CHAPTER ONE

BACKGROUND TO THE RESEARCH

"So we do not lose heart; though our outward self is wasting away, our inner self is being renewed day by day." 2 Corinthians 4:16a NIV

Introduction

In contemporary times, HIV is no longer perceived as a *death sentence.* The roll-out of antiretroviral therapy (ART) and increasing global access to these medications mean that children living with HIV with perinatal diagnosis are living longer (Domek, 2012). The UNAIDS Global Report estimated 2.1 million adolescents (10–19 years) living with HIV with perinatal diagnosis in 2012 in developing countries (UNICEF, 2014; UNAIDS, 2013). In response to the growing numbers of adolescents with a perinatal diagnosis of HIV, the global community has made great strides in protecting them by facilitating access to treatment, education and social services (UNAIDS, 2010). However, the impact of living conditions and the sexual, reproductive and health needs of this sub-group of adolescents living with HIV have been neglected (Hodgson, Ross, Haamujompa and Gitua-Mburu D, 2012).

Adolescents with a perinatal diagnosis of HIV have unique sexual, health and reproductive needs compared to those of an HIV negative adolescent (International Centre for AIDS care and Treatment Programs, 2010). Many of the adolescents with a perinatal diagnosis of HIV have to deal with the trauma of losing a parent, adapting to a new family, stigma and discrimination as a result of their HIV status and adhering to treatment to manage this chronic illness. In the event of a parent's death, orphans living with HIV are readily absorbed into the extended family network (Drew, Makufa and Foster, 1998). This usually follows kinship lines: aunts, uncles and grandparents (Gilborn, Nyonyintono, Kabumbuli and Jagwe-Wadda, 2001). It is assumed that in an extended family arrangement orphans are enabled to develop a sense of belonging to a familiar social group that can provide an affectionate continuum of care (Richter, Foster and Sherr, 2006). This makes it the most probable and preferred care arrangement for orphans (Freeman and Nkomo, 2006). A qualitative study conducted by Mavangira (2012) in Gauteng, South Africa on the experiences of adolescents with a perinatal diagnosis of HIV residing in Child and

Youth Care Centres concluded that numerous adolescents with a perinatal diagnosis of HIV reach the adolescent stage orphaned and due to gross neglect and/or abandonment by extended family, they are either placed in residential facilities or in foster care.

This sub-group of adolescents requires effective support and guidance from health and social work professionals to assist them to navigate through the complexities of the adolescent phase of life (Hodgson, et al 2012). In fact Raniga and Mathe (2011) found from a qualitative study conducted with adolescent mothers who were living with HIV, that gender inequalities, economic hardship and poverty are conditions that create the breeding ground for sexual exploitation against these young women. They therefore concluded that it is just as necessary to address their psychosocial needs as implementing other health and social work interventions.

In low income communities such as the deep rural community in KwaZulu-Natal, for example Umkhanyakude district, which was the context of this study, adolescents with a perinatal diagnosis of HIV seldom receive psychosocial support from foster parents as a result of high levels of poverty and structural constraints. In times of economic hardship foster parents in such low income communities prioritise putting food on the table for the adolescents with little or no focus on meeting the psychosocial needs of the adolescents who are living with HIV with perinatal diagnosis.

Currently the amount received by foster parents for state foster care grant is R830 per month (Social Assistance Act, 2004). Nyasani, Sterberg and Smith (2009) concluded from their qualitative study of grandparent's experiences of fostering children affected by HIV and AIDS that for many foster parents in low income communities it is usually the only source of reliable income in the household. These researchers add further that even though the foster care grant amount received from the state is much higher than the child support grant, it is still grossly inadequate to meet all the basic needs of a child living with a chronic illness such as HIV.

This unique study explored the psychosocial experiences of adolescents with a perinatal diagnosis of HIV who were placed in foster care residing in Umkhanyakude district.

Bearing the above considerations in mind, this paper presents first hand data which will be attained using the qualitative methodology to gain a better understanding of the psychosocial experiences of adolescents with a perinatal diagnosis of HIV who are placed in foster care, residing in Umkhanyakude District. Using social constructionist theory, I gave the adolescents an opportunity to construct their realities based on their social environment, cultural influences and interaction with society. The paper concludes with suggestions for social workers, policy makers and the relevant departments as to the way forward to realise the psychosocial development of adolescents with a perinatal diagnosis of HIV.

Rationale and background to the research problem
South Africa has one of the highest rates of HIV-infected children in the world (UNAIDS 2010; South African Department of Health: SADOH 2003; WHO 2007). A number of studies across the globe of perinatally HIV-infected adolescents suggest high rates of emotional and behavioral problems that are higher than non-infected adolescents and children with other chronic health conditions (Mellins and Malee 2013). Adolescents with a perinatal diagnosis of HIV often reach adolescence orphaned, and thus are placed in foster care.

The UNAIDS 2009 report indicated that South Africa was ranked the highest amongst developing countries with an estimated 3.7 million children who had lost one or both parents due to HIV-related illnesses (UNAIDS, 2009). We are currently in a critical transitional period, in which the first generation of perinatally infected South African children are navigating their way through the adolescent phase of life. It is thus important for social workers and health practitioners to understand their distinct psychosocial, sexual, reproductive and health needs (Jaspan, Li, Johnson and Bekker 2009). The majority of the children who have been orphaned due to HIV are placed in foster care and my experience as a social worker employed by a foster care agency is that a substantial number of these children are also infected with HIV

through mother to child transmission. My observation as a practitioner for the past two years has been that due to the high caseloads that social workers are dealing with,the placement of children in alternative care often becomes an administrative process rather than a therapeutic one. In recent news, Jamie Naidoo was gruesomely murdered by her foster parent in Chatsworth KwaZulu-Natal. When the community members demanded answers from the welfare agency on why this abuse case was not picked up in time, the Chatsworth child welfare president attributed the lack of foster supervision to the shortage of social workers and a massive backlog(http//:www.eyewitnessnews.co.za: Last accessed 30-11-2014: 11h54). Of course this is not an acceptable explanation for such negligence because no amount of work should come before the wellbeing of the child. According to the Children's Act 38 of 2005 section 2 (b) (iv) the objective of the Children's act is that the best interests of the child are paramount in every matter concerning the child. Given the unique needs of adolescents with a perinatal diagnosis of HIV who are placed in foster care, supervision and constant follow up in the foster placements becomes imperative to ensure that the psychosocial needs are met.

As a social worker working at a foster care agency, I have come in contact with a large number of adolescents living with HIV perinatal diagnosis who have been placed in foster care who reside in the Umkhanyakude district. It was also a major concern for social work practitioners involved in casework intervention that many of the adolescents with a perinatal diagnosis of HIV did not want to take their ARV's. Others were engaging in risky behavior such as unprotected sex, alcohol consumption, staying out late, bunking school isolated themselves. More often than not, these issues were dismissed and the adolescents were reprimanded by the social worker as well as the foster parent but the problem seldom went away. This led me to hypothesize that the negative behavior of the adolescents was heavily linked to their HIV status.

It was clear to me as a social work practitioner that the adolescents with a perinatal diagnosis of HIV were at a crucial stage in their lives where they were trying to find their identity. Erik Erikson calls this stage 'identity versus role confusion'. It is the stage where adolescents not to merely learn who they are, they must at the same time learn to define and invent themselves (Flemming, 2004). This may be tough on adolescents with a perinatal diagnosis of HIV as they are bombarded with

internalised stigma, loss of a parent and trying to 'fit in', especially in secondary school where the dynamics differ to primary school. All these factors weigh in on the adolescents ability to function fully in society. This study is unique in that it seeks to understand the psychosocial experiences of adolescents with a perinatal diagnosis of HIV who are in foster care residing in Umkhanyakude district. It will utilise the social constructionist framework to bring out the voices of adolescents living with HIV in Umkhanyakude district, which is a low income community. It will also include the views of the foster parents who foster adolescents with a perinatal diagnosis of HIV .

Overall Purpose of the Study

The overall purpose of this study was to explore the psychosocial experiences of adolescents living with HIV perinatal diagnosis who are in foster care, residing in Umkhanyakude district. HIV in Umkhanyakude district is rife and with multiple HIV and AIDS related deaths occurring each day, many children are being placed in foster care(Nyasani et al, 2009). When adolescents with a perinatal diagnosis of HIV are placed in foster care, it is assumed that they will receive the best possible love, care and security. This is not always the case, especially in Umkhanyakude as it is a low income community with staggering levels of poverty. Foster parents living in Umkhanyakude face several challenges every day like meeting the needs of their foster children in the midst of socio-economic barriers such as poverty, limited access to resources, little HIV and AIDS education and poor health care services. These challenges amplify when the foster parents living in low income communities are caring for adolescents with a perinatal diagnosis of HIV (Nyasani, Sternberg and Smith, 2009).

Objectives of the study

- To understand the psychosocial experiences of 15 adolescents living with HIV perinatal diagnosis who are placed in foster care living in Umkhanyakude district.

- To explore the coping strategies of 15 adolescents living with HIV perinatal diagnosis who are placed in foster care living in UMkhanyakude district.

- To comprehend the views of the foster parents of HIV perinatally infected adolescents about the psychosocial support that is available to the perinatally infected adolescents.

Research question

The research question that the study addressed was: what are the psychosocial experiences of adolescents living with HIV perinatal diagnosis who are in foster care residing in Umkhanyakude district?

For the above-mentioned question to be answered, the following questions had to be explored

- What are the psychosocial experiences of perinatally infected adolescents?

- What are the coping strategies of perinatally infected adolescents?

- What recommendations can perinatally infected adolescents and foster parents make in support of perinatally HIV infected children.

CONTEXT OF STUDY

The study took place in uMkhanyakude district, northern Kwa-Zulu natal. The district municipality is a newly formed entity in terms of the recent demarcation process and incorporates some of the poorest and most underdeveloped regions of KwaZulu-Natal (www.ukdm.gov.za). The district has an estimated population of 573 341. 45.2% of the population is male and 54.8% is female. The district experiences severe backlogs in the provision of infrastructure and services (Statistics South Africa, 2012).

Umkhanyakude faces high levels of HIV/AIDS infection. The district has adopted a slogan to mobilize stakeholders in the fight against HIV/AIDS: "War against HIV and AIDS: Breaking the chains of infection". The challenge is the integrated implementation for the district. The district is in partnership with Sibambisene civil society and other private and public sector (stakeholders/organisations) to develop an HIV/AIDS strategy. The Traditional Leaders have supported the Node on the HIV and AIDS Strategy (Umqhele Newspaper, 2013). The district has five district

hospitals, 50 primary health care (PHC) clinics, 13 mobile clinics and 152 mobile visiting points (www.kzndae.gov.za: last accessed 10/11/2014 16h08).

Economic profile: the total labour force within Umkhanyakude District is estimated to be 299 602 people, of this number, 38 193 are employed while 196 994 are not economically active. The district is characterised by a high level of unemployment due to lack of local employment opportunities (Zululand observer newspaper, 2012). Low education levels may impact negatively on the ability of the local residents to participate actively and benefit from the ongoing development programmes (http://www.kzndae.gov.za: last accessed 10/11/2014 16h08).

On the Umkhanyakude website (http://www.ukdm.gov.za: last accessed 14/11/2014 at 21h59), the following statistics were discussed:

- Access to electricity: the number of households that have below basic levels of electricity supply is 78.1%.
- Access to water: The percentage of the households that have access to below basic water levels in this district is 56%.
- Access to sanitation: The number of households that have access to sanitation below basic levels is 26.3% of the current household. Sanitation backlogs are one of the major infrastructural challenges facing the district; 57654 households do not have access to any form of sanitation

It is without a doubt that Umkhanyakude district has many socio-economic issues. This affects the lives of adolescents with a perinatal diagnosis of HIV , as the lack of resources in terms of poor access to health care, many adolescents may default on their medication or because of food insecurity, and they may not have proper nutrition to support the medication that they have to take on a daily basis. Furthermore, the lack of focus on the adolescent's psychosocial needs by various sectors in Umkhanyakude means less support in terms of services rendered to them. Because the context of a person plays such a huge role in their functioning, this study adopted the social constructionist lens that is briefly discussed below.

Theoretical Framework

This study adopted the social constructionist lens as a key conceptual framework for this study. Social constructionism may be defined as a perspective which believes that a great deal of human life exists as it does due to social and interpersonal influences (Gergen 1985). Social constructionism regards individuals as integral with cultural, political and historical evolution in specific times and places, and so resituates psychological processes cross- culturally in social and temporal contexts (Owen 2011: 2). Social constructionism rests on the firm belief that there is neither objective reality nor objective truth but reality is constructed from one's experiences and interpretation (Sarantakos, 2005:37). With regards to adolescents with HIV with perinatal diagnosis, their construction of the world is influenced by their interactions with people in their community, the media influences on HIV, the way in which HIV is interpreted and described in their communities and their personal experiences of being HIV positive.

Macht and Quam (1986) argued that the main goal of social work is to strengthen people's ability to cope with tasks and problems that they face. Moreover, it is necessary to pay particular attention to promoting improvements in the environment to meet clients' needs more adequately. Common definitions of social work refer to the change agent function of the profession, which is regarded as the basic mission of social work. I believe that mastering social constructionism, which supports the idea that reality can only be understood in relation to the beliefs, thoughts, and perceptions of an individual, will make a huge contribution to social work theory and practice. "Social constructionists within social work practice emphasize process; plurality of both knowledge and voice; possibility and the relational quality of knowledge and it is affirmative and reflexive focuses on dialogue, listening to and talking with the other"(Howe, 2002:244). With its emphasis on individualisation, participation, self-determination, human rights, and social justice, a social constructionist approach can be an important tool in enabling and empowering clients (Sashin, 2010).

For foster parents, social constructionism also applies as their paradigm and their relationships to the adolescents heavily rely on the social constructs. Unlike the adolescents, the foster parents come from a different generation, with different experiences and different beliefs which are profoundly socially constructed. It is not unlikely that the views and opinions from one generation differ from the next generation and from one context to the other. Using social constructionism as the basis of my research helped me understand these differences and co-constructed the realities of the adolescents as well as the foster parents.

Research methodology

Social research can serve many purposes. Three of the most common and useful purposes are exploration, description and explanation (Babbie, 2008:87). Babbie and Mouton (2001:74) define a research design as a "plan or blueprint" of how the researcher intends to conduct the research. The overall purpose of this study was to explore the psychosocial experiences of 15 adolescents living with HIV perinatal diagnosis (aged 15-18) in Umkhanyakude district.

My research was qualitative in nature. Qualitative research is concerned with subjective assessment of attitudes, opinions and behaviour. Research in such a situation is a function of the researcher's insights and impressions. It is also concerned with the opinions, experiences, and feelings of the individuals producing subjective data (Hancock 2002:3). Qualitative research gives the participants the opportunity to analyse and interpret the phenomenon and determine how their understanding of the phenomenon influences their own personal behaviour (Maxwell, 1998:75). The reason for choosing this paradigm is because I intended to look at the narratives, the untold stories that the adolescents with a perinatal diagnosis of HIV have to tell. One of the characteristics of qualitative research is that it looks at people in their environment and does not divorce them from their social contexts. Qualitative methodology using the social constructionist lens is useful for this study as no two contexts are the same. Understanding the psychosocial experiences of perinatally infected adolescents in their context yielded powerful and valuable results.

The interpretive descriptive design was used to guide this study. This design ensures that rich descriptions of phenomena are produced and that they merge after carefully selecting the participants in research (Marlow, 1998:32). Descriptive research permits the researcher to conduct an open, flexible investigation that adopts inductive reasoning (Terreblanche and Durrheim 1999). Babbie and Mouton (2001) add that this design enables the researcher to provide rich descriptions of the situation and events by interpreting and observing patterns that exist as well as their implications. Using this design helped me explore in depth the views of the adolescents as the aim of my research is to best describe the lived experiences of the participants. My research was qualitative in nature and my findings were a result of descriptive and explorative measures.

Sampling is a process of deliberately and logically selecting sources that will provide the required information (Babbie and Rubin 2008). Deliberate sampling is also known as purposive or non-probability sampling. The study took place in Umkhanyakude district and being an Umkhanyakude district resident was a prerequisite to participate in my study. Participants also had to be infected with HIV due to mother to child transmission and be between the ages of 15 to 18. I chose this age group because most of the adolescents living with HIV perinatal diagnosis are between this age according to the records of a local NGO. Additionally, due to the slow physical and mental development (of children with HIV), these children are usually still in school even after they have reached the age of 18. All my participants were selected on the basis that they were in secondary school and are adolescents who are on Anti-Retroviral Therapy.

My sample was obtained from the data base of children placed in foster care under the supervision of the NGO that I work under. The respondents also had to be part of a support group in Mseleni Hospital called 'Asithandwe Support Group'. This educational support group is for adolescents living with HIV perinatal diagnosis who are already on antiretroviral treatment and encourages them to take their medication independently and faithfully. The NGO that I am currently employed at worked very closely with this support group as therapeutic support was rendered to the adolescents that were part of the 'Asithandwe' support group. I chose to take my respondents from this support group because it had a membership of more than 180

adolescents from all over Umkhanyakude district and some of these adolescents had defaulted in their medication or have had complications with their medication, thus their health related problems were discussed in this group. This group was not therapeutic in nature. Attaining my participants from this group will ensure that all my participants are on antiretroviral treatment.

De Vos (1998) defines data collection methods as the way in which the data is actually obtained. When doing qualitative research, the researcher is often the primary instrument of data collection (Merriam, 1988 in Key, 1997). Data was collected in the following ways:

Through in-depth, individual interview: the individual interviews were conducted with the adolescents living with HIV perinatal diagnosis. Due to the fact that HIV is a sensitive issue, I met the adolescents on a one-on-one basis and ensured that the environment was conducive and non-intimidating. The interviews were semi-structured. Semi-structured interviews were ideal for this study as they not only allowed me to ask specific questions related to the research topic but also permitted the participants to be part of the research by giving them the freedom to formulate spontaneous questions and responses to the subject matter (Mann, 1998). The interviews were tape-recorded to ensure that the data was thick and rich and yielded true results.

Focus groups: According to Greef (2009:289), 'Focus groups are group interviews which give the researcher a better understanding of how people feel about or what they think about an issue'. I also desired to hear the foster parents' views of caring for adolescents living with HIV perinatal diagnosis. These foster parents were the foster parents that formed part of my study. The foster parents were divided into two groups and separate focus groups were held. Data from foster parents was crucial to this study as it ensured reliability and validity of data presented from in-depth-interviews.

Rubin and Rubin (1995:226) claim that analysis can be exciting, because you "discover themes and concepts embedded throughout your interviews". According to Bernard (2010:18), thematic analysis moves beyond counting explicit words or

phrases and focuses on identifying both explicit and implicit words and ideas within data, that is, themes. The reason I chose thematic analysis is that I wanted to look at the different themes that arose in the data that I collected.

Conclusion

In this chapter I presented the motivation and context of the study. The overall purpose, objectives and research question of the study are outlined. The value of the study, the context and the social constructionism framework as the key framework underlying this study were discussed. This dissertation is a temporary base or platform which I used to make known the psychosocial needs as constructed by perinatally HIV positive adolescents. As the reader engages in the material presented in this dissertation from his or her own context, he or she will co-construct ideas as constructs unfold.

Clarification of Concepts

Adolescent

An adolescent refers to young people between the ages of 10 and 19 years whom are often thought of as a healthy group (WHO, 2011).

Adolescence

Adolescence can be defined as the transitional period between childhood and adulthood that begins with puberty and ends when the individual has adult competencies and responsibilities (Sigelman and Rider, 2006). HIV-infected adolescents face additional stressors associated with their disease, including loss and bereavement, cycles of wellness and poor health, barriers to care and social services, anxiety and depression.

ART

Antiretroviral therapy (ART) refers to the use of pharmacologic agents that have specific inhibitory effects on HIV replication (Wilkin and Gulick, 2008). Antiretroviral drugs are medications for the treatment of infection by retroviruses, primarily HIV.

ARVs

This is the main treatment for HIV and AIDS, it is not a cure but it can stop people from becoming ill for many years (NAC 2009).

Child

A young person below the age of 18 years.

Foster Care

According to the Children's Act no 38 of 2005 Section 180(1) "a child is in foster care of a person who is not the parent or guardian of the child as a result of

(a) An order of a children's court

(b) A transfer in terms of section 171

(2) Foster care excludes the placement of a child
   (a) in temporary safe care; or
   (b) in the care of a child and youth care centre
(3) A children's court may place the child in foster care-
   (a) with a person who is not a family member of the child;
   (b) with a family member who is not parent or guardian of the child;
   (c) in a registered cluster foster care scheme".

Foster Parent

According to the children's act 38 of 2005 a foster parent is a person who has foster care of a child by order of the children's court, and includes an active member of an organisation operating a cluster foster care scheme and who has been assigned responsibility for the foster care of a child.

HIV

According to Shah (2005:3) HIV stands for "Human Immunodeficiency Virus" a virus that leads to a state of immune deficiency in humans. HIV is a retrovirus consisting of two single-strands of RNA.

HIV with perinatal diagnosis

Perinatally infected - refers to children who acquire HIV during gestation (uterus), at delivery or through breast feeding (Kalsh, Thea and Steketee, 1999). Perinatal infections include bacterial or viral illnesses that can be passed from a mother to her baby either while the baby is still in the uterus, during the delivery process, or shortly after birth (Edgren, 2006). This was a key criterion for the selection of the participants of this study.

Psychosocial

AIDS Relief (2009) simplified the term Psychosocial by breaking it down, Psycho: the mind (unique feelings, emotions, thoughts, understanding, attitudes and beliefs an individual has). Social: interpersonal relationships and what goes on in the natural

environment). Psychosocial can mean the dynamic relationship between social and psychological experiences where the effects of one continually influences the other (AIDS Relief, 2009:64). In other words, the term psychosocial stresses interconnectedness between the social environment and ones psyche therefore social experiences may lead to psychological consequences and psychological problems may have social consequences.

Psychosocial support

Psychosocial Support is a scale of care and support which influences both the individual and the social environment in which people live and ranges from care and support offered by caregivers, family members, neighbours, teachers, health workers, community members, friends, neighbours, teachers and health workers on a daily basis (AIDS Relief, 2009:78). It also extends to the care and support offered by specialised psychological and social services.

Summary of chapters

Chapter 2: Global Overview of HIV AND AIDS

This chapter will comprise of a comprehensive background of the research. The global and local overviews of adolescents living with HIV perinatal diagnosis are deliberated. The South African policy and legislation regarding foster care and the dynamics around foster care are also discussed in this chapter.

Chapter 3: Social constructions of HIV AND AIDS

The theory of social constructionism will be discussed in-depth in relation to adolescents living with HIV perinatal diagnosis and HIV as a whole. This framework will give greater insight at how adolescents construct HIV.

Methodology

Chapter 4: Research methodology

All logistical information will be included in this chapter. The research methodology, research design, population and sample, data collection and data analysis will be discussed. An overview of the research process will be laid out. The research participants and methods of data collection and analysis will be described as well. Issues relating to reliability and validity in relation to the triangulated research design are discussed. A consideration of ethical issues and the way in which the study was conducted in adherence to standards of trustworthiness and authenticity is presented and the chapter concludes with a discussion of the limitations of the study.

Data Analysis

Chapter 5: Through the eyes of the adolescents with a perinatal diagnosis of HIV

This chapter will present the data collected from the semi-structured interviews with the perinatally HIV infected adolescents. Verbatim phrases from the interviews will be included in this chapter. Common themes that arose during the interviews will also be discussed.

Chapter 6: Voices of the foster parents caring for adolescents with a perinatal diagnosis of HIV

The data acquired from the focus groups with the foster parents will be discussed in this chapter. Challenges experienced by foster parents in relation to adolescents living with HIV perinatal diagnosis will be discussed. This chapter ensures the trustworthiness of data obtained from adolescents.

Chapter 7: Summary and Recommendations

In this chapter a conclusion drawn from the results will be discussed. Suggestions will be made for future studies. Recommendations will also be made to service users about psychosocial support programs that can be put in place to meet the unique needs of perinatally HIV infected adolescents.

CHAPTER TWO

LITERATURE REVIEW

"Taking into consideration the maturation of the HIV pandemic and the uniqueness of HIV adolescents' needs, it is necessary to address their psychosocial problems in proportion to other interventions" (Raniga 2006).

Introduction

Increased access to antiretroviral treatment worldwide makes it more possible for children diagnosed with HIV before their 15th birthday to age into adolescence and beyond (Small, Mercado, Goplan, Pardo, Mellins and McKay, 2014) Prior to antiretroviral therapy (ART) becoming widely available to perinatally infected children, the vast majority died before adolescence (Chin, 1990). Some may ask why the emphasis on the 15th birthday, but as many may remember in 2001, Nkosi Johnson, a renouned child AIDS activist from South Africa, was confirmed as the longest surviving child born with HIV when he died at the tender age of 12.Prior to antiretroviral therapy (ART) becoming widely available to perinatally infected children, the vast majority died before adolescence (Mellins and Malee, 2009). This has changed drastically HIV is no longer viewed as a death sentence but rather as a managable chronic illness (Mavangira, 2012). The increased immortality of perinatally HIV infected children is a pleasing thing and it says a lot about where our country is going as a nation interms of medical development; unfortunately there are so many challenges that come with the benefit of a prolonged life for adolescents with a perinatal diagnosis of HIV .

Despite the increase in life expectancy, few studies have assessed the long-term psychosocial issues affecting adolescents with a perinatal diagnosis of HIV , especially in sub-Saharan Africa where a majority of HIV-positive children reside(Domek, 2013).Many HIV positive adolescents navigate stressors including poverty and resource scarcity, which may converge to produce emotional distress (Small, et al, 2014).Comprehensive services for HIV-positive adolescents in low-income and middle-income countries are underdeveloped despite the epidemiological importance of adolescents with a perinatal diagnosis of HIV

(UNICEF, 2010). Adolescents with a perinatal diagnosis of HIV must navigate the challenge of growing up with a chronic stigmatizing illness that requires intensive ongoing involvement with emerging HIV medical programs and consistent adherence to lifesaving medications (Small, et al 2014). Further, adolescents with a perinatal diagnosis of HIV are navigating their immediate context and developmental challenges while also confronting the additional strain of caring for or potentially losing their only parent to HIV (Small, et al 2014) and are often placed in foster care or in extreme situations, in child and youth care centres. For the purpose of this paper, foster care will be discussed in detail.

This chapter will give the reader an extensive indication of adolescents with a perinatal diagnosis of HIV globally and locally. The statutes that govern HIV intervention in South Africa will be outlined. An overview of the 'orphan crisis' that exists in Africa will be discussed and the models of care that have been put in place to meet the needs these orphans will be discussed.

Global synopsis in respect of adolescents living with HIV

Adolescents and youth are increasingly recognized as a priority on the global agenda as well as in national HIV polices (UNAIDS, 2013). With the advent of ART more and more adolescents are reaping the benefit of prolonged life globally. By 2012, there were 3.3 million children living with HIV worldwide (UNAIDS 2013). The majority of HIV infections are in sub-Saharan Africa, where 85% of all adolescents living with HIV were located in 2012. In 2012, an estimated 5.4 million young people aged 10-24 were living with HIV (UNAIDS, 2012). There are some 900 000 adolescents (10-14) living with HIV, the vast majority of whom acquired HIV through vertical transmission (UNAIDS, 2013).

Table 1: *Number of adolescents and youth living with HIV in 2001 and 2012*

Age	Number of adolescents and youth living with HIV (2001)	Number of adolescents and youth living with HIV (2012)
10-14	250 000	900 000
15-19	1 300 000	1 200 000
20-24	4 400 000	3 300 000
Total (10-24)	6 000 000	5 400 000

(Accessed from: UNAIDS, 2013)

From the table above it is startling to see that in the age group 10-14 there has been such an increase in the number of adolescents and youth living with HIV from 2001 to 2012 globally. And although the overall sum of adolescents and youth that are living with HIV has decreased from 2001; 5.4 million is still a substantial number. Below is a brief overview of adolescents with a perinatal diagnosis of HIV in different parts of the world.

According to the UNAIDS (2011), approximately 4500 HIV-infected children under 15 years of age lived in North America in 2011, a vast majority in the United States. However, given the ageing population of adolescents living with HIV, this number under the age of 15 years likely represents less than half of the total number who are perinatally infected. According to the Centers for Disease Control (2011), statistically 49% of adolescents living with HIV in the United States were over 15 years of age. The perinatally infected population in the United States is at a relatively stable number of over 10,000 individuals, most of whom are now young adults and with the oldest members now entering the third decade of life (Centers for Disease Control, 2011).

The UNAIDS estimate for the number of HIV-infected children under 15 years of age in Western and Central Europe in 2011 was 1600. As in the United States, this likely represents less than half of the perinatally infected population. The estimates for the number of deaths and new infections are similar to those for the United States (UNAIDS, 2011).The perinatally infected population in Europe is likely slightly

younger overall than in the United States and much more likely to have emigrated from abroad, as demonstrated by data from the Collaborative HIV Paediatric Study (Community Health Improvement Process, 2009). In this study, which follows almost all HIV-infected children from 2006 onwards in the United Kingdom and Ireland, 55% were born abroad with 51% females, and 31% were 15 years of age or older in 2011 (http://www.chipcohort.ac.uk).

In France, the native-born perinatally infected population is followed until age 18 years in the French Perinatal Cohort study (http://www.fpch.com. Last accessed 29 October 2014).Ofthe702enrolled, 211 had reached the age of 18 years (http://www.fpch.com accessed 29 October 2014).Researchers in Spain have established a Cohort of the Spanish Paediatric HIV Network that is following approximately 800 of the 1200 HIV-infected adolescents in Spain (De Jose, Jimenez, Espiau, Fortuny, Navarro and Solar, 2013).

The characteristics of the epidemic in Eastern Europe are quite different from that in Western and Central Europe. Here, the prevalence among children is actually increasing, fuelled predominantly by intravenous drug use (UNAIDS, 2013). According to UNAIDS, the number of infected children under 15 years of age in Eastern Europe and Central Asia is estimated to be 11,000, with more new paediatric infections and deaths among HIV-infected children than seen in the United States and other parts of Europe (UNAIDS, 2012). The number less than 15 years of age has been relatively stable for most of the past decade suggesting that the number of newly infected infants equals the number of deaths plus the number who reach 15 years of age every year (UNICEF, 2012).

The 2011 UNAIDS estimates for Latin America and the Caribbean were 60,000 HIV-infected children under 15 years of age, 3300 new paediatric infections, and 3500 deaths. The two countries with the most infected children in these regions are Brazil (20,000 infected children under 15 years of age), the largest economy in Latin America, and Haiti (13,000 infected children under 15 years of age), the poorest country in the Western hemisphere (Whitemore, Hughes, Taylor and Koening, 2010)

In Asia, China is home to 780,000 people living with HIV and only 1.1% acquired it through mother to child transmission and 2322 children under the age of 15 were receiving ART in 2011 (UNAIDS,2011). In 2011 the proportion of HIV positive children receiving ART was 85.2% and the HIV prevalence among children born to women living with HIV stood at 7.4%, down from 8.1% in 2009 (UNAIDS, 2011). In India 220,000 children are infected with HIV, it is approximated that every year 55,000 to 60,000 children are born to mothers who are HIV positive and 30% of these children are likely to be infected themselves (UNICEF,2012).

In East Africa, Uganda is said to have 1,000,000 AIDS orphans and 1,400,000 children in Uganda are living with HIV (UNAIDS, 2013). In Kenya however, there are 190,000 children living with HIV.In Zambia, there are 120,000 children living with HIV and 690,000 AIDS orphans (UNAIDS, 2010); of the children living with HIV in Zambia 90% were infected perinatally (WHO, 2008). Studies conducted in Zambia show that adolescents are now enjoying better health due to the advent of ART. The 2008 Demographic and Health Survey (DHS) reported the median age of sexual debut among Kenyan women was approximately 18 years. The prevalence of HIV among girls 15–19 years old was 3%, which was four times the HIV prevalence among boys of the same age.

Eastern and Southern Africa bear a larger burden with 2.2 million children with HIV, relative to the 990,000 in West and Central Africa. Paediatric ART coverage greatly lags behind that of adults at 21% compared to 55% (UNAIDS, 2012). The largest groups of children with HIV worldwide in 2009 and their ART coverage in 2010 were in Nigeria (360,000; 11%), South Africa (350,000; 50%), Kenya (180,000; 28%), Tanzania (160,000; 12%), Uganda (150,000; 21%) and Zimbabwe (150,000; 35%), (WHO, 2012). The above information depicts that there is an increase in the life expectancy on adolescents with a perinatal diagnosis of HIV , the challenge remains with quality of life that the adolescents need in terms of psychosocial support.

Overview of HIV among Adolescents in South Africa

Estimates suggest that approximately 350,000 children have been born HIV positive in South Africa, thus far (WHO 2011). Another study suggests that South Africa has

the highest number of cases of HIV AND AIDS among adolescents with an estimation of 1.3 and 1.9 million (Bankole, Singh, Woog and Wulf, and 2004:4). The latter indicates the prevalence of HIV among adolescents without specification of neither horizontal nor perinatal transmission. However in 2006, an estimated 38 000 South African children acquired HIV from their mothers around the time of birth and an additional 26 000 were infected during the breastfeeding period (Department of Health, 2007). UNAIDS also reported that South Africa has the highest number of children living with HIV in the world with an estimated 280 000 children younger than 15 years of age living with the infection (UNAIDS, 2008). Thus adolescents living with HIV are already sizeable and prominent sub-group in the South African epidemic having acquired the virus perinatally. From the above information it is clear that there is a large number of adolescent with a perinatal diagnosis of HIV in South Africa, and although their experience vary due to many factors they have one thing in common; all are living with a stigmatizing chronic illness at a crucial stage of their life. Due to the nature of their special needs, it is important that they be given a chance to express themselves in their context so that measures can be put in place to meet their needs.

Socio-Economic impact of HIV and AIDS

Since its onset in 1981, when the first AIDS cases were reported, the human immunodeficiency virus (HIV) epidemic has become not only the deadliest epidemic in contemporary history but also a major demographic, humanitarian and development crisis (United Nations, 2003).Poverty is likely to deepen as the epidemic takes its course. The socio-economic impact of HIV and AIDS combine to create a vicious cycle of poverty and HIV/AIDS in which affected households are caught up. Because expenditure on food comes under pressures, malnutrition often results, while access to other basic needs such as health care, housing and sanitation also comes under threat. Consequently, the opportunities for children for their physical and mental development are impaired (Booysen, Geldenhuys and Marinkov 2003).

It is at the level of the family and community that the fullest impacts of the HIV pandemic are unravelling. One such ramification is HIV and AIDS related poverty

among households. Across the African continent, the most vulnerable people are the most economically active. As these active people die, families are struggling to cope not just emotionally, but also economically (Booysen, et al 2003).Households headed by AIDS widows are also particularly vulnerable, because women have limited economic opportunities and traditional norms and customs may see them severed from their extended family and denied access to an inheritance (UNDP, 1998).One implication of this fragmentation of families is the rising numbers of orphan children on our continent.

Umkhanyakude is a community that is plagued with poverty with more than half of the households living in dire poverty (http//:www.kzn.gov.za). For adolescents with a perinatal diagnosis of HIV , the implications are devastating. HIV being a chronic illness requires a special diet and access to health care; this is a challenge for adolescents with a perinatal diagnosis of HIV . Mseleni hospital located in Umkhanyakude reported that there is an overwhelming number of adolescents that are admitted in the hospital for defaulting on their ARVs and the number one documented reason for defaulting was food insecurity (http//:www.mselenihospital.gov.za). Adolescents were not taking their medication because they did not have food to eat before taking their medication. Other adolescents reported that they have never missed a dose however they used to take their medication on an empty stomach, this had an adverse impact on their health.

On a daily basis social workers grapple with the dilemmas of how best to provide personal and interpersonal help to children living with HIV and their families, as many of the issues and problems that they face are rooted in structural inequalities (Govender, 2009). Primary caregivers of the adolescents with a perinatal diagnosis of HIV , who are the foster parents in this case, cannot meet the basic needs of the adolescents and because of that they have to focus more on trying to make ends meet while the emotional and psychological well-being of the adolescents are ignored. Many policies have been put in place to ensure the holistic development of people living with HIV and although much has changed in response to these policies, many people still view them as rhetoric rather than a reality. Below, legislation regulating HIV intervention in South Africa is discussed.

Legislation Regulating HIV Intervention in South Africa

The South African government has intensified the implementation of policies, strategies and programmes aimed at combating HIV and AIDS (UNICEF, 2012). All of the policies that re implemented have contributed positively in the fight against HIV and AIDS and although South Africa still has a long way to go in terms of combating HIV, with promising policies in place, the battle is half won. Below are brief overviews of legislation that govern HIV intervention in South Africa.

<u>The Constitution</u>

The foundation for all policies and legislation in the South African democracy are entrenched in the Bill of rights of the South African Constitution, Act 108 of 1996.Lombard (2008:156) postulates that the Bill of rights protects the rights of people in the country and affirms the democratic values of human dignity, equality and freedom. The bill of rights (which is part of the South African constitution) enunciates a number of basic human rights which apply to all citizens and which therefore also protect people living with HIV and AIDS. According to the constitution people have the following rights:

❖ the right not to be unfairly discriminated against, either by the state or by another person

❖ the right to bodily and psychological integrity, which includes the right to security and control over the body

❖ the right not to be subjected to medical or scientific experiments without the person's own informed consent

❖ the right of access to health care services, including reproductive health care

❖ the right not to be refused emergency medical treatment

❖ the right to information and a basic education

❖ the right to privacy

❖ the right not to have the privacy on one's communication infringed

The aforementioned rights are ideals that do not always materialise, especially for people living with HIV. The policy also called for a better balance of "generic' or generalist services and those that were structured around the needs of specialised client groups such as children, families, older persons and people with disabilities (Patel, 2005:73). "The implementation of the redesigning of developmental welfare and social work has proved to be a complex and slow process" (Patel, 2005:76). Lombard (2008) attributes this slow progress to lack of a clear conceptualisation of what developmental social welfare entailed. With the stigma and discrimination and other challenges that they face on a regular basis a new policy was designed to meet the unique needs of people living with HIV, this policy is called the National Strategic Plan (NSP). Since 1994, government policies and programmes have endorsed the principles of equity, quality and access. These are the vision, ideals and principles that guide the implementation of the NSP (http://www.laylacassim.co.za last accessed 2014/10/22).

The National Strategic Plan

The National strategic plan (NSP) is a framework to guide the activities of all partners whose work is relevant to HIV, sexually transmitted infections (STIs) and TB in South Africa. It provides goals and strategies for the country's response to the three diseases during the period 2012 to 2016(http://www.laylacassim.co.za last accessed 2014/10/22).The NSP guide the development of provincial strategic implementation plans, as well as sector implementation plans.HIV, STI and TB National Strategic Plan (2012–2016) provides a framework and guide for the South African national HIV, STI and TB response from 2012 to 2016. It is based on the expertise of a very wide range of people and organisations working in the field, as well as research reports and documentation on South Africa's three diseases This NSP also draws on the successes and challenges of the previous National Strategic Plan (2007–2011).

The NSP is firmly located within the constitutional framework of South Africa and strives towards its vision of human dignity, non-racialism, non-sexism and the rule of law. The Constitution lays down a set of ideals towards which the NSP must strive. These include the commitment to healing the divisions of the past and to improving the quality of life of all South Africans. The NSP is also aligned with the goals,

visions and targets of the government's Medium Term Strategic Framework. This framework covers issues relating to basic education, safety and security, employment, skills development, economic infrastructure, rural development, human settlements, responsive local government, environmental protection, public service and citizenship, as well as health(http://www.laylacassim.co.za last accessed 2014/10/22).Considering all the above, one can note that less emphasis has been put on the psychosocial impact related to the illness and deaths of parents, children and other family members; caring for people who are ill and dying of AIDS; as well as living and coping with an HIV positive diagnosis (Mavangira, 2012).

The Children's Act

The Children's Act No. 38 of 2005 as amended provides guidelines for children to be considered to be in need of welfare resources which was formulated to ensure that the implementation of this policy (Government Gazette, 2005). Chapter 2 section 11 (2) of the Children's' Act of 2005 states that:

> "*In any matter concerning a child with chronic illness due consideration must be given to-*
>
> *(a) Providing the child with parental care, family care or special care as and when appropriate;*
>
> *(b) Providing the child with conditions that ensure dignity, promote self-reliance and facilitate active participation in the community; and*
>
> *(c) Providing the child with the necessary support services"*

Effectively, ensuring that the needs of children with chronic illnesses are catered for becomes an onus that befalls social workers as a consequence of the Act. Joubert (cited in Petty, 2002) pointed out that in many instances, a grandparent, aunt or older sibling, becomes the most significant caregiver of a particular child. As a result of the economic burden placed on kinship caregivers, some children become victims of neglect or abuse; some suffer secondary trauma (Petty, 2002).

The Millennium Development Goals (MDGs) present specific development and health targets for 2015 towards which South Africa and other countries are striving.

The targets of the MDGs guide the NSP. Therefore the implementation of the NSP must assist South Africa to reach the Millennium Development Goals, even if this is after the 2015 deadline set by the UN.

The White Paper of Social welfare

With regards to HIV infected and affected children, the White Paper states that the combination of material, social and emotional stresses caused by stigmatization and discrimination make it extremely difficult for people with HIV/AIDS to mobilize what is an already limited set of support mechanisms effectively (White Paper, 1997). To address this problem, service providers are required to intervene by assessing, monitoring and ensuring that the needs of children whose parents are ill as a result of HIV/AIDS, children who have already either lost a mother or both parents, as well as children with HIV/AIDS are met (Mavangira, 2012:27).

Regrettably, most research that has been conducted focuses on children orphaned due to HIV but makes very little mention on adolescents with a perinatal diagnosis of HIV . One of the shortcomings of this legislation/policy is that it makes no mention of integration of HIV and AIDS services but it should be assumed that these are integrated across the key programs for children and youth services, for older persons and for people with disabilities (Patel, 2008:78).

As a result, the burden falls on social workers to find ways to integrate the two policies and come up with solutions that address the needs of adolescents with a perinatal diagnosis of HIV .All these policies focus on HIV/AIDS in a family and community setting therefore, there is no specific statement in reference to adolescents with a perinatal diagnosis of HIV in Child and Youth Care Centres. This shortfall can be attributed to strong movement away from institutional care to alternative care for orphaned and vulnerable children (Ramsuran, 2009; Browne, 2009). This poses a greater challenge on organizations as they have to develop own programs and services to address this emerging group in the South African community. As noted by Raniga (2006), the pandemic has attained maturation - the focus should be on care, support and treatment not only for infected adults and children, but also perinatally infected adolescents.

'Orphan Crisis'

The ways in which the AIDS epidemic cuts short adult lives, with the concomitant implications for the breakdown of family structures, have led scholars to talk of an emerging "orphan crisis". In 2004, an estimated 1.1 million children were orphaned in South Africa and by 2015 it has been predicted that almost 12% of children will be "AIDS orphans" (UNAIDS, 2006). The sheer numbers are likely to put greater pressure on poor communities. Emotional welfare, access to schooling, nutrition and health are all issues confronting orphans; unfortunately, these issues are magnified when it comes to perinatally HIV infected children.

In 2010, South Africa was home to 3.7 million orphans, of whom 600,000 were maternal orphans, 2.48 million were paternal orphans and 660,000 were double orphans (Meintjes, Halla, Mareraa and Boulleb, 2010). While orphans have largely been absorbed by extended family, many households are struggling to meet the needs of orphans under their care (Deininger et al., 2003; Mutangadura, 2003). Adolescents with a perinatal diagnosis of HIV often reach the adolescence stage orphaned and due to structural and economic barriers, their basic needs are unmet.

Orphans' needs are often unmet as a result of a caregiving gap that currently exists in many communities (Kidman, Petrow and Heymann (2007).Many orphans live on their own, or are cared for in child-headed households or by grandparents or relatives in foster care, who because of their own health limitations, are unable to provide adequate care and support (Kidman, et al 2007) and in extreme circumstances, some are placed in Child and Youth Care Centres (CYCC).

Models of care

South Africa is predicted to have 2.3 million children orphaned by Acquired Immune Deficiency Syndrome (AIDS) by 2020 (Actuarial Society of South Africa, 2005). The number of orphans in sub-Saharan Africa is growing, but the number of caregiver households is dwindling, and caregivers are getting older and poorer (UNICEF 2006). Fostering responsibilities exacerbate the poverty and marginalization of older

caregivers and worsen their poor nutritional and health outcomes (King 2008:107; Tarimo et al. 2009).Foster care has greatly expanded in recent years, in part due to a policy in 2000 that legalised the placement of children with extended family members. By September 2008, data from the South Africa Social Security Agency showed that close to half a million children were in formal, court-ordered foster care. About 80 percent of these children are placed with relatives (UNICEF 2009).Foster care is preferred over the institutional care as it allows the child to grow in a family environment. Below is a brief discussion on the models of care that are available in South Africa:

(i)   Adoption

According to the children's act 38 of 2005 section 228, a child is adopted if the child has been placed in a permanent care in terms of a court order that has the effects contemplated in section 242. In section 229 of the children's act 38 of 2005 it provides the purposes of adoption which are to:

(a) *protect and nurture a child by providing a safe, healthy environment with positive support; and*

(b) *Promote the goals of permanency planning by connecting children to other safe and nurturing family relationships intended to last a lifetime.*

Adoption is considered the best model of care as it gives the child security and stability in the adoptive home. Unfortunately, there has been a steep decline in the number of adoptions in South Africa in the past decade. Only 1699 adoptions took place in 2013, from 2840 in 2004 (News24, 2014). One could assume that the reason for the decline is that the adoption process is cumbersome and lengthy or it could be due to the increased foster child grant. It is still the most preferred model of care for children who are in need of care and protection.

(ii)   Child headed households

(1) A provincial head of social development may recognise a household as a child-headed household if—

(a) *The parent, guardian or care-giver of the household is terminally ill, has died or has abandoned the children in the household;*

(b) *No adult family member is available to provide care for the children in the*

household;

> *(c) A child over the age of 16 years has assumed the role of care-giver in respect of the children in the household; and*
> *(d) It is in the best interest of the children in the household.*

In 2005 there were in the region of 64,000 households in South Africa without an adult present, comprising 120,000 children. Most (70%) child-only households consist of only one child and the majority (90%) are headed by individuals of 15 years or older. Many argue that kinship networks are stretched to their limits and are struggling to provide support to orphaned children (Department of Social Development, 2005; Foster, 2000; Germann, 2006; Gow and Desmond, 2002; Howard et al., 2006; Nyambedha, Wandibba, and Aagaard-Hansen, 2003; Republic of South Africa, 2006a; UNICEF, 2006). Popular images of large numbers of young orphans thrust into premature parenting of their siblings and left to fend for themselves are pervasive (Meintjes and Giese, 2006). There is widespread concern that the number of children living without adults in so-called ''child- headed households'' is rapidly increasing as a result of AIDS-related adult mortality in South Africa and elsewhere in sub-Saharan Africa (Meintjes, Halla, Mareraa and Boulleb, 2010).

The children's act 38 of 2005 section 137 (3), states child-headed households must be supervised by a suitable adult so as to assist the children living in child headed households. Subsection (5) (*a*) of the same section states that the child heading the household or the adult contemplated in subsection(2) may collect and administer for the child-headed household any social security grant or other grant in terms of the Social Assistance Act, 2004 (Act No. 13 of 2004) or other assistance to which the household is entitled. Having said that, it is an immutable fact that children who are in child-headed households suffer immensely from poverty and food insecurity, it also makes the children who live in Child-headed households vulnerable to exploitation and jeopardy. In my view, no child should ever bear the brunt of becoming responsible for the lives of his/her siblings from a tender age as this alters the psychosocial development of children and leads to role confusion.

(iii) Child and Youth Care Centers(CYCCs)

According to the Children's Act no 38 of 2005 Section 191(1) "A child and youth care centre is a facility for the provision of residential care to more than six children outside the child's family environment in accordance with a residential care programme suited for the children in the facility, but excludes-

(a)   A partial care facility;

(b)   A drop-in centre;

(c)   A boarding school;

(d)   A school hostel or other residential facility attached to a school;

(e)   A prison; or

(f)   any other establishment which is maintained mainly for the tuition or training of children other than an establishment which is maintained for children ordered by a court to receive tuition or training" (Government gazette, 2005).

Due to the increasingly devastating impact of HIV and poverty, many orphans have found themselves growing up in CYCCs around the world where it is assumed they will receive better healthcare, food, educational opportunities and housing (UNICEF, 2003). Despite evidence that there is an increase in the number of residential care facilities worldwide, (Davis and Rebecca, 2006:20; Foster and Geoff, 2003:12), the statistics on the actual numbers of CYCCs around the world are still vague attributable to inadequate monitoring by governments (UNICEF,2003).

In spite of this, based on extrapolations from limited existing data, UNICEF estimates that at least two million children are in orphanages around the world, acknowledging that this is probably a significant underestimate (UNICEF, 2003). It is important to note that in South Africa, the placement of children in CYCCs is seen as the last resort as children are said to thrive better in a family and community setting as compared to institutionalising them. However, due the excess of children that are in need of care and protection more and more children are being placed in CYCCs.

(iv) Foster Care (alternative care)

The increasing number of orphans affected by HIV or AIDS and an equally increasing number of elderly carers is a phenomenon of global proportions (Foster,

Makufa, Drew, Kambeu and Saurombe, 1996; UNDP, 2005; Makiwane and Kwizera, 2006).

According to the Children's Act no 38 of 2005 Section 180(1) "a child is in foster care of a person who is not the parent or guardian of the child as a result of

    (a) An order of a children's court

    (b) A transfer in terms of section 171

(2) Foster care excludes the placement of a child

    (a) in temporary safe care; or

    (b) in the care of a child and youth care centre

(3) A children's court may place the child in foster care-

    (a) with a person who is not a family member of the child;

    (b) with a family member who is not parent or guardian of the child;

    (c) in a registered cluster foster care scheme.

Within the formal child care system in South Africa, foster care is normally considered to be the preferred form of substitute care for children who cannot remain with their biological families and who are not available for adoption (Ambrosino, Ambrosino, Heffernan and Shuttlesworth, 2005). This reflects the belief that the family is normally the environment most suited to the healthy growth and development of the child. According to Cohen and Garret (2006), foster care is defined as a complex of services which serves children who have experienced abuse or neglect, death of their birthparents and dysfunctional families. Children in foster care may live with unrelated foster parents, with relatives, or in group homes or residential treatment centres.

According to the Children's Act No. 38 of 2005, a child is in foster care when the child has been placed in the care of a person other than a parent or guardian. The child may be placed with a family, relatives or strangers, in a group home (where up to a dozen foster children live under the continuous supervision of a parental figure) (McDonald, Westerfelt and Piliavian 2008:4). There are multiple challenges that adolescents living with HIV perinatal diagnosis experience and some of these are death of parents, trauma, anger, fear, depression, change in body form, stigma and discrimination (Heresi, 2012:21). Joubert (cited in Petty, 2002) pointed out that in

many instances, a grandparent, aunt or older sibling, becomes the most significant caregiver for this particular child.

There is not much literature available with regards to adolescents living with HIV perinatal diagnosis who are in foster care; thus this study intends to investigate the psycho-social experiences of perinatally infected adolescents who have been placed in foster care residing in a low income rural community named; Umkhanyakude District.

In contrast to the amount of data available on the impacts of HIV and AIDS on orphans, limited information exists on the experiences of older people who become their foster-carers and their specific care roles (UNICEF, 1994; World Health Organization [WHO], 2002).In the event of a parent's death, orphans are readily absorbed into the extended family network (Drew, Makufa and Foster, 1998) usually according to kinship lines: aunts, uncles and grandparents (see Gilborn, Nyonyintono, Kabumbuli and Jagwe-Wadda, 2001; Jones, 2005). It is assumed that in an extended family arrange- ment orphans are enabled to develop a sense of belonging to a familiar social group that can provide an affectionate continuum of care (Richter, Foster and Sherr, 2006), which makes it the most probable and preferred care arrangement for orphans (Jones, 2005; Freeman and Nkomo, 2006). This study explored the psychosocial experiences of adolescents with a perinatal diagnosis of HIV who were placed in foster and residing in Umkhanyakude District.

The Adolescent Stage
Adolescence is a stage that is characterised by changes in the body and the sexual organs mature, new expectations for social and academic adjustments. Adolescents become aware of their sexuality and naturally they want to explore. With the help of effective ART, however, growing numbers of adolescents living with HIV will reach adulthood and become sexually active during their adolescence (Levine, Aaron, and Foster, 2006; Rice, Batterham, and Rotherham-Borus, 2006). With the stigma that comes with being HIV positive, most adolescents with a perinatal diagnosis of HIV opt not to disclose their status with their sexual partners; this is a major cause for concern. Due to the lack of psychosocial support that is given to adolescents with a perinatal diagnosis of HIV , especially in low income communities such as

Umkhanyakude district; the risk of infection increases. Adolescents who are living with HIV need access to effective psychosocial interventions such as cognitive behavioural or group therapy (Domek, 2009). Below are some psychosocial issues faced by adolescents with a perinatal diagnosis of HIV :

(i) Identity Versus Role confusion

Identity versus Identity Confusion as identified by Erik Erikson sets in when the adolescent is approximately the age of 12- 18 years. The adolescent at this stage is expected to develop a sense of self and personal identity (Fleming, 2004). Hall and Lindzey (1978) noted that it is a stage when the person becomes aware of individual inherent characteristics such as likes, dislikes, anticipated goals of future and the strength and purpose of to control one's own destiny. This is a time when the adolescents wish to define themselves, where they are at the moment and whom do they want to become, yet at that moment, because of HIV, they are not even sure how the effects of ART will affect their future. Adolescents with a perinatal diagnosis of HIV are often uncertain of what tomorrow holds for them and are most likely to easily get confused. This period when puberty is also setting in, the adolescents are seriously aware of the implication of their illness for the future and present and the fact of being different from other HIV negative adolescent. This creates a lot of anxiety in the adolescents; the more anxious the adolescents are about their illness and their future, the more they are likely to throw caution to the winds (Wolff, 1981). Bearing in mind this unique developmental stage, it is safe to say that the dynamics of adolescents with a perinatal diagnosis of HIV have a unique psychosocial challenges and needs.

(ii) Disclosure, Stigma and discrimination

Stigma is the number one enemy in the fight against HIV. Despite the education and awareness that has been directed towards HIV, stigma and discrimination against people living with HIV is appalling. A qualitative studytitled*psychosocial challenges and protective influences for socio-emotional coping of HIV positive adolescents in South Africa* conducted by (Petersen, Bhana, Myeza, Alicea, John, Holst, McKay and Mellins (2010) indicated HIV positive adolescents have difficulty incorporating a

chronic and stigmatising illness into a healthy identity. Identity development is a key psychosocial developmental task during adolescence, often based on social comparisons (Coleman and Hendry, 2002). Studies have reported that persons living with HIV often incorporate negative stigma into their sense of self, resulting in internalized stigma associated with being a member of an "outgroup" (Joffe, 1999). Peterson et al (2010) indicate that over half of HIV adolescents inter- viewed demonstrated internalized stigma and may be at risk of developing a "spoiled identity".

Another qualitative study conducted in Zambia by Hodgoson et al (2012) concluded that stigma could lead to non-disclosure or delayed disclosure to friends or sexual partners. This could lead to poor sexual practices hence the risk of infection increases. In the community of Umkhanyakude, derogatory names are still being used to describe HIV therefore, internalized stigma in adolescents with a perinatal diagnosis of HIV magnifies. A community's construction of meaning around the nature of HIV largely determines the impact that being HIV positive will have on the psychological well-being of the infected person and their immediate as well as extended family (Muller andPienaar, 2004).Actions to reduce or protect against stigma may be the most significant step that can be taken to improve the psychosocial well-being ofadolescents with a perinatal diagnosis of HIV (Schweitzer, Mizwa and Ross, 2010). There is a great need for stigma to be minimized so that the internal resources of adolescents with a perinatal diagnosis of HIV are cultivated.

(iii)   ART Adherence Issues

Adherence to ART among HIV-infected adolescents is highly problematic. A qualitative study conducted in the United States of America discovered that only 41% of the adolescents that formed part of their study reported adhering consistently to their medication regimen. The strongest and most consistent finding was the relationship between depression and adherence. Depressed mood among adolescents may occur in response to many situations, such as the loss of a relationship or failing at a task; such moods may last briefly or for extended periods of time (Petersen, 1993). Mavangira's qualitative study concluded that adolescents with a perinatal diagnosis of HIV in CYCC's lack autonomy when it comes to taking

medication and thus their long term self- efficacy is affected (Mavangira, 2012). Lack of adherence to ART by adolescents living with HIV may be caused by different things, stigma may be one of the causes that adolescents may refuse to take their medication, if they have to take them in school or around their friends, they may not take them in fear of being judged or ridiculed by their peers. Other adolescents feel hopeless and feel that it is pointless to take medication when ultimately facing a reduced life span. Remember, social constructionists rest on the firm belief that people construct their realities according to their beliefs.

(iv)   Sexual and reproductive needs

In addition to a growing population of vertically infected adolescents in South Africa, youth are among those at greatest risk of HIV acquisition. adolescents living with HIV need to learn how to make healthy decisions about reproductive and sexual health. Like their HIV-negative peers, HIV-positive adolescents will be maturing sexually and will have questions about their ability to date and engage in sexual activity. With sexual behaviour comes the potential for unwanted pregnancy, acquisition of other sexually transmitted infections, re-infection with more pathogenic virus, and transmission of the virus to others (Jaspen, Li, Johnson and Bekker, 2009). The potential costs of unsafe sex are therefore exceptionally high for infected young people and their partners. Young people need age-specific sexual and reproductive health services, and information and counselling to minimise risky sexual behaviour and encourage positive sexual identities.

Conclusion

This chapter has deliberated much on the literature pertaining perinatally HIV infected adolescents. There is much that needs to be done to meet the needs of these adolescents from the micro to the macro level. Social constructionism will be discussed in the next chapter as the over-arching framework for this study.

CHAPTER THREE

SOCIAL CONSTRUCTIONS OF HIV/AIDS

Introduction

Global unity is pivotal in the war against HIV, and the universal strategies that have been put in place have had an insurmountable impact on the prolonged of life of people living with HIV; however it is important to understand that the views and experiences of people living with HIV varies depending on the context one is in. Different economic, political, and cultural contexts account for these variations (Zhang, 2011:1). "The meaning we attribute to HIV and AIDS are decisive in shaping our response to this condition; if we misdefine HIV and AIDS, we risk ineffectual and counter-productive policies" (Keniston, 1989:3). The aforementioned obstacles have a lot to do with socially constructed beliefs about HIV in different countries and regions in the world.

There are increasing numbers of adolescents living with HIV, and they are confronted with three major challenges: (a) stopping HIV transmission to others, (b) initiating and maintaining health care regimens, and (c) maintaining or improving their quality of life (Luna, 1997; Luna and Rotheram-Borus, 1999). Given the rates of HIV infection among young people, it is clear that secondary prevention targeting HIV-positive adolescents is needed to reduce transmission of the virus (Rotheram-Borus, O'Keefe, Kracker, and Foo, 2000).

Social constructionism will therefore be the framework for this study. The fundamental assumption of this paradigm is that "reality is socially constructed"(Bergerand Luckmann, 1966:1). The following discussion will focus on social constructionism perspective, social constructions of HIV and AIDS: the cultural meaning of HIV AND AIDS as an illness; the illness experience as constructed in the interplay of various social factors and the medical knowledge as constructed; and

psychosocial constructs of the adolescence phase in relation to the sociology of HIV and AIDS

Social constructionism Perspective

Social constructionism may be defined as a perspective which believes that a great deal of human life exists as it does due to social and interpersonal influences (Gergen 1995). Although genetically inherited factors and social factors are at work at the same time, social constructionism does not deny the influence of genetic inheritance, but decides to concentrate on investigating the social influences on communal and individual life (Owen, 1995). Social constructionism insists that we take a critical stance towards our taken-for-granted ways of understanding the world (including ourselves). It invites us to be critical of the idea that our observation of the world is unproblematically yield its nature to us, to challenge the view that conventional knowledge is based upon objective, unbiased observation of the world (Burr, 1995:3)

A recent influence within social constructionism is to investigate the ways in which events, processes and qualities are presented and modelled in language, the discursive, which could be called linguistic analysis, as it concentrates on how descriptions of what is real are made, passed on and change through time (Edwards and Potter 1992, Grace 1987). The role language plays in memory has also been tackled (Harre 1990, Edwards, Potter and Middleton 1992, Harre and Gillett 1994).

Social constructionism also focuses on historical and cultural specificity. The ways in which we commonly understand the world, the categories and concepts we use, are historically and culturally specific (Burr, 1995:3). This means that all ways of understanding are historically and culturally relative. Not only are they specific to particular cultures and periods of history, they are seen as products of social and economic arrangements prevailing in that culture at that time.

Another premise of the Social constructionist theory is that knowledge is sustained by social processes. Burr (1995) suggests that it is through our daily interactions

between people in the course of social life that our versions of knowledge become fabricated. Therefore, social interaction of all kinds, and particularly language, is of great interest to social constructionists. Therefore what we regard as 'truth' is a product not of objective observation of the world, but of the social processes and interactions in which people are constantly engaged with each other (Burr, 1995).

In social constructionism, it is also important to understand that knowledge and social action go together. In essence, social constructionism makes us conscious of the diversity and differences in humanity (Parker, 1998:17).

Premise of Social constructionism

Burr, (1995) identified seven features that make social constructionism different to traditional psychology and social psychology. Below is each feature defined and discussed in relation to adolescents with a perinatal diagnosis of HIV .

Anti-essentialism

Essentialism as defined by Twine (2001) refers to the belief that people have an underlying and unchanging 'essence'. Essentialists believe that certain phenomena are natural, inevitable, universal and biologically determined (Irvine, 1990) in contrast, Social constructionists maintain that there are no 'essences' inside things or people that make them what they are (Burr, 1995). Anti-essentialists have argued that people are not creatures of determinism, whether natural or cultural, but are socially constructed and constructing (Sayer, 1995). For adolescents with a perinatal diagnosis of HIV , their psychosocial experiences depend on their environment and how they construct reality is based on their experiences and social world.

Anti-realism

Social constructionism denies that our knowledge is a direct perception of reality. In fact, it may be said that we construct our own versions of reality (as a culture or society) between us (Burr, 1995:6). Within social constructionism there can be no such thing as an objective fact. Social constructionists believe that all knowledge is derived from looking at the world from some perspective or other, and is in the service of some interests rather than others (Burr, 1995). What is the 'truth' or 'real' to one adolescents with a perinatal diagnosis of HIV may not be so for the other.

Their knowledge of HIV, what their peers tell them, how they interpret it and their experiences of HIV shape their own reality of it and attitudes towards it.

Historical and cultural specificity of Knowledge

Social constructionists firmly believe in the influence of knowledge and culture in the construction of reality. Sampson argued that a person can never be considered as a unit but is heavily influenced by the systems around them. In fact, all forms of knowledge are historically and culturally specific (Burr, 1995). The narratives that adolescents with a perinatal diagnosis of HIV have influence their construction of reality and their cultural background also impacts their view on the adolescent stage and living with HIV.

Language as a pre-condition for thought.

We are born into a world where the conceptual frameworks and categories used by people in our culture already exist. Basically what constructionists are saying here is that the way people think is a result of the language they use. "The very nature of ourselves as people, our thoughts, feelings, and experiences are all the result of language" (Burr, 1995:33). For adolescents with a perinatal diagnosis of HIV , the language that is used to define HIV has a great impact on how they construct it. In Umkhanyakude, there are various derogatory names for HIV and upon hearing those names, adolescents with a perinatal diagnosis of HIV structure their thoughts around them since "the way that language is structured determines the way that experiences and consciousness are structured" (Parker,1998).

Language as a form of social action

When we talk to each other, the world becomes constructed. By placing center-stage the everyday interactions between people and seeing these as actively producing the forms of knowledge we take for granted and their associated social phenomenon, it follows that language too has to be more than simply a way of expressing ourselves (Burr: 1995). The Gugu Dlamini story is an example of this; is an example of this, in 1998 she was stabbed and stoned to death when she disclosed her status. The community that did this probably discussed it within themselves what HIV is and how unworthy HIV positive people are of living; that discourse transpired into social action that led to the death of Gugu Dlamini. Today,

people living with HIV still experience discrimination (action) based on the language that is used to define HIV.

<u>A focus on interaction and social practices</u>

Social constructionism regards proper focus on our enquiries the social practices engaged in by people, their interactions, with each other (Burr, 1995). For adolescents with a perinatal diagnosis of HIV , interactions with people in pivotal as it influences the way the choices they make, whether to disclose or not and so forth. It thus becomes important to focus in the interactive processes that take place routinely between people.

<u>A focus on processes</u>

Social constructionists believe that the process is just as important as the outcome, if not more. They maintain that knowledge is not something that a person *has* but is something that people *do* together (Burr, 1995). As in scientific terms, the process determines the outcome hence it becomes imperative for the social constructionist to look at the processes that people undergo, which may be influenced by culture, society, language and so on. For adolescents with a perinatal diagnosis of HIV , a focus on processes is pivotal. I believe that no adolescent would refuse to take ART or have unprotected sex knowing that they are HIV positive just for the sake of it; somewhere during the process something happened to produce this self-defeating outcome.

Social constructionism and HIV and AIDS

<u>Culture as a social construction of HIV and AIDS</u>

In 2005 the Commission for Africa noted that 'Tackling HIV and AIDS requires a holistic response that recognises the wider cultural and social context'. Cultural factors that range from beliefs and values regarding courtship, sexual net- working, contraceptive use, and perspectives on sexual orientation, explanatory models for disease and misfortune and norms for gender and marital relations have all been shown to be factors in the various ways that HIV/AIDS has impacted on African societies (UNESCO, 2002). Cultural sensitivity is increasingly recognized as a means to enhance the effectiveness of health promotion programmes all over the world. Sociocultural meanings and terminology of diseases are important in

understanding how different groups perceive and interpret illness (Sifunda, Reddy, Braithwaite, Stephens, Bhengu, Ruiter and Van Den Borne, 2012).

Webb (1997) notes that community perceptions and individual perceptions of HIV and AIDS integrate culturally specific beliefs relating to its origins and etiology, risk perception and attitudes towards those infected. The subject of culture and local meanings attributed to sexual behaviour and sexual infections is a relatively underdeveloped area in HIV/AIDS intervention research, due to the almost exclusive focus on descriptive data that are often viewed as high-priority information that could lead to quick preventative measures (Sifunda et al, 2012). The tendency to give little focus on the sociocultural and linguistic factors that shape sexual experience has been detrimental in the long-term management of HIV and AIDS.O'Connor (in Ungvarski & Flaskerud, 1999) also notes that culture and ethnicity are substantial determinants of individuals' perceptions and their understanding of HIV/AIDS. However, these cultural values and interpretations constructed may in turn manifest into behavior and attitudes, which may be potentially dangerous; at times reinforcing stereotypes, stigmatization and isolation of perinatally infected children.

There are distinct cultural-based, learnt patterns and interpretations of how individuals experience and explain illness which ultimately dictates how they manage them. Additionally, Parker (1998) emphasizes that seeking more comprehensive measures should go beyond the frequency of certain behaviours to include the 'subjective and interjective' social, cultural and linguistic meaning associated with HIV in order to gain a deeper understanding of these issues in different sociocultural contexts.

Social constructions of HIV AND AIDS by society

Social constructionists posit that reality is constructed through dynamic socialization and that the sociology of knowledge must examine the process in which this reality construction occurs (Berger and Luckmann, 1966: 1). Reverend Jerry Falwell, a well-known reverend described HIV as "Gods judgment on a society that does not live by the rules" yes, HIV is classified as a 'life style' disease but in the case of adolescents with a perinatal diagnosis of HIV , that is not the case. The society has constructed HIV in countless destructive ways and the way that HIV is portrayed in

society impacts the manner in which people living with HIV are treated. In Umkhanyakude HIV has been given many names that portrays it as a disease for the promiscuous, the homosexuals and outcasts, thus people living with HIV are stigmatized.

Much of the construct circumscribing the HIV pandemic is plagued by stigma. Stigma may be thought of in terms of a language of relation- ships, resulting in the construction and application of deeply discrediting attributes (Goffman, 1963: 3). Stigma represents a deviation from some socially constructed ideal or expectation, such as adhering to an accepted sexual orientation or remaining free from a disfiguring disease (Alonzo and Reynolds, 1995: 304). Blatant stigma-related rejection, prejudice, and discrimination are manifested-overtly and covertly-where HIV and AIDS are concerned. Attributes involving the disease are stigmatized because of a variety of biomedical and non-biomedical factors, including modes of viral transmission, psycho-demographics of populations most affected, and obvious visibility of the disfiguring nature of the illness. Fear of contagion, homophobia, racism, sexuality, social perception of drug abuse, and the close association of AIDS with an anaesthetic form of death feed the stigma branding this pathological condition

Adolescents with a perinatal diagnosis of HIV are perceived as the 'victims' of this plague; however the fact that they are deemed as 'innocent' does not take away the negative social contrast that are imposed by society because the mode of transmission is neglected by society and the focus remain on the stigmata-prone virus.

Medical construction of HIV

The social construction of illness is a major research perspective in medical sociology. This article traces the roots of this perspective and presents three overarching constructionist findings. First, some illnesses are particularly embedded with cultural meaning which is not directly derived from the nature of the condition that shapes how society responds to those afflicted and influences the experience of that illness. Second, all illnesses are socially constructed at the experiential level,

based on how individuals come to understand and live with their illness. Third, medical knowledge about illness and disease is not necessarily given by nature but is constructed and developed by claims-makers and interested parties (Conrad and barker, 2010).

Here, one key line of sociological research is that which considers the cultural meaning of stigmatized illnesses. Drawing on the work of Goffman, Gussow and Tracy (1968) were the first to distinguish "stigmatized illness" as a category using the case of leprosy. Subsequent researchers examined the construction and impact of a number of stigmatized illnesses, including mental illness, epilepsy, cancer, HIV/AIDS, and sexually transmitted diseases (STDs).

In the case of HIV/AIDS, other research has shown how stigma limits access to treatment and affects relationships and identity (Epstein 1996; Weitz1990). The lesson from a constructionist standpoint is that there is nothing inherent about a condition that makes it stigmatizing; rather, it is the social response to the condition and some of its manifestations, or the type of individuals who suffer from it, that make a condition stigmatized (Conrad 1987).

For perinatally HIV infected adolescents, they are born with an incurable disease, the fact that it is labelled as 'incurable' makes them feel powerless and hopeless. Thus internalised stigma kicks in. This has a negative impact on their identity as well as on their self-esteem.

Media construction of HIV

Despite a comprehensive national HIV/AIDS/STD Strategic Plan for SA, HIV prevalence has continued to increase, indicating inadequate implementation of the plan.SA has created one of the most progressive and far-sighted policy and legislative environments in the world. Despite the existence of a well thought out plan, sufficient time, a large economy to draw on, a reasonable pool of skilled health and education workers and a sophisticated media, these policies and laws have not been adequately implemented and have not impacted significantly on the ground

(James, 2001). The media has a pivotal role to play in the fight against HIV and AIDS. Many media organisations are rising to the challenge by promoting awareness of HIV and AIDS and educating listeners and viewers about the facts of the epidemic and how to stop it (UNAIDS 2010). In many cases the media served as a primary educational vehicle for the public regarding the information about HIV and AIDS, but what happens when this information is incorrect or bias? (Brodie, Hamel, Bray, Kates and Altman 2004:1). In the past, the media has come up with very deceptive message of HIV and AIDS which makes it dangerous because people are impressionable when it comes to the media. Below is a newspaper article that was published by a popular newspaper article:

> *"AIDS – THE FACTS NOT THE FICTION. At last the truth can be told. The killer disease AIDS can only be caught by homosexuals, bisexuals, junkies or anyone that has received a blood transfusion. FORGET the television adverts, FORGET the poster campaigns, FORGET the end-less boring TV documentaries and FORGET the idea that ordinary heterosexual people can contract AIDS. They can't…the risk of catching AIDS if you are a heterosexual is 'statistically invisible'. In other words impossible. So now we know – anything else is just homosexual propaganda. And should be treated accordingly" (The Sun, 17 November 2006)*

This message is clearly deceptive and bais, a person living with HIV could be stigmatized based on this article. Furthermore, when people read and ingest such they reconstruct and co-construct their views on HIV.

In modern times, the main message on the media when it comes to HIV is unfaithfulness and promiscuity. Any movie that depicts HIV in South Africa is always enacted by a promiscuous man or woman that makes the wrong choices in life and end up with HIV, I am by no means contesting that most people acquire HIV through sexual intercourse however for adolescents with a perinatal diagnosis of HIV that is not the case. The media portrayal of HIV makes it difficult for the adolescents to disclose their status to other people as they fear rejection and being associated with shameful behavior and shameful behavior.

Conclusion

Adolescents with a perinatal diagnosis of HIV can be viewed as 'victims' of the pandemic. They are at the receiving end of effects presented by social constructions of HIV&AIDS (Mavangira, 2012). Based on the social construction theory it was necessary to look at the needs of adolescents with HIV with perinatal diagnosis in relation to their social lives and cultural influences. The next chapter will discuss the research methodology that was utilized for this study.

CHAPTER FOUR
RESEARCH METHODOLOGY

Introduction

Kumar (2012: 94) succinctly describes the research design as a "plan, structure or strategy of investigation so conceived as to obtain answers to a research question or problems". Burns and Grove (2003:195) define a research design as "a blueprint for conducting a study with maximum control over factors that may interfere with the validity of the findings". This qualitative study narratively explored the psychosocial experiences of adolescents with a perinatal diagnosis of HIV who were residing in foster care in the Umkhanyakude district.

In this chapter I will provided a detailed description of how the research process was conducted. The research methodology, the sampling strategy and the data collection method will be discussed in this chapter.

Qualitative research

Babbie and Mouton (2001:278) state that qualitative research "places emphasis on studying human action in its natural setting through the eyes of the actors themselves, together with an emphasis on detailed description and understanding of the phenomena within the appropriate context". Qualitative methodology is an 'umbrella' phrase covering an array of interpretive techniques which seek to describe, decode, translate and otherwise come to terms with the meaning of naturally occurring phenomenon in the social world (Welman, Kauger and Mitchell 2002:188). Qualitative research is concerned with subjective assessment of attitudes, opinions and behaviour. Research in such a situation is a function of the researcher's insights and impressions. It is also concerned with the opinions, experiences, and feelings of individuals producing subjective data (Hancock 2002:3).

Qualitative research gives the participants the opportunity to analyse and interpret the phenomenon and determine how their understanding of the phenomenon influences their own personal behaviour (Maxwell, 1998:75). The reason for

choosing this paradigm is because I intended to look at the life stories, the untold stories that the adolescents living with HIV perinatal diagnosis in foster care have to tell. Qualitative methodology using social constructionism was purposeful for this study as no two contexts are the same and understanding the psycho-social experiences of adolescents with a perinatal diagnosis of HIV in their context will yield potent and valuable results.

This research used the interpretive, descriptive design. This design centres on the way adolescents with a perinatal diagnosis of HIV make sense of their subjective reality and attach meaning to it. Social scientists approach people not as individual entities who exist in a vacuum but explore their world within the whole of their life context (Kumar, 2012). Researchers within this worldview believe that understanding human experiences is as important as focusing on explanation, prediction and control. This design is in line with the social constructionism theory as it is also centred not only on human experiences but also the context in which people operate. For adolescents with a perinatal diagnosis of HIV , it was imperative that subjective realities that they socially constructed were explained accurately and truthfully so that no meaning was lost between the adolescents and me.

Methodology:

Sampling

Sampling is defined as a strategy for deciding which people, settings, events, behaviours and social processes are to be researchable in a way that represents the population of interest (Bless and Higson-Smith 1995). The population are basically the people that formed part of the sample. Purposive or judgemental sampling was used in this study. The primary consideration in purposive sampling is my judgement as to who can provide the best information to achieve the objectives of my study (Kumar 2012:207). Kumar (2012) continues to say that this sampling is extremely useful when you want to construct a historical reality, describe a phenomenon or develop something about which only little is known (Kumar, 2012:207). This sampling strategy is very appropriate for my research as little is known about the psychosocial experiences of adolescents with a perinatal diagnosis of HIV . Below is a discussion on how the sample for my study was selected.

Sample 1: Adolescents

Sampling is a process of deliberately and logically selecting sources that will provide the required information, (Babbie and Rubin 2008). Deliberate sampling is also known as purposive or non-probability sampling was used to select the participants. This sampling method involves purposive or deliberate selection of particular units of the universe for constituting a sample which represents the universe. The sample was obtained from the data base of children placed in foster care under the supervision of a local NGO that is a fostering agency which is funded by the KwaZulu-Natal Department of Social Development in Umkhanyakude district. Those participants who were receiving social work services from the fostering agency as well as from the educational support group facilitated by the local hospital were selected to participate in this study.

Hence the selection followed a purposive process where fifteen adolescents with a perinatal diagnosis of HIV were chosen using the following guidelines:

➢ Adolescents who were perinatally infected with HIV.
➢ Adolescents who were residing in foster care for at least two years.
➢ Adolescents who were attending secondary school.
➢ Adolescents who were 15-18 years of age.
➢ Adolescents who were on Anti-Retroviral Therapy.
➢ Adolescents who reside in Umkhanyakude District.

Table 2: Brief overview of adolescents with a perinatal diagnosis of HIV

Table 2: Profile of adolescents

Adolescent	Age	Gender	Years in Foster care
Senzo	18	Male	6
Mthobisi	17	Male	3
Sakhile	16	Male	2
Sipho	16	Male	6
Nzuzo	15	Male	5
Nkazimulo	16	Male	9
Ndumiso	18	Male	8
Mandla	17	Male	5
Amile	15	Female	3
Sthembile	17	Female	2
Happy	16	Female	12
Nomfundo	17	Female	5
Sindy	16	Female	9
Philile	18	Female	7
Thandeka	17	Female	6

The above table provides basic information of the participants, a more detailed description is provided in chapter five. Please note that all the names utilized in the above table are pseudo names. The study comprised of 15 participants who were all in secondary school and have acquired HIV perinatally. All of them were on antiretroviral treatment at the time of the study.

Sample 2: Foster parents

The foster parents were selected using the criterion sampling method. This involves searching for cases or individuals who meet a certain criterion (Palys 2012:3).The foster parents were selected on the basis of being the foster parents of the adolescents with a perinatal diagnosis of HIV who participated in this study. Umkhanyakude district values tradition immensely and it is a common practice that everything that concerns the child must be discussed with the carer of the child. Prior to obtaining permission from the adolescents to participate in the study; it was expected that I obtain informed consent from the foster parents (see Annexure c). Criterion sampling was applicable for selecting the foster parents

- The carer had to be a foster parent in terms section 182 of the children's act no. 38 of 2005 as amended to an adolescent living with HIV with perinatal diagnosis.
- The foster parent had to be a foster parent of an adolescent that was part of this study.
- The foster parent also had to reside in Umkhanyakude district.
- The foster parents were receiving services from the fostering agency.

Below is a table with the profiles of the foster parents who are taking care of the perinatally HIV infected adolescents.

Table 3: Brief overview of foster parents caring for adolescents with a perinatal diagnosis of HIV

Participant	Gender	Years as a foster parent	Relationship with adolescent
Mama G	F	8	Maternal grandmother
Thokozile	F	9	Maternal grandmother
Ethel	F	3	Maternal aunt
Hlaleleni	F	6	Maternal grandmother
Delani	M	4	Maternal uncle
Bongi	F	9	Maternal aunt
Themba	F	3	Family friend
Nomonde	F	8	Paternal grandmother
Nomusa	F	7	Maternal grandmother
Nokuthula	F	5	Maternal aunt
Sondiwe	F	8	Maternal grandmother
Ungiwe	F	12	Maternal grandmother
Thandiwe	F	6	Maternal aunt

Table 3 above provides a brief overview of the foster parents that participated in the study, a detailed description of the foster parents is provided in chapter six. In table 3, the number of adolescents that participated in the study was 15 and there are 13 foster parents documented in this study. This is due to the fact that some children share a foster parent: Sakhile and Sipho were placed in the same foster family and Ndumiso and Amile were also placed in the same foster family.

Method of Inquiry

The primary sources for data collection in this study were the perinatally infected adolescents and foster parents of the adolescents that formed part of the study. Data was collected using two methods; the methods are discussed below:

Semi-structured in-depth interviews

Semi-structured interviews are suitable for this study as they not only allow the researcher to ask specific questions related to the research topic but also permit the participants to be part of the research by giving them the freedom to formulate spontaneous questions and responses to the subject matter (Mann, 1998).Interviews also gives us an opportunity to get to know people quiet intimately so that we can really understand how they think and feel (Terre Blanche, et al 2006:297). Individual, in-depth semi-structured interviews were held with the adolescents living with HIV perinatal diagnosis. Having the individual interviews was most appropriate for the adolescents because I desired to create a safe environment where they feel comfortable enough to discuss anything with me. Furthermore, due to the sensitivity of the topic of HIV, It was important that the interviews be individual interviews so that the adolescents were protected and that their anonymity is maintained.

Semi-structured interviews are flexible and an interview guide, usually including both closed-ended and open-ended questions, is prepared; but in the course of the interview, the interviewer has a certain amount of room to adjust the sequence of the questions to be asked and to add questions based on the context of the participants' responses (Zhang and Wildemuth, 2009) during the semi structured interviews, it was interesting to see how each adolescent constructed their own meaning of life as adolescents with a perinatal diagnosis of HIV my interview served as a guide but the unprompted views that came through were so rich because it was each

adolescents interpretation of their uniquely similar psychosocial experiences.Hence Terre Blanche and Durrheim's (1999) view that whatever meanings are created in the interview they are treated as being co-constructed between the interviewer and interviewee. This was useful to the study as rich 'thick' data came through from the participants, the flexibility of the semi structured interviews allowed for an influx of information that contributed to the quality of data.

Focus groups

Two separate focus groups was conducted with foster parents. Focus groups are a form of strategy in qualitative research in which attitudes, opinions or perceptions towards an issue are explored through a free an open discussion between the members and the researcher (Kumar 2012:127-128). Terre Blanch et al (2006:304) postulate that a focus group is typically a group of people who share the similar type of experience. A total of 13 foster parents took part in the study, these foster parents were from all over Umkhanyakude district therefore I could not bring them all together into one location; as a result I conducted two focus groups. This helped me because the focus groups had fewer people in each so I was able to control the groups and I was also able to observe the non-verbal communication of each foster parent in both groups. The focus groups were semi-structured in nature and I created an interview schedule with open ended questions that were in line with my research objectives. The interview schedule ensured that the focus group maintained focus on the topic at hand while giving the foster parents to construct further information based on their experiences of caring for perinatally HIV infected adolescents.

 Data Analysis

Content analysis was used to analyse data. In content analysis, researchers examine artifacts of social communication. Interestingly, social constructionists believe language provides us with a way of structuring our experiences of ourselves and the world, and the concepts that we use do not pre-date language but are made possible by it (Burr, 1995) Typically, these are written documents or transcriptions of recorded verbal communication. According to Kumar (2005:223), descriptive information first goes through a process called content analysis, whereby you identify

main themes that emerge from the descriptions given by respondents in response to questions. The analysis of the data was done in the way described below:

Steps in the data analysis process

The data was analyzed using a system of analysis that was outlined by Kumar 2012: 278. He described this method of analysis as a comprehensive process that ensures authenticity of data in qualitative research (Kumar, 2012). Below are the steps that I used to analyze the data:

Step one: identify the main themes

I carefully went through the responses of both the adolescents with a perinatal diagnosis of HIV as well as the foster parents' responses in order to understand the meaning they communicated. I then developed broad themes that reflected those meanings. My field notes came in handy when I was identifying the main themes as they had a detailed account of everything that occurred throughout the data collection process.

Step 2: assign codes to the themes

I made use of different color highlighters to code common themes, due to the vast information I collected, it was important that I found the themes that came through the most. I then wrote the themes down and I assigned a code to each of them using keywords. This made it easy to structure my themes that are discussed in the next chapter.

Step 3: classify responses under the main themes

After I identified the themes, I went through all the transcripts of my interviews and allocated subthemes under the main themes; this was done for logical flow and better ease for the reader.

Step 4: integrate themes and responses into the text of my report

The final step I used was to integrate the themes into the text of my report. I made use of verbatim responses of the adolescents as well as those of foster parents for the enhancement of quality of my research.

Ensuring Trustworthiness of the data

In qualitative research, the concept of validity has been adopted to mean more appropriate terms such as quality, rigor and trustworthiness (Stenbacka 2001; Seale 1999). According to Hesse-Bibber and Leavy (2011:48), 'Validity is a process by which the researcher earns the confidence of the reader that he or she has done it right.To ensure the validity of the data, during interviews and focus groups I did not ask leading questions, double barrel questions and when transcribing the data was kept as authentic as possible. I was also well acquainted with the adolescents that participated in my study therefore the adolescents were more open to discuss even the deepest issues with my in a non-intimidating environment. To ensure validity of my study, I also had an interview schedule with me that framed the interview; the questions that were in the schedule were in line with the objectives that guided this study. All interviews that took place between my participants and I were tape recorded, this ensured accurate transcribing and maintained the authenticity of the data obtained. The data was collected in IsiZulu due to the fact that my sample were not fluent in English, however the data was transcribed in English, I made sure that no meaning was lost during the transcribing process by making use of peer reviews. During the peer review process, the transcripts were revised in relation to the tape recordings and the reviewers helped me demystify unclear concepts and elaborate on the vague transcriptions.

Reliability

To ensure reliability in qualitative research, examination of trustworthiness is crucial. Seale (1999:226), while establishing good quality studies through reliability and validity in qualitative research, states that the "trustworthiness of a research report lies at the heart of issues conventionally discussed as validity and reliability". This relates to the concept of a good quality research when reliability is a concept to evaluate quality in quantitative study with a "purpose of explaining" while quality concept in qualitative study has the purpose of "generating understanding" (Stenbacka 2001:551). Reliability is regarded as a positivist notion which assumes the unchanging universe is where inquiry could quite logically be replicated (Lincoln

and Guba, 1985: 290 in De Vos, 2005). This is in contrast to the social constructionist assumption that social world is always constructed and the concept of replication is itself problematic (Lincoln & Guba, 1985:290). The results that my study yielded may not be replicated in another setting as they will be context specific to Umkhanyakude district. Dependability refers to the researchers attempts to account for changing conditions in the phenomenon chosen for study, as well as changes in the design created by an increasingly refined understanding of the setting (De Vos, 2005: 346).

Triangulation can be defined as a strategy used to enhance trustworthiness through the use of multiple sources and perspectives to reduce systematic bias (Letts, Wilkins, Law, Stewart, Bosch and Westmorland, 2007). Padgett cited in de Vos (2005:361) describes triangulation in qualitative research as the convergence of the multiple perspectives that can provide greater confidence that what is being targeted is accurately captured. Triangulation was achieved by the individual interviews with the adolescents where I was able to the focus groups with the parents and the synergy with other literature.

Ethical considerations

Research should be based on mutual trust, acceptance, cooperation, promises and well -accepted conventions and expectations between all parties involved in a research project (De vos, Strydom, Fouche, Delport 2011:113). De Vos et al (2005) defines ethics as a set of moral set of principles which is suggested by an individual or group and is subsequently widely accepted, which offers rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents. This is how the researcher upheld ethical behaviour:

Participants were informed about what the research entailed, what was expected of them and that they had a right to refuse to be part of the research or leave at any given time without any repercussions.

All participants signed the consent form after I, the researcher explained everything that as written on the form. The participants were given a platform to ask question if confusion arose.

The participants were told about confidentiality and that no one would see the interview transcripts (but a few verbatim responses will be used in the analysis chapter) or listen to the audio recording, except my supervisor. However, it was emphasized to the participants that anonymity will be maintained at all times and pseudo names will be used to protect their identity.

Permission to conduct my study was obtained from the traditional authority of Umkhanyakude district as well as from the local NGO in which the sample was obtained.

Ethical clearance was obtained from the University of Kwa-Zulu Natal's ethics committee to conduct the research.

Due the sensitivity of the issues that were discussed, some of the participants showed signs of distress and needed on-going therapy and follow up; these participants were referred to a local psychologist for further assistance. This aimed at helping children through their psychosocial problems and cultivates a better coping ability.

The researcher followed the following the principles of interviewing:

- All participants were treated with respect and dignity.

- The questions were asked in a clear manner, no leading questions were utilised

- A debriefing session happened after each interview

Limitations of the study

Although I was determined to ensure that the study was conducted in an authentic manner, several limitations arose during the process of the entire study. Although some limitations were overcame, some remained as challenges. The challenges are listed below.

Possibility of respondent bias

The participants that took part in my study are also service users in the NGO that I work under. They knew me as a social worker and therefore held me in very hard esteem. the adolescents may have withheld some important information from me due to fear of reproach. The foster parents may have also been under pressure because they were being interviewed by me (their social worker); they may have felt a need to impress me with their responses rather than painting the real picture.

Small Sample

My research is only based in Umkhanyakude District, and only a small portion of it, therefore my study will not yield data that can be generalised to the entire population. Some of the findings can be useful for further studies in terms of comparison of different contexts but the overall generalizability in other provinces and countries is limited.

Time Constraints

I am a full time social worker, the adolescents were full time learners and some of the foster parents were either employed or working in the fields during the day. This made it very difficult for me to organise to meet with the participants. For the focus groups, it was particularly difficult as the foster parents lived far apart and they were all busy with other commitment. It took almost one month to ensure that everyone will be able to come to the focus groups.

Financial Constraints

My research was self-funded and the money it caused to finance this study was one of the major confounding factors. I had to make various field trips to the schools and to the homes of the participants, sometimes I did not find the foster parents at home

and I had revisit the same home more than once, this meant extra costs. I also had to provide refreshments at our meetings with the participants; this made it difficult for me to keep within the budget that I had initially set.

Conclusion

This chapter provided an overview of the research process; the research design was discussed as well as the sampling strategy and method of enquiry. The issue of ethical consideration and data analysis was also discussed. The next chapter will discuss the result from the data analysis from the data collected from adolescents with a perinatal diagnosis of HIV

CHAPTER FIVE

FACILITATING AND/OR CONSTRAINING FACOTRS THAT IMPACT EXPERIENCES OF ADOLESCENTS WITH A PERINATAL DIAGNOSIS OF HIV

Introduction

Adolescents born with HIV in sub-Saharan Africa are now surviving into young adulthood and face a host of treatment, reproductive health and psychosocial challenges that the health sector is unprepared to manage (UNICEF, 2009). Of the estimated 2.1 million adolescents living with HIV globally, 85% live in Sub Saharan Africa (UNAIDS, 2012). They face a large, unmet need for treatment and support, and many barriers to care (Ross and Cataldo, 2010). Since social constructionists believe that there is no objective truth but one constructs ones reality based on social influences (Burr, 1995) it thus becomes important to pay attention to the life processes and views of adolescents with a perinatal diagnosis of HIV in their socio-economic context.

The empirical findings presented in this chapter emerged from the analysis of the in-depth semi-structured interviews held with fifteen perinatally HIV infected adolescents. The discussion on the findings will be presented in two sections: a biographical profile of the participants; and a discussion of three closely connected themes which are interpersonal factors, interaction with family and beyond and private lives public issues. The reader is urged to engage with the discussions presented in this chapter from his or her own context as he or she will co-construct ideas and reality based on the verbatim responses of the adolescents presented in this chapter.

Biographical Profiles

A brief description on the profile and background of each adolescent was presented in Chapter four in Table 2 This table provides a more detailed overview of the level of education and reasons for placement in foster care. I conducted one in-depth interview with 15 adolescents living with HIV perinatal diagnosis who are in foster care residing in Umkhanyakude. The study comprised of 8 male and 7 female adolescent respondents. The interviews were conducted in Isizulu because the participants did not have a good command of English. Please note that the names below are pseudonyms to ensure that the identity of the participants is protected.

Table 4: Biographical profiles of Adolescents

Adolescent	Age	Grade	Gender	Years in Foster care	Biological Parents
Senzo	18	10	Male	6	Mother passed away in front of him when he was 7 years old. He does not know his father.
Mthobisi	17	12	Male	3	Has a vague recollection of his mom. Does not remember his father.
Sakhile	16	8	Male	2	Mother died recently after short hospitalization. Father is not known by the maternal family.
Sipho	16	9	Male	6	He remembers his mother but has never met his father.
Nzuzo	15	8	Male	5	Child remembers her mother's death. But he has only heard about his father.
Nkazimulo	16	10	Male	9	Child does not remember mother but his father passed away in his presence.

Ndumiso	18	9	Male	8	Child has a picture of his mother but does not remember much about her. He doesn't know his father.
Mandla	17	10	Male	5	The child does not know his father and mother.
Amile	15	9	Female	3	The child remembers her mother very well but has a vague idea of her father.
Sthembile	17	12	Female	2	The child remembers what her mother looked like but she has never met her father.
Happy	16	8	Female	12	The child has no recollection of both her parents.
Nomfundo	17	11	Female	5	Mother died when child was 2 years old, but child has a picture of her mother.
Sindy	16	9	Female	9	The child remembers both her parent, they died in the same month on the same year.
Philile	18	10	Female	7	The child was abandoned by her mother at a young age she grew up thinking her aunt is her mother.
Thandeka	17	9	Female	6	The child still remembers her mother but she is aware that her father abandoned her mother while she was pregnant.

Table 6 above illustrates that 11 out of the 15 adolescents have never seen or met their biological fathers. The absence of biological fathers in South Africa has been constructed as a problem for children of both sexes but more so for boy children; and absent fathers have been highly attributed to HIV infections (Ratele, 2012). It is also evident that of the 15 adolescents, 12 of them were in a lower grade than their ages

dictate for instance, Senzo is 18 years old which means he should have been in grade 12 in the time of the study but he is two classes behind. Thandeka is also behind as she is 17 years old and is in grade nine. This could be attributed to the slow cognitive development as a result of a compromised immune system (Brown, Lourie and Pao, 2000).The adolescents have been in foster care for (n=5.9) years, which means that they have been living with their foster parents for a reasonably long period and this may impact the relationship between the adolescents and the foster parents.

Figure 1 below illustrates 3 major themes, namely interpersonal factors, interaction with foster family and beyond and 'private lives, public issues'. And sub-themes, unresolved grief, who am I, the father that I never knew, painful disclosure, to tell or not to tell, relationship with foster parents, ambivalent feelings about foster care, my friend with AIDS is NOT my friend, medication: my life my responsibility, Relationships and sex and coping skills. Below are the themes that immerged from the semi structured interviews.

Figure 2: Emerging Themes and Subthemes from the Individual Interviews with the Adolescents.
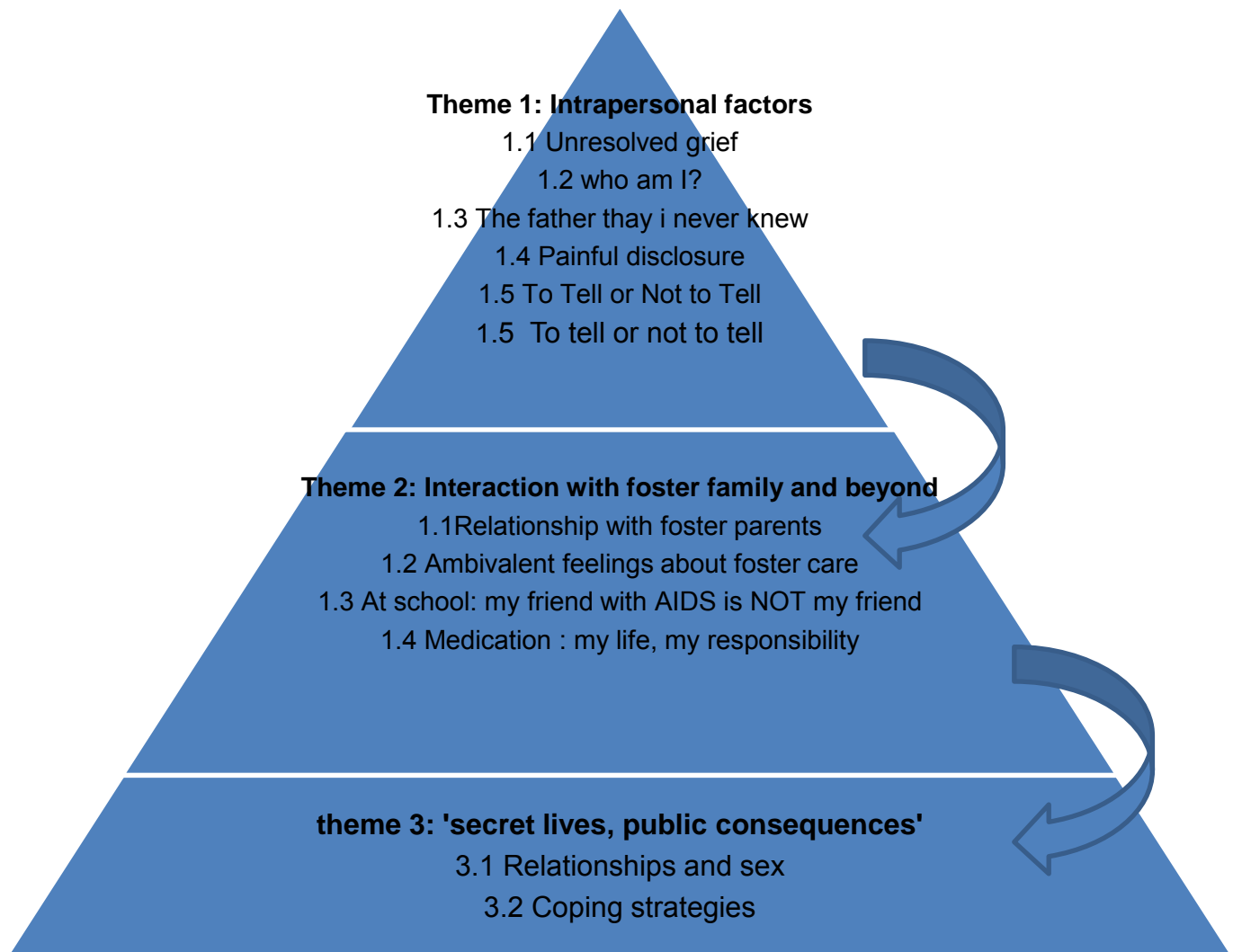
Summary of themes and subthemes

Theme 1: Intrapersonal factors
1.1 Unresolved grief
1.2 who am I?
1.3 The father thay i never knew
1.4 Painful disclosure
1.5 To Tell or Not to Tell
1.5 To tell or not to tell

Theme 2: Interaction with foster family and beyond
1.1Relationship with foster parents
1.2 Ambivalent feelings about foster care
1.3 At school: my friend with AIDS is NOT my friend
1.4 Medication : my life, my responsibility

theme 3: 'secret lives, public consequences'
3.1 Relationships and sex
3.2 Coping strategies

Figure 1: themes and subthemes that emerged from the one-on-one in-depth interviews with the perinatally HIV infected adolescents

1.1 Intrapersonal Factors

Social constructionist theorists argue that "a great deal of human life exists as it does due to social and interpersonal influences" (Gergen 1985: 18). However, embracing a systemic perspective, it is important for social workers to also consider the intrapersonal factors have a major impact on one's physiological and intrapersonal functioning (Richter and Foster, 2005). Adolescents living with HIV face unique illness-related stressors including compromised immune system, low birth weight, prone to secondary illnesses, treatment adherence (Brown, et al, 2000). Additionally interpersonal factors such as social stigma, secrecy, isolation, complex disclosure issues, and multiple losses, have serious implications on the psychosocial experiences and adjustments to the adolescent phase of life amongst those that are perinatally infected (Lewis, 2001; Murphy, Moscicki, Vermund, and Muenz, 2000).

The first major theme that emerged from the data analysis was interpersonal factors, the discussion below provides an overview of the voices of the adolescents and the sub-themes with regard to their history, their identity and disclosure issues.

Unresolved Grief

One of the views that came across in the in-depth interviews with the adolescents was that of unresolved grief. Grief refers to the cognitive and emotional reactions that follow the death of a loved one (Newman 1999:491). According to Lewis (1998:6), there is great hurt in grief, generally a feeling that no one really understands, that no one has ever suffered in quiet the same way or to quiet this extent. Because of cultural beliefs most of the adolescents were not encouraged or allowed to grieve for their deceased parents as a result many still walk around with baggage and resentment due to unresolved grief. These were some of the responses from the adolescents regarding the experience of losing their parents:

Senzo, *"my mom passed away in front of me, I haven't spoken about it till today. I remember it like it was yesterday"*

Lindo, "*my mother went to the hospital, she never came back. My grandmother did not even tell me that she has passed away, I saw people from church coming in and I figured it out, I didn't say goodbye to her*"

Sthembile, "*after my mother's death, I had to move to my grandmother's home. I can't even remember where she was buried. I wish I could go back and tell her I love her*"

Happy, "*my mother died when I was very young and I didn't know what was going on because no one told me. I didn't even know that she had died. My grandma instructed everyone not to tell me because I was too young. When I was about five years old I asked my grandmother where my mother went and she pointed to the tomb that is in our yard. It was the worst day of my life*"

Sindy, "*my parents died at around the same time, I used to cry but my grandmother said I must stop crying because tears won't bring my parents back*"

In the Zulu culture, children are usually sidelined during the grieving process. It is assumed that they do not understand what is going on when a loved one passes away. Malherbe (2004) notes that Zulus do not work through the death of a loved one emotionally, but instead involve themselves in the funeral rituals surrounding the actual burial. The purpose of this ritualistic behavior is to protect people from becoming too emotional and so the Zulu's divert the focus from the unpleasant experience to a complexity of ritual behavior (Ngubane 1977:82). Where possible, children are kept away from an ill or dying person and excluded from the rituals surrounding the burial of the deceased, even if the deceased are their own parents (Richter and Muller 2005:9), this is evident in the responses of the adolescents above. No emotional assistance or counseling was given to the children and as a result they feel like they have unfinished business with their late parents. Once the burial rituals have been fulfilled, the grieving process is regarded as complete (Malherbe 2004) however, when the dust settles; the pain of losing a loved one lingers on. It is safe to say that the process of bereavement in the Zulu culture is socially constructed as a process for adults who have the emotional maturity to deal with it. It is rather unfortunate children tend to harbor the traumatic experience of

losing their loved ones but are not given an opportunity to share their feelings of grief. It is very clear that the lack of support during grief has left a gap open in the children's lives; this has an impact one their psychosocial functioning.

1.2 'I am a product of disobedience'

Growing up with both parents is a privilege and so is being accepted by relatives after losing both parents which can be considered a great opportunity (Mavangira 2012). Nevertheless, when a child is placed in foster care, the child is forced to adapt to a new environment and find their identity in that new context. The society has imposed a negative 'orphan status' to children who are placed in foster care. They are constructed as needy and difficult to live with, so much so that there is a saying in isiZulu that says 'intandane ayiphatheki' meaning 'no one can handle living with an orphan'. The child's identity very much depends on the social constructions of the child.

Nzuzo, *"all I know about my mother is that she came back from Durban with me as an infant and died, my gran once said I am a product of disobedience"*.

Thandeka, "*my mother died when I was very young, people say I am a spitting image of my mom, when my gogo shouts at me, she says I am just like my mother. I wish I could meet her"*

Mandla, *"I can't remember my mother's face, I don't know the woman who gave birth to me"*

Sthembile, *"my aunt always warns me not to make the mistakes my mother made because I will end up like her. I don't even know those mistakes"*

The first stage in Erik Erikson's theory of psychosocial development (trust versus mistrust) solidifies the crucial social interactions between a child and the biological mother which takes place during infancy. Most of the adolescents that participated in the study did not get a chance to create a bond with their mothers and it was evident

this had created a lot of psycho-social problems for them in terms of their ability to form and maintain healthy relationships and/or their ability to trust or to love others. According to Erickson, successful psychosocial outcomes in infancy and childhood are regarded as the foundation for coherent identity (Berk, 2000:456). One participant, Nzuzo spoke about not having any memories or information about his biological mother. Thus he relied on his grandmother to paint a picture for him but his grandmother not only described his mother as a bad person but the grandmother labeled Nzuzo as 'a product of disobedience'. During the interview Nzuzo revealed that these words still linger on today and as a result Nzuzo and his grandmother have a strained relationship. The findings corroborate Dwivedi's (1999) argument that if a child fails to attain secure attachments to a primary caregiver; then it is likely that the child will experience psychological problems in adolescence and adult life. Clearly the findings support that there is a dire need to offer psychosocial support to the adolescents so that they can deal with the insecure attachment and be able to move on so that they can create healthy relationships with their faster parents and the wider community.

1.3 The father that I never knew

Historically, the awareness of the influences of paternal absence on children had been overlooked by society, as maternal presence had been perceived as the most important parental influence necessary for the child's growth and development; yet this is not so. It is an immutable fact that South Africa is a 'fatherless nation' (ref). Many children are growing up without a father and the impact is devastating. Out of the 15 adolescents that were interviewed in the study, 9 said they had never met their father. This implies that 60% of the children interviewed had never had a relationship with their biological father. Most of the adolescents that took part in the study are from single parents foster families that are headed by women, some of them are also placed in foster care where the foster parents are in a polygamous marriage, this means that the father figure was inconsistent in the adolescents lives as the father did not permanently stay with the foster parent. Furthermore, some of the boys that participated in my study were the eldest males in their foster families and consequently had to assume the role of the father in the household. This has had a distressing effect on the adolescents' identity. Some of the comments are as follows:

Sakhile: *"my father was a coward; he did not want to take care of me"*

Thandeka: *"my father gave my mother AIDs and ran away. I hate him"*

Senzo: *"I do not know my father; my mom told me that he left when I was a few months old… I wish my father was man enough to take care of his responsibilities"*

Nzuzo: "*maybe my dad left because he couldn't support me, I don't care about the money, I want him… that's all I want"*

It is evident that the absence of paternal love in the adolescents' lives has resulted in deep pain and frustration. The grudge that they carry because of the abandonment by their fathers still hurts them to this day. Howe postulated that children who develop avoidant patterns of attachments have parents who are indifferent, hostile, rigid or rejecting (Howe, 2002:176) this is evident in the aforementioned responses especially Thandeka's who blatantly admits that she hates her father. The image that the adolescents have of their fathers may be a barrier in the future. Thandeka may have difficulty forming relationships with the opposite sex because the man (her father) that was supposed to love her most, abandoned her. Studies from many different countries have found that girls raised without fathers are more likely to be sexually active, and start early sexual activity (Muehlenberg, 2013). Father deprived girls show precocious sexual interest, derogation of masculinity and males and poor ability to maintain sexual and emotional adjustments with one male (Muehlenberg, 2013).

The responses that Sakhile, Senzo and Nzuzo presented show that their constructions of what a father should be are similar. All of them implied that the roll of the father is to take care of his offspring and to support, financially and emotionally. This deprivation of care and support from their fathers could be detrimental to the emotional development of the adolescents. A study conducted in the USA revealed that males that grew up without their fathers are 82% more likely to join gangs or get involved in self-defeating behavior such as consuming alcohol

(Muehlenberg, 2013); consequently Sakhile and Senzo were reported to be defiant and alcohol consuming by their foster parents.

On the contrary, It is also interesting to note that children that did have their father's present in their lives had a different, more positive perspective on life. There was a sense of love, joy and a zeal for life when they spoke of their fathers, some adolescents had this to say:

Sipho: "*My dad was my hero, he worked in the mines and always said I should be an engineer because his bosses were engineers… he believed in me that's why I will be an engineer*"

Amile "*I miss my dad so much, I want to be like him when I grow up… he used to call me a 'Nkosazane' (princess) and that is exactly what I am*"

1.4 Painful Disclosure

During the in-depth interviews with the adolescents, they were asked to share how they came to know their status, the stories they shared were shocking to say the least. According to the New York State Department of Health AIDS Institute (2009) HIV disclosure to infected adolescents should take place in a supportive environment with collaboration and cooperation among caregivers and providers. Unfortunately this was not the case for most of the adolescents; they had this to say:

Philile, "*I was told by my aunt, she first told me I was taking pills for TB but when I learnt about TB at school, I knew that she was lying to me because I had been taking the pills for more than 6 months. When I asked her she just said, 'you have the same thing that killed your mother' I was so sad I wish …..I could take HIV out of my body*"

Nomfundo, "*I heard that I was HIV positive when my mother was very sick, my grandmother was telling neighbours that came to pray, that my mom has HIV and she looked at me and said 'shame she even gave the disease to my granddaughter' everyone looked at me with pity…. I hate HIV with all my heart*"

Mandla *"I was told by my grandmother, she said 'can you see that your parents are dead, if you don't take your medication you will die like them…I hated HIV since then"*

Mthobisi *"I was told by a nurse at the clinic because my grandmother did not want to tell me, I cried so much I wish I didn't have HIV. It would have been better if my grandma had told me, now I don't trust her"*

There were other stories that the other adolescents shared that were similar to the ones above. The painful memories of how they were told about their HIV status still affect them. In essence, it's not what was said it's how it was said; A recent influence within social constructionism is to investigate the ways in which events, processes and qualities are presented and modelled in language, the discursive, which could be called linguistic analysis, as it concentrates on how descriptions of what is real are made, passed on and change through time (Edwards and Potter 1992). Nomfundo heard that she is HIV positive in the presence of other people, a double-jeopardy occurred here; not only did she hear life changing news but she also had to bear the humiliation of being 'exposed' in public. Philile's story is not rare, most caregivers deceived the adolescents by telling them that the medication they are taking is for TB; they do this to 'protect' the child because TB is seen to carry less stigma than HIV. However, these harms the adolescents as their sense of self are impaired and also lose trust towards their caregivers. Socially, HIV is constructed as deadly disease, even in the mist of HIV education and increased life expectancy due to the accessibility of Antiretroviral Treatment. In isiZulu one of the names of HIV and AIDS is *umashayabhuqe* meaning it 'destroys everything in its path'. Philile and Mandla have constructed their understanding of HIV around death; firstly because that is how society has labelled it and secondly, when they found out that they were HIV positive, death was emphasized and not life.

One participant had a good story to tell about the way his status was disclosed to him. His biological mother disclosed the status to him before she died and he was given an opportunity to ask question during his disclosure. It was done in a loving and supportive environment that enabled him to deal with his status. These were his words:

Senzo: "*It was my birthday and my mom threw me a party. haaa I had so much fun with my friends and there was a big cake, when the party was over, she sat me down and told me that she loves me and there is something I need to know. She told me that I have HIV, I asked her what HIV was because I was turning 7 years old and I did not know what it was and she tried to explain it to me the best way she could….. I have accepted my status, it's not easy, I am optimistic about the future"*

It is interesting to see that relationship that comes across in the above data, the adolescents that had painful disclosures have ill-feelings about HIV but Senzo, who was told in a supportive and enabling environment, was optimistic about the future. I am by no means concluding that better disclosure leads to a better coping ability, because all children are different but it does play a huge role. A supportive environment allows adolescents to flourish even in the face of adversity.

1.5 To Tell or Not to Tell?

The issue of disclosure is a sensitive one, with the stigma attached to HIV it becomes one of the most difficult things one can decide to do. If one decides to share their status with the people they stand the risk of being ostracized and discriminated against, on the other hand if one decides not to disclose the risk of infecting others is greater. For adolescents with HIV perinatal diagnosis, the dilemma is no better; Research has shown that youths who have not told others about their HIV status may experience internalized stigma in the form of shame and self-blame (Swendeman, Rotheram-Borus, Comulada, Weiss and Ramos, 2006:502).Thus growing in a society where HIV is still stigmatized becomes a challenge for these young adults as they often find it difficult to reveal their status. When asked if they will disclose their status to friends they responded:

Senzo *said, "no one knows my status, only my family and I want to keep it that way"*

Mthobisi said**,** *"I can't afford for people to know, I can't go through the humiliation"*

Nzuzo said, *"I do not want to tell anybody about my status, people are not nice out there"*

Amile said "*never! No one can ever know, I would rather die than to tell somebody"*

Sthembile said "*no I do not want to tell people because the will tease me about it*"

Mandla said "*haaa! I will not tell, what if they stop hanging out with me?*"
Philile said "*I don't want to tell because I am sure if my friends will tell other people*"

From the above responses, it is evident that the adolescents have internalized the stigma that comes with being HIV positive. The problem is not necessarily being HIV positive but how people will react when they come to the knowledge of the adolescent's status. Mandla's response shows that there to some degree, the adolescents fear the unknown; Their uncertainty of the responses they might get from their friends makes them reluctant to share their secret. Trust is a very important factor when it comes to disclosure, Philile's response demonstrates that although there might be a willingness to share ones status, there is always that fear of not knowing if the other person will tell other people. This could explain the blatant refusal of the adolescents to share their status.

It is important to note that out of all the 15 children that formed part of this study only one had shared their HIV status with someone other than a family member. However, her disclosure had terms and conditions. This is what the child had to say:

Thandeka "*I have told some of my friends, and my boyfriend knows too; but I never tell first… when my friends tell me that they tested positive for HIV I tell them they will be okay and also tell them about my status. This way I know they will not gossip about me because we are the same*"

Theme 2: interactions with foster family and beyond

2.1: Relationship with Foster Parents

Erik Erikson postulates that at the adolescent stage, the basic task of this period is to separate oneself from one's parents/caregiver (Fleming,2004), the friends voice become more important than the carer and the adolescent is really trying to construct their own identity. Because of this the relationship with the foster parents may be challenged. However, the adolescent's relationship with the foster parents is still

pivotal for the complete psychosocial development of adolescents with a perinatal diagnosis of HIV . These were some of the response from the adolescents:

Senzo, *"I have a good relationship with my grandma, she is very supportive."*

Mthobisi *said, "I get along well with my aunt, she treats me the same way as her other children "*

Happy *"I am happy with my grandma. I wish we spoke more about things"*

Sipho *"I have been staying with my aunt since I was a little child, she treats me well."*

Thandeka *said, "eish things become tough between gogo and I, she doesn't understand me, she says I am being disrespectful all the time"*

Nkazimulo *said, "most days we get along but sometimes she makes me feel like an outsider, sometimes I don't get money for lunch and her children do"*

Amile *said, "she is very moody, she wants me to adapt to her mood all the time, I don't have time for that. I hate moody people"*

There are key words that the adolescents expressed that made the researcher co-construct the realities with the adolescents. Senzo used the term 'very supportive' this means that his foster parent was there for Senzo and gave Senzo the ability to form a warm relationship with his foster parent. When the adolescents feel supported, they are able to enjoy a better standard of care, foster care does not only revolve around the foster child grant but the pricessless connections of family. Mthobisi and Sipho also share the same sentiments.

2.2 Ambivalent feelings about foster care

When the children's act was amended in 2005, the foster placements were revised. Prior to the amendment, a child could only be placed in foster care until s/he turns 18 years old, this has changed. Section 176 (2) of the children's act 38 of 2005 allows for the extension of the foster placement until the person reaches the age of 21 on

condition that the current alternative care giver is <u>willing</u> and able to care for that person. Some of the adolescents' interviews expressed that they lacked a sense of belonging and felt that their foster parents will no longer be willing to take care of them when they age out of care. Here are some of the responses of the adolescent's:

Mthobisi *"I am turning 18 soon and I'm not sure if my grandmother will still want to stay with me. I think she was forced by the social workers to look after me"*

Ndumiso *"I don't think my gogo would look after me if there was no money involved"*

Sindy *"I have nobody, my aunt does not treat me like her children. I know she loves them more"*

Nomfundo "*my family expires when the court order expires"*

Nkazimulo "*when my foster money stopped coming out, my grandmother treated me differently, it's all about the money. My parents did not leave me an inheritance"*

From the above responses one can note that participants have mixed feelings towards their foster parents. They did not show any attachment but resentment towards them. Currently in south Africa, the foster child grant is R860 which is much higher than the child support grant; this may one of the reasons why many people opt for foster care instead of adoption. Foster care has its benefits but the uncertainty that lingers in the minds of foster children is a cause for concern. Social constructionists believe that there is neither objective reality nor objective truth reality, but reality is constructed from one's experiences and not interpretations (Sarantakos, 2005:37). The fact that they do not know what tomorrow holds explains why they feel abandoned, unwelcome and lonely too. This can make them feel as if the world is against them reflecting in them a lack of resilience and increased anger and depression.

2.3 'My friend with AIDS is NOT my friend'

The adolescents that formed part of this study were all secondary school, at the adolescent stages friends become a very important part of one's life. The relationship that adolescents have with their friends has a strong influence on how they construct their realities. It is with friends that teens learn how to begin, maintain, and terminate relationships; practice social skills; and become intimate (Huebner, 2009:5).

Their image is very important and anything that can dent their image is the enemy. An adolescent at a local school in uMkhanyakude is known by the whole school and community that she is HIV positive, she has a skin disorder and she is very thin; the whole school calls her 'born to die'; she has no friends, she is ridiculed constantly and has tried to commit suicide on multiple occasions. All of the adolescents know this child and the way the community treats her makes them that much more reluctant to share their status. When they were asked how they feel about the way that this girl is treated, here were some of the responses:

Senzo "eish I feel for her, sometimes I wish I could help her but I can't risk that. What will my friends say?"

Sthembile "when they talk about her, I also add bad comments and laugh, I do not want anyone to know that we have the same thing"

Thandeka "I feel very bad when my friends speak about her but I don't show it. School children can be really cruel"

Nomfundo "if I were her I would have dropped out of school a long time ago, she doesn't even have friends"

It is interesting to note that the adolescents divorce themselves from HIV, Senzo calls helping the ostracized child 'a risk' and the views of the friends are more important that stranding up for someone. Social constructionism lies on the premise that our social interactions influence the way we perceive things and our experiences alter our views. Social constructionists believe that there is neither objective reality

nor objective truth reality, but reality is constructed from one's experiences and not interpretations (Sarantakos, 2005:37). I believe that the fact that the adolescents observe how HIV positive people are treated by society makes them fear the possible rejection that is experienced by the child.

2.4 Medication: My life, my responsibility

In the African culture, children assume a lot of responsibilities from a young age, but not when it comes to issues of life and death. The adolescents living with HIV perinatal diagnosis are encouraged to be at the forefront of administering their own medication and depend less on their foster parents and they are deemed to be mature enough to do so, but this responsibility bestowed upon them is not without problems. When asked about medication responsibility they said:

Sindy said, *"I take my own medication but my aunt makes sure I keep time".*

Ndumiso said, *"I am in charge of my medication, I keep it in my room coz there are many of us on ARV's".*

Sthembile said *"I take my medication by myself, no one supervises me, sometimes I forget"*

Nomfundo said, *"I set an alarm on my phone, when it rings I know its time, I never forget"*

The above responses were the general consensus among most of the children. Since they are all part of the group 'Asithandwe' which was initiated by the local hospital, they are equipped with skills and are empowered to move towards autonomy with regard to taking their medication. Ndumiso's answer is very interesting because it shows great accountability; he keeps his medication separate from that of the other family members because he wants to keep it safe. This shows that he values his medication because of the benefits it has for him. The other children also show that they are willing to go to great lengths to ensure that they are faithful to their medication.

In contrast, a few children expressed their unwillingness to take their medication for various reasons. It was upsetting to listen to the distorted views of these adolescents when it comes to adherence to medication. This is what some of the adolescents had to say:

Sakhile said "*sometimes I don't take them (ARV's) so that I can blackmail my grandmother to do something for me, it's the only way she listens*"

Mandla said "*most of the time I go home very late when my gogo is sleeping so that she doesn't annoy me and tell me to take the pills, when she asks in the morning I said I have taken them*"

Thandeka said "*I get tired of taking pills, I have seen many people die of AIDS and they take their medication religiously, we are all going to die*"

The above responses are a cause for concern, it is clear that the refusal to take medication by these respondents is deeper than it seems. No one, with the full understanding of HIV would want to risk their life by boycotting to take medication, it is clear that Sakhile is yearning for his grandmothers attention and he feels he has to go to extremes to get it. As for Mandla, it appears that he has not really come to terms with his status and is resorting to self-defeating behaviors to deal with the pain he of being an adolescent with perinatal diagnosis. He feels that if he doesn't take the medication he doesn't have to face HIV. Thandeka on the other hand is full of despair, seeing others around her die of HIV gives her a sense of hopelessness and an disinclination to fight for her life.

Theme 3: Secret lives, Public Consequences

3.1 Relationships and sex

Table 5: Overview of relationships

Adolescent	Age	Gender	Sexual relationships
Senzo	18	Male	No
Mthobisi	17	Male	No
Sakhile	16	Male	Yes
Sipho	16	Male	No
Nzuzo	15	Male	No
Nkazimulo	16	Male	Yes
Ndumiso	18	Male	No
Mandla	17	Male	No
Amile	15	Female	Yes
Sthembile	17	Female	Yes
Happy	16	Female	No
Nomfundo	17	Female	No
Sindy	16	Female	No
Philile	18	Female	Yes
Thandeka	17	Female	No

As shown in the table 7above, most of the adolescents were not sexually active during the time of the interviews. Most of them also expressed that they were not involved in relationships because they would feel obliged to share their status with whomever they are dating; they were not ready to do so. They were well informed of the precautions they needed to take if they were to get involved in sexual relationships and it was pleasing to know that the majority of adolescents knew they were not ready for such a responsibility and therefore did not want to start sexual relation until they were utterly ready.

For the few that revealed that they are involved in sexual relationships, there seemed to be negligence when it came to safety precautions. It was not a lack of

knowledge that informed their action but rather poor decision making. These are some of the responses that came through:

Amile mentioned that, *"yes I have a boyfriend and we sleep together. He doesn't know my status and I don't know his"*.

Philile said *"my boyfriend and I have had sex, I told him to use a condom but he did not want to"*

Sakhile *"my girlfriend and I do a lot of sexual stuff, we do it in the thighs and blowjob, I haven't penetrated her"*

Nkazimulo *said " ahh I do sleep with my girlfriend, if I remember condoms, I use it"*

Sthembile said *"I have sex with my boyfriend, I didn't tell him my status. No one told me that they are going to give me HIV so I don't owe anyone anything"*

The above responses are a cause for concern. The respondents speak so freely about having unprotected sex with their partners and do disclose their status with them prior the sexual engagement. Amile's response depicts carelessness when it comes to such a serious issue, her convictions are that perhaps her boyfriend also has HIV but didn't tell her so neither should she. This is a self-defeating action as it poses a threat on both Amile and her boyfriend. The way Philile phrased her response shows that she is convinced that she was doing the right thing by asking her boyfriend to use a condom and it was his fault that he didn't listen; this is distorted communication, perhaps Philile's boyfriend thought that Philile wanted him to use a condom because she did not wish to fall pregnant and being misinformed, he refused to use a condom.

The risk of HIV transmission from an infected partner through oral sex is much less than the risk of HIV transmission from anal or vaginal sex but there is a risk nonetheless. Sakhile thinks he is playing it safe by not having penetrative sex with his girlfriend but his girlfriend is at risk of contracting HIV. The dissemination of

information regarding different kind of sexual encounters and the risks attached remains essential.

Nkazimulo's response shows a certain level of negligence when it comes to protecting his girlfriend from the transmission of HIV. This lack of responsibility is possibly one of the reasons HIV continues to increase despite of all resources and education available.

Sthembile's response shows that she has not dealt with being HIV positive. Her response was that of anger and vengefulness. She feels she has been done wrong and no apology or explanation was given to her, so she does not owe anyone that courtesy as well. During the time of the interview, Sthembile was two months pregnant and her partner was still not aware of her status. Sthembile would benefit a great deal from therapy, as she would be able to deal with her anger and cope better with living with HIV. If not, her unborn baby may also suffer the consequences.

The adolescents who were sexually active had knowledge on how to protect themselves, but they did not put that use into practice and all of them were willing to disclose their status to their partners. Stigma could lead to non-disclosure or delayed disclosure to friends and sexual partners (Hodgson, et al, 2012) Thus social constructions associated with HIV influence their ability to disclose.

3.2 Coping Strategies

Coping strategies are typically categorized into those that are active (e.g., direct action taken to solve the problem) and those that are emotion-focused or passive (e.g., not dealing directly with the problem) (Lazarus and Folkman, 1984). The third objective of my study was to explore the coping strategies of perinatally HIV infected adolescents. These were some of the responses:

Sindy *I try not to think about it (HIV), when it comes to my mind, I just sing. Singing makes me feel better"*

Senzo *"I know that I am bigger than the HIV, I know of people that have lived for very long with it and they are happy, I know that the same will happen for me"*

Sakhile *"I don't know, I just take each day as it comes, some days are better than others"*

Sthembile *"I pray, I know God is in control"*

Sipho *"I play sports and I'm really good, I hope one day I will play professional football that is what keeps me going"*

Mandla *"I have a little sister that I love so much, I live for her. She keeps me going"*

All the adolescents that were interviews has a 'happy place' where they escaped from the world others, like Sindy escaped to the world of music, Senzo clung to the testimony of a longer life span, Sthembile immersed herself in spirituality, Sipho's dream kept his going and Mandla found strength in his little sister. The hope of a better tomorrow was Sakhile's fuel. Some adolescents had passive coping skills while others adopted the more active ones but all of them found a way to cope with the stressors that come with being a perinatally HIV infected adolescent.

Conclusion

In this chapter it became evident that although the adolescents with a perinatal diagnosis of HIV have different stories to tell, there are so many common themes that came across because the issues that they faced were similar; this can be attributed to the fact that they came from the same community. However, it is interesting to note that their approach to the issues faced differed with the level of support they received. The adolescents who had not dealt properly with the death of their parents and came from broken foster homes had a very negative perception of life and had no goals for the future. Negative interaction with their foster families and other people also had a negative impact on the psychosocial functioning. Adolescents with a perinatal diagnosis of HIV who had not come to terms with their status were comfortable with spreading HIV with no remorse. On the contrary, adolescents that had support from their foster family and various sectors were very responsible and had a positive outlook on life. Needless to say, the role of the foster parents was crucial in the lives of all the adolescents and the level of their interaction with them was a matter of life and death, literally. In the next chapter I will bring out

the voices of the foster parents that participated in my study and will co-construct their perceptions in relation to other literature.

CHAPTER SIX

VOICES OF FOSTER PARENTS CARING FOR ADOLESCENTS WITH A PERINATAL DIAGNOSIS OF HIV

Introduction

Traditionally and in contemporary times in South Africa, foster care has been the preferred model of care for children who cannot remain with their biological families and who are not available for adoption (Perumal and Kasiram 2009). Many thousands of South African children have benefited from court-ordered foster care (Nyasani, et al, 2009). It is, however, doubtful whether this form of care as provided for in the Children's act can adequately deal with the country's changing needs as vast numbers of children are being left parentless owing to HIV and AIDS. With the deepening of poverty in Umkhanyakude, foster parents caring for adolescents with HIV with perinatal diagnosis have a lot to carry and are often left to their own demise due the lack of support available for them.

The pervious chapter highlighted the common themes of adolescents with a perinatal diagnosis of HIV; it became apparent that although there are so many common themes across most adolescents, the social construct is different in each adolescent. It also became evident that the home circumstance played a big role in how the adolescents deal with their status and their relationship with their foster parent had an insurmountable impact on their view of life as a whole. To ensure the trustworthiness of data, focus groups were conducted with foster parents of the adolescents living with HIV perinatal diagnosis that formed part of this study. In this chapter, results from the two focus groups were analyzed separately because of the different settings which influenced the findings leading to the emergence of different themes. Below is the biographical information of the foster parents that took part in my study – use the same framework as the previous chapter.
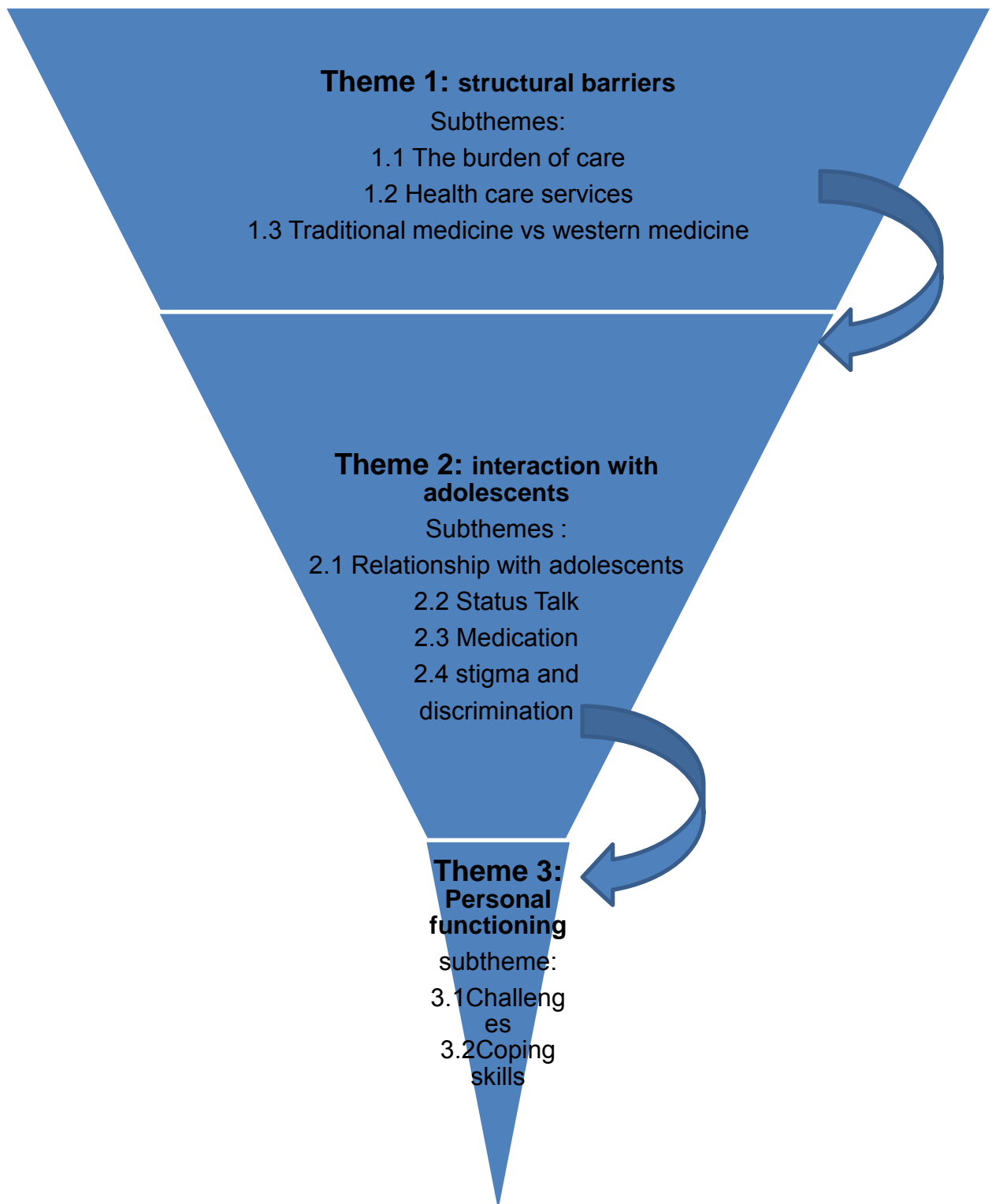
Table 8: Comprehensive Profile of Foster Parents

Participant	Age	Gender	Employed?	Marital Status	Years fostering HIV positive adolescent	Relationship with adolescent
Mama G	56	F	No	Widowed	8	Maternal grandmother
Thokozile	42	F	No	Widowed	9	Maternal grandmother
Ethel	33	F	No	Single	3	Maternal aunt
Hlaleleni	44	F	No	Widowed	6	Maternal grandmother
Delani	50	M	Yes	Married	4	Maternal uncle
Bongi	48	F	Yes	Polygamous marriage	9	Maternal aunt
Themba	38	F	Yes	Married	3	Family friend
Nomonde	49	F	No	Widowed	8	Paternal grandmother
Nomusa	54	F	No	Polygamous Marriage	7	Maternal grandmother
Nokuthula	37	F	Yes	Single	5	Maternal aunt
Sondiwe	55	F	No	Married	8	Maternal grandmother
Ungiwe	52	F	No	Single	12	Maternal grandmother
Thandiwe	32	F	Yes	Single	6	Maternal aunt

Table 8 illustrates the foster parents are unemployed therefore the foster child grant is the main source of income in these homes. Furthermore 8 of the 13 foster parents are raising the adolescents as single parents as some are widows and some are not married; consequently the responsibility of caring for the adolescents with a perinatal diagnosis of HIV rests on their shoulders alone. Table 7 also concurs with Nyasani

et al, (2012) findings that revealed that women are at the forefront of foster care as 11 out of 13 (85%)of the foster parents that participated in the study were females, the majority being the children's' grandmothers. Additionally, 12 of the 13 foster parents that participated in this study shared kinship relations with the adolescents. This correlates with the Children's Act 38 of 2005 section 7 (f)(i)(ii) which states that it is in the best interest of the child to remain in the care of his or her parent, family and extended family and to maintain a connection with his or her family, culture or tradition. On average, the foster parents have been fostering adolescents with a perinatal diagnosis of HIV for 5.8 years and according to Nyasani et al, 2009, foster children that have been placed in foster care for above four years have a better relationship with their new family and the environment that they find themselves in.

Figure 2 below depicts the interrelatedness in the themes that emerged from the focus groups with the foster parents. In Chapter 5 the diagram that illustrated the themes that emerged from the adolescents was upright, showing that for the adolescents with a perinatal diagnosis of HIV , intrapersonal issues affected their interactions with people and their behavior which had public implications. Interestingly, for the foster parents the themes that emerged revealed the opposite. The foster parents were facing tough structural constraints that affected their relationship with the adolescents and coping strategies. Below the themes that emerged from the foster parents focus groups are discussed.

Figure 2: Emerging Themes and Subthemes from the Individual Interviews with the Adolescents

Theme 1: structural barriers

Subthemes:

1.1 The burden of care

1.2 Health care services

1.3 Traditional medicine vs western medicine

Theme 2: interaction with adolescents

Subthemes :

2.1 Relationship with adolescents

2.2 Status Talk

2.3 Medication

2.4 stigma and discrimination

Theme 3: Personal functioning

subtheme:

3.1Challenges

3.2Coping skills

Theme 1: Structural Barriers

In South Africa, the HIV pandemic collided with poverty and poor service delivery which increased stress within extended families that were expected to shelter for orphans (UNAIDS, 2009). The likelihood of HIV and AIDS exacerbating poverty and heightening social instability is real in many communities (Hearle and Ruwanpura, 2009). Many fostering relatives experience hardship and material deprivation because of public sector expenditure cuts (Akintola, 2008). Still, relatives are the first port of call as households under stress "rely heavily on their kin, via entitlements defined through notions of responsibility and reciprocity" (Baylies, 2002: 622). In Umkhanyakude high levels of poverty have equated to poor structural support for the adolescents and foster parents. The following subthemes arose from the discussions with the foster parents.

1.1 The burden of care

During the focus group interviews with the foster parents became clear that the foster parents did not speak much about the emotional and psychological well-being of the children but they spoke much about the grant money and the financial challenges that they face on a day to day basis. Conventionally, caregivers are seen as providing everything children need in their daily lives, enriching their quality of life, feeding them and keeping them healthy. Such a role implies a strong sense of responsibility and duty, particularly as many orphans tend to be the grandchildren of caregivers. In this regard, child fostering is a traditional mechanism of support and is considered vital for children's welfare (Madhavan, 2004). However the foster parents felt that they were not given adequate support to meet the needs of the adolescents especially given their unique circumstances. The resentment that they harbored was evident; in addition they indirectly stated they were fostering more out of obligation than choice.

Nokuthula *"if I had a choice I would not be a foster parent, looking after a sick child is very hard"*

Sondiwe *"I am too old to be a foster parent, I asked my other children to be a foster parent to my grandchild but they all refused, if there was no money involved I would have given up on my grandchild a long time ago"*

A study conducted by Nyasani et al (2009) also show that foster parents living in low income communities such as Umkhanyakude district resent being foster parents especially if they are caring for adolescents because of the behavioral changes that occur in the adolescents lives. The behavior of the adolescents with a perinatal diagnosis of HIV had a lot to do with the foster parent's perception of fostering them. It seemed that those that did not have any issues with the behavior of the foster children did not have a problem with being foster parents. However a vast majority of the foster parents felt underappreciated by both the adolescents and the public sector and felt as if their needs are being put aside. This made the foster parents ask the question 'in the best interest of the child, What about us?'

Thokozile *"In children's court, the magistrate only spoke about my responsibilities towards the child, not that the child should respect me. He thinks that I abuse him when I rebuke him and always threatens to tell the social workers"*

Delani *"the social worker always asks how I am treating the child, never about how the child is treating me"*

Mama G *"I'm grateful for the foster child grant, it helps us meet the basic needs. All my grandchild needs is food and a place to live, the rest is not important"*

Nokuthula *"I think the grant money should increase for us who are looking after children born with HIV"*

Despite the economic realities of poverty and hardship, kin are the most likely people to be the carers of orphans because they are embedded in a social space where the mores of responsibility and reciprocity are aspects of the social fabric (Akintola, 2008). Even as the foster child grant draws on the relatives to become carers of

orphans, little attention is paid to supporting elderly kin especially as their abilities are constrained by material privation (Hearle and Ruwanpura, (2009). As noted from the above responses, the foster parents are in need of more support emotionally as well as structurally so that they may be able to care for the adolescents holistically. Mama G's response concurs with Freeman and Nkomo, (2006) who state that in the Zulu culture physical well-being is more important that all other aspects of life, and thus the other aspects are neglected. Delani's response identifies a gap in social work practice that is very common, because the Children's Act 38 of 2005 tells us that the best interest of the child is paramount, the focus tends to be on the child alone however service providers need to understand the severity of the social environment of the adolescents so that services will yield better results. An enabling environment is the answer to the psychosocial development of perinatally HIV infected adolescents.

1.2 Health care Services

Given the unique needs of adolescents with a perinatal diagnosis of HIV , it is important that the health sector create a welcoming and conducive environment for the adolescents, however the foster parents alleged the opposite. The foster parents made reference to the fact that the children sometimes do not want to go to hospital because the PMTCT clinic is in a distinct building and everybody knows that that is where people with HIV go.

Nokuthula *"if the PMTCT clinic was not so obvious maybe it would be easier to convince my niece to go get medication"*

The PMTCT clinic is made distinct from the rest of the hospital because of the high numbers of HIV positive people. It being separated from the hospital allows for ease of access; it also has all the necessary resources that are needed by HIV positive patients ie pharmacy, lay counsellors, laboratory and equipment that meet the unique needs of people living with HIV. Nevertheless, the children see it as a thorn in their flesh because it's a threat to maintaining their secrets thus feel that they will be easily discriminated against. This means added pressure for the foster parents who have to constantly struggle to get the adolescents to keep doctor's appointment and clinic dates. In many instances, this leads to a strained relationship between the

foster parents and the adolescents. Mavangira (2012) also discovered similar results with regards to this. In her qualitative study of the adolescents with a perinatal diagnosis of HIV who are residing in CYCC's in Pretoria, it became evident that one of the issues that the care workers reported was that adolescents did not want to go for checkups and collect their ARV's from clinic because the doors were labelled 'HIV clinic'. This made the adolescents feel stigmatized and that their secret was being involuntary shared. This was a thorn in the flesh for the foster parents because all they wanted was for the adolescents to remain healthy.

1.3 Traditional medication vs Western medication

A huge topic that was deliberated in the group was that of tradition medicine that is used by most of the foster parents in the support group for the children. When the question of why they think their foster children refuse to take medication one response was:

Themba *"because it is too slow, I take the foster child to the traditional healer and it makes his soldiers stronger"*

The response Themba provided may come as a shock but it is quite a common practice in many homes, there is very little faith in ARV's and the media pounds the message of the use of herbal products to help the ARV's work better and although I do not have the medical authority contest this view, I do know that it has caused a number of problems for people who use traditional medication with ARV's. This is also an issue for the perinatally infected adolescents as they are often dictated to by the foster parents to use traditional medication, when it fails the children loose trust in the foster parents.

Delani, *"my nephew became very sick and started blaming me because the doctor told him that his CD4 count dropped because of the traditional medicine. He said I wanted to kill him because he is a burden to me. Our relationship has never been the same"*

In Africa, traditional herbal medicines are often used as primary treatment for HIV/AIDS and for HIV-related problems including dermatological disorders, nausea,

depression, insomnia, and weakness (Fleming, 1995). Traditional herbal medication is trusted by most of the foster parents because they maintain that their ancestors used it for many years without the assistance of western medication meaning it still works today. However, some herbal and traditional medicines are not well-researched, poorly regulated, may contain adulterated products, and may produce adverse effects (Morris, 2002). The adolescents and social workers rely on the foster parents to ensure that good health of the adolescents is maintained and when the health is threatened, the foster placement is questioned and the adolescents' loose trust in the foster parents.

Theme two: Interactions with Adolescents with a perinatal diagnosis of HIV

The social constructionist theory states that as we interact, we construct (Burr, 1995). The interaction of the adolescents and the foster parents are very important because it is at this stage where the adolescent construct their identities. Although Erik Erikson maintains that at this stage the adolescents want to separate themselves from their foster parents, the guidance of their carers influences heavily on how they construct their identities. The subthemes below emerged from the focus groups:

2.1 Relationship with Adolescents with a perinatal diagnosis of HIV
During the focus group discussions the foster parents often described a feeling of disharmony in their relationships with the children they were fostering. Some thought that this stemmed from the wide generation gap between them. In rural areas, in particular, this seemed to be manifest in the grandparents' very different views on discipline.

Thokozile, *"I hate how my niece uses the fact that she is HIV positive as an excuse to be rude; when I discipline her she says 'ohho, it's because I'm positive neh?' she needs to grow up"*

Nomonde *"My grandchild isolates himself and writes sad letters and puts them on my bed, I don't know that he wants from me".*

Nokuthula, *"Hayi, I also have a problem with my nephew, he gets angry very easily and I also become angry and shout at him"*

Hlaleleni *"I get upset when my grandson says 'I wish my mom was still here' it makes me feel like I am not doing enough"*

The foster parent's responses show that there is a strained relationship between them and the adolescents. The carers associated that strained relationships to the adolescent stage and felt like they could never win when it comes to the adolescents. It also became clear that there was a communication issue between the adolescents and the foster parents. Many things were not open for discussion yet some issues were pivotal to the development of the adolescents. Drew et al (1998) conducted a qualitative study in Zambia where they looked at the perceptions of cares on caring for adolescents living with HIV and the major theme that came across was the level of disrespect that the cares had to endure. This led to dysfunctional foster families and often the adolescents were constantly moved from one home to another. Although none of the foster parents wished for the adolescents to be removed from under their care, they were all desperately looking for ways to build a good relationship with the adolescents. The foster parents believe that the adolescents have an obligation to listen to them and respect them no matter what the circumstances. Growing up, they were socially constructed to revere their elders at all times, so when the adolescents act in a manner that is unfamiliar to them, they take it as a sign of disrespect. Thokozile's response depicts a misinterpretation of her foster child's comments, when the adolescent refers to her status, she is may be crying out for sympathy but Thokozile takes it as an attack. The communication gap may be the cause of most problems experienced by the foster parents.

2.2 Status Talk

There are many things that adolescents with a perinatal diagnosis of HIV hear about HIV. In schools it is taught primarily as a life style disease that affects mainly the promiscuous and irresponsible. Their peers my talk of it in a derogatory manner that paints it as a monster which does not deserve to be in their company and the health sector describes it as a disease without a cure making the adolescents feel trapped

with no way to run away from it (Sifunda et al, 2012). All this can be very depressing for the adolescents, thus makes discussing the adolescents status with the foster parents necessary.

One of the things that came out during the interview with the children is that the foster parents do not talk to them about HIV; how they are coping with it and how they can better handle the things they go through. However, the foster parents did not feel it was necessary to discuss HIV with the adolescents and they maintained that they are only willing to talk about HIV when they are asked questions about them.

Themba, *"there is no need to speak about HIV, unless it's about taking pills as long as he eats nje, that's enough"*

Nomusa *"I am also on ARV's and I hate it when people talk about HIV, it's depressing; that's why I don't discuss it"*

One can hypothesize that the lack of communication causes more problems in the relationship of the children and foster parents. This makes it hard for the foster parents to reprimand or advise the children on certain aspects of like because neither the adolescents nor the foster parents are accustomed to a healthy foster parent-foster child relationship. Close relationships, healthy open communication, and perceived parental support are especially important during adolescence, as children experience many physical and emotional changes (Mounts, 2001). For example, research shows adolescents who have positive relationships with their parents are less likely to engage in various risk behaviors, including smoking, fighting and drinking (Resnick, Ireland and Borowsky (2004). The strained relationship always leads to such problems:

Bongi, *"when I tell my grandchild not to do a certain thing, he says I'm not the boss off him"*

Ungiwe, *"I hit my grandchild if he asks me stupid questions, he must learn to respect his elders"*

Ungiwe's response shows the necessity for the enlightenment of most foster parents that were part of this study. Since the adolescents are in a stage finding their identity, it is only normal that they ask many questions, it is part of growing up. The misinterpretation of their inquisitive nature may increase the already huge barrier between the foster parents and the children. Appropriate and inappropriate things are socially constructed (Burr, 1995); when the adolescents ask questions about their status it would seem like a normal way of coping and healing to some but to the foster parents it is a sign of major disrespect that warrants corporal punishment. This may leave the adolescents confused and not open to discuss their issues around their status, thus impairing their psychosocial development.

2.3 Adherence to treatment

In chapter 6, some of the adolescents revealed that they sometimes do not want to take medication however; the way they view their non-adherence differs from the way that the foster parents view it. It is however clear that it is a struggle that goes on in many households. From the responses of the foster parents, much change needs to occur for the well-being of both the foster parents and the children.

Nokuthula *"I no longer beg my niece to take her medication, it's her life anyway"*

Thokozile *"when my grandchild refuses to take medication, I just point to her mother's grave which is on my backyard and tell her, you will end up dead just like your mother"*

Sondiwe *"my grandchild takes his medication every day and on time but I worry because he recently started drinking alcohol. I know that will make him sick"*

Mama G *"when my grandson wants something from me he refuses to take his pills until I buy whatever he wants, I do it because I do not want him to get sick. I love him"*

According to the American Academy of Pediatrics, during adolescence a number of psychological and social factors influence decision-making and create challenges for

effective ARV adherence. The Academy also asserts that Factors that have been implicated in poor levels of adherence and ARV efficacy include poverty, inadequate food access, unstable housing, limited educational attainment, lack, substance abuse, denial, stigma and discrimination. Thokozile's response is a rather shocking one, when she points her foster child to her mother's grave, she thinks that she is doing her a favour by showing her the consequences of non-adherence. What she does not realise is that by so doing she may be increasing her foster child's despair because whenever the adolescent thinks of HIV, she thinks of death. On the other hand, Mama G's response is also a cause for concern, she does whatever her foster child asks her to do, just to get him to take his ARV's, this arrangement might work for a short period but the child will learn that he has to be bribed doe him to get what he wants and when he doesn't get it he may stop taking his ARV's altogether. Sondiwe faces an issue of an adolescent that has taken the wrong turn in life, according to the UNAIDS (2012) many young people living with HIV turn to self-defeating behaviours like substance abuse, unprotected sex and grievous bodily harm. It is supposed that they do this for attention seeking and a cry for help. There are many caregivers who have the same problem as Sondiwe who need ongoing support and foster supervision.

2.4 Dealing with Stigma and discrimination

Most of the foster parents had a hard time dealing with the stigma and discrimination that the children faced. In some foster families, the child is the only one who is HIV positive and on ART; and it that is often used against the child by the children of the foster parent. The community also discriminated against the Adolescents with a perinatal diagnosis of HIV where other parents in the community tell their children not to play with the Adolescents with a perinatal diagnosis of HIV because of the risk of infection.

Mama G, *"It is really difficult, my granddaughter always comes home and tells me what the neighbour said to her and she always expects me to do something about it but there is nothing I can do"*

Thokozile *"my niece also faces such things. One child told her she is going to die soon like her mother. Such things are really hard for us"*

Sondiwe *"I have a problem at home, my other grandchildren fight they always remind her of her status and laugh at her and when I want to hit them they run away"*

Themba *"I try to avoid the issue of discrimination with my child, what if he asks me question I can't answer? I just say such things make a person stronger in life"*

Ethel *"they call my child 'born to die' every day at school, there is nothing I can do about it. She never talks about it so I don't too"*

The responses above reveal psychosocial support deficit in the lives of adolescents. This is consistent with Wiener et al., (2007) with the assertion that discussing a potentially life threatening, stigmatized and transmissible illness is one of the greatest psychosocial challenges faced by caregivers and parents with perinatally HIV infected children. What was interesting to note was that some of them thought it was acceptable to share the children status with their neighbours and friends without the children's consent. Needless to say, that has caused problems and the depletion of trust in the relationship between the foster parent and the adolescents living with HIV with perinatal dignosis. Some responses of the foster parents were:

Ethel *"I went to my neighbour to ask her to borrow me some money so I can go to the clinic, out of concern she asked me if I was sick and I said no I am going to fetch my grandsons pills for HIV. After I left, she told her grandchildren about my grandchild's status. Now the children in the community do not want to play with him"*

Thandiwe *"I once called my niece while she was playing outside with other children I said 'come and take your pills' the other children started laughing and they just knew that I am talking about ARV's"*

The involuntary disclosure of the children's status by the foster parents has had devastating effects on the children's lives and made them an object of ridicule in the community. Their relationships with the adolescents were also compromised as the adolescents felt they could not trust their foster parents with their secret. In chapter five where I discussed the adolescents lived experiences; they felt very strongly about sharing their status with just anybody. They wanted to be ready psychologically and disclose to the people they trust at an opportune time. This conviction of the adolescents is supported by Kimberly and Serovich (1996) who emphasized that disclosure of HIV status involves a process of decision-making, based upon numerous factors, including psychological state, communication skills, motivation and anticipated reactions. The stages of disclosure involve: coming to terms with the traumatic diagnosis; deciding upon the appropriateness of disclosure to a specific person, weighing the anticipated consequences and benefits of disclosure; and then choosing an appropriate situation for disclosure (Kimberly &Serovich, 1996: 18). It is understandable why the adolescents and the foster parents' relationship experienced hardship, and it is rather unfortunate that in the midst of the humiliation that the foster parents caused the adolescents, they still felt no need to apologize or speak about the issues around stigma and discrimination that the adolescents faced.

Theme 3: personal Functioning

3.1Challenges

The foster parents had a difficult time dealing with the issues that they have with their foster children their main issues were around disobedient adolescents and ineffective discipline methods thus leaving the foster parents feeling distressed and unappreciated, they felt as if they were of no value to the children's lives and they deduced that from the disrespect that the children show them. Seemingly there were a lot of attachment issues between both parties and the bigger the gap the bigger the problems. "Attachment figures provide the child with security and her first opportunity to be in a relationship. In turn, the more sensitive, empathetic and reciprocal the communication within relationships, the fuller the child understands their own state of mind" (Howe, 2002:173). If this does not occur, the adolescents may experience insecure, ambivalent attachment. Parents in this category fail to empathise with their children's moods, needs and feelings resulting in misunderstandings and inaccurate

communication. Insensitive and inconsistent care is interpreted by children and adults as meaning that they are ineffective in securing love and sustaining comforting relationships (Howe, 2002:176). The foster parents had this to say about the challenges they experience.

Nokuthula *"I don't think that my niece loves me, and I don't think she knows I love her"*

Ethel *"I do not know how to discipline my grandson, children of this time don't even know who we are these days. If he wants to take his medication, he does. If he doesn't want to there is not a lot I can do"*

Mama G *"I would attend any workshop that can teach me about taking care of my grandchild better"*

The foster parents expressed their desire to learn how to deal with the issues that arise between them and the adolescents that they are caring for. Communication was a huge barrier between the adolescents and the foster parents and the breakdown in communication leads to broken relationships. With the economic hardship that the foster parents face, it becomes harder to deal with the emotional turmoil that exists between them and the adolescents thus as need for constant foster supervision and support for such foster parents becomes critical. Foster parents require their own therapeutic interventions to address issues of loss and bereavement, as well as family or support-based interventions to strengthen the protective influence afforded by a caring and supportive caregiver child relationship (Hearle and Kanchana, 2009).

3.2 Coping strategies of foster parents

The trio of HIV/AIDS, poverty and food insecurity is a pressing social and development problem facing southern Africa (Lemke, 2005). one in five South African households is chronically poor (Aliber, 2003), and one in three households is

vulnerable to food insecurity (Statistics South Africa, 2009). Unfortunately in Umkhanyakude these statistics are a reality. The foster parents caring for adolescents with a perinatal diagnosis of HIV have a heavy load to carry with ensuring that the adolescents not only have something on the table but also that they remain healthy amidst their chronic illness.families in poverty-stricken communities are increasingly struggling and failing to provide optimally for the economic and psycho-social needs of PWAs who are in their care (Bartlett & Finkbeiner, 2006; Darling, Olmstead & Tiggleman, 2009). This is what the foster parents had to say:

Mama G *"uhm, we have to be strong for the family, we must do everything we can order to survive"*

Nokuthula *"every day in our lives is a struggle, if the family doesn't have food to eat then that means that we are failures. I sell tribe in order to provide for my family"*

Ungiwe *"People do not understand the stress we are under, we have to be the mother and the father to these children. I work as a road cleaner and I also sell airtime from home, but still that is not enough to meet the needs of the family"*

Delani *"I am a taxi driver, the money I make is very little but it does put food on the table"*

Nomonde *"I am unemployed so I sew school uniforms to make a living"*

All the foster parents that took part in this study are court ordered foster parents. This means that they are all in receipt of the foster child grant which was sitting at R830 at the time of the research. The grant was acknowledged as very helpful to the foster parents but it was unable to meet the needs of the adolescents. The foster parents therefore had to seek for employment or initiate micro businesses to ensure that they make ends meet.

A qualitative study conducted by Drew et al, (2002), reflected that caregivers in Zambia faced the same issue; there were too many socio-economic barriers that necessitated the carers of adolescents with a perinatal diagnosis of HIV to find other

income generating activities. It was interesting to note that the foster parents were very particular about ensuring that the adolescents have food on their table and cared very little on investing on the emotional aspect of the adolescent's development. They assumed that having food on the table equals happy and healthy adolescents. As I co-constructed this, I came to realization that the foster parents were socialized in this way; the foster parents had no relationship with their own parents, especially their fathers. It was unheard of that children even sit in the same place as their elders let alone have a heart to heart conversation with them, which is what culture dictated. This is confirmed by Freeman and Nkomo (2002), who asserted that in the Zulu culture there is historically no great emphasis placed on the emotional self especially where a generation gap is present.

Conclusion

The voices of the foster parents provided insights on their experiences of caring for the adolescents in their care who were living with HIV with perinatal diagnosis. It was clear that the majority of the foster parents experience complex structural barriers which had implications for the provision of optimal care for the children. Although a multi-disciplinary team is not the panacea for all the problems that the foster parents face; it is crucial for the holistic well-being of the adolescents with a perinatal diagnosis of HIV as well as for the provision of information, guidance and health and therapeutic services for foster parents. In addition, many of the foster parents felt like they are caught between a rock and a hard place as they are caring for children who are 'acting out' because of the adolescent stage with no form of solid assistance from external sources. A serious look is needed in the services available for foster parents caring for Perinatally HIV infected adolescent. That in turn will influence how they relate to the children born with HIV. This is explored further in the final chapter where I discuss the conclusions and key recommendations from the findings of this study.

CHAPTER SEVEN

CONCLUSIONS AND RECOMMENDATIONS

Introduction

There is currently an estimated 5.4 million young people, ages 10 - 24, living with HIV worldwide (WHO/UNICEF, 2008). This group represents one of the most vulnerable, yet overlooked populations affected by the HIV/AIDS pandemic. Despite the increasing effectiveness and availability of highly active antiretroviral treatment (ART) during the past decade, young people still make up 45% of new infections. Whether infected during the perinatal period or during adolescence, young people living with HIV have unique and pressing psychosocial needs, in addition to the daily challenges of adolescence (Greifinger and Dick, 2011:34).

For adolescents with a perinatal diagnosis of HIV who are in foster care, it is particularly important to pay attention to their special needs and what assistance they need to be given in order to ensure their psychosocial well-being. Managing a serious and at times life-threatening chronic illness within the context of an already demanding developmental phase is an intricate process for both adolescents living with HIV perinatal diagnosis and for foster parents who have to ensure their needs are catered for. An HIV positive boy or girl faces a barrage of additional demands including dealing with concerns about treatment regimens, doctor's appointments, reduced life expectancy, disclosure, stigma and the possibility of infecting others (Vujovic, Meyersfeld and Struthers, 2011). There has been an over emphasis on the medical side of HIV and not enough emphasis on the unique needs of people living with HIV. It is an irrefutable fact that the health sector has made ground-breaking improvements with regard to HIV research; however psychosocial support is imperative for people living with HIV.

The study was based on qualitative inquiry, the qualitative paradigm assumes that reality is socially constructed and it is what participants perceive it to be. This lens suggests the importance of checking how accurately participants' realities have been represented in the final account (Creswell and Miller, 2000). In this study adolescents with a perinatal diagnosis of HIV were given an opportunity to share their narratives as they constructed them. Social constructionist social workers emphasize processes which focus on voice reflexive on dialogue, listening to and talking with the other (Howe, 2002:244).

One In-depth semi-structured interview was with each of the 15 adolescents with a perinatal diagnosis of HIV , the interviews lasted for a minimum of 30 min and a maximum of 45 min. the Adolescents were asked a series of question to which, depending on how they constructed the question, gave a detailed account of their psychosocial experiences and how they construct their reality. Two focus groups were held with two groups of foster parents. A total of 15 parents took part in the study therefore when they were separated into two groups, one group had seven members and the other, six members; Morgan (1997) confirms that small focus groups are more useful when the researcher desires a clear sense of each participant's reaction to a topic simply because they give each participant more time to talk.

This chapter provides a synopsis of findings from the study as co-constructed by the researcher. Recommendations will be provided with potential contribution to the practice field of social work especially designated social workers who work with adolescent living with HIV with perinatal diagnosis. The strengths and shortcomings which necessitate future research will be indicated. This chapter will conclude with reflections of my study's processes and outcomes.

Synopsis of the Study

The main aim of this study was to explore the psychosocial experiences of adolescents with a perinatal diagnosis of HIV who are placed in foster care, residing in Umkhanyakude District. The main objectives which were addressed by the study were:

- To understand the psychosocial experiences of 15 adolescents living with HIV perinatal diagnosis who are in foster care living in Umkhanyakude district.

- To explore the coping strategies of 15 adolescents living with HIV perinatal diagnosis who are in foster care living in Umkhanyakude district.

- To comprehend the views of the foster parents of adolescents with a perinatal diagnosis of HIV about the psychosocial support that is available to the perinatally infected adolescents.

Summary of Findings

Objective 1: Psychosocial experiences of adolescents with a perinatal diagnosis of HIV .

Theme 1: interpersonal factors

Adolescents with a perinatal diagnosis of HIV often harbor pain and resentment.When their parents or caregivers die, children not only suffer the loss of material provision, but also lose important nurturers, role models and family bonds (Heijden and Swarts, 2010). From the study, it became evident that the adolescents had so much unresolved feeling that they were never given a platform to talk about. The fact that they were excluded during the death of their parents meant that they were robbed of the opportunity to grieve; this unresolved grief haunted them even in the present. The adolescents also revealed in the study that it hurts them that they do not know anything about their mothers, they only rely on what their foster parents and other family members tell them and when they are told, it is not in a reassuring manner but comes as a warning that they should not be like their mothers. This affected the adolescent so much because most of them did not view their mother's as a nurturer but instead as a symbol of defiance. This had a major impact on their identity because the adolescents did not have secure attachment with their primary caregiver as stressed by Erik Erikson.

The numbers of children that are growing up without fathers in South Africa are staggering, the role of the father in a child's life has been overlooked and the care of the mother was seen as the most important one; however researchers have identified that the effects of not having a father present in a child's life is detrimental, more so to boys (Ratele, 2012). 80% of the adolescents that participated in my study had never seen met or even have a vague idea on how their fathers looked. As a result the adolescents had feelings of hatred towards their fathers and blamed them for their HIV positive status. It was interesting to note that those adolescents that had a relationship with their fathers before they died, had positive self-images, they had

dreams and aspirations that were influenced by their fathers and they had no resentment towards their fathers even in the midst of HIV.

The adolescents in the study were all aware of their status but they reacted differently towards it. During the one on one interviews, I asked them to share with me how they came to know about their status and some of the stories that came through were appalling, what became evident to me is that 'It's not what you say, it's how you say it'. The adolescents that had painful disclosure had a very negative self-image and that led to poor adherence to ART, anger and strife. In contrast those adolescents that had good disclosure and received guidance and education during their disclosure have a very positive outlook on life and full adherence to ART.

Consequently, adolescents with painful disclosure blatantly said that they would rather die than share their status with anybody; they felt that that could be the worst thing that could happen in their lives. It then became clear to me that the adolescents suffered from internalized stigma, they had judged themselves so much that they could stand being judged by someone else.

Theme 2: interactions with foster family and beyond
Social constructionists are of the view that explanations of social phenomenon are to be found neither in the individual psyche nor in social structures, but in the processes that take place routinely between people (Burr, 1995:3). The interaction between the adolescents and the foster parents was explored. Because the adolescents lacked proper bonding with their biological parents, their relationship with their foster parents became the most important relationship in the adolescents life; however due to the dynamics of the adolescent stage the adolescents relationship was stressed. The adolescents felt that they were misunderstood by the foster parents and the misunderstanding was interpreted as disrespect.

They also expressed that because of the strained relationship with the foster parents, they were not sure what the future held for them in terms of their placement. The adolescents seemed to have a good understanding of foster care and they stated that their family will expire with the court order.

Because of the unwillingness to disclose, the adolescents stated that most adolescents had never experienced 'real' discrimination, but what was really interesting was the lack of empathy that they had towards other adolescents who were being discriminated against because of their status. Their friends' approval was so much more important than helping or standing up against HIV based stigma and discrimination.

When it came to adherence to medication, the adolescents were the ones that were responsible for administering it, some with the supervision of their foster parents and some without any supervision. Although most adolescents adhered to their ART properly; some used it as collateral against the foster parent, they had the understanding that if they default, then the social workers and health professionals will blame the foster parent, so the foster parent would do anything for the adolescent if s/he were to ask for anything in the name of adherence, this distorted view is harmful to the health of the adolescents.

Objective 2: Coping strategies of perinatally HIV infected adolescents.
Theme 3: secret lives, public consequences
It is very important to note that in the case of perinatally HIV infected adolescents, their private lives have public impact. The way that the adolescents viewed HIV and the manner in which they cope with it has public implications. Relationships and sex will be discussed under coping strategies because during the interviews, some adolescents shared that they have never experienced love before in their lives and forming 'romantic' relationships with others makes them cope better with HIV, some expressed that they forget that they are HIV positive when they are with their partners. Few adolescents admitted to being sexually active but the ones that did admitted to not using protection. One purposefully engaged in sexual activity without protection because she felt she did not owe anybody anything; for her HIV was a tool of destruction as her own life had been destructed by HIV.

The adolescents did not understand the concept of coping they didn't feel like there was much that they were doing or could do to cope better with the stressors that come with being HIV positive, I had to rephrase the question so many times wo that

could realize the strength that was embedded in each of them and the power and will to go on that all of them subconsciously possessed. Eventually all of them realized that they are each holding on to something, some had a dream to beat HIV, some of them wanted to live to take care of their siblings, some put their trust in God as the author and the perfector of their lives and some were just taking it a day at a time.

Objective 3: views of the foster parents

Theme 1: Structural Barriers

Due to the socio-economic challenges that come with the HIV and AIDS pandemic, foster parents that take care of children orphaned by HIV bear a huge brunt, but the stakes are higher for those caring for perinatally HIV infected adolescents. Darling, Olmstead and Tiggleman cited in Raniga and Motlong (2013) noted that caregivers to people living with HIV and AIDS also face intense levels of stress in the physical, economic and social spheres of their lives as a result of intolerable care demands. The foster parents that participated in the research expressed that they are very grateful for the foster child grant and that it does help them meet some needs in their households. However, they expressed that the foster child grant money is not enough to ensure that all the basic needs of the adolescents are met adequately. Another view that came across strongly was that most foster parents fostered not by choice but by obligation and as a result the foster parents struggled to form strong relationships with the adolescents.

The foster parents also shared that the HIV and AIDS clinic was too recognizable and as a result the adolescents did not want to fetch their medication or see a doctor, for the fear of being recognised and thus stigmatised. They maintained that it was hard to instil in the children that they were just like other adolescents when the health sector is saying that they are different and need to be put in their own building that is largely labelled 'PMTCT', it was the view of the foster parents that the hospital and clinic structures amplified stigma.

Umkhanyakude is a rural community with strong IsiZulu cultural practices. In this community it is believed that traditional medicine can cure anything even HIV, they believe that mixing ART with traditional medicine is the best weapon in this fight

against HIV. Although this is strongly frowned upon by health care workers, it is still quiet famous in the community. Foster parents in the group admitted to using a mixture of ART and traditional medication with the children. They seemed to be well informed of the risks involved but they seemed desperate to help the adolescents any way they knew how. Some also expressed that when the adolescents became ill, their relationships with the adolescents became stretched as the adolescents blamed them for their ill-health.

Theme 2: Interactions with the Adolescent

Child discipline equally reverberated as a challenge among the participants in both focus groups. The foster parents belong to a generation where corporal punishment, 'grounding' and commanding were once advocated as tools for child discipline, while the adolescents belong to a generation where human rights are commonly advocated and taught at school. The foster parents felt that children were too demanding, disrespectful and did not fully understand the circumstances they were in.

The foster parents expressed that they were unwilling to discuss the challenges that the adolescents face because of their status because it is considered a taboo topic in the community. The foster parents expected the children to deal with the issues that arise on their own, and regarded that as a way of growing up. The only issue that the foster parents were concerned about was providing food and shelter for the adolescents. It was sad to note that most of the foster parents have never uttered the words 'I love you' to the adolescents and did not see the importance of it. The lack of communication between the foster parents and the adolescents leads to distorted relationships between them.

Adherence to medication was said to be a major issue in the households of the foster parents. While some foster parents still administered medication for the adolescents, many foster parents believed that it was totally the responsibility of the adolescent.

Theme 3: Coping Strategies

Eleven out of the thirteen foster parents that participated in the study were unemployed and thus the brunt caring for adolescents became heavier consequently, most foster parents relied in small-scale businesses to make a living. The foster parent's views concurred with Frye and Kirsten cited in Raniga and Motloung (2013) who argue that as a result of the skewed distribution of resources and income, millions of women who embark on small-scale livelihood activities rarely earn enough income to lift themselves and their families out of poverty. The foster parents struggled to make ends meet and stated that the pressure to take care of the adolescents needs by social workers and other sectors did not help. The foster parents felt as if they had been thrown into the deep end and little guidance and support was offered to them to maneuver through the obstacles that they face on a daily basis.

With regard to coping with the adolescents behavioral issues, 60% of the foster parents admitted to using corporal punishment as a form of discipline. 40% just left the adolescents to their own demise because they strongly believed that the adolescents were a lost generation who were beyond repairs.

The potential value of my study

Adolescents (age 10-19 years) born with HIV in sub-Saharan Africa are now surviving into young adulthood for the first time and face a host of treatment, reproductive health and psychosocial challenges that the health sector is unprepared to manage (Pettitt, Greifinger, Phelps and Bowsky 2010). A study conducted by Pettitt et al, (2010) concluded that the majority of adolescents living with HIV in South Africa come from very poor socio-economic backgrounds and a vast majority of them are living with grandparents in rural areas where conditions are very poor and receive little or no psychosocial support. Such approaches need to be tailored to the reality of different settings and may be particularly challenging in resource- poor settings (Greifinger and Dick, 2011). My study zoomed into the lived of poverty stricken adolescents with a perinatal diagnosis of HIV who have very little resources and services to cater for their unique needs. The uniqueness of my study rested on the context of my study. Umkhanyakude is a place rich with culture and

natural resources but there is minimal research that has taken place about the social issues that go on, on a day to day basis.

I am hoping that my study will be an eye-opener for service users in Umkhanyakude and beyond and that upon the completion of the research paper, many organizations may realize the importance of psycho-social workshops and support groups for perinatally HIV infected adolescents. I can only hope that the adolescents that formed part of my study were able to express themselves and vent out anger and feelings of resentment and will benefit from the referrals that were made with the local psychologist. The foster parents that participated also got a chance to speak their minds with no fear of judgment and they formed a support system as they were able to identify other foster parents that were going through what they are going through, during the focus group meetings. I am of the opinion that my study will produce ground-breaking discoveries into the untold stories of adolescents with a perinatal diagnosis of HIV that can be used as the basis of more research in the same field in Umkhanyakude district.

Recommendations for:

Foster Parents.

A child placed in foster care needs an enabling environment in order to thrive; as with all other children they need to be disciplined when they are wrong and acknowledged when they do good. There is a saying that is famous in the Zulu culture that says 'intandane ayiphatheki' which means 'it is hard to care for an orphan'. Although many people believe this to be true, it is very hard for those perinatally infected adolescents to hear that they are burdens to family members who are entrusted to care for them. Adolescents living with HIV perinatal diagnosis have a lot to deal with and they are longing for a sense of belonging and support from you. An open relationship is paramount between the foster parents and perinatally HIV infected adolescents. Issues around taking medication, challenges at school, disclosure issues, dealing with discrimination need to be discussed on a continuous basis. Furthermore, the responsibility of caring for a perinatally HIV positive child who is orphaned is a hard one; seek counsel from service users e.g. social workers and nurses, and from other foster parents who are also caring for

children born with HIV. It is also highly recommended that all foster parents caring for adolescents with a perinatal diagnosis of HIV receive basic training about HIV so that they gain an understanding of the special needs of adolescents with a perinatal diagnosis of HIV and necessary precautions that they need to take to ensure that new infection do not occur in their homes. Foster parents caring for adolescents with a perinatal diagnosis of HIV could benefit from a support group in where they can discuss issues around HIV stigma, disciplining a child, safety precautions and how they can discuss HIV related issues with the adolescents in an open manner.

Health Care Workers

For any chronically ill young person growing up through the health care system, a multidisciplinary team approach that combines continuity of primary health care with preventive intervention and confidential counselling is crucial for establishing long-term and trusting relationships with providers (Michaud, Suris & Viner, 2007). Solidarity is crucial in the fight against HIV and AIDS related stigma, therefore more awareness programs in schools about HIV would be beneficial as well as an all-encompassing sexual and reproductive health education campaign is needed. It is also important that health worker refer the adolescents with a perinatal diagnosis of HIV to social workers, lay counsellors and psychologists to help them deal with through emotional and psychological trauma of being born with such a stigmatizing chronic illness.

Social workers

There is a great need of therapeutic programmes that need to be put in place for adolescents living with HIV as well as foster parents. Regular follow up supervision on adolescents living with HIV perinatal diagnosis is very important as it gives clarity on the child's development and also the opportunity to identify challenges in the foster placement. Foster placements are not merely administrative but tapping into the individual needs of individual children. Social workers could implement psychosocial workshops that are strictly directed to meeting the needs of adolescents with a perinatal diagnosis of HIV; this will enable their adolescents to share their views and experiences and can be a source of support to each other.

Department of Social development

There is still a great need for HIV and AIDS education and awareness in the community and more especially schools to dissolve the social construct attached to the illness. In Umkhanyakude, there has been a decline in awareness programmes about HIV and thus the stigma and discrimination experienced by people living with HIV is unattended thus it continues to negatively impact on the lives of perinatally HIV infected adolescents. The department should thus continue with HIV and AIDS context specific campaigns that pay detailed attention to managing the illness and improving one's self concept in the midst of a stigmatizing illness. There is dire need to educate the public that HIV AND AIDS is no longer considered a death sentence, but it is a chronic illness due to the availability of treatment. This could help curb the propagation of stigma and discrimination constructs long surrounding the illness (Mavangira 2012:146).

The Media

A great concern voiced out from the adolescents interviewed is that they feel that there whole picture of HIV is not painted correctly. HIV is a lifestyle disease but the perinatally HIV infected did not acquire it through 'poor choices' as the media emphasizes and as long as those are the only messages that are being accentuated; perinatally HIV adolescents will have a hard time accepting their status because of the label that is created by the media.

Recommendations for further research

There is need for further research on the following areas:

➢ What is the relationship between the psychosocial experiences of adolescents with a perinatal diagnosis of HIV residing in child and youth care centres and those in foster care?

➢ Psychosocial experiences of adolescents with a perinatal diagnosis of HIV who have are placed in foster care but are aging out of care (turning 18)

➢ Comparison of psychosocial experiences of adolescents with a perinatal diagnosis of HIV who reside in urban and rural areas.

➢ A qualitative longitudinal study across provinces in South Africa could be done to look at the commonalities and differences of adolescents with a perinatal diagnosis of HIV.

Final reflections

This study revealed that Adolescents with a perinatal diagnosis of HIV who are placed in foster care are unique. The context of Umkhanyakude added a unique touch and attempted to close a gap in literature available for this setting. Interacting with adolescents with a perinatal diagnosis of HIV gave me an opportunity to co-construct the lived experiences of these adolescents and the following things became apparent to me:

Adolescents living with perinatal HIV diagnosis are in a constant battle to construct their identities in the midst of an unforgiving community, unrecognized human rights and a low self-concept. The adolescent stage is a very hard stage in one's life, but to go through adolescents with a highly stigmatized chronic illness is very tough. There is a great need for a continuum of support from all sectors to be offered to perinatally HIV infected adolescents.

Foster care aims to ensure that a child is placed into a suitable home and that all basic needs are met, for adolescents with a perinatal diagnosis of HIV in particular, one of their greatest needs is to have a sense of belonging. With the trauma that comes with being abandoned or losing both parents, being placed with the wrong family in alternative care could be detrimental to the adolescents. During the interviews with the adolescents, I realized that the adolescents' valued emotional support was valued over and above financial or material support; this is something the foster parents have missed completely.

Sexual and reproductive health education remains a need for the adolescents. The adolescent stage is characterised by one becoming aware of ones sexuality and thus wanting to experiment with sex usually with the opposite sex. Lack of education and guidance when it comes to these aspects could literally be a matter of life and death

for the adolescents, not to mention the risk of infection that negligent behavior could produce. 40% of the adolescents in my study admitted to being sexually active admitted to not using protection during sexual intercourse but what became evident to me is that they did not do this due to lack of education but due to deep-seated unresolved emotions such as anger and resentment. These issues need to be dealt with so that the psychosocial well-being of adolescents with a perinatal diagnosis of HIV can be realized.

Conclusion

Adolescents living with HIV perinatal diagnosis need support from every sector in society. They require open and honest discourse and education about HIV. They need to be given a platform to discuss their needs and anxieties without fear of reproach. A loving and enabling environment is crucial for the holistic development of perinatally HIV infected adolescents. Adolescents need social, emotional, spiritual, and physical support. This study explored the psychosocial experiences of perinatally HIV infected adolescents. The findings presented in this study show that there is still much that needs to be done to meet the unique needs of the adolescents. Unique needs require tailored interventions and holistic, context specific interventions would be steps in the right direction. The placing in foster care of these adolescents ensures that they are in a family setting with all familial benefits; however foster parents need continuous assistance to help adolescents with psychosocial difficulties on a day-to-day basis. A lot has been done against the fight against HIV and its stigma but there is a long way to go but there is an everlasting hope that people living with HIV will lead lives free of stigma, free of internalized oppression and free from discrimination.

Reference List

Adams, G.R.(1994). *Psychosocial Development During adolescents: Progress in developmental contextualism*London: Sage Publications.

American Academy of Pediatrics, Bright Futures Steering Committee.Introduction to the Bright Futures Visits.

Babbie, .E. Rubin, A (2011).*Research Methods for Social work:* United Kingdom: Brooks/coleGengage learning.

Babbie,E. and Mouton, J. (2001). *The practices of Social research.* Cape Town: Oxford University Press.

Babbie,E. and Mouton, J. (2006). *The practices of Social research.* 6thed Cape Town: Oxford University Press.

Bankole, A., Singh, S. Woog, V., Wulf, D. (2004). 'Risk and Protection: Youth and HIV AND AIDS in Sub-Saharan Africa'.. www.guttmacher.org

Bartlettm, J.G &Finkbeiner, A.K. (2006). The guide to living with HIV infection (6thed). United States of America: The John Hopkins University Press.

Berger, P. &Luckmann, T. (1966) The social construction of reality: A treatise in the sociology

Berk, L. E. (2000).*Child development* (5th ed.). Needham Heights, MS: Allyn & Bacon.

Bernard, H. R. (2010). Analyzing qualitative data: Systematic approaches. Thousand Birungi, H., Mugisha, F., Nyombi, J., Obare, F., Evelia, H., Nyinkavu.(2008). *Sexual and reproductive health needs of adolescents perinatally infected with HIV in Uganda.* Population Council .www.popcouncil.org [accessed 10 June 2013].

Braithwaite RL, Hammett TM, Mayberry RM. Prisons and AIDS. San Francisco: Jossey-Bass, Inc., 1996.

Burr, V. (1995). An Introduction to Social Constructionism. London: Routledge.

Care: A Research Synthesis," Institute for Research on Poverty special report, in press Children Orphaned by AIDS', *AIDS Care* 10 (Supplement 1): 9–15.

Children Health Insurance Plan http://www.chipcohort.ac.uk : United Kingdom

Children's Act. (2005). South Africa: Government Gazette.

Coon D & Mitterer, .J. O. (2010).Introduction to psychology: Gateways to mind and behaviour. (12 edition). Wadsworth. Brock University

Creswell, J. W. & Miller, D. L. (2000).Determining validity in qualitative inquiry.*Theory into Practice, 39*(3), 124-131.

Creswell, J.W. (2003). Research design: Qualitative, Quantitative and mixed methods approaches. London: Sage.

Darling, C.A., Olmstead, S.B. &Tiggelman, C. 2009. Persons with Aids and their support persons: stress and life satisfaction. Stress and Health, 26:33-44.

De Vos, A.S. (2005). Combined quantitative and qualitative approach. In De Vos, A.S. (Ed) 2005.*Research at Grass roots: For Social sciences and Human service professions.* 3rd ed. Pretoria: J.L. Van Schaik Publishers.

Department of Health (2007).HIV, AIDS and STIs National strategic plan on for South Africa, 2007–2011. Pretoria: Department of Health.

Department of Social Development [South Africa] (2005) Integrated Service Delivery Model: Towards Improved Social Services. Pretoria, South Africa, Department of Social Development.
Department of Welfare (1997).*White Paper for Social Welfare*. Pretoria. http://www.gov.za/whitepaper/1997.

Domek, G.J. (2006). Social Consequences of antiretroviral therapy: preparing for the unexpected futures of HIV-positive children. *The Lancet, 367,* 1367-1369

Domek, G.J. (2012). 'Psychosocial needs of HIV-positive children on antiretrovirals: A Survey of South African Children's homes' *Vulnerable Children and Youth Studies.* 1.Pp 1-12

Drew, R.S., Makufa, C. & Foster, G. (1998) Strategies for providing care and support to children orphaned by AIDS. AIDS Care 10(1), pp. 9–15.

Durrheim, K. (1999). Research design. In M. Terre Blanche and K. Durrheim (Eds.).

Dwivedi, K.W. (1999). *Group work with children and adolescents.* London: Jessic Kingsley.

Dwivedi, V. (1995).The status of right extraposition. In P. Koskinen, (Ed.),

Edgren, R.A. (2006). Perinatal infection.Health / Encyclopedia of Medicine / Apr 06, 2001 accessed 2011/10/01.

Edwards, D., & Potter, J. (1992).Discursive psychology.Sage, London.

Erikson, E. H. (1963). Childhood and Society (Rev. ed.). New York: W. W. Norton.

Erikson, E. H. (1963). *Childhood and Society.* New York: W. W. Norton and Company.

Fleming, J. (1995). Mozambican healers join government in fight against AIDS. *J IntAssoc Physicians AIDS Care* 1995, 1:32.

Flemming, J. S. (2004). Erikson's Psychosocial developmental stages. Gmahanti.

Foster G, Makufa C, Drew R et al. Perceptions of children and community members concerning the circumstances of orphans in rural Zimbabwe. AIDS Care 1997, 9:391-406.

Foster, G. (2000) The capacity of the extended family safety net for orphans in Africa, Psychology, Health and Medicine, 5(1), pp. 55–62.

Foster, G. (2002). Supporting community efforts to assist orphans in Africa.New England Journal of Medicine, 346(24), 1907/1910.

Foster, G., Makufa, C., Drew, R., Mashumba, S. &Kambeu, S. (1997) Perceptions of children and community members concerning the circumstances of orphans in rural Zimbabwe. AIDS Care 9(4), pp. 391–405.

Freeman, M. & Nkomo, N. (2006) Guardianship of orphans and vulnerable children: a survey of current and prospective South African caregivers. AIDS Care 18(4), pp. 302–310.

Freeman, M., & Nkomo, N. (2006). Guardianship of orphans and vulnerable children: a survey of current and prospective South African caregivers. *AIDS Care*, 18(4), 302-310.

Gergen, K.J. (1985) The social constructionist movement in modern psychology. American Psychologist, 40(3), 266-275

Gergen, K.J. (1999). The social constructionist movement in modern psychology.*American Psychologist, 40*, 266-275.

Gilborn, L.Z., Nyonyintono, R., Kabumbuli R. &Jagwe-Wadda, G. (2001) Making a Difference for Children Affected by AIDS: Baseline Findings from Operations Research in Uganda.Washington, D.C., Population Council, Horizons.

Gilborn, L.Z., Nyonyintono, R., Kabumbuli R. &Jagwe-Wadda, G. (2001) Making a Difference for Children Affected by AIDS: Baseline Findings from Operations Research in Uganda.Washington, D.C., Population Council, Horizons.

Gouws E, Kruger N, & Burger S (2008) The Adolescent 3rd edition. Heinemann: Sandton

Govender, V. 2009.The experiences of social workers in the provision of reconstruction services to HIV infected children. Durban: University of KwaZulu-Natal. (Unpublished MA Thesis)

Greef, M. 2005. *Information Collection: Interviewing.* In De Vos, A.S. (Ed) 2005.*Research at Grass roots: For Social sciences and Human service professions.* 3rd ed. Pretoria: J.L. Van Schaik Publishers.

Guba, E. and Lincoln,Y. (1989). *Judging the Quality of fourth generation evaluation.* Newbury Park .CA:Sage

Hancock, B. (2002). Trent focus for research and development in primary health care: An introduction to qualitative research. University of Nottingham.

Helman CG. Culture Health and Illness, 4th edn. London: Butterworth Heinemann, 2001.

Heresi, G.P (2012). Issues in Perinatally HIV infected Adolescents. UTHealth: Houston

Hesse-Biber, S.N. and Leavy, P. (2011).*The Practice of Qualitative Research.* 2nd ed. London: Sage Publications

Hesse-Biber, S.N. and Leavy, P. (2011).*The Practice of Qualitative Research.* 2nd ed. London: Sage Publications

Hodgson I, Ross J, Haamujompa C. (2012). Living as an adolescent with HIV in Zambia—lived experiences, sexual health, and reproductive needs. AIDS Care. ;24:1204–1210.

Hodgson, I., Ross, J., Haamujompa, C. &Mburu, G. (2012). Living as an adolescent with HIV in Zambia: lived experiences , sexual health and reproductive needs. AIDS care.

Howe, M. (2002).'Psychosocial social work'. In Adams, R., Dominelli,L., Payne, M. (2002). *Social work: Themes, Issues, Critical debates.* Palgrave Macmillan: New York.

Human Rights Task Team "Recommendations of the Human Rights Task Team", first draft: www.hrtt.gov.za

International Journal for Educational Law and Policy, 1:248-257.

James D. (2001) "To take the information down to the people": life skills, HIV/AIDS peer counsellors, NGOs and the State in the Durban area. AIDS in context conference; Johannesburg

Jaspan HB, Berwick JR, Myer L, (2006) Adolescent HIV prevalence, sexual risk, and willingness to participate in HIV vaccine trials. J Adolesc Health.

Jaspan, H.B., Li, R., Johnson, L., Bekker, L.G. (2009) 'The emerging need for adolescent focused HIV care in South Africa' *The Southern African Journal of HIV medicine.*

Jaspan, Li, Johnson and Bekker (2009) 'The emerging need for adolescent focused HIV care in South Africa' *The Southern African Journal of HIV medicine.*

Jones, L. (2005) Childcare in poor urban settlements in Swaziland in an era of HIV/AIDS. African Journal of AIDS Research (AJAR) 4(3), pp. 161–171.

Kalsh,M.L; Thea .D.M; Steketee. R.W. 1999.Perinatal HIV Infection.In The evolution of HIV. Ed. Crandall, K.A. Johnpkins University Press.

Kenniston, K. (1989). *Living With AIDS Social Construction.*Strong Haul.

Kimberly, J.A., &Serovich, J.M. (1996).Perceived social support among people living with HIV/AIDS.Amer- ican Journal of Family Therapy, 24(1), 4153.

Kitzinger, J. (1995) Qualitative research: introducing focus groups. British Medical Journal 311, pp. 299–302.

Koenig LJ, Nesheim S, Abramowitz S. Adolescents with perinatally acquired HIV: emerging behavioral and health needs for longtermsur- vivors. CurrOpinObstet Gynecol. 2011;23:321–327.

Kumar, R. (2005). *Research Methodology: A step by step guide for beginners.* 2^nded London: Sage Publications.

Kumar,S. Mmari, K. & Barnes, W. (2009). Programming Considerations for Youth Friendly HIV Services.Establishing a Framework for Success.Volume 2.http://ftguonline.org USA.

Lemke, S, (2005). Nutrition security, livelihoods and HIV/AIDS: Implications for research among farm worker households in South Africa. Public Health Nutrition 8, 844–52.

Lewis J. (1998) Visualizing desire: HIV prevention dilemmas for women's sexual safety. NORA 122–32.

 Li R, Jaspan H, O'Brien V, (2010)l. Positive futures: a qualitative study on the needs of adolescents on antiretroviral therapy in South Africa. AIDS Care. :751–758.

Lincoln, Y. S., & Guba, E. G. (1985).*Naturalistic inquiry.* Beverly Hills, CA: Sage.
Lombard, A. (2008). *Social Change Through Integrated Social and Economic Development.* Department of Social Work and Criminology, Faculty of Humanities , University of Pretoria.

Louw, D.A., Van Ede, D.M., Louw, A.E. (1998). *Human Development.* 3rd ed. Pretoria:Kagiso Press.

Louw, L. (2005). The Experiences of Adolescents Orphaned by HIV AND AIDS - related conditions. University of Pretoria, South Africa.

Makiwane, M. &Kwizera, S. (2006) An investigation of quality of life of the elderly in South Africa, with specific reference to Mpumalanga Province. Applied Research in quality of life.

Malherbe R. (2004). The right to freedom of religion in South African schools: Recent disturbing events.

Mann J. Quoted in Cameron C (1998): The Deafening Silence of AIDS. First Jonathan

Mann Memorial Lecture. XIIIth International AIDS conference. Durban 2000.

Mariam, Fahmida and DharshiniSeneviratne, (2006) 'Children in Institutional Care: Rights and protections for children in Sri Lanka', Save the Children Sri Lanka.

Marlow, C. (1998). *Research methods for generalist social work*. 2nd ed. Canada: Cole Publishing company.

Marlow, C. (1998). *Research methods for generalist social work*. 2nd ed. Canada: Cole Publishing company.

Mavangira, V.P. (2012). Experiences of adolescents' living with HIV in Child and Youth Care Centers in Pretoria: An Exploratory Study. Master's thesis.University of KwaZulu-Natal.

Maxwell, J. A. (1992). Understanding and validity in qualitative research.*Harvard Educational Review, 62*(3), 279-300

Maxwell, J.A. (1998). "Designing a qualitative study."In Bickman, L.E. and Rog, D. (eds.) *Handbook for applied social research Methods.* New Delhi: SAGE Publications Inc.

Meintjes, H. & Giese, S. (2006) Spinning the epidemic: the making of mythologies of orphanhood in the context of AIDS, Childhood: A Global Journal of Child Research, 13(3), pp. 407–430.

Meintjes, H., Moses, S., Berry, L., &Mampane, R. (2007). Home truths: The phenomenon of resi- dential care for children in a time of AIDS. Cape Town:

Children's Institute, University of Cape Town & Centre for the Study of AIDS, University of Pretoria.

Meinttjes, H., Bundlender, D., Giese, S. & Johnson, L. (2004) Social security for children in the context of AIDS: questioning the state's response. AIDS Bulletin 13(2), p. 9.

Melbourne K, Geletko S, Brown S, Willey C, Chase S, Fisher A. Electronic adherence assessment versus self-report in HIV-infected individuals [ab- stract I-175]. In: Program and abstracts of the 38th Interscience Confer- ence on Antimicrobial Agents and Chemotherapy (San Diego). Washing- ton, DC: American Society for Microbiology, 1998:420.

Mellins, C.A. &Malee H. (2013). 'Psychosocial Implications of HIV Serostatus Disclosure to Youth with Perinatally Acquired HIV' AIDS Patient Care and STDs. 25(4).

Mellins, C.A., Smith, R., O'Driscoll, P., Magder, L., Brouwers, P., Chase, C., Matzen, E. (2003). High rates of behavioral problems in perinatally HIV-infected children are not linked to HIV disease. Pediatrics, 111(2), 384393.

Merriam, S. B. (2002). *Qualitative Research in Practice: Examples for discussion and practice.* San Francisco: Jossey-Bass.

Morris K: South Africa tests traditional medicines. *Lancet Infect*
Mounts, N. (2001).Young adolescents' perceptions of parental management of peer relationships.*Journal of Early Adolescence, 21*(1): 92-122.
Müller, J.C. and Pienaar, S. (2004). Stories about care: Women in a historically disadvantaged community infected and /or affected by HIV AND AIDS. *HTS,* 60(3): 1029-1046.

Murphy, D.A., Moscicki, A.B., Vermund, S.H., &Muenz, L.R. (2000). Psychological distress among HIV adolescents in the REACH study: Effects of life stress, social support and coping. Journal of Adolescent Health, 27, 391398.

National Intergrated Plan 2000. Government gazette, South Africa.

National Policy on HIV AND AIDS 1999. Department of Basic Education, *South Africa.* www.education.gov.za

National Policy on HIV AND AIDS 1999. Department of Basic Education, *South Africa.* www.**education**.gov.za

National Strategic Plan for HIV AND AIDS and STD for 2007-2011.

Neuman, W.L. (2000). Social research methods: Qualitative and Quantitative approaches, 4th ed. Boston: Allyn & Bacon.

Nglazi,D.M., Kranzer, K., Holele, P., Kaplan, R., Mark, D., Jaspan, H., Lawn,D., Wood, R., Bekker, I. (2012). BMC Infectious Diseases doi:10.1186/1471-2334-12-21

Ngubane, H 1977. Body and mind in Zulu medicine: an ethnography of health and disease in Nyuswa-Zulu thought and practice. New York: Academic press.

Ntozi, J.P.M. &Nakayiwa, S. (1999) AIDS in Uganda: How Has the Household Coped with the Epidemic? The Continuing African HIV/AIDS Epidemic.Kampala, Uganda, Makerere University, Department of Population Studies.

Nyasani E, Sterberg E and Smith H. (2009). Fostering children affected by AIDS in Richards Bay, South Africa: a qualitative study of grandparents' experiences. African journal of AIDS research: South Africa.

Orphans and Vulnerable Children Support Net (2011). Psychosocial Impact on Children. Available at: http://www.ovcsupport.net/ [Accessed 20 April 2011]

Owen, I. (1992). 'Appling social constructionism to psychotherapy' *Counseling Psychology Quarterly,* 5(4),385-402

Owen, I. (1992). 'Appling social constructionism to psychotherapy' *Counseling Psychology Quarterly,* 5(4),385-402

Owen, I. (2011). 'Appling social constructionism to psychotherapy' *Counseling Psychology Quarterly,* 5(4),385-402

Owen, I.R. (1990). Re-emphasising a person-centred approach. Counselling, 1(3), 92-94.

Parker GR.The social and cultural construction of sexual risk, or how to have (SEX) research in an epidemic. In: Brummelhuis H, Herdt G (eds). Culture and Sexual Risk: Anthropological Perspectives. Amsterdam: Gordon and Breach Publishers, 1995, 257–69.

Patel, L. 2005. Social Welfare and social development. Cape Town: Oxford: Southern Africa

Patel, L. 2005. Social Welfare and social development. Cape Town: Oxford: Southern Africa

Patton, M. Q. (2002). Qualitative evaluation and research methods (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.

Patton, M. Q. (2002). *Qualitative evaluation and research methods* (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.

Patton, M.Q. (1990) Qualitative Evaluation and Research Methods.Newbury Park, California, Sage Publications. Quality of Life

Patton, M.Q. (2002).*Qualitative Research and Evaluation Methods.* Thousand Oaks, California: SAGE Publications Inc.

Payne, R.L. & Jones, G. (1987).Measurement and methodological issues in social support. In: S.V. Kasl& C.L. Cooper (Eds), Stress and health: issues in research methodology (pp. 167–205). New York: John Wiley.

Petersen, I., Mason, A., Bhana, A., Bell, C., & McKay, M. (2006).Mediating social representations using targeted micro media in the form of a cartoon narrative in the

context of HIV/AIDS: The AmaQhawe family project (CHAMP) in South Africa.Journal of Health Psychol- ogy, 11(2), 197208.

Petty, A. (2002).Adapting a Western Model of Filial Therapy to a locally Specific form through a Participatory Process with Kinship Carers.University of KwaZulu Natal, Durban.

Raniga, T. and Mathe, B. Private lives, public issues: Childbearing experiences of adolescent mothers in the era of HIV and Aids in Bhambayi, KWazulu Natal, South Africa. University of KwaZulu Natal.

Raniga,T. 2006. *The implementation of the national life-skills and HIV AND AIDS School Policy and Programme in the eThekwini region.*Phd thesis.University of KwaZulu-Natal.

Research in Practice: Applied methods for the social sciences. Cape Town: University of Cape Town Press.

Resnick, M., Ireland, M. &Borowsky, I. (2004). Youth violence perpetration: What protects?. UK: Pelgrave

Richter, A & Muller, J. (2005).The forgotten children of Africa.University of Pretoria.

Richter, A.and Muller, J. (2005). The forgotten children of Africa: voicing HIV and Aids orphans' stories of bereavement: a narrative approach. University of Pretoria.

Richter, L. and Swart-Kruger, J. (1995). AIDS-risk among s t reet children and youth: implications for intervention. *South African Journal of Psychology ,*25(1): 31-37.
Richter, L., Foster, G. &Sherr, L. (2006) Where the Heart Is: Meeting the Psychosocial Needs of Young Children in the Context of HIV/AIDS. The Hague, The Netherlands, Bernard Van Leer Foundation.

Rider, E. A., andSigelman, C. K. (2005). Life-Span Human Development.

Ritchie, J. & Lewis, G. (eds.) Qualitative Research Practice: A Guide for Social Science Students and Researchers. London, Sage Publications.

Ritchie, J. and Lewis, J. (2003).*Qualitative Research Practice:* a guide for social science students and researchers. London: Sage Publications.

Rodwell, M.K. (1998). *Social work Construction Research.*Galand Publishing: London.

Rosenberg NE, Westreich D, Barnighausen T, et al. Assessing the effect of HIV counselling and testing on HIV acquisition among South African youth. AIDS. 2013;27:2765–2773.

Ross, J, &Cataldo, F. (2010). Adolescents living with HIV in low-income settings: A review of the evidence on gaps in HIV services. Poster session presented at the XVIII International AIDS Conference. Vienna: International AIDS Society, July 2010.

Rotheram-Borus M, Murphy DA, Kennedy M, Stanton A, Kulinski M. (2001)Health and risk behaviours over time among youth living with HIV. J Adolescent

Rotheram-Borus, M. J., Murphy, D. A., Miller, S., &Draimin, B. H. (1997).An intervention for adolescents whose parents are living with AIDS.Clinical Child Psychology and Psy- chiatry.

Rotheram-Borus, M. J., Murphy, D. A., Wright, R. G., Lee, M. B., Lightfoot, M., Swendeman, D., et al. (2001).Improving the quality of life among young people living with HIV. Evaluation and Program Planning, 24, 227-237.

Rubin, A.and Babbie, E. (200). *Research methods for social work.* 4th ed. Belmont,CA: Wadsworth.

Rubin, H., and Rubin, I. (1995). *Qualitative interviewing: The art of hearing data.* California: SAGE Publications Inc.

Sarantakos, S. (2000). Social research.South Yarra. Macmillan Education Australia

Sarantakos, S. (2005). *Social Research.*3rd . Palgrave MacMillan: China

Seale, C. (1999). Quality in qualitative research.*Qualitative Inquiry, 5*(4), 465-478.

Shah,I. (2006) 'Pediatric HIV in India' *Jk Science.*Vol. 8 No. 4.

Shah.I. (2005).Management of Pediatric HIV.Publisher. Mumbai, 2005: 3-7

Sherr, L. (2005) HIV and young children: An annotated bibliography on psychosocial perspectives.

Sherr, L., Hedge, B., Steinhart, K., Davey, T., &Petrack, J. (1992). Unique patterns of bereavement in HIV: implications for counselling. Genitourinary Medicine, 68, 37881.

Social Assistance Act 13 of 2004. Government gazette

Steinberg, M., Johnson, S., Scheirhout, G. &Ndegwa, D. (2002) Hitting the Home: Households Cope with the Impact of HIV/ AIDS Epidemics: A Survey of Households Affected by HIV/AIDS in South Africa. Washington, D.C., The Henry J. Kaiser Family Foundation.

Stenbacka,C. (2001) "Qualitative research requires quality concepts of its own, *Management Decision*, 39(7) 551-555.

Strauss, A., & Corbin, J. (1990).*Basics of qualitative research: Grounded theory procedures and techniques.* Newbury Park, CA: Sage Publications, Inc.
Struwig, F.W. & Stead, G.B. (2001).Planning designing and reporting research.Capetown: Pearson Education.

Terre Blanche, M, and Durrheim, E.(Eds). (1999). Research in practice applied methods for social sciences. Capetown: Formeset.

Terreblanche, M. Durheim, K. Painter, D. (2006). *Research In Practice*: Applied methods for the social science. South Africa: UCT Press.

UNAIDS (2008).*Report on the global AIDS epidemic.* Geneva, UNAIDS.

UNAIDS (2008).*Sub-Saharan Africa, Latest Epidemiological Trends.*

UNAIDS (2008).*Sub-Saharan Africa, Latest Epidemiological Trends.*

UNAIDS (2009): Agenda for Accelerated Country Action for Women, Girls, Gender Equality and HIV Operational plan for the UNAIDS action framework: addressing women, girls, gender equality and HIV

UNAIDS (2011): Key programmes to reduce stigma and discrimination and increase access to justice in national HIV responses

UNAIDS (2013): Getting to Zero in Eastern and Southern Africa regional report

UNAIDS (2013): Spectrum Estimates presentation to DOH

UNAIDS Country Progress Reports 2012, "Global UNAIDS Progress Report 2012, South Africa.

UNAIDS(2013)http://www.unaids.org/en//knowyourresponse/countryprogressreports/pdf

UNAIDS. (2010). Report on the Global AIDS Epidemic. *Global Report.*http://www.unaids.org/globalreport/Global_report.htm
UNAIDS. (2010). Report on the Global AIDS Epidemic. *Global Report.*http://www.unaids.org/globalreport/Global_report.htm

UNAIDS.(2011) Global Report (Accessed on the 10/11/2011).

UNAIDS: The Joint United Nations Programme on HIV AND AIDS.AIDS epidemic update 2009. Geneva, Switzerland: UNAIDS. http://www.unaids.org

UNDP.Adolescent sexuality, gender and the HIV epidemic. Available at http://www.undp.org

UNICEF (1989).*Convention on the Rights of the Child*. Geneva. Available online: http://www.unicef.org/crc/crc/htlm (accessed on 25/11/ 2011)

UNICEF (2003) *Africa's Orphaned Generations*. New York, UNICEF.

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

UNICEF, Progress for Children: A report card on Child protection, UNICEF, 2009, No.8, pp,19.

UNICEF. (2005). Fact Sheets [Online]. Retrieved from www.unicef.org/uniteforchildren

UNICEF2010. Alternative care http://www.unicef.org/southafrica/protection_6633.html

Vujovic, M., Meyersfeld.S. and Struthers, H. (2011). *Support for HIV positive adolescents.* Available at: www.anovahealth.co.za. (Accessed 27 May 2011)

Vujovic, M., Meyersfeld.S. & Struthers, H. (2011). *Support for HIV positive adolescents.* Available at: www.anovahealth.co.za. (Accessed 27 May 2011)

Walsh JC, Dalton M, Gill J, Burgess AP, Gazzard BG. Adherence to highly active antiretroviral therapy (HAART) [abstract I-171]. In: Program and Abstracts of the 38th Interscience Conference on Antimicrobial Agents and Chemotherapy (San Diego). Washington, DC: American Society for Microbiology, 1998:419.

Agwu AL and Fairlie L. Journal of the International AIDS Society 2013, 16:18579 www.hivaids/southafrica.com

Weiner, 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, 28, 155166.

World Health Organisation (2011). Progress report: Global HIV AND AIDS Response. Geneva, WHO

World Health OrganisationWHO (2012): Global Tuberculosis Report

World Health OrganisationWHO, (2009).Global facts and figures. Geneva, WHO Press

World Health OrganisationWHO, UNICEF and UNAIDS. (2010) *Towards universal access: scaling up priority HIV AND AIDS interventions in the health sector. Progress report 2010.* Geneva, World HealthOrganization.

WHO. (2010). *IMAI One-day orientation on Adolescents Living with HIV, Facilitator Guide*, Geneva, WHO Press

WHO. (2010). *IMAI One-day orientation on Adolescents Living with HIV, Facilitator Guide*, Geneva, WHO Press

Wilkin TJ, Gulick RM. (2008) When to start antiretroviral therapy? *Clin Infect Dis* 47:1580-1586. [PubMed].

Wooten, J (2005). We Are All the Same: A Story of a Boy's Courage and a Mother's Love. Penguin Books

Working Paper 34. The Hague, The Netherlands: Bernard van Leer Foundation
Centers for Disease Control, (2011) www.cdc.co.za: USA

Zhang, J. (2011). *The Rhetorics of Constructing HIV AND AIDS in the United States and China: A Comparative Analysis of two online discussion forums.* Graduate School of Clemson University .

Zhang, K.L., Ma, S.J., & Xia, D.Y. (2004).Epidemiology of HIV and sexually transmitted infections in China.Sexual Health, 1, 3946.