

**PSYCHOSOCIAL EXPERIENCES OF PERINATALLY HIV INFECTED
ADOLESCENTS RESIDING IN CHILD AND YOUTH CARE CENTERS IN
PRETORIA.**

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ABSTRACT

The roll-out of Anti-retroviral Therapy in South Africa has enabled perinatally HIV infected children to reach the adolescent phase. It is important to acknowledge that the psycho-social experiences of perinatally HIV infected children differ from other adolescents. This study explored the psychosocial experiences of perinatally HIV infected adolescents residing in Child and Youth Care Centres in Pretoria. Using qualitative interpretive-descriptive methodology, the sample consisted of eight perinatally HIV infected adolescents, two social workers and ten child and youth care workers from two Child and Youth Care Centres. Data was collected using semi-structured in-depth interviews with perinatally HIV positive adolescents and two focus groups were held with child and youth care workers and social workers. The use of these two data collection methods enhanced the reliability and trustworthiness of the data.

Using social constructionism as the key conceptual framework, there were four key themes and subthemes that distilled from the interviews and focus groups. The results revealed that perinatally HIV infected adolescents have difficulties discussing their status and that they used blocking as a coping strategy to avoid the subject. Disclosure was difficult for the adolescents as they were acutely aware of stigma and discrimination. With regards to adherence to medication there was lack of self-efficacy as the adolescents relied mostly on Child and Youth care workers and social workers. Finally in both Child and Youth Care centres, lack of on-going disclosure and discussion about HIV hindered the availability of psychosocial support services.

This study concludes that child and youth care centres should develop programs which focus on support topics such as sexuality, disclosure and self-esteem. The Department of Social development should implement psychosocial support training specifically for Child and Youth care workers and Social workers working with perinatally HIV positive children.

DECLARATION OF ORIGINALITY

I, Vimbai Precious Mavangira hereby declare that the study entitled

PSYCHOSOCIAL EXPERIENCES OF PERINATALLY HIV POSITIVE ADOLESCENTS
RESIDING IN CHILD AND YOUTH CARE CENTRES IN PRETORIA.

Is a result of my own investigation, unless specifically indicated to the contrary in the text, is my own original work. This thesis has not been submitted for a degree in any other university.

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DECLARATION BY SUPERVISOR

This thesis, which I have supervised, is being submitted with my approval.

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CHAPTER ONE

ABOUT THE RESEARCH

“Hope abides, therefore I abide. Countless frustrations have not cowed me. I’m still alive and vibrant” (Sry Chimnoy, 2010)

1.1 Introduction

The dynamics regarding the survival of children with perinatally acquired HIV have changed with the increased availability of Anti-retroviral therapy (ART) in South Africa. The advent of ART has transformed an inevitably fatal illness, with death occurring in childhood, into a chronic illness (Domek, 2012; Kumar, Mmari & Barnes, 2009). This has enabled perinatally HIV infected children to reach their adolescence phase. Sadly, most perinatally infected HIV adolescents grow up without a parental figure as a result of maternal mortality, with an estimated ratio of 310 deaths per 100 000 live births in South Africa (UNAIDS, 2012). As a result of increased mortality, South Africa was ranked the highest country with orphans due to HIV/AIDS with an estimated 3.7 million children who are regarded to have lost one or both parents to HIV-related illnesses (UNAIDS, 2009). In South Africa the epidemic collided with poverty and poor service delivery which increased stress within extended families that were expected to shelter for orphans (UNAIDS, 2009). This affected perinatally HIV positive children negatively as stigma and discrimination towards people with HIV has resulted in abandonment, abuse, neglect steering their admission into Child and Youth Care centres (Moses & Meintjes, 2010).

Child and Youth Care Centres seemed to be a source of refuge for neglected, abandoned and abused children, but previous studies have shown that institutional care impacts negatively on the child’s psychological and social well-being (Williamson & Greenberg, 2010; Browne, 2009). The latter can be attributed to the absence of significant parental figures in Child and Youth Care Centres hence lack of love, attention

and attachment which are foundations for the development of other relationships in later stages of life (Williamson & Greenberg, 2010). Inclusive of the negative implications of children growing in Child and Youth Care Centres (hereafter CYCC), the adolescence phase of perinatally HIV positive children residing in CYCC becomes unique. Their psychosocial needs are similar to those of any adolescent child, but owing to their condition, they have additional psychosocial needs in comparison to HIV negative adolescents (International Centre for AIDS care and Treatment Programs (ICAP), 2010). Perinatally HIV positive adolescents have a chronic illness to manage; HIV-related stigma and discrimination to endure; stigma attached to being in a CYCC and loss of identity from being in a CYCC. The latter, coupled with decision making with respect to romantic relationships, sexual activity, and experimentation with drugs and alcohol, as well as planning for the future make their psychosocial experiences a cause for concern (Beekman & Beest, 2007:5).

Considering the aforementioned concerns, there is still much focus in literature on the provision of material and shelter needs for HIV positive adolescents. However, their psychosocial needs have been neglected (Gelder & Kraakma, 2011:15; Richter et al., 2004). We are currently in a critical transitional period, in which the first generation of perinatally infected South African children are navigating their way through adolescence, it is important to understand their distinct needs (Jaspan, Li, Johnson, Bekker, 2009). The researcher agrees with Jaspan et al. (2009) that multidisciplinary adolescent specific programmes, addressing both the biomedical and the psychosocial aspects of perinatally HIV infected adolescents need to be formulated.

This study is aimed at exploring how perinatally HIV infected adolescents residing in CYCCs construct their psychosocial experiences, given their unique circumstances. It explores their psychosocial experiences as they reach the adolescence phase and perceptions of social workers and child care workers on psychosocial support services available. This chapter began with an introduction and following is an outline of the

research problem. The overall purpose of the study and key objectives and rationale of the study are outlined. Theoretical framework guiding the study and the methodology used are discussed. This chapter ends with an overview of the dissertation and the definition of terms

1.2 An Outline of Research problem

For social workers to understand the psychosocial world of an individual, it is essential to explore how these individuals construct their experiences. In South Africa, most HIV infected children were institutionalized as a result of an increased need for medical attention and to also handle HIV related stigma (Moses & Meinjties, 2010). Consequently, most CYCC admitted terminally ill HIV positive children for hospice care. However, their role has changed to caring for relatively healthy adolescents (Domek, 2012). Their needs have changed as education and psychosocial support are the most effective tools that help children and adolescents with HIV to survive and become psychologically healthy adults (Close, 2011). 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 perinatally HIV infected adolescents and for child and youth care workers who have to ensure their needs are catered for.

Despite the childhood experiences of receiving mercy and lack of social values, HIV infected adolescent are expected to define their identities, make plans for the future, interact with peers and deal with their sexuality (Vujovic, Meyersfeld and Struthers, 2011). 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). As a result, Close (2011) maintains that proper support will also help them to progress through this developmental stage and grow

alongside their peers. Smith and Green (2004) maintain that medical measures of HIV treatment efficacy are prioritized over socio-emotional issues of HIV-positive persons. The researcher agrees with Smith and Green (2004) "HIV has become a condition in which disease progression and treatment success are measured by medical technology, but this 'scientific' assessment may not equate with the lived experiences of the HIV-positive person." Yes, there are valuable lessons we can learn from medical research, but psychosocial support is an essential component of ongoing care for all people with HIV. Thus to allow transformation in CYCCs, there is a need to incorporate psychosocial support and medical care for perinatally HIV infected adolescents.

As a residential social worker, I observed that there was a change in behavior amongst perinatally infected children as they became adolescents. They had unanswered questions in relation to their status as they approached the adolescence phase of life. HIV is a complicated issue, regardless of age of the person, thus when relating to adolescents it becomes more complicated for child and youth care workers involved with the children because they were trained to work with HIV terminally ill infants as no one anticipated their survival. It is crucial to understand how they have constructed their lives and their interpretations of the world around them. Hence this study explored the psychosocial experiences of perinatally HIV adolescents' needs residing in CYCCs in Pretoria.

1.3 Overall Purpose of the Study

The overall purpose of this study was to explore the psychosocial experiences of perinatally HIV infected adolescents (14- 17) who reside in child and youth care centers in Pretoria.

The research was conducted at two Child and Youth Care Centres in Pretoria, Gauteng which cater for children of ages 0-18 years. Children are admitted at these facilities in terms of Section 158 of the Children's Act 38 of 2005 as amended (Government gazette, 2005). Section 158 of the Children's Act 38 of 2005 as amended states that:

“(2) If a children's court decides that a child should be placed in the care of a child and youth care centre, the court must-

- (a) Determine the residential care programme best suited for the child; and*
- (b) Order that the child be placed in a child and youth care centre offering that particular residential care programme.”*

The above indicates that the children's needs are of paramount importance when placing a child into a child and youth care centre. According to the United Nations Convention on the Rights of Children (1989) which was adopted by South Africa to serve, protect children and ensure their optimal development, South Africa is required to ensure that the articles within the Convention are expressed through policies and programmes for children (Donald, Dowe and Louw, 2000). The concept of “development” is defined by Gelphat, Brooks and Connell (1997) as the acquisition of physical, cognitive, social and emotional competencies required for engaging fully in a family and in society. It is important to make reference to the stability or change in the social, cultural, familial and materialistic contexts, when addressing the development of a child. Moreover, comprehensive social services for adolescents living with HIV in CYCCs in South Africa are low despite the importance of this group to human and social service professionals.

1.3.1 Objectives of the study

- To understand the psychosocial experiences of 8 perinatally HIV infected adolescents in three child and youth care centers in Pretoria.
- To understand the coping strategies of 8 perinatally HIV infected adolescents who reside in three child and youth care centers in Pretoria.
- To gain insight into perceptions of child and youth care workers and social workers on the psychosocial support services available in two child and youth care centers.
- To present recommendations to service providers in respect of gaps in psychosocial services for perinatally infected adolescents.

1.3.2 Research question

The research question which the study addressed was: What are the psycho-social experiences of perinatally HIV infected adolescents residing in child and youth care centres?

To address this question the following questions were examined in this study:

- What are the psychosocial experiences of perinatally HIV infected adolescents?
- What are the coping strategies of perinatally HIV infected adolescents?
- What support services and programs are available to perinatally HIV infected adolescents at three child and youth care centers?
- What recommendations perinatally HIV infected adolescents, as well as child care workers, make in the provision of support services to HIV infected children?

1.4 Rationale of the Study

Adolescents born with HIV are more likely to survive with appropriate medical treatment, psychosocial support, emotional support and care. In response to the influx of HIV positive adolescents, the global community has made great strides in protecting them by facilitating access to education and health services (UNAIDS, 2010). However, due to abandonment by parents, constant need for medical attention and neglect from immediate families, most children born with HIV find themselves in Child and Youth Care centers. As a result of the increase in ART rollout, there has been growing numbers of perinatally HIV infected children reaching adolescence in child and youth care centers

As a social worker working with HIV positive children at a child and youth care centre, I witness many psycho-social challenges these perinatally HIV infected adolescents face such as stigma associated with living in a child and youth care centre; difficulties in dealing with the disclosure of their status; and bereavement due to loss of parents. A number of the perinatally HIV infected children that I work with have entered secondary schools (which is a different environment from that in primary schools) and it seems their psychosocial experiences have changed. In this developmental stage, they are compelled to be independent and fit into the social system. They are also challenged with risk-taking behaviors which may complicate their lives as well as adherence to ART treatment. Clearly, the challenges faced by these adolescents have a ripple effect on their educational performance and the quality of their social lives.

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). For social workers, it is imperative that we are adequately equipped to deal with their increasing psychosocial needs as it is essential for HIV infected adolescents. Thus this study is unique in the sense that it explores the psychosocial experiences of perinatally HIV infected adolescents residing

in child and youth care centres in Pretoria. It endeavors to understand their psychosocial experiences a social constructionist perspective was used which is discussed below.

1.5 Theoretical Framework

Social constructionism focuses on the firm belief that there is neither objective reality nor objective truth reality, but reality is constructed from one's experiences and interpretation (Sarantakos, 2005:37). 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, 1991). Apart from the inherited and developmental aspects of humanity, social constructionism hypothesizes that all other aspects of humanity are created, maintained and destroyed in our interactions with others through time (Owen, 1991). Sarantakos (2005:37) postulates that meanings are not fixed but emerge out of people's interaction with the world.

Social constructionist beliefs are similar to those of social constructivism but the two theories deviate in conceptualizing how reality is shaped, formed or constructed (Rodwell, 1998:20). Social constructivists study multiple realities constructed by people and the implications of those constructions for their lives and interaction with others whereas constructionist refers to constructing knowledge about reality (Patton, 2002:96). With regards to perinatally HIV infected adolescents, their understanding of the world is greatly influenced by language (how HIV is understood in communities they interact with), their narratives (family backgrounds which are blurry) and cultural process (social constructions of HIV). Thus the social constructionism theory supported the researcher in understand the psychosocial experiences of perinatally HIV adolescents residing in CYCCs.

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). To understand psychosocial experiences of perinatally HIV positive adolescents in CYCCs it is imperative to engage in in-depth interviews, as it gives them the platform to express their worlds. Postmodernism theorists encourage constructive social workers to understand the construct of dialogue and language (Howe, 2002). They assert that words are understood by clients according to how they have constructed the reality embodied in the interaction (Howe, 2002:242). Language is also an important factor as it constitutes experiences and identity of both the self and the interaction which takes the diverse elements of the power involved seriously (Howe, 2002:242). Therefore, when conducting interviews with perinatally HIV positive adolescents, one should factor in words they use and also pay attention to how they conduct themselves as it can impact on their respondents' responses.

The narratives construct the future and anticipate change. Questions encourage the service user to identify exceptions to the apparently overwhelming nature of problems (Howe, 2002:244). Constructive social workers attempt to provide questions which elicit clear goals about what the service user wants, in their own words and entails him or her being involved in doing something in the immediate future which can launch a new beginning (Howe, 2002:244). This is similar to postmodern operation of deconstructions whereby phenomena are continually interrogated, evaluated, overturned and disrupted. In other words deconstruction is a way of analyzing texts, language and narratives that are sensitive to contextual dimensions and marginalized voices (Howe, 2002:243). Considering the attention given to HIV/AIDS by social scientist researchers, perinatally HIV adolescents residing in CYCC whom are a unique emerging group is limited. This study enabled them to speak out about their unique psychosocial experiences which deconstructed the generalized psychosocial experiences of perinatally HIV positive adolescents.

The social constructionist theory within constructive social work enabled the researcher to bring out the voices of perinatally HIV adolescents in CYCCs in Pretoria with respect to their psychosocial constructions.

1.6 Research methodology

The research methodology will be discussed in-depth in chapter 4 and only briefly mentioned in this chapter.

This study was based on a qualitative inquiry. Qualitative research studies aim for depth of understanding rather than quantity of understanding (Henning, 2004:3). In qualitative research, the researcher keeps focus on learning the meaning that participants hold about the problem issue, not the meaning that researcher brings to the research or writers express in the literature (Creswell, 2009:175). Hence in this study the researcher aimed at understanding and exploring the adolescents' psychosocial experiences from their perspectives. The researcher did not only explore how child care workers who are primary caregivers to adolescents perceive the psychosocial needs of perinatally HIV infected adolescents, but provided insight into the support services available to meet these needs.

The research methods were guided by an interpretive descriptive design which forms part of the qualitative paradigm. The interpretive descriptive design ensures that rich descriptions of phenomena are produced and they merge after carefully selecting the participants in research (Marlow, 1998:32). Babbie and Mouton (2001) added that this design enables the researcher to provide rich descriptions of the situation and events by interpreting and observing patterns that exist including their implications. The design permitted me to understand psychosocial experiences from the perspective of

adolescents, children and child care workers as well as social workers in two child and youth care centres in Pretoria.

For the purpose of this study, the researcher used purposive sampling. Purposive sampling focuses on selecting information-rich cases whose study will illuminate the questions under study (Patton, 2002:230). Creswell (2007:125) also maintains that the researcher selects individuals and sites for study because they can purposefully form an understanding of the research problem and central phenomenon in the study. Thus three purposive sampling methods were used to select participants and child care workers which are: criterion sampling, availability sampling and key informant sampling.

Firstly, availability sampling was utilized to select child and youth care centres. Next, criterion sampling was used to select eight adolescents from the two selected child and youth care centers. The third method of sampling identified key informants. Child care workers and social workers constituted this sample as they are primary psychosocial support providers to the adolescents. Consequently, five child care workers were chosen from two child and youth care centres in Pretoria as well as two social workers, one from each centre.

To achieve the objective of the study, data was collected using agency records, focus groups and in-depth interviews. All interviews and focus groups were recorded using a tape recorder. Access to the records of the perinatally infected adolescents at the two selected child and youth care centres enabled the researcher to have the selected participants' background information and ensured the credibility of participants.

Semi-structured interviews were 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). According to Greef (2005:289), 'Focus groups are group interviews which give the researcher a better understanding on how people feel or think about an issue'. Specific participants were selected because they have certain common characteristics that relate to the subject matter of the focus group.

With regards to ethical issues, it was ensured that the interview process was transparent and respondents knew the purpose of the research. Before conducting interviews and focus groups, all respondents were informed about the purpose of the study and they understood, leading to their willingness to participate (Singleton, Straits & Straits, 1993). The researcher also ensured that the research process was conducted in such a way that was not harmful to the participants and society. Before each interview, the researcher explained to participants that they were not compelled to answer any question if they didn't want to and that they could stop the interview at any time.

The researcher ensured that subjects could not potentially be harmed by the research. Informed consent forms were filled by participants giving their consent to ensure they are not coerced to participate in any way. A full account of how the researcher adhered to ethical conduct will be presented in chapter 4.

1.7 Clarification of concepts

The key concepts relevant to the study are as follows:

1.7.1 Perinatally infected

Perinatally infected - refers to children who acquire HIV during gestation (uterus), at delivery or through breast feeding (Kalsh, Thea & 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 is the key criterion which singles out the participants for the study.

1.7.2 Psychosocial

The term psychosocial is used to emphasize the close connection between psychological aspects of the human experience and the wider social experience (<http://www.arconline.org>, 2009). Psychological effects are those that affect different levels of functioning including cognitive (perception and memory as a basis for thoughts and learning), affective (emotions) and behavioral. Social effects concern relationships, family and community networks, cultural traditions and economic status, including life tasks such as school or work (<http://www.arconline.org>, 2009). Hence the use of the term psychosocial on the basis of the idea that a combination of factors are responsible for the psychosocial wellbeing of people, and that these biological, emotional, spiritual, cultural, social, mental and material aspects of experience cannot necessarily be separated from one another.

Erikson (1973) refers to psychosocial as the relation of one's psychological development in, and interaction with, a social environment. The individual needs not be fully aware of this relationship with his or her environment (Erik Erikson, 1973). This is the central concept for this study. The researcher aimed at exploring how unique perinatally HIV infected adolescents relate to their social environment.

1.7.3 Psychosocial support

Psychosocial support is a continuum of care and support which influences both the individual and the social environment in which people live (UNICEF, 2005). This continuum ranges from care and support offered by caregivers, family members, friends, neighbors, teachers, health workers, and community members on a daily basis.

Psychosocial support includes constant nurturing relationships that communicate understanding, unconditional love, tolerance and acceptance, and extends to care and support offered by specialized psychological and social services (UNICEF, 2005).

1.7.4 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).

1.7.5 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 & 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.

1.7.6 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.

1.7.7 Child and Youth Care Centre

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).

1.7.8 Child care worker

A child care worker is a caregiver who provides for the child’s physical and social needs. Armstrong’s (2000) definition of a caregiver will be adopted In this case, the term caregiver refers to non-medically qualified people, falling outside of the formal health services, who have been recruited, trained and are supervised by the organization within which they are employed. They may be trained in basic nursing care, terminal care, pain management, psychosocial counseling and bereavement counseling skills.

1.7.9 ART

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

1.8 Conclusion

In this chapter I introduced the rationale and background to the study. Subsequently, 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 conceptual base underlying this study are discussed. This dissertation is a temporary

base or platform which I used to reveal 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. The following provides an outline of the chapters that form the basis of this thesis.

Synopsis of chapters

Literature review:

Chapter 2: Global Overview of HIV/AIDS

This chapter will contain a comprehensive background into the research. The global and national overview of perinatally infected children surviving into adolescence is discussed. The South African legislation and Policy with regards to HIV and CYCCs was also outlined. Effects of CYCCs on adolescent's psychosocial well-being are also tackled in this chapter.

Chapter 3: Psychosocial Support

In this chapter, social work understanding on psychosocial is outlined and its relation to perinatally HIV positive adolescents, psychosocial support with regards to adolescents and the psychosocial impact of HIV on adolescents.

Chapter 4: Social constructions of HIV/AIDS

The theoretical framework on which the study is formulated will be discussed in this chapter. Social constructionism theoretical framework will be deliberated in relation to HIV & AIDS and psychosocial constructs with regards to the adolescence phase.

Methodology

Chapter 5: Research methodology

The research methodology, research design, population and sample, data collection and data analysis will be discussed in this chapter. 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 6: Voices of Perinatally HIV positive adolescents

This chapter presents data obtained from semi-structured interviews conducted with perinatally HIV positive adolescents. For the reader to understand, their biographical profiles are presented followed by themes which emerged from the interviews.

Chapter 7: Understanding institutional dynamics

In this chapter data obtained from the two focus groups with social workers and child and youth care workers was analyzed separately because of the different facility settings which influenced the findings. This chapter ensures the trustworthiness of data obtained from adolescents.

Chapter 8: Summary and Recommendations

A summary will be provided and conclusions drawn from the results will be discussed. Recommendations as well as further interpretation of the study will be contained in this chapter. Suggestions for further research will be presented. This chapter brings this study to a close and provides insight into the key themes and recommendations that emerged from the data analysis.

CHAPTER TWO: LITERATURE REVIEW

GLOBAL OVERVIEW OF HIV/AIDS

“Psychosocial support is an intrinsic part of primary care for all people with HIV, meeting psychosocial needs is paramount in caring for adolescents.”

(Samples, Goodman and Woods,1998)

2.1 Introduction

Globally, there has been increasing interest in HIV and AIDS which has been the fastest growing pandemic in the world. The earliest reports on children who are perinatally HIV infected described severe disease and short survival times. This pattern has changed as subsequent studies documented a highly variable clinical course and recent advances in antiretroviral therapy have resulted in longer lifetimes for HIV-infected adults and children (Sendi, Bucher, Craig, Pfluger & Battegay, 1991:377). A study carried out in the United States proved that survival rates of children and adolescents in the birth cohorts from 1997 to 2001 have increased since the introduction of triple ARV therapy (McConnell, Byers, Frederick, Peters et al., 2005:492). In South Africa, adolescents living with HIV are already a sizeable and prominent sub-group in the epidemic with an estimated 280 000 under the age of 15 having largely acquired the virus perinatally (Vujovic, Meyersfeld and Struthers, 2011). Success in the survival of perinatally infected children has been a great achievement in the HIV era. This has enabled HIV to be recognized as a chronic childhood disease which complicates the childhood phase due to adherence to medication (Thorne, Newel, Botet et al., 2002:396).

As the HIV pandemic matures, increasing numbers of children infected perinatally survive and will present HIV-related symptoms in older childhood and adolescence

(Gray, 2010:2; Thorne, Newel, Botet et al., 2002:396). Many studies have described cohort studies of perinatally infected children, proving their survival to into adolescents and showing the effectiveness of the Anti-Retroviral Therapy (Dolifus, Chenadoc, Faye, Blanche et al., 2010:214; Thorne, Newel, Botet et al., 2002:396). With much emphasis placed on the improvements in the treatment regimens and how it has improved survival, the researcher agrees with Dolifus et al. (2010) in that living conditions and health status of this unique group have been ignored. This ignorance is a cause for concern considering the UNICEF (2010:41) report which revealed that AIDS is estimated to be only ranked eighth as a leading cause of death among adolescents aged 15–19, and the sixth leading cause among 10–14-year-old. Loos et al. (2010) acknowledges that the needs of adolescents living with HIV are much more sensitive and varied than those of adults as they simultaneously deal with ‘adult’ issues like disclosure, practicing safe sex and adhering to treatment, while also addressing issues traditionally associated with adolescence, such as body image, first sexual experience, peer pressure and forming personal identity. Thus a strong psychosocial foundation is critical for the future well-being of perinatally HIV infected adolescents residing in Child and Youth Care Centres. This poses a challenge on researchers to divert their attention from successful treatment to psychosocial support and guidance needed by perinatally infected adolescents.

There is limited available research into the psychosocial needs of perinatally HIV infected children and adolescents residing in Child and youth care centres - much that exists is found in the grey literature. This chapter focused on the global and national overview of perinatally infected children surviving into adolescence. To understand the nature of this study, literature on the psychosocial impact of HIV and its relation to the adolescence phase were discussed which will enable us to understand the constructs of this unique group.

2.2 Global overview in respect of perinatally infected adolescents

UNAIDS (2010:23) report revealed that an estimated number of children living with HIV increased to 2.5 million [1.7 million–3.4 million] in 2009. In regions of the world with access to ART, children with perinatally HIV are surviving through childhood to adolescence with increasing numbers transitioning into adulthood (Foster & Fidler, 2011:12). Among developing countries, Brazil was the first country in 1992 to provide free universal access to antiretroviral treatment for AIDS hence the first evidence regarding survival of perinatally acquired HIV (Matida, Marcopito, Succi, Marques, Negra et al., 2004:419). Evidence on survival was first gathered from ten cities in Brazil amongst developing countries with children amounting to 914 perinatally to have acquired cases to ART (Matida, Marcopito, Succi, Marques, Negra at el., 2004:420). This study proved that there is substantial improvement in survival among Brazilian children with perinatally transmitted HIV but there is no evidence on the cohorts as they reach adolescence.

In Europe, the European Collaborative study, which prospectively observes children born to HIV infected mothers, has also confirmed the survival of perinatally infected children into adolescence (Thorne, Newel, Botet et al., 2002:397). They identified that as infected children grow up, issues of disclosure of infection status and their right to participate in decisions relating to their management as patients become increasingly important. They also noted that perinatally infected children and adolescents may become sexually active and are thus potential sources of subsequent transmission to their sexual partners and unborn children. Thus it is important to identify psychosocial characteristics of these children which may help identify their potential needs (Thorne, Newel, Botet et al., 2002:397). Despite their concern on the psychosocial needs of this group, little information is available about perinatally HIV infected adolescents.

In the United States, a study was carried out including birth cohort groups from 1989-2001 which showed increased survival into adolescence and adulthood population of children infected with HIV from birth (McConnell, Byers, Frederick, Peters et al., 2005: 488). Due to introduction of prevention of mother-to-child transmission, very few young children are becoming infected with HIV in the United States. However those who were infected 10 or more years ago comprise an increasing proportion of the pediatric/adolescent HIV patient population (Wiener, Battles & Wood, 2007: 471). As treatment advances it became evident that HIV-infected children were indeed entering adolescence, concerns pertaining to virus transmission, diagnosis disclosure, and complicated medical regimens began to take priority for parents as well as service providers (Grubman et al., 1995).

McConnell et al. (2005) and Wiener et al. (2007) are in agreement that, it is vital to access the HIV transmission knowledge of HIV-infected adolescents and young adults who are coming to sexual maturity so that appropriate prevention messages and intervention programs can be delivered. They noted that it is imperative that highly active antiretroviral therapy be carefully monitored and evaluated as children and adolescents go through hormonal changes (McConnell, Byers, Frederick, Peters et al., 2005:493). As noted, not much information on the sexual knowledge of adolescents and young adults infected with HIV early in life is known.

In Asia, India is home to 95,000 adolescents living with HIV. It has been listed along with Sub-Saharan countries having the highest number of adolescents infected (UNAIDS, 2010). However, very few children in India had access to ART in 2005 even though children represent about 4% of the total population of HIV/AIDS, they accounted for almost 18% of the deaths in 2005 (Shah, 2006:183). In comparison to Western Europe and USA with good Prevention of Parent to Child transmission (PPTCT) programs, newly acquired perinatally transmitted HIV in children is less than 500/year (UNAIDS, 2010). In India, according to UNAIDS, the percentage of pregnant women

receiving treatment to reduce mother-to-child transmission is only 1.6% (Shah, 2006:183). In India HIV in children is unchecked and will keep on rising until an effective PPTCT program is put into place.

According to the UNAIDS 2010 report, an estimated 90% of the world's children living with HIV reside in sub-Saharan Africa. Ironically Sub-Saharan Africa, being the lead in HIV among children globally, ART coverage of children in this region is slightly below the global average, at just 26% (UNAIDS, 2010). Amongst the 25 countries with the greatest number of people living with HIV, only Botswana reported antiretroviral therapy coverage of children greater than 80% (UNAIDS, 2010). Despite the high antiretroviral coverage among children, little is known about the survival of this group in Africa beyond 5 years of age (Gray, 2010:2). In Southern Africa, most of the studies have focused on the epidemiology of sexually acquired HIV infection amongst 15-24 year olds (Gouws, Stanecki, Lyerla & Ghys, 2008:7). Therefore data on the prevalence and disease patterns of perinatally acquired HIV infection in older children and adolescents exists (Gray, 2010:4). However, the fact that there is antiretroviral therapy in Southern Africa, especially in South Africa, survival of perinatally infected children should be prevalent.

In East Africa, Uganda is on the forefront with regards to research on perinatally HIV positive adolescents in contrast to Southern Africa where there is relatively little research on the subject matter. In Uganda, the population of perinatally HIV infected young people is rapidly growing due to increase in roll-out of ART enabling survival into adolescence and adulthood (Birungi, 2007). Conversely, in just about every other country, true numbers of children and young people aged between 10 to 19 years born HIV-positive are almost impossible to find, but some indications are available.

Despite lack of data on this age group, The AIDS Support Organisation (TASO Uganda) has registered 4,696 young people living with HIV since infancy, proving progress on the pandemic in Uganda (Birungi, Mugisha, Nyombi, Obare, Evelia & Nyinkavu, 2008:1). According to Birungi (2007:3) Ugandans have their first sexual experiences very early in life and keeping in mind the number of registered perinatals, sexuality among adolescents is a cause for concern as perinatally infected children are surviving to this phase. To address this concern in Uganda, a situational analysis was carried out with the intention of understanding the sexual and reproductive health concerns of adolescents perinatally infected with HIV (Birungi et al, 2008:18). A key finding from this analysis was that perinatally infected adolescents aspire to live their lives just like their peers who are not HIV-infected (Birungi et al, 2008:18). It also confirmed the existence of wide programmatic gaps in addressing the sexual and reproductive health needs of perinatally infected adolescents, which could be strengthened by involving them during development of any programs (Birungi et al, 2008:19). Thus Uganda has more advanced research regarding perinatally infected adolescents compared to other African countries.

Considering the aforementioned information, one can agree that the survival of perinatally HIV infected adolescents is increasing. Relatively little information is known about their current psychosocial needs, especially those residing in institutional care, and this calls for more social research to be conducted to address their specific needs.

2.3 Overview of HIV in South Africa among Adolescents

There is not much data available on treatment outcomes of adolescents living with HIV infection (whether perinatally acquired or sexually acquired in sub-Saharan Africa (Nglazi, Kranzer, Holele, Kaplan, Mark, Jaspán, Lawn, Wood and Bekker, 2012:1).

Despite the unavailability of data, South Africa has the highest number of cases of HIV/AIDS among adolescents with an estimation of 1.3 and 1.9 million (Bankole, Singh, Woog &Wulf, 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 2007b). 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.

The World Health Organisation (2009) indicated that the first cohorts of perinatally infected children with access to ART are now reaching the adolescence phase of life. As indicated earlier, there is not much information available regarding perinatally infected adolescents in South Africa as most research focuses on the prevalence of HIV among adolescents without specifying the mode of transmission. Hence to understand perinatally infected adolescents in South Africa, it is crucial to discuss the prevalence of HIV among children.

In 2008, a household survey conducted in South Africa estimated the prevalence of HIV in children aged 2-14 years to be 2.5% (Shisana,Rehle, Simbayi, Zuma Jooste, 2010) . Shisana, Mosala et al. (2005) also estimated an HIV prevalence of 3.3% for children 2–14 years of age from a population-based survey, while HIV prevalence among those 15–19 years of age was estimated at 6.3% - females having three times higher rates (9.4%) than males (3.2%). Most children under the age of 15 living with HIV acquire it via mother-to-child transmission. Consequently, considering the roll out of ART, we can be assume these children have high chances of survival keeping in mind CYCCs are witnessing perinatally HIV positive children reaching adolescence (Domek, 2012).

Table 1: HIV prevalence among children by age groups, South Africa 2008

Age(years)	N	HIV (%) [95% CI]
0-4	1 552	3.3 [2.1-5.2]
5-11	1 708	2.5 [1.7-3.7]
12-14	964	1.1 [0.5-2.4]
15-18	1 551	4.5 [2.8-7.2]
Total 0-18	5 745	2.9 [2.2-3.7]

(South African National HIV Prevalence, Incidence, Behavior and Communication Survey, 2010)

Table 1 shows the prevalence of HIV in children for various age groups. Overall HIV prevalence among children aged 18 years and younger who participated in this survey was 2.9%. The HIV prevalence among the various age strata was 3.3% for children 0–4 years of age, 2.5% for those 5–11 years of age and 1.1% for children 12–14 years of age (Stocktaking Report 2009).

Despite the data from the survey, South Africa still has a greater coverage of ART rollout among children, which improves health outcomes and long term survival of any child that is infected early in life (UNAIDS, 2010). In 2008, there were 57 228 children on treatment which translates into a 61% coverage rate (Stocktaking Report 2009). From the above statistic, it is evident that perinatally infected adolescents are prevailing in the country.

Adolescence is a time when young people explore their sexuality and take risks in many aspects of their life including sexual relationships. Those that have sex may have different partners either engaging in protected or unprotected sex. With perinatally infected children surviving into adolescence and keeping in mind the age at which adolescents become sexually active (12 years) in South Africa (Van Dyke, 2003) there

is need for greater awareness. UNAIDS (2010:25) emphasizes making the provision of services and knowledge to adolescent girls but it is imperative to focus on both girls and boys as the present situation does not single out anyone from being infected in this age group.

For a successful prevention strategy with respect to the spread of HIV at this phase, greater support is required for adolescents. South Africa lacks traction with regards to attending the needs of perinatally HIV infected adolescents in comparison to Uganda which already has support programs for this group of adolescents. For such programs to be formulated in South Africa, it is crucial that we explore and understand their psychosocial experiences.

2.3.1 Legislation Guiding HIV Intervention in South Africa.

The cornerstone 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. However, the welfare model inherited from colonialism and apartheid was inequitable, discriminatory and relied on inappropriate and unsustainable methods of service delivery (Lombard, 2008). Thus to ensure equality for all, the Mandela government adopted and implemented the White Paper for Social Welfare (Department of Welfare and Population Development, 1997) as a national policy in 1997 which Patel (2005) acknowledges was a bold step in the right direction. Lombard (2008) is in agreement with Patel (2005) with respect to the notion that aforementioned policy framework broke with the country's apartheid social welfare paradigm and charted a new path for social welfare to promote national reconciliation, reconstruction and development. According to Patel (2005:71), the policy governing social welfare services was refashioned to be more developmentally oriented and to redress past neglect of welfare services to the majority of the population. The developmental approach to social welfare was intended

to modernise the welfare system to be more just, equitable, participatory and appropriate (Patel, 2005:73).

In the South African context, social development is conceived as a strategy promoting participation of the socially excluded in development activities to achieve social and economic justice, human rights, social solidarity and active citizenship (Patel, 2005:73). 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 (2008:168) attributes this slow progress to lack of a clear conceptualisation of what developmental social welfare entailed. However, the Integrated Service Delivery Model for Developmental Social services of 2006 provides a comprehensive national framework that clearly sets out the nature, scope, extent and level of social services that forms the basis for the development of appropriate norms and standards for service delivery (Department of Social Development 2006). The levels of intervention are as follows:

2.3.1.1 Prevention

Prevention is the most important aspect of social service delivery. Services delivered at this level are aimed at strengthening and building the capacity and self-reliance on the part of the client. At this level the client is functioning at an adequate level but there is a possibility of risky behavior at a later stage (ISDM, 2006). In order to enhance the social functioning of perinatally HIV infected adolescents, primary focus should be on their psychosocial needs.

2.3.1.2 Early intervention (non-statutory)

Services delivered at this level make use of developmental and therapeutic programs to ensure that those who have been identified as being at risk are assisted before they require statutory services, more intensive intervention or placement in alternative care

(ISDM, 2006). This level of intervention encourages CYCC to have programs which cater for the adolescents needs.

2.3.1.3 Statutory intervention/residential/alternative care

At this level, an individual has either become involved in some form of court case or is no longer able to function adequately in the community, and services are aimed at supporting and strengthening the individual affected. In addition, a client may have to be removed from his/her normal place of abode, either by court order or on the recommendation of a service provider, and placed in alternative care (e.g. foster care), or a residential facility (Integrated Social Service Delivery Model, 2006). This level of intervention has been abused by many communities where some deliberately neglect or abandon their perinatally HIV infected children, resulting in them being placed in institutions.

2.3.1.4 Reconstruction and aftercare

The previous intervention is aimed at providing alternative care which should wherever possible be a temporary measure, followed by reconstruction/aftercare services to enable the client to return to their family or community as early as possible. Services delivered at this level are aimed at reintegration and support services to enhance self-reliance and optimal social functioning (Integrated Service Delivery Model, 2006). One can note HIV and AIDS as reasons for family disintegration and connotations associated with the chronic illness were not considered. This poses a greater challenge on social workers as it becomes difficult to deliver the aims of the ISDM and serve in the best interest of the children as well. The reintegration services are thus difficult to implement as most perinatally HIV infected children maturing into adolescents lost biological parents and relatives neglect them due to the stigma associated with the illness.

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). Despite the ISDM (2006) not specifying much regarding HIV and AIDS services, the White Paper of 1997 the National Strategic Plan 2007-2011 acknowledged the Impact of HIV/AIDS on infected and affected individuals, especially children. Resultantly, the burden falls on social workers to find ways to integrate the two policies and come up with solutions that address perinatally HIV infected adolescents in Child and Youth Care Centres.

The National Strategic Plan for HIV and AIDS 2007-2011 was designed to guide South Africa's response to HIV/AIDS & STI control and is used as a baseline for engagement with national and international partners on matters pertaining to HIV and AIDS (National HIV & AIDS and STI strategic plan, 2007). It ensures comprehensive care and treatment for people living with HIV and AIDS, as well as facilitates the strengthening of the national health system (National HIV & AIDS and STI strategic plan, 2007).

Treatment, care and support are some of the priority areas that the National strategic plan addresses. The aim is to reduce HIV and AIDS morbidity and mortality as well as the resultant socioeconomic impact by providing appropriate packages of treatment, care and support to 80% of HIV positive people and their families by 2011 (National HIV & AIDS and STI strategic plan, 2007). This would be achieved by:

Extending the coverage of voluntary counseling and testing plus promoting regular HIV testing

- Increasing access to VCT services that recognize the diversity of needs
- Increasing the uptake of VCT

Enabling people living with HIV to lead healthy and productive lives

- Up-scaling coverage of the comprehensive care and treatment packages
- Increasing the retention of children and adults on ARTs
- Ensuring the effective management of TB/HIV co-infection
- Improving the quality of life for children and adults with HIV and AIDS who require terminal care

- Strengthening the health system and removing barriers to access

Addressing the special needs of women and children

- Decreasing HIV and AIDS related maternal mortality through women-oriented programs.
- Providing an appropriate package of services that include wellness, opportunistic infection management, ARTs and nutrition to children and adolescents who are HIV positive and/or exposed.

Mitigating the impact of HIV and AIDS and creating an enabling social environment for care, treatment and support.

- Strengthening the implementation of OVC policies and programmes
- Strengthening the implementation of policies and services for older people affected by HIV and AIDS
- Mainstreaming the provision of appropriate care and support services to HIV positive people with disabilities and their families. (National HIV & AIDS and STI strategic plan, 2007)

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.

In support of the strategic plan, a number of policies and guidelines have been developed in a bid to safeguard the implementation of HIV and AIDS strategies in South Africa. These policies include Policy Framework for Orphans and other children made vulnerable by HIV and AIDS (2005), Children's Act No. 38 of 2005 and The National HIV/AIDS School Policy (Department of Education, 1999) all emphasizing the need to create an enabling environment that helps curb infection rates and meeting the needs of young people.

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. Conversely, most research focuses on the needs of children orphaned by HIV while perinatally HIV infected children and adolescents' needs are neglected.

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). In such a case, social workers are expected to intervene and act in the best interests of the child as well as make for the provision of social welfare services (Chapter 9 Section 150 (1)(a)(h)(j) of the Children's Act no 38 Of 2005 (Government Gazzette,2005).

The child is removed from their family and placed in alternative care with the first priority being related or unrelated foster care placements. Kinship or foster care placements enable children to live with people that they know and trust. They also support the transmission of a child's identity from a family perspective, culturally and ethnically - helping the child stay connected to siblings, build and retain connections to the extended family (Scannapieco and Hegar, 1996).

However, due to the fact that many communities are affected by poverty and conflict, they tend not to prioritize the needs of children. One may find themselves neglecting the suffering children while focusing on finding a means of survival (Ramsuran, 2009). This becomes a drawback to the policy of social development to place children in foster care as their needs will be violated. Despite economic difficulties, most children orphaned by the HIV pandemic may already be infected hence family members' reluctance to live with such a child. In some instances, HIV positive children are abandoned by their biological parents or relatives, making it difficult to place them in foster care because of the stigma surrounding HIV/AIDS. The latter leaves children who are perinatally HIV infected placed in Child and Youth Care Centres as it is the only viable option to ensure their wellbeing. Child and Youth Care centres are expected to offer psychosocial support to adolescents who are perinatally HIV infected. Nonetheless, this turns out to be a challenging task for most organizations as most policies make no mention of this specific group.

The National Integrated Plan (NIP) for Children and Youth Infected and Affected by HIV/AIDS 2000 (NIP) launched in 2000 to make sure that individuals, households and communities, especially the children affected by HIV/AIDS have access to an appropriate and effective integrated system of prevention, care and support services at

community level. In implementing the NIP, programs would include the development of coordinating structures, income generating activities, specific prevention activities targeting children and youth, community based care, capacity building, access to grants and placements, training of teachers, as well as voluntary counseling and testing (Department of Health and Social development , 2000). This is evidence that this emergent group of perinatally HIV infected adolescents were not foreseen.

All these policies focus on HIV/AIDS in a family and community setting therefore, there is no specific statement in reference to perinatally HIV infected adolescents 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). Ramsuran proposed that, CINDI (Children in Distress) supports this change as well as the Department of Social Development's policy of placing children with extended families in communities, instead of placement in institutional care facilities which is considered a last resort. This initiative is forthcoming but there is need for intensive HIV and AIDS education in communities for them to accept perinatally HIV infected children and adolescents, but more importantly to understand their unique psychosocial needs.

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. To ensure that this would be achieved, Child and Youth Care centres were developed to cater of the needs of neglected and abandoned orphans.

2.3.2 Child and Youth Care Centre (institutional care)

Residential care for children, Institutions and Orphanages are defined by the following criteria: a group-living arrangement for more than ten children without parents or surrogate parents, in which care is provided by a smaller number of paid adult carers

(Browne, 2009:1). In South Africa, the term Child and Youth Care Centre is used in reference to Institutions. A Child and Youth Care Centre is a facility for the provision of residential care to more than six children outside the family environment in accordance with a residential care programme suited for the children in the facility (Section 191 (1), Children's Act no 38 of 2005). Browne (2009) explains that residential care implies an organized routine and impersonal structure to the living arrangements for children and a professional relationship rather than parental relationship. 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 & Rebecca, 2006:20; Foster & 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). This lack of data can be attributed to a lack of resources in some countries leaving them unaware of the numbers of orphans, leading to the generalization that every child in a CYCC is an orphan (Moses & Meintjes, 2010). Not only is there grey data on residential care, but also limited available research with regards to CYCCs (Foster, 2004). In Sri Lanka, the government counted 223 registered CYCCs in 2002 as compared to 121 in 1991 and in Liberia 117 CYCCs existed, with more than half of them unregistered and unmonitored (Mariam, Fahmida & Dharshini, 2006).

There are an estimated 3.7 million orphans in South Africa, about half of whom have lost one or both parents to AIDS and 150,000 children are believed to be living in child-headed households (UNICEF, 2010). Statistics on children in institutional care are not complete, but it is known that there are 345 registered CYCC in South Africa, looking after some 21,000 children (UNICEF, 2010). These facilities qualify as 'child and youth care centres', a provision of the new Children's Act that will establish a system of

specialized alternative childcare programmes with proper standards and governance structures.

According to a study conducted in four provinces in South Africa, the audit recorded a high proportion of HIV-positive children in CYCCs with an estimate of 16% at the time of the study (Moses & Meintjes, 2010). The qualitative study revealed that 39% of the children were admitted due to abandonment, 31% were HIV-positive had been admitted because they had no one available to provide them with care, 5% had their mothers ill-health lead to their admission and 11% had been admitted because they were ill themselves (Moses & Meintjes, 2010). Social constructs surrounding HIV are also a contributing factor to these placements as acknowledged by social workers who participated in the study regarding HIV-related stigma and the increased required care for HIV positive children as well as increased admissions (Moses & Meintjes, 2010).

Placements into CYCCs in South Africa are governed by the Children's Act No. 28 of 2005 and guided by the "Best interest of the child" principle. A child is placed in a CYCC with accordance to Section 158 (1) of children's Act No. 38 of 2005 which states that, *"A children's court may issue an order placing a child in the care of a child and youth care centre only if another option is not appropriate"* (Government Gazette, 2005). The Act in Section 191 (2) of the Children's Act No. 38 of 2005, clearly stipulates that a CYCC must offer appropriate therapeutic programmes designed for the residential care of children (Government Gazette, 2005). However, regardless of the mandate by the Act, there are certain general problems which are inevitable in institutional settings. In other words, these problems arise as a result of placing children in institutions.

2.3.3 Challenges experienced at Child and Youth care centres

2.3.3.1 Effects of CYCCs on emotional attachments

Children living in institutions without parents are reported to perform poorly on intelligence tests and to be slow learners with specific difficulties in language and social development in comparison to children with foster parents (Browne, 2009:11). For the last half century, child development specialists have recognized that residential institutions consistently fail to meet children's developmental needs for attachment, acculturation and social integration (Williamson & Jan, 2009). They also present problems with concentrating and forming emotional relationships, often being described as attention-seeking - attributable to the lack of mother figure during early childhood (Browne, 2009:11). The researcher is in agreement with Williamson and Greenberg (2010:5) that children need more than good physical care, they also need the love, attention and an attachment figure from whom they develop a secure base on which all other relationships are built.

Another shortcoming of institutional care is that young children typically do not experience the continuity of care that they need to form a lasting attachment with an adult caregiver (Williamson & Greenberg, 2010:5). Ongoing and meaningful contact between a child and an individual care provider is almost always impossible to maintain in a residential institution because of the high ratio of children to staff, the high frequency of staff turnover and the nature of shift work (Williamson & Greenberg, 2010:5). Dwivedi (1999:63) is of the view that a young infant's psychological needs are centered on being cared for, nurturance, warmth, physical closeness and touch. He proceeds to say that healthy emotional bonding takes place in contexts in which parents are genuinely pleased at the arrival of the newborn, expressing their joy in gentle confidence, 'giving' as much as is needed. When the infant has its needs adequately fulfilled a sense of belonging and security, trust in self and optimism about life (expressed in curiosity and creativity) proceed (Dwivedi, 1999:63). In turn, these

children might have difficulties forming and maintaining relationships throughout their childhood, adolescence and adult lives.

Their lack of secure attachment is also presented by the behavior of wanting to touch or hold the hands of visitors. Bower (2000) maintains that such behavior may initially seem to be an expression of spontaneous affection but it is actually a symptom of a significant attachment problem (Bower, 2000). Bower's assertion corresponds with a study by Johnson et al, (2006) which reported significantly more indiscriminate friendliness or disinhibited behavior which he referred to as "disorganized attachment disorder". Thus a child from a normal family setting with a secure sense of attachment is more likely to be cautious even fearful of strangers, rather than seeking to touch them. As for children who grew up in child and youth care, they lack a sense of security and belonging.

2.3.3.2 Effects of CYCCs on social behavior

A European study conducted by Johnson et al. (2006) revealed evidence of negative social and behavioral consequences for children raised in institutional care. This was reported by 16 of the studies highlighting problems with anti-social conduct, social competence, play and peer interactions. Browne (2009:12) also confirms that observations carried out in European residential care homes have since confirmed more stereotypical behavior in children who are under-stimulated in institutions. Furthermore, child and youth care centres uproot children from their communities and add to their feelings of isolation and alienation (Cluver & Gardener, 2007). Black (2009) postulates that children resent being labeled as 'orphans' as it has negative connotations. Children placed in child and youth care centres often feel that they are defined by their orphan status, which translates into being unwanted and rejected (Cluver & Gardner, 2007). Thus it can be argued that children living with HIV in child and youth care centres live with a doubly negative stigma which may well have a negative impact on their sense of self hence the development of anti-social behavior.

According to Neuman & Neuman (1997:84), the environmental provision of consistency and predictability are fundamental to the confirmation for the growing infant that there are people in the world who are trustworthy and caring. Erikson identified basic trust versus basic mistrust as the psychosocial crisis for this period, manifesting after successful adaptation in hope. Mutuality with the caregiver is the central process used to adapt, hence withdrawal is a sign of pathology at this stage (Neuman & Neuman, 1997:65). Consequentially, children who are deprived of constructive guidance and parenting at this stage of development may become passive, withdrawn and dependent.

In addition, children who are in Child and Youth Care centres lack personal involvement with an adult role model hence more likely to engage in sexual activity at an early age (Cohen & Abromowitz, 1990; Richter & Swart-Kruger, 1995). With all the negative feelings and stigma which are faced by any adolescent residing in a Child and Youth Care centre, it becomes double jeopardy for perinatally infected counterparts as they have HIV which complicates their lives. Hence, it is of great importance to focus on this population as they are at risk of acting out of frustrations posed by HIV, residing in a Child and Youth Care Centre and the adolescence phase. From the researchers' perspective, in order for us to meet the needs of perinatally HIV infected adolescents in institutional care, it is crucial to explore their psychosocial experiences.

2.3.3.3 Effects of CYCCs on intellect and language

The disruption to the development of the mind which is associated with under-stimulated children in institutional care is most obviously expressed by the delay in language acquisition (Browne, 2009:13). A study done by Goldfarb (1944,1945) which investigated speech and language organization in infancy, at six to eight years, and at adolescence revealed a clear deficiency in language development in all three age groups compared with same age groups of fostered children. Other studies have since reported deficits in the language skills and early reading performance of children raised in institutions (Roy and Rutter, 2006). These deficits include inferior vocabulary and less spontaneous language (Tizard and Joseph, 1970). Nevertheless, Croft et al. (2007)

found that children recover well from these deficiencies in language development once placed in a family, although the socio-economic status and background of the child's new family have profound effects on their language development (Geoffroy et al., 2007).

2.3.3.4 Effects of CYCCs on the Cognitive functioning.

Trevarthen and Aitken (2001) maintain that the human infant is genetically predisposed to interact with others, but for this process to result in optimal brain development, the infant needs to interact with a caregiver who will handle, talk and respond to them in a sensitive and consistent way, repeatedly introducing new stimuli appropriate to their stage of development. It is at this stage the presence of a primary care giver or mother is essential. While a socially rich family environment promotes infant brain growth, an impoverished environment through parental neglect or institutional care has the opposite effect and suppresses brain development (Glaser, 2000). Without a supportive and predictable parent providing a one-to-one relationship to 'scaffold' infant learning, there is no process to guide synaptic connections and the development of neural pathways (Browne, 2009:14). The absence of stimulatory experiences delays their development may lead to learning difficulties (Dwivedi, 1999:65). Dwivedi (1999:65) concludes that individuals whose needs have not been adequately met at this stage tend to endure extreme discomfort before taking care of themselves. Motivational problems and boredom are common and pleasure is frequently absent from the life of such individuals.

2.4 Conclusion

Drawing from the prior discussion, information on perinatally infected adolescence is still vague, especially in Africa and Asia. This affects the success rate with curbing the pandemic as perinatally infected adolescents are not guided through this confusing stage of life, more specifically those residing in Child and Youth care centres. They may exhibit anger and blame their biological parents for the "involuntary infection". It is

essential that support for this age group be specified so that relevant programs can be formulated and implemented. The chapter that follows explores the psychosocial needs of these adolescents.

CHAPTER THREE

PSYCHOSOCIAL SUPPORT

3.1 Introduction

Psychosocial approaches emphasize on making thorough, carefully observed, theoretically informed assessments of people, their relationships and their sociocultural environment. In a nutshell, psychosocial assessments are centred on how people act and relate with each other; how they behave with their children; how children react to parents, peers and teachers; and how they play and react to demands and difficulties (Howe, 2002:177). In this chapter, the social work understanding on psychosocial will be outlined together with its relation to perinatally HIV positive adolescents, psychosocial support for adolescents and the impact of HIV on adolescents.

3.2 Social work perspective on psychosocial work

From a social work perspective, the term psychosocial relates to an area of human experience which is a product of the interplay between the individual's psychological condition and the social environment (Howe, 2002:170). Howe goes further by postulating that psychosocial matters define most of what is of interest to social work, particularly people having personal problems or problems with others (Howe, 2002: 170). The social work perspective on psychosocial work can be aligned with the social constructionist theory. Social constructionists believe that our knowledge of the world and common ways of understanding are not derived from the nature of the world as it is, but that it is we who construct them from our own reality (Burr, 1995:4). It is believed that the basic dynamic between psychology and the setting can be used to explore all aspects of people's psychosocial functioning (Howe, 2002:173). These aspects include

the person's past social, emotional and environmental experience and they help us to understand the present. Howe (2002:177) states that the ability of people to feel in control of their own mental, social and economic state is recognised as fundamental to their general well-being. One's psychosocial functioning is greatly influenced by their social self and attachment relationships.

3.2.1 Social self

One's personality and the self are formed as the developing mind relates with and tries to make sense of the world in which it finds itself (Howe, 2002:171). During this process of conceptualising the world around us, we take many properties of the environment which we seek to understand and negotiate. This is consistent with the social constructionist perspective which states that we construct our realities as we interact with our social world (Patton, 2002:96). However, how we understand, think, feel, see and conceptualise is greatly influenced by inherited temperamental and biological dispositions which lead to the development of personality and the emotional make-up of the individual (Howe, 2002:171). The more inferior the quality of people's relationship histories and social environments, the less vigorous their psychological make-up and ability to deal with other people, social situations and emotional demands will be (Howe, 2002:172). Perinatally HIV positive adolescents residing in CYCCs' sense of the self can be confusing because they came from unstable homes and are growing up in an institutionalised environment. Some of their biological parents might have had unstable emotional backgrounds resulting in them neglecting their children. These traits might have an impact on perinatally HIV positive adolescents' emotional well-being.

3.2.2 Attachment theory

The Attachment theory explores how the quality of a child's relationship with their carer affects their socio-emotional development, which then influences the way they relate to and deal with other people (Howe, 2002: 173). Adverse environments which lack love,

mutuality and empathy are less conducive to the formation of secure and confident personalities (Howe, 2002:173; Mohangi, 2009). 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; Frith, 1989:169).

Successful psychosocial outcomes in infancy and childhood are regarded as the foundation for a coherent identity by Erikson (Berk, 2000:456). From this, we can infer that perinatally infected HIV adolescents' psychosocial experiences are greatly influenced by the quality of the attachment relationships they held in their previous developmental phases. The attachment theory identifies four types of relationship experiences and their impact on psychosocial development and social competence. A narrative of these types of relationships follows.

3.2.2.1 Four types of relationship experiences

According to Howe (2002:175), a basic understanding of these relationship environments helps practitioners make sense of the way children and adults react to and deal with the social and emotional demands of others. This clarification of relationships is useful in helping child and youth care workers to understand children's emotional experiences and psychosocial functioning. The four types are:

❖ Secure attachments

In secure attachment parent/child relationships are caring, loving, responsive, predictable and consistent (Howe, 2002:175). There is mutual interest and concern in the thoughts and feelings between care giver and child. Children from such relationships have the ability to understand and handle themselves in social relationships as they feel valued, socially competent and interpersonally effective - hence they cope well with conflicts, upsets and frustrations of everyday life (Howe, 2002:175). This type of attachment is not consistency with CYCCs as most of the children are regarded to be "in need of care" as stated in the Child Care Act No. 38 of 2005 (Government Gazette, 2005) but do not have secure attachments.

❖ **Insecure, ambivalent attachments**

When a parent is inconsistent and unpredictable, children begin to experience increasing levels of anxiety, distress which lead to clingy dependence due to neglect and insensitivity from parents (Howe, 2002:175). 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). Children who have grown up in these relationships are beset by insecurity, henceforth they cling to relationships yet conduct them with high level of tension and conflict (Howe, 2002:176). Most of the adolescents in CYCCs have experienced this attachment.

❖ **Insecure avoidant attachments**

Children who develop avoidant patterns of attachments have parents who are indifferent, hostile, rigid or rejecting (Howe, 2002:176). Their parents respond reasonably well when their child appears content but when presented with problems withdraw which decrease chances of forming emotional bond (Howe, 2002:176). When separated from their parents, these children show few signs of distress and upon reunion; the children either ignore or avoid their attachment figure (Howe, 2002:176). This is consistent with many children in CYCCs when they are removed from the care of their parents they do not show emotion which enables them to adapt in any setting. Children from these relationships find it difficult to form intimate (Dwivedi, 1999:65), emotionally reciprocal relationships because of the fear of rejection - they may resort to bullying to get their way (Howe, 2002:176). This explains why most children in CYCCs exhibit uncontrollable behaviour and there are high incidences of bullying.

❖ **Disorganised attachments**

This type of attachment pattern is apparent in children who suffer physical abuse and maltreatment as they show a confused mixture of resistant and avoidant patterns of attachment (Howe, 2002:176). Relationships of this kind produce disorganised and disturbed attachment patterns in which the parent's violent scary behaviour causes the child to feel extremely anxious (Howe, 2002:176). Children from these relationships do

not know how to seek comfort nor do they seem to know how to respond to other people's warmth and concern (Howe, 2002:177). Adolescents who experienced this pattern are likely to be withdrawn and apathetic. Later, they may also display intellectual deficits, behaviour problems and reactive behaviour disorders.

Dwivedi (1999:67) adds on that the failure of young children to attain secure attachments to a primary caregiver is considered significant in the development of psychological problems in adolescence and adult life. He summarises that insecurely attached children are:

- Less cognitively competent.
- Less able to show social proficiency
- Less able to get along well with their peers.
- More likely to develop emotional or behavioural problems. (Dwivedi, 1999:65-67).

3.4 Psychosocial support

Psychosocial support is the process of meeting a person's emotional, social, mental and spiritual needs for positive human development (www.ovcsupport.net). Psychosocial support helps to build resilience in children, but when faced with extreme adversity and trauma, they and their families need extra support. Psychosocial support builds internal and external resources for children and their families to understand and cope with adverse events (www.ovcsupport.net).

All children need psychosocial support for their psychological and emotional wellbeing, not forgetting their physical and mental development as well. The term psychosocial relates to one's psychological development in, and interaction with, a social environment

(Erik Erikson, 1973). Thus, to understand the psychosocial support of perinatally HIV adolescents it is essential to understand the adolescence phase in relation to HIV.

3.5 Adolescence and HIV

The previous discussions clearly highlight childhood development of these adolescents' influences their psychosocial experiences considering that HIV impacts every level of their functioning. Scholars suggest that their social support systems within the family and the broader community are severely disrupted, their sense of self-worth and meaning is undermined, their health and well-being is challenged on every level, and often their schooling is disrupted, thereby limiting perceived career opportunities (Richter & Swart-Kruger, 1995; Snell, 2003). In many instances adolescents living with HIV find themselves in foreign environments, among strangers and this further exacerbates the problem (Johnson *et al.*, 2004; Le Marcis & Ebrahim-Vally, 2005). This is mainly due to the fact that they end up being committed to institutions hence losing sense of belonging and purpose.

According to the pediatric research team in California, independence and future planning can be difficult for teens that are growing up infected with HIV (The Body, 2006). The reason for lack of future planning can be attributed to the fact that treatment and the survival outlook for people in the earlier years of the epidemic was not very optimistic (The Body, 2006). This led to lack of future planning for these adolescents and empathy towards them. Hüsler *et al.* (2005) suggest that adolescents who fail to perceive the potential of the future are at greater risk of engaging in unprotected sex, alcohol and drug abuse and other life-threatening activities. He adds on stating that a lack of purpose and meaning also increases their risk of suicide (Hüsler *et al.*, 2005). This was also evident from research conducted in Uganda and Kenya that many adolescents "lived in the moment" and wanted to get "the most out of life with HIV"

which resulted in early sexual experiment as they did not “want to die without having sex” (Loos, et. al., 2010). The aforementioned are likely to occur in the lives of perinatally infected adolescents as they are not optimistic about the future because of the stigma attached to the illness. This poses a great challenge on social workers and child care workers as they have to stir these adolescents in the right direction.

In order to facilitate the process of gender identity, adolescents need to engage in interaction with peers from the opposite sex (Louw et al., 1998). Given the physiological changes related to adolescence and the innate desire to establish interaction with the opposite gender, adolescents are propelled into sexual interaction that challenges them on many levels, particularly within the context of HIV (Campbell et al., 2005). These adolescents with HIV have lived their lives with the stigma associated with HIV, issues of disclosure to their peers and potential sexual partners can be very frightening, overwhelming, and isolating (The Body, 2006). They mostly guard their HIV status as a secret while they may desire to be like their peers, having romantic relationships and experimenting with sexual behaviour. Hence they are bound to carry the burden of knowing that they risk infecting another as they feel disclosing their HIV status to a potential romantic or sexual partner may mean rejection.

An adolescent’s audacity and perception of invincibility adds to their vulnerability as they often believe that they are exempt from being infected (Foster, 2006). Adolescents who are HIV positive believe that there is no need for protection if their partner is also infected disregarding the repercussions of re-infection. This makes for a greater challenge on social workers and child care workers to educate adolescents who are infected and not infected about sexual relationships at this life phase.

Developmentally, adolescents are often reluctant to engage in direct communication concerning their thoughts and feelings (Louw et al., 1998). Black (2009) is of the

opinion that creative alternatives to traditional therapies are needed especially for perinatally infected adolescents in child and youth care centres. Traditional therapies encompasses family support, thus most of perinatally infected adolescents residing in child and youth care centres might lack that. Foster care is the popular form of family support available, however they are still strangers hence there is no healing for them as they would want to know more about their family backgrounds. Hence communication with HIV perinatally infected adolescents is still difficult due to the aforementioned shortfalls in their lives.

Adolescents with chronic illness are often challenged with adhering to their medication regimen as taking medications on a regular schedule may not fit well with their active lifestyles. The inconsistent adherence can result in the development of drug resistance and an increase in viral load (The Body, 2006). As mentioned earlier in the chapter, fitting in and feeling "normal" is just as important as it is for most adolescents. Thus they try to balance the importance of taking the medication and being with their peers. Moreover, understanding the importance of medication adherence may be difficult for youth who may question why they need medications now when they are healthy and may have never been seriously ill, and when medication side effects make them feel sick (The Body, 2006). It is thus imperative for health care and social service providers to work as a multi-disciplinary team in delivering the required education and support on dealing with HIV to our future generation.

Self-identity is often tied in with body concept, and the physical threat related to HIV can severely undermine the adolescent's self-concept (Cohen & Abromowitz, 1990; Strydom & Raath, 2005). This is difficult for an adolescent who is faced with HIV and does not the whereabouts of their family. Thus psychosocial support helps one overcome these challenges.

3.6 Psychosocial effects of HIV/AIDS.

A key task in working with HIV-infected adolescents is helping them adjust to their HIV statuses. Without proper support, adolescents have enormous difficulty accessing care, adjusting to the social environment and adhering to treatment (Samples, Goodman and Woods, 1998). According to the Orphans and Vulnerable Children support (OVC, 2006) psychosocial effects of HIV/AIDS describe the feelings and reactions experienced by children and young people when they are affected by HIV/AIDS in some way. The psychosocial effects include the following:

3.6.1 Bereavement and grief

Children may experience a wide range of feelings as part of their grief. These include anxiety, fear, anger and guilt. Initially, they may not understand or accept the permanence of their loss. These needs are overlooked during this time of loss, and children are not given full recognition or support. This problem is usually due to the belief that children are too young to understand what is happening or are better served not dwelling on their grief (Close, 2008:319). Regardless, feelings of anger may surface during their adolescence, directed against the deceased parent(s), who they think have abandoned them and left them to suffer alone (The Alliance, 2003:6). These feelings should not be overlooked when dealing with HIV infected children as it has a greater impact on their behaviour. This warrants a need to provide support services to help children deal with these unresolved feelings.

Grief may also occur in “spurts” and the child may re-grieve at subsequent developmental stages or as their cognitive perception of death and the world changes (Pillay, 2009). This can be apparent for perinatally HIV positive adolescents as they might face certain challenges which need explanation from their biological parents.

3.6.2 Loss of self-esteem and confidence

Self-esteem is a concept that includes a person's sense of self, of competence, and their acceptability to others (Hoffman, 1996:61). The adolescence phase is described by Declemente (1992) as a time for growth and experimentation marked by establishing autonomy and confronting new challenges. Youth living with HIV encounter additional challenges while passing through this stage. If the disease is untreated, the youth may have a delay in physical development, including youthful changes (The Alliance, 2003). Consequently, HIV-positive youth may appear younger and smaller than other adolescents. They may also experience physical changes as a result of their illness, including wasting and opportunistic infections that may cause noticeable physical symptoms. If youth look different from their peers they might have a harder time bonding with them, adversely affecting the adolescents' peer attachments (The Alliance, 2003). These changes may also contribute to a negative self-image hence poor self-esteem and confidence.

According to The Alliance (2003), low self-esteem can also be caused by loss of parents. For most HIV infected, the loss of a father can deprive children of social and economic security, while the loss of a mother deprives them of emotional security (International HIV/AIDS Alliance (The Alliance), 2003:5). Children without parents may lose their confidence and self-esteem as a result. HIV infected children are however, faced with a double impact as they feel ashamed that one of their parents has died of AIDS because of the social stigma attached and also the fact that they are infected themselves. This may cause children to feel that adults don't notice them or their needs may not be certain whether they are accepted and some cases, they are not sure how to respond (The Alliance, 2003:5). Thus it is important that support be available to them at school and from the centre as they also face the stigma of living in child and youth care centre to build on their confidence and self-esteem.

3.6.3 Stress

Stress is an emotional condition. It is experienced when a person has to cope with an unsettling, frustrating or harmful situation. It involves a disturbing sense of helplessness (Wiener, Mellins, Marhefka and Battles, 2008:157). Stressors can be divided into two groups that are secondary and primary stressors. Primary stressors include the sickness or death of a parent which are made worse by the loss of a home (The Alliance, 2003). Second stressors include poverty, dropping out of school, stigma and discrimination as well as separation from brothers and sisters. Children who are stressed often feel anxious and lack confidence and may suffer from depression. This can have long term harmful effects on a child's health and development.

3.6.4 Disclosure

With increased survival, one of the greatest psychosocial challenges that parents and caregivers of perinatally HIV-infected children face is disclosure of HIV serostatus to their infected children or child (Wiener, Mellins, Marhefka and Battles, 2008:155). HIV diagnosis disclosure entails communication about a potentially life threatening, stigmatized and transmissible illness and many caregivers fear that such communication may create distress for the child (Wiener, Mellins, Marhefka and Battles, 2008:155). Disclosure is one of the main challenges of HIV infected people. As for adolescents it conveys fear of discrimination and rejection from fellow peers. Hence teens should be fully informed of their health status so that they can make informed decisions regarding their actions and life choices (Close 327:2008). The youth will often need repetitive education around daily living with the virus and how it will mold decisions that they make in their social lives. These decisions involve managing their own health, disclosing to friends and significant others, and sexual choices. Clinical reports have indicated positive outcomes associated with disclosure including the promotion of trust, improved adherence, enhanced access to support services, open family communication, and better long-term health and emotional well-being in children

(Wiener, Mellins, Marhefka and Battles, 2008:155). Santamaria et al. (2011:262), states that one of the theorized benefits of disclosure to youth is that once they know their status, they may make informed decisions about sexual behaviour and serostatus disclosure to sexual partners. In their study they also found that the longer a child had known their status the higher were their intentions to disclose to potential sex partners after adjusting for age, suggesting that a longer duration between disclosure and sexual partnership may strengthen comfort and confidence in discussing HIV with partners (Santamaria et al, 2011:262). Other studies have also associated disclosure with reduced rates of anxiety, depression and other internalizing behaviour and conversely elevated internalizing behaviour problems (New, Lee & Elliot, 2007). Youth 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) which can be equated to internalized behavioural problems mentioned by New et al. (2007).

The general view on disclosure is that youth who have known their HIV status for a longer (versus shorter) period of time may be more comfortable with their identity as people living with HIV and may be more comfortable talking with others about HIV (Santamaria, Dolezal, Marhefka, Hoffman, Ahmed, Elkington, Mellins, 2011:258). Thus to avoid complications for perinatally HIV infected adolescents it is essential they become aware of their status at an early age as it enables them to adjust hence the advocating for early disclosure for them. It is the duty of the caregiver to let them understand and the community at large, to create a safe environment for them.

3.6.5 Stigma and discrimination

A major distinction between HIV/AIDS and other chronic or terminal illnesses is the stigma associated with the disease. HIV/AIDS in Africa has often been considered a form of punishment for wrongdoing and associated with “promiscuity” and witchcraft (The Alliance, 2003:5). Hence stigma can adversely affect children and their caregivers

in ways that have long-term negative psychological and social effects (Close, 2008: 321).

The stigma that a person carries can alter how he or she perceives and interacts with the world, even affecting how a person thinks and feels about him- or herself as an individual (Close, 2008: 322). Thus for HIV infected children, it is a harsh environment as they have to learn about the stigma associated with the illness and also trying to fit into the social system at high school phase.

Every person living with HIV and AIDS belongs to a community. 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 & Pienaar, 2004). People who are diagnosed as HIV positive are often subjected to stigmatization by society, which in turn rebounds on their family members (Campbell et al, 2005; Skinner & Mfecane, 2005). In addition to external stigma attached to HIV, Cameron (2006) argues that those infected also suffer from internalized stigmatization which leads to feelings of being dirty, reprehensible and unlovable. Children who are HIV positive are subjected to the same negative responses, which can severely undermine their concept of self (Campbell et al, 2005). As they learn about stigma and rejection associated with HIV and they adjusting to the knowledge that they are living with HIV, they may become less open about their status.

HIV is associated with sexual promiscuity, and as such generates a great deal of moral judgment and blame (Campbell et al., 2005). Infected individuals are often perceived of as being responsible for their plight and therefore not deserving of sympathy. This perception is generalized to children as well (Campbell et al., 2005). Adolescents who have contracted the disease as a result of unprotected sex are often perceived of as

being evil and are at risk of being rejected by their communities , including their parents and family (Campbell et al., 2005). Judgment is not based on objective information around the nature of the virus as fear generated by the knowledge that HIV is not curable exacerbates the situation (Cameron, 2006; Campbell *et al.*, 2005). People living with HIV and/or AIDS of all ages are generally subjected to humiliation and rejection due to these perceptions (Campbell et al., 2005; Van Dyk, 2001).

Research indicates that women are more likely to be tested and to reveal their status, and as a result women are often perceived of as being the cause of HIV and AIDS (Campbell, et al, 2005; Van Dyk, 2001). The belief that women are responsible has led to many women and their children being driven out of communities (Letlaka-Rennert Luswazi, Skinner & Mfecane, 2004) hence the neglect and abandonment of most children.

3.6.6 Sexuality

Sexuality is an important topic for adolescents, who are at the age when sexual exploration begins. Their drive to explore their sexuality makes adolescents a pivotal population in the HIV/AIDS pandemic (Close, 330). In South Africa most of the children are introduced to sex around the age of 12 years (Dyk, 2008:166) and in Uganda by age 18 years, 64% of women and 50% of men already reported being sexually experienced (Close, 2008:329). Many youth are poorly educated about sex and safe sex methods. This lack of education on practicing safe sex methods, and the subsequent likelihood that they will not use protection, leaves teens at high risk of contracting and transmitting sexually transmitted infections. HIV infected youth are at a greater disadvantage as they already faced with conflicting decisions weather to disclose their status and whether to engage in sexual behaviour.

There is thus a need for support services at child and youth care centers and communities at large to help HIV infected children deal with these psychosocial challenges they face. This is the reason why this research was aimed at finding out the specific needs of these children so as to provide appropriate support services.

3.7 Psychosocial needs of adolescents

All adolescents exhibit common psychosocial needs, however, their social background and environment influences how they construct them. Perinatally HIV infected adolescents have additional psychosocial needs as a result of HIV. ICAP (2010) summarised these psychosocial needs as illustrated in the table below:

Table 2: Psychosocial needs for negative and perinatally positive adolescents

Psychosocial needs	Negative adolescents	Perinatally HIV positive adolescents
Significant physical, emotional and mental changes	Yes	Yes
Risk taking behaviour	Yes	Yes
Sexual desires	Yes	Yes
Insecurity/ confusion	Yes	Yes
Anxiety	Yes	Yes
Reactive emotions	Yes	Yes
Criticism of caregivers	Yes	Yes
Focus on body image	Yes	Yes
Sense of immortality	Yes	Yes
Support in understanding their own HIV status	No	Yes
Support with grieving loss of	No	Yes

parents		
Support with disclosure process	No	Yes
Strategies to deal with stigma	No	Yes
Medication adherence	No	Yes
Developing self-esteem and confidence	No	Yes
Sense of belonging, fitting in with peers	No	Yes
Sexual and reproduction concerns	No	Yes

From the above table one can note that all adolescents have similar needs, however for perinatally HIV positive adolescents in CYCCs have extra needs. They need support to deal with bereavement with parents, understanding HIV, support with disclosure, strategies to deal with stigma and developing self-esteem and confidence. Hence the psychosocial experiences of perinatally HIV positive adolescents in CYCCs are of paramount importance.

3.8 Conclusion

Rogers' (1987) person-centered view states that, "every individual exists in a continually changing world of experience of which he is the centre" (Du Toit, Grobler & Schenck: 2001). In turn, for social workers to understand psychosocial experiences of perinatally HIV positive adolescents residing in CYCC, the children's own realities should be explored, not the general psychosocial effects of HIV. In the following chapter, the social constructionism theory will be discussed in relation to HIV & AIDS and how adolescents construct the world around them.

CHAPTER FOUR

SOCIAL CONSTRUCTIONS OF HIV/AIDS

4.1 Introduction.

As global solidarity in response to AIDS remains a necessity, there are still geographic variations in responses to AIDS across and within countries and regions. Different economic, political, and cultural contexts account for these variations (Zhang, 2011:1). An international survey conducted by UNAIDS with a polling company Zogby International, proved that awareness about HIV prevention, availability of funding, stigma and discrimination are the top three obstacles that keep the world from effectively responding to AIDS (UNAIDS, 2010). These obstacles are highly associated with local cultures and social norms that are profoundly related to changing dialogues on HIV/AIDS. The social constructionist thus suggests that every phenomenon, including the 'natural' world, as well as the social world, is given meaning through human conversation and cultural process (Gergen, 1999).

In medical sociology, diseases are regarded as socially constructed entities not simply biological phenomena (Crystal, 1989:4). In agreement with medical sociology, Keniston (1989) maintains that, "The spread of HIV infection and, consequently, AIDS is the product of human behaviors enacted in social contexts". This perception is absolutely true of AIDS as such constructs shape societal response to the epidemic and therefore experiences of people with AIDS are derived from these constructs (Crystal, 1989:4). Therefore, behaviors and circumstances in which they occur are conditioned and shaped by culture and larger social structures (Keniston, 1989:2). In this sense, both the disease and the meanings of illness are socially constructed and interpreted making it difficult to deal with the epidemic as there are various perceptions on HIV&AIDS.

As mentioned above society generates people's perceptions of diseases. To understand the psychosocial experiences of perinatally infected adolescents, social constructions of HIV/AIDS should be explored seeing as individuals create their own reality, which in turn creates the individuals through socialization; and social influence through which individuals internalize social norms and knowledge (Alvesson & Sköldbberg, 2009). Social constructionism will therefore be the framework for this study. The following discussion will focus on social constructionism perspective, social constructions of HIV&AIDS: the cultural meaning of HIV/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 perinatally infected children.

4.2 Social constructionism Perspective

Social constructionism may be defined as a perspective which believes that a great deal of human life exists as it does as a consequence of social and interpersonal influences (Gergen 1985). According to Berger and Luckman (1966:1), social constructionism is a conceptual framework that emphasizes how the meanings of a phenomenon do not necessarily define the phenomenon itself but develop through interaction in social context. It examines how individuals and groups contribute to producing perceived social reality and knowledge (Berger and Luckman, 1966:1). Burr (1995:4) is of the view that our knowledge of the world and common ways of understanding it are not derived from the nature of the world as it is, but people construct it between them from one's own reality. He continues to postulate that what "we regard as truth is our current accepted way of understanding the world, 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, 1995:4). Therefore, it is through daily interactions

between people in the course of social life that our versions of knowledge on HIV & AIDS become fabricated.

According to Patton (2002:96), “constructionists study the multiple realities constructed by people and the implications of those constructions for their lives and interaction with others”. Social constructionism focuses on the firm belief that there is neither objective reality nor objective truth reality, but reality is constructed from one’s experiences and interpretation (Sarantakos, 2005:37). He continues to hypothesize that meanings are not fixed but emerge out of people’s interaction with the world. Social constructionists are interested in the discourses that have taken on a normative standard and in how people have come to align or judge themselves accordingly (Doan, 1997). Thus HIV should be understood from an individual perspective not a generalistic view regarding the illness experiences with special reference to perinatally infected adolescents as there are social background differences, geographical and economic differences.

Sarantakos also maintains that meanings attached to one’s reality do not exist before a mind engages in them. Creswell (2009) also agrees that meanings are constructed by human beings as they engage with the world they are interpreting. This also correlates with Rogers’ (1987) person-centered view that, “every individual exists in a continually changing world of experience of which he is the centre” (Du Toit, Grobler & Schenck: 2001). Speed (1991) is also of the view that even though reality is filtered through our perceptions, it does not mean that it does not exist and does not affect those perceptions. Hence it involves questioning and re-evaluating opinions in the light of new data and entails an evolving set of meanings that emerge from the interactions between people. (Doan, 1997).

4.2.1 Social constructionism belief system

4.2.1.1 Anti-essentialism

Essentialism is the view that, for any specific entity (such as a group of people), there is a set of incidental attributes, all of which are necessary to its identity and function. Anti-essentialism is the view that for any given kind of entity, there are no specific traits which entities of that kind must possess (Cartwright, 1966). Thus social constructionists are anti-essentialist. They believe that, since the social world (including ourselves as people) is the product of social processes, it follows that there cannot be any given determined nature to the world or people as there are no essences inside people that make them what they are (Burr, 1995:5). To elaborate on the belief, Alvesson & Sköldbberg (2009) speak of primary socialization and secondary socialization. They mention that in primary socialization the child learns the basics of what is important in society from their “significant others”. The identity is built up through role-taking - we see one another with the eyes of significant others, reflect over this and successively generalize the experiences (Alvesson & Sköldbberg, 2009). Thus one’s identity/view of the world depends on his/her immediate family or people he/she socialize with. Therefore, despite the common entity of being perinatally HIV infected adolescents and being orphans, they all have different backgrounds hence different psychosocial needs.

With secondary socialization, the process is adjusted for the mature. Secondary socialization, for instance the school system, involves less of important people and is more formalized and abstract, the people included in this are often interchangeable (Alvesson & Sköldbberg, 2009). Thus, subjective reality can be changed in schools and also through conversations.

4.2.1.2 Anti-realism

Social constructionism denies that our knowledge is a direct perception of reality, we construct our own versions of reality between us. There is no such thing as objective fact, but all knowledge is derived from looking at the world from some perspective or another and is in the service of some interest rather than others. Roles are very important to the development of the individual self since they are internalized and together will form a whole self as a subject. The roles further illustrate and mediate the basic dialects between the institutional and the individual levels of society. By playing roles, the individual participates in a social world. By internalizing these roles the same world becomes subjectively real for him (Sic, 1966:91).

4.2.1.3 Language as a pre-condition for thought.

Social constructionists maintain that our ways of understanding the world come not from objective reality but from other people, both past and present and we are born into a world where the conceptual frameworks and categories used by the people in our culture already exist (Burr,1995:5). These concepts and categories are acquired by all people as they develop the use of language and thus are reproduced every day by everyone who shares a culture and language. In turn, the way we think, the categories and concepts that provide a framework of meaning for them are provided by the language that they use.

4.2.1.4 Language as a form of social action.

Burr (1995:5) also states that by placing centre-stage the everyday interactions between people and seeing these as actively creating the forms of knowledge we take for granted and their associated social phenomena, it follows that language too has to be more than simply a way of expressing ourselves (Burr, 1995:5). It is further argued that,

we assimilate and influence our world as it is expressed in cultural norms and values - hence we create our own reality (Becvar & Becvar, 1996). Thus human life-world is fundamentally constituted in language and language itself should be the object of study (Anderson & Goolishian, 1988). Therefore, as people talk to each other, the world is constructed.

4.2.1.5 A focus on interaction and social practices

Traditional psychology looks at explanations of social phenomena inside the person such as attitudes and motivations. These entities are held to be responsible for what individual people do and say. However, social constructions reject and regard, as the primary focus of our enquiry, the social practices people engage in, as well as their interaction with each other (Burr, 1995:5). The explanations are therefore to be found neither in the individual psyche nor in social structure, but in the interactive process that take place routinely between people.

Resultantly, it is of great importance that the psychosocial experiences of perinatally infected adolescents be the focus, not the general psychosocial effects of HIV as their needs depend on the current circumstances of the world. Consequently, their lived experiences shape who they are and how they perceive the world around them. We should keep in mind that those children also change as they reach the adolescent phase hence it is important that their life experiences are explored, not their childhood needs.

4.3 Social constructionism and HIV/AIDS

4.3.1 Culture as a social construction of HIV and AIDS.

According to Conrad and Becker (2010:69), certain illnesses have particular cultural meanings attributed to them, which may have independent consequences on patients and health care. Illness and HIV/AIDS specifically, may be interpreted and experienced in variable ways depending on the cultural codes available for reasoning about them (Marsella & White, 1982). Despite illness being experienced and interpreted in various ways, it is however experienced privately and the ideology encapsulating the meaning is influenced by participation in that specific culture (Bruner, 1990). Thus, culture provides perinatally infected adolescents with tools which may hypothesize their existential crisis.

Webb (1997) notes that community perceptions and individual perceptions of HIV/AIDS integrate culturally specific beliefs relating to its origins and etiology, risk perception and attitudes towards those infected. The nature of one's response to "HIV/AIDS is in part habituated by the macro determinants of the HIV epidemiology, the behavioral context of sexual activity and the heterogeneity within the social make-up of communities, expressed through the responses of individuals" (Webb, 1997:158). 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.

4.3.2 Social constructions of HIV/AIDS by society

HIV/AIDS is socially constructed as a plague or punishment against society advanced by moralists, who equate HIV with taboo social and sexual behavior (Polgar, 1996;

Goldstein et al., 2003). HIV/AIDS came to be viewed as an illness affecting those who willfully violated the moral code - "a punishment for sexual irresponsibility" (Gilman, 1988:91). This theme has impacted on the consciousness of common perceptions of HIV seen as "divine retribution" for the sin of sexuality (Sontag, 1991). Dansky (1994) is in agreement with Sontag (1991) in the regard that people with HIV are seen as victims and are located on a continuum of "innocence" or guilt and therefore suggest that HIV summons up an older metaphor analogous with syphilis, that of pollution. As a consequence, 'plague' has become the principal metaphor by means of which HIV has been understood (Goldstein et al., 2003). Due to this metaphor, stigma manifested towards HIV infected people resulting in negative socialization with them in the community. The fact that HIV, in most communities (especially South African ones), is regarded as a disease of promiscuity (Ashford, 2011), encourages or constructs stigmatization towards people with HIV.

In 1989, Susan Sontag published her book *AIDS and Its Metaphors*, in an attempt to deconstruct the various metaphors that demonize AIDS in the society. Expanding on her earlier work of *Illness as a Metaphor*, she found that the metaphors contribute not only to stigmatizing the disease, but also to stigmatizing the individuals who are ill (Sontag, 1991). This notion does not consider the faithful wife, the widow, the little baby and the children who are innocent in this "plague". Thus perinatally infected adolescents are viewed as products of promiscuity, hence they are neglected in most communities as a result of this myth.

Gilman (1988:88) suggests that icons of this disease appear to have an existence independent of the reality of any given disease. The creation of the image of AIDS must be understood as part of this ongoing attempt to isolate and control disease. In explaining this boundary Gilman (1988) explains that early conceptions of HIV & AIDS came to view it as a "gay" disease. This in turn structured the understanding of AIDS in a very marked manner. Consequently, PWAs (Persons with AIDS) were stigmatised as

carriers of an infectious disease and also located within a very specific category of sexual orientation (Douard, 1990). As a result, Gilman (1988) explains that HIV/AIDS was understood as a subset of sexually transmitted diseases (STDs), as well as a disease which afflicted gay individuals as a result of their sexual practices and lifestyle. Watney (1987:9) noted that HIV&AIDS is "not only a medical crisis on an unparalleled scale, it involves a crisis of representation itself, a crisis over the entire framing of the knowledge about the human body and its capacities for sexual pleasure". Thus, Crewe (1992) suggests that HIV&AIDS confronts society with its prejudices, stereotypes and discrimination.

From the above discourse, one can note that there is a need for greater awareness about the disease especially in South African townships. The fact that there still is increasingly high neglect and stigma towards HIV infected people proves that, 'we have learned very little that is new about the disease, but much that is old about us.'

4.3.3 Medical construction of HIV

Another aspect of the social construction of HIV&AIDS which affects infected people's experiences involves medical arbitrary disease definitions (Crystal & Jackson, 1989:4). According to Keniston (1989:2), the very "disease" of AIDS itself is socially constructed. It is caused by the "Human Immunodeficiency Virus", a virus that leads to a state of immune deficiency in humans (Shah, 2005:3). Much of the symptomatology of AIDS is caused by opportunistic infections to which the body is made vulnerable by the suppression of the immune system (Keniston, 1989:3). It is a retrovirus, with a viral DNA integrated into human chromosomes, so it cannot be removed (Galtung, 1986:4). From this medical understanding of HIV&AIDS, various aspects of the understanding of this disease are constructed. The meanings we attribute to AIDS are crucial in shaping our responses to this condition; and hence by incorrectly defining the disease we risk incompetence. By defining HIV/AIDS through certain perspectives, we orient our critical

attentions and channel available resources to selected phenomena, groups of people, organizations, institutions, and publications (Zhang, 2011:8).

Jackson and Crystal (1992) point out that the terminology commonly used to describe the experience of HIV&AIDS often makes use of the metaphorical figure of speech (synecdoche) AIDS even when HIV is what is really meant. This socio-linguistic construction emphasizes the acute disease model of the HIV&AIDS illness, focusing on the terminal, incapacitating and stigmatizing consequences of the condition (Jackson & Crystal, 1992). Thus from the description of the disease, the language used to talk about HIV&AIDS focuses on people dying from AIDS rather than on people living with HIV (Crystal & Jackson, 1992). On the other hand, due to increased awareness of HIV&AIDS in communities, these perceptions of the disease are changing as people now realize that HIV does not mean death as a result of the increased availability of Anti-Retroviral Therapy treatment. Despite change in perceptions about the disease, infected individuals still experience feelings of uncertainty, helplessness, hopelessness and experience stigmatization from the society.

Most of perinatally infected adolescents residing in child and youth care centres, originate from disadvantaged communities in which HIV&AIDS is stigmatized. It is regarded as a disease contracted due to prostitution thus there is no positive attitude towards people assumed to be infected. This has a greater impact on the relationship of adolescents and their families as they are petrified by the reaction from fellow community members, if they are reunified with their children. Adolescents are forced to view being HIV positive as a 'curse or punishment' as some become alienated by their families. Their social constructs of HIV, combined with being in the adolescent phase, brings out different feelings and behaviors which pose additional psycho-social challenges for their development. Thus, lived experiences of perinatally infected adolescents shape who they are and how they perceive the world around them. The psychosocial needs of perinatally infected children also change as they reach the

adolescent phase making it paramount that their life experiences are delved into, not their childhood needs.

4.4 Psychosocial constructs of the adolescence phase.

The above discussion explained general constructions of HIV&AIDS. In order to understand psychosocial experiences of perinatally infected adolescents, it is essential to investigate the psychosocial constructs of the adolescence phase. According to Hill (1983), it is important to study these psychosocial variables as the central idea to the study of normal development in adolescence. These variables include detachment; autonomy; sexuality; intimacy; achievement motivation and behavior; and identity crisis and its resolution (Adams, Montemayor &Gullotta, 1996:2).

4.4.1 Detachment

The Detachment variable relates to aspects of object relations that involve emotional independence from parents whom Alveesson and Skoldberg (2009) refer as the “significant other”. It involves the reorganization of sexual object ties such that attachments to parents come to be replaced by attachments to peers (Adams et al, 1996:3), which forms part of secondary socialization. As mentioned earlier, in primary socialization, the child learns the basics of what is important in society from their “significant others” and secondary socialization involves less important people. Consequentially, detachment is in line with the tenant of anti-essentialism of the social constructionist. However, this psychosocial construct is different for perinatally HIV positive adolescents residing in child and youth care centres as they have already been detached from their parents at an early age. This can be a frustrating phase for them as

they try to deal with stigma attached to HIV and endeavor to form relationships with peers without being discriminated.

4.4.2 Autonomy

Autonomy refers to independence in decision-making and to feelings of confidence in personal goals and standards of behavior. From the perspective of developmental issues, the intrapsychic model views increased autonomy as being based on an increasing sense of detachment (Adams et al., 1996:4). In contrast to the latter, the interpersonal model proposes that situational demands for autonomous behavior acted out in the form of individual decision making and supported by other (family or peers), would either instigate or maintain the process of detachment (Adams et al., 1996:4).

Huebner (2009) points out that people assume that autonomy refers to becoming completely independent from others and they equate it with teen "rebellion." She suggests that establishing autonomy during the teen years really means becoming an independent and self-governing person within relationships (Huebner, 2009:3). Autonomous adolescents have gained the ability to make and follow through with their own decisions, live by their own set of principles of right and wrong and have become less emotionally dependent on parents. Autonomy is a necessary achievement if the adolescent is to become self-sufficient in society.

As for adolescents residing in child and youth care centres, their level of autonomy protrudes more on a survival level than independence in decision making. The fact that they do not have a stable or permanent support system elevates chances of low self-confidence in their personal goals.

4.4.3 Sexuality

In the traditional psychoanalytic view, childhood sexuality is recognized, and the process of development in sexuality is seen as a gradual and continuous with new phases occurring due to puberty and the formation of a new sexual motive away from parents to peers (Adams et al., 1996:5). For adolescents in child and youth care centres, the experience is different as their sexual motives are already focused on their peers at an early age, conditioned by the early absence of their parents.

The teen years mark the first time that young people are both physically mature enough to reproduce and cognitively advanced to think about it - it is prime time for the development of sexuality (Huebner, 2009:4). Teens who are educated about and exposed to sexuality will largely determine whether or not they develop a healthy sexual identity. Many experts agree that the mixed messages teens receive about sexuality contribute to problems such as teen pregnancy and sexually transmitted diseases (Huebner, 2009:4).

4.4.4 Intimacy

Hill refers to Sullivan's (1953) notion that adolescents develop intimate relationships with opposite-sex peers. This process begins with a need for interpersonal intimacy with a close friend and with genital maturity it expands to opposite-sex relationships that satisfy the lust dynamism. Huebner (2009) also suggests that intimacy is usually first learned within the context of same-sex friendships, then utilized in romantic relationships. In addition, it refers to close relationships in which people are open, honest, caring and trusting. Friendships provide the first setting in which young people can practice their social skills with those who are their equals. It is with friends that teens learn how to begin, maintain, and terminate relationships; practice social skills; and become intimate (Huebner, 2009:5). As for perinatally infected adolescents residing in child and youth care centres, it may be complicated for them as they lack sense of

trust resultant from the trauma experienced when they were abandoned or admitted to the centre.

4.4.5 Achievement motivation and behavior

Hill (1983) defines the achievement situation as one that requires the individual to make a personal evaluation in the form of adequacy. He emphasizes that distinctions between abilities and skills, motivation of performance, disposition to respond to achievement situations, and situational factors that determine the intensity of effort should be specified. He argues that we should make distinctions between achievement motivation and achievement behavior that may be affected by other motives (Adam et al., 1996:6). Huebner (2009:5) argues that our society fosters and values attitudes of competition and success. For the reason of cognitive advances, the teen years are a time when young people can begin to see the relationship between their current abilities and plans and their future vocational aspirations. They need to figure out what their achievement preferences and areas in which they are willing to strive for success. The way people reacted to perinatals especially in child and youth care centres, was filled with sympathy as no one anticipated them to survive into adolescence. This has negatively impacted them as they lack motivation and society's views on HIV & AIDS (death) make it difficult for these young ones to have positive attitude and a future orientated mind.

4.4.6 Identity crisis and its resolution

This resolution functions as an interfacing force regarding issues of the concept of self, body image changes, sexuality, and intimacy among other psychosocial features (Huebner, 2009:7). This has been called one of the most important tasks of adolescents. The question of "who am I?" is not one that teens think about at a conscious level. Instead, over the course of the adolescent years, teens begin to integrate the opinions of influential others (e.g. parents, other caring adults, friends, etc.) into their own likes and dislikes (Huebner, 2009:7). The eventual outcome is that they

develop a clear sense of their values and beliefs, occupational goals, and relationship expectations. This can be frustrating for perinatally infected adolescents as their views of their parents are corrupted with the societal construct of 'promiscuity' in relation to HIV&AIDS. They also deal with an involuntary chronic illness which has led to neglect and abandonment from families leading to their institutionalization. This results in their lack of a sense of belonging and may develop in them insecure identities which make it difficult for them to fit in the world.

4.4.7 Effects of psychosocial constructs.

The psychosocial constructs causes the adolescent to:

- To spend more time with their friends than their families
- To ask more questions about sexuality.
- Invest in personal journals.
- When they are in their rooms, adolescents may begin to lock their bedroom doors.
- Become involved in multiple hobbies or clubs.
- May become elusive about where they are going or with whom.
- May become more argumentative
- May not want to be seen with parents in public.
- May begin to interact with parents as people. (Heubner, 2009:5).

The aforementioned psychosocial construct effects are in relation to adolescents without any chronic illness, residing in a normal family setting. Most research has also focused on psychosocial experiences of perinatally infected adolescents in a normal

family setting, hence those in Child and youth care centres are marginalized. As for adolescents perinatally infected with HIV and residing in child and youth care, the effects might turn out to be more complicated as they have to deal with society's constructs of HIV, living in an institution and adapting to the adolescence phase. There is a consequential need to focus on this marginalized group psychosocial constructs.

4.5 Conclusion

Perinatally infected adolescents can be viewed as 'victims' of the pandemic. They are at the receiving end of effects presented by social constructions of HIV&AIDS. These children are confronted with stigma and neglect from society and families specifically those residing in Child and youth care centres. As they reach the adolescence, society's perceptions and views become increasingly apparent in their lives making it important to explore their psychosocial constructs. In terms of this dissertation, perinatally HIV positive adolescents cannot be viewed in isolation. How they construct meanings and their understanding of HIV is influenced by the society. Culture and history inform their perspectives as they interact with other individuals in processing meaning of their experiences.

The following chapter discourses the research methodology, outlining the research design, how the sample was selected and how the research was conducted in the study conducted.

CHAPTER FIVE

RESEARCH METHODOLOGY

5.1 Introduction

The overall purpose of this study was to explore the psychosocial needs of perinatally HIV infected adolescents (14- 17) who reside in child and youth care centres in Pretoria. Babbie and Mouton (2001:74) define a research design as a "plan or blueprint" of how the researcher intends to conduct the research. It is a detailed plan for the study and identifies how the sample was selected, the data collection methods used and how the data was analysed. Creswell (1998:2) defines a research design as "the entire process of research from conceptualizing a problem, to writing the narrative". The present study was conducted within the qualitative paradigm.

The nature and purpose of a study determines a researcher's method of data collection and data analysis (Henning, Smit & Van Rensburg, 2004:3). If the purpose of the research is to study phenomena as they unfold in real-life situations, as interrelated wholes rather than split up into discreet predetermined variables without manipulations, then a qualitative approach is required (Terre Blanche & Durrheim, 1999). In accordance to this, unfolding the psychosocial experiences of perinatally HIV positive adolescents required a qualitative inquiry. This chapter outlines the research process within the qualitative inquiry.

5.2 Qualitative research

Qualitative research studies aim for a depth of understanding rather than a quantity of understanding (Henning, 2004:3). In qualitative research, the researcher keeps focus on

learning the meaning that participants hold about the problem issue, not the meaning the researcher brings to the research or writers express in the literature (Creswell, 2009:175). This means the researcher had to investigate how perinatally HIV infected adolescents constructed or viewed their psychosocial experiences. 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). This consistent with the social constructionist belief that “our knowledge is a direct perception of reality; we construct our own versions of reality between us” (Burr 1995: 5).

The relationship between qualitative researchers’ observations of everyday life and their analyses of it are relevant because this involves a variety of interpretive concerns and processes (Dingwall & Miller, 1997). Qualitative research accommodates non-linear causality where elements feedback to influence their own subsequent behaviour (Stiles, 1993). In that respect, qualitative research may be defined as a positioned activity that locates the observer in the world, which consists of a set of interpretive material practices that make the world visible. Researchers thus study things or events in their environmental settings with the attempt to make sense of or interpret phenomena in terms of the means people bring to them (Denzin & Lincoln, 2003).

Durrheim (1999) maintains that qualitative research is a naturalistic, holistic and inductive process. Therefore, it is crucial to choose an appropriate method to conduct a study, where the objective is to bring about in-depth experiences and bring forth richly textured material of human experience in a specific context.

Based on the above discussion, a qualitative research design was an appropriate method of inquiry for this study as it gave the researcher the opportunity to explore how perinatally HIV infected adolescents have constructed their psychosocial experiences.

The intention was not to produce an 'objective' description of their experiences but to construct an analytical interpretation of perinatally HIV adolescents' psychosocial constructs as they experienced them. The researcher did not only explore how child care workers, who are the primary caregivers to adolescents, perceive the psychosocial needs of perinatally HIV infected adolescents, but provided insight into the support services available to meet these needs.

5.2.1 Interpretive descriptive paradigm

The interpretive descriptive design was used to guide the 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). To ensure rich descriptions of the phenomena, the researcher used purposive sampling as method of selecting participants - this will be clearly outlined in a later part of this chapter.

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. According to Denzin and Lincoln (2003), there is a need for the researcher to understand and make sense of what has been researched. The social constructionist theorist's interpretation of the social world as a kind of a language that is a system of meanings and practices, constructs reality as of relevance (Terre Blanch & Durrheim, 1999). Thus it is of importance to use an inductive approach to understanding their constructions and making my interpretations of their views explicit.

Researchers working in this paradigm assume that people's subjective experiences are real and should be taken seriously; and that researchers can understand others' experiences by interacting with them and listening to what they tell us - that is, their responses and stories in relation to the questions asked, and qualitative techniques such as interviews are best suited for the task (Terre Blanche and Kelly, 1999: 123). In

order to gain the integrity of what is being investigated, the researcher must make every effort to get inside the participants heads and to understand them from within. The interpretive researcher tries to begin with the individual and then tries to understand their interpretations of the world around them (Denzin and Lincoln, 2003). Social constructionists also maintain that “neither objective reality or objective truth is reality, but reality is constructed from one’s experiences and interpretation” (Sarantakos, 2005: 37). In-depth interviews were used to understand the subjective psychosocial experiences of perinatally HIV positive adolescents in this study.

Further, interpretive research relies on first-hand accounts, tries to describe what it sees in rich detail and presents its findings in engaging language (Terre Blanche and Kelly, 1999). As mentioned in the previous chapter, language is regarded as a form of social action by social constructionists. They maintain that language is not simply a way of expressing ourselves, but as we talk to each other, our world is constructed (Burr, 1995:5). Rather than “translating the stuff of everyday experiences into a mathematical formula, as we would do if we were following a positivist approach, the interpretive approach tries to harness and extend the power of ordinary language and expression, to help us get a better understanding of the social world in which we live” (Terre Blanche and Kelly, 1999: 123). In turn, content analysis was used to bring out the psychosocial experiences of adolescents and verbatim was used to bring out their subjective views.

This design gave me the opportunity to understand psychosocial experiences from both the adolescents and child care workers’ perspectives in two child and youth care centres in Pretoria.

5.3. Methodology

In order to accomplish the study, a number of techniques will be used. These include sampling, data collection and analysis using content analysis.

5.3.1 Selection of Participants

Purposive sampling focuses on selecting information-rich cases whose study will illuminate the questions in contention (Patton, 2002:230). Creswell (2007:125) also suggests that a researcher selects individuals and sites for study because they can purposefully inform an understanding of the research problem and central phenomenon in the study. This lead to three purposive sampling methods being used to select participants and child care workers, namely - criterion sampling, availability sampling and key informant sampling. Criterion sampling involves picking cases that meet some condition for quality assurance; justifying this sampling method for use to select perinatally HIV positive adolescents (Patton, 2002:243).

Sample 1 Selection of Child and Youth Care Centres

Firstly, to select child and youth care centres availability sampling was used as there were limited numbers of child and youth care centres which have “known status” of perinatally HIV infected adolescents. However, this type of sampling is classified as non-probability sampling because it does not ensure the representation and thus findings cannot be generalized (Babbie and Mouton 2001). The researcher contacted CYCCs around Pretoria, enquiring if they had perinatally HIV adolescents and agency records were used to select the correct participants for the study. Two Child and Youth Care centres emerged to have the correct sample for the study, one of which the researcher was then employed. The correct procedure was followed to get permission

to conduct research at each CYCC. This procedure will be explained later in the chapter.

Sample 2: Adolescents

Secondly, criterion sampling was used to select perinatally HIV infected adolescents from the two available child and youth care centres with the intention to understand how they construct their psychosocial experiences. However, because the two Child and Youth Care centres had the appropriate sample for this study, six adolescents were selected from one CYCC and two from the other CYCC. Thus a total of 8 perinatally HIV infected adolescents were selected. Although the sample turned out to be less than anticipated, the researcher was able to obtain information that was central to the research questions. According to Patton cited in Marlow (1998:147), the sample size depends on the amount of information generated; the size of the sample is no larger than that needed to gather the information of interest. The following criterion was used:

This sample comprised of:

- Adolescents who were perinatally infected with HIV.
- Adolescents who have been admitted in the child and youth care centre for more than two years.
- Adolescents who were attending secondary school.
- Adolescents who are within 14-17 years age range.
- Adolescents who are on Anti-Retroviral Therapy.

Table 3. Profile of adolescents

Adolescent	Age	Gender	Years at the CYC.	Name of CYCC
Chris	15	Male	11	M
John	16	Male	6	S
Lacastor	15	Male	11	M
Baby L	16	Female	11	M
Mary	14	Female	8	S
Lorraine	15	Female	11	M
Unkown	14	Female	7	M
Tariro	15	Female	7	M

Sample 3: Child and Youth Care Workers and Social workers.

The third method of sampling comprised of key informants. This sample comprised of Child and youth care workers who are primary caregivers to adolescents and social workers as they have a better understanding of their psychosocial needs and the support services available. Five child and youth care workers and one social worker were chosen from each of the two child and youth care centres in Pretoria. The initial plan was to choose one child and youth care worker from three anticipated CYCCs and one social worker but due to limited numbers of CYCCs this was not possible.

The criteria used to select child and youth care workers were:

- The number of years of experience working at the selected child and youth care centre.
- Their personal experience working with perinatally infected adolescents and their willingness to participate in the study.

The table below illustrates the child youth care workers' length of service at the centre and their type of work. Child Youth Care workers at S are live-in-mothers and get off-days; whereas at M they partake in shift work at the following times: 7:00AM -1:00PM, 1:00PM – 7:00PM then 7:00PM – 7:00AM – making for multiple caregivers. Only one Child care worker at M is a live-in-mother at a satellite house.

Table 4: Profile of the child and youth care workers

Child and Youth Care Worker	Years at the CYC.	Working hours	CYCC Name
Female	5	Live in	S
Female	6	Live in	S
Female	7	Shift work	M
Female	10	Shift work	M
Female	11	Shift work	M
Female	7	Shift work	M
Female	8	Live in	S
Female	6	Live in	S
Female	9	Live in	S
Female	6	Live in	M

Table 5: Profile of social workers

Social workers	Years at the CYCC	Working hours	CYCC
Female	4	8-4	S
Male	2	8-4	M

5.4.2 Method of Inquiry

As noted earlier, research design provides a guideline for the choice of data collection. Data collection design provides a guideline for the choice of data collection. De Vos (1998) defines data collection methods as the way in which the data is actually obtained. The primary sources for data collection in this study were the perinatally infected adolescents and Child care workers from various child and youth care centres in Pretoria. Information was collected using three methods - agency records, semi-structured interviews and focus groups. This allowed for the data to be compared and used to influence further questions for a complete and detailed account of perinatally infected adolescents' psychosocial experiences.

The researcher was able to use the various ways of collecting data as a method of checking the 'trustworthiness' of the information. When doing qualitative research, the researcher is often the primary instrument of data collection (Merriam, 1988 in Key, 1997). The researcher started the data collection process by accessing records of perinatally infected adolescents at the two selected child and youth care centres. This enabled the researcher to possess crucial background information pertaining to the selected participants. Being a social worker was an advantage as the child and youth centre shared information with the knowledge that I abide by the code of ethics of social work. For the second child and youth care centre, I already had access to the files as I work there in close contact with the participants. Accessing adolescents' files was crucial as it ensured that selected participants made up an appropriate sample for the study. Furthermore, it also provided insight into the number of perinatally infected children admitted in child and youth care centres.

5.4.3.1 Semi-structured interviews.

A positivist social scientist does not take into account the unique personal theoretical stances upon which each person bases his/her actions. By contrast, adopting the interpretivists approach, I was bound into the human situation I was studying and able to observe the phenomenon as part of the system (Walliman, 2005). This enabled me to bring my meaning and understanding to the investigation from my perspective as shown in the next chapter.

Semi-structured interviews were appropriate for this study as they not only allowed the researcher 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). This type of interviewing gave the adolescents the opportunity to speak their mind on their beliefs, perceptions or accounts on a particular topic hence allowing the researcher to get detailed information (Greef, 2005:289). This directly aligned with the purpose of this research which was to understand in-depth the psychosocial experiences of these perinatally HIV infected adolescents, drawing from them information-rich responses to the subject matter.

The conception of knowledge as a mirror of reality is replaced by conceptual of the social construction reality (Berger & Luckman, 1966:1), the focus of this research was on the interpretation and negotiation of the meaning of the social world and how it affects perinatally HIV positive adolescents. Thus one can say in-depth interviews are a construction site of knowledge as particular linguistic patterns are revealed through interaction between the researcher and interviewees. 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.

By using this method I had an opportunity to gain more insight on the phenomena from spontaneous questions which stemmed from the questions asked. As a result, eight semi-structured interviews were conducted with adolescents from the two child and youth care centres in Pretoria.

The researcher was able to examine the level of understanding that an interviewee had and how they felt about a particular topic. This allowed the interviewer to become a student as she learnt more about the research topic from the interviewee (Rubin & Rubin, 1995). All interviews were started by obtaining verbal informed consent from the participants. The reason for the study and the value of the study was then explained. Confidentiality and anonymity was discussed and agreed upon. The researcher also requested permission to tape record the interview. The participants were informed that the findings of the research will be shared and that there might be a possibility of publishing the results. All participants were given an opportunity to stop the interview at any given moment. According to Patton (2002: 45), the purpose of interviewing permits a researcher to enter into the other person's viewpoint. Semi-structured questions from the interview schedule (see appendix) gave the researcher the opportunity to explore, probe or ask questions that were relevant and participants were given the choice of not answering questions that made them feel uncomfortable.

According to Struwig and Stead, (2001:98) the semi-structured interview offers the researcher an opportunity to "obtain multiple responses to set questions and allows for detailed responses". The interview schedule was a list of general open-ended questions. The researcher had the freedom to follow their instincts and to improvise depending on the participant. The interviews took place as per adolescents' willingness, convenience and availability. As the researcher worked at one of the child and youth care centres, she asked the other social worker to ask the six adolescents if they were interested in participating and explained the purpose of the research. These interviews were conducted during weekends. At the second child and youth care centre, issues

about confidentiality were raised as they felt if I was to conduct the interviews it was “involuntary disclosure” of the adolescents’ status. Thus it was requested that social worker for the child at that particular centre conduct the interviews. The fact that I am a social worker and understood the code of ethics had them reconsider and I was later allowed to conduct the interviews as the respondents would open up more to an outside social worker. The interview was useful to the study as it allowed for:

- More specific information to be collected.
- All responses could be clarified by the researcher.
- The researcher could ask detailed questions and questions that produced 'rich' and 'in-depth' data.

The researcher followed the following the principles of interviewing:

- All participants were treated with respect
- Acceptance and an empathetic understanding was illustrated with caution over becoming emotionally over-involved
- No hidden agendas were kept
- The interview was terminated in a sensitive manner

The researcher provided debriefing during and after each interview. The researcher then transcribed the interviews.

5.4.3.2 Focus groups

According to Greef, 'Focus groups are group interviews which give the researcher a better understanding of how people feel about or what they think about an issue (2005:289)'. Specific participants were selected because they possessed certain characteristics in common that related to the topic of the focus group. Child care workers in child and youth care centres are the primary caregivers to the adolescents hence have a better understanding of their psychosocial experiences. The initial plan was to conduct one focus group with all child care workers from selected child and youth care centre, but the logistics with regards to this arrangement proved difficult - it was impossible to get them all together at once because some were involved in shift-work at the same CYCC. Thus focus two focus groups comprising of five child care workers and a social worker were conducted at each CYCC. All focus groups were conducted during working hours when all the children were at school. Therefore the child care workers voluntarily participated. Data from child care workers is crucial to this study as it ensures reliability and validity of data presented from in-depth-interviews.

5.5 Analysis

Content analysis was used to analyse data. 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. A code was assigned to each emerging theme and categorised (Kumar, 2005: 223). During content analysis of transcribed data from perinatally infected adolescents and child care workers, codes were assigned to each emerging pattern of experience and similar codes were categorised into themes. Themes emerging from adolescents responses formed the basis of the findings and the expressed views were put in verbatim. Integrating, into the report, the expressed views in verbatim either supported or contradicted my argument which ensured trustworthiness of data. These themes are further analysed and discussed in the research findings.

Seven key phases provided by Cresswell in De Vos (2005:334) were used in the data analysis process.

➤ ***Planning for the recording***

In preparation for recording the researcher bought a digital tape recorder, which was used to tape record the interviews. Before tape recording the interviews the researcher asked for permission from each respondent and permission was granted by all respondents. The researcher made sure the tape recorder was in perfect working condition before conducting each interview.

➤ ***Data collection and preliminary analysis***

Semi-structured one-on-one interviews were used to collect data. Each interview was tape recorded and field notes were written. Each interview was converted into mp3 format on the computer making it easy to store the date and to transcribe each interview word for word.

➤ ***Management and organization of data***

The researcher made hard copies of each transcription and created a folder for the transcription for future reference. Each transcription was labeled alphabetically for ease of use by the researcher.

➤ ***Reading and writing memos***

The transcriptions and filed notes were read over and over again by the researcher in order to familiarize themselves with data. As the researcher read the transcriptions and field notes, notes (comments) were made in the margins.

➤ ***Generating categories, themes and patterns***

As the researcher read the data common themes, subthemes were identified. These were mainly the words and phrases that were repeated often in the interviews.

➤ ***Coding data***

The researcher used abbreviations for the keywords to identify the themes and subthemes.

➤ ***Testing emergent understandings and searching for alternative explanations***

The emerging data was analyzed through linking the themes and subthemes and the different perspectives of the individual respondents and also the researchers' co-constructs. Literature was consulted to verify empirical findings and/or seek alternative explanations.

5.6 Limitations

As a social worker working with HIV perinatally HIV positive children and being part of the research process, my ideas on psychosocial experiences of perinatally HIV positive children were impacted and this subsequently influenced how I understood and interpreted the psychosocial experiences of perinatally HIV positive adolescents. To acknowledge this impact my reflections are included.

Finding out about your HIV status is hard enough for adults and for perinatally HIV positive adolescents it is clearly a nightmare as they contracted unwillingly. Talking about it is difficult hence some participants were not willing to open up during the interviews. Their openness could have enhanced the quality of the data produced.

The fact that I work with some respondents affected their responses during interviews and may have had a positive or negative impact on the data.

This study targeted three child and youth care centres around Pretoria which were home to perinatally HIV infected adolescents. However due to the fact that HIV is a sensitive issue most of them were not aware of the status of their adolescents. Thus the sample was drawn from two centres and cannot represent all CYCCs in Pretoria.

The study was also limited by the small study sample and the fact that each adolescent was interviewed only once. In addition, focus groups had been planned to be conducted in a specific manner but that did not materialize according to initial plan as they were held separately. Despite the limitations data was drawn from the correct sample for the study.

5.7 Ethical considerations

With regards to ethical issues, I ensured that the interview process was transparent and respondents knew the purpose of the research. Before conducting interviews and focus groups, I explained to all respondents the purpose of the study and they understood which led to their willingness to participate. I also took into consideration three broad areas of ethical concern in research: first, the ethics of data collection and analysis; second, the ethics of responsibility to society; and lastly, the ethics engulfing treatment of participants (Singleton, Straits & Straits, 1993).

One could argue that being ethical is synonymous with being a good researcher. First, with respect to the ethics of data collection and analysis, it is important for researchers to ensure that the process of data collection and analysis is rigorous and follows the correct methods and procedures (Adil, Shamoo & Resnik, 2009). Falsehoods and biases can be minimised if researchers adhere to scientific methods of data collection and analysis. Focus groups and semi-structured interviews were conducted to collect

data and to avoid bias the researcher avoided asking double-barrel and leading questions. I also ensured that detailed and accurate records of the research were kept (Shamoo & Annau, 1987; Cheny, 1993; Kitcher, 1993). I ensured that I was accountable for the research by keeping proper documentation of all aspects of data collection; these documents make it possible for future analysis, verification, and replication to occur.

Second, regarding the ethics of responsibility to society, I ensured that the research process was conducted in such a way that was not harmful to the participants and society. Before an interview, I explained to participants that they were allowed not to answer any question if they didn't want to and also they could stop the interview at any time. The research maintained the dignity and welfare of participants and society by presenting accurate findings and complying with the law and professional standards governing the conduct of research (American Psychological Association 2011).

Lastly, concerning the ethics on treatment of participants, I ensured that subjects were not potentially harmed by the research. Informed consent forms were filled by participants giving their consent as an acknowledgement that they were not coerced in any way to participate. Participation was voluntary and adequate information was provided about the research in order to allow the participants to make informed decisions. To ensure privacy and anonymity, I had the option of using pseudonyms. To ensure no deception took place during data collection, the researcher explained to the participants how data was going to be analysed and that they had access to documents at any given time if they wish to do so (Singleton, et al. 1993; Struwig & Stead, 2001).

Main respondents of this study were adolescents perinatally HIV infected thus there was potential for emotional harm. I took the responsibility to make sure that respondents were not harmed in any way. To make sure that there was no harm on the respondents, I carried out debriefing sessions and the child and youth care centres were encouraged

to closely monitor the adolescents. Debriefing occurs when, after the study, subjects get the opportunity to work through their experience and its aftermath (Strydom, 2005:67).

During the focus groups, the child care workers expressed that all information be kept confidential. The necessary steps were taken to ensure that the confidentiality of the participants was protected. All identifying information was changed without distorting the results. Disclosure of one's status is sensitive and it should be a voluntary act especially regarding research purposes. Despite the fact that I am a social worker, in the eyes of the adolescent participants at the other child and youth care centre, I was a stranger and mere researcher. For me, interviewing them about their status was involuntary disclosure thus to ensure their privacy, the child and youth care centre social worker discussed the matter with them first and they consented. To ensure accuracy of data all information was recorded and all documents generated were kept.

The final ethical concern was the obligation and responsibility of sharing the research findings and the recommendations. The researcher has committed to publishing the findings and distributing the information to various helping professions. The researcher will take advantage of all opportunities to present the findings at both local and international conferences.

5.8 Credibility of the study

5.8.1 Triangulation

The credibility of the study is enriched by triangulation. The idea behind triangulation is that data produced through applying different methods can be compared in order to conform or refute other results (Flick, 2007:46). 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. However, in this instance, I used triangulation to gain more insight on how child care workers perceive as the psychosocial needs of adolescents living with HIV and also adolescents' own perceptions as they are their primary caregivers. In-depth interviews with adolescents and focus groups with child care workers and social workers enhanced the validity of the study. The focus groups enabled the researcher to view the phenomenon from various dimensions, despite some contrast and it allowed for different interpretations. The multiple perspectives gave greater confidence in ensuring the dependability of the study. The use of secondary data through direct observation, tape recording of the interviews and focus groups helped to ensure the validity of the study. As a result, potential gaps were addressed in this manner and it ensured validity of the material.

5.8.2 Validity and Reliability

In qualitative research it is crucial to convince the reader the trustworthiness of your findings hence the importance of validity. According to Hesse-Biber 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'. Klave and Brinkman (2009) are of the view that validity refers to the truth, correctness and the strength of a statement. They continue to propose that, "validity takes the form of subjecting one's findings to competing claims and interpretations and providing the reader with strong arguments for your particular

knowledge claim” (Klave & Brinkman, 2009:264). To ensure trustworthiness of the findings I verified with the agency records that all selected participants were a correct sample for the study. 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 original as possible.

According to Klave and Brinkman (2009:245), ‘reliability pertains to the consistency and trustworthiness of research findings in relation to the aspect of whether a finding is reproducible at other times and by other researchers’. However, within the social constructionist framework, dependability will be appropriate. Reliability is regarded as a positivist notion which assumes the unchanging universe is where inquiry could quite logically be replicated (Lincoln & 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). 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).

5.8.3 Transferability

Transferability refers to the extent to which the findings can be applied in other contexts or with other respondents (Babbie & Mouton, 2006:277). They maintain that in qualitative study, the obligation for demonstrating transferability rests on those who wish to apply it to the receiving context, that is, the reader of the study (Babbie & Mouton, 2006: 277). Thus results from this study cannot be generalised owing to the variability in meaning attributed to the unique experiences of each adolescent. However, providing methodical descriptions of contexts enables one to transfer findings. The findings can only be generalised in theory and not in a representative population as experiences differ with each individual’s social constructs influenced by language and culture.

5.9 Conclusions

In this chapter, the following methodological components used to conduct the research were discussed: research instruments; research design; population and sample; data analysis, validity and reliability; ethical considerations; and limitations to the study.

The next chapter will examine the responses of all participants in relation to the critical questions and will present a discussion of the findings.

CHAPTER SIX: DATA ANALYSIS

VOICES OF PERINATALLY HIV POSITIVE ADOLESCENTS

6.1 Introduction

Social constructionists believe that we construct our own reality as we experience the world. The emerging data was analyzed by linking the themes and subthemes. The different perspectives of the individual respondents were illustrated in form of verbatim transcriptions to bring out their psychosocial experiences and the support services available at each CYCC. The themes identified are a reflection of how the researcher understood the psychosocial constructs of these adolescents. As the reader engages with the material presented in this chapter from his or her own context, he or she will co-construct ideas as the constructs unfold. This chapter presents data obtained from semi-structured interviews conducted with perinatally HIV positive adolescents. For the reader to understand, their biographical profiles are presented followed by themes which emerged from the interviews.

6.2 Biographic Profiles

A brief description on the biography and background of each adolescent respondent is presented. These profiles serve as a point of reference for the analysis section. There were two sample groups, which were drawn from two Child and Youth Care Centres in Pretoria. The study comprised of three male and five female adolescent respondents. Data for this study was collected by conducting in-depth interviews with each child and focus groups with social workers and child care workers. The interviews were conducted in English. Pseudonyms were utilized to protect the identity of all participants.

Table 6: Biographic profiles of the sample group of perinatally HIV infected adolescents.

Participants	Age	Years in the CYCC	Reason for admission	Biological parents
Unknown (Female)	14 yrs	7 years	Placed at M due to ill health and was from a child headed family	Mother died in her presence in the hands of an elder sister.
Baby L (Female)	16yrs	12years	Placed at M due to neglect and unstable health conditions.	Had a relationship with her mother before she died.
Lacastor (Male)	15yrs	12years	Placed at M due to neglect and ill health.	Both parents passed on and was left in the care his of grandmother.
Lorraine (Female)	15yrs	12years	Placed at M centre due to neglect.	Her mother passed on and her family resented her but they are now back in her life.
Tariro (Female)	15yrs	7years	Was placed at M centre due to neglect and need for medical attention.	The mother passed on and was left in the care of maternal grandparents.
Chris (Male)	15yrs	12years	Placed at M due to ill health after death of his mother.	Mother passed on and was left in the care of his brothers whom

				have not visited him for years now.
Mary (Female)	14yrs	7years	Placed at S due to unstable health.	Mother passed on and was left with her sister
John (Male)	16yrs	5years	Placed at S due to neglect from the sister.	Mother passed on and was left in the care of his sister.

6.4 Themes from semi-structured intreviews

From the content analysis carried out the following themes and subthemes emerged:

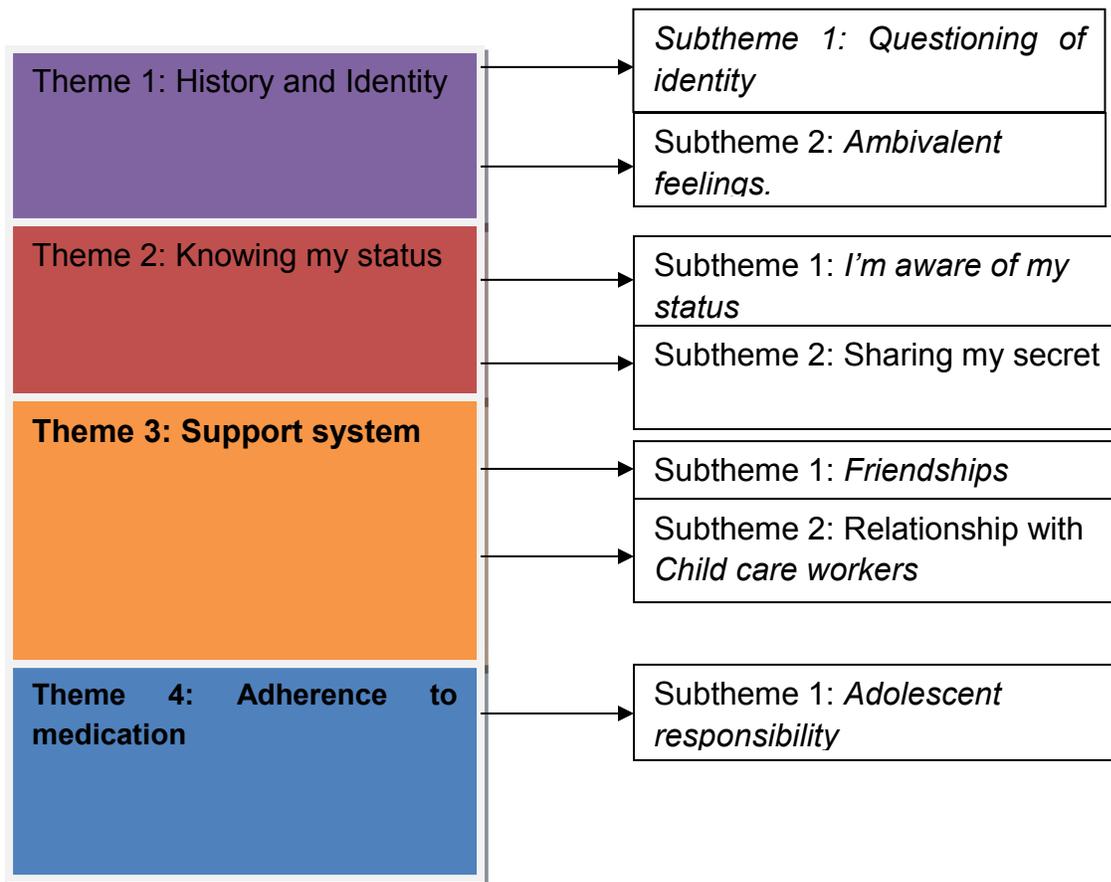


Figure 1.

6.4.1 Theme 1: History and Identity

During the process of grieving, children's feelings are often ignored as it is assumed that they are too young to completely comprehend what would have happened. It is socially constructed as a process which is for adults as they are emotionally developed to understand the process. These needs are overlooked during this time of loss, and children are not given full recognition or support. As children growing in CYCC, questions arise and some start remembering traumatic events in the past regarding the losses they experienced. However, because this is not addressed most children grow up without knowing their parents culminating in a loss of identity. Proper support during

bereavement helps one deal with arising emotions. The following subthemes emerged from this theme:

6.5.1.1 Questioning of identity

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. Most of the children residing in CYCC find themselves with no one to call their own hence they did not know much about their background but had bad childhood memories. When asked about their parents most of the adolescents had no vivid memories about them. Some remembered the death of their parents but had no happy memories.

Tariro, *“I only know my mother, I know her face”.*

Chris, *“I have never asked about my parents but I would want to know.”*

Lacastor, *“I’m not sure about my mother.....”*

Lorraine, *“I have no idea about my parents....”*

Unknown, *“Social worker told me about my family, I don’t know anything about my parents, they were told not to tell me*

The fact that most of the adolescents never had the chance to receive good nurturance from their parent has a negative impact on their ability to form relationships. According to Erickson, successful psychosocial outcomes in infancy and childhood are regarded as the foundation for coherent identity (Berk, 2000:456). Shaffer continues to say adolescents who were socially deprived or abused as infants are likely to be withdrawn and apathetic and may later display intellectual deficits, behavior problems and reactive behavior disorders (Shaffer, 2002:416). The problem appears to stem more from their lack of responsive social stimulation than from failure to receive care (Shaffer,

2002:416). As noted by social constructionists, a child learns the basics of what is important in society from their immediate family as constructed in that particular family and this builds up our identity (Alvesson & Sköldbberg, 2009). Failure of young children to attain secure attachments to a primary caregiver is indicated as significant in the development of psychological problems in adolescence and adult life (Dwivedi, 1999:65). Adolescents from this study were deprived a significant parental figure as a result of maternal mortality. As observed by the social worker, most of these adolescents experience behavioral problems, which is in alignment with Dwivedi's (1999:66) assertion that insecurely attached children are less cognitively competent and are more likely to develop emotional or behavioral problems.

6.5.1.2 Ambivalent feelings

The most painful thing in life is to have questions you need answers to, but the person in question is not available for questioning. Whilst answering the questions about their parents, participants expressed their feeling towards their parents in an indirect way. Their response could have also been affected by the length of time spent in the CYCC. When asked they had this to say:

Lacastor, *"I don't want to know about her"*

Lorraine, *".....sometimes I don't want to know sometimes I want to know when I'm scared"*

Chris said, *"sometimes I get stressed, I think about my parents why they put me in this place. I would like to face them"*.

From the above responses one can note that participants have mixed feelings towards their parents. They did not show any attachment but resentment and anger towards them. The fact that Lacastor is not interested in knowing his parents can be due to the fact that he found himself HIV positive and growing up in a CYCC. Lacastor's facial

expressions also showed a lack of interest and disappointment. Lorrain also displayed feelings of anxiety and anger towards her parents as indicated by her response. Chris openly admitted that he gets frustrated because he doesn't know his parents and would like to see them. This showed that he has many unanswered questions and he had so much anger which surfaced due to the frustrations. The above responses also show that they had an avoidant pattern of attachment. As postulated by Howe (2002:176), children who develop avoidant patterns of attachments have parents who are indifferent, hostile, rigid or rejecting (Howe, 2002:176). From the agency records, most of the participants were abandoned and neglected hence their responses. The fact that their parents died when they were young and they do not have any memories of them could be the cause of all these surfacing feelings. 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 their parents and grew up in a CYCC explains why they feel neglected, unwanted and isolated too. This can make them feel as if the world is against them reflecting in them a lack of resilience and increased anger.

Tariro, *"She was sick and I was with her and I was hurt and it still hurt me now.....sometimes I cry and I don't wanna talk about it"*

Unknown, *".....I only know when my mother passed away it makes me feel sad, I was even there"*

Mary, *"I would like to know why mother got infected because she was fine"*

6.4.2 Theme 2: Knowing my status

6.4.2.1 I am aware of my status?

Disclosing the diagnosis of human immunodeficiency virus (HIV) to a child is a controversial and emotionally charged issue amongst both the health care communities, parents and the caregivers of these children (Wiener et.al, 2008). It becomes a challenge for Child and Youth care centres to disclose statuses to their children as they already carry the burden of neglect and abuse. Respondents acknowledged awareness of their status in the following words:

Unknown said, *“Yes I’m aware of my status.....I can’t remember when I was told but I think I was about 11-12years”*

Baby L said, *“I was told last of last year (2009)”*

Mary said, *“Yes I know my status, my young sister (older) told me because my older sister (aunt) didn’t want to tell me because I’m still young. She told me when I turned 14 that is why I have drinking this medicine”*

Lorraine said, *“I was told in 2006 about my status”*

Tariro said, *“I’m aware of my status the doctor told me about it, I was 13 years”*

John said, *“Yes I do know about my status I was told in 2008, I was told my mama Hana (house mother)”*

The findings from the study have shown that respondents were aware of their status. From observations during interviews, their responses were said without any emotion or concern, which should be a cause for concern. This could be due to the fact that they have accepted the situation or they have developed a coping strategy which enables them to think selectively about the matter effectively enabling them to control their

feelings. 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. From the responses given by participants, one can speculate that disclosure was not given in a supportive environment as there was inconsistency with who disclosed the children's statuses to them, hence the display of an inability to express their emotions. As a result of becoming aware of their status after the age of ten, there is evidence that correlates to research and clinical reports from United States of America which suggests that many HIV infected children particularly younger than 13 are unaware of their statuses (Mellins, Bracks-Cott, Dolzezal, Nicholas, Richods and Abrams, 2002). The reason behind children not having their status disclosed to them at an early age it is because of their understanding ability at that point in time.

South African Pediatric immunology doctors (Kalafong Hospital) are encouraging all care givers to disclose to children, their statuses, especially to those of age 12 and beyond. As found that these children start engaging in sexual activities at this age, it became crucial that perinatally HIV infected children became aware of their status as early as possible. According to Santamaria et al, (2011:258) knowledge of HIV status may be critical to decision making around both health and sexual risk behaviors for adolescents. However, a challenge experienced by both doctors and social workers is that most adolescents attended by a new doctor tend to deny their awareness of their HIV status. This has caused much confusion between social workers and doctors. The disclosure of the HIV diagnosis to children or adolescents transforms the "unknown secret" of their HIV status into HIV as reality (Mellins et al. 2002:112). How they make sense of this information, that is, the meanings they construct of their illness depend on the dynamic social and cultural contexts of their lived experience (Fife 1994:315; Thorne 1999:400). For HIV and AIDS, these contexts include stigma, shame, and secrecy - which become more or less salient as the child ages and his or her social world changes. The reason most children deny their status knowledge could be due to the fact that they wish and hope the news would be different, waking them up from their nightmare. This in turn can prove that participants have constructed being HIV positive

as chronic illness which will fade with time hence motivation to adhere to medication. As one of the social workers explained that some of the kids believe they will not die of AIDS.

Despite participants not showing emotions when asked about their status, learning about your HIV status it is not easy and is more complicated when you never had a choice about it. They however reacted differently when their statuses were disclosed. They had this to say:

Baby L, *“I felt normal, things have been going on well because I don’t really talk about it and I don’t worry much about it”.*

Lorraine said, *“I felt weird, like why me, why do I have it, but now I don’t feel anything”*

Lacaster, *“I don’t feel nice about it, I don’t wanna tell anyone, I can’t say everything is normal”.*

John, *“I felt was going to hate my parents (I hate my parents), sometimes I go down and start to think”*

Chris, *“Anybody can be very very well, anyone can live. Sometimes I don’t feel like a normal child especially when people say you can’t live until you are 20 I feel a bit scared and I don’t talk to anyone”.*

Their responses also show that they have constructed coping mechanisms in dealing with the matter. However feelings of anger, uncertainty and anxiety surfaced from their responses as well. They also use blocking strategies to cope with their feelings. From the above responses, adolescents present themselves with unresolved emotions and

denial symptoms. As social constructionists say, “meanings attached to one’s reality do not exist before a mind engages in them” (Sarantakos, 2005:37). Chris’ view that ‘people say you cannot live until 20 years”, shows that his view on HIV is affected by the society social construct of HIV with imminent death. Hence the participants’ feelings could be influenced by how people around them construct HIV as an illness.

Clinical reports have indicated positive outcomes associated with disclosure, amongst them trust; improved adherence to medication; enhanced access to support services; and the emotional well-being of the children (Wiener, Mellins, Marhefka and Battles, 2007:155). The clinical reports are from studies (Birungi, 2008; Wiener et.al, 2007) conducted with children or adolescents who were from normal family settings hence it is difficult to compare such with orphaned adolescents living in CYCCs. From this study one can note that adolescents have not emotionally dealt with the news. The children’s frustrations of not knowing their parents, compounded by residing in a CYCC, seem to render them emotionally unstable.

As mentioned in the earlier in chapter 4, adolescence is a period often characterized by experimentation hence there is need to equip these adolescents with necessary information on how to deal with possible future challenges. Thus disclosure is not a one-time event, but rather a process, involving ongoing discussions about the disease as the child matures cognitively, emotionally and sexually.

6.4.2.2 Sharing my secret?

Disclosing one’s status to society is a challenge for adults let alone for adolescents who are unfortunate to have been caught up in the dilemma. Given the extremely high prevalence and incidence of HIV & AIDS in South Africa, coupled with relatively wide ranging access to anti-retroviral therapy (ART), many point to an HIV positive diagnosis transitioning from a ‘death sentence’ to a ‘manageable illness’ similar to other chronic conditions such as diabetes and high blood pressure (Austin-Evelyn, 2011). While some

argue that HIV status disclosure is no longer rare, the stigma associated with disclosure is identified as a major driver of the HIV & AIDS epidemic. Stigma is a multi-faceted phenomenon, which is a culmination of a set of societal factors that prevent, harm and delay disclosure of one's HIV status (Campbell, Nair Maimane, and Nicholson, 2007:403). 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:

Baby L said, *"I don't tell people, friends that I'm HIV positive only my granny knows"*

Tariro said, *"I never told anyone, I think I will tell my husband when I get married"*

Chris said, *"I have not disclosed to anyone and I will never, I don't feel comfortable, I understand people are scared of HIV"*

Lacastor said *"I don't wanna tell anyone"*

Unknown said, *"No I will never tell anyone, but maybe later on I don't want them to know because they will start teasing"*

Mary said, *"No I didn't tell anyone, only my family knows"*

HIV is constructed as an "untouchable" subject at the CYCCs and the stigma attached to HIV in most communities enhanced participants' acceptance of this construct. Disclosure, for most participants thus becomes difficult as they are afraid to be discriminated against and hence second rejection resulting in them constructing their own coping mechanism - "non-disclosure". The general view on disclosure is that youth who have known their HIV status for a longer (versus shorter) period of time may be

more comfortable with their identity as people living with HIV; and may be more comfortable talking with others about HIV (Santamaria, Dolezal, Marhefka, Hoffman, Ahmed, Elkington, Mellins, 2011:258). From the above responses one can note that the adolescents are not yet comfortable with their identity. The above responses are also in line with view that, “as youth adjust to the knowledge that they are living with HIV, they may experience stigma and rejection related to their HIV status and be less open about their status” (Santamaria et al., 2011:258). This might be attributed to their unwillingness to disclose their status.

As mentioned earlier, disclosing one’s status is one of the most difficult situations HIV positive people have to deal with. HIV is a disease which surrounded by a lot of stigma and not a lot of people understand, particularly adolescents. During the interviews, respondents were first asked about their sexual status so as to understand their position in terms of disclosing their statuses to their partners. Their responses are shown in the table below:

Table 7: Overview of relationships

Adolescent	Age	Gender	Sexual relationships
Chris	15	Male	No
John	16	Male	Yes
Lacastor	15	Male	No
Baby L	16	Female	No
Mary	14	Female	No
Lorraine	15	Female	No
Unknown	14	Female	No
Tariro	15	Female	Yes

As shown above the majority of the adolescents were not sexually active during the time of the interviews. They all seemed aware of the precautions they should take if and when they decide to have sex. When asked about sex, Chris mentioned that he would

use protection when having sex and Unknown elaborated that, “she would use a condom from protection of HIV and pregnancy”. However Lacastor was not comfortable discussing about sex with the researcher. Tariro and John openly admitted that they were sexually active.

Tariro mentioned that, *“I had sex in grade seven with one of the kids, didn’t used protection”*.

Deducing from Tariro’s response one might speculate that she had sex with one of the boys whom are participants above but denied being sexually active as they are from the same centre. Thus there is bias in their responses on being sexually active. Their refusal to open up about their sex life could be attributable to the fact that in most black cultures, sex is constructed as a “taboo” subject. John also admitted that he was sexually active and mentioned that,

“I have had sex but used protection, had sex with the girl from the village and we see each other often, maybe have sex once or twice”

When asked if they will disclose their HIV status to their sexual partners they all had different views. For some, trust was important for them to reveal their “secret”. Baby L mentioned that,

“I used to have a boyfriend, I never told him about my status because he was not my type, if I meet my type I will tell them that is if I trust him enough. Trust is important for me to disclose”

All the responses from the boys did not show any emotion or condition attached to revealing their HIV status to their partners as compared to the girls.

Chris said, *“I would tell my girlfriend about my status”*

Lacastor said, *“of course I will tell my partner”*

John said, *“I will tell her about my status”*

The response from the participants did not display genuineness. Their responses seemed to be based on their knowledge of knowing that one should open up about their status. However, because they admitted they can share their secret with their sexual partners shows their willingness to do so. As compared to the study by Santamaria et al., (2011:262) in New York, intentions to disclose to sexual partners was low. However, non-disclosure to sexual partners is regarded as common with youths living with HIV (Santamaria et al., 2011:262). 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). This was evident from the responses from Tariro and Unknown.

Tariro mentioned that, *“I won’t tell my boyfriend because I will be embarrassed”*

Unknown mentioned that, *“yes I will tell my boyfriend but expect him to react normal”*

Adolescents seem to be affected by their immediate and broader social context which stigmatizes HIV, propelling their chances of hiding a potentially damaging “secret” from

others as they engage with the negative evaluations of what it means to be HIV positive. HIV is constructed as illness contracted by means of promiscuity in most South African communities (Ashford, 2011) and hence this notion's impact on how participants construct the illness.

The study done by Mills and Maughan-Brown (2009) indicated that, in a township outside of Cape Town with high prevalence of HIV, disclosure was not only met with positive but also with supportive responses from household members as they started to dissociate the virus from conceptions of promiscuity and death. Mills and Maughan-Brown (2009) problematize disclosure and describe it as a complex process, but their findings demonstrate that while stigma was still a significant barrier to living positively with the virus, the barriers are slowly eroding, especially at the household level. The study done by Maughan-Brown (2009) is also a true reflection of the changes happening in CYCC. At one the CYCC there has also been an increase in families being reunited with their children, and some becoming more involved. From my observation when working with these children, there has been a deconstruction of stigma associated with HIV which enabled families to own up to their children. However, these findings cannot be generalized to all communities in South Africa and with specific mention to CYCC.

In a nutshell, adolescents who were sexually active knew how to protect themselves and their partners during sexual activity, but they did not all practice safer sex, nor did they declare that they did or would disclose their status before engaging in sexual activity. As maintained by Close (2011) stigma surrounding HIV/AIDS makes people more cautious about disclosure thus to manage stigma, adolescents often are selective about whom they tell and when, protecting themselves against negative reactions and social isolation. Thus social constructions associated with HIV influence their ability to disclose.

6.4.3 Theme 3: Support System

Social support requires the existence of social relationships. Social relationships have the potential to provide supportive resources which include emotional support, material resources and health support. Lazarus and Folkman (1984) have indicated that supportive social relationships mediate the effects of stress and facilitate coping. Social support may also change with alterations in a person-environment relationship. This means that the kind of social support required by adolescents differ as they encounter each life phase hence they construct their social support need along the way. Two sub-themes emerged which are friendships and relationships with the child care workers which are discussed below.

6.4.3.1 Friendships

During the adolescence phase, making outside relationships signifies that one is becoming emotionally independent from parents. This is referred to as detachment by Adams et al., (1996:3). Detachment involves the reorganization of (sexual) object ties such that attachments to parents come to be replaced by attachments to peers (Adams et al., 1996:3). Participants in this study were detached from their parents at an early age hence they never experienced much attention from their caregivers also considering their circumstances. Shaffer (2002) construct that children who are deprived of secure attachments from care givers fail to respond to the normal social stimuli, tend to withhold close bodily contact, and have difficulties forming relationships later in life. However, during the interviews most of the participants turned out to have friends. They were not socially withdrawn. When asked if they had friends they all presented themselves as sociable people. They said:

Baby L said, *“I have five friends female and male. My friends know about my circumstances (living in a CYCC)”*.

Unknown said, *"Yes I have friends"*.

Chris said, *"I have 3 friendsno I don't talk about my problems"*

Lacastor said, *"I have a lot of friends at school and I have a very close friend"*.

Lorraine said, *"I have friends, some are close and some are not"*

Mary said, *"Yes I do have four friends in the centre"*.

John said, *"Yes I do have friends at school and 2 in the centre"*.

From the responses they all mentioned they had friends, but one can question if these relationships were true or just to fit in the society which is consistent with adolescents' psychosocial needs (ICAP, 2010). For Baby L, she seemed to have a genuine relationship with her friend as she mentioned that she was aware of her circumstance. This ascertains that she had accepted her background hence she could share it with an outsider. However, for some participants, they seemed as if they did not talk about their background hence it can be a concern as it can affect them socially as they might try hard to fit in to cover their background. Van Dyke (2008:188) maintains that adolescents have an intense desire 'to belong', thus their social development is characterized by an increasing interest in and involvement with the peer group. He goes forth to postulate that interaction with friends satisfies the adolescents' emotional needs thus conformity and acceptance from peers is crucial at this stage (Van Dyke, 2008:188). Because they had outside socialization, this shows that they were at par with the psychosocial construct of the adolescent phase of detachment as mentioned earlier. Some mentioned that they had close friends also shows that they could form secure attachments.

Another interesting point was that participants from M centre did not have a brotherly/sisterly relationship amongst them despite the fact that they grew up together under the same roof. They seemed comfortable with outside relationships. When asked about their relationships in the centre they mentioned that:

Baby L said, *“The other children do not like each other because they live in a home, they want a normal home circumstance with mother and father”*.

Tariro said, *“I don’t get along with other kids, I am afraid and scared sometimes they want to hit me”*.

Unknown said, *“I’m tired of the centre, yes I get along with the other kids”*.

Chris said, *“I get along with other children but no brotherly relationship”*.

Lacastor said, *“I get along with all of them I have a good relationship”*.

They all portrayed mixed feeling about their relationships. This could be because they grew up in a dormitory setting and certain principles were not enforced as compared to S CYCC which has a normal home setting. The social constructs associated with dormitories might have influenced they sense of belonging. This could be the reason why Tariro feels really scared of other children as they all have to compete for survival and attention. The above responses present different personalities of participants. Some seemed overconfident and others presented with low self-esteem, which are both psychosocial effects of HIV. According to The Alliance (2003), low self-esteem can also be caused by loss of parents. For most HIV infected children, the loss of a father can deprive children of social and economic security, while the loss of a mother deprives them of emotional security International HIV/AIDS Alliance (The Alliance, 2003:5). Low self-esteem may cause children to feel that adults do not notice them or their needs

may not be certain whether they are accepted and some cases, they are not sure how to respond (The Alliance, 2003:5). This could account for Tariro's response.

As much as they all admitted that they had friends, their degree of friendship had limitations for some participants. When asked whom they confide in when they are faced with challenges, most of them mentioned that they talk to the child care workers. Only Lorraine admitted that she talks to her friend when she has problems when she said "I talk to my friend when I'm sad" but the rest of the participants mentioned child care workers. They said:

Tariro said, *"I talk to the child care worker when im bored".*

John said, *"Yes we talk about my problem if there is something I don't feel comfortable with."*

Unkown said, *"I get along with her when it comes to cleaning, giving each other advice and school"*

Chris said, *" I tell mother if I have problems"*

The responses from the adolescents show that they still have a barrier between them and the outside. They try to follow the norms of the society, that is, socializing by making friends but emotionally, they have constructed the CYCCs as their source of refuge. This makes it difficult for them to confide in their friends about their problems and they also feel the child care workers understand them better as they are aware of their status thus there would be no need to disclose their status. For them to fit in with society, they have constructed emotional isolation as a way of adapting and avoiding the stigma associated with the virus and the pity associated with residing in a CYCC.

For Lacastor, however, he presented himself as emotionally withdrawn from everyone hence he does not confide in any one. He mentioned that:

Lacastor said, *"I don't talk to anyone I keep it to myself"*

6.4 3.2 Relationship with Child Care workers

In the setting of a CYCC, the relationship between the children and child care workers is of paramount importance. Child care workers represent the parental figure to children in CYCC (Browne, 2009). In a CYCC, child care workers spend the majority of their time with these children hence there should emerge a close relationship between the two which will enable adolescents to confide in them. When asked about their relationship with child care workers they responded that:

Baby L, *"sometimes I get along with them sometimes I don't, I feel like I'm not the loved one because I'm rude. I'm rude because I miss my parents and I don't want to call them mother because they are not my real parents I want to call them aunt"*.

Tariro, *"I get along with child care workers"*.

Chris said, *"Sometimes I get along with the mothers and sometimes I don't when they are in a bad mood so I just keep quiet."*

Unknown said, *"I get along with the child care workers."*

Lorraine said, *"Sometimes I get along with child care workers, sometimes not, others they hate me, but school psychologist said she will come and talk to them."*

Mary said, *“Yes I stay with house mother we get along, we can talk at me and he always tells me that he loves me that’s why he always tells me to take tablets.”*

Lacastor said, *“Not sure if I get along with child care workers, sometimes they shut you up.”*

The above responses show that there is some sort of relationship between the child care workers and the adolescents. In spite of this, one cannot ignore the fact that different settings of each CYCC influence the relationships. Mary and John reveal that they have a good relationship with their child care workers and their responses reveal that they have a strong bond. The other participants’ point out they get along with the child care workers but at the same time reveal that the child care workers are not approachable because of their moods, while some practice favoritism. Favoritism is typical in any family setting, however since these participants have insecurity issues, they interpret this as being unloved. Mary and John were admitted to CYCC when they were slightly older, so they had the opportunity to live in a family setting resulting in a mature ability to construct relationships with care workers. In contrast to the rest of the participants who suffered great trauma before their admission and found themselves living in a hospice setting at a young age, they also do not exhibit signs of having trust issues.

Baby L feeling that it is unfair for her to refer to the child care worker as ‘mother’ illustrates that she too has not dealt with the loss of her mother. The moods and negative responses given by child care workers towards the participants are dangerous especially at their current phase in life, it may force them to seek attention outside the CYCC. This is consistent with a study conducted by Naidu (2005) on experiences of caregivers. The caregivers in the study reported that although they were generally in good health, the long hours of work during their week long shifts made them feel disorientated, irritable and tired at times.

6.4.4 Theme 4: Adherence to ART adherence

Medication adherence is one of the important psychosocial concerns with regards to perinatally HIV infected adolescents. Adherence to medication shows their level of autonomy. Autonomous adolescents have gained the ability to make and follow through with their own decisions, live by their own set of principles of right and wrong and have become less emotionally dependent on parents.

6.4.4.1 Adolescent Responsibility

The fact that adolescence is characterized by rapid changes in physical maturation, cognitive processes, and life style, predicting long-term adherence in an adolescent can be very challenging. However, from the study, participants still do not have full responsibility of their medication hence adherence is in place. When asked about medication responsibility they said:

Unkown said, *“Mum manages the medication but I take full responsibility of my medication”*.

Tariro said, *“Mum manages my medication but I would like to take full responsibility when I turn 16”*.

Baby L said *“I will start taking care of my medicine when I’m 16years”*

Lacastor said, *“mum manages my medicine”*.

Mary said, *“the house mother manages my medicine, but I take watch and set time”*.

Therefore the child care workers have full responsibility of the adolescent’s medicine intake at child and youth care centres. This also shows that they have not gained their autonomy and might have a long term impact on their self-efficacy. Self-efficacy can be defined as the patient’s belief that he or she is capable of organizing and executing the

course of action required to perform a particular activity (Bandura,1994). Bandura stressed that self-efficacy is a prerequisite for behavioral change, because it affects how much an individual invests in a given task. From the above responses, self-efficacy is lacking in the adolescents' lives as the child care workers are fully responsible for their medication and appointments to the clinic.

This proves that the adolescents are unable to execute the course of action required as they feel “they are doing a favor” to the child care worker. It is essential for the adolescents to have autonomy to enhance self-efficacy bringing about increased adherence to medication.

6.5 Conclusion

Perinatally HIV infected adolescents require knowledge and understanding of their HIV status. They require frank ongoing communication and education to ensure an adequate understanding of the implications and acceptance of living with their illness. Adolescents need social, emotional, spiritual, and often material support. Adherence to treatment is integral for sustaining positive health outcomes in HIV-positive young people who need support in managing their treatment. The following chapter is a continuation of data analysis obtained from focus groups.

CHAPTER SEVEN

UNDERSTANDING INSTITUTIONAL DYNAMICS

7.1 Introduction

The previous chapter presented the voices of perinatally HIV infected adolescents, shedding light on how they construct their psychosocial experiences. To ensure the

trustworthiness of data, focus groups were conducted at both CYCCs with social workers and child and youth care workers who were primary care givers to the adolescents. Each focus group comprised of one social worker and five child and youth care workers. In this chapter, results from the two focus groups were analyzed separately because of the different facility settings which influenced the findings leading to the emergence of different themes. This chapter will be presented as follows:

7.2 Profiles of the Child and Youth Care Centres

Table 8: Profile of Child and Youth Care Centres

CYCC	M	S
Location	It is located within hospital premises.	It is located within the community
Type of facility	Dormitory setting which caters for 37 children.	15 Cluster houses which accommodate 10 children per house.
Area of specialization	HV infected and affected, abandoned, neglected children	Orphaned, abandoned and neglected children
Satellite houses	Yes which accommodates 8 adolescents	Youth houses for discharged - 18 and above.
Professionals	Social workers, staff nurse, child care workers	Social workers and child care workers
Working system	Shift work for Child and youth care workers.	Live-in for child and youth care workers.
Number of HIV + Children	40	

7.3 Themes from focus groups

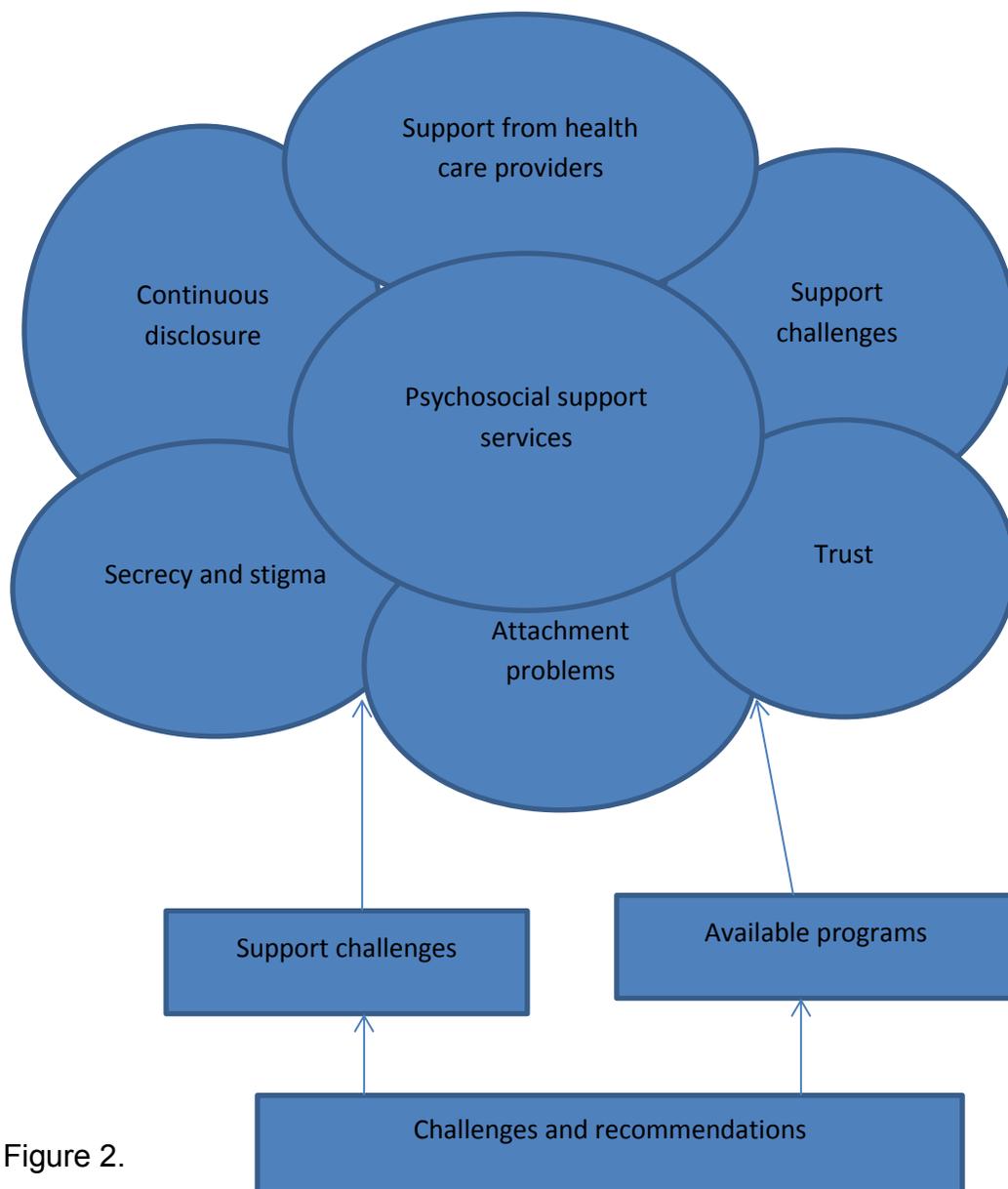


Figure 2.

7.3.1 Focus group S

From the focus group conducted with S child and youth care workers and social workers, it became apparent that working with HIV positive children in a CYCC which does not fully cater for that unique group is difficult. From a qualitative study conducted with 34 CYCCs from four provinces in South Africa in 2006, results revealed that some social workers prefer to transfer perinatally HIV positive children to facilities which only focus on HIV positive children (Moses & Meintjies, 2010). The focus group revealed that youth care workers and social workers had sympathy for perinatally HIV positive

adolescents which made it difficult for them to discuss their problems. They also mentioned that they had concerns with regards to administering medication and that it was difficult working with HIV positive adolescents. The results also proved that children who grow up in a family setting behave differently when compared to those in dormitory institutions.

7.3.1.1 Continuous Disclosure of HIV statuses.

Williamson & Greenberg (2010) and Browne (2009) state that children who grow up in CYCCs may demonstrate attachment problems owing to the absence of a stable caregiver as a result of shift work in institutions. This assertion with regards to S was not consistent with this study as adolescents mentioned good relationships with child and youth care workers. The fact that CYCC S has a house setting structure within enables child care workers to provide each child with needed attention. Despite their good relationships, it became clear that they experienced problems with regards to HIV in the house. With the ratio of 1:9, they found it difficult to discuss matters related to the chronic illness as they felt it to be discriminatory towards perinatally infected adolescents. The social worker expressed that:

Social worker said, *“We do not talk about the children’s status or HIV, it’s an untouchable subject”*

Child and Youth care worker said, *“It is hard as they are few children who are positive whilst the rest are negative”.*

Social worker said, *“We don’t want to make the children feel discriminated”.*

The responses above reveal psychosocial support deficit in the lives of adolescents at this centre. 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. The Regional Psychosocial Support Initiative (REPSSI), states that psychosocial support includes ensuring the meaningful participation of children in issues affecting them, listening and responding to children's problems and allowing children to express their feelings and needs (REPSSI, 2012). The responses show that CYCCs are still in the transitioning period (Jaspan et al., 2009) with no clue as to how to address the needs of perinatally infected adolescents. Social constructions associated with HIV influence (Keniston, 1989) social workers and child and youth care workers' attitudes towards the needs of perinatally HIV adolescents. Ongoing disclosure promotes trust, improves adherence to medication and promotes emotional-wellbeing of adolescents (Wiener et al., 2007). The lack of ongoing disclosure complicates the adolescence phase of these adolescents as they would be dealing with the adolescent phase's psychosocial experiences in addition to other needs that arise from the chronic illness. It is therefore apparent that, at this centre, there are no psychosocial support services available for perinatally HIV infected adolescents.

7.3.1.2 Secrecy and Stigma.

Social support is essential for one to continue taking their medicine. As mentioned earlier, there are few HIV positive adolescents at this centre and it makes it difficult to administer medication. Perinatally HIV positive adolescents find it difficult to adhere as they find it embarrassing to take medication in the presence of their negative peers. From the study, the child and youth care workers pointed out that,

Child and youth Care worker said, “It is hard to administer medication, they pretend to be drinking medication and they throw it away”.

Adolescents not taking their medication can be attributed frustrations of depending on medication. In addition, the child and youth care workers mentioned that the fact that their peers in the house were aware of their position made it worse. Despite this, they also mentioned that their peers were supportive as they would remind them when it is time to take their medication.

Child and Youth Care worker said, “other children at each house are aware of their status hence they constantly remind them if it time for medication which is embarrassing for them”

This is a positive initiative from the other children but for the positive adolescents it is embarrassing. These negative feelings can be caused by the fact that they understand the stigma associated with the chronic illness and how their mothers could have contracted the virus. This could be as a result of the fact that the child and youth care workers do not discuss their concerns making it more difficult for them because they need clarity on certain matters regarding the illness. The fact that the social workers do not discuss HIV or their status infiltrates different feelings in perinatally HIV infected adolescents. These feelings may result in feeling of unworthiness, pessimism over life and non-adherence to medication. The youth care workers mentioned that:

Child and Youth Care worker said, “They feel they are going to die soon, hence they are not concerned about taking medication”

Child and Youth care worker said, *“The other children at home discriminate them, hence it is hard”*

The difficulties in adhering to medication can be attributed to the changes associated with the adolescence phase. The fact that adolescence is characterized by rapid changes in physical maturation, cognitive processes and lifestyle becomes a challenge for them to balance the aforementioned with medication adherence (Grubman, Gross, Lerner-Weiss, 1995). The British organization Avert also asserts that adolescents with chronic illnesses are often challenged with adhering to their medication regimen as the schedule may not fit well with their active lifestyles.

7.3.1.3 Support from Health care providers

The relationship between adolescents and doctors/nurses was one of the concerns held by the child and youth care workers. The relationship between the adolescents and their health care providers had a weaker impact on how well adolescents adhered to their medication regimens. Adolescents attend their immunology appointments at local clinics which presented a difficult situation. The local clinics' rooms are identifiable by the services provided in that particular room. This makes it difficult for adolescents to attend immunology sessions as they felt that entering such rooms indicated their status publicly. One child and youth care worker mentioned that:

Child and Youth Care worker said, *‘clinic nurses does not make it easier for them as they discriminate because every room marked TB,HIV hence children find it difficult to go see doctors to the marked rooms’.*

As mentioned by Kenniston (1989), the term HIV is medically constructed which means immune deficiency in humans. In today's society synecdoche AIDS is used more often

denoting an acute stage of illness (Jackson & Crystal, 1992). This has had profound effects on perinatally HIV adolescents as mentioned by the child and youth care workers, where some of the children even refuse to take medication. A response from one of the children shows their pessimism regarding their future.

Child and Youth care worker said, *“They feel they are going to die soon, hence they are not concerned about taking medication”*

Regardless of what they hear from their families and healthcare providers about HIV being a chronic illness that can be kept under control by medication, teens with HIV may still feel that their future is uncertain. This uncertainty can cause ambivalence about planning for the future. They may not be focused on getting good grades and setting themselves up for employment. As they enter adulthood, they are confronted with learning how to live independently (The Body, 2006). In effect, the social constructions surrounding the terms has made it difficult for adolescents to attend appointments and because of their awareness of their statuses, they feel they are involuntarily disclosing to the world by entering marked rooms. This does not correlate with Wiener et al (2008) with respect to the assertion that one’s awareness of their status leads to enhanced access to support services. This also affects how they relate with the doctors. One of the Child and Youth care workers mentioned that even when they finally enter the room, the adolescents find it difficult to communicate. The child and youth care worker stated that:

Child and Youth care worker said, *“Some do not even talk to the doctor, they hide their faces and let the mothers speak”*

7.3.1.4 Challenges and recommendations

Child and Youth care workers and social workers found it difficult to address the needs of perinatally HIV positive adolescents as their survival of perinatally HIV positive children was not anticipated (Domek, 2012; Wiener et al., 2007; Kumar et al., 2009) hence the importance of their psychosocial experiences. At this CYCC psychosocial experience of perinatally HIV infected adolescents were not apparent to the Child care workers and social workers. Personal social constructions associated with the illness could also be a contributing factor to their ignorance. When asked about programs available at the centre they mentioned that:

Social worker said, *“There are no programs at the centre we only get them when we go out and there also no workshops for child and Youth care workers”.*

This made it difficult for them to keep up to speed with the unique needs of perinatally HIV positive adolescents. It explains why HIV/ status discussions were “untouchable” topics at this centre.

The Child and Youth care workers suggested that workshops and seminars addressing the needs of HIV infected children should be initiated by the Health department as well as the department of Social Development. This could equip them with necessary information with regards to psychosocial support for this growing group of perinatally HIV positive adolescents. They also suggested that there is need to liaise with other CYCCs dealing with HIV so that perinatally HIV positive adolescents can understand that they are not alone in this situation, hopefully providing insight and a sense of solidarity with other children in the same bracket. This initiative helps adolescents to share their experiences and ideas on how to deal with certain situations. The focus groups also revealed that there is no support focusing on the psychological, behavioral and developmental effects of HIV on adolescents. This is consistent of CYCC that do not focus exclusively to HIV (Moses & Meintjes).

7.3.2 M centre Focus group

Results from this CYCC were different from that of S CYCC. The researcher has attributed these differences to settings in each CYCC as derived from the profiles. As mentioned earlier in the profile descriptions, this centre focused primarily on HIV and the perinatally HIV infected children. The aim of this focus group was to gain various perspectives from child and youth care workers and social workers on the matter regarding any psychosocial support services that were available. However, during the course of the group discussions themes emerged pointing out behavioral problems, trust, support challenges and health care service providers' relationships with perinatally infected adolescents. The setting of this CYCC has had an effect on the relationships between the children and youth care workers and perinatally HIV positive adolescents. During the course of this study, it came to light that institutional care impacts negatively on adolescents' development (Browne, 2009). The results from this focus group will be discussed below.

7.3.2.1 Attachment problems

Child and Youth care workers mentioned that perinatally HIV positive adolescents are disrespectful towards them and they do not listen when they ask them to do chores. They mentioned that it is difficult to control them as they present uncontrollable behavior. They feel unappreciated as they try hard to bond with them and give them love but their efforts are rejected. They also mentioned that:

Child and Youth care worker said, *“When you try to reprimand them they tell you, you are not my real mum or relative and they behave which ever they want”.*

Child and Youth care worker said, *“They do not respect us, they say you are not my mother”.*

Their attitudes towards the child and youth care workers can be attributed to the fact that they understand these adults to be professionals and not their parents (Browne,

2009) thus there is no need to respect them. It could be, a perception on the part of the adolescents, that they view the activities and efforts of the child and you care workers and social workers as mere attempts to carry out their jobs, for which they are remunerated. This may also reflect perinatally infected adolescents' disorganized attachment as they seem not to know how to respond to other people's warmth and concern (Howe, 2002:177. A study conducted Johnson et al,(2006) in Europe revealed evidence of negative social and behavioral consequences for children raised in institutional care. These problems included anti-social conduct, social incompetence, play and peer interactions. Browne (2009:12) also confirms the observations carried out in European residential care homes have since confirmed more stereotypical behavior in children who are under-stimulated by the conditions under which institutions operate. This behavior is consistent with that experienced in residential care settings.

Young children need to experience continuity of care that they need to form a lasting attachment with an adult care giver (Williamson & Greenberg, 2010:5). A direct consequence of shift work at this particular institution makes it difficult to maintain meaningful contact with the child, which could be reason for their bad relationships. Dwivedi states that healthy emotional bonding takes place in contexts in which parents are genuinely pleased at the arrival of the newborn, expressing their joy in gentle confidence, 'giving ' as much is needed – something lacking in the institutional environment as observed in this research.

Perinatally HIV infected adolescents have not experienced this nurturance but only neglect, abandonment or abuse. It will be difficult for them to form sound relationships with the child and youth care workers.

7.3.2.2 Trust

According to Neuman & Neuman (1997:84), environmental provision of consistency and predictability are fundamental to the confirmation of the growing infant that there are people in the world who are trustworthy and caring. However, for children who are raised in CYCC, they are deprived of this and as they become adolescents they might struggle with trust issues. During the discussions in focus groups, child and youth care workers mentioned that the adolescents always share their problems with them despite

their sour relationship. Despite this, there were inconsistencies in terms of trust, as the adolescents were aware of the different professions that the youth care workers and social workers practiced. Adolescents demonstrated certain problems to child and youth care workers which they felt were at their level of competence and some problems were presented to the social worker as they trusted them specifically for better advice regarding specific issues. This issue of trust is also apparent when it comes to educational matters. They mentioned that:

Child and Youth care worker said, *“They undermine us as they can tell who is educated so they don’t want us to help them with homework”.*

Child and Youth care worker said, *“They are aware that we do not have social work background thus they are not open at times”.*

The adolescents’ knowledge that the child and youth care workers lack social work background impacted adversely on psychosocial support provision at the centre. This means that even if social workers develop programs to be implemented by child and youth care workers, the adolescents will not commit to participating fully. On the other hand, developmentally, adolescents are often reluctant to engage in direct communication concerning their thoughts and feelings (Louw et al., 1998) which could be the reason for their actions and attitudes towards the child and youth care workers. These adolescents have mixed emotions to dealing with caused by the adolescence phase in addition to being perinatally HIV infected. This can often lead to them displaying uncooperative behavior. Consequentially, there could be miscommunication between the adolescents and child and youth care workers. Social constructionists maintain that our ways of understanding the world comes not from objective reality but from other people, both past and present and we are born into a world where the conceptual frameworks and categories used by the people in our culture already exist (Burr,1995:5). It is crucial for Child and youth care workers to understand the frame of

reference of each of these adolescents because they all trace back to very unique backgrounds despite them sharing a common struggle. They need to understand their psychosocial constructions from their personal experiences and re-construct their psychosocial constructions as an adolescent in a family setting.

7.3.2 3 Support from health care provider

As stated in the profile the CYCC is located in a hospital. This is an advantage for adolescents because there are no marked rooms as compared to local clinics. Child and Youth care workers mentioned that they had good relationships with the doctor and most of them preferred their privacy with the doctor.

The social worker mentioned that there were relatively no problems with adherence to medication. At M CYCC, a nurse makes sure medication for the children is prepared and administered. The social worker also mentioned that the children seem to have a better understanding of the social constructions concerning the illness. She mentioned that:

Social worker said, *“They do not want to go with the mothers to see the doctor because they felt the child and youth care workers gossip to hospital staff on their way so they believed they were discussing their status to everyone”*

This also shows sign of mistrust and paranoia from the adolescents towards the child and youth care workers. One of the shared concerns by child and youth care workers and social workers was the fact that, adolescents always pretend not to be aware of their status on most visits to the doctor especially when attended to by a new doctor. A study carried out in the United states of America on adolescents who were perinatally HIV infected, reported that participants had a good and trusting relationship with their health care team, and generally thought that their clinicians understood their particular issues regarding HIV medicines and adherence (Szelag, 2011). This is also true of this

study, to a certain extent, as discovered that they always denied that their status has been disclosed to them with the hope that they will be examined otherwise, trusting the new doctor to save them perhaps by providing a different HIV status diagnosis. For HIV and AIDS, these contexts include stigma, shame, and secrecy, which become more or less salient as the child ages and his or her social world changes. Most children deny their status knowledge with the expectation that the results could come in different if tested again. This does prove that participants have constructed being HIV positive as chronic illness which may perhaps fade with time motivating an adherence to treatment regimens supplied to them.

7.3.2.4 Support challenges.

Most of the child and youth care workers at the centre are adults and have children who are also at the adolescence phase or in young adulthood. They often employ their general knowledge with dealing with adolescents from a personal experience as a basis for dealing with this special group of children. During the focus group, child and youth care workers mentioned that adolescents ask them about relationships and pregnancy which they find hard to answer. One child and youth care worker mentioned:

Child and Youth Care worker said, *“They ask us about pregnancy, birth and what happens when you are with a boy”.*

According to the pediatric research team in California, independence and future planning can be difficult for teens that are growing up infected with HIV (The Body, 2006). The reason for lack of future planning can be attributed to the fact that treatment and survival outlook for people in the earlier years of the epidemic was not very optimistic (The Body, 2006). This necessitates a need for positive talk with the adolescents as Husler et al., (2005) suggest that adolescents who fail to perceive the potential of the future are at greater risk of engaging in reckless behaviors such as

unprotected sex, alcohol and drug use and abuse as well as other life- threatening activities.

Shift work in many CYCC makes it difficult for them for them to give adolescents adequate attention (Browne, 2009). They mentioned that they don't get enough time with the adolescents and when they try to address certain problems they feel judged by child and youth care workers.

Child and Youth care worker mentioned, *“When you tell them they feel you are judging them”*

Child and Youth care worker mentioned, *“We didn't have enough time to talk to the kids”.*

This is a problem which comes with the difficulties of living in institutional care as paranoia becomes heightened. It amounts to great challenges for child and youth care workers at this centre with respect to addressing the needs of perinatally HIV infected adolescents' issues within a CYCC context. The fact that they were used to dealing with toddlers is another critical factor exacerbating their difficulty in attending to the adolescents' needs.

7.3.2.5 Programs at the centre

The child and youth care workers mentioned that they used to go to the University of South Africa for training and Weskopies on how to work with the children. There were suggestions that training should be available with specific focus on working with perinatally HIV positive adolescents. The social worker acknowledged that there were no specific programs at the centre that effectively delivered psychosocial support, but they simply received external help from psychologists and speech therapist. This was

also consistent with a study carried out by Moses and Meintjies (2010) at a CYCC which cared exclusively for HIV positive children. At this particular centre, programs were established to address HIV-positive children's developmental delays and psychological and behavioral problems which included sending some children to speech therapists and psychologists (Moses and Meintjies, 2010).

7.4 Conclusion

Child and youth care centre S and M youth care workers brought out different perceptions on working with perinatally HIV positive adolescents. The differences were greatly influenced with context of the settings in each institution. Adolescents in Centre S were raised in a family setting hence their social interaction constructs were greatly influenced by the setting, facilitating less behavioral problems. Most of the concerns/ views of child and youth care workers are more focused on the illness itself rather than social behavior. As compared to centre M, the children were raised in a dormitory setting of an institution with a shift system, resulting less nurturance creating a greater influence in their behavior. The child and youth care workers had issues more with behavioral problems than medical concerns. Essentially, one can note that the psychosocial concerns from each CYCC differed - M was HIV oriented and S was a more balanced CYCC. However, the researcher is in agreement with Williamson and Greenberg (2010) in the regard that alternative care in form family setting should be considered before placing a child in an institution.

CHAPTER EIGHT

CONCLUSIONS AND RECOMMENDATIONS

8.1 Introduction

An increase in ARV roll-outs has enhanced the survival of perinatally HIV infected children into adolescents. Adolescence is a period in which an individual undergoes major physical, psychological and emotional changes (WHO, 2010:14). However it becomes complicated for perinatally HIV positive adolescents residing in CYCCs as they face 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). According to Close (2011) psychosocial support is the most effective tools that help children and adolescents with HIV survive into psychologically healthy adulthood. Hence, Close (2011) maintains that proper support will also help them to progress through this developmental stage and grow alongside their peers and will enable them to take charge of their own medical care and protect themselves and those around them (Close, 2011:331). The Global UNAIDS Report for 2010 indicates that the psychosocial needs of infected children are the most neglected area of research and support. This study aimed at exploring the psychosocial experiences of perinatally HIV positive adolescents in CYCCs in Pretoria.

The study was based on qualitative research which aimed for depth in understanding the psychosocial experiences of perinatally HIV positive adolescents (Henning, 2004:3). To select adolescents' purposive sampling was used as the researcher aimed for information-rich cases whose study will illuminate the questions under study (Patton, 2002:230). Constructive social workers emphasize processes which focus on voice reflexive on dialogue, listening to and talking with the other (Howe, 2002:244). Thus

eight semi-structured interviews are suitable for this study as they allowed the researcher to formulate spontaneous questions and responses to the subject and also permitted the participants to be part of the research (Mann, 1998). Two focus groups were also conducted which comprised of one social worker and four child and youth care workers from two CYCCs in Pretoria. This study enabled them to voice out their psychosocial experiences which the researcher co-constructed as they presented them into themes as elaborated in the previous chapters.

This chapter provides a summary of findings from the study as co-constructed by the researcher. Overall recommendations will be provided with potential contribution to the practice field of social work when working with perinatally HIV positive adolescents in CYCCs. The strengths and weaknesses which call for further research will be stated and closed with my reflections on the study.

8.2 Overview of the Study

The main aim of the research project was to explore the psychosocial needs of perinatally HIV infected adolescents (14- 17) who reside in child and youth care centers in Pretoria. The main objectives which were addressed by the study were:

- To understand the psychosocial experiences and coping strategies of 8 perinatally HIV infected adolescents in child and youth care centers in Pretoria.
- To gain insight into the perception of child and youth care workers about the psychosocial support services available in two child and youth care centres.
- To present recommendations to all service providers in respect of gaps in psychosocial services for perinatally infected adolescents.

8.3 Summary of Findings.

Objective 1: Psychosocial experiences and coping strategies.

Theme 1: History and Identity.

HIV/AIDS mortality deprived perinatally HIV infected adolescents from this study the opportunity of growing up with their parents. Despite this disadvantage they managed to escape poverty and received good treatment and education by being placed in CYCC. However growing up in CYCC dispossessed their opportunity to have normal psychosocial infant outcomes. According to Erickson, successful psychosocial outcomes in infancy and childhood are regarded as the foundation of coherent identity by Erikson (Berk, 2000:456). From the study adolescents had never experienced normal childhood upbringing due to neglect, abuse and abandonment. When asked about their parents most of the adolescents had no idea about them. Some had vivid memories of them which were all sad memories as they remembered the death of their parents and there were no happy memories. Social Constructionist theorists maintain that a child learns the basics of what is important in society from their immediate family as constructed in that particular family and this builds up their own identity (Alvesson & Sköldberg, 2009). Participants had loss of identity and this impacted on them emotionally. Adolescents who are socially deprived or abused as infants are likely to be withdrawn and apathetic and may later display intellectual deficits, behavior problems and reactive behavior disorders (Shaffer, 2002:416). This was true of perinatally HIV positive in this study as they were indifferent about their parents, which is a cause for concern. This indifference can be attributed to lack of bereavement at the time of death of their parents. A qualitative study conducted with adolescents at Durban Children's home revealed that bereavement had a healing effect on children which helped them to gain closure as well as improve their behavior and academic performance (Pillay, 2009). Participants revealed that they had not gained closure from the death of their

parents and they had unanswered questions pertaining to their HIV status and also residing in CYCC hence unresolved emotions.

Theme 2: Knowing my status

From the interviews, it was apparent that perinatally HIV positive adolescents' statuses have been revealed to them. However, a shortfall was evident with regards to disclosure procedures. Both child and youth care centres had no formal disclosure procedure as both the social workers and child and youth care workers revealed their statuses to them. The fact that they became aware of their status after the age of ten years was consistent with research and clinical reports from United States of America which suggested that many HIV infected children particularly younger than 13years do not know their status (Mellins, Bracks-Cott, Dolzezal, Nicholas, Richods and Abrams, 2002). . In most South African hospitals, pediatric immunology doctors (Kalafong Hospital) are encouraging all care givers to disclose children's statuses, especially for those of the age of 12 years and older. However, it seems that a supportive environment was not created during disclosure as participants showed signs of denial symptoms. 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. Disclosing one's status transforms the "unknown secret" of their HIV status into reality (Mellins et al., 2002:112) thus the importance of continuous disclosure. As the researcher engaged with participants during interviews, she observed feelings of anger, uncertainty and anxiety from their responses. However they also showed that they have constructed blocking as a coping strategy in dealing with these emotions hence they avoid talking about the subject.

As social constructionist say, "meanings attached to one's reality do not exist before a mind engages in them" (Sarantakos, 2005:37). This is true of perinatally HIV infected adolescents views on disclosure of their status to society. They seemed to be aware of

the stigma and discrimination towards people with HIV, hence they expressed that they would not disclose their status to anyone except their sexual partners. Santamaria, et al., (2011:258) maintains that, "As youth adjust to the knowledge that they are living with HIV, they may experience stigma and rejection related to their HIV status and be less open about their status". In comparison to a qualitative study conducted in New York (Santamaria et al., 2011:262) with youth living with HIV, these adolescents proved to have the willingness to disclose to their sexual partners. It is maintained that youth 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). Despite their acknowledging disclosure and preventative measures, adolescents who were sexually active did not all practice safer sex. As maintained by Close (2011) stigma surrounding HIV/AIDS makes people more cautious about disclosure thus to manage stigma, adolescents often are selective about whom they tell and when, protecting themselves against negative reactions and social isolation. Thus social constructions associated with HIV influence their intentions to disclose.

Theme 3: Support system

Lazarus and Folkman (1984) have indicated that supportive social relationships mediate the effects of stress and facilitate coping. This means that the kind of social support required by adolescents differ as they encounter each life phase hence they construct their social support need along the way. Participants had relationships in and outside the CYCC. They all admitted that they had a friend which was consistent with the psychosocial construct of detachment experienced during the adolescence phase. Detachment involves the reorganization of (sexual) object ties such that attachments to parents come to be replaced by attachments to peers (Adams et al., 1996:3). However they seemed not to have secure attachments with their friends as they did not discuss personal problems with them. This shows that perinatally HIV positive adolescents from CYCC have the desire 'to belong' as acceptance and conformity and acceptance is crucial at this stage (Van Dyke, 2008:188).

Participants in this study were detached from their parents at an early age hence they never experienced attention from a significant primary care giver. This has impacted their ability to form secure attachments with Child and youth care workers. They mentioned that they did not have good relationships with child and youth care workers but at the same time they discussed their problems with them. They exhibit disorganised attachment as they do not know how to seek comfort nor do they seem to know how to respond to other people's warmth and concern (Howe, 2002:177). Thus support towards perinatally HIV positive adolescents came from Child and Youth care workers as they understood their position hence no second disclosure to friends.

Theme 4: Adherence to medication

Bandura stressed that self-efficacy is a prerequisite for behavioral change, because it affects how much an individual invests in a given task (Bandura, 1994). From the study, participants had no full responsibility with regards to their medication. Child and youth care workers were responsible for participants' immunology appointments dates and also preparing medicines. This had negative long term effects on their ability to adhere to treatment as they were growing older but still not yet independent. As they turn 18 soon they will be discharged from the pediatric clinic and the CYCC and without this ability to organize and execute their treatment it becomes a great problem as it increases chances of defaulting. Lack of self-efficacy is also a short fall in many CYCCs as they work in routine thus it's a job requirement for child and youth care workers hence deprives developing adolescents to be self-sufficient.

Objective 2: Perceptions of Child and youth care workers and Social workers on psychosocial support services.

Psychosocial support is best provided by families and communities. In child and youth care centres, social workers and child and youth care workers automatically act as caregivers to children. Hence they are legally responsible for their psychosocial well-being. From the study, it was evident that there were barriers and concerns in ensuring adolescents receive psychosocial support.

Theme 1: Continuous HIV Status Disclosure

Continuous HIV status disclosure was lacking in the lives of perinatally HIV positive adolescents residing in CYCCs from this study. Social workers regarded it an “untouchable subject” and child and youth care workers thought of discussing HIV as discriminatory. Wiener et al., (2007) assert 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. This was one of the challenges faced by CYCCs in this study. The Regional Psychosocial Support Initiative (REPSSI) states that psychosocial support includes ensuring the meaningful participation of children in issues affecting them, listening and responding to children’s problems and allowing children to express their feelings and needs (REPSSI, 2012). The fact that the social workers do not discuss HIV or their status infiltrates different feelings in perinatally HIV positive adolescents. These feelings may result in feeling of unworthiness, pessimism with regards to life and non-adherence to medication

Lack of ongoing disclosure impacted on their ability to adhere to medication as they did not understand the importance of taking medication. Their difficulties in adhering to medication can be attributed to the changes associated with the adolescence phase. The fact that adolescence is characterized by rapid changes in physical maturation,

cognitive processes and life style becomes a challenge for them to balance with medication adherence (Grubman, Gross, Lerner-Weiss, 1995). The British organization Avert also asserts that adolescents with chronic illness are often challenged with adhering to their medication regimen as the schedule may not fit well with their active lifestyles. Thus lack of ongoing disclosure complicates the adolescence phase of these children as they deal with the adolescent phase psychosocial experiences plus additional needs from the chronic illness. It is thus apparent that there were no available psychosocial programs for perinatally HIV infected adolescents.

Theme 2: Support from Health care providers

The location of each CYCC centre influenced the relationship the adolescents had with health care providers. Adolescents who attend their immunology appointments at local clinics found it difficult to handle, which made it difficult for them. The local clinic's rooms are labeled according to the services provided in that particular room. This made it difficult for adolescents as they felt that by entering such rooms everyone became aware of their status. As mentioned by Kenniston (1989), the term HIV is medically constructed which denotes immuno-deficiency in humans. However, in our society synecdoche AIDS is used instead which explains the acute stage of illness (Jackson & Crystal, 1992). This has a great impact on perinatally HIV adolescents as mentioned by child and youth care workers that some even refuse to take medication and responses from one of the children showed they were pessimistic about their future. At CYCC S there are no support services to help adolescents understand that no one knows that they are positive as it is an "untouchable subject". At CYCC M adolescents had a better relationship with healthcare providers and the fact that there is a staff nurse to administer medication its makes it easier for them to adapt to the situation.

Theme 3: Challenges and recommendations

Child and Youth care workers and social workers found it difficult to work with perinatally HIV positive adolescents. The fact that survival of perinatally HIV positive children was not anticipated (Domek, 2012; Wiener et al., 2007; Kumar et al., 2009) exposed the importance of their psychosocial experiences. At this CYCC, the psychosocial experiences of perinatally HIV infected adolescents were not apparent to Child care workers and social workers. The Child and Youth care workers suggested that workshops and seminars addressing the needs of HIV infected children should be initiated by the Health department and the Social Development department. This might equip them with necessary information pertaining to psychosocial support for this emerging group of perinatally HIV positive adolescents. They also pointed out that there is need to liaise with other CYCCs dealing with HIV so that perinatally HIV positive adolescents can understand that they are not alone. This initiative helps adolescents to share their experiences and ideas on how to deal with certain situations. CYCC S had no support services with regards to psychological, behavioral and developmental effects of HIV on adolescents. Moses & Meintjes' (2010) qualitative study also revealed that CYCCs which did not exclusively focus on HIV experienced the same challenge. On the contrary, CYCC M social workers acknowledged that there were no specific programs at the centre with regards to psychosocial support, but outside help from psychologists and speech therapist which reflected findings from a study conducted by Moses and Meintjies (2010) which revealed a CYCC which exclusively cared for HIV positive children. At this particular centre, programs were established to address HIV-positive children's developmental delays and psychological and behavioral problems which included sending some children to speech therapists and psychologists (Moses and Meintjies, 2010). Child and youth care workers also suggested that the children's background information should be at their disposal to enable them to understand their needs better.

In summary psychosocial needs of perinatally HIV positive adolescents residing in CYCC are still not recognized. This was evident from the study as the child and youth

care workers still misunderstood or misread the feelings and behavioral patterns of perinatally HIV infected adolescents. The latter may be a result of the lack of training on the part of child and youth care workers dealing with this unique group. In addition, the way CYCCs are structured influences their psychosocial needs immensely, thus family settings enhance positive behavioral outcomes.

8.3 The potential contributions of my study

Long term survival of perinatally HIV infected children is no longer exceptional with the increase and availability of ART in South Africa (Domek, 2012; Kumar, Mmari & Barnes, 2009). A qualitative study conducted by Moses and Meintjes (2010) in four provinces in South Africa with 34 residential facilities, examined the provision of residential care to HIV positive children. Their study revealed overlooked opportunities for non-institutional placements for HIV-positive children and identified important gaps in the HIV prevention, treatment, care and support interventions within facilities. Domek (2012) assessed the current state of CYCCs caring for HIV-positive children and psychosocial challenges they face. From the study he concluded that the provision of antiretroviral treatments would be best accompanied by a number of medical, psychological, educational and social services that help prepare HIV-positive children for future. These studies identified the gap within the provision of psychosocial support for perinatally HIV children. Therefore, to fulfil this gap, this research identified psychosocial experiences as they are constructed by adolescents residing in CYCC.

This study revealed that there was an improvement in the disclosure of HIV statuses to perinatally HIV positive children in CYCCs, as compared to findings from previous studies. However, it was still disputative with regards to formal disclosure policies which were also revealed from Domek (2012) study. This shows that there has been relatively

little improvement pertaining to this matter. This, in turn, affects perinatally HIV positive adolescents' understanding of their position. Disclosure is not a once-off activity but should be a continuous process. Wiener et al., (2007) assert that ongoing disclosure promotes trust, improves adherence to medication and promotes emotional-wellbeing of adolescents. Ongoing disclosure in CYCCs was hindered by social constructions of HIV/AIDS which still have an impact on social workers and child and youth care workers' frames of reference. They perceived discussing issues pertaining to HIV, such as sexuality, as discriminatory towards the adolescents. There is need to deconstruct pity as HIV is now a chronic illness and encourage ongoing disclosure. In order to deal with emotions which surface, perinatally HIV infected adolescents have adopted blocking as a coping strategy, hence they selectively respond to questions. Deficiency in ongoing disclosure impacts on perinatally HIV positive adolescents' acceptance of their status as they hope for better results from doctors.

8.4 Recommendations

8.4.1 To Child and Youth Care centres.

Child and youth care centres are encouraged to develop programs which focus on the following support topics:

- Discussions on sexual and reproductive health issues, including disclosure to partners, safer sex or delaying sexual debut,
- Discussion of views surrounding taking medication.
- Help with developing self-esteem and confidence.
- Developing a sense of belonging, acceptance or fitting in with peers, community, etc.
- Strategies to disclose their HIV-status to their peers, family and community members.
- Strategies to deal with stigma and discrimination.

Workshops for children in Child and Youth Care Centres

From the study, child and youth care workers suggested that adolescents from child and youth care centres should liaise with each other. This will enable them to share experiences making for a fuller understanding of the situation they face as well as providing the solace of knowing they are not alone.

8.4.2 Psychosocial support training

To social workers

In response to increased numbers of perinatally or behaviorally HIV infected adolescents, ICAP developed adolescent HIV Care and treatment curriculum in Zambia aimed at empowering multidisciplinary health care workers to have confidence in working with adolescents (www.columbia-icap.org). Another 2-week course was developed by Susan Strasser (2010) in Zambia with focus on Psychosocial Care and Counseling for HIV Positive Children & Adolescents. Both these training programs can be implemented conducted with social workers in South Africa.

Training of child and youth care workers

It is imperative that child care staff receive ongoing training to provide adequately for the needs of children in residential facilities Jackson (2008). The researcher agrees with Pillay (2009) that for effective service, child care workers need to be adequately skilled in providing psychosocial support for perinatally HIV infected adolescents. For that reason, refresher courses should be available to child and youth care workers on developmental phases of child to enable them to understand their behavior. This also provides the children with confidence in the child care staff responsible for them as the study at the CYCC indicated.

8.4.3 Department of Social development

The first notion in addressing psychosocial needs of perinatally HIV positive adolescents is to move away from institutionalization and encourage foster care or house system of CYCCs. Browne (2009) expresses that normal child development requires the opportunity for frequent and consistent one-to-one interaction with caregiver. Thus the department of Social Development should start considering de-institutionalizing CYCCs with dormitory system. The researcher also acknowledges the already running project of temporary CYCCs such as one in Cape Town at James House in Hout Bay which focuses on reintegrating children in the community and not permanent placements.

The second most important recommendation is to dissolve the social constructs attached to the illness. Stigma attached to HIV is still prominent in most communities, thus it continues to adversely impact the lives of perinatally HIV infected adolescents. The department should thus continue with HIV/AIDs campaigns that pay specific attention to managing the illness. There is dire need to educate the public that HIV/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.

8.5 Recommendations for further studies

There is need for further research on the following areas:

- What is the relationship between the psychosocial experiences of perinatally HIV positive adolescents residing in child and youth care centres and those in foster care?
- Psychosocial experiences of perinatally HIV positive adolescents with biological parents.
- Psychosocial experiences of perinatally HIV positive children after family discharge from a child and youth care centre

8.6 Final reflections.

This study demonstrated that perinatally HIV positive adolescents who reside in CYCCs have unique psychosocial experiences. Their experiences are not tangible but one needs to have a greater understanding of what their psychosocial experiences entail. It becomes apparent from the study that emotional isolation is a common coping strategy evident by the fact that they were not willing to openly share their experiences during the study. They have adapted to their situation through this mechanism which is not healthy as it can lead to depression and suicide.

As demonstrated in my study, adolescents' experiences seem to exist on a continuum with emotional well-being on one extreme and despair on the other. Their emotions and behaviors seem to be dependent on interpersonal relationships and acceptance. Considering that the child care workers fail to understand them, it becomes a challenge to balance this continuum. The adolescent needs closure with losses suffered which can

be fulfilled by their family of origin. They also require constant encouragement to instill an optimistic mind frame with respect to life to balance this continuum.

At this stage, it is essential to consider strategies that enhance the adolescents' well-being as they might be at risk of re-infecting themselves and others. They soon will be young adults, fulltime participants in society and will no longer be protected. It would also mean thoughtful planning on ways to equip them with essential life lessons to help them face greater challenges when they are eventually discharged from the CYCC.

This study has demonstrated that adolescents who are perinatally HIV infected and live in Child and Youth Care Centres have unique psychosocial experiences - mainly attributable to their chronic illness and their childhood backgrounds, which are either based on neglect or abandonment and orphanage.

8.7 Conclusion

The adolescence phase is a confusing time for everyone and becomes more complicated when coupled with a stigmatized chronic illness. In spite of their often rebellious and difficult behavior as adolescents, it is essential for child and youth care workers and social workers to understand what psychosocial support entails. This will enable them to understand this emerging group of perinatally HIV positive adolescents and the challenges of working with these unique adolescents. Understanding their unique psychosocial experiences and needs helps focus attention on nurturing more balanced individuals that will be able to function as any other normal adult in society, giving them a more fulfilling life despite facing a stigmatized chronic illness that throws a plethora of struggles their way.

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APPENDIX 1

Semi- Structured Interview Guideline for adolescents

Personal Details

Gender :

Age:

Grade:

Key Questions.

Question 1: Assessing living situation and support system.

- How long have you been living in this centre?
- How well do you get along with other children?
- How well do you get along with child care workers?
- Tell me about your parents?
- What happened to them?
- How have you dealt with the situation?
- Who do you go to for emotional support?
- Which school do you go to?
- How many friends do you have?

Question 2: Disclosure and coping strategies

- When were you told about your status?
- Can you tell me how things have been going since you learned about your status?
- To whom have you disclosed your HIV status?
- What was their reaction?
- How are you coping?
- Do you want to disclose to anyone else to get the support you need?
- Have you experienced any negative attitude from school after disclosure?

Question 3: Relationships

- Do you have a boyfriend?
- Are you sexually active?
- Do you practice safe sex?
- Would you tell your partner about your status?

Question 4: Adherence to medication

- Who manages your medicines?
- What will you do to remember?
- Do you have to go with your medicine to school?

What else would you want to talk about?

Focus group guideline for Child and Youth Care workers and Social workers.

Personal Details

Gender :

Position at the organisation:

Number of years at the organisation:

Key questions

Question 1. Support services

- How can you describe your relationship with the adolescents?
- How often do you discuss their concerns?
- What kind of problems do they mostly present during your discussions?
- What are the support programs available at the child and youth care centre?
- Do you have specific programs which are directed to the needs of adolescents?

Question 2: Challenges

- What are the challenges you face that affect your provision of services to adolescents living with HIV residing in child and youth care centres?
- What difficulties have you encountered since they became adolescents?
- Do you think these problems will be the same for all the young children when they are in their adolescence phase?

Question 3: Recommendations

- What are your recommendations with regard to the problems children encounter when they are in their adolescence phase?
- What do think can be the best way to deal with the problems of the current adolescents?

APPENDIX 2

INFORMATION LETTER for Adolescents

My name is Vimbai Precious Mavangira from the University of KwaZulu-Natal. I am conducting research towards the fulfilment of my Masters degree at the University of KwaZulu-Natal in the Department of Social work and Community development. The title of my dissertation is *Experiences of adolescents' living with HIV in Child and Youth Care Centers in Pretoria: An Exploratory Study*. I would therefore like to ask your formal permission to take part in an interview to be held at an agreed time and place about your 'psychosocial needs' as an adolescent born with HIV. The research seeks to explore the psychosocial needs of adolescents born with HIV living in child and youth care centres.

Your participation in this study is entirely voluntary. You can choose not to be involved. If you do agree to participate in the interview, you may choose to leave the interview at any time or not to give your comments when you do not feel like commenting. The interview will take about an hour and with your permission I would like to tape record the interview. Anonymity is assured; this means that your real name and identity will not be revealed. Pseudonyms will be used.

Your transcribed responses will be stored for up to 15 years after the completion of the study at the Department of Social work and community development, University of KwaZulu-Natal. In the course of the study, your consent form will be kept separately from your transcribed answers. The information that you contribute in the interview will be integrated with the comments of others and analysed to offer general understandings of the psychosocial needs of adolescents born with HIV living in Child and Youth Care Centres.

At the end of the study there will be no way of identifying *who* said *what*. If you agree to participate in this study I would request that you please sign the consent form indicating that you are a willing informant in this study. If you have any questions about any aspect of this research (now, in the course of the study or even later please do not hesitate to contact me on the following number: 076 7272 992).

Thank you

Vimbai P. Mavangira

INFORMATION LETTER for Child Care givers

My name is Vimbai Precious Mavangira from the University of KwaZulu-Natal. I am conducting research towards the fulfilment of my Masters degree at the University of KwaZulu-Natal in the Department of Social work and Community development. The title of my dissertation is *Experiences of adolescents' living with HIV in Child and Youth Care Centers in Pretoria: An Exploratory Study*. I would therefore like to ask your formal permission to take part in an interview to be held at an agreed time and place about your perception on the 'psychosocial needs of adolescents born with HIV' as the Care giver. The research seeks to explore the psychosocial needs of adolescents born with HIV living in child and youth care centres.

Your participation in this study is entirely voluntary. You can choose not to be involved. If you do agree to participate in the interview, you may choose to leave the interview at any time or not to give your comments when you do not feel like commenting. The interview will take about an hour and with your permission I would like to tape record the interview. Anonymity is assured; this means that your real name and identity will not be revealed. Pseudonyms will be used.

Your transcribed responses will be stored for up to 15 years after the completion of the study at the Department of Social work and community development, University of KwaZulu-Natal. In the course of the study, your consent form will be kept separately from your transcribed answers. The information that you contribute in the interview will be integrated with the comments of others and analysed to offer general understandings of the psychosocial needs of adolescents born with HIV living in Child and Youth Care Centres.

At the end of the study there will be no way of identifying *who* said *what*. If you agree to participate in this study I would request that you please sign the consent form indicating that you are a willing informant in this study. If you have any questions about any aspect of this research (now, in the course of the study or even later please do not hesitate to contact me on the following number: 076 7272 992).

Thank you

Vimbai P. Mavangira

The Chairperson

The board of management

Dear Sir/Madam

I am a currently registered student at the University of KwaZulu-Natal for Masters in Social work Research. The requirement of my degree is to submit a full research dissertation.

The topic for this study is: *Experiences of adolescents' living with HIV in Child and Youth Care Centers in Pretoria: An Exploratory Study* The purpose of this study is to explore the psychosocial of adolescents born with HIV living in child and youth care centres. It is predicted that this study will give insight on the needs of adolescents born with HIV as it is assumed they have unique experiences due to the challenges they face. The sample will include adolescents in child and youth care centres and their care givers.

All responses will be kept confidentially and the results will be used to make recommendations to all Child and Youth care centres. The study will be undertaken under the guidance of the school of Social work and Community Development at the University of KwaZulu-Natal. There will be no costs incurred to your organisation.

Thank you

Vimbai Precious Mavangira

076 7272 992

Formal Acknowledgement form for Care givers

I,on this day of.....2011, agree to be interviewed for the Masters research study conducted by Vimbai Precious Mavangira. The

purpose and procedure of the study have been explained to me. I understand that the participation is voluntary and that if I do agree to participate in the interview, I may choose to leave the interview at any time or not to give my comments when I do not feel like commenting.

Name of participants:

Signature:

Date:

Formal Acknowledgement Consent form for Adolescents

Signature of Guardian

I _____ Parents/ Guardian of _____ hereby confirm that I have understood the above explanations and all my questions have been answered. I agree that my child can take part in this study

Parents/ Guardian signature _____ **Date Signed** _____

Signature of Child

I _____ hereby confirm that I have understood the above explanations and all my questions have been answered. I agree to take part in this study.

Participant signature _____ **Date signed** _____

Signature of Researcher _____ **Date signed** _____