theoretical framework and methodology employed were briefly discussed. The researcher additionally presented the structure of the thesis.

CHAPTER 2 - LITERATURE REVIEW

2.1 Introduction

The literature review chapter demonstrates the relationship between the present research and previous research. Moreover, the review of the literature shows the relevance of the research problem statement. The literature review will commence with a review of the current literature on HIV and children globally and in South Africa. The discussion will give a critical review of the contextual background on progress achieved to date in the management of HIV among children globally. Existing gaps, opportunities and achievements will be discussed as well. As part of this discussion, a review of the South African legislation and policies applicable to children and families of children who are living with HIV will be critically discussed to understand South Africa's legislative framework supporting children who are living with HIV and their families.

Families are the first line of support and protection for children. Therefore, the literature about the status and composition of families in South Africa, as well as the coping mechanisms of families in the era of HIV, will be explored. The discussion will point to the difficulties families experience as well as the family's abilities to provide psycho-social support to children who are living with HIV. The third section of the chapter will review the literature on specific psycho-social needs most children with HIV experience. This will be followed by a discussion about the psycho-social interventions that are provided in HIV care services to support children and families. In this study, psycho-social support encompasses ongoing counseling for children who live with HIV, treatment adherence support, assessment of mental health issues, HIV disclosure, family support and educating children about HIV.

2.2 HIV and Children in contemporary times

HIV remains a global health issue. In 2017, close to 36.9 million people were living with HIV, 35.1 million were adults, while 1.8 million were children under the age of 15 years (UNAIDS & PEPFAR, 2018). Amongst 36.9 million, an estimation of 21.7 million people living with HIV was on antiretroviral treatment, while 9.4 million people did not know their HIV positive status. Amongst 1.8 million children age 0-14 years living with HIV, only 52% of these children are accessing antiretroviral treatment. Therefore, access to antiretroviral treatment remains a challenge that could increase AIDS-related mortality. Access to antiretroviral treatment is important to control viral replication and reduce viral load, thereby increasing longevity (Azétsop & Diop, 2013).

Ever since the widespread of HIV/AIDS started, close to 35.4 million people have died, and in 2017, close to 940, 000 people died from HIV/AIDS-related illness globally (UNAIDS, 2019). It is encouraging to note that, to date, HIV/AIDS-related deaths have decreased by more than 50% since its peak in 2004. In 2018, around 770 000 (570 000–1.1 million) people died from AIDS-related illnesses worldwide, compared to 1.7 million (1.3 million–2.4 million) in 2004 and 1.2 million (860 000–1.6 million) in 2010 (UNAIDS, 2019). In 2004, the rollout of antiretroviral treatment was initiated in public sectors, so that people living with HIV can live a long healthy life and reduce AIDS-related deaths (Johnson et al., 2012). In support, Khan (2015) stated that the world's assurance in increasing access to antiretroviral treatment has expressively improved the survival of people living with HIV.

The massive number of people who are living with HIV are situated in low-middle income countries, and Africa is mainly in the region that is knockout hard by HIV. East Africa and Southern African region has the highest number of 19.6 million people living with HIV, of whom 66% are adults, and 59% are children on antiretroviral treatment (UNAIDS & PEPFAR, 2018). The statistics of people on antiretroviral treatment indicate that regardless of a large number of people living with HIV in East and Southern Africa, the provision and availability of antiretroviral treatment has increased as well as more than half of people living with HIV are on treatment. In support, UNAIDS and PEPFAR (2018) noted that in 2016, an estimation of 11.7 million people was on antiretroviral treatment in the region. This is a three-fold increase from the 2010 numbers and represents 60% of people living with HIV in East and Southern Africa.

Moreover, in 2016, the number of children on HIV treatment increased to 51% from 19% in 2010. This shows that in the past years, the rollout of antiretroviral treatment has been scaled-up in East and Southern Africa drastically. However, in the year 2017, close to 380 000 people have died due to HIV/AIDS-related death and 800 000 were newly infected with HIV. This shows that HIV/AIDS is still a challenging epidemic that still forms part of the health reality of East and Southern Africa.

HIV in West and Central Africa is less prevalent than in East and Southern Africa. In West and Central Africa, close to 6.1 million people were living with HIV, of which 41% were adults, and 26% were children who were on antiretroviral treatment in 2017 (UNAIDS & PEPFAR, 2018).

The number of people on antiretroviral treatment reveals that regardless of a smaller number of people living with HIV, people in West Africa and Central Africa do not access antiretroviral treatment services as much as other regions of the continent earlier discussed. Insufficient antiretroviral treatment services makes West and Central Africa the regions that are most affected by AIDS-related deaths globally. In 2017, close to 280, 000 people died due to HIV/AIDS-related death; on the other hand, there were 370 000 newly HIV infected the same year. This further reiterates the importance of increasing access to antiretroviral treatment in the region.

Paying attention to the regional status, East and Southern Africa are known as the hardest-hit regions in Africa, with South Africa having the most significant burden of HIV in the world. In the year 2017, close to 7.2 million people were living with HIV, of which 280,000 were estimated to be children under the age of 15years (UNAIDS & PEPFAR, 2018). Amongst the 7.2 million people living with HIV, 61% were adults, and 58% were children (UNAIDS & PEPFAR, 2018). Furthermore, the statistics show that more than half of both adults and children living with HIV are accessing antiretroviral services. In support, UNAIDS and PEPFAR (2018) mentioned that globally South Africa provides the most extensive antiretroviral treatment services. In 2018, UNAIDS and PEPFAR reported that 4.4 million of 7.2 million people were receiving antiretroviral treatment in South Africa. This shows that more than fifty per-cent of the infected people are on treatment, which is a positive sign that South Africa is on track with the fight against HIV (UNAIDS & PEPFAR, 2018). However, close to 110 000 South Africans have died due to HIV/AIDS-related death and 270 000 people who were newly HIV infected. In the next section, a specific discussion on the progress and developments made to support children who are living with HIV is presented and debated.

2.3 Progress and developments in managing HIV in children

South Africa is one of the nations that is hardest hit by HIV, as stated earlier. However, significant progress has been made in the treatment of HIV in general and in providing specialized care for children living with HIV. Prior to 2004, the introduction of antiretroviral treatment programmes in South Africa was delayed as a result of political interference. Simelela, Venter, and Daniel (2014) pointed out that in the past decades' limited information was given regarding HIV transmission dynamics, the preservation of the response to HIV throughout the 1980s was the provision of condoms and a ‘safe-sex’ edification approach hindered by stigma, fear and other behavioural and social factors. Many lives were lost because of the failure to accept the use of available antiretroviral treatment to prevent and treat HIV/AIDS in a well-timed manner. Supported by Simelela, Venter, Pillay, and Barron (2015), as mentioned that in the past decades, the South African government's response to HIV/AIDS was regarded as "denialist" because antiretroviral treatment was not provided to people in need which resulted in a number of deaths. While this period records the highest number of HIV related deaths, it also impacted children who were living with HIV; basically as a result of parent-to-child transmission negatively.

South Africa has an exceptionally severe epidemic of HIV and AIDS. One in six adults and children infected with HIV globally are South Africans. Close to half of the estimated three million orphans in the country have lost their parents to HIV/AIDS-related diseases (WHO, 2014). AIDS is the leading cause of death in children and women. HIV/AIDS-related illnesses cause a third of all deaths of children under the age of five. Close to 30 percent of pregnant women attending antenatal care are HIV-positive (WHO, 2014). Most children acquire HIV from their mothers during pregnancy, birth or through breastfeeding, and, without care and treatment, most of these babies would die in the first two years of life. Many died at home before they have been adequately diagnosed and treated (UNICEF & WHO, 2018).

The Department of Health, UNICEF and other partners are working on a comprehensive approach to protect children from HIV and prolong their lives. This means providing a complete package of services in the community, linked to health clinics, has become essential. The package includes HIV testing for pregnant women, antiretroviral drugs to reduce mother-to-child transmission, early diagnosis of HIV infection in babies, and early treatment, counseling, and support for women and children who are infected (UNICEF & WHO, 2018). As a response to the global call to end new HIV infections in children by 2015, South Africa has developed an operational plan to integrate mother and child healthcare and Prevention of Mother-to-Child Transmission (PMTCT) programmes in the country with support from UNICEF (WHO, 2014**)**. The Action Framework for the Elimination of Mother-to-Child Transmission of HIV has clear baseline indicators, targets and a user-friendly monitoring system. It is also linked to the new National Strategic Plan for HIV/AIDS, STI, and TB for 2012–2016 (UNICEF & WHO, 2018).

In Addition, South Africa has initiated the provision of antiretroviral treatment to mothers living with HIV during pregnancy and post-pregnancy (WHO, 2018). Globally, between 2010 and 2018, close to 1.4 million HIV infections among children were prevented due to the implementation of HIV prevention programmes (UNAIDS & PEPFAR, 2018). Thus, allowing nationals to access antiretroviral treatment was the smartest call to make in fighting against HIV as children born with HIV were less likely to see their second birthdays due to the unavailability of antiretroviral treatment in previous decades. Prendergast, Tudor-Williams, Jeena, Burchett, and Goulder (2007) declared that it is vital for HIV infected children to be diagnosed early to allow the timely start of appropriate treatment, reduce morbidity and mortality, guide decisions related to child nutrition and improve the quality of life of HIV-infected children. Supported by Allison et al. (2011), as mentioned that early diagnosis of HIV infection in children is important as it provides the alleyway to proper care, treatment and support. In comparing the HIV prevention progress with the past decades, Bernays, Jarrett, Kranzer, and Ferrand (2014) revealed that in the past years, children born with HIV experienced unavoidable death while those born with HIV now have access to antiretroviral treatment which increases the number of children surviving to the adolescent stage and beyond. This shows that policymakers and healthcare workers working in pediatric HIV care are vigilantly optimistic.

The test and treat programme allows children who are HIV infected to start antiretroviral treatment as soon as they are discovered HIV infected. Violari et al. (2008) noted that antiretroviral treatment helps HIV infected children to preserve, enhance, and reconstitute their immune system and therefore reduce the risk of opportunistic infections such as tuberculosis; to suppress HIV replication; to restore their growth; to improve mental functioning, and enhance their quality of life. South Africa has genuinely made significant progress in fighting HIV infection among children. HIV infected children deserve to live a healthy, normal and fulfilling life just like any other children regardless of their HIV status. Through different programmes made in managing HIV in children, it is perceived that children who are infected by HIV are not left behind in the provision of life-saving treatment in South Africa. It is well known that children in South Africa are significant, and they have been regarded as an autonomous being; as a result, they have their fundamental rights that are found in Children's Act, which fundamentally is the right to life (WHO, 2014). Some of the rights that are regarded as necessary for children irrespective of their HIV status are discussed below.

2.4 The rights of children in the context of HIV in South Africa

The issue of children and HIV is often conceptualised predominantly as a health problem. However, this assumption disregards the social and structural dynamics associated with the disease. Many children living with HIV face a myriad of problems. Stigma, discrimination, social isolation, poverty, child abuse, treatment adherence, grief and bereavement are some of the issues children who live with HIV experience, and it affects their psychosocial well-being (Amzel et al., 2013). This section will explore the various South African legislation protecting children and advancing their well-being.

In South Africa, all children are protected by the Constitution and the United Nations (UN) Convention on the Rights of the child, 1992. The WHO Constitution (1946) stated that children have their general rights regardless of their health status, which includes the right to equality and non-discrimination, the right to privacy and dignity**.** The Constitution recognised that children need special protection. Section 28 (c) of the Constitution states that every child has a right to basic health care services (Tyabazayo, 2009). This means that children who are living with HIV have a right to access antiretroviral treatment in health care facilities. Allison et al. (2011) noted that antiretroviral treatment could keep the child healthy and help them maintain a normal, fulfilling life with HIV. However, South African Statistics on HIV/AIDS have revealed that out of 280 000 children living with HIV, only 58% are on antiretroviral treatment (WHO, 2014). This picture indicates inequality in accessing treatment. However, some researchers argue that social barriers such as non- disclosure prevents young people from accessing life-saving treatment. Bernays et al. (2014) pointed out that due to HIV-related parental death, most children are then taken care of by their grandparents or relatives who are most likely unaware of their HIV positive status, therefore, preventing them from accessing antiretroviral treatment.

Article 12 on the United Nations Convention on Rights states that children have the right to express views and have them taken seriously into consideration. This means that children have a right to participate, get involved in raising awareness by talking about the effects of HIV/AIDS in their lives and their families. Children living with HIV can participate in HIV/AIDS developmental programmes, become peer educators within and outside schools, but due to stigma and discrimination, children are less likely to be part of HIV/AIDS awareness programmes (UNAIDS, 2005). Vranda and Mothi (2013) affirmed that HIV/AIDS-related stigma and discrimination are still a global challenge in local communities. This was linked with the struggle of disclosure of HIV status due to fear of rejection and isolation. Due to the issue of stigma and discrimination, the right of children to participate in an HIV/AIDS setting is violated as children are likely to be unaware of their HIV status. Christie and Pierre (2012) mentioned that caregivers delay disclosing HIV status to their HIV infected children because they fear the consequences of stigma and discrimination as their children may tell others. Hence the child's right to express views about HIV/AIDS becomes effortlessly violated.

Article 2 on the United Nations Convention on Rights states that children have the right to non-discrimination. This means that no matter who you are, whether you are living with HIV or not, you should not be treated unfairly on any basis (Abramson, 2008). HIV discrimination is a complex social issue; children of a parent who are living with HIV are often victims of stigma and discrimination as they are often assumed to be HIV infected. As a result of discrimination, children are rejected, isolated, and they are denied access to education, health or social care services or community life (Vranda & Mothi, 2013). Discrimination also increases the prevalence by making children from certain clusters like children living in distant or rural areas where services are less accessible, more vulnerable to HIV infection. These children are thus doubly victimized. Due to stigma and discrimination, Vermund et al. (2014) acknowledged that caregivers of HIV infected children prefer keeping their children's illness to themselves, which prevents them from receiving support from family and friends. However, receiving necessary support services is important to strengthen the well-being of the child and caregiver, even though children living with HIV now live longer and healthier lives due to the more extensive accessibility of antiretroviral treatment (Cloete et al., 2010). As enriched in Bill of Right, it also important for them to live a happy, normal life like those living without HIV. Since HIV is known as a life-threatening infection, children living with HIV must be provided with necessary psychosocial support. Some of the psychosocial support services provided to children receiving HIV care are discussed in the next section.

2.5 The provision of psychosocial support services for children receiving HIV Care in health establishments.

According to WHO (2014), 58% of children living with HIV are on antiretroviral treatment in South Africa. This shows that accessing antiretroviral treatment is pointedly lower on children than on adults. To increase children's access to antiretroviral treatment, Van Rooyen, Strode, and Slack (2016) suggest that HIV counseling and testing service for children should be improved so that HIV infected children could be diagnosed early and as such be exposed to effective care which will, in turn, reduce HIV/AIDS-related deaths among children. For this study, HIV care refers to the services that are provided by healthcare workers to every individual in HIV care, including clinical and non-clinical care such as counseling, support with HIV disclosure, family support and mental health services.

HIV is one of the chronic illness that needs care and support, Skovdal, Ogutu, Aoro, and Campbell (2009) mentioned that chronic illnesses are a long-term illness that calls for careful management and adjustment by the HIV infected person and their caregivers. Therefore, the provision of HIV care service and psychosocial support is significant as it enables fast access to antiretroviral treatment when a child is diagnosed with HIV, it supports adherence to treatment to conquer viral suppression in children living with HIV (Mugavero, Amico, Horn, & Thompson, 2013). In addition, Jose et al. (2018) mentioned that the provision of HIV care services and psychosocial support is important to HIV infected people as it helps them to maintain their health and prevent HIV infection to other people; it also helps to improve the prevention and management of HIV interrelated infections; assist people living with HIV to cope with challenges that may arise. This shows that it is important for children living with HIV to receive appropriate HIV care services and psychosocial support so that HIV will be diagnosed, and treatment prescribed early. This section will unpack the various HIV support services offered children, the psychosocial issues that emanate from the process are also highlighted.

2.5.1 Facilitating child-friendly HIV counselling and testing

The provision of HIV care services begins with HIV infection diagnosis through HIV testing. According to Lawrence, Struthers, and Van Hove (2015), HIV testing requires counselling by a trained counsellor. HIV counselling is a confidential discussion between a counsellor and a client to enable the client to make an informed decision on HIV testing or providing information on the HIV test result. Rai, Bruton, Day, and Ward (2018) pointed out that HIV testing and counselling is a process that enhances a person's understanding of HIV/AIDS and helps the person make informed choices for the future. Gardner, McLees, Steiner, del Rio, and Burman (2011) noted that when providing counselling to children living with HIV, the counsellor must be assessing children's knowledge and their understanding of HIV/AIDS and be able to give age-related HIV/AIDS information to the child. In HIV testing, counselling unfolds in two processes, namely pre-test counselling and post-test counselling.

Drawing from SAG (2005) Children’s Act no 38 of 2005 state that children must be provided with proper pre and post-test counselling by properly trained counsellors that will be able to work with different developmental stages of childhood and adolescence. Deeks, Lewin, and Havlir (2013) noted that when providing counselling, counsellors should be aware of the important connections between successive stages of development and that counselling should be attuned to the developmental level of the child, rather than being determined only by the chronological age of the child. Strode, Toohey, Singh, and Slack (2015) discovered that for HIV testing, children who are under the age of 12 years are most likely to be accompanied by their parents or caregivers. Therefore the circumstances surrounding the initiation of the HIV test must be acknowledged.

Flowing from above, these processes are not usually easy to follow through as it requires a skilled counsellor who will be able to do the following as recommended by WHO (2011): Create a safe space that is private and quiet, establish a relationship with the child by showing an interest in his or her world, meet the child at his or her level, use language that is appropriate for the child's level of insight, understanding, education and emotional readiness. Show respect for the child's needs, feelings and responses. Listen attentively to what the child is saying. Help to put the child's feelings into words. Be calm, unhurried and caring during their interactions with the child. Find appropriate ways to help a child express himself or herself, e.g., stories, books, drawings or games.

One of the critical issues for HIV infected children is to access HIV testing and receive HIV care services using an approach that will be easy for the children to understand and engage in HIV care settings. Amongst the reasons why HIV infected children are not receiving HIV care services, according to Van Rooyen et al. (2016) included that parents fear of stigma and discrimination as their own HIV status will become known. Rwemisisi, Wolff, Coutinho, Grosskurth, and Whitworth (2008) revealed that parents are anxious about HIV testing of their children because they are unsure of their own HIV status. However, Rwemisisi et al. (2008) pointed out that for children living with HIV to benefit from HIV care services provided in a health establishment, they need to know that they are HIV infected, be involved in regular HIV care and receive effective antiretroviral treatment therapy.

According to the Children's Act no 38 of 2005, children who are above the age of 12 years may independently test for HIV while those who are under the age of 12 years may only test if they understand the benefits, risks and social implication of HIV testing or be accompanied by parent or caregiver for HIV testing. Van Rooyen et al. (2016) emphasized that children who must be allowed for HIV testing are those who meet the aged standard. The child must understand the benefit of HIV testing such as access to antiretroviral treatment and knowledge of HIV prevention, understand the risks such as the trauma of receiving HIV positive results and lastly understand social implications, as well as, HIV-related issues like stigma and discrimination that may come with HIV testing. Thus, it is significant that healthcare workers consider the child's condition such as age, HIV knowledge and experience and provide HIV counselling to the child before HIV testing and status disclosure.

After the procedure of HIV testing and counselling, HIV disclosure comes into place. Wilfert et al. (1999) defined HIV disclosure as a gradual process of giving children age-appropriate information regarding their illness, leading to full disclosure when the child has the cognitive and emotional maturity to process this information. National guidelines stipulate that HIV infected children should be told about their illness and treatment gradually in an ethically sensitive way with the agreement and participation of the child’s parent or caregiver (WHO, 2011).

Corneli et al. (2009) highlighted that HIV disclosure is important because it improves adherence to antiretroviral treatment and helps people with HIV cope with the illness and HIV related issues such as stigma and discrimination. However, HIV disclosure is still a globally debated issue within healthcare providers and caregivers. Some of the issues debated are at what age can a child’s HIV status be disclosed to the child, who should disclose the status; and, what processes must be followed and what factors must be considered in this process. Several studies, including Rujumba et al. (2010) have shown that there is a confusion between healthcare workers and caregivers on who is the best person to disclose HIV positive status to the infected child. Lester et al. (2002) revealed that the confusion of “Who to disclose” is related to the lack of counselling skills or communication skills between healthcare workers and caregivers.

Information about HIV and antiretroviral treatment among children and adolescents hinge on open communication with them about their health and treatment. Therefore, when working with children and adolescence, excellent communication skills are the key. Kajubi, Whyte, Muhumuza, Kyaddondo, and Katahoire (2014) noted that when communicating with a child, one must consider their different abilities, the child's needs at different ages and must be central to the child age-appropriateness. Tindyebwa et al. (2004) detailed that when communicating with the child in HIV care, the communication should be in a simple language based on the child's age and understanding to allow the child to participate. There is evidence to suggest that there are various child-friendly tools that are used by healthcare workers to communicate with children. In some context, Sariah et al. (2016) revealed that healthcare workers use tools such as toys and books to communicate with children about HIV. Sariah et al. (2016) reported that at times healthcare workers use a book called "Policeman" where health care worker talks to the child about the role of the policeman in protecting citizens, the aim is to emphasize the importance of adherence to treatment.

Furthermore, Kincaid, Kincaid, and Cheney (2009) mentioned that health communication tools are intentionally designed to simultaneously address multiple psychosocial and behavioural issues that may act as barriers to risk reduction or as motivators of service. Thus, communication tools are significant in helping children to become familiar with the information that needs to be gathered in HIV care and treatment. In providing HIV care, there are different challenges that healthcare workers experience, which affects their way of working.

2.5.2 HIV disclosure support: The psycho-social experiences of living with children

Years ago, antiretroviral treatment was limited in South Africa; most children living with HIV failed to survive into adulthood because the care system could not first diagnose their status and treatment was not given to them. Access to antiretroviral treatment for children living with HIV and the introduction of programmes like prevention of mother-to-child transmission has led to a radical reduction in HIV/AIDS-related death of children and adolescence (Vreeman et al., 2014). However, there are still HIV-related challenges that children living with HIV experience that are likely to affect their psychosocial well-being and development. Nasaba et al. (2013) defined psychosocial well-being as the social and emotional well-being of a child and the ability to fulfill his/her potential as a human being. It includes many areas of the child’s life: the psychological aspects, such as emotional, cognitive, mental health and spiritual issues, while the social aspects refer to relationships with others, the environment and the society. These aspects of well-being influence physical health and how children participate in their treatment, adherence or disclosure issues. Vreeman, McCoy, and Lee (2017) mentioned that ever since HIV was diagnosed, people who are HIV infected have experienced various psychological and behavioural challenges. Challenges such as stigma and discrimination, disclosure, mental health issues and adherence to treatment schedule are discussed below.

2.5.2.1 Stigma and Discrimination

Stigma and discriminatory attitudes have a negative impact on HIV prevention, testing, and treatment, as well as on family and social networks. Living with HIV is now a different experience compared to what it was twenty years ago. Additionally living with HIV in South Africa is quite different from living with HIV in other countries. The role of context and prevailing attitudes towards health and illnesses matter a lot. Moreover, UNAIDS and PEPFAR (2018) revealed that South Africa has the most extensive antiretroviral treatment programme in the world, and South Africa has invested billions in tackling the HIV epidemic in recent years. The accessibility of antiretroviral treatment to children living with HIV has brought a longer and healthier life. However, Tsai et al. (2013) noted that children living with HIV are loved, accepted and supported by those close to them, but they still experience silent stigma and discrimination within social spaces and institutions in society. While legislations are addressing this, these stigmas and discrimination are more of euphemisms and silent attitudes that exclude or reinforce difference.

For this study, stigma refers to humiliation attached to something socially unacceptable. Many people who are living with HIV fear negative attitudes that people in their society have about HIV. Feyissa, Abebe, Girma, and Woldie (2012) mentioned that due to stigma, children living with HIV are likely to be isolated, rejected and sometimes excluded from social activities. Additionally, Feyissa et al. (2012) pointed out that when some people hear that someone is HIV infected, they see that person as a dying person that is not supposed to be touched by anyone. Tsai et al. (2013) mentioned that myths about HIV can lead to isolation, feeling unwanted and unsupported, which can have a significant impact on the health and psychosocial wellbeing of the child. Furthermore, families of children living with HIV also experience stigma and discrimination.

In a study conducted by UNICEF in 2011, amongst adolescents living with HIV in Harare, it was discovered that the psychosocial well-being of adolescents living with HIV was poor. Sixty-three per-cent (63%) of adolescents were at risk of depression, with 23 per-cent reporting suicidal ideation and a higher percentage amongst those with poor adherence. The qualitative aspect of the study showed that the challenges faced by HIV positive children include verbal abuse, stigma and discrimination in their homes and communities (UNICEF, 2011).

As presented in the above study, stigma and discrimination does not only impact on children's psychological well-being and mental health but also their adherence to ARVs. The success of antiretroviral therapy is reliant on the optimal suppression of HIV through strict adherence to the drug regimen. Yet children go to considerable lengths to conceal their ARV drugs from family members, neighbors and classmates so that their HIV status is not revealed. This commonly results in drug doses being missed or taken late. While they are fully aware that poor adherence will result in treatment failure and the deterioration of their health, these children are driven by fear of the way others will treat them if their HIV status is revealed (UNICEF, 2011).

Thus, living with HIV is a different experience for everyone infected; for some, taking antiretroviral treatment and accessing health services is a routine, part of care requirement, and for others, insufficient information and fear of marginalization impact their experience. Stackpool-

Moore et al. (2013) noted that the issue of HIV-related stigma and discrimination continue to be a substantial challenge because it influences the accessibility and orientation of services such as healthcare services and support services, and it also has an impact on the self-esteem and general quality of life of the HIV patient. Hence, stigma and discrimination have been obstacles to care and support services in the context of HIV/AIDS treatment. Tsai et al. (2013) pointed out that the issue of stigma and discrimination towards HIV infected people is a significant factor that impacts HIV care and treatment adherence. It also influences HIV testing, HIV disclosure, social support and mental wellbeing. Thus, HIV-related stigma and discrimination continue to be a critical public health issue that affects the psychosocial well-being of people living with HIV, including children.

2.5.2.2 Child HIV Disclosure

HIV disclosure is defined as a gradual process of giving children age-appropriate information regarding their illness, leading to full disclosure when the child has the cognitive and emotional maturity to process this information (Wilfert et al., 1999). The literature suggests that HIV disclosure is one of the most challenging processes in HIV care among children. (Vreeman et al., 2014) reveals that children living with HIV always need help from others to deal with self-disclosure; they first need to deal with their emotions before telling others. Although HIV was exposed as a fatal disease, alerting children living with HIV about their HIV positive status is important from the viewpoint of accessing antiretroviral treatment and receiving psychosocial support interventions (Vreeman et al., 2014). However, deciding to inform the child about his or her HIV status is one of the main problems among caregivers (Wiener et al., 2007).

Das, Detels, Javanbakht, and Panda (2016) states that HIV diagnosis and disclosure of status to newly infected individuals, including children, may be deeply traumatic that it leaves the person in a state of shock, distrust and nervous. Lack of social support may contribute to poor mental health, and, in turn, treatment adherence may be interrupted. This is clear in Vreeman et al. (2017) assertion that children and adolescents with HIV face an increased burden of mental health challenges. HIV-infected children and youth are at higher risk of psychiatric hospitalizations, compared with the general pediatric population (Vreeman et al., 2017). A 2013 systematic review of the literature on the mental health of adolescents living with HIV found few studies describing the prevalence of psychiatric diagnoses in HIV-infected adolescents, but the existing studies suggest that psychiatric disorders such as depression and anxiety are more prevalent among perinatally infected adolescents compared to non-infected adolescents (Mellins & Malee, 2013).

With the advent of antiretroviral therapy (ART), despite a significant decline in the incidence of severe, AIDS-defining neurocognitive diseases like HIV encephalopathy (Vreeman et al., 2017), HIV-infected children may still experience neurocognitive complications, such as deficits in cognitive, speech, gross motor and excellent motor functioning, that can substantially impact their quality of life, social relationships, academic achievements, and risks for abuse and substance use (Ettenhofer, Foley, Castellon, & Hinkin, 2010). These complications can be seen despite early ART treatment and viral suppression (Crowell et al., 2015). Moreover, HIV-infected adolescents are growing up and developing in a milieu that includes exposure to biomedical, genetic, familial, economic, and social or environmental factors that may increase their risk for mental health problems (WHO, 2011).

As mentioned before HIV-related stereotype and stigma is a serious issue that affects adolescents and children living with HIV and subsequently makes it a challenge to facilitate disclosure. This is because, in most cases, it is likely that children living with HIV aged 0-14 years acquired the virus from their mothers, so disclosing HIV status to the child is often seen as disclosing the family secret, including the parental history of sexual behaviour. Hence, many caregivers consider it is best to protect their children from the emotional problems and social prejudgments associated with knowing HIV status (Das et al., 2016). This indicates the difficulties most parent/caregivers experience in disclosing HIV status to their children. Kidia et al. (2014) revealed that caregivers of HIV infected children typically assume that their children are too young to understand what HIV is and how they became infected. Wiener et al. (2007) state that caregivers hesitate to disclose HIV status to their HIV infected children because they think that their children are not mature enough to handle stressful situations like adults and that HIV disclosure may lead to psychological harm, which may affect their psychosocial well-being.

Apart from the fear of automatically disclosing the parent’s HIV status to the child, Mahloko and Madiba (2012) discovered that caregivers deliberately delay the process of disclosing HIV status to their infected child due to fear that their child may tell others which could results into social rejection and discrimination by the community. Domek (2010) noted that the experience of social discrimination and stigma results in many caregivers withholding HIV information and pretending that the child has a disease different from HIV. This shows that certain circumstances shape HIV non-disclosure, and social stigma makes it hard for people living with HIV to live happily as they are always worried about who knows their status.

However, Linda (2013) argued that HIV disclosure is of benefit to HIV infected children, considering the need to promote antiretroviral treatment adherence. As children living with HIV survive to adolescence and adulthood, Ssali et al. (2010) stated that HIV disclosure should be encouraged to reduce sexual risk behaviour and transmission of the virus, increase access to support and HIV care services. HIV disclosure, therefore, can be instrumental in preventing the spread of HIV as people infected will be aware of their status and prevent risky behaviours. As children grow, they tend to be more suspicious; they want to know everything happening around them, Mahloko and Madiba (2012) reveals that HIV infected children frequently ask questions about the reasons why they are taking treatment as well as wanting to know the nature of their disease which pressures the caregiver to disclose the child's HIV status. Mahloko and Madiba (2012) discovered that as children start schooling, caregivers live in fear as their children are most likely to learn about HIV diagnosis at school, so their secret will be unintentionally revealed. This shows that the growth of children living with HIV leaves caregivers with fewer choices but to disclose.

Other researchers are of the view that disclosing HIV status to the child at an early age is the best option as the child would sooner or later know about his or her HIV status or know about his or her treatment. HIV disclosure is associated with psychosocial benefit and positive effect, Corneli et al. (2009) noted that HIV disclosure improves adherence to treatment, improve one's ability to cope with HIV-related issues such as fear, isolation, stigma, and discrimination. Additionally, HIV disclosure is an advantage to caregivers as it helps children to understand what HIV is about, which helps in promoting a healthy lifestyle and monitors adherence to treatment progress, which results in children beginning to be responsible for taking their antiretroviral treatment as prescribed. The scientific knowledge suggests that HIV infected people can live longer and have healthier lives when accessing antiretroviral treatment, Lesch et al. (2007) exposed that "knowledge of HIV status may affect compliance with antiretroviral therapies and influence children's participation in healthcare decision-making". This illustrates that HIV disclosure is associated or shaped by the needs and circumstances of individuals living with HIV and shows that there are reasons that caregivers of children living with HIV decide to disclose and not-disclose their children's HIV status.

2.5.2.3 Adherence to treatment

Adherence to treatment refers to taking the prescribed treatment in an approved manner (Lesch et al., 2007). Boussari et al. (2015) noted that good adherence to antiretroviral treatment is vital for successful viral suppression, as half-finished adherence leads to an increase in virus, risk of treatment failure, and accumulating resistance changes. Mehta et al. (2016) emphasized that adherence to antiretroviral treatment is an important aspect in the health of HIV infected children, it has been found to reduce the virus, increase CD4 counts, decrease the occurrence of opportunistic infections and improve the growth and development of children. Kaplan et al. (2015) admit that accessing antiretroviral treatment help children living with HIV to live longer and survive to adulthood; however, adherence to antiretroviral treatment is one of the challenges that children experience. Williams, Van Rooyen, and Ricks (2018) specified that most children living with HIV refuse to adhere to antiretroviral treatment because they are vomiting due to the pill's unpleasant smell, while some children find it hard to swallow the pills saying they are too big for their throats. Mafune et al. (2017) agreed that antiretroviral treatment is mostly supplied in formulations that may be difficult for children to tolerate, such as large pills, bitter-tasting liquids and loose powders, which results into non-adherence. Ugwu and Eneh (2014) pointed out that among the reasons children living with HIV refuse to adhere to antiretroviral treatment is because treatment may not have been disclosed to them; they do not have a reason for taking the treatment. Kaplan et al. (2015) argued that children who have had their status disclosed to them have better adherence. This may be because the resolution of disclosure issues in the household improved family support and adherence strategies devised by families.

As mentioned earlier, South Africa is the highest country with HIV/AIDS infected people, and it also has the most extensive antiretroviral treatment program among most developing countries. This notwithstanding, HIV care services are not well developed as well as, poor adherence to antiretroviral treatment and defaulting from antiretroviral treatment are some of the main challenges faced in HIV care in the country (Deribe, Hailekiros, Biadgilign, Amberbir, & Beyene, 2008). There are many reasons associated with non-adherence to antiretroviral treatment among children. Ngarina et al. (2013) revealed that caregivers are the central reason for non-adherence to antiretroviral treatment for children and adolescence. Ugwu and Eneh (2014) also pointed out that due to the issue of stigma and discrimination, caregivers cannot disclose the child’s HIV status to family members so if the caregiver forgets, travels or work long hours no-one will help the child with the treatment. Antiretroviral adherence in children poses unique and formidable challenges; many children are mostly reliant on a caregiver to take their antiretroviral treatment. Monjok, Smesny, Okokon, Mgbere, and Essien (2010) noted that mothers of children living with HIV are likely to be the reason for non-adherence to antiretroviral treatment. Due to HIV/AIDS-related illness, the mother may be too ill, and because they have not disclosed their status to the family, no-one takes up the responsibility of handling the treatment of the child while the mother is sick. This shows that adherence to antiretroviral treatment is strongly associated with HIV disclosure. However, it is well-known that caregivers tend to hide HIV infection status from their children and disclosure is often delayed until adolescence due to fear of stigma and other reasons. This results in the child missing the treatment repeatedly, leading to defaults in the treatment plan.

Moreover, Rachlis, Mills, and Cole (2011) identified financial constraints as another reason for non-adherence among children. Tuller et al. (2010) demonstrated that caregivers face difficulties as time and again, they have to choose between using their income on paying for transportation to the clinic or to feed their families satisfactorily. As a result, their children may miss their scheduled clinic arrangements and, as a consequence, not receive their antiretroviral treatment at the systematic time intervals critical for optimal adherence. This shows that transportation costs to the clinic to get antiretroviral treatment is a socioeconomic challenge to adherence. In the context of free antiretroviral treatment, Mukhtar-Yola, Adeleke, Gwarzo, and Ladan (2006) noted that the cost of transportation to fetch antiretroviral treatment from the clinic is still a barrier to adherence; children living with HIV remain at risk for HIV-AIDS-related death as they regularly miss their treatment due running out of treatment and the inability to get more. This shows that the issue of transportation cost is disturbing the antiretroviral treatment programme that South Africa has implemented to eliminate the number of HIV-AIDS-related death. Thus, increasing access to reasonably priced transportation as well as increasing the number and proximity of antiretroviral treatment clinics may help to improve HIV treatment adherence among children and adolescences.

Concerning HIV care services provided to people living with HIV, including children, the South African government has committed to expanding the antiretroviral treatment rollout programme. The success of this programme will depend significantly on the healthcare workers implementing it. However, some challenges are experienced by healthcare workers in the process of providing and implementing health services to people, and those challenges are likely to go unnoticed. In the following section, the researcher will present a critical review of some of the challenges health care practitioners encountered in the discharge of their duties in HIV care.

2.6 A critical review of the challenges experienced by healthcare workers in HIV care settings

HIV is a global health challenge, Koto and Maharaj (2016) mentioned that the rapid spread of HIV throughout the country affected both rural and urban areas similarly. Hence, healthcare professionals play a fundamental and life-threatening role in improving access and quality health care for the people. They provide essential services that promote health, prevent diseases and deliver health care services to individuals, families and communities based on the primary health care approach (Joseph et al., 2012). Guidelines to manage people who are living with or affected by HIV are available but rarely relevant and applicable to the healthcare worker's expertise. For this session, this chapter considered Section 27 Constitution of the Republic of South Africa, 1996 guarantees a right of access to health care; the National Health Act 61 of 2003 holds extensive provisions on the rights of users and providers of the health system; and a range of other legislation such as the Occupational Health and Safety Act 85 of 1993. As these sections verify that South Africa is well-known for its progressive and robust constitution that protects human rights, including protecting people using public health services. In the same light noteworthy recent dissertation and legal theories have concentrated on examining the rights of patients; the circumstances and rights of healthcare workers in health care settings have not been sufficiently discussed. Therefore, in this section, the researcher will identify and discuss challenges that healthcare workers experience in providing HIV care services to children living with HIV and on antiretroviral treatment

Earlier in this chapter, eminent progress and developments in managing HIV/AIDS among children, South Africa were adequately discussed. Nonetheless, Vawda and Variawa (2012) noted that the key to an effective result of implementing such developmental strategies and programmes lies with healthcare workers. Thus, it significant to highlight the challenges healthcare workers experience in turning the tide on HIV widespread. In general, healthcare workers play a very crucial role in implementing health policies and in providing health care services to people who are in need. Nevertheless, the rights of healthcare workers are often overlooked, the study by Vawda and Variawa (2012) revealed that healthcare workers complain of poor working conditions, inadequate facilities, long working hours and low wages. As a consequence, many healthcare professionals prefer to work in private sectors where working conditions are better, while some chose to go abroad. For example, in 2001, close to 23 000 healthcare professionals from South Africa were working in developed countries (Lutge & Mbatha, 2007).

According to Lutge & Mbatha (2007) challenges such as staff shortages, lack of an adequate supply of antiretroviral treatment have been necessarily well exposed. However, many of the challenges that healthcare workers experience in providing HIV care services such as HIV testing, counselling, antiretroviral rollout on a day-to-day basis have not been sufficiently researched. Hence, the researcher aims to highlight more significant challenges experienced by healthcare workers employed in public health settings, which includes the risk of HIV infection, environmental challenges (inadequate access to information system), treatment challenges (availability of antiretroviral treatment) and the emotional impact of providing HIV care services. This study advances a need for a focused investigation into the challenges healthcare workers face and possible remedy.

2.6.1 The risk of HIV infection

HIV infected people, including children, pose a negligible but actual danger to healthcare workers who sustain exposure to such a patient's blood. In support, Wyżgowski, Rosiek, Grzela, and Leksowski (2016) mentioned that HIV is transferred mainly via sex intercourse and exposure to infected blood or body fluid. This assertion highlights the role of blood contact or the exchange of bodily fluids plays in the transmission of HIV. During HIV testing, healthcare workers are exposed to the blood of an HIV infected child, which puts them at risk of HIV infection, and this remains a real threat in their everyday life. Healthcare workers are at countless risk of HIV infection due to work-related threats. In support of this, the study conducted by Kakizaki et al. (2011) revealed that needle stick injury is the leading risk factor for blood-borne infections in healthcare settings. Pirozzolo and LeMay (2007) defined a blood-borne as a disease (virus or bacteria) that can be spread through contamination by blood and other body fluid. The most common example of blood-borne disease is HIV. The findings by Kakizaki et al. (2011) also reveals that healthcare workers reported that they are likely to be exposed to HIV infection if they have worked more than 35 hours per week and administrated more than ten injections per day. Other healthcare workers reported that needlestick injuries decrease if they adhere to universal safety measures.

Comparable results were highlighted by Ashat, Bhatia, Puri, Thakare, and Koushal (2011) in their study, which consisted of 107 female healthcare workers in two public health hospitals to determine needle stick injury and HIV risk among various categories of healthcare workers. The study involved doctors, nurses and paramedics; the study revealed that the occurrence of needle stick injury and exposure to blood was reported by 73% of healthcare workers. The main factor attributed to this exposure was heavy patient load (42.5%). The maximum accidents happened during emergency care (30.1%). The most common action following exposure was cleaning with the spirit (46.3%). Only 51 (47.7%) of healthcare workers confessed following universal safety measures. This shows that because of workload and other motives, healthcare workers are regularly exposed to needle stick injuries, which pose a serious risk of HIV infection to their psycho-psychical health. It is, therefore, essential to realize that every patient can be HIV positive or can be infected with other blood-borne diseases, hence it is of importance that healthcare workers apply safety rules whenever they provide HIV care services.

2.6.2 Environmental challenges

It is a reasonable assumption that a safe and well-equipped work environment influences productivity, as well as a healthier workforce and improved patient management. For this section, the physical environment (such as space and ventilation) and functional environment (personal protective equipment and medical consumables) will be focused on as efficient HIV care service delivery. In providing HIV care services to children receiving HIV care, Yusuf, Hussin, and Azali (2015) highlighted that it is important that HIV care environment for children are child-friendly to help lessen, if not to alleviate, the suffering experienced by a child and to involve him or her during care. Yusuf et al. (2015:35) made an example that “the child could be taught about the treatment that he or she will have to undergo. This will be informed to him or her in a way that is suitable to the child’s level of knowledge and understanding. Educational materials that will be provided to the patient will include presentations or drawings that will help in making the child visually understand what is happening to him or her in a way that is not frightening. In this way, it will be much easier for the child to participate while the procedure or treatment is being done”. In support, Lankston, Cusack, Fremantle, and Isles (2010) revealed that when an environment is more eye-catching to the child, they become less anxious and scared of the hospital setting.

Despite the importance of a child-friendly environment for children in HIV care, healthcare workers experience environmental challenges. Vawda and Variawa (2012) exposed that poor infrastructure leads to both negative patient sensitivities of the value of care they will receive at the competence and disappointment amongst healthcare workers because of their working conditions. Concern regarding the physical environment, Lutge and Mbatha (2007) noted that there is a lack of space in many HIV care clinics, in most cases, consultation rooms are shared by a variety of disciplines of healthcare workers consulting with different patients. It can be argued that this tempers with an ethical subject because it violates the patient's constitutional right to privacy. Vawda and Variawa (2012) noted that the problem with the lack of space is the overpopulation of waiting rooms, which can result in patients with communicable diseases infecting other immune-compromised patients. Koto and Maharaj (2016) interrelated to this is the lack of adequate ventilation and/or air-conditioning and ultraviolet light in many of the health care settings, which further contributes to the spread of air-borne bacteria or viruses. In providing HIV care service, healthcare workers spend a minimum of 40 hours per week, not including overtime in the working environment. Hence the work environment must is suitably adapted to provide adequate primary prevention measures. Most literature, however, argued that few comprehensive studies aimed at determining the health effects of poor infrastructure, for example, the lack of proper ventilation, electricity (for refrigeration and sterilization) or an adequate water supply exists. Therefore, it has become pertinent that the government reconsiders its responsibility in the provision of adequate measures to protect healthcare workers against health hazards.

2.6.3 Treatment challenges

One very common challenge that healthcare workers experience is a shortage or inadequate supply of antiretroviral treatment. This is also referred to as treatment 'stock-outs' and has a damaging effect on the antiretroviral treatments rollout programme Ndlovu-Gatsheni (2009); Vawda and Variawa (2012) mentioned that in 2008 there was a shortage of antiretroviral treatment in the Free State Province in South Africa that led to increased death roll of people living with HIV. More disturbingly, the Department of Health in Free State suspended the enrolment of new patients in an antiretroviral treatment programme, and more than 30 people were estimated to have died daily. However, Ndlovu-Gatsheni (2009) mentioned that later in 2009, the MEC for health, Dr. Dhlomo denied that the healthcare setting in certain provinces had treatment 'stock-out'.

The treatment of children with HIV/AIDS is also part of the challenges that healthcare workers experience. Healthcare workers need to be specifically trained in the skill of communication with children, using language that the child can identify with. Rujumba et al. (2010) revealed that healthcare workers find providing HIV care services to children difficult because some children are fearful. Focusing on HIV counselling and testing for children, Rujumba et al. (2010) noted that healthcare workers lack counselling skills, failure to cope with the knowledge demand, difficulty to facilitate disclosure, heavy workload, and lack of other support services create challenges in effective care delivery. Health settings were found to be unnatural by limited space and lack of antiretroviral for children. Dageid, Sedumedi, and Duckert (2007) mentioned that many healthcare workers are concerned with treating children because of their 'lack of training and experience' in this field. Adequate training in performing common procedures such as drawing blood samples or performing lumbar punctures is vital. At present, this training is lacking at several HIV care settings Rujumba et al. (2010) concluded. This shows that there is a need for the provision of child-friendly services, guidelines that may offer an opening of hope to improve HIV counselling and testing services for children receiving HIV care services.

2.6.4 The emotional impact of providing HIV care services

The suriving studies point at out that stress, burnout and emotional exhaustion are mutual amongst healthcare workers in HIV care settings. Dageid et al. (2007) stated this is likely to occur when healthcare workers are unable to deal with the day-to-day stressors effectively. The researcher has realized that the evidence with respect to the emotional experiences and burdens faced by healthcare workers providing HIV care services is inadequate. However, studies reveal that despair, depression, helplessness and aggression are common amongst healthcare workers (Katabira & Oelrichs, 2007). Emotional tiredness and exhaustion are tremendously common amongst healthcare workers as they work under great compulsion, dealing with an outsized number of patients daily and meeting death and misery daily; all of this without sufficient reimbursement, encouragement and training (Vawda & Variawa, 2012). At present, there are no structured programmes in place to identify healthcare workers at risk for emotional burnout and to provide them with the required counselling and support. Ndlovu-Gatsheni (2009) mentioned that most healthcare settings that provide for HIV care services employ unprofessional counsellors as part of their healthcare workforce in order to relieve the burden that their daily experience. This shows that the need for emotional support for healthcare workers must be addressed and progressive strategies implemented. In support, the study by Dageid et al. (2007) recommended that counselling and interrogation should be mainly focused on the emotional challenges that healthcare workers experience. Those challenges include anger issues, death and depression. Counselling sessions should be provided to healthcare workers with different strategies that they can use to cope with such emotions. At the same time, healthcare workers should be recognised for their accomplishments, and their professional growth should be encouraged.

As the literature suggests; healthcare workers play a vital role in the implementation of the provision and implementation of health care services. They have the responsibility of ensuring that the government's health policies are translated into effective and efficient service delivery. However, the current literature suggests that their rights are often overlooked, and many are subject to poor working conditions, long hours and inadequate remuneration. As a result, many healthcare workers have chosen to leave the public health sector. South Africa may provide the largest antiretroviral treatment services in the world, but healthcare workers are the backbone of HIV care services, including the rollout of antiretroviral treatment. Thus, their challenges need to be urgently addressed.

2.7 Conclusion

This chapter has provided a critical review of essential and sacrosanct arguments in the body of knowledge examining HIV care. It became evident that the provision of psychosocial support plays a profound role in understanding HIV infection progression, challenges experienced by key role players in HIV care services as well as in HIV infected children. Despite the extent of work that has been done on HIV/AIDS, the existing literature shows that there is still a challenge in HIV care concerning HIV disclosure and adherence to treatment. In relation to the process of HIV disclosure, little has been researched on the tools, strategies, and skills used by healthcare workers to communicate in a child-friendly way to HIV infected children. This leaves a gap in how healthcare worker communicates with children about HIV when providing HIV care services.

CHAPTER 3 - RESEARCH METHODOLOGY

3.1 Introduction

In this chapter, the process of data collection for this study will be discussed. The discussion will include the research paradigm, research design and sampling techniques used in this study. The chapter unpacks the data collection techniques adopted and how data was analyzed. Ethical considerations will also be discussed. It concludes with a reflection on the ethical issues encountered during the process of data collection and how these issues were addressed.

3.2 Research paradigm

Blanche, Blanche, Durrheim, and Painter (2006) were conviced that paradigms pave the way for the research process, including techniques of data collection and data analysis and interpretation. A paradigm plays an essential role in research design, as it guides the research questions and how they will be answered. To answer the key research questions of this study, a qualitative research approach informed by interpretive paradigm was used. Interpretivism calls for the exploration and understanding of phenomena by interacting with the participants (Snape & Spencer, 2003). According to Blanche et al. (2006), interpretivism focus on interpreting the social world in the form of language, which is a system of meanings and practices that construct reality. According to Blanche et al. (2006), interpretivism studies are qualitative and focus on meaning-making. Besides, interpretivism uses in-depth interviews as one strategy to understand the experiences of research participants.

Fortune et al. (1999) describe the qualitative approach as an excellent method that researchers can use to gain a first-hand, comprehensive understanding of phenomena of interest through a flexible strategy of data collection as the study proceeds. Newman and Hitchcock (2011) also argued that qualitative study depends on personal experience. Correspondingly, qualitative studies seek to understand, explain, explore, discover and clarify situations; people’s feelings, perceptions, beliefs and experiences (Newman & Hitchcock, 2011). According to Blanche et al. (2006), the qualitative approach allows the researcher to study selected issues in openness, detail and depth to identify and attempt to understand the categories of information that emerge from the data. This research approach was best suited for this study as it allowed the researcher to gain an in-depth understanding of how psychosocial support services are provided to children who are living with HIV and the role of their families in HIV ART programs.

3.3 Sampling

Sampling encompasses the identification of suitable participants who are best suited to provide information to address the research question and to provide an in-depth understanding of the phenomenon being studied (Berg & Lune, 2004). The identification and selection of research participants from the entire population involve a decision about which people to select and which behaviours or social processes to observe (Blanche et al., 2006). Observation of human behaviour and interviewing plays an important role in the qualitative research approach and within the interpretative paradigm. For this study, a purposive sampling strategy and snowball sampling strategy were used to select fifteen (15) participants- seven healthcare workers and eight caregivers were selected for face to face in-depth interviews. This study was conducted in the Pinetown Municipal clinic in Durban, KwaZulu-Natal., because it is a public primary healthcare facility that provides for HIV and TB related treatment, care and support services to the community of eThekwini and surrounding municipalities. The clinic also has a large cohort of children on HIV care and treatment.

3.3.1 Criteria and Recruiting process

The following is the selection criteria that guided the recruitment process for healthcare workers and caregivers:

(a) Criteria used for recruiting healthcare workers:

1. Health care workers who work who with children recieivig HIV care in Pinetown Municipal Clinic,

2. A healthcare worker who has provided psycho-social support to children in HIV care, including pre-and post-test counselling, and HIV disclosure.

(b) Criteria used for recruiting caregivers:

1. Caregivers of children aged between 6 to 18 years who are receiving HIV treatment and care at Pinetown Municipal Clinic,

2. Caregivers who have been providing care for the same child for at least a year; to understand their perspectives about the impact and quality of psychosocial services they receive as well as the support provided to their children in HIV care.

According to Palinkas et al. (2015), purposive sampling is a non-probability sample that is selected based on the characteristics of a population and the objective of the study. Utilizing a purposive sampling strategy was very convenient for this study as it helped the researcher in ensuring that participants who were selected were likely to provide meaningful and relevant information based on their characteristics. In this study, healthcare workers and caregivers were purposely selected considering the recruitment criteria noted above.

Pinetown Municipal clinic is a large clinic that provides different healthcare services to people, and it also has several healthcare professionals. Therefore, the researcher used snowball sampling in recruiting participants that are suitable for this study. According to Palinkas et al. (2015), snowball sampling is where research participants recruit other participants for a test or study. It is used where potential participants are hard to find. Using snowball sampling was an advantage to this study because it allowed this study to recruit participants in a study that the target group is generally considered hard to reach. The researcher was in contact with two healthcare workers, who then recommend the other five healthcare workers who met the researcher’s criteria. In this study, healthcare workers were asked to identify eight caregivers of children receiving HIV care services in the clinic. The participants recommended anyone they knew who could be eligible to participate in the study considering the criteria mentioned earlier.

3.3.2 Sampling Process

This study had two different sets of participants- seven health care workers, as well as eight caregivers of children who are living with HIV. The following section discusses the sampling process for each category of participants.

3.3.2.1 The recruitment process for healthcare workers

Once the ethical clearance was obtained, the research site was visited by the researcher to get to know the clinic and to meet with the persons responsible. The meeting included recommendations of potential healthcare workers who can be recruited to participate in this study in line with the selection criteria. Two healthcare workers were recommended, and the clinic staff member assisted the researcher in making an appointment with them. Following the qualitative research approach, purposive sampling was used to recruit healthcare workers who provide HIV care services to children. Snowball sampling was also utilized in the recruitment of 5 healthcare workers, and the researcher was assisted by the healthcare worker's referrals to meet the target number of participants. The researcher then approached the potential healthcare workers to enquire about their willingness to participate in the study. The researcher discovered that using snowball sampling was an effective recruitment strategy, as seven healthcare workers agreed to participate in the study.

To make things much easier for the data collection process, the researcher made an appointment with all of the healthcare workers who were willing to participate in this study. The researcher met all seven healthcare workers as a group and provided them with an accurate description of the research purpose. By meeting them as a group, it was an advantage to the researcher because it saved time for recruitment as the information regarding the study was shared once. The questions that were raised enabled others to get more clarity. After providing the information about the study, the participants were given an informed consent form to read and sign, which included the aim of the study, estimated duration of the interview session and the emphasis of voluntary participation for this study and assurance of anonymity and confidentiality. After participants voluntarily agreed and signed the informed consent form to participate in this study, the researcher then allowed all of them to choose a suitable day and time for the interview sessions. This process took about an hour.

3.3.2.2 The recruitment process for the caregivers

Collecting data from caregivers was done after completing the interviews with healthcare workers. An arrangement was made with healthcare workers to identify caregivers of children who receive HIV care services from the chosen clinic. The researcher selected caregivers of children aged between 6 and 15 years because they are likely to have new information and experiences regarding HIV care services provided to their children after the development of HIV care services in health settings. With the help of healthcare workers, a list of potential caregivers who met the selection criteria was drawn up, and healthcare workers assisted the researcher to access the appointment schedule to find out when the potential caregivers were to visit the clinic for their clinical appointments. Through this process, eight caregivers were identified, and the researcher then made sure that on caregiver's appointment days, she was in the clinic to seek their consent to participate in the study. Healthcare workers further assisted the researcher by directing the researcher to the caregivers when they came for appointments to enquire about their willingness to participate in this study. The researcher found that this was an effective recruitment strategy, and eight interviews were carried out through the clinic.

Because the researcher used a qualitative research approach, purposive sampling was applied to recruit caregivers of children receiving HIV care services in the chosen clinic to gain rich information for the study. During the recruitment process of caregivers, the researcher explained the purpose of the study, and those who were willing to participate were given an informed consent form to read and sign, the form included the estimated duration of the interview session, the voluntary nature of the study and assurance of anonymity, confidentiality and privacy. Not every potential participant the researcher approached agreed to participate in the study, and this showed that the caregivers understood that their participation was voluntary, and they could refuse to give their consent.

Caregivers who were willing to participate were given a chance to choose a suitable date for their interview sessions. All of the interviews with the caregivers were conducted during the participants’ clinic appointment date, before and after they have seen their healthcare workers. Interview sessions were conducted on the first Friday and Saturday of May and June 2019 as per their appointment schedules. In May, the researcher interviewed five caregivers, and the other three caregivers were interviewed in June. Interviewing caregivers also took the researcher four days- two days in May and two days in June. All the interviews were conducted in isiZulu, which made it much easier for the sessions to be much quicker as there was no language barrier.

3.4 Data collection

Blanche et al. (2006) defined data collection as a systematic method that is used to get information from research participants. In this section, the researcher elaborates on how the data collection process was carried out.

3.4.1 Research instrument

In-depth interviews were used for data collection. In defining the interview**,** Maree (2007; 45) noted that "an interview is a two-way conversation in which the interviewer asks the participant question to collect data and to learn about the ideas, beliefs, views, opinions and behaviours of participants. The qualitative interview aims to see the world through the eyes of the participant, and they can be a valuable source of information, provided they are used correctly". The interview guide, which contained open-ended questions, was used to elicit responses from participants.

The interview is regarded as effective when the researcher seeks to gain insight into people's emotions, feeling and experiences. Moreover, an interview is regarded as the best natural form of interacting with people as it offers the researcher an opportunity to get to know the participants intimately and understand how they think and feel (Blanche et al., 2006).

(a) Data Collection Process with participants

The data collected from all participants (healthcare workers and caregivers) took about six weeks and all interviews were conducted at Pinetown Municipal Clinic. This was because the target population within the clinic had specific dates that they preferred for the interviews that would not interfere with their work schedules. The following explains the data collection process with seven healthcare workers and eight caregivers:

(b) Data Collection Process with healthcare workers

Most of the interviews with the healthcare workers were conducted on Tuesdays and Wednesdays; in the morning and after lunch because on those chosen days, a small number of people visited the clinic. The researcher conducted two days' interview sessions with healthcare workers in a week considering their availability. The interviews were conducted in their work offices. Interviewing healthcare workers was completed in four working days in April 2019.

The researcher started the interviews by greeting and exchanging pleasantries with the participants so they can feel accepted and comfortable. This was followed by a small talk, which included open-ended questions like "Tell me about yourself and your duty at the clinic". This gave participants opportunities to express themselves, and it enabled the researcher to collect more information. At the commencement of the interviews, the researcher assured the participants about confidentiality and anonymity. Most of the interviews with the healthcare workers lasted for about 45 to 60 minutes. In order to facilitate the conversational flow of the interview, the interviews were conducted in the preferred language (IsiZulu/English) of participants. All of the participants preferred the interviews to be conducted in IsiZulu, and that saved time and eliminated the communication barrier as participants were speaking in the language that they were comfortable with.

Babbie and Mouton (2001) noted that audio-recording interviews and confirming notes with participants improve the trustworthiness of data analysis and reveal things that the researcher has not spotted during the interview process. Due to the nature of the study and concerns about potential anonymity and privacy issues, participants were strongly against being audio-recorded. Therefore, extensive notes were taken during and immediately after each interview. Upon completion, the interviewing notes were transcribed, shown and discussed with the participants for accuracy and completion. This process was completed before conducting the next interview.

(c) Data Collection Process with caregivers

The interviews began by the researcher greeting the participants with a smile and exchange of pleasantries to make participants feel welcomed and comfortable. The researcher started the interview off with some small talk, which consisted of open-ended questions like “Tell me more about yourself and your relationship with your child.” These kind of question allowed the researcher to better access the participant’s true feelings and gained extra information from the participants, such as demographic information (current employment, gender, age, etc.). The usage of open-ended questions allowed participants to include more information, including feelings, attitude and understanding of the subject studied. When participants were talking about their relationship with their children, their narratives were embedded with so much love as most were smiling whenever they mentioned their children’s names. The researcher tried, by all means, to avoid the use of close-ended question because it gives limited answers- “yes/no”.

The interviewing process required participants to share confidential and sensitive information, such as talking about their children’s HIV status. Therefore, the caregivers were given reassurance that the information shared during interview sessions will remain confidential, private, and they will remain anonymous. The person in charge of the clinic permitted the researcher to conduct the interview sessions with caregivers at the clinic boardroom. This was beneficial to both participants, and the researcher as the clinic boardroom was a private setting, no one could disturb or hear what the interview was all about. The interviews were conducted during the day because most caregivers came early in the morning for their appointments. Half of the participants were interviewed before and the remaining were interviewed after they appointed healthcare workers. The interviews with the caregivers lasted for about 45 to 60 minutes and in allowing the interview to flow, the interviews were conducted in the language the participants were conversant with.

All the participants chose to be interviewed in IsiZulu and that saved time as participants clearly understood the research questions. Usually, interviewers have physically written or typed the responses provided. However, audio-recording is increasingly being utilized and, in this regard, Rita and Rohman (2013) argues that tape-recording is a more accurate, effective and transparent method of capturing information than traditional methods. Notwithstanding the effectiveness of tape-recording, caregivers were unwilling to have their interview sessions being recorded and this was respected by the researcher. Therefore, the interviews were written down, the researcher tried to be as quick as possible to ensure consistency as losing track of important information could have possibly compromised research data. During the interview, the researcher strived to be a good listener who chose not to lead but allowed the participants to share their experiences, thoughts, feelings and emotions. The researcher wrote most of the responses in English and some in IsiZulu, which made it much easy for the transcribing and data analysis process.

3.4.2 Data Analysis

Data analysis involves digging deep into the narratives that were expressed by participants and captured by the researcher to reveal patterns and themes. This allows the researcher to obtain rich data to recognize factors that could explain the nature of the study (Denscombe, 2014). Different styles of data analysis can be utilized as long as it supports either qualitative or quantitative research approach. Since this was a qualitative study, the researcher selected to use thematic analysis as it blended well with research design. (Braun & Clarke, 2006) stated that thematic data analysis is a method for identifying, analyzing and reporting patterns of themes within data. Furthermore, the goal of thematic analysis is to identify themes that are domineering or interesting and use those themes to address the research questions. Through the usage of the thematic analysis method, the researcher was able to summarise all the views that have been collected from the participants.

The researcher initiated the data analysis process by re-transcribing all data collected neatly in English and started analysing it. This was advantageous as it enabled the researcher to gather as much information as possible from the interview sessions. Through the process of transcribing, the researcher was becoming familiar with the data collected in the interviews. This made it easy for the researcher to draw up a list of prospective themes. After transcribing, the researcher then looked for similarities, categories, themes and comparison as it related to research questions. The challenge with this was to carefully evaluate the transcripts so as not to make quick assumptions about the content that emerged. The researcher read through each transcript several times over a couple of weeks to find a correct meaning rather than making quick assumptions. After that, the researcher made use of the themes to organise the data collected and used quotations from the interviews to validate the findings. The findings were then linked to relevant literature reviewed and the researcher added it critical interpretation. Thematic analysis was an appropriate form of data analysis for this study as it allowed the researcher to analyse and interpret data collected from the field notes and then identify the main themes that merged during the interviews. The data analysis process was important for the researcher to complete and ensure that the researcher did not compromise the results.

3.5 The trustworthiness of the study

Rubin and Babbie (2005) argued that trustworthiness is achieved when the researcher is convinced and can prove to others that the research findings are valuable. In this study, trustworthiness will be discussed under four components: Credibility, Transferability, Dependability, and Conformability (Elo et al., 2014).

(a) Credibility

Credibility refers to how confident the researcher is in the study's findings (Babbie and Mouton, 2001). The researcher ensured credibility through member checks, frequent briefing sessions between the researcher and supervisor. Member checks is a process whereby the researcher asked participants to review both the data collected during the interview and the researcher's interpretation of that interview data to correct errors of facts.

(b) Transferability

Transferability is like generalizability, Blanche et al. (2006) noted that transferability is simply the ability of a researcher to provide answers to another context. The researcher used a detailed description of the information in the write-up of the research findings to show that the research's findings can apply to other contexts. Purposive sampling and snowball sampling was used in the selection of participants, where effort was made to interview a diverse range of participants across socio-economic standing, culture and age.

(c) Dependability

Babbie and Mouton (2001:249) define dependability as "providing the audience with evidence that if the study were to be repeated with the same or similar respondents in the same context, its finding would be similar". In this study, a clear review trail detailing how this study was conducted and how the conclusion was arrived at was presented. Dependability was achieved by keeping all the notes and transcripts taken during the interview session.

(d) Confirmability

The last component, Babbie and Mouton (2001:249), defines confirmability as "the degree to which the findings of the study are the product of its focus and not of the biases of the researcher". The researcher has kept all the original data, including the interview guide, field notes and transcriptions. This will ensure that the data and findings can be revised and confirmed by a third party, should the need arise.

3.6 Ethical consideration

Ethics concerns the morality of human conduct. With social research, it refers to moral deliberation, choice, and accountability on the part of the research process (Greyling, 2004). The ethical clearance for the study was obtained from the Humanities and Social Sciences Research Ethics Committee at the University of KwaZulu-Natal based on the Westville campus (see appendix 5). To ensure these ethical considerations are followed, the following principles were followed:

(a) Gatekeeper Consent

Gatekeeper consent is one of the most important aspects of ethical requirements. According to Greyling (2004), it is important to gain permission to enter the field that has been decided on and it is of prime importance to get a permission before the study may started. The researcher received permission from the eThekwini Municipality Health Units, eThekwini Department of Health and from KwaZulu-Natal Department of Health to conduct the study and get a consent form for every individual participating (See appendix 1 for copies of gatekeeper letters).

(b) Informed consent

Informed consent entails giving participants or their legal representation adequate information about the aim of the research; the expected duration of involvement; the procedures which will be undertaken during the research; the probable advantages, disadvantages and dangers to which the participants may be exposed; as well as the credibility of the researcher (De Vos et al., 2011). Informed consent written in IsiZulu and English were given out to all participants considered the language they preferred. The forms educated the participants on what the research was about, the duration it will take to complete the interview, their rights as far as the study is concerned, a chance to ask questions before interviews and then the decision to participate or not through the signing of the informed consent form. Written and signed informed consent was obtained from all participants before participating in the study. (See appendix 2, English (a) and IsiZulu (b) for a copy of the informed consent form).

(c) Voluntary participation and privacy

Rubin and Babbie (2005) posited that participation should always be voluntary and that no one should be forced into participating in a research study. In efforts to ensure voluntary participation, participants were informed about the nature of the research study before participation and be given a choice to read a written informed consent form and sign it if willing to participate. This, therefore, ensured voluntary participation as participants were given a chance to make an informed decision on whether to participate or not. The researcher also made it clear during the recruitment process that the relationship of the clinic with those who were not willing to participate in the study will not be jeopardized, they are still going to receive healthcare services for their children.

(d) Avoidance of harm

The researcher was aware of the potential psychological harm that accompanies the disclosure of sensitive and personal information related to HIV. For the study, the researcher made efforts to minimize harm to the participants. As a qualified social worker, the researcher sought to conduct the interviews respectfully and did not ask purposeless intrusive questions such as asking participants HIV status, how they were HIV infected or how their children were HIV infected to protect the participants from emotional harm. The researcher wrote a letter of support to the person in charge at Pinetown Municipal clinic to request for psychological support from their clinic Social Work. (See appendix 3 for the letter of support). Two of the interviews with the caregivers were emotional, and they broke into tears, especially when they talked about challenges that they have experienced in taking care of their children in HIV care. In every interview, the researcher brought bottles of water and a box of tissues to give to the participants when it is required.

The topic was emotional and challenging, and the researcher had to utilize her social work therapeutic skills to attend to the emotions that arose during the interviewing process. Some participants were crying during the interview, and it was time-consuming and emotional. The researcher was tempted to intervene when the reserarcher encountered some of the experiences of caregivers, but being aware of this, the researcher attempted to adhere to the function of data collection without engaging in therapeutics intervention, while still providing containment and assistance where it was applicable. Those who became emotional were requested to see the clinic Social Workers to get proper assistance and counselling.

(e) Privacy

Privacy is defined as that which is not normally intended for others to see and analyze (De Vos et al., 2011). In ensuring this ethic, the interviews were conducted on a one-on-one basis in a private office space where no one else could overhear or see what's written on the interview questions, therefore affording participants' privacy. The researcher used the clinic space to conduct the interviews. The healthcare workers were interviewed in their offices when there was no patient or a colleague. Caregivers were interviewed at the clinic’s boardroom when it was not being used.

(f) Deception or subjects/ respondents

Gredler (1995) defines deception as the deliberate withholding of information or offering incorrect information to ensure the participation of respondents when they would have possibly refused to participate. In this study, transparency about the purpose of the study was outlined and deception of participants was avoided. Before the commencement of the data collection process, the aim and objectives of the study were discussed with the participants and they had the opportunity to raise concerns and one of them was the non-use of the audio-recording during the interviews. As a sign of respect and to ensure that the researcher upholds the rights of the participants, the audio recording was not used.

(g) Anonymity

Anonymity refers to ensuring that the identity of respondents is unidentifiable and confidential. On the other hand, it refers to the handling of information confidentially, and it refers to agreements between persons that limit other's access to private information (De Vos et al., 2011). Concerning the special vulnerability of the population, anonymity and confidentiality were ensured through the electronic coding and storage of the data, which fulfills the highest and most secure data encryption standards. The participants were informed that the information received from the research interview would be accessed by only the researcher and the researcher's supervisor; however, the researcher used pseudonym instead of participant’s real names in writing up the study report.

3.7 Limitations of the study

According to De Vos et al. (2011), limitations exist in all research studies even when the research is carefully planned; due to this they need to be stated clearly. The research study consists of limitations that affected gaining essential information and influenced the interpretation of the findings in the data analysis phase. There were several limitations that the researcher expected to occur during the data collection process of the study. Namely, healthcare workers may report socially desirable answers because they may think the researcher wants to evaluate if they are doing their job or not. To minimize this limitation, during the recruitment process, the purpose of the study was clarified and concerns about how the results were going to be utilized were clarified. The participants of this study were unwilling to be audio-recorded and this was time-consuming as the researcher had to write everything down. To minimize this limitation, the researcher conducted an interview that was less than 60 minutes and in writing down the responses, the researcher was quick as possible to ensure consistency as memory loss could have possibly compromised the research date. The language was another limitation as all participants were isiZulu speaking and the data collected had to be translated into English. The meaning of their responses could have been lost during translation. However, the research worker was able to translate the data into English because the reserracher is equally a IsiZulu speaker. Lastly, the researcher wished to collect data in a month, but the data collection process was prolonged (it took two months) as data was collected based on appointment dates fixed with individual participants.

3.8 Conclusion

This chapter discussed the research methodology used to conduct this study. It highlighted the research paradigm, research design, sampling, data collection tools, data analysis, trustworthiness, ethical considerations and the study’s limitations. The following chapter presents and analyses the data collected and discusses the study’s findings.

CHAPTER 4 - PRESENTATION OF FINDINGS

4.1 Introduction

In this chapter, the researcher will present the findings of the study that emerged from semi-structured interviews conducted with 15 participants. A qualitative research approach was used to understand the provision and implementation of psychosocial support services for children receiving HIV care in Pinetown Municipal Clinic. To achieve the aim of the study, experienced health care workers and caregivers of children living with HIV were interviewed.

The findings presented in this chapter emanates from the narratives of the study participants. The themes developed are linked to the key objectives of the study. Before data collection, the participants were informed about the purpose of the study. This chapter begins with a brief demographic description of the participants and this is followed by the summary of themes and sub-themes that emerged from the data collected. After that, the discussion of themes and sub-themes is presented.

4.2 Socio-Demographic details of participants

To understand the provision and implementation of psychosocial support services for children receiving HIV care from Pinetown Municipal Clinic, 15 participants were questioned; 7 were professional healthcare workers who work in Pinetown Municipal Clinic and 8 were caregivers that are the primary or secondary carer of HIV infected children were deliberately selected. The years of which healthcare workers have been providing psychosocial support services for children receiving HIV care have been indicated., majority of the healthcare workers have provided services to children living with HIV for more than a year. The age of healthcare workers ranged between the 30s to 50s. Table 4.1 below indicates that the youngest healthcare worker is 32 years and the oldest is 49 years. Table 4.2 indicates that the age of caregivers ranged from the late 30s to the early 60s. The youngest caregiver is 38 and the oldest is 64 and it also indicates that most children are taken care of by their grandmothers.

Table 4.1: Showing demographic details of healthcare workers

Names	Gender	Age	Marital Status	Years in HIV care	Profession
Participant 1	Female	36	Married	1 year	Nurse
Participant 2	Female	42	Married	5 years	Nurse
Participant 3	Female	49	Married	22 years	Nurse
Participant 4	Female	32	Single	3 years	Nurse
Participant 5	Male	36	Single	3 years	Nurse
Participant 6	Female	33	Single	3 years	Nurse
Participant 7	Female	37	Single	6 years	Nurse

Source: Researchers compilation 2020

Table 4.2: Showing demographic details of caregivers

Names	Gender	Age	Marital Status	Employment Status	Relationship with the child
Participant A	Female	52	Single	Domestic Worker	Grandmother
Participant B	Female	41	Single	Unemployed	Mother
Participant C	Female	39	Widow	Unemployed	Mother
Participant D	Female	55	Married	Pensioner	Grandmother
Participant E	Female	38	Single	Unemployed	Mother
Participant F	Female	54	Single	Domestic Worker	Grandmother
Participant G	Female	64	Widow	Pensioner	Grandmother
Participant H	Female	53	Single	Domestic Worker	Grandmother

Source: Researchers compilation 2020

4.3 Presentation of Themes

In this section, the researcher presents the themes developed from the in-depth individual interviews with the participants. The research objectives were used to form the themes and sub-themes that developed from the narratives of participants. Below is the table of developed themes and subthemes.

Themes	**Subthemes**
4.1. Available psychosocial support services	- Individual support services - Support groups services
4.2. Challenges experienced by healthcare workers	- Lack of **c**hild-friendly counselling skills - Children's inability to communicate verbally - Caregivers unwillingness to disclose to children - Missed clinic appointments and lost to follow-up - Shortage of staff members
4.6 Challenges experienced by caregivers	- Financial difficulties - Adherence to treatment - HIV disclosure and non-disclosure - Caregivers perspectives on the provided psychosocial support services
4.7. Child-friendly communication tools	- Usage of electronic tablets
4.8.Training of healthcare workers	- Professional training

Source: Researchers compilation 2020

4.4 Available psychosocial support services

In this study, participants indicated that children enrolled in HIV care receive treatment and psychosocial support services that aim to improve health outcomes and quality of life among children living with HIV. The findings of the sudy learnt that children in HIV care were subjected to both individual support and support group services. According to Bhadra (2016), psychosocial support refers to ongoing care and support of children and adolescents to meet their age-appropriate and identified emotional, spiritual, social, cognitive and psychical needs through interactions with their surroundings. The usage of ecosystem theory in this study links with the findings of the study because children living with HIV require support from individuals, families and the community. These three key points of psychosocial support are implicit in the ecosystem theory. The study participants highlighted that children receive individual support and group services support in the clinic services. The following psychosocial support programs were reported:

4.4.1 Individual support services

Participants revealed that children in HIV care are offered individual support that helps them to talk about their concern or worries, including HIV related issues such as HIV disclosure, acceptance issues that affects their psychosocial well-being. The provision of individual support services offers children living with HIV and their caregivers with an opportunity to gain more information about HIV and get support so they can cope with HIV. Baggaley et al. (1998) stated that individual support is a personal opportunity to receive support and experience growth during challenging times in life. One of the study participants noted that in ensuring children's well-being, they are working with a social worker and a non–profit organization called Thuthuzela Care Centre.

Individual support is offered by a social worker whose role is to help children and their families coping with the illness, make practical decisions by availing them with the recent HIV information and help them obtain needed resources such as health, social support, and education (Gaitley, Mallinson, & Taylor, 1993). People who have been diagnosed with HIV experience a variety of psychosocial stressors that can negatively affect their lives. In this study, participants expressed that they are working with a social worker who is well skilled about how to advise children with regards to a variety of health and social conditions. The participants indicated the following:

> *"We have a clinic social worker that helps children, caregivers, and families with health-related problems, including facilitating compliance to treatment. The social worker also performs a comprehensive assessment of a patient's social, emotional, environmental, financial, and support needs and informs the health care team about these factors, which may affect the patient's health and well-being" (P2).*

In the same manner, another participant noted that:

> *"We have a professional social worker that provides counselling sessions to children and their caregivers. During these sessions, children and their caregivers are allowed to discuss their conditions and help them overcome challenges. The social worker also assists so much with adherence support" (P4).*

The study outcomes suggests that collaborating with other organizations that offer psycho-social support played a big and important role. Therefore, the Thuthuzela Care Centre was identified as the key partner. A participant stated that Thuthuzela is a facility that has been introduced as a critical part of South Africa's anti-rape strategy, to reduce secondary victims and to build a case ready for successful prosecution. Furthermore, it was revealed that not all children who are living with HIV are born with it, as some get raped by their family or community members. This is also in agreement with a study conducted by Meel (2003) which noted that some children contracted HIV through rape. Therefore, there is need for those children need to open rape case and see psychologists or other professionals, attend counselling sessions so to be able to make sense of difficult emotions' experiences and continue with their lives. One of the participant stated the following:

> *"Not all children and adolescents are born HIV infected, and some got raped; therefore, we are working with an NGO called Thuthuzela Care Centers that operate best in public hospitals close to communities where the incidence of rape is particularly high. The aim of working with this care centre is to turn victims into survivors, help children regain their strengths and cope with life challenges. The care centre is linked to sexual offenses courts, which consist of skilled prosecutors, social workers, magistrates, other NGOs and police" (P4).*

The findings of this study reveal that HIV infection affects all dimensions of a person's life-physical, psychological, social and spiritual. Therefore, the provision of individual support is very important as it helps children and their caregivers to cope more effectively with each stage of the infection and it equally enhances the quality of life. Furthermore, this study proved that healthcare workers are not alone in ensuring that children receive sufficient psychosocial support; there are other professionals and non-profit organizations that work with them to ensure and improve healthcare services. Bateganya, Amanyeiwe, Roxo, and Dong (2015) noted that support groups are initiated and supported by non-governmental organizations, civil society or community-based organizations and may convene in a health facility or the community. The following certifies the roles of community based organisations in facilitating support groups.

4.4.2. Support group services

The participants stated that children who are in HIV care also receive psychosocial support from groups that are facilitated by trained professionals or organizations to address the special needs of children living with HIV. The group serves the purpose of sharing experiences, improving self-esteem and enhance their coping skills and psychosocial functioning and support treatment adherence. UNAIDS and PEPFAR (2018) indicated that HIV care and support is important for people who are HIV infected so they can access treatment and get support for adherence to treatment to suppress the viral load. Adolescent Youth Friendly Support Group was one of the groups identified and was regarded as a very effective educational support group. The study discovered that support group services promotes services for HIV infected adolescents and youth with effective prevention, management, care, and support. Rotheram-Borus et al. (2014) mentioned that support groups provide health education and promote adherence to antiretroviral treatment. Participants indicated the following:

> *"The clinic has a program that is called Adolescence Youth Friendly Support Group (AYFS) that consists of trained clinic staff (nurses and community workers) that provides effective and friendly health services to young people living with HIV. From the program, children receive adequate psychosocial support, information, educational sessions and other communication services that promote their healthy behaviour. The program is for both parents and their children and they attend it on Saturdays. It is very effective as it allows children to express themselves about living with an HIV" (P1)*

Participant 2 also shared the same opinion:

> *"… AYFS is attended on Saturdays by children together with their parents and it is very effective as it provides helpful health information about HIV, including HIV prevention strategies and treatment management" (P2).*

Some of the participants also reported that there is an active NGO called Youth of Christ that provides spiritual support to children in HIV care. Lyon and D'Angelo ((Eds.) 2006) noted that spirituality is one of many ways that adolescents living with HIV and their families cope with the burdens of HIV. To elaborate, Szaflarski (2013) highlighted that spiritual interventions utilize the power of prayer and meditation to address spiritual struggle. Furthermore, the authors stated that spiritual interventions have focused on HIV related issues such as stigma and could improve individual outcomes through access to spiritual or social support and care or treatment for people living with HIV. Participants revealed that Youth for Christ believes that every child is precious and wonderfully made by God and deserve to live a life filled with hope and purpose, despite being HIV positive. Participants specified the following:

> *"… We are also working with NGO's like Youth of Christ, this organization provides children in HIV care with spiritual support that helps children to cope and feel loved regardless of living with HIV status. The organization also provide food packages for Saturday sessions" (P5)*
>
> *"… Youth for Christ is another supportive organization that helps children and youth living with HIV. The organization aims to give hope to children and youth by providing holistic development including mental, spiritual, social and physical help. The youth of Christ also gives children in HIV care an opportunity to become a follower of Jesus Christ" (P7).*

One of the study participants mentioned that there is also an NGO called Health System Trust that provides life skills education to children in HIV care. Based on the participant's narratives below, the organization offers counselling and food packages for children:

> *"Health System Trust is an old NGO that was established in the '90s, it helps in improving health equality. The organization provides life skills education, individual and group counselling sessions and also food packages to children in HIV care when attending the program" (P4).*

Based on the findings presented above, it is clear that a wide range of psychosocial support services is available for children and their families around the study location. Bateganya et al. (2015) argued that attending psychosocial support groups and programs could result in coping well with HIV and accepting being HIV positive, improve well-being and mental health among people living with HIV. Thus, it is significant for children to receive psychosocial support services that will keep them engaged in HIV care services and encourage them to adhere to their antiretroviral treatment. Given the above, the provision of psychosocial support help children improves their lives, develop better cognitive and emotional skills and cope with various challenges that one might be facing. However, healthcare workers appear to face multiple challenges in their work with children and these are discussed below.

4.5. Challenges experienced by healthcare workers in HIV care

Healthcare workers play a vital and life-threatening role in improving access and quality healthcare for the people. Tomori et al. (2014) mentioned that healthcare workers provide essential services that promote health, prevent diseases and deliver healthcare services to individuals and their families. However, there are challenges that healthcare workers experience as they put effort to ensure that children in HIV care are receiving effective healthcare services. In this study, different challenges were identified by participants (health care workers).

4.5.1. Lack of child-friendly counselling skills

Healthcare workers mentioned that they lack skills in children counselling and treatment management. This is inline with Rujumba et al. (2010) who also noted that healthcare workers lack counselling skills and Dageid et al. (2007) additionally mentioned that many healthcare workers are uneasy about treating children because of the lack of training and experience in this field. However, Kanekar (2011) stated that the diagnosis of HIV, together with pre-test and post-test counselling is important for psychosocial support establishment and de-stigmatization**.** In this study, participants revealed that they lack skills because they are not used to working with children. The following replies were specified:

> *"It is my first year working with children in HIV care, so I lack counselling skills of working with children as I am familiar with providing HIV counselling to adults" (P6)*
> *"I am struggling with working with children as they need patience and understanding which I lack as I am used at working with youth and adults who understand things much quicker than children" (P1)*
>
> *"Providing HIV care services to children is very challenging, some children refuse to take treatment and require counsellors or social workers who may not be available all the time. While others ask so many questions which need time to be answered yet clients are too many" (P3).*

The surviving literature has confirmed that child-friendly counselling helps children discover any concerns that may be causing difficulties in their social, emotional or cognitive development. Furthermore, the counselling process allows children to express challenging or confusing feelings in a safe environment with clear limitations (Burton, Pavord, & Williams, 2014). However, the findings of this study showed that healthcare workers are constrained by inadequate knowledge about pediatric HIV care and the lack of child friendly counselling skills. This shows that the provision of HIV care services such as HIV counselling and testing to children remains an uphill task for healthcare workers in HIV endemic. Allen and Marshall (2008) highlighted that the concerns of vulnerable populations, including HIV infected children are that they are often difficult and demand more patients from both their families and the health workers.

4.5.2. Children's inability to communicate verbally

Counselling and communication are the fundamental components of a holistic approach to caring for children living with HIV and can facilitate the expression of their concerns, worries and general perceptions, which in turn forms a basis for appropriate care interventions. However, it can be argued that because of children's young age, they may have not developed language abilities to communicate clearly. In line with Yusuf et al. (2015) argument, children are not comfortable when visiting healthcare settings, which could further contribute to the child's uneasiness. Therefore, it was not surprising to hear that some participants in this study felt that they were finding it difficult to communicate with children. In noting healthcare workers' barriers to providing effective HIV care services to children, Rujumba et al. (2010) stated that children are unable to express themselves, which makes it difficult for healthcare workers to communicate with them, especially on sensitive issues like HIV/AIDS. Regarding children's inability to communicate, the participants stated the following:

> *"Some children are fearful, and they cannot express themselves or explain much when having HIV-related discussions" (P1)*
>
> *"Some children are afraid of visiting clinics; as a result, they become afraid of talking freely or even responding to the questions I ask them" (P4)*

Some of the children were collecting their medication unaccompanied, and some of the health care workers were finding it difficult to have a meaningful discussion with children alone. The following as this participant indicated:

> *"Some children are sent alone to the clinic, and they cannot explain much. This makes the session difficult because I do not know what the child is thinking or if the child is even listening to what I am saying" (P5)*

Children’s inability to communicate could be attributed to some socio-cultural context; also, many of these issues may reflect the health workers’ inadequacy in handling and caring for HIV-infected children, coupled with the age limitations of the children (Rujumba et al., 2010).

The narrative above is an indication that healthcare workers are not full confident regarding working or engaging with children about HIV-related discussion. However it can be argued that the competence of a healthcare worker is important in ensuring the well-being of a child when he/she comes to the healthcare setting.

The first contact for children living with HIV or any child is their family environment; this includes interaction with parents or caregivers. The findings of the study suggests the relationship between a child and a caregiver at a micro-level is important when it comes to the healthcare of a child.

The above narrative indicates and certifies the dynamics of the ecosystem theory, the mesosystem is where a person's microsystems do not function independently but are interconnected and assert influence upon one another. These interactions have an indirect impact on the individual (Urdang, 2006). Based on the expressions shared by study participants; children living with HIV are depending on their caregivers

4.5.3. Caregiver’s unwillingness to disclose to children

The healthcare workers reported that a majority of caregiver’s have an attitude of unwillingness to disclose HIV status to children in HIV care. Drawing from study participants in some cases, caregivers refuse to have their children tested for HIV. In a previous study conducted in Gauteng and Mpumalanga provinces, Madiba and Mokgatle (2015) revealed that caregivers are often unwilling to approve HIV counselling and testing of their children, fearing that such action will lead to revealing their HIV secrecy to children. Moreover, Kidia et al. (2014) findings indicated that caregivers of HIV infected children normally assume that their children are too young to understand what HIV is and how they become infected. This results in many children, not knowing their HIV status. However, HIV testing and disclosure play a vital role in ensuring that the child is diagnosed early and access treatment is provided. The participants reported the following:

> *“Some of the caregivers are unwilling to have their children tested for HIV as they fear that their HIV positive status will be automatically revealed to us and they fear hurting their children” (P2)*

> *"Caregivers tend to be very protective and resist disclosure. Some of the caregivers fear telling their children about their HIV positive status because they think that their children are too young to understand their HIV status" (P7)*

> *"Some caregivers have stopped me from initiating the process of HIV disclosure to their children; they say it is not the right time to tell their children…" (P4)*

However, Beima-Sofie et al. (2014) illustrated that HIV disclosure is beneficial to children because it gives them a chance to understand their health condition and understand the importance of adherence to treatment and acceptance of their HIV status. However, the narrative above shows that caregivers might be unaware of the benefits of disclosure as they are the reason why some children in HIV care do not know their HIV status. Madiba and Mokwena (2012); Mahloko and Madiba (2012) and Oberdorfer et al. (2006) acknowledged that one of the major hurdles to HIV disclosure is that caregivers lack knowledge, skills, and guidance on how to approach disclosure to HIV-infected children. This shows that HIV disclosure is crucial for effective healthcare delivery in the management of HIV in children.

4.5.4. Missed clinic appointments and lost to follow-up

It attempts to better understand challenegs encountered by healthcare workers, the study learnt that some of the caregivers were inconsistent with treatment collection from the clinics. (Rujumba et al., 2010) mentioned that some caregivers of children in HIV care find it difficult to meet up with the clinic appointments frequently due to lack of money for transportation. As a result, some children would disappear and resurface when they are too ill. Some study participants reported the following:

> *"Caregivers of children in HIV care often miss their appointment dates and come to the clinic when the child is very sick and need to be hospitalized" (P3).*

> *"Caregivers delay treatment for their children as they assume that their child is better and no longer in need of treatment and its result in their children being defaulters" (P4).*

The literature suggests that in HIV management, treatment adherence includes continuing on a programme, attending scheduled visits, taking medicines as prescribed as well as lifestyle modification. Okoronkwo, Okeke, Chinweuba, and Iheanacho (2013) also noted that adhering to antiretroviral treatment is important for successful treatment outcomes. However, the findings of this study indicate that there are caregivers of children living with HIV who often do not to attend to their children's health because their children do not look sick and they only come to the clinic when the child is defaulting. This shows that adherence to treatment among HIV infected children is a major factor for the treatment success rate as poor adherence leads to higher defaulting rate and increases treatment resistance, which is contributed by ignorance of caregivers.

4.5.5. Shortage of staff members

The healthcare workers reported that there are challenges that are clinically related. However,the most disturbing is the shortage of staff members in HIV care, which puts a lot of workload on the limited staff leading to extended periods of appointments- caregivers and their children, therefore, wait for hours to be assisted. Rujumba et al. (2010) stated that the major challenge that healthcare workers in HIV care face is the inadequate number of counsellors, which results in patients waiting for long hours and healthcare workers becoming exhausted. Also, Vawda and Variawa (2012) mentioned that overtiredness is very common amongst healthcare workers as they work under extremely tedious conditions, dealing with a large number of patients daily and meeting death and misery daily; all of this without sufficient reimbursement, encouragement, and training. The following was noted:

> *"The main challenge that we face is the having is a shortage of staff members and that results in caregivers and children waiting for a very long time while we also get tired" (P3).*
>
> *"The clinic has a very large number of people enrolled for HIV care service, yet the number of healthcare workers trained to provide HIV care services is very short. It is very frustrating to work all day without resting." (P1).*

The shortage of staff members appears to be contributing to heavy workload and fatigue among healthcare workers. The study conducted by Vawda and Variawa (2012) indicated poor working conditions, poor facilities and long working hours have resulted in many healthcare specialists preferring to work in private sectors where working conditions are better, while some prefer to work abroad. In light of this, the work context appears to impact the quality of psychosocial care and support children receive from health care workers. Caregivers are key to supporting children who are living with HIV. The following section discusses the challenges encountered by caregivers in caring for children living with HIV.

4.6. Challenges experienced by caregivers of children in HIV

The caregivers revealed that taking care of children living with HIV comes with many challenges. Schulman-Green et al. (2012) stated that people who are enrolled in HIV care need to adhere to treatment, meet healthcare workers, and make changes to their life in terms of managing HIV and their health and coping with challenges such as stigma. This poses major medical, social and economic challenges. Drawing from the data collected from caregivers, different challenges experienced by caregivers were discussed below.

4.6.1. Financial difficulties

The study discovered that financial burden is one of the challenges encountered by most caregivers of children living with HIV. South Africa is one of the countries with a high unemployment rate. Consequently, many families depend on social security income such as foster care grants and child support grants (Hall, 2010). Traveling costs for clinic appointments were reported as a burden for many participants since they are required to also accompany the child during these visits. The study revealed that caring for children on ARV medication often resulted in caregivers borrowing money, accumulating and living in debt, footing or hiking for lifts to get access to the health facilities for follow-up. The following was discussed:

> *"I am not working, and sometimes I do not fetch my grandchild treatment because of not having money to go to the clinic as it is far from where we stay. I will miss the appointments dates maybe for two months in a row…" (PC).*
>
> *"Since I do not have a proper job and am the only one who supports my child, I feel the financial burden. Sometimes when I don't have money for transportation, I hike or walk to the clinic" (PE).*
>
> *"Among the challenges that I experience, it an issue of fetching treatment to the clinic. Sometimes I will not have money to come to the clinic, and I would borrow it from my neighbours and pay it back with my old-age pension" (PH).*

According to these findings, financial problems often contribute to non-adherence to treatment since caregivers are sometimes unable to fetch medications for their children. Tuller et al. (2010)

confirmed that caregivers face difficulties as they have to choose between using their income for transportation to the clinic or to satisfactorily feed their families. As a result, their children may miss their scheduled clinic appointments, thus disturbing their adherence routine.

4.6.2. Adherence to treatment

Non-adherence to medication in children who take ARVs is one of the major challenges the participants reported. Caregivers are expected to remind children to take medication and ensure that they do not miss daily doses. The study participants communicated that helping children to remember to take their medication daily was a huge problem for caregivers. Some of the caregivers who are working stated that returning home late from work when the child was already asleep contributed to poor adherence monitoring. Moreover, medication-related factors such as the medication smell and the big size of some of the tablets children taken have an impact on adherence. This is qualified by the following statements shared by the participants:

> *"Adherence to treatment is the main challenge, I am tired of forcing her daily to take treatment. I come back home from work tired and sometimes I forget that she needs to take her treatment and she will also not remind me." (PA).*
>
> *"The challenges that I am currently facing is adherence to treatment, my daughter complains about the pills saying that they smell bad, she can't swallow. Sometimes she will dodge taking treatment by sleeping early or by doing school-work non-stop" (PD).*
>
> *"The challenges that I am currently facing is adherence to treatment, my daughter complains about the pills saying that the pills are "too big" so she can't swallow. Sometimes she will not swallow the pills and go vomit outside secretly" (PH).*
>
> *"... The most challenging thing is managing treatment adherence. When it is time for him to take treatment, he would start telling me that he is tired of drinking the pills" (PF).*
>
> *"He ran away at the time of taking medications. I used to chase him, and he will come back and pretend as if he is drinking his pills meanwhile, he was hiding the pills to be taken behind the curtains. I beat him with a belt to force him to take treatment" (PB).*

Based on these findings, socio-economic, medication-related factors and child-related factors contribute to poor treatment adherence. The findings of this study revealed that children in HIV care complain about both the big size of pills and the bad smell which is likely to results in them vomiting. These finding are similar to the study conducted by Williams et al. (2018) also discovered that children living with HIV also reflected poor adherence to antiretroviral treatment because of side effects such as vomiting whilst some children find it hard to swallow the pills saying that it was too big for their throats. However, Mehta et al. (2016) argue that adherence to antiretroviral treatment is an important aspect in the health of HIV infected children, it has been found to reduce the virus and decrease the occurrence of opportunistic infections and improve the growth and development of children.

One of the participants indicated that in ensuring that her child takes treatment, she beat him with a belt. According to Afifi, Mota, Dasiewicz, MacMillan, & Sareen (2012), physically disciplining children has a dramatic impact on the child as it deliberately causes physical pain or discomfort to a child in response to some undesired behavior. In many cultures, parents have historically been regarded as having the right, if not the duty, to physically punish misbehaving children in order to teach appropriate behavior. However, Gershoff (2010) mentioned that physical punishment leads to more aggressive behavior in children and less long-term obedience. In understanding that children's brain is not fully developed and they are not capable of greater self-control, caregivers must be more patient with their children in treatment till they fully understand the importance of taking treatment daily without being reminded or beaten up, although in societies physical punishment is regarded as a discipline or control. Evaluation of adherence at regular intervals should be an important aspect of health care for adolescents because patient adherence is important for the success of any medical treatment (Taddeo, Egedy, & Frappier, 2008).

4.6.3. HIV disclosure

HIV disclosure is reflected as an important phase in HIV care however, the study ahs learnt that it is a difficult process for caregivers to initiate. One of the participants noted that she does not know how to start telling her child about her HIV status while other participants fear the reaction of the child after being told. The following reasons for non-disclosure were identified by caregivers.

> "*Currently, I am facing a challenge of HIV disclosure. My granddaughter is 12 years old and she is always asking me a question concerning her treatment and clinic visits. I do not know where I will even start telling her that she is HIV infected" (PH).*

> *"The reasons for not telling her is that I am afraid that she will be angry at me I have kept this from her, and I do not know how to tell her about this" (PD).*
>
> *"My granddaughter is still young, she knows nothing about HIV, so I do not want to confuse her" (PA).*

The findings of this study show that HIV non-disclosure is shaped by a variety of circumstances. Kidia et al. (2014) revealed that caregivers of HIV infected children normally assume that their children are too young to understand what HIV is and how they become infected. This shows that caregivers play a part in delaying the process of HIV disclosure.

Nonetheless, Linda (2013) highlighted that HIV disclosure is of benefit to HIV infected children considering the need to promote antiretroviral treatment adherence. It is key to stress that some study participants revealed that they have disclosed the HIV status to the child. The major reason is being the inquisitiveness of the child. Mahloko and Madiba (2012) revealed that HIV infected children frequently ask questions about the reasons they are taking treatments. Moreover, they want to know the nature of their disease which pressures the caregiver to disclose the child's HIV status. The following was indicated:

> *"He (referring to a child) wanted to know why he was taking the pills every day, so I had to explain to him that he has a virus and he must take his treatment every day so that this virus won't make him sick" (PB).*
> *"When it was time for her to take her treatment, she would ask a lot of stressful questions like "what are these pills for, why my sister is not taking these pills?". So, to avoid answering these questions now and again, I decided to tell her" (PC).*
>
> *"I told him about his HIV positive status because I wanted him to be responsible for his daily treatment and know that as he grows, he must take care of himself" (PF).*

The findings of this study show that caregivers of children living with HIV are somehow pressured to disclose HIV status to their children. However, as stressed by the literarure; it is beneficial to them as it avoids answering stressful questions and makes the child responsible for his/her treatment. In supporting these findings, Hayfron-Benjamin, Obiri-Yeboah, Ayisi-Addo, Siakwa, and Mupepi (2018) stated that HIV disclosure to infected children is essential for both health maintenance and HIV prevention as the child grows. Therefore, disclosure is a process that should be initiated early to children to avoid the widespread of HIV as they survive to youth and adult stage.

4.6.4. Caregiver's perspectives on psychosocial support intervention Provided

Although the caregivers experienced several challenges as mentioned above, it is significant for their HIV infected children to receive HIV care services and psychosocial support services to cope with HIV. Jose et al. (2018) noted that the provision of HIV care services and psychosocial support is important to HIV infected people as it helps them to maintain their health, suppress their viral load and assist people living with HIV with coping with HIV-related challenges. The participants revealed that they are grateful for HIV care services, including treatment and counselling provided to their children. The following was revealed:

> *"I am thankful for HIV care services provided by healthcare workers, our children receive free antiretroviral treatment and counselling which help them to survive and live a normal life like other children who are not HIV infected" (PB).*
>
> *"I am pleased with the HIV care services provided to my child. Through the provided support groups, she now knows her HIV status and understands what HIV is" (PA)*

Both the child and the caregiver appear to benefit from counselling and care provided by the healthcare workers. The evidence is as follow:

> *"When my grandchild, she tested HIV positive, I received counselling which helped me to accept that my grandchild is HIV infected and counselling helped me understand that HIV does not kill if you are taking treatment accordingly" (PD).*
>
> *"The nurses never get tired of providing counselling and share words of encouragement whenever we come to collect treatment and whenever I am having challenges concerning caring for the child, I tell her, and she will help me with a smile. Or transfer me the social workers if she cannot assist me…" (PF)*

The participants reported a range of psycho-social support services they receive from the clinic which help gain more knowledge about HIV and their health. The following was discovered:

> *"… There is are educational programs like Adolescent Youth Friendly Support Group (AYFS) and Youth of Christ that we attend to with our children on Saturdays. These programs are very useful as they teach us about HIV and other diseases" (PF).*

> *"...with awareness programs provided by the ladies from Health System Trust, we are always motivated and encouraged about raising healthy HIV infected children." (PG)*

The study revealed that support groups serve important roles in the lives of HIV infected children and their HIV affected caregivers as they get an opportunity to learn more or new information on HIV and get motivated. Loeliger, Niccolai, Mtungwa, Moll, and Shenoi (2016) noted that a supportive attitude of healthcare workers during the provision of HIV care services is crucial to build rapport and establish a partnership of care between each other. This is supported by the statement expressed by participant (PF) shared above, she declared that she is encouraged to discuss openly and honestly with the healthcare worker about anything that concerns or worries her regarding the child. Caregivers of children in HIV care are happy with the support that they receive from healthcare workers.

During the discussion with caregivers, they recommended the need for an exclusive support group for only caregivers where they will be able to discuss certain issues that they experienced and help one another in raising healthy HIV infected children. The following was indicated:

> *"I've received counselling for myself as am also living with HIV and when my daughter started receiving HIV care services, I also received counselling which was based on how to raise a health HIV positive child, which helped me a lot. But I would also like to receive more counselling (group sessions) with other mothers that will keep us encouraged especially in ensuring that our children take treatment as they should" (PC).*
>
> *"... I would like it if we as caregivers have our group sessions with nurses because there are a lot of challenges that we are coming across in raising our HIV infected children, we need to be empowered. Maybe if I talk to others with the challenges that I have, they can help me come up with solutions. The participant made an emphasis that "ayikho into ehlula abafazi" which simply means there is nothing women cannot handle ..." (PE).*
>
> *"It would be nice if we as caregivers of children living with HIV can have our support group, where we meet maybe once a month just to share our feelings and experiences" (PA)*

The study findings showed the importance of the provision of HIV care services and psychosocial support in helping caregivers and children adjust and cope with being on HIV care program, this includes accessing antiretroviral treatment and support services. However, caregivers feel the need to have their support group where they share their feelings and experiences. Purgato et al. (2018) stated that focused psychosocial support services have an important role in protecting people against negative outcomes and promote the well-being of people. This supports the caregivers call for their own support group. Communicating with children require healthcare workers to be age-appropriate and meet the child's level of understanding. The following theme discusses how healthcare workers communicate with children in HIV care.

4.7. Child-friendly communication tools

Communication is a central feature of humanity. According to UNICEF (2011), communication with children should be age-appropriate and child-friendly through the use of child-appropriate language, characters, stories, music and model positive interaction, and critical thinking. In this study, healthcare workers revealed that they use two strategies to communicate with children in HIV care; which are electronic tablets for storytelling and child-friendly toys.

4.7.1. Usage of electronic tables for storytelling

All participants in this study revealed that they use electronic tablets to communicate with children in the HIV care services provided by the Department of Health. Participants noted that the use of electronic tablets as educational tools has positive effects on children. The electronic tablets offer opportunities for children to learn and stimulate his/her mind because it featured apps with child-friendly awesome sound. The featured apps result in children being able to engage, cooperate and willing to speak with healthcare workers. Study participants revealed that the electronic tablets consist of different short stories that children watch for less than 10 minutes; these stories help to develop a child's imagination by introducing the child to the healthcare setting. The participants in this study noted that they take the electronic tablets home because of the few break-in situations that have occurred in the clinic.

> *"In communicating with children, we use electronic tablets that consist of short stories that are less than 10 minutes long and very educational. The stories presented in the tablets have a good effect on children as it provides knowledge about healthcare setting including what is happening in the clinic and it allows children to think and ask questions about the story. These tablets do not stay at the clinic, we take these tablets home with us because there was twice a there was a break-in, they took all of these tablets" (P1)*

Participants in this study noted that the positive element about these short stories is that they are realistic and play-based. These stories differ and are purposely for different clinic visits days, some are about children who are living with HIV and some are about sick children, but all stories represent children who require healthcare services. Makaudze (2013) noted that the purpose of storytelling is to instill a sense of hope in children and give them the strength to carry through with the belief that things will always turn out all right. These stories give sick children hope of getting better as they have visited the clinic.

Participants communicated that children who visit a clinic for the first time or recently started receiving HIV care service, watch the story of "Papa Noah" which is divided into two sections. The first section of the short story is about a grandfather who has a sick coughing child and he takes the child to the clinic; the child gets tested for HIV which is presented as a "germ" in the story. Participants of this study indicated that the first section presented in the story helps in preparing the child for HIV blood tests. The following participant indicated that:

> *"The Department of Health has provided us with electronic tablets that help us to communicate well with children. The tablets have a different story that we use when children come for HIV testing or follow updates. When the child comes for the first time to the clinic or recently started accessing HIV care service, he or she watches the story of papa Noah, who takes his sick coughing grandchild to the clinic. The story has two scenarios, one is before HIV testing and the other is after HIV testing. The usage of these tablets with the presented story is very helpful as it prepares the child for blood tests and receiving treatment" (P3).*
>
> *"The use of tablets with the presented story is operative as it makes the child ready for blood tests, when watching the story, the child's get an idea of what is going to happen after the child has watched the story, some children tend to ask questions like "Are you going to inject me like Noah?" which becomes makes it easy to initiate communication" (P6).*

This gives the clarity that communication tools are an essential component in a healthcare setting, and it shows that the usage of tablets helps children to become aware of what is about what is happening to them. Beato and Telfer (2010) mentioned that health communication tools are intentionally designed to simultaneously address multiple psychosocial and behavioural issues that may act as barriers to risk reduction or as motivators of service. After watching the short story children get a chance to communicate with the healthcare worker, as study participants communictaed that children normally ask questions. This shows that healthcare workers do not only depend on electronic tablets for communication. They also do communicate with children even without the tablets.

The second scene of papa Noah's story is provided to HIV infected children only after they have been tested. It aims to prepare the child for the results. In the story, the healthcare worker tells the child that he has an awake germ (HIV) and that the germ must be kept asleep all the time by taking treatment (antiretroviral treatment) daily and if the germ is awake the child will become sick. The story is basically about being communicated about HIV diagnosis and accessing antiretroviral treatment accordingly. This is supported by the following:

> *"The second story of papa Noah continues after the child has tested HIV positive. In the story, HIV is represented as an awake germ which requires the child to take treatment (antiretroviral treatment) every day so that the germ will be kept asleep. The use of tablets with the presented story is very helpful as it prepares the child for blood test results and accessing antiretroviral treatment. It also emphasizes the importance of taking the treatment daily so that the germ will be kept asleep" (P1).*
>
> *"In the second story, the child has an awake germ (HIV) which requires the child to take antiretroviral treatment to keep the germ asleep. The use of tablets with the presented story is very supportive to us as it makes the child ready for receiving treatment" (P4).*

The study by Kajubi et al. (2014) noted that when communicating with children, one must consider their different abilities, needs at different ages and must be central to the child age-appropriateness. Also, Tindyebwa et al. (2004) detailed that when communicating with a child in HIV care, the communication should be in a simple language based on the child's age and understanding to allow the child to participate. Thus, the usage of the term "germ" in representing HIV shows that healthcare workers use language that is age-appropriate and that children can understand. However, the findings of this study did not discover how healthcare workers check the child's level of understanding when it comes to HIV. Tindyebwa et al. (2004) mentioned that checking for child understanding is an important step in the learning process and is beneficial as it provides the best starting point for planning for the next step of supporting the child's progress.

The tablets have other features that are useful in the process of providing HIV care services to children, one of the participants noted that in making children feel comfortable and relaxed, there is a child-friendly exercise that has facial expressions. Participants revealed that the usage of facial expressions helps in giving them an idea of how the child is feeling on that particular day. This is supported by the following:

> *"There is also a facial expression quiz, we use this quiz to get an idea of how the child is personally feeling and how the child is coping with the treatment so to give the child the help that he/she needs" (P2).*

This suggests that healthcare workers are aware of basic child-friendly communication tools that help them assess the child's emotional well-being during the clinic visit. Facial expressions are important parts of how we communicate and how we develop impressions of the people around us (Staebler et al., 2011). The findings revealed that facial expression quiz consists of different types of emotional reactions, including sad, happy, angry, surprised faces etc. and the child is shown these faces so he/she can choose one that resembles how he/she is feeling. This helps healthcare workers in engaging with children to understand how the child is feeling and what contributes to those emotions using a child-friendly language. In support to this, Harley (2016) stated that facial expression quiz is one of the more important aspects of human communication as it is not only communicating thoughts or ideas but also emotions such as anger, disgust, fear, happy, sad, surprise, embarrassment, interest, pain, and shame. This shows that healthcare workers have access to some of the useful child-friendly communication tools in HIV care and treatment programs. However, it is unclear whether they use these tools consistently or once when the child visits the clinic. The following theme will be discussing how healthcare workers are trained or prepared to provide HIV care services to children in need.

4.8. Training of healthcare workers

Healthcare workers play the central role in HIV care management including HIV counselling and testing, HIV prevention and provision of HIV care and support (Driessche, Sabue, Dufour, Behets, & Van Rie, 2009). The participants in this noted that before they started providing HIV care services to HIV infected people including children, they received professional training from the Department of Health.

4.8.1. Professional healthcare training

All participants in this study stated that they have attended Nurse Initiated Management of Antiretroviral Treatment (NIMART) training, which is the program that is designed for nurses who are working at health sectors in a hospital where HIV positive patients access HIV care services and other communicable diseases. The following was revealed:

> *"I have attended NIMART training that was organized by the Department of Health a year ago which help with providing integrated basis knowledge mainly on HIV, TB and STI's in association with communicable diseases" (P3)*
>
> *"In 2018, I attended NIMART training that was organized by the Department of Health which helps with providing included basis knowledge mainly on HIV and strategies to improve antiretroviral treatment services" (P6).*
>
> *"I have attended NIMART training once in 2017, whose aim was to capacitate nurses who work at HIV care services. The training was on HIV and more on antiretroviral treatment" (P7)*

Although health workers acknowledged that they were provided with training before they started providing HIV care services to people who are in need and living with HIV; most of the health workers stated that they still need more training sessions. Some study participants felt that further training will make them feel fully equipped with everything they need to provide effective HIV care services to children in HIV care. Mataboge et al. (2014) uncovered that training programs are essential for healthcare workers to know how to access HIV care services for themselves and patients in need without any fear. The following findings emerged:

> *"I am trained but not fully trained to provide appropriate HIV care services to children living with HIV. We need to be specifically trained on how to work with children in HIV care. I am used in providing HIV care services to adults and I find it very difficult to communicate HIV with a child in a manner that the child understands" (P6).*
>
> *"… but I would like to attend more training that will prepare me to provide HIV care services to children, improve my child-friendly communication skills and help us work excellently with children" (P4).*

> *"I would truly appreciate it when the department could offer us with more training. Maybe have a training every after three months just to remind us how things should be and help us improve in what we already know" (P3)*

Vawda and Variawa (2012) noted that healthcare workers play a vital role in the implementation of the provision of health care services. They have the responsibility of ensuring that the government's health policies are translated into effective and efficient service delivery. Thus, healthcare workers need to be fully armed with knowledge, training, and resources that they need to provide effective HIV care services to those enrolled in HIV care.

4.9. Conclusion

This chapter has detailed the narratives of participants on the provision and implementation of psychosocial support services for children receiving HIV care services. The findings of the study represented in chapter 4 indicate that Pinetown Municipal Clinic has two types of a psychosocial intervention for HIV infected children, namely individual (Social Worker and Thuthuzela Care Centre) and psychological support groups (Adolescent Youth Friendly Support Group, Youth of Christ and Health System Trust). These psychosocial support groups deal with issues around HIV care, which includes HIV testing, counselling and treatment programs, with the aim to increase the child's knowledge about HIV and address the psychosocial needs of children. The study also revealed communication tools that healthcare workers use to communicate with children in a child-friendly manner and aged-appropriate style. The findings of the research highlighted the challenges experienced by healthcare workers and caregivers in the process of providing HIV care services to HIV infected children. Tthis chapter has a detailed review of the research results was presented, revealing the psychosocial support services provided to HIV infected children enrolled in HIV care.

CHAPTER 5 - CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

The previous chapter provided findings of the study and a detailed discussion based on the provision and implementation of psychosocial support services for children receiving HIV care from Pinetown Municipal Clinic. This chapter evaluates the level to which the study's aim, objectives and questions were achieved. It will provide a brief discussion on the objectives of the study, recommendations and, conclusions that emanated from the findings.

The key objectives that the study addressed were:

1. To identify the types of psychosocial support services provided by healthcare workers to children in HIV care,
2. To detect challenges experienced by healthcare workers when providing psychosocial support services to children in HIV care,
3. To understand the perspectives of caregivers about the impact and quality of psychosocial support services they receive with their children in HIV care,
4. To identify the tools and strategies that healthcare workers use to communicate with children in HIV care, and
5. To determine how healthcare workers are trained and prepared to communicate with children in HIV care.

In the discussion, the researcher will be comparing the study findings and the literature reviewed to give meaning to the study. This section will also draw from the theoretical framework employed to guide study.

5.2 Overview of the achievement of the main aim and objectives of the study

The aim of this study is to explore the provision and implementation of psychosocial support services for children receiving HIV care from Pinetown Municipal Clinic.

5.2.1 Objective 1: To identify type of psychosocial support services is provided by healthcare workers to children in HIV care.

To determine the types of psychosocial support interventions provided by healthcare workers to children living with HIV, individual interviews were conducted with 7 healthcare workers. Both the literature and the findings of the study have confirmed that HIV is one of the chronic illnesses that require care and support. In the literature review, Skovdal et al. (2009) stated that chronic illnesses such as HIV require careful management and adjustment by the HIV infected person, healthcare workers and their caregivers. The findings of the study represented in chapter 4 indicated that Pinetown Municipal Clinic has two types of psychosocial intervention for HIV infected children, namely through individual (Social Worker and Thuthuzela Care Centre) and psychological support groups (Adolescent Youth Friendly Support Group, Youth of Christ and Health System Trust). These psychosocial support groups deal with issues around HIV care, which includes HIV testing, counselling and treatment programs, with the aim to increase the child's knowledge about HIV and address the psychosocial needs of children. This corresponds with what Bateganya et al. (2015) stipulated when they highlighted that HIV programs use support groups as an opportunity for healthcare professionals to provide information to people living with HIV.

Drawing from the Psychosocial Framework of 2005–2007 of the International Federation, psychosocial support can be defined as a process of facilitating resilience within individuals, families and communities by respecting the independence, dignity and coping mechanisms of individuals and communities. The study recognises that a number of participants reported that psychosocial support programmes help children to cope with HIV and treatment. The findings have also revealed that psycho-social support programs for children living with HIV are provided by a multi-disciplinary team and collaboration with external stakeholders (Botton, 2008). This relates with what Hewitt, Herdman, and Holland (2004) asserted when they reported that psychosocial support services are usually provided by a multi-disciplinary team and collaborative stakeholders, which includes mental health professionals, such as psychologists, social workers, counsellors, specialized nurses, clergy, pastoral counsellors, and others. This supports the significance of working with other professionals in addressing the childrens psychosocial needs. Hence, this research has successfully identified different types of psychosocial support provided within the study milieu.

In line with the findings, psychosocial support services provide children with adequate support, information, educational sessions and other communication services that promote their healthy behaviour. A majority of participants noted that available support groups provide caregivers and children with useful health information about HIV which includes HIV prevention strategies and treatment management. This is similar to Hilary (2003) argument that psychosocial support is important because it includes the provision of mental health counselling, education, spiritual support, group support for people who are in need. The findings of this study indicated that children living HIV have access to ongoing psycho-social support which is provided by health care workers and external non-governmental stakeholders. However, there is adequate access to psychosocial support services to HIV infected children. It also highlighted that there are challenges that health care workers are faced with, which affect their effectiveness in handling children in HIV care.

5.2.2 Objective 2: To identify challenges healthcare workers experience when providing psychosocial support services to children in HIV care.

As mentioned in Chapter two, it has been extensively highlighted that multiple challenges are encountered by healthcare workers in provision of HIV care services to children. In identifying these multiple challenges, healthcare workers were individually interviewed. The majority of healthcare workers noted that due to inadequate child counselling skills, they could not provide proper and effective counselling to children in HIV care. This was because some were used in working with adults, while others stated that they were new in HIV care settings. This is similar to what was previously stated by Rujumba et al. (2010) that fewer healthcare workers had been trained in pediatric HIV care. The findings of this study revealed that lack of child counselling skill makes it difficult for healthcare workers to work effectively as they are not able to provide age-appropriate counselling. These findings show that healthcare workers need an additional training in working with children.

The majority of healthcare workers interviewed also stated that it was difficult to work with children because some children cannot express themselves, and they had less experience of working with children in the HIV program. In addition, they noted that children required more time for counselling. As a result, healthcare workers find it difficult to understand the child's level of understanding regarding HIV and in knowing whether the child is getting the help that he/she needs. This relates to the findings of Rujumba et al. (2010) that children are nothing like adults, they need patience and understanding, which most healthcare workers lack as they are used in working with adults. Wiener et al. (2007) also mentioned that children are more emotional than adults, hence it becomes more difficult to communicate with them on sensitive issues like HIV.

Winestone et al. (2012) emphasized that HIV testing and disclosure play a vital role in ensuring that the child is diagnosed early and there is adequate access to antiretroviral treatment. This study revealed that among complicated challenges that healthcare workers experience is child disclosure. Healthcare workers stated that they are constrained by the unwillingness of caregivers to disclose the childrens health status, this includes the refusal to test for HIV and disclosing the HIV status to the infected child. They noted that caregivers of children with HIV refuse to disclose the child's HIV status to the child because they think the child is too young to understand HIV. Some feel like it is not the right time to disclose while other fear that their HIV status will be automatically known, particularly those who are the biological parent of the child living with HIV.

Similarly to the literature review, Kidia et al. (2014) reveal that caregivers of HIV infected children generally assume that their children are too young to understand what HIV is and how they become infected. In addition, Rujumba et al. (2010) also noted that some caregivers, especially males, are unwilling to have their children tested for HIV due to fear of being identified with HIV infected child. Moreover, they fear that if the child's HIV result is positive, people would think that the caregiver is also HIV positive. Some caregivers prefer to keep the child's HIV status private due to the fear of unforeseen consequences on the child.

The shortage of health care workers in HIV care poses more challenges to healthcare workers as it results in heavy workload and exhaustion. Vawda and Variawa (2012) also identified a shortage of staff workers as one of the crucial problems that healthcare workers experience. Poor working conditions, long working hours and low wages are commonly shared challenges. As a consequence, many healthcare professionals prefer to work for private sectors where working conditions are reportedly better whilst some choose to go and work abroad. Thus, the above-mentioned factors contribute to the challenges faced by healthcare workers when it comes to working with children in HIV care.

5.2.3 Objectives 3: To understand the perspectives of caregivers about the impact and quality of psychosocial support services they receive with their children in HIV care.

The findings of the study presented in chapter 4 indicated that caregivers are pleased with HIV care services provided to their children. The provision of psychosocial support groups such as

Adolescent Youth Friendly Support Group, Youth of Christ and Health System Trust etc. plays a significant role in their children living with HIV and parents especially in relation to gaining more information about HIV that assist them to cope and live a healthy lifestyle with their infected children. As highlighted in chapter two, Mavhu et al. (2013) mentioned that children living with HIV have different clinical needs; this includes health support needs, psychosocial support needs and social protection support needs in order to strengthen their ability to cope with HIV to improve adherence to treatment. The study also discovered that support groups are important as healthcare workers because the facilitators allow children and caregivers to share their feelings and experiences, share information on treatment and resources. Furthermore, caregivers mentioned that they are encouraged to discuss openly and honestly with the healthcare worker about anything that concerns and worries them regarding children. This serves as an important tool in building the cordial relationship between the caregivers and support group facilitators which will give the openness required to manage the children living with HIV adequately. Vermund et al. (2014) also noted that a supportive attitude of healthcare workers during the provision of HIV care services is crucial in order to build rapport and establish partnership of care between themselves.

Deeks et al. (2013) noted that psychosocial support encompasses continuous counselling for children who live with HIV, treatment adherence support, assessment of mental health issues, HIV disclosure, family support and educating children about HIV. The study also revealed that caregivers of children receiving HIV care would like to have their own counselling program, which will focus on certain issues that they experience in caring for their HIV infected children. Particularly on the issue of HIV disclosure and adherence to treatment. This shows that caregivers of HIV infected children are having HIV care challenges as well. Therefore, they need support services to strengthen their coping abilities, emotional wellbeing and provide strategies of managing HIV-related challenges such as adherence and HIV disclosure.

Mafune et al. (2017) asserted that HIV infected children depend solely on their caregivers for treatment management. The majority of caregivers interviewed reported financial issues. Financial issues reselts from by transportation costs to meet clinic appointments and get antiretroviral pills. The findings revealed that caring for children enrolled in antiretroviral treatment often resulted in caregivers borrowing money, accumulating and living in debt, footing or hiking for lifts to get access to the health facilities for follow-up. Tuller et al. (2010) confirmed that caregivers face problems time and again as they have to choose between using their income for transportation to the clinic or to satisfactorily feed their families. Considering the above mentioned, financial issues can have a negative impact on caregivers in meeting the basic needs of the whole family, including HIV infected children in their care.

The results of this study exposed that treatment management is an issue that caregivers of HIV infected children experience. Caregivers noted that their children find it very hard to take treatment due to spiteful smell, while others say the pills are big. This links with what was noted by Williams et al. (2018) when specified that most children living with HIV refuse to adhere antiretroviral treatment because they are vomiting due to the pills unpleasant smell while some children find is hard to swallow the pills saying they are too big for their throats. However, Mehta et al. (2016) mentioned that adherence to antiretroviral treatment is an important aspect in the health of HIV infected children, it has been found to reduce the virus and decrease the occurrence of opportunistic infections and improve the growth and development of children.

The findings of this study made it clear that there are reasons and experiences that made caregivers decide to disclose or not to disclose the HIV status of their child. The major reasons for caregivers to disclose the HIV status to the HIV infected child is because they want the child to be responsible of their daily treatment. While others disclose because their children were inquisitive. Mahloko and Madiba (2012) revealed that HIV infected children frequently ask questions about the reasons why they are taking treatment as well as wanting to know the nature of their disease which pressures the caregiver to disclose the child HIV status. Whiles Mafune et al. (2017) acknowledged that some caregivers were bound to disclose the HIV status to their HIV infected children because some children were not adhering to antiretroviral treatment. This shows that there is something that drives caregivers to disclose HIV status to their infected children.

The reason why some of the caregivers choose not to disclose the HIV status of the child is that they think that their children are young to understand. Some are afraid that their children will react with anger, while some caregivers feel like it is not their responsibility to disclose the child’s HIV status. Kidia et al. (2014) also revealed that caregivers of HIV infected children normally assume that their children are too young to understand HIV. One of the caregivers noted that she does not know how to start with the process of HIV disclosure. In agreement with the findings of this study, Kennedy et al. (2010) mentioned that caregivers are believed to delay or avoid the process of HIV disclosure of an HIV positive status to children because they do not know how to disclose properly. This shows that certain circumstances shape HIV disclosure or non-disclosure.

Apart from challenges that caregivers of children living with HIV experience, they are provided with some level of care and support. The provision of support such as counselling is regarded as helpful as it reduces depression. In support to this, Reinhard, Given, Petlick, and Bemis (2008) stated that counselling is effective in improving the quality of life for caregivers. To understand the perspectives of caregivers about the impact and quality of psycho-social services they receive as well as the support provided to their children in HIV care, 8 caregivers of children receiving HIV care were individually interviewed. According to Mugavero et al. (2013), the provision of HIV care services and psychosocial support is important to HIV infected people as it help them to maintain their health and prevent the transmission of HIV to other people; it help to improve the prevention and management of HIV interrelated infections; and assist people living with HIV with coping with the challenges of living with HIV.

5.2.4 Objective 4: To identify the tools and strategies that healthcare workers use to communicate with children in HIV care.

In the context of HIV, Vermund, Mallalieu, Van Lith, and Struthers (2017) noted that communication can encourage people to get tested, obtain their results, support access to antiretroviral treatment, connect people living with HIV to care, support maintenance in care, and help reduce HIV related stigma and discrimination. In communicating with children, healthcare workers revealed that the South Africa Department of Health provided them with child-friendly and age-appropriate electronic tablets. These tablets consist of educational apps like stories and facial quiz. The stories uploaded in tablets are less than 10 minutes and they are very useful because they give the child an idea of what is happening in health settings, mostly in HIV care. This includes the process of HIV testing, counselling, HIV disclosure and the provision of antiretroviral treatment. This links with what was stated by Beato and Telfer (2010) when mentioned that health communication tools are intentionally designed to simultaneously address multiple psychosocial and behavioural issues that may act as barriers to risk reduction or as motivators of service.

The study by Sariah et al. (2016) revealed that healthcare workers use tools such as toys and books to communicate with children about HIV. Some healthcare workers used a book called "Policeman," and they talked to the child about the role of the policeman in protecting citizens, with the aim to emphasize the importance of adherence to treatment. To that effect, McLeod (2018) argued that any communication with children must be child-centered and age-appropriate friendly.

5.2.5 Objective 5: To determine how healthcare workers are trained and prepared to communicate with children in HIV care.

Healthcare sectors today are undergoing rapid transformation in terms of quality of service delivery, technology, operations and workforce management (Tomori et al., 2014). Healthcare workers and HIV counsellors attended Nurse Initiated Management of Antiretroviral Treatment (NIMART) Training before initiating the process of HIV care. The process of HIV care includes HIV testing, counselling and HIV disclosure. Healthcare workers revealed that the program is designed for professional nurses who are working in health sectors in a hospital where HIV positive patients access services. Moreover, the training help with providing integrated basis knowledge mainly on HIV, TB and STI's in association with communicable diseases.

The need for further training was reported as a lack of child counselling skills was reported as a major gap. Dageid et al. (2007) mentioned that many healthcare workers are concerned about treating children because of their 'lack of training and experience' in this field. In relation to HIV counselling and testing for children, Rujumba et al. (2010) also noted in the same vein that healthcare workers lack counselling skills is a disservice to HIV care. Similarly, McCarthy, O'Brien, and Rodriguez (2006) stated that a number of healthcare workers require HIV training. To do this, such a program will require a comprehensive training plan, a clear assessment of ongoing training needs, a plan to operationalize training on a large scale, and adequate funds budgeted for training. Implicatively, despite the fact that healthcare workers are trained, there is still a need for more training that will ensure that they are fully prepared to work with HIV infected children.

5.3 Recommendations

The following recommendations are made based on the study findings and discussion presented in the previous chapter and this chapter.

5.3.1 Recommendations for social work practice

This study highlighted the importance of psychosocial support; therefore, this study recommends that social workers should provide healthcare workers with therapeutic programmes in order to empower them to be more self-efficacious or self-sufficient in handling the emotional demands that comes with caring for children living HIV. This should cover how healthcare workers will deal with cases of children in HIV care. Social workers should assist both healthcare workers and caregivers with the process of HIV disclosure and educational programs to improve adherence to treatments. This is because social workers will apply their skills in assisting HIV infected children to cope with HIV-related challenges. Thus, healthcare workers should be encouraged to refer to cases that go beyond their space of practice to the appropriate department.

5.3.2 Recommendations for HIV Clinics

Healthcare workers play an important role in ensuring that children living with HIV access healthcare service. Therefore, healthcare workers need to be trained properly in pediatric care in order for them to be prepared to provide effective HIV care services to HIV infected children. To avoid mass workloads, the Department of Health must train and hire more healthcare workers or community counsellor so that they can assist with the provision of HIV care. Caregivers need to be provided with appropriate guidelines and training to support HIV status disclosure to a child at an early age and help them with adherence to antiretroviral treatment managing.

To avoid caregivers from missing clinic appointments, especially on collecting treatment, the Department of Health must consider initiating mobile clinics that will be delivering treatment for all communicable or chronic illnesses including antiretroviral treatment to people's homes. The Department of Health and Department of Social Development should offer financial and material support to the Non-Governmental Organizations that have Home Based Care workers so as to boost their morale and encourage them to continue caring for HIV infected individuals in the community. It is recommended that the findings of this study be circulated in conferences and seminars that target practitioners and policymakers in the field of HIV/AIDS.

5.4 Recommendations for further research

In consideration of the study findings and limitations, the target population was quite small and might not include other people’s opinions and perceptions. Therefore, the researcher proposes the following recommendations for further research:

1. Further research is needed to maximize the benefits of psychosocial support groups as an integral component of HIV care and treatment. This is because it was discovered from the research that healthcare worker encounters enormous challenge while dealing with child HIV care. Thus, further research needs to be conducted on how these challenges can be addressed and how children

with HIV can get better and effective care to reduce HIV related death among children in South Africa.

2. The researcher recognises the need for further research concerning healthcare worker's involvement in the process of HIV status disclosure to HIV infected children. Further research may concentrate on ways to improve access to health, rehabilitation, prevention, and diagnosis services, as well as the latest models of service provision in different communities.

3. Additional research and operational lessons are needed to investigate how children and caregivers experience challenges in meeting up with appointments and poor HIV medication adherence. This will facilitate interventions to improve adherence to treatment among children as well as meeting up with scheduled appointments and also improve ways to care for HIV infected children.

5.5 Conclusion

The aim and objectives of the study were met as the study outcomes were able to highlight the available psychosocial support services for children in HIV care and equally , the challenges of both healthcare workers and caregivers in caring for HIV infected children. This chapter presented an overall conclusion that highlighted the provision and implementation of psychosocial support services for children receiving HIV care from Pinetown, Ethekwini Municipal Clinic. The provision of psychosocial support services to children in HIV care have an impact on retention in care and has the potential to improve quality of life and mortality. Throughout the presented findings of the study, healthcare workers are noted to be playing a vital role in the provision and implementation of health care services. They have the responsibility of ensuring that the government's health policies are translated into effective and efficient service delivery. However, the study learnt that their rights are often overlooked, as they are subjected to poor working conditions with long working hours, which often has a negative impact on their productivities. Another significant challenge in the delivery of HIV care services to children was found to be related to the knowledge gap in HIV care, lack of counseling skills, and healthcare constraints.

Caregivers of children living with HIV also play a very critical role in ensuring that their children access HIV care services. However, there are some challenges that they come across while providing care to their children, such as financial issues to receive antiretroviral therapy, adherence to medication use, and issues of disclosure of status to children living with HIV. Apart from challenges that caregivers come across, they are pleased with HIV care services, including psychosocial support; this is critical for the health and development of children and adolescents living with HIV. Children enrolled in HIV care receive support groups that prepare them for HIV disclosure and emphasize the importance of adherence to antiretroviral treatment, and lastly, the use of electronic tablets to communicate with children in HIV care is much appreciated by both healthcare workers and caregivers.

Reference list

Abramson, B. (2008). A Commentary on the United Nations Convention on the Rights of the Child, Article 2: The Right of Non-Discrimination: Brill.

Afifi, T. O., Mota, N. P., Dasiewicz, P., MacMillan, H. L., & Sareen, J. (2012). Physical punishment and mental disorders: results from a nationally representative US sample. Pediatrics, 130(2), 184-192.

Ahonsi, B. A., Abdel-Tawab, N. G., Geibel, S., Kalibala, S., Okal, J., Mane, B., Green, E. P. (2014). HIV/AIDS vulnerabilities, discrimination, and service accessibility among Africa's youth: Insights from a multi-country study.

Alan, W., & Sunter, C. (2000). AIDS: The Challenge for South Africa. Cape Town: Human and Rousseau Tafelberg., 35.

Allen, D., & Marshall, E. S. (2008). Children with HIV/AIDS: A vulnerable population with unique needs for palliative care. Journal of Hospice & Palliative Nursing, 10(6), 359-367.

Allison, W. E., Kiromat, M., Vince, J., Wand, H., Cunningham, P., Graham, S. M., & Kaldor, J. (2011). Development of a clinical algorithm to prioritise HIV testing of hospitalised pediatric patients in a low resource moderate prevalence setting. Archives of disease in childhood, 96(1), 67-72.

Amzel, A., Toska, E., Lovich, R., Widyono, M., Patel, T., Foti, C., Mark, D. (2013). Promoting a combination approach to pediatric HIV psychosocial support. AIDS (London, England), 27(0 2), S147.

Ashat, M., Bhatia, V., Puri, S., Thakare, M., & Koushal, V. (2011). Needle stick injury and HIV risk among health care workers in North India. Indian journal of medical sciences, 65(9).

Azétsop, J., & Diop, B. A. (2013). Access to antiretroviral treatment, issues of well-being and public health governance in Chad: what justifies the limited success of the universal access policy? Philosophy, Ethics, and Humanities in Medicine, 8(1), 8.

Babbie, E., & Mouton, J. (2001). The Practice of Social Research (Cape Town: Oxford University Press South Africa).

Baggaley, R., Kelly, M., Weinreich, S., Kayawe, I., Phiri, G., Mulongo, W., & Phiri, M. (1998). HIV counselling and testing in Zambia: the Kara Counselling experience. SAfAIDS news: Southern Africa AIDS Information Dissemination Service bulletin, 6(2), 2.

Bateganya, M., Amanyeiwe, U., Roxo, U., & Dong, M. (2015). The impact of support groups for people living with HIV on clinical outcomes: a systematic review of the literature. Journal of acquired immune deficiency syndromes (1999), 68(0 3), S368.

Beato, R. R., & Telfer, J. (2010). Communication as an essential component of environmental health science. Journal of Environmental Health, 73(1), 24.

Beima-Sofie, K., John-Stewart, G., Shah, B., Wamalwa, D., Maleche-Obimbo, E., & Kelley, M. (2014). Using health provider insights to inform pediatric HIV disclosure: a qualitative study and practice framework from Kenya. AIDS patient care and STDs, 28(10), 555-564.

Berg, B. L., & Lune, H. (2004). Qualitative research methods for the social sciences. 5th (edn). In: Boston: Pearson.

Berkowitz, A. R., Ford, M. E., & Brewer, C. A. (2005). A framework for integrating ecological literacy, civics literacy, and environmental citizenship in. Environmental education and advocacy: Changing perspectives of ecology and education, 227.

Bernays, S., Jarrett, P., Kranzer, K., & Ferrand, R. A. (2014). Children growing up with HIV infection: the responsibility of success. The Lancet, 383(9925), 1355-1357.

Bhadra, S. (2016). Psycho-social support for protection of children in disasters. In Child Safety, Welfare and Well-being (pp. 259-278): Springer.

Blanche, M. T., Blanche, M. J. T., Durrheim, K., & Painter, D. (2006). Research in practice: Applied methods for the social sciences (Vol. 112): Juta and Company Ltd.

Botton, A. d. (2008). Inner resilience: mental health and psychosocial support.

Boussari, O., Subtil, F., Genolini, C., Bastard, M., Iwaz, J., Fonton, N., group, A. s. (2015). Impact of variability in adherence to HIV antiretroviral therapy on the immunovirological response and mortality. BMC medical research methodology, 15(1), 10.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative research in psychology, 3(2), 77-101.

Bronfenbrenner, U. (1979). The ecology of human development: Harvard university press.

Burton, M., Pavord, E., & Williams, B. (2014). An introduction to child and adolescent mental health (Vol. 134): Sage.

Chan, B. T., & Tsai, A. C. (2017). Personal contact with HIV-positive persons is associated with reduced HIV-related stigma: cross-sectional analysis of general population surveys from 26 countries in sub-Saharan Africa. Journal of the International AIDS Society, 20(1), 21395.

Christie, C., & Pierre, R. (2012). Eliminating vertically transmitted HIV/AIDS while improving access to treatment and care for women, children and adolescents in Jamaica. West Indian Medical Journal, 61(4), 396.

Cloete, A., Strebel, A., Simbayi, L., van Wyk, B., Henda, N., & Nqeketo, A. (2010). Challenges faced by people living with HIV/AIDS in Cape Town, South Africa: Issues for group risk reduction interventions. AIDS research and treatment, 2010.

Collins, I. J., Jourdain, G., Hansudewechakul, R., Kanjanavanit, S., Hongsiriwon, S., Ngampiyasakul, C., . . . Duong, T. (2010). Long-term survival of HIV-infected children receiving antiretroviral therapy in Thailand: a 5-year observational cohort study. Clinical infectious diseases, 51(12), 1449-1457.

Corneli, A., Vaz, L., Dulyx, J., Omba, S., Rennie, S., & Behets, F. (2009). The role of disclosure in relation to assent to participate in HIV-related research among HIV-infected youth: a formative study. Journal of the International AIDS Society, 12(1), 17-17.

Crowell, C. S., Yanling, H., Tassiopoulos, K., Malee, K. M., Yogev, R., Hazra, R., . . . Williams, P. L. (2015). Early viral suppression improves neurocognitive outcomes in HIV-infected children. AIDS (London, England), 29(3), 295.

Dageid, W., Sedumedi, S. D., & Duckert, F. (2007). Exploring perceptions and emotional burdens of HIV/AIDS health care workers.

Das, A., Detels, R., Javanbakht, M., & Panda, S. (2016). Issues around childhood disclosure of HIV status–findings from a qualitative study in West Bengal, India. Child: care, health and development, 42(4), 553-564.

De Vos, A. S., Delport, C., Fouché, C. B., & Strydom, H. (2011). Research at grass roots: A primer for the social science and human professions (Vol. 123): Van Schaik Publishers.

Deeks, S. G., Lewin, S. R., & Havlir, D. V. (2013). The end of AIDS: HIV infection as a chronic disease. The Lancet, 382(9903), 1525-1533.

Denscombe, M. (2014). The good research guide: for small-scale social research projects: McGraw-Hill Education (UK).

Deribe, K., Hailekiros, F., Biadgilign, S., Amberbir, A., & Beyene, B. K. (2008). Defaulters from antiretroviral treatment in jimma university specialized hospital, Southwest Ethiopia. Tropical Medicine & International Health, 13(3), 328-333.

Domek, G. J. (2010). Debunking common barriers to pediatric HIV disclosure. Journal of tropical pediatrics, 56(6), 440-442.

Driessche, K. V., Sabue, M., Dufour, W., Behets, F., & Van Rie, A. (2009). Training health care workers to promote HIV services for patients with tuberculosis in the Democratic Republic of Congo. Human resources for health, 7(1), 23.

Dyk, V., & C, A. (2010). HIVAIDS care and counselling: a multidisciplinary approach: Pearson South Africa.

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. (2014). Qualitative content analysis: A focus on trustworthiness. SAGE open, 4(1), 2158244014522633.

Ettenhofer, M. L., Foley, J., Castellon, S. A., & Hinkin, C. H. (2010). Reciprocal prediction of medication adherence and neurocognition in HIV/AIDS. Neurology, 74(15), 1217-1222.

Feyissa, G. T., Abebe, L., Girma, E., & Woldie, M. (2012). Stigma and discrimination against people living with HIV by healthcare providers, Southwest Ethiopia. BMC public health, 12(1), 522.

Fortune, A. E., Reid, W. J., & Smith, A. (1999). Research in social work: Columbia University Press.

Gaitley, R., Mallinson, W., & Taylor, D. (1993). HIV-AIDS: a social work perspective: Venture Press.

Gardner, E. M., McLees, M. P., Steiner, J. F., del Rio, C., & Burman, W. J. (2011). The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. Clinical infectious diseases, 52(6), 793-800.

Gershoff, E. T. (2010). More harm than good: A summary of scientific research on the intended and unintended effects of corporal punishment on children. LAW & contemp. probs., 73, 31.

Gredler, G. R. (1995). Corey, G., Corey, MS, & Callanan, P. (1993). Issues and ethics in the helping professions. Pacific Grove, CA: Brooks/Cole Publishing, 438 pp. Psychology in the Schools, 32(2), 142-144.

Greyling, M. (2004). Research at Grass Roots: For the social sciences and human services professions, AS de Vos, (ed), H. Strydom, CB Fouche and CSL Delport: book review. SA Journal of Industrial Psychology, 30(1), 100.

Hall, K. (2010). Income poverty, unemployment and social grants.

Hankins, M. S. (2015). International Federation of Red Cross and Red Crescent Societies.

Harley, J. M. (2016). Measuring emotions: a survey of cutting-edge methodologies used in computer-based learning environment research. In Emotions, technology, design, and learning (pp. 89-114): Elsevier.

Hayfron-Benjamin, A., Obiri-Yeboah, D., Ayisi-Addo, S., Siakwa, P. M., & Mupepi, S. (2018). HIV diagnosis disclosure to infected children and adolescents; challenges of family caregivers in the Central Region of Ghana. BMC pediatrics, 18(1), 365.

Hewitt, M., Herdman, R., & Holland, J. (2004). The effectiveness of psychosocial interventions for women with breast cancer. Paper presented at the Meeting psychosocial needs of women with breast cancer.

Hilary, H. (2003). Youth friendly health services: Responding to the needs of young people in Europe. Geneva: United Nations Inter Agency Group on Youth Friendly Services.

Johnson, M. O., Dilworth, S. E., Taylor, J. M., Darbes, L. A., Comfort, M. L., & Neilands, T. B. (2012). Primary relationships, HIV treatment adherence, and virologic control. AIDS and Behavior, 16(6), 1511-1521.

Jose, S., Delpech, V., Howarth, A., Burns, F., Hill, T., Porter, K., Anderson, J. (2018). A continuum of HIV care describing mortality and loss to follow-up: a longitudinal cohort study. The Lancet HIV, 5(6), e301-e308.

Joseph, J. K., Rigodon, J., Cancedda, C., Haidar, M., Lesia, N., Ramanagoela, L., & Furin, J. (2012). Lay health workers and HIV care in rural Lesotho: a report from the field. AIDS patient care and STDs, 26(3), 141-147.

Kail, R., & Cavanaugh, J. (2010). The study of human development. Human development: A life-span view, 7-11.

Kajubi, P., Whyte, S., Muhumuza, S., Kyaddondo, D., & Katahoire, A. R. (2014). Communication between HIV-infected children and their caregivers about HIV medicines: a cross-sectional study in Jinja district, Uganda. Journal of the International AIDS Society, 17(1), 19012.

Kakizaki, M., Ikeda, N., Ali, M., Enkhtuya, B., Tsolmon, M., Shibuya, K., & Kuroiwa, C. (2011). Needlestick and sharps injuries among health care workers at public tertiary hospitals in an urban community in Mongolia. BMC research notes, 4(1), 184.

Kanekar, A. S. (2011). HIV/AIDS counseling skills and strategies: can testing and counseling curb the epidemic? International Journal of Preventive Medicine, 2(1), 10.

Kaplan, J. E., Hamm, T. E., Forhan, S., Hassani, A. S., Bang, G., Weyant, E., Bateganya, M. (2015). The impact of HIV care and support interventions on key outcomes in low and middle-income countries: a literature review. Introduction. Journal of acquired immune deficiency syndromes (1999), 68(Suppl 3), S253.

Katabira, E. T., & Oelrichs, R. B. (2007). Scaling up antiretroviral treatment in resource-limited settings: successes and challenges. Aids, 21, S5-S10.

Kennedy, D. P., Cowgill, B. O., Bogart, L. M., Corona, R., Ryan, G. W., Murphy, D. A., Schuster, M. A. (2010). Parents' disclosure of their HIV infection to their children in the context of the family. AIDS and Behavior, 14(5), 1095-1105.

Khan, R. (2015). Perspectives on disclosure of HIV status to others among 12-19-year-old HIV-infected adolescents attending an HIV care clinic at a tertiary hospital in Harare, Zimbabwe: a qualitative study. University of Cape Town, (43) Kidia, K. K., Mupambireyi, Z., Cluver, L., Ndhlovu, C. E., Borok, M., & Ferrand, R. A. (2014). HIV status disclosure to perinatally-infected adolescents in Zimbabwe: a qualitative study of adolescent and healthcare worker perspectives. PloS one, 9(1).

Kincaid, D., Kincaid, D. R., & Cheney, E. W. (2009). Numerical analysis: mathematics of scientific computing (Vol. 2): American Mathematical Soc.

Kose, S., Mandiracioglu, A., Mermut, G., Kaptan, F., & Ozbel, Y. (2012). The social and health problems of people living with HIV/AIDS in Izmir, Turkey. The Eurasian journal of medicine, 44(1), 32.

Koto, M. V., & Maharaj, P. (2016). Difficulties facing healthcare workers in the era of AIDS treatment in Lesotho. SAHARA-J: Journal of Social Aspects of HIV/AIDS, 13(1), 53-59.

Lankston, L., Cusack, P., Fremantle, C., & Isles, C. (2010). Visual art in hospitals: case studies and review of the evidence. Journal of the Royal Society of Medicine, 103(12), 490-499.

Lawrence, E., Struthers, P., & Van Hove, G. (2015). HIV counselling and testing in secondary schools: What students want. Southern African journal of HIV medicine, 16(1), 1-6.

Legal, U. S. (2012). Primary Care-giver Doctrine Law & Legal Definition.

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. AIDS care, 19(6), 811-816.

Lester, P., Chesney, M., Cooke, M., Weiss, R., Whalley, P., Perez, B., Wara, D. (2002). When the time comes to talk about HIV: factors associated with diagnostic disclosure and emotional distress in HIV-infected children. JAIDS-HAGERSTOWN MD-, 31(3), 309-317.

Li, M., Betancourt, T., Eustache, E., Oswald, C., Louis, E., Mukherjee, J., . . . Fawzi, M. C. S. (2015). Risk and protective factors for internalizing and externalizing outcomes among HIV-affected youth in Haiti. AIDS care, 27(8), 995-999.

Liechty, C. A., & Bangsberg, D. R. (2003). Doubts about DOT: antiretroviral therapy for resource-poor countries. Aids, 17(9), 1383-1387.

Linda, P. (2013). To tell or not to tell: negotiating disclosure for people living with HIV on antiretroviral treatment in a South African setting. SAHARA-J: Journal of Social Aspects of HIV/AIDS, 10(sup1), S17-S27.

Loeliger, K. B., Niccolai, L. M., Mtungwa, L. N., Moll, A., & Shenoi, S. V. (2016). Antiretroviral therapy initiation and adherence in rural South Africa: community health workers' perspectives on barriers and facilitators. AIDS care, 28(8), 982-993.

Lutge, E., & Mbatha, T. (2007). PHC facility infrastructure: a situation analysis of data available. Durban: Health Systems Trust.

Lyon, M. E., & D'Angelo, L. J. ((Eds.) 2006). Teenagers, HIV, and AIDS: Insights from youths living with the virus. Greenwood Publishing Group.

Madiba, S., & 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. PeerJ, 3, e893.

Madiba, S., & Mokwena, K. (2012). Caregivers' barriers to disclosing the HIV diagnosis to infected children on antiretroviral therapy in a resource-limited district in South Africa: A grounded theory study. AIDS research and treatment, 2012.

Mafune, R. V., Lebese, R. T., & Nemathaga, L. H. (2017). Challenges faced by caregivers of children on antiretroviral therapy at Mutale Municipality selected healthcare facilities, Vhembe District, Limpopo Province. curationis, 40(1), 1-9.

Mahloko, J. M., & Madiba, S. (2012). Disclosing HIV diagnosis to children in Odi district, South Africa: reasons for disclosure and non-disclosure. African journal of primary health care & family medicine, 4(1).

Makaudze, G. (2013). It still makes sense!: Shona ngano (folktale) and the contemporary Zimbabwean socio-economic and cultural setup. International Journal of development and sustainability, 2(2), 521-529.

Maree, K. (2007). First steps in research: Van Schaik Publishers.

Mataboge, M. S., Peu, M. D., Chinuoya, M., Rikhotso, R., Ngunyulu, R. N., & Mulaudzi, F. M. (2014). Healthcare workers' experiences of HIV testing in Tshwane, South Africa. curationis, 37(1), 01-08.

Mavhu, W., Berwick, J., Chirawu, P., Makamba, M., Copas, A., Dirawo, J., . . . Corbett, E. L. (2013). Enhancing psychosocial support for HIV positive adolescents in Harare, Zimbabwe. PloS one, 8(7).

McCarthy, E. A., O'Brien, M. E., & Rodriguez, W. R. (2006). Training and HIV-treatment scale-up: establishing an implementation research agenda. PLoS medicine, 3(7).

McLeod, S. (2018). Communication rights: Fundamental human rights for all. International journal of speech-language pathology, 20(1), 3-11.

Meel, B. (2003). 1. The myth of child rape as a cure for HIV/AIDS in Transkei. Medicine, science and the law, 43(1), 85-88.

Mehta, K., Ekstrand, M., Heylen, E., Sanjeeva, G., & Shet, A. (2016). Adherence to antiretroviral therapy among children living with HIV in South India. AIDS and Behavior, 20(5), 1076-1083.

Mellins, C. A., & Malee, K. M. (2013). Understanding the mental health of youth living with perinatal HIV infection: lessons learned and current challenges. Journal of the International AIDS Society, 16(1), 18593.

Monjok, E., Smesny, A., Okokon, I. B., Mgbere, O., & Essien, E. J. (2010). Adherence to antiretroviral therapy in Nigeria: an overview of research studies and implications for policy and practice. HIV/AIDS (Auckland, NZ), 2, 69.

Mturi, A. J. (2012). Child-headed households in South Africa: What we know and what we don't. Development Southern Africa, 29(3), 506-516.

Mugavero, M. J., Amico, K. R., Horn, T., & Thompson, M. A. (2013). The state of engagement in HIV care in the United States: from cascade to continuum to control. Clinical infectious diseases, 57(8), 1164-1171.

Mukhtar-Yola, M., Adeleke, S., Gwarzo, D., & Ladan, Z. F. (2006). Preliminary investigation of adherence to antiretroviral therapy among children in Aminu Kano Teaching Hospital, Nigeria. African Journal of AIDS Research, 5(2), 141-144.

Nasaba, R., Tindyebwa, D., Musiime, V., Iriso, R., Ingabire, R., Nansera, D., . . . Duffy, M. (2013). On counselling and psychosocial care for children and adolescents living with and affected by HIV in Africa. African network for the care of children affected by HIV/AIDS – anecca.

Ndlovu-Gatsheni, S. J. (2009). Do 'Zimbabweans' exist?: trajectories of nationalism, national identity formation and crisis in a postcolonial state (Vol. 3): Peter Lang.

Newman, I., & Hitchcock, J. H. (2011). Underlying agreements between quantitative and qualitative research: The short and tall of it all. Human Resource Development Review, 10(4), 381-398.

Ngarina, M., Popenoe, R., Kilewo, C., Biberfeld, G., & Ekstrom, A. M. (2013). Reasons for poor adherence to antiretroviral therapy postnatally in HIV-1 infected women treated for their own health: experiences from the Mitra Plus study in Tanzania. BMC public health, 13(1), 450.

Oberdorfer, P., Puthanakit, T., Louthrenoo, O., Charnsil, C., Sirisanthana, V., & Sirisanthana, T. (2006). Disclosure of HIV/AIDS diagnosis to HIV-infected children in Thailand. Journal of pediatrics and child health, 42(5), 283-288.

Okoronkwo, I., Okeke, U., Chinweuba, A., & Iheanacho, P. (2013). Nonadherence factors and sociodemographic characteristics of HIV-infected adults receiving antiretroviral therapy in Nnamdi Azikiwe University Teaching Hospital, Nnewi, Nigeria. Isrn Aids, 2013.

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. Administration and policy in mental health and mental health services research, 42(5), 533-544.

Pirozzolo, J. J., & LeMay, D. C. (2007). Blood-borne infections. Clinics in sports medicine, 26(3), 425-431.

Prendergast, A., Tudor-Williams, G., Jeena, P., Burchett, S., & Goulder, P. (2007). International perspectives, progress, and future challenges of pediatric HIV infection. The Lancet, 370(9581), 68-80.

Purgato, M., Gross, A. L., Betancourt, T., Bolton, P., Bonetto, C., Gastaldon, C., Peltonen, K. (2018). Focused psychosocial interventions for children in low-resource humanitarian settings: a systematic review and individual participant data meta-analysis. The Lancet Global Health, 6(4), e390-e400.

Rachlis, B. S., Mills, E. J., & Cole, D. C. (2011). Livelihood security and adherence to antiretroviral therapy in low-and-middle-income settings: a systematic review. PloS one, 6(5).

Rai, T., Bruton, J., Day, S., & Ward, H. (2018). From activism to secrecy: Contemporary experiences of living with HIV in London in people diagnosed from 1986 to 2014. Health Expectations, 21(6), 1134-1141.

Reinhard, S. C., Given, B., Petlick, N. H., & Bemis, A. (2008). Supporting family caregivers in providing care. In Patient safety and quality: An evidence-based handbook for nurses: Agency for Healthcare Research and Quality (US).

Richard, P., Sato, T., Nakayama, K., Takahashi, T., & Ding, H. (2011). Fe-based superconductors: an angle-resolved photoemission spectroscopy perspective. Reports on progress in physics, 74(12), 124512.

Rita, E., & Rohman, K. (2013). Capturing the Witness Statement. AWI Journal, 4(3), 1-20.

Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (2013). Qualitative research practice: A guide for social science students and researchers: sage.

Rotheram-Borus, M. J., Richter, L. M., Van Heerden, A., Van Rooyen, H., Tomlinson, M., Harwood, J. M., . . . Stein, A. (2014). A cluster randomized controlled trial evaluating the efficacy of peer mentors to support South African women living with HIV and their infants. PloS one, 9(1).

Rubin, A., & Babbie, E. (2005). Research methods for social work (ed.). Belmont, CA, USA: Brooks/Cole.

Rujumba, J., Mbasaalaki-Mwaka, C. L., & Ndeezi, G. (2010). Challenges faced by health workers in providing counselling services to HIV-positive children in Uganda: a descriptive study. Journal of the International AIDS Society, 13(1), 9-9.

Rwemisisi, J., Wolff, B., Coutinho, A., Grosskurth, H., & Whitworth, J. (2008). 'What if they ask how I got it? 'Dilemmas of disclosing parental HIV status and testing children for HIV in Uganda. Health Policy and Planning, 23(1), 36-42.

Sariah, A., Rugemalila, J., Somba, M., Minja, A., Makuchilo, M., Tarimo, E., Siril, H. (2016). “Experiences with disclosure of HIV-positive status to the infected child”: Perspectives of healthcare providers in Dar es Salaam, Tanzania. BMC public health, 16(1), 1083.

Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., . . . Whittemore, R. (2012). Processes of self-management in chronic illness. Journal of Nursing Scholarship, 44(2), 136-144.

Simelela, N., Venter, W., & Daniel, F. (2014). A brief history of South Africa's response to AIDS. SAMJ: South African Medical Journal, 104(3), 249-251.

Simelela, N., Venter, W. F., Pillay, Y., & Barron, P. (2015). A political and social history of HIV in South Africa. Current HIV/AIDS Reports, 12(2), 256-261.

Skovdal, M., Ogutu, V. O., Aoro, C., & Campbell, C. (2009). Young carers as social actors: Coping strategies of children caring for ailing or ageing guardians in Western Kenya. Social science & medicine, 69(4), 587-595.

South African Govenrment (2005). Children’s Act 38 of 2005. https://www.justice.gov.za/legislation/acts/2005-038%20childrensact.pdf.

Snape, D., & Spencer, L. (2003). The Foundations of Qualitative Research in Richie, J. and Lewis, J. Qualitative Research Practice: A Guide for Social Science Students and Researchers London: Sage, 113.

Srithanaviboonchai, K., Chariyalertsak, S., Nontarak, J., Assanangkornchai, S., Kessomboon, P., Putwatana, P., Aekplakorn, W. (2017). Stigmatizing attitudes toward people living with HIV among general adult Thai population: Results from the 5th Thai National Health Examination Survey (NHES). PloS one, 12(11).

Ssali, S. N., Atuyambe, L., Tumwine, C., Segujja, E., Nekesa, N., Nannungi, A., Wagner, G. (2010). Reasons for disclosure of HIV status by people living with HIV/AIDS and in HIV care in Uganda: an exploratory study. AIDS patient care and STDs, 24(10), 675-681.

Stackpool-Moore, L., Chirwa, M. L., de Croy, S., Hudson, A., Kamkwamba, D., Kundecha, R. M., Sinyemu, E. (2013). An Antidote to Stigma? The People Living with HIV Stigma Index in Malawi and the United Kingdom (UK). In 80 (Ed.), Stigma, discrimination and living with HIV/AIDS (pp. 337-355): Springer.

Staebler, K., Renneberg, B., Stopsack, M., Fiedler, P., Weiler, M., & Roepke, S. (2011). Facial emotional expression in reaction to social exclusion in borderline personality disorder. Psychological medicine, 41(9), 1929-1938.

Stokols, D., Allen, J., & Bellingham, R. L. (1996). The social ecology of health promotion: implications for research and practice. American Journal of Health Promotion, 10(4), 247-251.

Strode, A. E., Toohey, J., Singh, P., & Slack, C. M. (2015). Boni mores and consent for child research in South Africa. South African journal of bioethics and law, 8(1), 22-25.

Szaflarski, M. (2013). Spirituality and religion among HIV-infected individuals. Current HIV/AIDS Reports, 10(4), 324-332.

Taddeo, D., Egedy, M., & Frappier, J.-Y. (2008). Adherence to treatment in adolescents. Paediatric & child health, 13(1), 19-24.

Tindyebwa, D., Kayita, J., Musoke, P., Eley, B., Nduati, R., Coovadia, H., Kieffer, P. (2004). Handbook on pediatric AIDS in Africa: African Network for The Care of Children Affected by AIDS Kampala.

Tomori, C., Risher, K., Limaye, R. J., Van Lith, L., Gibbs, S., Smelyanskaya, M., & Celentano, D. D. (2014). A role for health communication in the continuum of HIV care, treatment, and prevention. Journal of acquired immune deficiency syndromes (1999), 66(0 3), S306.

Tsai, A. C., Bangsberg, D. R., Kegeles, S. M., Katz, I. T., Haberer, J. E., Muzoora, C., Weiser, S. D. (2013). Internalized stigma, social distance, and disclosure of HIV seropositivity in rural Uganda. Annals of Behavioral Medicine, 46(3), 285-294.

Tuller, D. M., Bangsberg, D. R., Senkungu, J., Ware, N. C., Emenyonu, N., & Weiser, S. D. (2010). Transportation costs impede sustained adherence and access to HAART in a clinic population in southwestern Uganda: a qualitative study. AIDS and Behavior, 14(4), 778-784.

Tyabazayo, P. (2009). The duty of the state to give effect to the rights of children in child-headed households in the context of Section 28 (1)(b) and (c) of the Constitution of the Republic of South Africa, 1996. University of South Africa,

Ugwu, R., & Eneh, A. (2014). Factors influencing adherence to paediatric antiretroviral therapy in Portharcourt, South-South Nigeria. Pan African medical journal, 16(1).

UNAIDS. (2013). Global Report on the global AIDS epidemic 2013. Geneva: Joint United Nations Programme on HIV.

UNAIDS. (2019). Factsheet: global AIDS update. 2019. In: UNAIDS Geneva.

UNAIDS, & PEPFAR. (2018). Start Free, Stay Free, AIDS Free: A Super-Fast Track Framework for Ending AIDS in Children, Adolescents and Young Women by 2020. In.

UNICEF. (2011). Opportunity in Crisis: Preventing HIV from early adolescence to young adulthood: UNICEF.

UNICEF, & WHO. (2018). Capture the Moment–Early initiation of breastfeeding: The best start for every newborn. New York: UNICEF.

Urdang, S. (2006). The care economy: Gender and the silent AIDS crisis in Southern Africa. Journal of Southern African Studies, 32(1), 165-177.

Van Rooyen, H. E., Strode, A. E., & Slack, C. M. (2016). HIV testing of children is not simple for health providers and researchers: Legal and policy frameworks guidance in South Africa. SAMJ: South African Medical Journal, 106(5), 451-453.

Vawda, Y. A., & Variawa, F. (2012). Challenges confronting health care workers in government's ARV rollout: rights and responsibilities. Potchefstroom Electronic Law Journal/Potchefstroomse Elektroniese Regsblad, 15(2).

Vermund, S. H., Blevins, M., Moon, T. D., Jose, E., Moiane, L., Tique, J. A., . . . Vaz, L. M. (2014). Poor clinical outcomes for HIV infected children on antiretroviral therapy in rural Mozambique: need for program quality improvement and community engagement. PloS one, 9(10).

Vermund, S. H., Mallalieu, E. C., Van Lith, L. M., & Struthers, H. E. (2017). Health communication and the HIV continuum of care. Journal of acquired immune deficiency syndromes (1999), 74(Suppl 1), S1.

Violari, A., Cotton, M. F., Gibb, D. M., Babiker, A. G., Steyn, J., Madhi, S. A., McIntyre, J. A. (2008). Early antiretroviral therapy and mortality among HIV-infected infants. New England Journal of Medicine, 359(21), 2233-2244.

Vranda, M., & Mothi, S. (2013). Psychosocial issues of children infected with HIV/AIDS. Indian journal of psychological medicine, 35(1), 19.

Vreeman, R. C., McCoy, B. M., & Lee, S. (2017). Mental health challenges among adolescents living with HIV. Journal of the International AIDS Society, 20, 21497.

Vreeman, R. C., Scanlon, M. L., Mwangi, A., Turissini, M., Ayaya, S. O., Tenge, C., & Nyandiko, W. M. (2014). A cross-sectional study of disclosure of HIV status to children and adolescents in western Kenya. PloS one, 9(1).

World Health Organization (WHO) (2011). Global HIV/AIDS response: epidemic update and health sector progress towards universal access: progress report 2011.

World Health Organization (WHO) (2014). World AIDS Day: Business Unusual: Time to end the AIDS epidemic. Retrieved from [accessed June 2020]

World Health Organization (WHO) (2016). HIV Country Profile: 2016 (South Africa). Retrieved from http://apps.who.int/gho/data/node.country.country-ZAF?lang=en.:

Wiener, L., Mellins, C. A., Marhefka, S., & Battles, H. B. (2007). Disclosure of an HIV diagnosis to children: history, current research, and future directions. Journal of developmental and behavioral pediatrics: JDBP, 28(2), 155.

Wilfert, C., Beck, D., Fleischman, A., Mofenson, L., Pantell, R., Schonberg, S. K., Rogers, M. (1999). Disclosure of illness status to children and adolescents with HIV infection. Pediatrics, 103(1), 164-166.

Williams, M., Van Rooyen, D. R., & Ricks, E. J. (2018). Provision of antiretroviral therapy for children in Nelson Mandela Bay: Health care professionals' challenges. African journal of primary health care & family medicine, 10(1), 1-10.

Winestone, L. E., Bukusi, E. A., Cohen, C. R., Kwaro, D., Schmidt, N. C., & Turan, J. M. (2012). Acceptability and feasibility of integration of HIV care services into antenatal clinics in rural Kenya: a qualitative provider interview study. Global public health, 7(2), 149-163.

Wyżgowski, P., Rosiek, A., Grzela, T., & Leksowski, K. (2016). Occupational HIV risk for health care workers: risk factor and the risk of infection in the course of professional activities. Therapeutics and clinical risk management, 12, 989.

Yusuf, S. Z., Hussin, K., & Azali, N. H. (2015). Child safety policy in high-rise building as preventive measures of child falls–A review. Jurnal Teknologi, 73(5).

Zenzano, T., Allan, J. D., Bigley, M. B., Bushardt, R. L., Garr, D. R., Johnson, K., . . . Shannon, S. C. (2011). The roles of healthcare professionals in implementing clinical prevention and population health. American journal of preventive medicine, 40(2), 261-267.

Appendices

Appendix 1: Interview Guide for Healthcare Workers

DEMOGRAPHIC CHARACTERISTICS

Age:

Gender:

Language:

THEMES TO BE EXPLORED

General Perception

1. What is your general perception about children living with HIV?

1.1 Has your perception changed overtime and if so how?

2. What is your general perception about HIV disclosure to children living with HIV?

2.1 Has your perception changed overtime and if so how?

3. At what age do you think is appropriate to disclose their HIV status?

Health Care Workers Training

1. How prepared are you to interact with children who are HIV Positive?
2. Is there any training for Health Care Workers that is provided by the Department of Health that make sure that Health Care Workers are fully prepared to provide services to children receiving HIV Care?
    2.1. If yes, how often in a year?
    2.2. If no, would you attend any HIV/AIDS training offered?
3. In the past six months, have you attended any training or sensitization session about HIV/AIDS?
    3.1. If yes, which organization provided the training?
    3.2. If no, have you ever attended a training or sensitization session about HIV/AIDS?

Children receiving HIV Care

1. How many children on average do you provide HIV Care to at Pinetown Municipal Clinic per day?
2. Does this reflect your normal workload? If not, is it too much or too little.
3. Which gender receives HIV Care the most?
4. What age do you normally provide care to?
5. Are the children receiving HIV Care aware of their HIV status?
6. What are the reasons and importance of HIV disclosure to a child?
7. What are the factors that hinder HIV disclosure to a child?
8. Who do you think is the best person to disclose HIV status to the child?

Provision of services

1. What kind of support do you give to children in HIV Care?
2. What services or programs does Pinetown Municipal Clinic have/provide to children living with HIV beside HIV Care?

HIV Care Process

1. What is your primary role within HIV Care?
2. What communication skills, tools or strategies do you require when you providing children receiving HIV Care?

2.1. Are the tools or strategies you use to communicate with children receiving HIV Care effective?

2.2. If yes, how do you note that?

2.3. If no, would you recommend the implementation of tools or strategies to communicate with children in receiving HIV Care?

3. What challenges have you experienced in the provision of psychosocial support to children in HIV Care.
4. Do you think the HIV care provided is appropriate for this community?

4.1 If not, any recommendations

5. How is the participation if caregivers in HIV care?

5.1 Does this have an impact on e.g. disclosure and adherence? Elaborate

Appendix 2: Interview Guide for Caregivers

DEMOGRAPHIC CHARACTERISTICS

Age:

Gender:

Language:

Relationship to child:

THEMES TO BE EXPLORED

General perception

1. What are your perceptions on HIV in general?
2. What are your perceptions on HIV Care in general?
3. What are your perceptions about HIV care provided by Health Care Workers at this clinic?
4. What are your perceptions on health care workers giving HIV Care?
5. What are your perceptions about children living with HIV?

Children Infected

1. What is the gender of your child?
2. How old is your child?
3. How was your child infected with HIV?
   3.1 Did the parent know about ways of protecting the child from contracting the virus?
4. What does he/she know about HIV?
5. What are his/her attitudes about HIV?
6. What challenges have you experienced for having HIV infected child?
7. What kind of support do you provide to your HIV infected child?

HIV Disclosure

1. Does your child know about his/her HIV status?
   1.1. If no, why he/she is not aware?

    1.2. If yes, how did you disclose to him/her?

2. Who do you think is the best person to disclose HIV status to the child?
3. In the family, who else know about the child's HIV status?
4. Is there any other family member (child) who is HIV positive?
5. What are the reasons that can make you to disclose/not disclose HIV status to a child?
    - 5.1 Reasons for disclosing
    - 5.2 Reasons for not disclosing
6. How long has your child been receiving HIV Care?
7. To what benefit does HIV Care help your child, if any?

Caregivers Counselling

1. How prepared are you to interact with your child about HIV?
2. Is there any counselling for caregivers that is provided by the Department of Health that make sure that caregiver provides adequate care and support for their children living with HIV?
    - 2.1. If yes, how often?
    - 2.2. If no, do you think you need it and how often?

Appendix 3: Informed Consent Form for both Healthcare workers and Caregivers**.**

UKZN HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE (HSSREC)

APPLICATION FOR ETHICS APPROVAL

For research with human participants

INFORMED CONSENT RESOURCE TEMPLATE

Note to researchers: Notwithstanding the need for scientific and legal accuracy, every effort should be made to produce a consent document that is as linguistically clear and simple as possible, without omitting important details as outlined below. Certified translated versions will be required once the original version is approved.

There are specific circumstances where witnessed verbal consent might be acceptable, and circumstances where individual informed consent may be waived by HSSREC.

Information Sheet and Consent to Participate in Research

Date: 07/01/2019

My name is Samukelisiwe Ndaba. I am a Master's student from Social Work Discipline in the School of Applied Human Science, University of KwaZulu-Natal.

You are being invited to consider participating in a study that involves research in "Understanding the provision and implementation of psychosocial support for children receiving HIV Care in Pinetown Municipal clinic". The aim and purpose of this research is to explore the provision and implementation of psychosocial support services for children receiving HIV care from Pinetown Municipal Clinic. The duration of your interview will be approximately 45 minutes to 60 minutes. The study is not funded by any organization or individuals.

This study has been ethically reviewed and approved by the UKZN Humanities and Social Sciences Research Ethics Committee (Approval number: HSS/1920/018M).

Please note that:

- The information that you provide will be used for scholarly research only.
- Your participation is entirely voluntary. You have a choice to participate, not to participate or stop participating at any stage during the research. You will not be penalized for taking such an action.
- Your views in this interview will be presented anonymously. Neither your name nor identity will be disclosed in any form in the study.
- The interview will take about 45 minutes to 60 minutes.
- The record as well as other items associated with the interview will be held in a password-protected file accessible only to myself and my supervisors. After a period of 5 years, in line with the rules of the university, it will be disposed by shredding and burning.
- Please note that there will be no form of reward or compensation if you choose to participate in this research.

In the event of any problems or concerns/questions you may contact the researcher via Email: samndaba96@gmail.com/ 218085686@stu.ukzn.ac.za or telephonically at 073 7472 318. You can also contact my supervisor Dr. Maud Mthembu at Mthembum4@ukzn.ac.za/ or telephonically at 031 260 358 or the UKZN Humanities & Social Sciences Research Ethics Committee, contact details as follows:

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001
Durban
4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604557- Fax: 27 31 2604609

Email: HSSREC@ukzn.ac.za

CONSENT (Edit as required)

I,………………………………… have been informed about the study entitled “Provision and implementation of psychosocial support for children receiving HIV Care in Pinetown Municipal clinic” which will be conducted by Samukelisiwe Ndaba.

- ☐ I understand the purpose and procedures of the study which the researcher explained.
- ☐ I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.
- ☐ I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any of the benefits that I usually am entitled to.
- ☐ I have been informed about any available compensation or medical treatment if injury occurs to me because of study-related procedures.
- ☐ If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at 073 7472 318 or email her on samndaba96@gmail.com.
- ☐ If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001
Durban
4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604557 - Fax: 27 31 2604609

Email: HSSREC@ukzn.ac.za

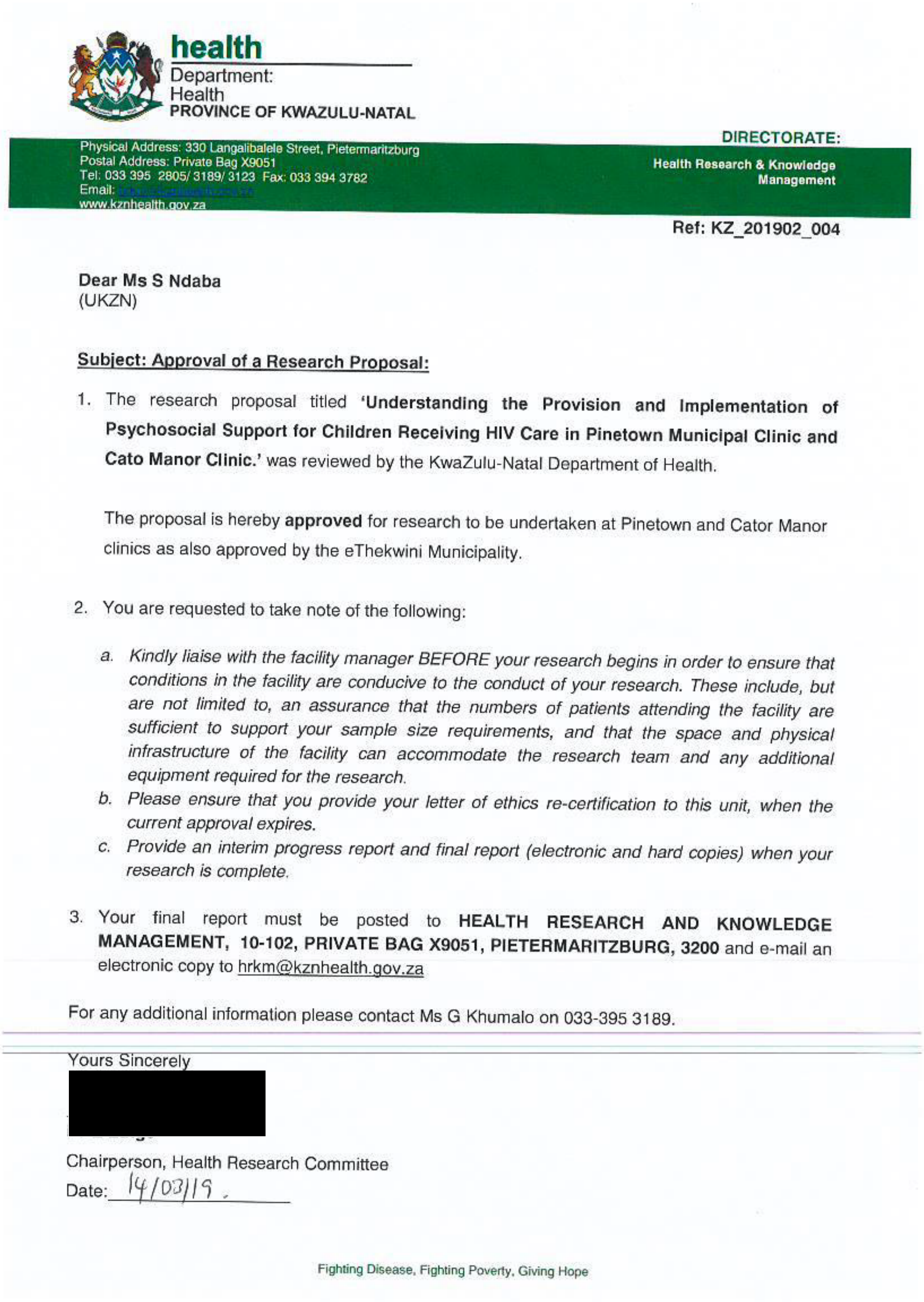
Additional consent, where applicable

I hereby provide consent to:

Audio-record my interview / In-depth interview YES / NO

____________________	____________________	____________________
Signature of Participant	**Signature of Witness**	**Date**

Appendix 4: Gate Keeper approval



health
Department:
Health
PROVINCE OF KWAZULU-NATAL

Physical Address: 330 Langalibalele Street, Pietermaritzburg
Postal Address: Private Bag X9051
Tel: 033 395 2805/ 3189/ 3123 Fax: 033 394 3782
Email: [illegible]
www.kznhealth.gov.za

DIRECTORATE:
Health Research & Knowledge Management

Ref: KZ_201902_004

Dear Ms S Ndaba
(UKZN)

Subject: Approval of a Research Proposal:

1. The research proposal titled **'Understanding the Provision and Implementation of Psychosocial Support for Children Receiving HIV Care in Pinetown Municipal Clinic and Cato Manor Clinic.'** was reviewed by the KwaZulu-Natal Department of Health.

   The proposal is hereby **approved** for research to be undertaken at Pinetown and Cator Manor clinics as also approved by the eThekwini Municipality.

2. You are requested to take note of the following:

   a. *Kindly liaise with the facility manager BEFORE your research begins in order to ensure that conditions in the facility are conducive to the conduct of your research. These include, but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.*
   b. *Please ensure that you provide your letter of ethics re-certification to this unit, when the current approval expires.*
   c. *Provide an interim progress report and final report (electronic and hard copies) when your research is complete.*

3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za

For any additional information please contact Ms G Khumalo on 033-395 3189.

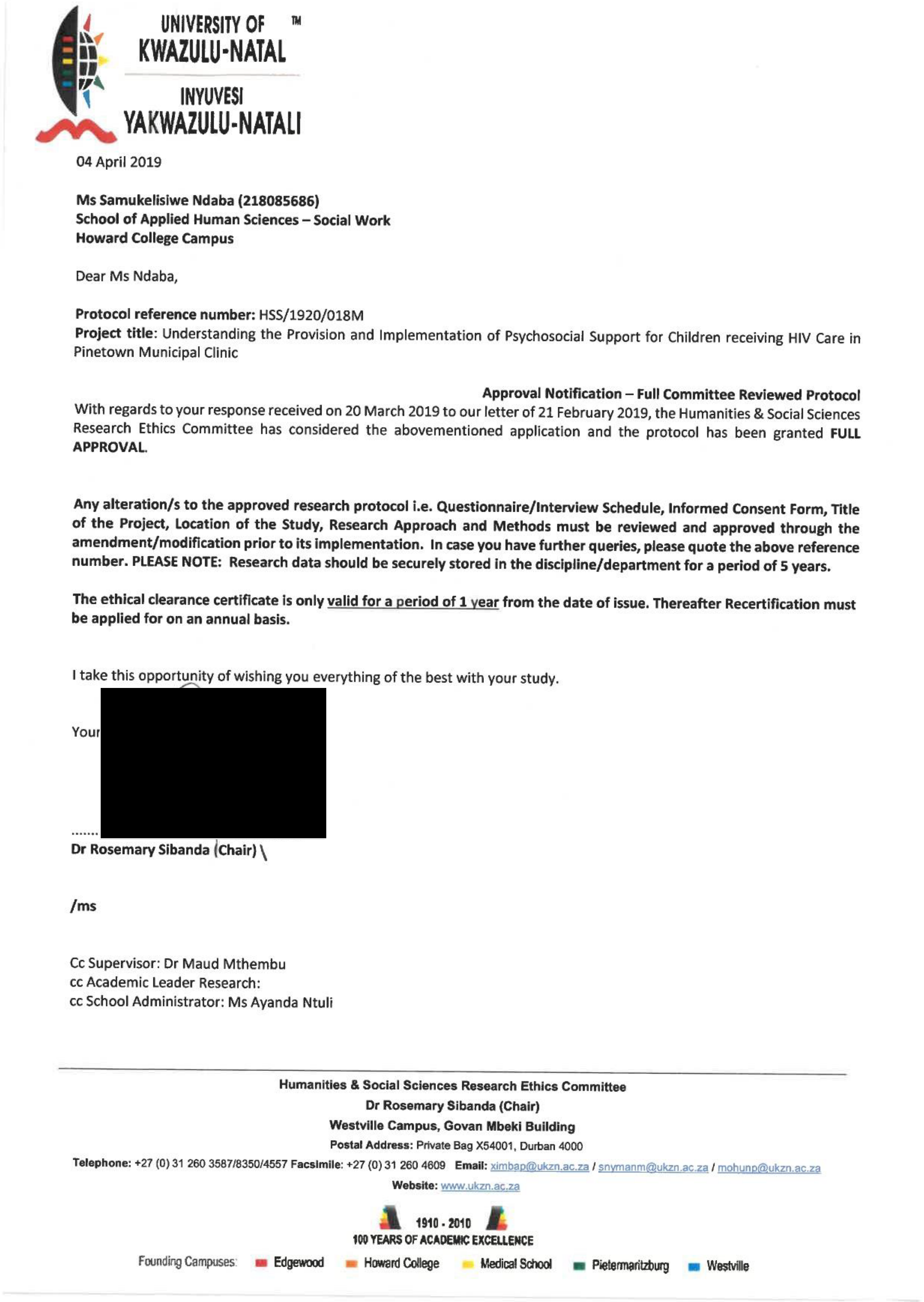
Yours Sincerely

[redacted]

Chairperson, Health Research Committee
Date: 14/03/19.

Fighting Disease, Fighting Poverty, Giving Hope

Appendix 5: HSSREC ethical clearance



UNIVERSITY OF ™
KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI

04 April 2019

Ms Samukelisiwe Ndaba (218085686)
School of Applied Human Sciences – Social Work
Howard College Campus

Dear Ms Ndaba,

Protocol reference number: HSS/1920/018M
Project title: Understanding the Provision and Implementation of Psychosocial Support for Children receiving HIV Care in Pinetown Municipal Clinic

Approval Notification – Full Committee Reviewed Protocol

With regards to your response received on 20 March 2019 to our letter of 21 February 2019, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL**.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only <u>valid for a period of 1 year</u> from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Your [redacted]

....
Dr Rosemary Sibanda (Chair)

/ms

Cc Supervisor: Dr Maud Mthembu
cc Academic Leader Research:
cc School Administrator: Ms Ayanda Ntuli

Humanities & Social Sciences Research Ethics Committee
Dr Rosemary Sibanda (Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 260 3587/8350/4557 **Facsimile:** +27 (0) 31 260 4609 **Email:** ximbap@ukzn.ac.za / snymanm@ukzn.ac.za / mohunp@ukzn.ac.za
Website: www.ukzn.ac.za

1910 - 2010
100 YEARS OF ACADEMIC EXCELLENCE

Founding Campuses: 🟥 Edgewood 🟧 Howard College 🟨 Medical School 🟩 Pietermaritzburg 🟦 Westville