

# **The experiences of adolescents living in households with mothers who are HIV/AIDS positive**

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## **KEYWORDS**

Adolescence

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Psychosocial well-being

Coping mechanisms, stigma

Narrative approach

Story telling



I declare that

**THE EXPERIENCES OF ADOLESCENTS LIVING IN HOUSEHOLDS WITH  
MOTHERS WHO ARE HIV/AIDS POSITIVE**

has not been submitted by me for a degree or examination at this or any other university, that it is my own work and that all sources I have used or quoted have been indicated and acknowledged by complete references.

**Ms M P Tsweleng**



**In loving memory of my mother**  
**Raisibe “Machangane” Joyce Tsweleng**

**16 April 1954 – 21 January 2009**

Mom, your unconditional love remains the pillar of my strength, the foundation of all my successes. I couldn't have asked for more. Your words of wisdom shine the light throughout my life. I thank you, many thanks. Till we meet in the next life. I love you.

Your beloved daughter,  
Nnana



## **DEDICATION**

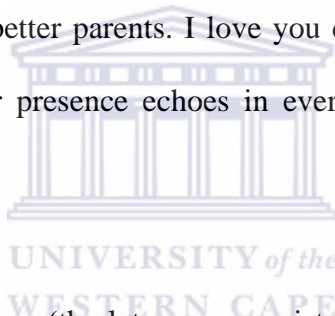
This dissertation is dedicated with love to all adolescents who are experiencing the effects of HIV/AIDS pandemic.



## **ACKNOWLEDGEMENTS**

My heavenly father, how great and unfailing is your love, how wonderful are your deeds. When you said to me in Isaiah 55: 10-11 that ‘the word that you speak will not return to you empty, but will accomplish what you desire and achieve the purpose for which you sent it’, I believed. You planned that I would carry out this task and complete it, and according to your will it has happened. Amen, and thank you.

To my late parents, Joyce and Alfred Tsweleng I would like to say thank you very much for having raised me the way you did. My successes are a clear reflection of your excellent parental skills. I wouldn’t have asked for better parents. I love you dearly. You both left me the way I wouldn’t have expected, but your presence echoes in every single day of my life, now and forever.



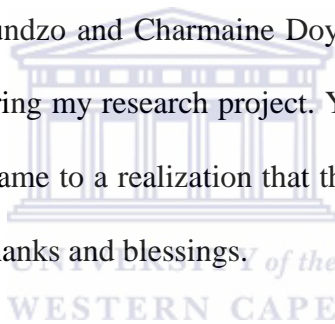
To my siblings Shirley, Portia, Lizzy (the late younger sister), Nkholo and Kagiso I thank you for each positive impact you’ve made in my life. I love you all dearly and unconditionally so.

To my second mother Gabriella Gaby Saurma-Jeltsch, words cannot even begin to express how I love and appreciate you. You have such a great heart, full of love and warmth. You did everything to me only a biological mother would do to her child. You continually supported me in many awkward times of writing up my thesis. I thank God endlessly for having brought you in my life. May the Lord add many more days to your life. I love you dearly.

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## **ABSTRACT**

South Africa is reported to have the highest prevalence of HIV/AIDS infections in Sub-Saharan Africa. As a result the quality of life of families living with HIV/AIDS is negatively affected. Literature indicates that the majority of affected persons are young children and adolescents whose siblings or parents are infected with HIV/AIDS. Most affected adolescents are reported to have difficult social lives due to their parent's illness, difficult financial situations at home, stigma and discrimination within the society. The study attempts to explore the experiences of adolescents in households where the mother is HIV/AIDS positive. This research project is an exploratory study using a narrative approach within a qualitative methodological design. The study was conducted with 6 Xhosa-speaking adolescent boys (2) and girls (4) aged 12 to 15 years. An open-ended interview schedule was used to prompt participants to tell their stories. Data was collected by means of a voice recorder in order for adolescents to tell their stories. The responses were transcribed verbatim, translated and verified with the participants. The data were analysed by means of narrative analysis. The results indicate that most adolescent participants were coping with the mother being HIV/AIDS positive and maintained hope for their futures. Adolescents were coping due to support from friends and relatives. Some adolescents experienced rejection and discrimination. The biggest challenge in the home was due to socio-economic status. The study is intended to benefit the community in terms of making recommendations to social workers at NGO's and the government sectors in terms of strengthening the existing support programmes in the community.



## **DEFINITIONS OF ABBREVIATIONS**

HIV: Human Immunodeficiency Virus

AIDS: Acquired Immune Deficiency Syndrome

NGO: Non- Governmental Organization

PLWA: People Living With AIDS

OVC: Orphans and Vulnerable Children

## **DEFINITIONS OF TERMS**

The term '**adolescence**' derives from the Latin verb *adolescere*, meaning 'to grow up' or 'to grow to adulthood', thus referring to a development phase in the human life cycle that intervenes between childhood and adulthood, [Gouws & Kruger, 1996: 3]

**HIV** is the virus that attack and destroy the immune system, causing the person to be vulnerable to infections (Whiteside & Sunter, 2000). **AIDS** is "the presence of a reliably diagnosed 'opportunistic' disease and of an underlying defect in cell mediated immunity in the absence of known causes of immune defects such as immunosuppressive therapy or malignancies" (Onin, cited in Salati, 2004: 7).

A **household** according to Woodford (2007: 348) refers to "a family or group of people who live together in a house".

**Experience** is "a knowledge that you get from doing a job, or from doing, seeing, or feeling something," (Woodford, 2007: 248).

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# CHAPTER 1

## CONTEXT

### 1.1 Introduction

This study focuses on the experiences of adolescents living in households with mothers who are HIV/AIDS positive. Context for this research is in the community of Khayelitsha, within the Western Cape Metropole.

South Africa has continuously been ravaged by the effects of HIV/AIDS over the past two decades. A mid-year report from Statistics South Africa (2009) found that the HIV positive population is estimated at approximately 5, 21 million (Statistics South Africa, 2009: 3). The number of people believed to be HIV positive has ‘increased from nine percent in 2001 to 12 percent in 2008,’ (Cape Times, 2009: 7). It is estimated that 413 000 people in South Africa contracted HIV during 2009 (Statistics South Africa, 2009). As the HIV prevalence multiplies, so is the rate of children affected by HIV/AIDS. It is stated that “according to statistics in its latest South Africa Survey, by 2015, 32 percent of all children here would have lost one or both parents due to HIV/Aids,” (Cape Times, 2009: 7). Apart from this resulting in orphanhood, HIV/AIDS severely contributes to the vulnerability of the affected children. Currently children who are living in households where a parent is ill with AIDS have to witness the whole process of illness (Simbayi et al. 2006). There has been a notable suggestion that such experiences could be harmful as they have a negative impact on the child’s social, emotional and educational wellbeing.

A number of HIV/AIDS research findings have indicated that children affected by HIV/AIDS through parents’ illness suffer in terms of the following: material loss, HIV/AIDS related stigma and discrimination, loss of parental love and support, malnutrition, household economic deteriorations, loss of educational opportunities and having to take over adults’ responsibilities (Richter, 2004; Ranchod, 2005; Mbambo, 2005; Davids et al. 2006; Linsk & Mason, 2007). Most of the behavioural studies concerning children have mentioned that a negative experience in early childhood can

have long-term effects on the psychological well being of a child (World Health Organization, 2007; Richter, 2004; Rotheram-Borus, Stein & Lin, 2001; Deacon & Stephney, 2007). Other studies which focus more on adolescents have concluded that adolescents who witness a parent suffering from HIV/AIDS related illnesses have mostly displayed greater emotional distress, depression and even committed suicide (Bauman et al. 2006; Gunther, Grandles, Williams & Swain, 1998). In an environment so emotionally harmful to children affected by HIV/AIDS, the question of what life could be like for adolescents in households where the mother is suffering from AIDS related illnesses, becomes a concern. The importance of addressing this concern is based upon searching for effective strategies towards strengthening care and support programmes in terms of psychosocial support. Psychosocial support refers to the holistic approach given to a child in meeting the following needs: physical, social, emotional, mental and spiritual (Richter, Manegold & Pather, 2004).

Adolescence is commonly characterised as fascinating, stormy and stressful. Being a transitional period from childhood to adulthood, certain internal and external changes of life are experienced for the first time in the life of an individual involved. During adolescence youth are faced with difficult social and psychological challenges (Arnett, 2001). Major physiological cognitive and behavioural changes occur to enhance growth and development (Ariganjoye & Daigneault, 2007). Adolescence can be challenging as adolescents have to “deal with rapid changes in physical appearance, hormonal fluctuation, mental and physical abilities, and a growing pressure and increased expectations from family, teachers and other adults”, (Ariganjoye & Daigneault, 2007: 1). Difficult experiences which are likely to occur throughout the developmental stages can lead to feelings of stress, confusion and depression which may negatively affect the emotional and mental health of a young adult (Arnett, 2001; Andrews, 1997; Ariganjoye & Daigneault, 2007). In addition, at this stage adolescents are bound to experience identity problems. According to Erikson (1968) adolescents undergo identity crisis which he describes as a combination of becoming independent and exploring identity formation. Identity formation is defined by Erikson (1968) as a thinking and self reflection time, whereby an adolescent focus more on finding out who they are, what is their purpose in

life and how do they really fit into the world around them. For Erikson the central issue in adolescence is identity versus confusion. Hence, failure to form a stable psychosocial self-definition in the process of identification may result in identity confusion, (Erikson, 1968: 165-166).

## **1.2 Problem Statement and research question**

Adolescence is a crucial developmental stage for young people. This is a phase of life that comes with its own challenges and young people in this stage require all the necessary support ranging from financial, emotional, social and educational to moral support. In the event that an adolescent is deprived of these support structures and even forced to play supportive roles such as fending for the family simply because the parents are either ill or dead, then the life of this young person becomes challenging. This is typical of what most adolescents experience when the parents become infected with HIV/AIDS. It is against this background that the researcher has explored the experiences of these adolescents, with particular focus on adolescents whose mothers are HIV/AIDS positive. In South Africa, there is very limited research evidence with regards to the aforementioned focus area. Other relevant studies have focused on the attitude, behaviors, knowledge, and beliefs of South African youth towards the HIV/AIDS pandemic (Eaton, 2002; Pharaoh, 2002; Plaatjie, 2003; Simbayi, Chauveau, & Shishana 2004). However, this research contributes to new knowledge regarding the experiences of adolescents living in a household where the mother is HIV/AIDS positive to improve service delivery. This is intended through providing relevant information and recommendations in attempt to strengthen the existing support programmes for these adolescents.

The primary question in this research study is: How do adolescents experience life living in households where the mother is HIV/AIDS positive?

The following sub questions emerged in support of the main research question:

- (a) How do they feel about their mothers having to live with HIV/AIDS?
- (b) What are the consequences for adolescents whose mothers are HIV/AIDS positive?

### **1.3 The aims and objectives of the study**

This research aims to explore and describe the experiences of adolescents living in households where the mother is HIV/AIDS positive. Furthermore, the study sought to:

1. Explore adolescents' feelings and thinking with regard to the mother's HIV/AIDS status.
2. Identify the types of experiences which adolescents endure in households where the mother is HIV/ AIDS positive.
3. Explore how adolescents' daily processes are affected.
4. Describe the coping mechanisms used by adolescents in households where the mother is HIV/AIDS positive.

### **1.4 Significance of the Study**

Adolescents are emotionally hardest hit by the HIV/AIDS pandemic as they are also dealing with the psychosocial problems associated with this developmental stage. It is apparent that adolescents affected by HIV/AIDS are experiencing psychosocial problems, due to stigma and discriminations in the community. Additional to these problems is the economic need to earn a living as their ill parent is not able to provide economically. This situation is due to a lack of well developed support structures for adolescents affected by HIV/AIDS (Black, 2009). A number of NGO's exist which run support groups and home-based care programmes for PLWA but no evidence could be found on academic researched support systems in place for HIV affected adolescents. No trace of a structured support system from the government either, as there is no practical approach in this regard to exercise adolescent children's rights (Mbambo, 2005). The information gained in this study will reveal perceptions and experiences of adolescents. This will contribute towards knowledge reflecting the psychosocial experiences of adolescents affected by HIV/AIDS, thereby identifying effective and more appropriate strategies to strengthen and support their coping capacities in terms of emotional and material needs (Richter, Manegold & Pather, 2004; Taylor, Dlamini, Kagoro, Jinabhai & de Vries, 2003). In addition, the



findings of this study could inform intervention programmes for different NGO's which supports HIV/AIDS affected adolescents.

## **1.5 Thesis layout**

**Chapter 1** presented the problem statement, the aim of the study and its significance.

**Chapter 2** examines the literature on the experiences of adolescents affected by HIV/AIDS and adolescents development, i.e. cognitive, emotional, psychosocial, physical and biological maturity.

In **Chapter 3** the theoretical framework related to this study is presented. The Social Constructionist epistemology was opted for as it seeks to make interpretations of a link between language, beliefs and the social actions of a person. Social constructionism is defined by a number of scholars as a sociological description of knowledge (Burr, 1995; Hruby, 2001; Nkosi, 2006). Social constructivist approach was found appropriate as the study has a particular focus on the story telling of adolescents living in households where the mother is HIV/AIDS positive. In the study the researcher has used language as a tool to interact with the participants in order to co-construct reality.

**Chapter 4** describes the research design and methodology. As the study focuses on enquiring about the participants' experiences, feelings and thoughts, the chapter adequately presents the framework for the qualitative research used. Qualitative research focuses more on producing explanations and not on offering mere descriptions, (Mason, 2002). Hence it is appropriately usable to present people's experiences and feelings for the world to view and gain insight (Terre Blanche & Durrheim, 1999; Allan, 1991).

A narrative approach is used for its emphasis on language as the significant tool in a social context through which people are able to communicate and share their feelings, perceptions, ideas, beliefs and stories, and most of all their self-conception, (Gubrium & Holstein, 2009; Knowles, 2007). It is thus for such purpose that this study uses a qualitative method with a narrative approach to collect and analyse data. The chapter

further discusses the research instrument and method of data analysis. It concludes by stating the ethical considerations which are taken into account.

**Chapter 5** presents a detailed narrative analysis of the research data. According to Dainte and Lightfoot (cited in Nkosi 2006: 75), narrative analysis “is the process that involves explaining psychological phenomena as meanings that are ordered from some theoretical perspective”. In this chapter, narrative analysis identifies themes drawn from the individual story. The chapter also outlines the presentation of themes which unfold from the interview data. Each participant’s personal experience of living in a household with HIV/AIDS positive mother is discussed. The chapter concludes by weaving the analysis together into a coherent story.

**Chapter 6** presents conclusions and recommendations. In extend, the chapter provided summary of findings, methodological limitations and further research possibilities.



## CHAPTER 2

### VULNERABLE ADOLESCENTS OF MOTHERS WITH HIV/AIDS

#### 2.1 Introduction

Adolescence is often highlighted as a period of ‘storm and stress’ (Colten & Gore, 1991). It is a time during which an identity is formed as well as finding freedom to live and the meaning thereof. During this time adolescents experience an awakened self-awareness of the other in relation to the self (Arnett, 2001). Adolescents living in a household where the mother is ill with HIV/AIDS may perceive themselves differently from others since they face the stigma, discrimination, rejection and maltreatment from others as a result of HIV/AIDS. HIV/AIDS is often associated with promiscuity and in most cases adolescents affected are disregarded within their families and communities (Hikuam cited in Roman, 2006: 33-34). Adolescents living in a household where the mother is HIV/AIDS positive may therefore be psychosocially challenged.

This chapter focuses on adolescents living in households with mothers living with HIV/AIDS, their psychosocial needs and experiences, their vulnerability, fears and how they cope in their households and within the community. It also examines the gaps in terms of how these adolescents are supported, according to their unique needs, and how adolescents cope with their challenges.

#### 2.2 Origins of HIV/AIDS

There is a belief that this disease was identified between the middle and late seventies, but went unnoticed. Furthermore, in 1981 in Los Angeles in the United State of America, a group of homosexual men were diagnosed with the skin cancer known as Kaposi Sarcoma and Pneumocystis Carinii Pneumonia, which was very concerning to the doctors (Cichocki, 2007). It was then discovered by the Institute Pasteur in France that the Lymphadenopathy Associated Virus (LAV), was an underlying cause for these illnesses (Cichocki, 2007). In 1984 Robert Gallo of America isolated HumanT-Cell Leukemia Virus Type-111 (HTVL-111) as the causal organism of AIDS (Papadopulos-Eleopulos,

Turner, and Papadimitriou, 1995). LAV and HTLV-111 were later called HIV (Cohen, 2000). To date there has been many debates and speculations around the history and origins of HIV/AIDS. Most of these debates are political (Seckinelgin, 2002). In South Africa the former president of the country, Thabo Mbeki, caused much controversy when he remained unconvinced that HIV caused AIDS. Furthermore, according to the Mail & Gurdian online news source (November, 2009: 1) a study conducted at Harvard University “found that Mbeki and Tshabalala-Msimang were directly responsible for more than 330 000 Aids-related death during their tenure.” This was based on Thabo Mbeki and his government’s denial about HIV/Aids and treatment for disadvantaged South Africans living with HIV/AIDS (Mail & Gurdian Online News Source, 2009).

### **2.3 HIV/AIDS Phases of discovery**

HIV is known as a virus that causes AIDS. Once a person gets infected with HIV, it attacks the immune system which is the body’s defense mechanism. The system becomes weak and unable to function, therefore immunodeficiency. HIV is a virus that is only found in humans; thus it is called ‘human’. Furthermore, It is also documented that HIV needs human cells to survive and for self replication (Fox et al. 2001). Since its diagnoses, it has been categorised as a retro virus family as it is capable of changing its genetic material, RNA (ribonucleic acid) and again back to DNA (deoxyribonucleic acid) (Coates, 1990). It is therefore incurable since it is unlikely controllable.

HIV is known to be acquired from a person to a person as no one can be born with it. It fights against a person’s immune system and makes it difficult for the system to protect the body from any possible infection. As a result the body becomes weak and unable to fight infections. At this stage a person can suffer more than one opportunistic infection simultaneously. One of these infections could cause the death of this person (Cohen, 2000). AIDS is called a syndrome due to the fact that it presents different types of signs and symptoms for a certain disease.

## 2.4 Psychosocial effects of HIV/AIDS

HIV/AIDS presents its effects in accordance with different stages. According to Maartens (1999), the progression of HIV/AIDS is classified into four clinical stages which are normatively experienced by the sufferers. The stages are as follows: primary HIV infection, the asymptomatic stage, symptomatic disease, and progression from HIV to AIDS (Cichocki, 2007). After getting infected a person might have unobservable symptoms such as fever, headaches, and muscle pains, (Levy, 2007). Although these symptoms are not fatal, their occurrence is more frequent as they re-appear time and again. Also presented but as the main symptom in early stage of the HIV infection are the swollen glands. This is the symptom which was found to be rather persistent (Maartens, 1999). However, at this stage the person can appear asymptomatic as these symptoms are actually minimal. Hence the person might still be able to perform normal activities. Although the infection stage may have negative impact physiologically, there is no report of any noticeable emotional implications as the person might not be aware of his or her HIV status, (American Psychiatric Association, 2000). Additionally, an HIV infected person can be in the window period for several weeks to three months during which the HIV test is negative (Levy, 2007). Nevertheless, the person can however pass HIV to other people, even if she or he feels healthy.

According to Shebi (2006: 10), during stage two of the infection, “the infected person experiences repeated infections of the upper airways as well as mouth ulcers and less than 10% of unintentional body weight loss”. However, as its name suggests, stage two appears to be free from major symptoms. The infected person may continue to look and feel well for many years (Durham & Lashley, 2000). Nevertheless, the HIV virus may still be very active and damaging to the immune system. The infected person can still actively perform normal daily activities. Seeking early care for prevention of opportunistic infections can provide better chances of survival and improved quality of life. Opportunistic infections according to San Francisco Aids Foundation (2003: 3) are called opportunistic because they are caused by organisms which do not ordinarily induce illness in people with normal immune systems, but take opportunity to flourish in people with compromised immune systems. Failure to seek early care in stage two may lead to

stage three which presents observable symptoms. As stage three progresses, symptoms develop. Initially the person may experience some mild HIV infection symptoms such as skin rashes, fatigue, fevers and night sweats, fungal skin and nail infections. However, as the immune systems fails a person may become seriously ill even if she or he has not yet been diagnosed with AIDS, (Durham & Lashley, 2000). According to Molassiotis et al. (2002: 88) when the person becomes ill she or he may experience “mood disturbance as well as anger and hostility, tension and anxiety, depression and dejection, fatigue and inertia, confusion and bewilderment”. Although infections at this stage can occur in almost all body systems, the typical symptoms include chronic oral or vaginal thrush, recurrent herpes blisters on the mouth or genitals, weight loss and wasting, uncontrollable diarrhea, oral hairy leukoplakia and sexual dysfunction, (Maartens, 1999; American Psychiatric Association, 2000). According to Shebi (2006: 11), at this stage “the person is bedridden for less than 50% of the day during the last month”. According to Mullan (1998) a person may experience feelings of discomfort as their sense of autonomy becomes compromised. With regards to tiredness and mental fatigue the conditions may require deployment to light job for a working person. As the immune system deteriorates the infections worsen, which leads to AIDS disease



It is imperative that the infected person in stages two and three receive social, physical and psychological support as they experiences the physical and psychological effects of HIV/AIDS. According to Cichocki (2007: 2) it has been realized that HIV affected both the physical and emotional self. Hence, neurological and emotional symptoms of HIV can include (i) depression, (ii) numbness, (iii) confusion, (iv) weakness or changes in level of consciousness (Cichocki, 2007). Research studies which examined the mental health consequences of HIV/AIDS revealed that the affected individuals are more likely to experience mental health problems (Mullan, 1998; Scheid, 2005; American Psychiatric Association, 2000). Apart from the cognitive impairment some mental conditions such as depression and anxiety might be the due to lack of social and/or family support systems as well as being aware of the reality of their HIV/AIDS status, (van de Wouwer, 2005; Roman, 2006; Shebi, 2006; Black, 2009). In addition, the person may consequently

experience behavioural problems which usually leads to suicidal thoughts in some cases, (Scheid, 2005).

Stage four is whereby the progression from HIV to full blown AIDS occurs. The immune system at this stage becomes severely damaged, and any illness that occur seem even more severe (Levy, 2007). The clinical features observable during stage four are severe weight loss and wasting, persistent diarrhea which is resistant to treatment and last for a longer period, confusions and signs of mental disorders due to affected brain functioning, (Mullan, 1998; Maartens, 1999; Molassiotis et al. 2002). This stage can also presents multi-infection such as pneumonia, tuberculosis, Kaposi Sarcoma, brain infections, fungal infections in the lungs and the meninges, and blood related infections, (American Psychiatric Association, 2000; Levy, 2007). At this stage “the infected person will be bedridden for more than 50% of the day during the last months thus requiring 100% nursing care”, (Shebi, 2006: 11).

## **2.5 Vulnerable adolescents**

Vulnerability according to Little et al. (2000: 495) refers to “susceptibility to any kind of harm, whether physical, moral or spiritual at the hands of any agent or agency, and it is related to disempowerment and loss of autonomy”. The fact that adolescents are vulnerable as they have terminal ill parents’ results in circumstantial vulnerability which becomes a theoretical perspective employed to explain the psychosocial impact of HIV/AIDS among individuals and groups. The concept of circumstantial vulnerability creates a platform for examining behavioural problems developed as a result of stresses, losses and trauma, and therefore makes a provision for understanding them. There are number of factors leading to these conditions: the effects of social stigmatisation (Deacon & Stephney, 2007), anxiety about who will take care of them should the parent die (Richter, Manegold & Pather, 2004), and how will they cope without parental support and love (Strode & Barret-Grant, 2001).

Being a transitional period of human development, adolescence brings about a combination of physical and psychological changes in a human’s life. According to Black

(2009: 15) “adolescence is particularly vulnerable period of development”. During this stage a person’s body undergoes rapid changes including biological maturity. This is due to the hormonal changes. These hormonal changes also trigger experimentation and exploratory behaviour. Adolescents at this time experience urges to experiment and explore variety of life possibilities which put them in vulnerable situations (Arnett, 2001). Majority of adolescents engage in sexual practices for the first time and that is mostly done without any protection (Arnett, 2001). Unprotected sex exposes adolescents to vulnerable situations as they are at risk of contracting HIV and other sexually transmitted diseases as well as unintentionally falling pregnant.

According to D’Angelo, Samples, Rogers, Peralta and Friedman (2006), the highest prevalence of HIV/AIDS was found among young people aged between 15 and 24. The study was conducted in United State of America. Some adolescents begin to experiment with drugs and alcohol use, smoking cigarettes and risky driving (Andrews, 1997). Breaking laws of various kinds is also common among adolescents, especially for males (Andrews, 1997). Experimentation is normally due to curiosity but also used at times to relieve unpleasant emotions such as loneliness, sadness, anxiety and stress. However, these are risky behaviours as they have the potential to become a habit and often adolescents begin to depend on them to feel good physically and psychologically (Black, 2009). Unfortunately, the continued use of alcohol and drugs may lead to impaired judgement and as well prolong the high-risk behaviour. Loss of autonomy creates vulnerability in adolescents’ lives as most of them feel disempowered, depressed and suicidal, (Jonson, 2009). Research shows that adolescents living in households with HIV/AIDS positive mothers lose autonomy as they have to be emotionally supportive to their mothers due to the ill health (Lee, Lester & Rotheram-Borus, 2002; Bauman et al. 2006; Black, 2009). According to Lyon and D’Angelo, (2006), effective parental and social support can help adolescent overcome problem behaviour and unpleasant risky habits.

Research indicates that adolescents from lower socioeconomic communities are particularly vulnerable in many different ways due to the fact that most of them have poor



educational backgrounds, less access to information about HIV/AIDS, experience high level of poverty, low self esteem, and less access to health care services (Deacon & Stephney, 2007; Black, 2009; Jonson, 2009). These types of groups are more likely to engage at-risk activities to earn a living. The activities include committing crime, prostitution or dropping out of school and becoming a street child, etc. As a result, adolescents from lower socioeconomic status are at risk of ending up in jail, contracting and living with HIV/AIDS. With all these challenges adolescents affected by HIV/AIDS have to face the consequences of stigma and discrimination. In addition to the socioeconomic impact, adolescents affected by HIV/AIDS are specifically vulnerable to the HIV infection. Their situation is usually intensified through engaging in early sexual intercourse, commercial sex and sexual abuse (Black, 2009). “All of these may be precipitated by economic need, peer pressure, lack of supervision, exploitation and rape”, (Simbayi et al. 2006: 12).

Another factor that contributes to the vulnerability of adolescents affected by HIV/AIDS is based on how the HIV/AIDS epidemic has been socially constructed. Research states that adolescents affected by HIV/AIDS have been perceived as evil and immoral (Campell, Foulis, Maimane, & Sibiya, 2005; Lyon & D’Angelo, 2006; Deacon & Stephney, 2007). This type of perceptions are based on the socially constructed ideas and beliefs that HIV positive people are sinners, sexually immoral and promiscuous, (Soskolne, 2003; Francis & Francis, 2006). Furthermore, adolescents affected by HIV/AIDS have a tendency to acquire self stigmatisation based on their experiences of social environments (Deacon & Stephney, 2007). According to Corrigan, Larson and Rusch, (2009: 75) self-stigmatization refers to the following three steps: “awareness of the stereotype, agreement with it, and applying it to one’s self.” Self-stigmatization creates high level of vulnerability as the affected individuals are at risk of continuing risky behaviours due to self pitying and lack of self valuing. Stigma and discrimination could disturb adolescents’ psychosocial well being which develops through identity, (Jaffe, 1998: 176). This research study investigates whether there are any implications with regards to self-stigmatisation in the context of adolescents living in households with HIV/AIDS positive mothers.

### **2.5.1 Adolescents' experiences of HIV/AIDS**

According to Alvarex (2001: 1) “adolescents and young people are now infected and affected by HIV more than any other population group”. Similarly, Black (2009), and Jonson (2009) found that adolescents constitute one of the most visible populations affected by the HIV/AIDS epidemic. Although there have been reports regarding vertical transmissions, there is also sufficient evidence that adolescents have generally acquired HIV infection through sexual intercourse (D’Angelo et al. 2006; Black, 2009). Most adolescents who test HIV positive usually experience denial (Black, 2009). The denial process, in the context of adolescence, may have more to do with the nature of the stage as most of young people tend to think that they are immune to any negative outcomes on at-risk lifestyle.

Adolescents, who become aware of their HIV positive status, often do not follow up for health and clinical care, due to lack of access to appropriate care or because of fear to be found out, and mistrust of the medical system in terms of confidentiality (Lyon & D’Angelo, 2006). Also, it has been indicated that adolescents who disclosed their HIV positive status were stigmatised and rejected by community, health care facilities and their own parents (Campell et al. 2005; Francis & Francis, 2006; Lyon & D’Angelo, 2006). These adolescents are as well experiencing difficulties in terms of coping with their HIV diagnosis, and the physical and emotional implications thereof. It is reported that some of them experience anxiety, depression, substance use, academic failure and other psychiatric illness, (Richter, Manegold & Pather, 2004; Deacon & Stephney, 2007).

Research examining the psychosocial well-being of adolescents whose mothers are HIV positive revealed that these children are at risk of developing social adjustment problems. This includes academic performance difficulties, psychological and behavioural difficulties and loneliness (Linsk & Mason, 2004; Tompkins & Wyatt, 2008).

### **2.5.2 Sense of self in adolescence**

During adolescence, adolescents begin to develop a sense of self. These adolescents become more aware of their individual self and the environment around them. Such a development does not occur in children as they have less ability for abstract thinking and less cognitive capacities for self reflection (Arnett, 2001). In this stage adolescents not only mature physically, but also at the same time experience brain growth which equips them for self identity formation. The self identification process includes components of cognitive and moral development, self awareness, self esteem, ego identity and social interactions. Thus, the identity formation process has frequently been viewed as the most challenging and rather difficult as adolescents are desperately seeking for a satisfactory sense of belonging (Erikson 1980: 95).

For Erikson the major challenge in adolescence stage is identity versus identity confusion, (Erikson, 1968). He believed that a timetable of development has much to do with genes and that social and psychological development only play a subordinate role. This is due to the fact that social and psychological development has much to do with the process of child socialisation. Usually, the role players in the socialisation of a child are family, community, schools and recreational centres. He therefore called the process the psychosocial stages which he believed contributes for the formation of identity (Bigner, 1998). Erikson's psychosocial stages are divided into eight. Each of them, according to Erikson presents age appropriate crisis which may result in either negative or positive personality outcomes. According to Erikson if the previous experience in earlier stages has been problematic, then the outcomes will be identity confusion in adolescent development and vice versa (Arnett, 2001). In the context of this particular study, it is discovered that adolescents living in households where the mother is HIV/AIDS positive are often have to endure the responsibility of keeping their mother's status a secret, and the constant fear of losing a parent through death (Dorn, Henderson & South, 1994). Such situations may be difficult to cope with and can, if not properly dealt with, have a negative impact on the process of identity formation in the lives of these adolescents. The negative impact herein may be evident through negative personality outcomes such as confusion, anti-social and destructive behaviour (Bigner, 1998; Black, 2009).

There are numerous theories which possess information relevant to identity formation. Kohlberg (1963) has provided a comprehensive theory on moral development. In his moral development theory Kohlberg (1963) asserted that both moral reasoning and moral behaviour contributes to identity formation in accordance with relevant age. His argument was supported by Jane Kroger (2004: 114) when she stated that “as one develops toward higher modes of moral logic, one’s action become more moral”. His theory background has a link to Piaget’s theory of cognitive development. Both these theories emphasise on developing adolescents’ thinking through facilitated environment whereby participants use their own intelligence to actively construct their own knowledge. In the context of adolescents living in households with HIV/AIDS positive mothers, an opportunity can be provided for this group to construct the reality of their situations through story telling. Vygotsky’s (cited in Overall, 2007: 73) theory has a different approach in the cognitive development of adolescents in that it has incorporated social context as an influential instrument in the developmental process. This theory has identified social interaction as important aspects since adolescents also need to learn from significant others. Hence Vygotsky social constructivist view of development is also relevant as research shows that peer involvement in the lives of adolescent affected by HIV/AIDS is very important in terms of emotional support (Gunther et al. 1998; van Niekerk, 2003; Jonson, 2009).

In contrast, other studies reveals that adolescents whose parents are known to be HIV/AIDS positive are often excluded from or treated unfairly at school (Dorn et al. 1994; Poindexter, 2005; Deacon & Stephney, 2007) a place through which their intellectual abilities could be developed by collective aspects of one’s own construction of knowledge and social interaction. In addition, these adolescents also experience rejection from within the family during the process of their mothers illness (Nashandi, 2006), which means that there is no moral development or support due to lack of adult supervision. Ultimately adolescents living in households where a mother is HIV/AIDS positive may not have any sense of intellectual and moral support to strengthen their self conception.

### 2.5.3 The self esteem and adolescence

According to Arnett (2001: 163), self-esteem “is a person’s overall sense of worth and well-being.” Adolescent’ self evaluation is enhanced by people’s positive reactions towards their actions, (Jones, 1980). Positive influences on self esteem encourage adolescents to have high self-esteem. Being approved and accepted by close people such as parents, peers and friends plays a major role in developing adolescent self esteem (Jaffe, 1998). However, adolescents affected by HIV/AIDS often feel ashamed of themselves. The experience is usually caused by negative remarks passed towards them by the people in their communities. A teenager whose parents are known to be HIV positive was quoted saying that, “they treat you badly, you don’t feel like walking in the street, they give you names” (Strode & Barret-Grant, 2001: 24). It is thus evident that adolescents affected by HIV/AIDS are negatively labeled due to beliefs and ideas that are socially constructed about HIV/AIDS, and its associated people. Also, it is rather difficult for these adolescents to maintain high self esteem due to constant criticism. It is evident that apart from physical appearance low self esteem in adolescence can also be linked primarily to feeling rejected by a group of peers and therefore feeling unimportant.

Through cognitive development adolescents become capable of thinking abstractly and analysing their own thoughts. Therefore, they become self conscious with regards to not being liked or accepted. The situations of not being accepted by other peers become a real challenge in terms of self reflection for adolescents living in households where the mother is ill with HIV/AIDS. For example, studies indicate that these adolescents experience ‘courtesy stigma’ (Deacon & Stephney, 2007; Poindexter, 2005). Courtesy stigma according to Angermeyer & Matschinger (cited in Deacon, Stephney & Prosalendis, 2005: 26), refers to “stigmatisation of families of the affected individuals.” This leads to individuals being isolated, hidden, fearful and stressed. As a result their self esteem becomes negatively affected. (Shebi, 2006).

#### **2.5.4 Cognitive development of adolescents**

Similarly to a healthy self esteem cognitive development is as important and essential in the transition period between childhood and adulthood. Cognitive development according to Hook, Watts and Cockcroft (2002: 175) refers to “the way in which people acquire various cognitive abilities and how these abilities change overtime.” A healthier cognitive development contribute to a formation of a positive self concept as adolescents brain begin the ability to process more abstract thoughts which enable them to answer the question “who am I?”, (Cronje, 1984). As this period is challenging, adolescents need to be positively responded to in order to move smoothly through these cognitive transitions.

According to George Herbert Meade “cognition rather than emotion is the central element of self” (Brown, 1998: 84-86). He feels that a positive family support system and a healthy social interaction effectively lays a foundation for a positive self as adolescents value and adopt the perspective of a particular other for self reflection. A positive self reflection has an influence in brain growth and maturity. According to Piaget’s formal operations stage which is believed to begin about age eleven and reaches completion at about the age of twenty, adolescents become capable of solving problems through the developed ability to think scientifically (Arnett, 2001: 66). Such problem-solving abilities are achieved through cognitive conflict according to Kohlberg’s theory, which lead to reorganisation of cognitive structures and progression into the next developmental stage of cognitive and moral development (Vasta, Haith & Miller, 1999). Both Kohlberg and Piaget theories believe that a process of adaptation and accommodation stimulates cognitive ability to higher levels. For Kohlberg a higher performance in dealing with moral dilemma is the outcomes for operating on a higher moral and cognitive level (Light, Sheldon & Woodhead, 1993).

As cognitive development and self esteem are similarly enhanced through positive response from peers and significant others, the situation is however different for adolescents affected by HIV/AIDS as they are rather criticised and devalued by their peers (Deacon & Stephney, 2007). According to Roman (2006) experiencing stigma may strongly affect mental abilities of a person as they are being treated differently and

unjustly. The situation often creates anxiety, stress, loneliness and depression (Molassiotis et al. 2002). Additionally all these negative effects experienced by HIV/AIDS affected adolescents can interrupt or impair their academic performance. The consequences can thus negatively affect the cognitive development and self image of adolescents.

Adolescents affected by HIV/AIDS also experience ill treatment at a time when they mostly needed emotional support. Usually, an effective emotional support is offered by a family member, relatives, peers, friends and teachers. However, adolescents in households where the mother is ill with HIV/AIDS often get rejected by these people they have put their trust in. The community also appears unsupportive due to lack of effective interventions in terms of programmes relating to HIV/AIDS education (Simbayi, Kaseje & Niang, 2007). It is therefore concerning how this group of adolescents copes psychologically and socially. Such a concern arises from the fact that adolescents affected by HIV/AIDS can be negatively impacted in terms of how they think and also how they perceive matters concerning them. The experience may be harmful to their cognitive capacities due to self pity, shame and a fear of what they have become. In addition, it might be difficult for abstract thinking to take place.

As this study seeks to describe adolescents' experiences of living in households with HIV/AIDS positive mothers, it is thus significant to provide information regarding the mothers' situation. The following discussion illustrates the link between the mother's HIV/AIDS status and how it affects the adolescent child.

## **2.6 Mothers with HIV/AIDS**

Due to HIV/AIDS related illnesses most of the infected mothers find themselves in rather disabled conditions, in which their adolescent children have to take personal care of them and additionally perform major household tasks (Bauman et al. 2006; Tompkins & Wyatt, 2008). The conditions brought about by the ill mother are known to have negative impact on adolescent child's behaviour as they can result in psychological crisis. As for the mothers "worrying about the effect of their illness on their children" becomes such an emotional pain (Strode & Barret-Grant, 2001: 45). Not only do these mothers have to deal

with their own ill-health challenges, but also have to focus on monitoring the psychosocial well-being of their affected adolescent children. According to Gunther et al. (1998), some HIV positive mothers in New York City took extra measures as they specifically requested that their affected adolescent children should have a special support group for the non-infected.

In some situations even though they are physically weak, these HIV/AIDS positive mothers still have to perform a nurturing role in order to provide care and support to their children as well as meeting the needs of their demanding husbands (Were in Nashandi, 2006; Roman, 2006). As a result, they end up not able to take care of themselves in accordance with their HIV/AIDS status. These mothers are often blamed by husbands for bringing the virus in the family (Nashandi, 2006). Additionally, the situation become emotionally aggravated when a mother discover that even her own children blame and reject her for being HIV/AIDS positive (Roman, 2006). In some situations HIV/AIDS positive mothers prefer not to disclose their status as they fear encountering negative responses from their partners, relatives and communities. Their choices of preference lead to feelings of isolation and loneliness as they are thus unable to talk to anyone about their health conditions (Roman, 2006).

Issues around HIV/AIDS pandemic indicate that mothers are more likely vulnerable in incidences of HIV than men. Most research conducted with regards to topics such as gender roles, gender inequality and HIV/AIDS have revealed similar findings as in the following: (1) mothers being culturally subordinate to their husbands (2) mothers inability to negotiate safer sex (3) and women being in a submissive position both sexually and economically (Anarfi, 2003; Hallman, 2005; Plaatjie, 2003). The existence of these social and cultural constraints of women put them in the vulnerable position in terms of HIV infection and male violence. These socially constructed norms which serve to demote women have also made severe their experiences of living with HIV/AIDS, (Vetten & Bhana, 2001; Soskolne, 2003; Roman, 2006).

Submissively, binding by the existence of these social and cultural constraints in the society mothers find themselves continuing engaging in sex with unfaithful partners



(Arnafi, 2003). The cause of such situations may have much to do with fear of being assaulted by their partners, as well as fearing to lose the sole provider (Roman, 2006; Nashandi, 2006). Furthermore, society places men in power-exercising positions where it is socially acceptable for them to experience sexual practices with different women, but rather a disgrace for a woman to act the same way (Roman, 2006). According to researches conducted on women it is evident that men have more access to generating economic resources for the sustainability of family with regards to financial support (Vetten & Bhana, 2001; Soskolne, 2003; Roman, 2006). Thus women are socially placed in vulnerable positions where, circumstantially, they become less likely to say 'no' to the oppressive structures made acceptable by the society at large.

In addition, physiology is perceived as one other aspect that put women at higher risks of HIV infection, compared to men. The latter is due to the biological make up of female's private parts which is more susceptible to a male's infected semen (Levine & Ross, 2002). Thus, physiology makes it easier for a woman to contract HIV/AIDS. Since men are more sexually dominant, it is therefore identified that "involving men in prevention and care as a crucial intervention for reduction of HIV/AIDS morbidity and mortality" could perhaps innovate HIV prevention as well as decreasing women's vulnerability (Okunga-Nambassi, 2006: 41). Other recommendations based on the belief that men can change have suggested that existing interventions on HIV/AIDS and behavioural change should be more focused on men (Moletsane, 2004). It is evident that there is a gap in terms of implementing intervention programmes with a focus on changing men's behaviour, (Moletsane, 2004). Research also reveals that due to lack of knowledge men tend to perceive women (and not themselves) as transmitters of HIV/AIDS (Delius & Glaser, 2005). Such perceptions have led HIV positive mothers into experiencing social discrimination more than their male counterparts (van de Wouwer, 2005). In Gaborone, Botswana, a teenage girl told the story of how her HIV positive mother committed suicide because she "could not bear the rejection of her community or the suffering of untreated disease" (Brink, 2003: 5).

## **2.7 Socio-economic and psychological factors**

With reference to the literature, HIV/AIDS negatively affects the social and economical well being of a family which is a child's place of belonging (Francis & Francis, 2006). The conditions usually occurs when the parents gets seriously ill or die of HIV/AIDS, leaving the children in a financial crisis, and vulnerable. The consequences of the parent's death automatically translate into child headed-households. An adolescent child is to take larger challenges as she or he might be forced to drop out of school and commence a new phase to device means of surviving, as well as looking after the younger children (Scott, 2004). In some situation other adolescents become vulnerable to HIV infection as girls get involved in commercial sex due to financial need (Simbayi et al. 2006). Boys tend to get involved in crime and end up in jail where they get sodomised by HIV positive inmates, (Ranchod, 2005: 4).

Furthermore, families which are affected by HIV/AIDS are often isolated from the community (van de Wouwer, 2005: 155). These experiences usually cause family distress and subsequently affect an adolescent child's psychosocial well-being as it interferes with his or her social relationships. Stressors caused by HIV/AIDS "can have profound effects on the quality of life of people living with HIV/AIDS because they affect the perception of well being, social relations, independence, self-esteem and the energy reserved to cope with the illness" (Molassiostis et al. 2002: 84).

The experience of the adolescence stage, caring for ill mothers with HIV/AIDS and dealing with HIV/AIDS stigma and discrimination in the community place adolescents in a precarious situation. Consequently, most of them experience cognitive problems, fear, anxiety and depression (Deacon & Stephney, 2007; Bauman et al. 2006; Gunther et al. 1998).

HIV/AIDS also places the economic status of the family at stake. Having to take care of the ill person at home can place strain on the family finances, (Katongo, 2002). The conditions may be due to certain diet the person needs to follow, as well as the type of medication regime. At times the ill person is the sole provider for the entire family. The

situation, however, poses a challenge as the only source of income is interrupted and badly affected, causing the whole family experience financial struggle. Some families even face the danger of getting scattered as a result of the HIV/AIDS related death (Booyesen, van Renburg, Bachman, Englebrecht, & Steyn, 2002). Death results in orphans, left with nothing to live on and that they will be forced to cope with limited financial recourses (Ankrah, Mhloyi, Manguyu & Nduati, 1994). The children may need the support of the extended families which may not be provided as these families also have their own children to look after (Shebi, 2006), whereas in some cases they might have fear of becoming infected with the virus (Nashandi, 2006).

## **2.8 Adolescents and coping**

As Woodford (2007: 154) stated “to cope is to deal quite successfully with a difficult situation.” According to Lazarus and Folkman (cited in Rose & Clark Alexander, 1999: 337) coping refers to “ a person’s constantly changing cognitive and behavioural efforts used to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person.” Lazarus and Folkman (1980) have categorised coping mechanisms as problem-focused and emotion-focused. Problem-focused coping occurs when a person identifies factors that caused or causes the problem and then devise means and ways to deal with that in an effective manner (Rose & Clark Alexander, 1999). This type of coping is also known as confrontative and goal directed.

According to Sarafin (cited in Melnick, 2001) problem-focused is directed at defining the problem, gathering alternative solutions, comparing the costs and benefits, and then deciding and acting on the suitable solution. Rose and Clark Alexander (1999) states that emotion-focused coping occurs when a person chooses to avoid the problem and carry on as if what has happened does not matter, and that there is no need to address the consequences thereof. However, in other cases, the person might be avoiding the problem in order to maintain hope and optimism (Rose & Clark Alexander, 1999). Emotion-focused coping is also known as passive and emotive coping, and it is usually exercised when a person believes that she or he is unable to change the situation.

### **2.8.1 Adolescents and coping styles**

As adolescence is commonly characterised as fascinating, stormy and stressful, a number of studies have since discussed the coping mechanisms used by adolescents (Jaffe, 1998; Lyon & D'Angelo, 2006; Gunther, et al. 1998; van Niekerk, 2003; Shebi, 2006; Nkosi, 2006). Most of these studies focused on the context of HIV/AIDS and the affected adolescents. The motive behind that was to explore how this group copes with the psychosocial challenges brought within by adolescence stage, as well as living in households where a parent or both parents are HIV/AIDS positive. Studies which examined the emotional well being of these adolescents have reported that the majority were found to be emotionally distressed, displayed behavioural problems, had low self esteem and suffered depression (Lee, Lester & Rotheram-Borus, 2002; Richter, 2004; Black 2009). According to Gunther et al. (1998), Jonson, (2009), Black, (2009) adolescents support groups and psychotherapy sessions seemed more effective in helping adolescents affected by HIV/AIDS to cope with their situations. It is suggested that the positive impact therein occurred as a result of peer involvement which plays an important role during adolescence. According to Shebi (2006), a constant reassurance from peers and friends can make this challenging stage easier for the adolescent child to cope with. Effective parental and social supports were also identified as another coping style utilised by adolescents experiencing the effects of HIV/AIDS (Rotheram-Borus, 2001; Lee, Lester & Rotheram-Borus, 2002; Lyon & D'Angelo, 2006; Deacon & Stephney, 2007).

Research indicates that the disregarded and belittling treatment experienced by the HIV/AIDS affected adolescents has left them with limited coping mechanisms, such as hope or sometimes no coping at all due to lack of social and family support (Molassiotis et al. 2002; Nashandi, 2002). Ineffective coping or lacks of coping are factors that usually lead to stress and hopelessness. Research indicates that due to lack of emotional support adolescents affected by HIV/AIDS encounter psychosocial adjustment problems (Deacon & Stephney, 2007). This is mainly because during the adolescent stage adolescents rely on other people for acceptance, approval and acknowledgement (Jaffe, 1998). The social support according to Hansel (cited in Shebi, 2006: 17) consists of three subdivisions

which are emotional, cognitive and instrumental. This adolescent stage is also a process of seeking to feel respected, comforted and worthy through interaction with other people, (Hansell cited in Shebi, 2006; Ackermann, 2004). HIV/AIDS related stigma has a negative impact on the cognitive functioning of the affected adolescents (Deacon & Stephney, 2007). It is thus imperative that cognitive support takes place. According to Nkosi (2006: 94) cognitive support can be “in a form of knowledge, information and advice”, as well as “the unconditional acceptance and behaviour displayed” in providing such support. She further posits that the manner in which the cognitive support is provided matters as it also improves the emotional well being of the affected person.

Also proven effective are workshops conducted with a focus on enhancing adolescents’ affective and behavioural skills to cope with the parent’s HIV/AIDS related illness (Rotheram-Borus et al. 1997; Black, 2009; Tompkins & Wyatt, 2008). Other research findings have reported that as parents’ distress and illness have an influence on adolescents’ adjustment so are their healthy coping mechanisms, (Rotheram-Borus, Stein & Lin, 2001). It is therefore clear that the parent’s ability to cope with her illness plays a major role in helping an adolescent child adjust to the situation.

## **2.9 Conclusion**

Reflecting on aspects of vulnerability discussed in this chapter it is evident that adolescents living in households with HIV/AIDS positive mothers are subject to vulnerability in different forms. These adolescents are emotionally hit hardest by the HIV/AIDS pandemic as they are also dealing with the psychosocial problems associated with the current developmental stage: adolescence. The role of stigma and discrimination has deprived adolescents’ opportunities to receive the appropriate support from the family and society. Additionally, the stigma and discrimination experienced by adolescents affected by HIV/AIDS has intensified their conditions. The situation is primarily caused by the lack of well developed support systems for adolescents living with HIV/AIDS positive mothers.

## CHAPTER 3

### THEORETICAL FRAMEWORK

#### 3.1 Introduction

Being interested in the story telling of adolescents living in households where the mother is HIV/AIDS positive, the researcher has opted to use social constructionist epistemology. Social constructionists believe that “words are not just abstract tools used to describe things, rather, they are used to construct the self and the world and thus to make things happen” (Crossely, 2000a: 28). Using qualitative approach, social constructions seek to make interpretations of a link between language, beliefs and the social action of a person. Emerson and Frosh (2004: 8), suggest that a researcher needs to “pay close attention to the social construction of subjectivities in relation to dominant discourse” in order to make meaning of what is being interpreted. Social constructionism is defined by a number of scholars as a sociological description of knowledge (Burr, 1995; Hruby, 2001; Nkosi, 2006).

Social constructionists acknowledge that every form of meaning is fundamentally appropriate based on the context from which it has emerged. Social constructionists believe that knowledge is created through social conversations, academic disciplines, our culture and society, and not particularly from a “single truth” (Nkosi, 2000). According to Vygotsky (cited in Miller, 1993: 370) “humans are embedded in a social matrix and human behaviour cannot be understood independently of this matrix”. In effect, society and culture teaches us how to relate to one another. Language is a tool through which we share beliefs and make collective agreements in terms of meanings which therefore lead us to socially constructed realities (Speed, 1991). Since the HIV/AIDS pandemic has permeated society, there have been controversial beliefs surrounding it. Adolescents in HIV/AIDS affected households experience ‘courtesy stigma’ due to a socially constructed view that people associated with the disease are socially immoral (Deacon & Stephney, 2007). Such socially constructed beliefs are not based on factual evidence, but rather led by social interest and values.

The HIV/AIDS pandemic with its physical, spiritual, psychological and social effects forms a reality from which various socially constructed concepts emerge. These concepts are nevertheless the matrices that produce in general stigma, discrimination, ostracization and rejection of people infected with or affected by HIV/AIDS. They unmask a picture of how the social construction of HIV/AIDS came into existence. As Hacking (2001: 24) states that “nothing has reality until it is spoken of, or written about.” This study has explored in the context of social constructionism all the four effects of HIV/AIDS and how the situation affects adolescents in households where the mother is HIV/AIDS positive.

### **3.2 Socially constructing the physical effects of HIV/AIDS**

Due to the fact that HIV/AIDS has a negative impact on the health and physical appearance of the infected person, it has become a socially constructed reality that any woman looking thinner and/or having pimples must have HIV/AIDS (Nashandi, 2002; Goffman, 1990). Such is the communicated language used to describe people who are HIV/AIDS positive. These descriptions will then be agreed upon and given a meaning by the society in the context of community norms and values. As a result HIV/AIDS positive women are treated badly and called names such as ‘skeleton’ (Nashandi, 2002), or infected with ‘that thing’ (Romans, 2006). Adolescents living in households where the mother is HIV/AIDS positive suffers the consequences of the mother’s status as they also shouldn’t, according to the society, appear physically ill or present any symptoms of HIV/AIDS related infections.

In a South African study commissioned by Save the Children (United Kingdom), one of these adolescent children who has never mentioned anything about being HIV positive or not, was quoted saying that “my skin was bad looking, it had funny things on it, they told themselves that I’ve got AIDS and they ran away from me” (Strode & Barret-Grant, 2001: 29). Such social reactions towards mothers and adolescents infected and affected by HIV/AIDS have somewhat given them a new identification based on their health and physical appearance, thus depriving them of the right to human dignity. These

individuals' bodily appearance is seemingly viewed as deviant to the norms of the society (Shebi, 2006).

### **3.3 Socially constructing the spiritual effects of HIV/AIDS**

Attached to the HIV/AIDS epidemic is the question of morality. There has been moral reasoning and interpretations with regards to HIV/AIDS, and moral principles to create socially constructed beliefs (Deacon & Stephney, 2007). Out of such moral reasoning and interpretations came a collective agreement that mothers infected with HIV/AIDS have sinned before God, they have been promiscuous and have engaged in sexual immorality, hence they deserve the punishment (Poindexter, 2005; Nashandi, 2002). With such attitudes people from the community are unable to accept and support individuals infected and affected by HIV/AIDS, including the adolescents. Instead they discriminate against them, stigmatise and demoralise them (Roman, 2006). Contrary, research indicates that many HIV/AIDS positive mothers have turned to God with regards to coping and finding the purpose and meaning of their lives (Stanley, 1999).

As the world seems to be turning against them, the HIV/AIDS mothers have alternatively found their strength and sense of belonging in God. God in this sense is an employed imagery used by HIV/AIDS positive mothers to make sense of who they are (Crossley, 2000). By so doing these HIV/AIDS positive mothers have created their own construction of the self which differs from the self as socially constructed and conditioned by the society. Adolescents living in households with HIV/AIDS positive mothers experiences moral misjudgment, and courtesy stigma and discrimination within their communities due to their mothers' status. According to society's constructed set of moral principles, these adolescents also deserve God's punishment as they are born from immoral mothers (Nashandi, 2002). The socially constructed moral principles are not necessarily based on the spiritual realities but rather on how the society views the moral realm (Nkosi, 2006; Hacking, 2001). With regards to constructed moral and spiritual realm this research seeks to explore what could be the experiences and views of adolescents living in households, where the mother is HIV/AIDS positive.



### **3.4 Socially constructing the psychosocial effects of HIV/AIDS**

The social construction of the HIV/AIDS positive mother has resulted in stigma and discrimination. These social constructions consists of ideas, facts and beliefs which rather emphasise that the HIV/AIDS positive mother is promiscuous, an HIV transmitter, (Sontag, 1991) and a danger to the community (Roman, 2006). It is therefore justified that the HIV/AIDS positive woman deserves to be excluded from the group. HIV/AIDS positive mothers are often made to feel humiliated and ashamed of themselves by being labeled and stigmatised, (Soskolne, 2003). Society often categorises HIV/AIDS positive mothers as deviant due to the fact that they do not meet the socially constructed norms and values acceptable within their communities (Roman, 2006). These norms and values require that a woman should not be perceived as sexually immoral and promiscuous. Rather she should appear faithful, obedient and submissive to her husband (Boonzaier & de La Rey, 2003; Plaatjie, 2003; Soskolne, 2003; Roman, 2006). In addition, adolescents living in households where the mother is HIV/AIDS positive are also reported to have experienced rejection, stigma and discrimination as they are suspected to be HIV/AIDS positive themselves. These adolescents are denied the interaction with their peers as it is feared that they could pass the infection to them (Roman, 2006).

Both the HIV/AIDS positive mothers and their adolescent children are reported to be experiencing psychological problems such as depression, loneliness and low self esteem due to negatively constructed interpretations of the HIV/AIDS pandemic, which produces stigma (Deacon & Stephney, 2007; Nashandi, 2002). Stigma, according to Alonzo & Reynolds (cited in Roman, 2006) derives from the broader society's perception of what is acceptable as deviant. In case of deviant the affected individuals or groups will then be treated with less value and less acknowledgement as humans. In addition, they will be allowed a very limited access to "humanising benefit of free and unfettered social intercourse." (Alonzo & Reynolds cited in Roman, 2006: 30). Being seen and treated by own family and community as an outcast and worthless human being may have negative impact on the psychological wellbeing of the HIV/AIDS positive mothers and their affected adolescents. As mentioned by the Director of Save the Children (UK) Kevin

Byrne in his foreword that “HIV/AIDS’s social effects are as dangerous and debilitating as its physical effects” (Strode & Barret-Grant, 2001: unnumbered foreword page).

Through social and cognitive support the affected adolescent is provided with the most relevant information thus to enabling him/her to deal effectively with the situation through the knowledge. Even though adolescents do not reach mental maturity at the same time, most of them do “achieve matured levels of cognitive function”, (Nkosi, 2006: 39). Therefore they are able to use acquired knowledge for problem solving (Erikson, 1968). Research indicates that adolescents living in households where the mother is HIV/AIDS positive experiences multiple losses (Mbambo, 2005; Davids et al. 2006; Richter, 2004; Linsk & Mason, 2004). Material loss, which includes home and clothing, has also taken its toll in making a living difficult for these adolescents. This type of a loss occurs when a sole provider dies or can no longer afford to finance the basic expenses of a home, due to inability to continue working because of HIV/AIDS related illnesses. Hence, it is essential that they are provided with instrumental (or material) support which can be viewed as social resources. Instrumental support according to Shebi (2006: 18) “refers to goods and services that are moved toward problem-solving.”

Certain cultures contribute in stigmatising HIV/AIDS positive mothers and their affected adolescents. This occur when the society indirectly approves of man’s unfaithfulness by not calling them names, labeling or discriminating against them when they were found to have multiple partners or any type of sexually transmitted infection (Plaatjie, 2003; Roman, 2006; Nashandi, 2002; Shefer et al. 2002). Socially constructed beliefs and perceptions produce stories that are insensitive towards gender (Doan; 1997). It is socially constructed that a man’s unfaithfulness is an acceptable sign or proof of manhood (Roman, 2006; Plaatjie, 2003; Shefer et al, 2002). In most cases, women have put themselves at risk of HIV infection as they are culturally and socially expected to accept their husbands’ promiscuity and submit to their demands for unprotected sex (Anarfi, 2003; Hallman, 2005).

### **3.5 Conclusion**

Social constructionism is a knowledge building process that is maintained through different interpretations of the world. The social constructionist approach has been applied in this study in order to discover the reality about the experiences of adolescents living in households with mothers who are HIV/AIDS positive. The discussions herein indicate the depth and insensitivity of beliefs, ideas and perceptions socially constructed to stigmatise people infected and affected by HIV/AIDS.



## CHAPTER 4

### RESEARCH METHODOLOGY

#### 4.1 Introduction

This chapter describes the research methodology, specifically the narrative approach analysis. The six steps introduced by Crossley (2000a) are presented and discussed in accordance with the research data. Details about the research design, research setting, population and sampling technique are provided. This is followed by the description of data collection and data analysis. The chapter also discussed the ethical considerations of the study.

#### 4.2 Qualitative research

This study is an exploratory study which is intended to generate qualitative data in relation to the experiences of adolescents living in households where the mother is HIV/AIDS positive. With the qualitative research method the study focused on understanding people through how they define their own world rather than describing or quantifying the situations that are happening to them, which makes it differ from a quantitative research method (De Vos, Strydom, Fouche & Delpont, 2002). Qualitative research focuses more on producing explanations and not on offering mere descriptions (Manson, 2002). According to qualitative research the researcher's role of interpreting and explaining what has been produced through research will not make him/her an 'expert' (Becvar & Becvar, 1996). This is due to the fact that in qualitative research the focus is more on the subjective realm of the participants (De Vos, 1998), which is rather not known to the researcher. However, the researcher's interpretations of research findings are declared valid as "researchers seek to describe and explain the world as those in the world experience it" (Patton cited in Merriam, 2001: 491).

In the researcher's quest to explore the experiences of adolescents living in households where the mother is HIV/AIDS positive, this study has opted to use qualitative method of research as it deals holistically with participants' experiences (Owen cited in Nkosi, 2006). The participant's experiences are understood in complete detail as qualitative

methods enable the researcher to explore, in depth, the social context of the participants' world.

Qualitative methods allow spoken communication to take place between the researcher and the participant. Language is a significant tool in social context as it is used by many people to communicate and share their feelings, perceptions, ideas, beliefs and stories. It is thus appropriate to subscribe to Nicholas' (2003) point of view that linguistic data makes it easier for understanding humans' experiences of their social surroundings, and the meaning thereof. Hence, for the purpose of this study a qualitative method with a narrative approach was used to collect and analyse data. With the qualitative approach the researcher can be more flexible in exploring issues in relation to the research topic.

### **4.3 Narrative approach**

The narrative approach, according to Soskolne (2003: 4), is a method which “arguably gives voice to those who have been otherwise marginalized” in order for them to significantly share their self experience. It is a means for someone to tell his or her story about his or her experiences. Furthermore, Chadwick (2001: 20) states that the narrative approach emphasises language, meaning and interpretation. Additionally, she believes that the telling of stories and narratives about the self experiences “is a very important part of creating and consolidating personal identity”. The narrative approach has been opted for as a relevant method to do research that deals with people affected by HIV/AIDS and other incurable diseases (Crossley, 2000a; Crossley; 2000b; Davies, 1997; Ezzy, 2000; Garro, 1994; Soskolne, 2003). For this particular study, the focus is on the stories which adolescents wish to share regarding their experiences of living in households where the mother is HIV/AIDS positive. The rationale is to make known to the outsiders what life is like for these adolescents, and thus propose intervention strategies.

Researchers examining the psychosocial wellbeing of adolescents have created a link between story telling and identity formation (Van Niekerk, 2004; Carstens, 2003). These researchers believe that story telling has a great impact on the self expression ability of

the adolescent child, which promotes self esteem (Herman, 2003). In this study the researcher kept their intentions to create a relaxing, non threatening atmosphere where research participants would be enabled to deconstruct what has been socially constructed about them, and reconstruct their own truth about their experiences. In most cases, anyone given a voice to speak is empowered to tell his or her life story (Nkosi, 2006). According to Soskolne (2003: 27) the narrative approach “provides researchers with a valuable tool to move those whose stories have been suppressed, and voices silenced, beyond the margins, and makes way for the weaving of alternative stories that challenge or even subvert the limitations of dominant social narratives.”

It is thus appropriate to assert that narratives have a tendency to bring about transformation in the lives of the narrators, the researcher who is listening, and those who will encounter them. By telling their stories, adolescents living in households with mothers who are HIV/AIDS positive are able to comprehend the past experiences and the future thereby linking together sequences of events into a meaningful sense (Polkinghorne, 1988; Sabrin, 1986). In the process these adolescents are also taking role of a ‘co-experiential narrative’ (Hayden, 1997). This is where adolescents additionally tell stories about their mother’s illness and construct their own reality, based on how they feel about the situation.

#### **4.4 Research setting**

The study took place at HOPE Worldwide offices in Khayelitsha. HOPE Worldwide is a benevolence international organisation consisting of integrated programmes of prevention, care and support for both children and adults infected and affected by HIV/AIDS. HOPE uses a holistic approach thereby reaching out spiritually, socially, physically and emotionally to the HIV/AIDS youth and adults. HOPE’s community-based services include peer education, counselling, home-based care and psychosocial support for orphan and vulnerable children. According to Azevedo (2007), Khayelitsha is the area that has the highest rate of people infected with HIV/AIDS in the Western Cape, with 33% affected by HIV/AIDS.

As the research topic focuses mainly on adolescent children and their HIV/AIDS positive mothers, it is therefore important to provide a brief description of the Care and Support, and the OVC (orphans and vulnerable children) programmes which caters for these two groups.

#### **4.4.1 The OVC programme**

The OVC definition thereof encompasses children under the age of 18 years, who have lost a parent or both through death or desertion. These children are orphans, and are seen as vulnerable because they experience limited or lack of support emotionally, socially and materially (Skinner, et al 2004 cited in Davids et al 2006). The OVC Programme has a specific focus on the needs and the rights of such children. The programme provides psychosocial support to children aged between 0 and 17 years old. This programme seeks to explore problems that orphans and vulnerable children are facing. By so doing, the OVC Programme is able to holistically attend to the needs of these children. A holistic approach refers to optimal child care: physically, emotionally, spiritually, mentally and socially. Most of these children are orphaned by the HIV/AIDS pandemic. Others are vulnerable as they are infected or affected by HIV/AIDS. The OVC staff is trained to provide psychosocial support, bereavement counseling, play therapy, structured group therapy, assist in grants applications, and training local people with regards to the psychosocial needs of children. In addition the OVC staff play a role in mobilizing communities with regards to awareness of child abuse, and caring for such children, and strengthening the affected families.

#### **4.4.2 The care and support programme**

The main aim of the Care and Support Programme is to provide a comprehensive community based health care to people infected with HIV and their affected families. The programme consists of intensively trained staff that is incapacitated to provide Care and Support in terms of the following: nutritional, physical, psychosocial and spiritual. Care and Support Programme also promote HIV/AIDS awareness thus to enable positive living for people infected and affected by HIV/AIDS. This is done through workshops

conducted at the clinics and community halls. The programme enhances the capacity of HIV/AIDS affected families in order to respond positively to the infected person in a household. Through community based workshops the Care and Support Programme is able to reduce stigma and discrimination as it educate community people about the HIV/AIDS transmission, treatment and positive living. The Care and Support staff has established between 20 and 25 support groups within the community. These support groups play a significant role in helping people who are HIV/AIDS positive to cope with their status (Nashandi, 2002). The Care and Support Programme has also established a link with other partnerships to provide and strengthen holistic support to families and communities affected by HIV/AIDS. In addition, the programme has another internal link with other programmes such as OVC in order to ensure support system for children and adolescents living in households with HIV/AIDS positive parents.

#### **4.5 Participant selection**

Population refers to “the complete set of events, people or things to which the research findings are to be applied” (Bless & Higson-Smith 2000: 155). For the purpose of this study population refers to all adolescents whose mothers attend the HOPE Worldwide support groups for HIV/AIDS positive people.

##### **4.5.1 Sampling**

Sampling is defined as “the selection of cases from wider populations” (Bloor & Wood, 2006: 153). For the purpose of this study purposive sampling was used. According to Neuman (2000) purposive sampling occurs when a researcher chooses a particular case with a specific purpose in mind. The researcher chose purposive sampling because the study has an interest in exploring the experiences of adolescents living in households where the mother is HIV/AIDS positive (De Vos, 1998). The criteria for including this group was based on the fact that their mothers are HIV/AIDS positive and attend HOPE support group for people living with HIV/AIDS. The research project was conducted with adolescent boys and girls, aged 12 to 15 years, who speak Xhosa. As in the nature of qualitative research, I opted to use a small population size in order to pay closer attention



to each and every individual participant (Patton, 1997). Furthermore, the study's intention was not to generalise the findings but rather aimed at gaining an in-depth understanding of the phenomenon, using only the sample size of 6 (Neuman, 2000). Parents gave permission for their children's participation by signing a consent form. Participants also signed their own consent forms. The criteria for exclusion were based on age, and geographical view. Older adolescents aged 16 to 20 years were excluded due to the fact that their reasoning capacity might be higher than that of the younger ones. Adolescents residing out of Khayelitsha were excluded because the study intended to focus on the same area and not apply any residential comparison.

The study used both genders as to acknowledge that their situations might be similar, but they may have different ways of experiencing it. The age group was chosen in order to investigate if and how they are coping with their mothers' situations at their age. Interviews were conducted with 6 participants; 2 boys and 4 girls. With this sample, I was able to gain access to data which allowed me to develop, as specified by Mason (2002: 121) "an empirically and theoretically grounded argument" about the research question. Access to do this study (with Hope's psychosocial support group) was gained through a process of consultation with Hope's manager, each individual child and his or her parent. Participants were asked individually to be part of the study.

Ideally, the study would benefit from both mothers' and fathers' participation in the study, but the choice to involve only mothers in the study was due to the support groups consisting of women who had disclosed their status, rather than their male counterparts.

#### **4.6 Research instrument**

Open-ended questions were used in conjunction with prompts to guide the story teller in the interviewing process. For example: *how was life at home before your mother got ill from HIV/AIDS? Probe: happy occurrences, challenges?* In this way a deeper exploration of the lived experiences of adolescents living in households with mothers who are HIV/AIDS positive can occur. The interview questioning guide is the instrument intended for data collection (see Appendix 2). The open-ended approach allows for "fluidity and

flexibility” (Chadwick, 2001). The instrument was developed through the information gathered from the literature. It also considered the geographical area where the participants live, their age and their cognitive abilities.

#### **4.7 Data collection process**

According to Nkosi (2006: 68), it is very relevant in the context of qualitative narrative approach to begin by “identifying what it is meant by the term ‘data.’ ” Nkosi further cited Magwentshu (2000) who refers the term ‘data’ to the information which is gathered during the course of the study.

As the approach is a narrative approach using an open-ended thematic guide, the interview sessions were not allocated specific length of time. Participants were allowed to describe and explore the stories of their experiences living in households where the mother is HIV/AIDS positive. To facilitate participation, interviews were conducted in Xhosa as it is the participants’ mother tongue. All the interviews were then translated into English. Simple language was used for asking questions in order to make it less difficult for the participant to understand. In the event where misunderstandings arose, the researcher clarified them and also asks for further elaboration. The entire session took place in a quiet secluded room, and was audio taped with the permission of the participants.

#### **4.8 Data analysis**

Data analysis was conducted by means of a narrative analysis. All the interviews with the participants were transcribed and translated. The researcher read the translated material on numerous occasions in order to become familiar with the data. The analysis was divided into two sections: the previous life experiences before the mother got ill with AIDS, and the present experiences with the mother ill with AIDS. The focus was on producing connections of the content across these life experience stories and to uncover the meaning (Crossley, 2000a). In effect, the researcher followed the guide of Crossley’s (2000a) six steps for analysing personal narratives: 1. Reading and familiarizing, 2. Identifying important concepts to look for, 3. Identifying ‘narrative tone’, 4. Identifying ‘imagery’

and ‘themes’, 5. Weaving all of this together into a coherent story, 6. Writing up the research report. Step five and six are further discussed in chapter 5 as part of presentation of results.

As narrators, participants are discussed individually. According to Bal (1997) there are two reasons for beginning this chapter with the narrator. The narrator is the most central concept in the analysis of narrative texts. Bal (1997) further emphasises that the identity of the narrator, the degree to which and manner in which that identity is indicated in the text, and the choices that are implied all lend the text its specific character.

#### **4.8.1 A step-by-step analysis of personal narratives**

##### **4.8.1.1 Step one: Reading and familiarising**

The first step in the analysis began by reading narrative texts in order to become familiar with the data. As “the text contains a number of elements that project the narrator’s voice” it became possible to practically hear the participants speaking to me over and over in my mind, (Manfred, 2005: 2). Through this process the researcher gave each narrative voice an appropriate intonation and expression, which also led to formulating a mental picture of the story’s action, (Manfred, 2005). The researcher became familiar with different textual voices in order to establish who is telling the story, what the message were and how it was conveyed.

##### **4.8.1.2 Step two: Identifying important concepts**

Through reading and rereading the interview transcripts following three principal elements of the “personal narrative” were identified subscribing to McAdams (cited in Crossley, 2000a, 8): narrative tone, imagery and themes.

###### **4.8.1.2.1 Narrative tone**

A tone, in the context of narratives refers to the manner in which the writer expresses his or her attitude towards the subject and audience, (Emerson & Frosh, 2004). The tone is usually conveyed through point of view, allusion, diction, figurative language, imagery

and symbol. According to Robert Frost (cited in Thompson, 1964: 204) “only when we are making sentences so shaped [by spoken sentence tone] are we truly writing.” Hence, in order to give shape to the participants’ narratives the researcher detected the tone of their stories by picking up on the tone of their voices. The researcher did that by paying attention, not to what has been said or done but to the manner in which it was articulated, (Gubruim & Holstein, 2009).

#### **4.8.1.2.2 Imagery**

According to Wiehardt (2009: 1) imagery “is visually descriptive or figurative language in a literary work, it is also a pattern of images that run through a work.” In analysing narrative texts, the researcher identified images that offer the sensory impressions to the reader, and also convey emotions and moods through their verbal pictures. The participants’ narrative voice provided the senses and mental pictures of sights, sounds, feelings and actions.

#### **4.8.1.2.3 Themes**

A theme of the story according to Dan (cited in Smith, 2008: 113) is the “recurrent pattern of human intention, and ideology, which is revealed in the values and beliefs underlying the story.” As the intentions were to convey ideas and create a meaning with regards to participants’ lived and told stories, the researcher identified themes that are directly stated, and not implied. The motive behind that was to allow the reader to gain insight from the trials and tribulations related through characterisation, intonation, and points of view.

#### **4.8.1.3 Step three: Identifying narrative tone**

In this section the researcher looked at both what the participants have reported in relation to their past experiences, and the way in which they have done so. This was divided by the researcher into two sections: life before the mother’s illness and life after the mother’s illness. The researcher has identified narrative tones through investigating the link between the emotional tone and narrative style with regards to how participants’

cognitively and emotionally process information (Bolls et al. 2008). According to Haslam (2007: 248) “narrative tone sets the over all emotional quality of the story.”

#### **4.8.1.4 Step four: Identifying “imagery” and “themes”**

Being aware that it is useful to look for both imagery and themes together, the researcher found that the easiest way to identify imagery and themes was to work through the transcripts in a systematic manner, starting first with the life chapters’ question, and then proceeding separately through each of the interview questions. As the analysis is divided into two sections the researcher categorised imageries and themes according to the lives of adolescents, before and after the mother’s illness.

These themes and imageries will be thoroughly discussed in chapter 5 as presentation of results.

#### **4.8.1.5 Step five: Weaving all this together into a coherent story**

All the fore mentioned analyses presented are weaved together in this section into a coherent story. The section is also presented in chapter 5 after the discussions regarding themes and imageries.

#### **4.8.1.6 Step six: Writing up the research report**

According to Crossley (2000a) step six is intended to write up the research report. This thesis in this regard serves as a research report. Hence, the researcher opted to end the analysis with step five.

### **4.9 Self reflexivity**

Having a tendency to dig deeper into a human’s inner being, HIV/AIDS studies are more likely to awaken a researcher’s emotions (Soskolne, 2003). In having an interest in adolescence and conducting a research study which involves adolescents that are experiencing negative effects of HIV/AIDS, the researcher is aware of the possibility of her emotions being awakened. Hence, the researcher kept her intentions to seek psychological intervention through counselling in order to be able to separate her personal

feelings from those of the research participants (Janesick, 1998). Initially the researcher prepared to maintain professionalism from the point where data is gathered to the final stage of analysing it through psychological intervention. However, the researcher was instead strengthened by the participant responses, moving but yet positive.

#### **4.10 Trustworthiness**

The claims of trustworthiness were addressed as part of maintaining epistemological grounding. Trustworthiness was enhanced by two methods: Assuring credibility and Authenticity.

##### **4.10.1 Assuring credibility**

Assuring credibility according to Carboni (cited in Whittemore, Chase & Mandle, 2001: 530), “refers to the conscious effort to establish confidence in an accurate interpretation of the meaning of the data.”

The researcher enhanced credibility through spending sufficient time getting to learn and gain deeper understanding of the participants’ experiences. In the process it was continuously checked for any misinformation brought about by distortions either of the participant or by the researcher. In addition, the researcher listened to the tape recordings of the interviews on numerous occasions. After typing all the responses the researcher asked participants to review the transcripts. In terms of analysis, the researcher read the interview transcripts, paying attention specifically to the content of adolescents’ narratives (Boonzaier & de La Rey, 2003). Recursive and repetitive checks of the interpretation of data demonstrated attempts to maintain the integrity and criticality (Whittemore, Chase & Mandle, 2001: 531). As mentioned in the section of reflexivity, to minimise risks of bias, the researcher maintained a room to seek counseling and debriefing if need be. The researcher employed the member-checks method to ensure that interpretation of data is in concurrence with participants. Hence, the findings were corroborated (Lincoln & Guba, 1985: 313-316).

#### **4.10.2 Authenticity**

According to Sandelowski (cited in Whittemore, Chase & Mandle 2001: 530), “authenticity is closely linked to credibility in validity and involves the portrayal of research that reflects the meanings and experiences that are lived and perceived by the participants.”

In ensuring authenticity, the researcher made use of qualitative methods with a narrative approach to collect and analyse data. The chosen approach was found suitable due to its nature of using open-ended questions and answers, which allowed in-depth conversations between the researcher and the participants, (Boonzaier & de La Rey, 2003; Soskolne, 2003; Knowles, 2007). Furthermore, using qualitative methods with a narrative approach provided an open platform where participants told their own stories with regards to their lived experiences which only themselves can tell them better (Gubrium & Holstein, 2009). The ‘actual circumstances and sentiments of the individual’ were conveyed and captured through the authenticity of the participant’s own story telling (Gubrium & Holstein, 2009: 42). Hence, in an attempt to maintain the authenticity the researcher described and explained participants’ situations the way they experienced them.

#### **4.11 Ethical statement**

Qualitative research emphasise that the researcher should show respect to the participants and that it should be reflected in their methodology. In line with the ethical statement, the researcher conducted a workshop with all the participants to explain the nature of the project and its goals. Participants were also informed about voluntary participation and their right to withdraw at anytime if they so wish, without further questions or consequences. In terms of confidentiality, participants were assured that they would remain anonymous and that no identifying details would be quoted. It was explained to participants that confidentiality and anonymity would be applied to all their responses. Under no circumstances did the participants have to mention whether they are HIV positive or negative. Both parents and participants were asked to sign the informed consent letters, (see Appendix 3 & 4). The study has only focused on a certain area of

Khayelitsha, therefore the findings are not necessarily applicable to the entire community. The researcher made arrangements with HOPE managers to provide follow-up support with all participants, and to conclude the project with a workshop in order to be able to give feedback. Also made explicit was the fact that, if any of the participants had a need for further counseling, it would be provided by HOPE.

#### **4.12 Conclusion**

In summary, this chapter discussed research design, research setting and sampling methods. The data collection methods used for the study are also discussed. The chapter further described Crossley (2000a) step by step analysis of personal narratives. The reasons for choosing a qualitative paradigm with a narrative approach are discussed. In this chapter, HOPE's OVC and Care and Support programmes are explored as they cater for HIV/AIDS affected adolescents, and the HIV/AIDS positive mothers. Semi structured interviews with open-ended questions was used. Six adolescents living in households with HIV/AIDS positive mothers participated in the study. The researcher discussed trustworthiness according to the validity standards established in qualitative research methods (Crossley, 2000a; Whittemore, Chase & Mandle, 2001; Lincoln & Guba, 1985). Ethical issues were addressed as part of fulfilling responsibilities as a researcher.



## **CHAPTER 5**

### **FINDINGS AND DISCUSSION**

#### **5.1 Introduction**

The following chapter presents a narrative analysis of the research data in a form of a story. Having constructed a rough ‘working’ map of the various images and themes emerging from my interpretation of the interview data, the researcher began to weave this into a coherent story. The researcher attempted to construct the kind of account that is expected to be produced in relation to the experiences of adolescents living in the household with HIV/AIDS positive mothers. Narratives are ordered discourse which makes connections of human experiences and thus produces a meaning of. Narrative analysis provides a route to finding such a meaning by creating a link between the settings of storytelling, who is telling the story and how the story is being told (Gubruim & Holstein, 2009). According to Dainte and Lightfoot (cited in Nkosi 2006: 75), narrative analysis “is the process that involves explaining psychological phenomena as meanings that are ordered from some theoretical perspective.” Narrative analysis identifies themes drawn from the individual story.

#### **5.2 Description of the participants**

All research participants were from the same geographical area in Khayelitsha. They came from working class families. Four participants attended high school at the time of the interviews. Two were at the primary school. The following is a thorough description of each participant.

##### **5.2.1 Participant 1(P1)**

###### **5.2.1.1 Demographic view**

Participant 1 was a 13 year old adolescent black girl. She was doing grade 6 at the local primary school. She wishes to finish school and in the future study nursing. Her reasons

are that she would give HIV/AIDS people ARV Treatment and educate them about avoiding drinking alcohol, as such habits really hurts their children's emotions.

### **5.2.1.2 Family background**

The participant lives in a household with her HIV/AIDS positive mother. Not much was mentioned about the father. The participant is the youngest child of three children. Her mother is working as a laborer and she is the bread winner. The participant was hurt by her mother's HIV/AIDS status. While she was still trying to find her way to cope with the situation her mother started drinking. At the time of the interviews the participant felt emotionally hurt but still hoped that her mother's drinking situation would terminate.

### **5.2.2 Participant 2(P2)**

#### **5.2.2.1 Demographic view**

Participant 2 was a 15 year old adolescent black girl. She was doing grade 12 at the local high school. She was looking forward to completing school and to become a Peer Operator. Her reasons were that she enjoyed interacting with people of different backgrounds in different organisations.

#### **5.2.2.2 Family background**

The participant lives in a household with her HIV/AIDS positive mother, and the father whose HIV status was not revealed. Both the parents were unemployed at the time of interview. The participant is the second born child of two children. The participant was hurt by her mother's HIV/AIDS status, but reported during the interview session that she was coping with the situation. The participant felt hurt by other family members' negative reaction towards her mother's situation.

### **5.2.3 Participant 3 (P3)**

#### **5.2.3.1 Demographic view**

Participant 3 was a 14 year adolescent black girl. She was doing grade 5 at the local primary school. The participants' wish was to finish school, and in future work for her mother and take care of her. During the interview session the participant offered advice to adolescents whose mothers are HIV/AIDS positive. She mentioned that they have to accept it, take care of their mothers, and enjoy life again.

#### **5.2.3.2 Family background**

The participant lives in a household with her HIV/AIDS positive mother. Her parents were divorced 3 years prior to the interview. The participant is oldest child of four children. Her mother was working as a laborer and was a breadwinner. The participant was coping well with her mother's HIV/AIDS status. She reported that she was coping due to her mother's ability to cope with her own HIV/AIDS' situation. She also mentioned that she was previously shattered by other family members' negative reaction towards her mother's situation.



### **5.2.4 Participant 4 (P4)**

#### **5.2.4.1 Demographic view**

Participant 4 was a 15 year old adolescent black boy. He was completing grade 9 at the local high school. The participant's wish was that all the sufferings and problems could just go away so that the family could get all what they want.

#### **5.2.4.2 Family background**

The participant lives in a household with his HIV/AIDS positive mother. Not much was mentioned about the father. The participant is the second child of 6 children. His mother worked as a laborer and was a breadwinner. The participant was hurt by his mother's HIV/AIDS status, and did not seem to be coping with the situation. He felt hurt by his

mother's inability to provide for the family due to her HIV/AIDS status. The participant felt that he and his siblings are suffering the consequences.

## **5.2.5 Participant 5 (P5)**

### **5.2.5.1 Demographic view**

Participant 5 was a 14 year old adolescent black girl. She was completing grade 9 at the local high school. The participant's wish was to see "her mother able to stand up, get better and be well with her health."

### **5.2.5.2 Family background**

The participant lives in a household with her HIV/AIDS positive mother. Not much was mentioned with regards to her father. The participant is the fourth born child of four children. Her mother worked as a laborer and was a breadwinner. The participant was hurt by her mother's HIV/AIDS' status and did not seem to be coping so well with the situation at the time of the interview.

## **5.2.6 Participant 6 (P6)**

### **5.2.6.1 Demographic view**

Participant 6 was a 14 year old adolescent black boy. He was completing grade 8 at the local high school. The participant was looking forward to finish school in the future. His dreams included becoming an Archaeologist. He reported that he chose "Archaeology because it does research on things that happened long ago." He went further to explain that "Archaeologists dig bones and tell the story based on what happened with regards to those bones."

### **5.2.6.2 Family background**

Participant lives in a household with his HIV/AIDS positive mother, and the stepfather. Both parents were laborers doing odd jobs. The participant is the oldest child of 3 children. The participant reported that he was coping well with his mother's HIV/AIDS

situation. He also asserted that his coping abilities were due to his knowledge that AIDS does not kill people who manage themselves well by treating it and visiting the clinic.

### **5.3 Themes extracted from the narratives**

The following themes were dominant in the personal narratives of the adolescents living in households where the mother is HIV/AIDS positive. These themes are categorised in terms of life before and after the mother's illness. Themes describing life before the mother's illness are as follows: happiness and togetherness, sense of belonging, nutrition. Themes describing life after mother's illness are as follows: shock, hurt, fear, coping, acceptance, discrimination versus non-discrimination, rejection versus non-rejection, school attendance & performance, ARV Treatment, and HIV/AIDS & poverty.

#### **5.3.1 Life before the mother's illness**

##### **5.3.1.1 Happiness & togetherness**

Happiness refers to “the feeling of being happy”, and togetherness refers to “a feeling of friendship” (Woodford, 2007: 327 & 743). This study uses both the terms to discuss the parent-child interaction experiences between participants and their HIV/AIDS positive mothers before the mother's illness. As adolescents are to be understood in the way they employ imagery in developing sense of self, the researcher, needs to “pay careful attention to the kind of language used in describing their life chapters and key events” (Crossley, 2000a: 89). By doing that the researcher traces and explores the originality of the employed imagery to better understand their stories. The following extract characterises meaningful images of participant No. 3 before she discovered that her mother was HIV/AIDS positive.

*“It used to be nice before she got weaker. We used to play games together. I used to enjoy certain games about writing names in the blocks according to specific alphabets. I used to enjoy watching her singing and dancing”.* (Participant 3, 13 years old)

Participant 3's personal narrative reflects an expression of 'joy' spending time with her mother before she got ill with HIV/AIDS. Her story testifies who she was. Someone who

was having ‘nice’ experiences with her mother before discovering her mother’s HIV/AIDS status. According to Arnett (2001: 201) “secure attachments to parents are related to adolescents’ well-being in a variety of respects”.

Participant 5 described the activities, time frames, joy, and the pleasure shared with her mother: *We used to spend the whole day together, enjoying each other’s company. We joked together, played together.*

Participant 6 also explained the joyful moments he shared with his mother. His narratives indicate that it gave him such a pleasure when his mother told him about fairytales: *We would have good times, she would tell me fairytales. I used to enjoy that.*

Participant 4 shared the feelings of joy he experienced from spending time with his mother, playing cards: *My mother and I used to play cards, play cards and enjoy ourselves.*

Participant 1 recalled joyful memories spending time with her mother, and listening to her singing: *I used to like it, I used to like it when my mom sang songs that we sing at church. I used to enjoy that. We used to spend the whole day just enjoying ourselves.*

As indicated, most of participants’ narratives express a characteristic set of images of joy. The sense of happiness and togetherness represent a strong family unit which is, in most of the cases, a foundation to the psychological well being of a child, (Winnicott, 1984; Bigner, 1998; Arnett, 2001). Thus, it is reflected that participants had a healthy psychological foundation in their early childhood lives.

### **5.3.1.2 Sense of belonging**

Sense of belonging as defined by Arnett (2001) defines togetherness in friendships and peer groups consisting of adolescents who share similar interests in certain discussions and leisure time activities. In the context of this study, sense of belonging was used to discuss participants’ relationship with other adolescent peers before discovering their mothers’ HIV/AIDS positive status.

Participant 1, 3 and 5 expressed feelings of joy experienced through playing with other children. Their narrative accounts indicate that playing with other children was an important routine in their lives, and not just a schedule:

*I used to enjoy playing with other kids anytime I was done with everything I was supposed to do in the house. I used to enjoy that.* (Participant 1, 15 years old)

*I used to enjoy spending more time playing with other children, but I also had to pay attention to my school work.* (Participant 3, 13 years old)

*I love playing with other children, but most of the time I like spending at home because there's lots of skollies out there and I don't like that.* (Participant 4, 15 years old)

*I would play with other children for about an hour and go back to the house. I used to enjoy that.* (Participant 5, 14 years old)

The narrative extracts provide imageries that symbolise the significance of child play. These imageries are a reflection of childhood freedom which allows autonomy: a very important element with regards to enhancing psychosocial well being of a child, (Erikson, 1980; Arnett 2001). The child play imagery also shows that participants felt that they belonged with other children which seemed more significant in their own lives. As participants experienced care-free life through playing it showed that they had nothing to worry about, which symbolise a healthy psychosocial development, (Proudlock, 2005; Deacon & Stephney, 2007).

Peer relationships enhance confidence in social interaction. According to Berns (1997: 373) the word peers refer to a “group of equals, usually of the same age, gender and socioeconomic status, who share the same interest”. As peers, interacting with each other created a platform for participants to learn different social skills such as participation, communication, co-operation and validation support, (Papalia & Olds, 1989; Mc Coy, Metsch & Inciardi, 1996). In extend, social interaction enhanced the ability to make decisions and to distinguish between good and bad. This point of view subscribe to Lev Vygosky's theory (cited in Overall, 2007: 73) which incorporated social context as an

influential instrument in the developmental process. Participants 4 and 3 concur with Vygotsky's theory as one mentioned avoiding bad company 'skollies' and the other emphasised on having to balance playing and attending to school work.

### **5.3.1.3 Nutrition**

Nutrition refers to the food that the person eats and the way that it affects his or her health (Woodford, 2007). In the context of this study, nutrition is discussed with regards to adolescents' experiences with their HIV/AIDS positive mothers before they discovered the mother 'status.

Participant 6 expressed his feelings of joy and contentment experienced through watching his mother cooking: *I used to enjoy watching her cooking, she cooked very nice food.* Participant 4 also expressed feelings of satisfaction regarding his mother's cooking. He further appreciated his mother's efforts to provide whenever he needed anything. Participant 4 also acknowledged that his mother went extra mile to make him and his siblings happy: *She cooked very nice food, whenever I asked for anything she would just make a plan for me to get it. She'll go to work, just work – work and come back home and bring us something that could make us happy, something like food.*

Participant 4 shared positive memories of food, leisure time and contentment: *We would go to the beach from ten to four. We would have plenty food and play.*

Participant 1's narrative tone indicates that helping her mother with cooking and laundry had a positive meaning to her: *I used to help her with cooking and laundry.*

The nurturing image that is expressed in the narrative account of the participant symbolises parental love and the mother's ability to meet the nutritional needs of her family (De Genova & Rice, 2001). Hence, it is reflected that participants' physical and mental health was taken care of. Good nutrition is also associated with a child's high level of cognition functioning (Arnett, 2001; Freeman, 2003; Richter, 2004; Nkosi, 2006; Jonson, 2009).



The emotional response as examined from the narrative voice of the participants on nutrition resulted in emotional tone which can be described as pleasant and content, (Bolls et al. 2008). According to Bolls et al (2008) emotional response is based on how positive and negative people feel, and that can be detected through their emotional narrative tone.

### **5.3.2 Life after the mother's illness**

#### **5.3.2.1 Shock**

Shock is a feeling experienced after a person has received very surprising and upsetting or immoral news, (Woodford, 2007: 647). Most of the HIV/AIDS psychosocial researches have indicated that people who discover their HIV/AIDS positive status or that of their loved ones for the first time, experience shock, (Nashandi, 2002; Shebi, 2006; Roman, 2006; Black, 2009). Participant 1, 2 and 3 also expressed their feelings of shock:

*I was shocked, I was shocked when I heard of my mother's HIV/AIDS illness.* (Participant 1, 15 years old)

*My mom told me about her HIV status herself. She told me over the phone. But first time I heard I could not believe it because my mom was pregnant with my small brother.* (Participant 2, 14 years old)

*I was shocked because I hear other people say if you have HIV/AIDS you gonna die* (Participant 4, 15 years old)

The imagery of discovering the mother's HIV/AIDS status was reflected through the use of words that expressed feelings of shock. According to Woodford (2007: 647) a shock refers to "a big, unpleasant surprise." The fact that participants were shocked indicates that they did not expect that their mothers could be HIV/AIDS positive. Hence, the situation was shocking to them when the mothers disclosed their HIV/AIDS positive status to them. As in most HIV/AIDS studies, an element of shock took its toll to mark a

turning point in the shocked person's life (Nashandi, 2002; Shebi, 2006; Roman, 2006; Black, 2009)

### 5.3.2.2 Hurt

According to Woodford (2007: 351), the word hurt refers to "emotional pain." With regards to this study the word 'hurt' was used in relation to the participants' experiences of pain which was caused by having been informed of their mothers' HIV/AIDS positive status.

As she recalled, Participant 1 described how her mother disclosed that she was HIV/AIDS positive. She further expressed that she was hurt and saddened by such a disclosure: *She called us (the participant and her sister); she sat us down and told us she was HIV positive. I felt so sad.*

Participant 2 described her heartache with regards to her mother's HIV disclosure. She also described her inability to believe that it was actually a reality that her mother is HIV positive: *When I first discovered that my mom was HIV positive my heart was broken, I could not believe it.*

It took a week for participant 3 to absorb the news about her mother's HIV/AIDS positive status. She described her inability to express her feelings of disappointment to her mother. She was silent by her emotional pain for a week. Shedding tears remained the only way she could express how she felt hurt: *I cried when I discovered that my mom is HIV positive, after that I could not say a word to her, for about a week I could not engage in a conversation with her.*

Participant 4 also described how he was hurt to a point of not knowing how to express his feelings: *At first I was sad. I did not know how do I, how can I talk about that.*

Participant 5 recalled and described how her mother disclosed her HIV/AIDS positive status. She was not only affected by discovering her mother's HIV infection, but also by

the emotions expressed by her mother: *She called me and my sister and told us she is HIV/AIDS positive. I felt very bad. She was crying as she was telling us.*

Participant 6 clearly expressed that discovering his mother's HIV/AIDS status caused him pain: *It was so painful when I discovered about my mom's HIV/AIDS status. I thought she will leave me (through death).*

The participants expressed emotional disturbances with regards to their mothers' HIV/AIDS positive status. The images of emotions are reflected through hurt and pain which is articulated in their narrative accounts. Adolescents' emotional distress in the context of HIV/AIDS was also reported by other studies which examined this group's psychosocial well being (Carstens, 2003; Strode & Barret-Grant, 2001; Linsk & Mason, 2004; Bauman et al. 2006).

The narrative tone expressed through participants' responses reflected painful emotions, sadness and disappointment. According to Pequegnat and Szapocznik, (cited in Rotheram-Borus, Stein & Lin, 2001: 768) parents and children form an interdependent and interactive social unit; when parents become infected with HIV, the entire family is affected. It is also stated that adolescents have a tendency to develop behavioural problems following a parent's disclosure of his or her HIV status, (Gunther et al. 1998).

### **5.3.2.3 Fear**

Fear, according to Woodford (2007: 261) is "to be worried or frightened that something bad might happen or might have happened." Fear in this regard is in the context of HIV/AIDS epidemic and its devastating and debilitating effects socially, psychologically, emotionally physically and economically (Soskolne, 2003; Garson, 2005; Scheid, 2005; Theron, 2005). It has been stated that adolescents affected by HIV/AIDS experience intense fear of losing a parent through death caused by the epidemic (Gunther et al, 1998). As a result of such a fear these adolescents may experience emotional distress and behavioural problems (Rotheram-Borus et al. 1997; Rotheram-Borus, Stein, & Lin, 2001). In the context of fear, the following extracts express the experiences of adolescents living in households with HIV/AIDS positive mothers:

Participant 4's narrative indicates his experience of fear which was mixed with feelings of sadness. It is reflected through his narrative tone that these mixed feelings were triggered by fear of death: *I hear other people say if you have HIV/AIDS you gonna die. And now that made me sad.*

Participant 5 expressed that it was difficult to deal with her mother 'situation. The participant' situation was worsened by her perceptions that her mother would die earlier than if she was not ill with HIV/AIDS: *It was difficult; I thought she will die early.*

Participant 6 explained that his mind was occupied by thoughts of death. He could only imagine being left without a mother: *I thought she will leave me (through death).*

As stated, the voice of the narrator can be constructed (Manfred, 2005) and the message tone can as much be detected (Gubruim & Holstein, 2009). Hence, the tone of the message detected from the participants' narratives expressed sense of fear.

Being aware of the HIV/AIDS status of their mothers did create frightened feelings in these participants as they began to imagine death. Such imaginations are distressful as they can lead to feelings of anxiety and depression if not properly dealt with (Black, 2009; Deacon & Stephney, 2007; Gunther et al 1998). Participant 4 situation was intensified by the beliefs and interpretations regarding HIV/AIDS which were socially constructed by people in the community. (*I hear other people say if you have HIV/AIDS you gonna die*) These beliefs and interpretations are usually based on ideas and not factual information, (Speed, 1991). Some are based on the lack of knowledge. According to socially constructed knowledge, anyone who is HIV/AIDS positive is going to die from HIV/AIDS. Such point of views is based on myth and misconceptions around the epidemic. People living with HIV/AIDS can lead a healthy life through ARV Treatment, behavioural modifications, and clinical care for the prevention of opportunistic infections. Nevertheless, such socially constructed point of views has the capacity to cause psychological distress in the lives of people affected by HIV/AIDS. The fear of death has been captured in most of research findings regarding people infected and affected by

HIV/AIDS, (Nashandi, 2002; Soskolne, 2003; Shebi, 2006; Roman, 2006; Jonson, 2009; Black 2009).

#### **5.3.2.4 Coping**

According to Lazarus and Folkman (cited in Rose & Clark-Alexander, 1999: 337) coping refers to “ a person’s constantly changing cognitive and behavioural efforts used to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person.” Through telling their own stories participants outlined their coping mechanisms. Sense of surviving was expressed as imagery in coping with living in households with HIV/AIDS positive mothers. Also indicated in the narratives accounts was the fact that participants’ ability to cope was enhanced through witnessing the mothers’ ability to cope with her own illness. This finding concurs with reports provided in the study conducted by Rotheram-Borus, Stein and Lin, (2001) regarding adjustments of adolescents whose parents have HIV/AIDS.

*“My mom then bought a house. Then I went to stay with my mommy and to look after her. I watch the time for her to take her medicine. I must make her food before she take her medicine. I must sort out her bed to make it comfortable for her to sleep. After that I can go to play outside. I survive just to be with my mom. When I go to play I’m not scared to tell the people that my mom is sick of HIV/AIDS. When she goes to the clinic, I’m not going to school; I go with her to the clinic. So I feel better”*. (Participant 2, 14 years old)

It is evident that participant No. 2 felt very secure when she moved in with her mother. Having to perform activities that reflected both care and support towards her mother seemed to have brought sense of bondage and fulfillment in the participant’s life. The HIV positive mother-daughter bonding has been mentioned as one of effective methods in enabling coping for adolescent girls affected by HIV/AIDS through the mothers, (Lee, Lester & Rotheram-Borus, 2002). According to McAdams (cited in Crossley, 2000a: 89) a child’s narrative tones is influenced and shaped by “the achievement of secure or insecure attachment relationships during the early childhood years.”

*I was happy because after I heard about her status she told me, No Vuyo, don't worry, I'm gonna be alright.* (Participant 4, 15 years old)

*My mom disclosed her HIV/AIDS status herself. I felt so bad. But when finished telling me, she also explained more about what HIV/AIDS is to give me a better understanding.* (Participant 6, 14 years old)

Participants 4 and 6 indicated that their coping ability was enhanced through HIV/AIDS information provided to them by their mothers. It has been stated that effective parental and social supports were effectively used by adolescents experiencing the effects of HIV/AIDS as coping mechanisms, (Rotheram-Borus, 2001; Lee, Lester & Rotheram-Borus, 2002; Lyon & D'Angelo, 2006; Deacon & Stephney, 2007). The social support can be in a form of emotional, cognitive and instrumental (Hansel, cited in Shebi, 2006: 17) which can be caringly provided through, but not limited to, provision of relevant and resourceful HIV/AIDS information. As stated by Nkosi, (2006: 94), cognitive support can be “in a form of knowledge, information and advice.”

### **5.3.2.5 Acceptance**

Acceptance, according to Long (cited in Nkosi, 2006: 81) “is the underlying belief and attitude that is worthy of self-respect and the corresponding attitude of respect for others’ capability to be self-responsible”. Narratives show that participants were able to accept and live with their mothers’ situations without being judgemental. Hence, In this regard acceptance means a conscious choice to fully acknowledge and respect another person’s worthiness without questioning his or her capability to be self responsible. Psychologically, adolescents’ ability to perform higher in dealing with moral dilemma is the outcomes for operating on a higher moral and cognitive level, (Kohlberg, 1981; Light, Sheldon & Woodhead, 1993). Participants’ narratives indicates that they were able to accept their mothers’ HIV-infection without judgemental.

Participant 2 indicated that she made a decision to accept her mother’s HIV/AIDS status and move beyond the situation. It is also clear that she has opted to take care of her

mother: *Just for those (children) who their mothers have HIV they have to take it. They have to take care of their mothers and enjoy it.*

Although participant 3 indicated that she has accepted her mother's HIV/AIDS status, her feelings of disappointment were nevertheless reflected: *We do speak and that's nice yes, however I do get that feeling that she's not exactly what I expect of her, but she will remain my mother and nothing will change that.* However, even though she was disappointed, participant 3 still managed to accept her mother's situation.

Participant 6 explained that it was through receiving HIV/AIDS information he was able to accept her mother's HIV/AIDS status: *My grandmother and I have accepted my mom's situation. My grandmother understands because when my mom disclosed she also explained to her – more about HIV/AIDS. My grandmother said to my mom that she is still her child and nothing will ever change that.*

Positive images were expressed in the language used in the texts which was the tool to make themselves heard, (Speed, 1991; Nicholas, 2003; Emerson & Frosh; 2004; Gubruim & Holstein, 2009). The fact that they have agreed to be interviewed for this study is a positive point of view, which also symbolises the acceptance of the situation they are experiencing. The fact that the participants were able to express themselves in this regards proves that they are able to think abstractly and construct their own knowledge in accordance with their perspectives, (Kroger, 2004; Overall, 2004).

### **5.3.2.6 Discrimination versus non-discrimination**

Discrimination, according to Manser and Thompson (1999: 369) occurs mostly on behavioural and practical levels and it refers to the “unjustifiably different treatment given to different people or groups.” In the context of this study, discrimination is discussed with regards to the situations of adolescents affected by HIV/AIDS through the mother's status.

Participant 1 explained that she was discriminated due to her mother's HIV/AIDS status; her friends stopped visiting her. It is indicated that, participant's friends were influenced

by their mothers. These friends' mothers were aware of the HIV/AIDS positive status of the participant's mother. The friends' mothers also used to be friends to the participant's mother but deserted her after discovering that she was HIV/AIDS positive. Hence both the participant and her mother have both experienced discrimination: *My friends stopped coming to visit me. Their mothers told them about my mother's situation as they themselves used to be my mother's friends and knew about her status. Thus we did not get along anymore.*

Participant 2 described how she witnessed her mother being treated unfairly because of her HIV/AIDS positive status. *My uncle, when he saw my mom going to the toilet, he would do bad things. He would wait for my mom to come out of the toilet, and then he would take a toilet paper and wipe off the toilet even though there was nothing to wipe off. Even the spoon, even when my mom eats with a spoon. My uncle said she must have one spoon to use.*

Participant 6 emphasised that his family received a fair treatment from the people in the community. He further explained that the fair treatment was based on the fact that people had a clear understanding that there could be a reasonable cause of HIV infection: *In the community people treat us very well because they know that AIDS does not just infect a person. They don't gossip about us, they know that what my mom has she did not choose to have.*

Through their stories, participants 1 and 2 expressed negative feelings with regards to experiencing discrimination. The narratives demonstrate that these adolescents have encountered discrimination at the hands of family members, friends and relatives (Campbell et al 2005; Francis & Francis, 2006; Lyon & D'Angelo, 2006). According to research studies conducted in the context of HIV/AIDS, adolescents affected by the epidemic are marginalised due to social constructed beliefs about HIV/AIDS (Nashandi, 2002; Roman, 2006; Black 2009). Such negatively constructed interpretations of the HIV/AIDS pandemic also produces stigma (Deacon & Stephney, 2007; Nashandi, 2002). The narratives clearly indicate that individuals that discriminate have not received the right information with regards to HIV/AIDS transmission. Therefore, lack of knowledge



causes people to stigmatise and discriminate against people infected and affected by HIV/AIDS. Similar findings were reported by Simbayi, Kaseje and Niang (2007).

Conversely, participant 6's narrative accounts indicate that they were treated fairly by friends, relatives and community people. These were the people who are assumed to have clear knowledge and understanding of HIV/AIDS transmission and prevention, and have focused on providing emotional support to the HIV/AIDS affected individuals. The finding concurs with studies conducted by Jonson (2009) and Shebi (2006) which highlights that people with clear knowledge and understanding of HIV/AIDS are more supportive towards people infected and affected by HIV/AIDS.

### **5.3.2.7 Rejection versus non-rejection**

According to Woodford (2007: 591) rejection occurs "when someone does not give someone else the love or attention they were expecting." Research indicates that adolescents affected by HIV/AIDS do experience social rejection and the situation has a tendency to reduce their sense of self worth (Deacon & Stephney, 2007; Jonson, 2009; Black, 2009). The narratives herein reveal the situation with adolescents living in households with HIV/AIDS positive mothers:

Participant 1 expressed her emotional pain due to experiencing rejection associated with her mother's HIV/AIDS status. Her narrative tone indicates that she resisted the motive behind the rejection as she mentioned that they were judging her: *When my friends rejected me I felt so hurt because it was obvious they were judging me.*

Participant 3 indicated that her friendships did not change as some of her friends also have HIV/AIDS positive mothers. Hence, these friends were able to relate: *My friends have not changed towards me. More so as some of them have HIV positive mothers like "so and so" (referring to one of the participants she came with).*

*They react good when I tell them (about her mother's HIV/AIDS status), because they are nice friends.* (Participant 2, 14 years old)

In the context of friendship imagery the narrative texts indicate that participant 1 felt rejected by her friends. She felt so hurt by the situation. Given the fact that she was left by her friends, it is also appropriate to infer that she also felt lonely and devalued. Research indicate that when adolescents affected by HIV/AIDS experience unfair and unjust treatment, the situation creates anxiety, stress, loneliness and depression (Molassiotis et al 2002; Tompkins & Wyatt, 2008). Psychosocial studies also show that experiences of social behaviour may have a negative impact on the cognitive functioning of the affected adolescents (Deacon & Stephney, 2007).

Conversely, participants 2 and 3's narratives indicate that their friendships provided emotional support. Studies have demonstrated that a constant reassurance from peers can make easier this challenging situation facing adolescents living in households with HIV/AIDS positive mothers (Shebi, 2006; Deacon & Stephney, 2007; Black, 2009; Jonson 2009).

#### **5.3.2.8 School attendance and performance**

Participant 1 indicated that it was not her educational performance that was affected due to her mother situation, rather her school attendance: *At school I did not attend so well anymore because I sometimes did not have money to buy food for lunch, and I was not used to that.*

Participant 5 expressed her lack of stability regarding school attendance due to her mother's illness. Furthermore, her educational performance was affected as she battled to concentrate while writing tests for her assessments: *Sometimes I have to leave early at school because my mother would be very sick. My school performance dropped when I write tests my mind is always preoccupied with my mom's conditions.*

Participant 2 explained that even though her mother's situation has affected her she needed to be able to concentrate at school. She further expressed her fears of not performing successfully at school: *The situation has affected me, but when I'm at school I have to forget that to concentrate on my books because I was thinking I was going to fail this*

*year, but I did not fail. When she goes to the clinic, I'm not going to school; I go with her to the clinic.*

Participant 3 emphasised that her level of performance did drop due to her mother's situation: *At school it has affected me just a bit, my performance is not that bad.*

Participant 4 and 6 explained that they managed well with regards to educational performance:

*I always do my school work and I don't have any problem. My school performance is perfect.* (Participant 4).

*My mom's situation has not affected me at school. I have realized that when I passed all my tests.* (Participant 6, 14 years old)

The participants expressed how they managed handling school related challenges. Participant 1, 2 and 5's narratives account indicate that their school attendance was disrupted by various factors. Participant 1 did not have lunch at school due to lack of money. Participant 5 had to leave early from school because of her mother being sick and in need of close attention and monitoring. Participant 2 had to miss school in order to accompany the mother to the clinic. All these experiences regarding irregular school attendance has a potential danger that may lead to low school performance and dropping out of school (Linsk & Mason, 2004; Scott, 2004; Black 2009).

Other set of narratives texts indicates that participants 4 and 6 were doing well at school as there is no mentioning of school interruptions. Participants 3's narrative account indicates that although her mothers' situation did affect her, she nevertheless maintained her performance which seems to have dropped. Participants 4 and 6 extracts demonstrate that their school performance were not affected by their mothers' illness. This may suggest that as compared to the girls, boys have coped better with the situation they are experiencing, (Bauman et al, 2006; Francis & Francis, 2006).

### 5.3.2.9 ARV Treatment

ARV Treatment stands for anti-retrovirals which are drugs used to fight HIV infection (American Psychiatric Association, 2000). In this study the treatment is discussed in terms of the experiences of adolescents living with HIV/AIDS positive mothers who use ARV's. The emotional tone expressed through the participants' narratives was that of hope, as they positively believed that the anti-retrovirals will create change in their lives.

Participant 2 expressed her joy over the positive results brought about by the ARV treatment. She also explained that her mother has been enjoying her life ever since she started using ARV'S: *But now I'm enjoying, and my mom is enjoying her life. She is taking her medicine.*

Participant 3 indicated that she would like to become a nurse as she would improve the health of people infected with HIV/AIDS by providing ARV's: *My wish is to become a nurse in future. I would give HIV/AIDS people treatment.*

Participant 6 expressed his relief when he came to realise that ARV's can enable his mother to live longer with HIV/AIDS. He also illustrated his awareness that his mother will also need to maintain her health by visiting the clinic on regular basis: *But as time went by, I realized that AIDS does not kill when a person manage herself very well by treating it, and visiting the clinic.*

Participant 4 demonstrated his trust that his mother will not be killed by HIV/AIDS given the fact that she is using ARV treatment: *Only if you are not taking treatment then it (HIV/AIDS) will make you die.*

The set of images characterized in these narratives symbolise participants' faith in medication. The fact that ARV treatment is capable of improving the mother's health situation eased the participants' fearful feelings and added hope. The narratives indicate that they are no longer imagining death. Hence, ARV treatment can be linked to better

health conditions, coping mechanism, and enhancement of hope (Nashandi, 2002; Freeman, 2003; Roman 2006; Jonson, 2009; Black 2009).

### **5.3.2.10 HIV/AIDS and poverty**

Poverty according to Woodford (2007) refers to a situation where a person is very poor. Research shows that the HIV/AIDS epidemic is more intense in poor communities as it has been found that most people living there are HIV/AIDS positive ( Scott, 2004; Francis & Francis, 2006; Black, 2009). According to Black (2009: 44) “research suggests that when one or more family members are infected with HIV, family income drops substantially”.

Participant 4 explained how he relied on the support of a relative as his mother was unable to provide food for the family: *Her sister (mother's) will try to comfort me and she will give me her own money to buy food because at home we don't have money to buy enough food.* The extract also indicates that he needed to be comforted. It is hence inferred that the lack of food situation created a feeling of discomforts.

Participant 1 described how the insufficient money to buy food had interfered with her school attendance. She further asserts that she was not used to such situations. Thus, her stability with regards to attending school was affected: *At school I did not attend so well anymore because I sometimes did not have money to buy food for lunch and I was not used to that.*

Participant 5 relied on the older sibling to meet her nutritional needs. She also explained that her mother's inability to work and meet school fees requirements has caused her emotional pain: *There is an older sister at home who helps out with groceries. Her (the mother's) situation does hurt me, because she cannot work as she used to. At times she does not have money for our school fees.*

Financial struggles are clearly symbolised through images of the participants' narrative texts. These imageries infer that the mother's HIV/AIDS positive status has worsened the element of poverty. In the context of HIV/AIDS, poverty can cause distress in the lives of

adolescents as it is associated with malnutrition, low level of cognitive functioning, dropping out of school and committing crime for survival (Scott, 2004; Richter, 2004; Ranchod 2005; Deacon & Stephney, 2007; Black 2009).

Before the mother's illness the narrative tone of the personal narratives of the participants was positive. Their life experiences are characterised as 'happy,' 'good times,' and 'play times.' They collectively tell about how they enjoyed spending good times with their mothers. The 'good times' involves many different things to different individuals: 'chatting,' 'just keeping each other company,' 'playing games together,' 'sharing jokes,' 'having happy moments together,' and 'going to the beach'. According to De Genova and Rice (2001: 31), family closeness "helps children develop positive self images and self-esteem." There are certain activities individual participants used to enjoy sharing with their mothers. For girls these involved activities such as cooking, doing laundry or just watching and listening to their mothers singing. For boys, watching their mothers cooking good food was the most enjoyable activity shared with their mothers. Such close relationships with mothers reflect security, a sense of being loved and cared for, and sense of togetherness. According to the World Health Organization (2007) the psychosocial well being of a child lies in the roots of close, secured relationships with parents.

The participants' positive experiences were extended from home, which is the inner world and to the outside world which is playing out with other children. The narratives indicate that participants enjoyed sharing the outside world with other children. A sense of belonging with other children is therefore reflected. A child's playground represents a carefree world. In essence the life experiences of adolescents before the mother's illness indicate contentment. Then came the unexpected experience. Participants discovered for the first time that their mothers are HIV/AIDS positive. Things became different. This marked the beginning of the new phase in their lives. The phase brought along a number of new experiences of life. An element of 'shock' appeared to be the introductory part of these new experiences: *'I was shocked when I heard of my mother's HIV/AIDS' illness*'. This became the beginning of an emotional journey which also consisted of hurt and pain: *'I felt so sad', 'My heart was broken, I could not believe it', 'I cried', 'I felt very bad', 'It*

*was so painful*'. They feared for their mothers' lives and to be left behind in case their mothers died: *'I thought she will die early', 'I thought she will leave me', 'I hear other people say if you have HIV/AIDS you gonna die'*.

It became the situation of having to learn how to cope. Some found their coping mechanisms through supporting their mother, skipping school in order to accompany their mothers to the clinic. Seeing their mother's health improve helped them to feel better about themselves. Others coped through receiving HIV/AIDS information from their mothers after their disclosure. Having found the platform to cope with the HIV/AIDS status of their mothers, participants had to take new challenge of accepting the situation. When they realised that their mothers' HIV/AIDS statuses were irreversible, participants opted to convince themselves that they will 'have to take it'. Sad as it was, they chose to be there for their mothers to show that they 'have accepted the situation'. One participant even mentioned that *'she will remain my mother and nothing will change that'*. This is a clear reflection of courageous narrative tone. However, the outside world remained a challenge to the participants. In the outside world they had to deal with how other people perceive their mothers' HIV/AIDS status.

To some participants the outside world closed its doors against them and they felt discriminated against: *'my friends stopped coming to visit me', 'only few family members came to visit', 'even I couldn't go outside anymore', 'even when my mom eat with a spoon my uncle said she must have one spoon to use'*. It became evident that even the relatives made part of the discriminating outside world. To other participants the outside world was more understanding and accommodating: *'people treat us very well', 'they know that what my mom has she did not choose to have'*. Again the outside world is the place where friendships are made. As expected, participants also had friends 'out there.' In times when friends were mostly needed, some participants felt rejected by their own friends: *'When my friends rejected me I felt so hurt because it was obvious they were judging me'*. The participants felt let down and disappointed by friends. On the same note other participants felt supported and accepted by their friends: *'My friends have not*

*changed*, *'they react good because they are nice friends'*. Hence, participants with good friends benefited from the outside world.

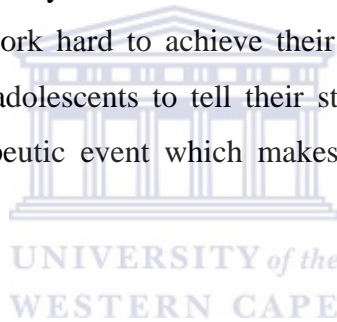
Attending school was another significant part of the participants' lives. Participants felt impressed by their own school performance in spite of their emotions due to the mother's HIV/AIDS status: *'Sometimes I have to leave early at school because my mom would be very sick'*, *'when she goes to the clinic I'm not going to school, I go with her'*. Passing tests and exams was a testimony for themselves and the world 'out there' that they are able to keep going: *'I was thinking I was going to fail this year but I did not fail'*, *'my school performance is perfect'*. Most of these participants have aimed high in terms of finishing school and studying further. They know what they want to become when they finish studying, and gave reason as to what motivated them to make such choices. Some showed interest in working with people, helping people: *'My wish is to become Peer Operator, I like interacting with many people of different backgrounds'*, *'My wish is to become a nurse, I would give HIV/AIDS people ARV treatment'*. The other participant was simply looking forward to work and take care of her mother when she finishes school.

Adding to their hope was the wish to see their mothers not ill. To most of the participants ARV's plays a significant role. They believe that if it wasn't for ARV's their mothers would be sick and dying from HIV/AIDS. They are convicted that their mothers are healthy due to ARV's intervention: *'My mom is enjoying her life, she's taking her medicine'*, *'I realised that AIDS does not kill when a person manage herself very well by treating it'*. Other participants are convinced that HIV/AIDS has brought poverty in their homes as their mothers cannot provide for the family as they used to: *'her situation does hurt me, because she cannot work as she used to'*, *'I sometimes did not have money to buy food for lunch and I was not used to that'*. Some participants and their families relied on family relatives to provide with money to buy food: *'Her sister will try to comfort me and she will give me her own money to buy food because at home we don't have money to buy enough food'*. Other family members provide groceries to the family: *'An older sister at home helps out with groceries'*



## 5.4 Conclusion

Story telling is the representation of reality (van Zyl, 1988; Garro, 1994; Crossley, 2000a; Manfred, 2005; Gubrium & Holstein, 2009). This narrative psychological project thus describes the real life experiences of adolescents living in households with HIV/AIDS positive mothers. The findings consist of different experiences due to different gender and socioeconomic backgrounds. Some participants experienced support from friends and relatives, whereas some experienced rejection and discrimination. Other participants experienced poverty based on the HIV/AIDS situation within the household, and others did not. Girls were more emotionally affected by the mother's HIV/AIDS status than boys. Although some of the participants' school performance and attendance were affected, all participants are nevertheless looking forward to finishing school, obtaining a job or even studying further. They all maintained the hope that the future can still be better if they aim high and work hard to achieve their set goals. It is evident that by enabling HIV/AIDS affected adolescents to tell their stories, and by listening to these stories is on its own a therapeutic event which makes a significant part of their life journeys.



## CHAPTER 6

### CONCLUSIONS AND RECOMMENDATIONS

#### 6.1 Introduction

Adolescents often find themselves engulfed by the adolescence tension brought about by rapid changes in physical appearance, social and psychological behaviour. Adolescence is a transitional stage where adolescents explore identity formation, self searching, conforming to societal expectations, finding freedom to live and the meaning thereof (Bigner, 1998; Arnett, 2001). Facing such major challenges, this study sets out to examine how adolescents experience life living in households where the mother is HIV/AIDS positive and what are the consequences for these adolescents. Chapter One and Two revealed that adolescents affected by HIV/AIDS often experienced stigma and discrimination within their families and in communities. Furthermore, these adolescents are supposed to live according to the society's social constructed expectations.

Chapter Five combines the insights captured from this study and indicates how the findings support the argument presented in chapter One and Two. Having enclosed information covered in this study the researcher will then discuss the implications of insights thus drawing a number of conclusions. The intentions is based on the attempt to interpret, make sense and reveal the meaning of the stories told by adolescents living in households where the mother is HIV/AIDS positive. According to Knowles (2007: 96) "as a narrative study in the qualitative tradition, the intention is not to verify or test any specific theory, but to make sense of the emerging patterns revealed through stories." Furthermore the researcher will provide methodological limitations and recommendations from this study.

#### 6.2 Summary of findings

Through story telling the participants in this research shared their personal narrative account and voiced the reality of living in households where their mother is HIV/AIDS positive. Even though their stories were uniquely narrated, there was clear common experiences which indicate that, participants' lives before the mother's illness consisted

of happiness and togetherness, sense of belonging, and good nutrition. It is highlighted that the participants' life stories took a turning point for the first time when they discovered their mothers' HIV/AIDS positive status. Within the context of participants' lives after the mother's illness, the following themes emerged: shock, hurt, fear, coping, acceptance, discrimination versus non-discrimination, rejection versus non-rejection, school attendance and performance, ARV Treatment, and HIV/AIDS and poverty. Apart from the element of discrimination and rejection all of the identified themes were common to all participants. In addition, irrespective of the differences in their personal narrative account participants' experiences shared a common central point which is self-identification. They knew who they are, what they want, and where they are going with life. They demonstrated courage to endure the odds within their situations.

The research data revealed that adolescents living in households with HIV/AIDS positive mothers have been faced with emotionally challenging situations. These adolescents have to live with the reality of their mothers' illness and also deal with the community responses, in addition to the psychological challenges created by the adolescence stage. As they undergo the process of self-identification the adolescents living in households with HIV/AIDS positive mothers also had to survive moral confrontations as HIV/AIDS is associated with a sinful realm. However, in the midst of the negative situation covering their vulnerable lives, these adolescents have found inner strength to cope with and endure their situation. The context of their narrative account revealed that they have previously experienced happy parent-child relationships before discovering their mothers HIV/AIDS positive status. The researcher concurs with Winnicott (1984), Bigner (1998) and Arnett (2001) in indicating that a positive experience in early childhood can have long term impact on the psychological well being of a child.

The stories of adolescents' lived experiences revealed that they survived situations that posed a potential threat to their cognitive and moral development, self awareness, self esteem and social interactions. This research data revealed that these adolescents are determined to have a positive future despite their experiences. Some of these adolescents felt rejected by friends, others were discriminated against at the hands of family members

and relatives. In extent, the majority of them had difficulties with regards to attending school regularly due to their mothers' ill health. Same findings regarding adolescents' ambitions to pursue their future dreams irrespective of their experiences of HIV/AIDS are also reported by Black (2009). Through examining the narratives it became clear that the hope placed on ARV Treatment contributed to enhancing emotional well being of these adolescents, as it brought sense of assurance that their mothers will be healthy. These findings subscribe to other studies which revealed that in many cases people who are affected by HIV/AIDS have since gained emotional healing through faith that ARV's will improve their loved one's health situations. Other studies have reported similar findings (Jonson, 2009; Black, 2009; Roman, 2006; Nashandi, 2002).

The narratives also reveal that the mother's ability to cope with her own health conditions has transferred into the participants' coping mechanism. Another factor that played a role in enhancing participants' coping ability was the HIV/AIDS information received from their mothers. This type of information clarified the myths and misconceptions that anyone who is HIV/AIDS positive will certainly die from AIDS. Thus, through the basic HIV/AIDS information participants gained knowledge that HIV/AIDS positive people can live healthier and longer if they manage their conditions well, including regular visits to the clinic as well as taking ARV's. However, as the participants' find strength and resources to cope with living in households with HIV/AIDS positive mothers, they also discovered that the situation, in part, brought along poverty. Their stories with regards to experiencing poverty indicated a sense of helplessness. Their part is to hope that the poverty situation could change for the better. These findings contribute to many other HIV/AIDS studies which revealed the negative impact of poverty in relation to HIV/AIDS pandemic (Black, 2009; Jonson, 2009; Roman, 2006; Shebi; 2006; Ranchod, 2005; Richter, 2004).

All participants have been aware of how negatively HIV/AIDS is socially constructed. They also understood how people who are infected and affected by HIV/AIDS are negatively perceived and regarded by society. Some of these adolescents have been directly affected by the negative perceptions through the unfriendly treatment they

received from friends and relatives. Such situations clearly indicate that they had to endure courtesy stigma. This finding supports Shebi (2006) and Deacon and Stephney (2007) reports of courtesy stigma experienced by HIV/AIDS affected adolescents. Those adolescents who have not directly experienced the unfair treatment have just been aware of it as they observed it happening to other people around them who also come from families that are affected by the HIV/AIDS. With all of these, adolescents living in households with HIV/AIDS positive mothers have chosen to perceive themselves differently from what was socially constructed about them, and thought about themselves positively. This was indicated through their resistance towards such negative perceptions and treatment, and also by setting attainable goals for themselves. In essence, such a response provided a clear reflection of a positive self identification, a healthy driven purpose and a positive mind set.

### **6.3 Recommendations**

Based on the findings of this inquiry I have set out the following important recommendations:

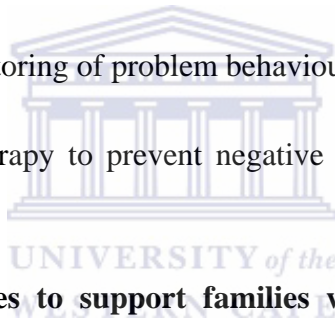
Adolescent health and development has been a central point in the worldwide context of research and literature as a means to contribute to the overall well being of an adolescent child. The World Health Organization has provided a set of guidelines to contribute in quality improvement process with regards to enhancing monitoring adolescents' well functioning. The South African constitution has set out the Bill of Right to care, protect and supports children due to their different ages. However, the researcher believes that there is a need for the government to develop strong alliances with the NGO sector to take collective action in strengthening the existing support programmes for adolescents living in households where the mother is HIV/AIDS positive.

I have categorised my recommendations in terms of the following: Ongoing therapeutic interventions, Governmental strategies to support families where parents are HIV/AIDS positive, Community-based HIV/AIDS education.

### **6.3.1 Ongoing therapeutic interventions.**

The government should consider building therapeutic centres for adolescents affected by HIV/AIDS where the following services can be rendered:

- Ongoing counseling for adolescents living in households where a parent or both, are HIV/AIDS positive.
- Regular monitoring of adolescents adjustment with regards to parents' illness.
- Enhancing group therapy where adolescents are enabled to talk about their unique experiences regarding their parents' HIV/AIDS status.
- Exploring different methods to improve coping skills.
- Identification and monitoring of problem behaviours.
- Provision of psychotherapy to prevent negative behavioural, social, and mental health outcomes.



### **6.3.2 Governmental strategies to support families where parents are HIV/AIDS positive.**

The government should identify strategies to assist and support families where a parent or both are HIV/AIDS positive. In doing that, the following services can be provided to sustain HIV/AIDS affected families:

- Ongoing family counseling where both parents and their adolescent child are involved. This type of intervention could help both parents, together with their adolescents to manage the challenges created by parents' HIV/AIDS positive status
- Assessment of the income generation to identify whether the family's nutritional need is catered for.

- In the case of low or no income generation, the family should be provided with food parcels.
- Exploring different methods to improve parent-child relationships for the enhancement of parental love.

### **6.3.3 Community-based HIV/AIDS education.**

The government and NGO's together should implement additional methods to provide HIV/AIDS education within the communities. Sufficient and effective provision of HIV/AIDS education could eliminate stigma and discrimination.

### **6.4 Methodological limitations**

Even though the sample size seemed adequate for the analysis, the fact that the study was limited to a certain population and a specific sample is regarded as a shortcoming. All six participants were at school, came from same area and were all black adolescents aged between thirteen and fifteen years. At the time of the interviews these adolescents lived with their HIV/AIDS positive mothers. All of the interviewed adolescents came from disadvantaged family backgrounds. Hence, this study cannot and does not aspire to represent the experiences of all South African adolescents living in households where their mother is HIV/AIDS positive. Focusing on the mother and not including the father's perspective also created a limitation in this study, as only one-sided experiences were sought. Interviews with mothers and fathers with which these adolescents live could have provided a valuable dimension to this study.

### **6.5 Further research possibilities**

The fact that the narrative account of adolescents living in households with HIV/AIDS positive mothers were not previously investigated, raising awareness regarding research could proceed from this study. The study began as an attempt to investigate how adolescents experience life living in households where the mother is HIV/AIDS positive. It might be interesting to explore the perceptions of unaffected adolescents with regards to adolescents living in households with HIV/AIDS positive mothers. Such research could

make a valuable contribution in terms of identifying intervention programmes with a focus on combating stigma and discrimination. It is also fitting to broaden the scope of this study and indicate that longitudinal studies are needed to assess adolescents' coping strategies at various stages, and as well as the psychological impact of living in households where their mother is HIV/AIDS positive.

## **6.6 Conclusions**

In conclusion, this research described the subjective experiences of adolescents living in households where their mother is HIV/AIDS positive. The description indicated that even though these adolescents were faced with psychological and socio-economic challenges they managed to hold on to the hope and belief that the future can be positive. However, the findings suggest that due to their level of maturity and social status these adolescents do need psychological, emotional and socio-economic support to withstand the challenges brought about by their experiences. Additionally, this study suggests that more research could be conducted with the aim to further investigate the psychological implication of living in HIV/AIDS affected households as an adolescent, and to explore effective support systems of. It is inferred that this study contributes to the body of knowledge which can be imparted in terms of development and enhancement of applicable policies and procedures in the HIV/AIDS field.

Thus the government has the responsibility to help develop and implement relevant support structures. This will have to involve relevant NGO's, NPO's, FBO's and other stakeholders. Effective support systems could lead to social deconstruction of HIV/AIDS positive mothers and their affected adolescent children.



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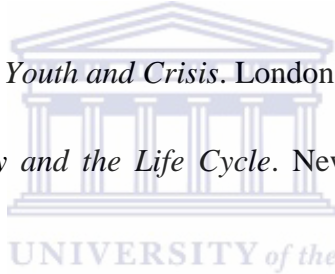
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## APPENDICES

### APPENDIX 1

10 November 2008

Petunia Tsweleng  
CC Dr. Nicolette. Roman  
Department Social Work  
UWC

#### **Re: Permission to do Research Project within Olive Leaf Foundation**

Dear Petunia

I received your letter requesting permission to do research involving clients who are being serviced through our programmes and I hereby grant you permission to do the planned research according to the specifications contained in your letter.

I would also like to remind you that HOPE worldwide changed its name to OLIVE LEAF Foundation as of 01 November 2008. I request that your verbal and formal reports and research publication reflect this reality. All information prior to the date of the name change can reflect the old name, but all activities post the name change should reflect the new name of the organisation.

I trust that your research will be fruitful and provide valuable information that we can use in the development of our programmes.

Yours sincerely

Joan Daries  
Area Manager W.C.  
OLIVE LEAF Foundation  
e-mail: [joan.daries@olf.org.za](mailto:joan.daries@olf.org.za)  
cell: 0828235624

## **APPENDIX 2: INTERVIEW GUIDE**

### **A. LIFE BEFORE THE MOTHER'S ILLNESS.**

**Prompt: Think about your family life before your mother's illness.**

1. How was life at home before your mother got ill from HIV/AIDS?
2. What sorts of things did you do with your mother?
3. Which activities did you enjoy most with your mother?
4. What sorts of things did you enjoy seeing your mother doing?
5. How frequently did you spend happy times with your mother?
6. How frequently did you play with other children? Did you enjoy that?

### **B. LIFE AFTER THE MOTHER'S ILLNESS.**

**Prompt: Go back to the moment of discovery about your mother's status.**

7. How did it feel when you first discovered that your mother is ill with AIDS?  
Probe: Sadness, challenges, difficulties?
8. Who disclosed her HIV/AIDS status to you? How?

**Prompt: Think about the present situation at home**

9. How is life at home after your mother got ill from HIV/AIDS?
10. How has the situation affected your own life within the family?
11. Do you think that your mother's illness has affected your life at school and in the community? How?  
Probe: School performance, interactions with peers?
12. How frequently do you spend happy times with your mother?
13. If you can make a wish, what would it be?

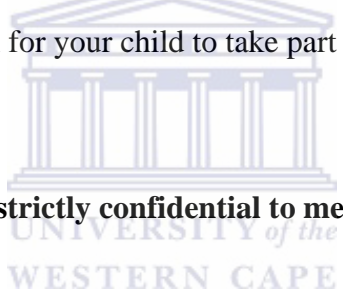
Private Bag X17, Bellville 7535, South Africa  
Tel: +27 21-959 2277, Fax 27 21-959 2845

**PARENT CONSENT FORM**

**20 May 2008**

**Dear Parent**

I would like to inform you about a research study that will be taking place at HOPE Worldwide in Khayelitsha. The study forms part of my master’s degree that is enrolled with the University of the Western Cape. The study project will be used to gather information concerning the experiences of adolescents living in households with mothers who are HIV/AIDS positive. I therefore humbly wish to ask for your permission for your child to take part voluntarily in this study.



I assure that:

**All information given will be strictly confidential to me & my academic supervisor: Dr Nicolette Roman.**

**Under no circumstances will the participants’ names be quoted.**

**Participation is voluntary and participants may at anytime withdraw.**

**Under no circumstances will the participants have to disclose their HIV/AIDS status**

You may please state by signing this letter if you give your child permission to participate. Your child’s participation will contribute to gaining of information valued to combat the HIV/AIDS epidemic, hence it will be highly appreciated.

Yours truly,

**Parent signature**

**Petunia Tsweleng**

.....

Student number 9408943

**Permission**

MA. Child & Family Studies

**Yes / NO**

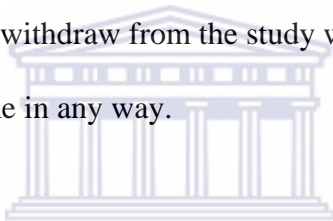
**APPENDIX 4 UNIVERSITY OF THE WESTERN CAPE**

Private Bag x 17, Bellville 7535, South Africa  
Tel: +27 21-959 2277, fax: 27 21-959 2845

**PARTICIPANT ASSENT FORM**

**Title of Research Project: The experiences of adolescents living in households with mothers who are HIV/AIDS positive**

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.



Participant's name.....UNIVERSITY of the

Participant's signature.....WESTERN CAPE

Date.....

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

**Dr Nicolette Roman**

**University of the Western Cape**

**Private Bag X17, Bellville 7535**

**Telephone: (021) 959 2838**

**Cell: 082 877 6691**

**Email: [nroman@uwc.ac.za](mailto:nroman@uwc.ac.za)**

**Participant No. 1 (15 yrs old)**

**LIFE BEFORE THE MOTHER 'S ILLNESS**

Life was easy going before my mom got sick with HIV/AIDS because as a family we used to be so unified. Family members used to share what they have amongst each other. We were happy.

I used to help her with cooking, and laundry.

I used to enjoy it when my mom and I spend time chatting and keeping each other company.

I used to like it; I used to like it when my mom sang songs that we sing at church. I used to enjoy that.

We used to spend the whole day just enjoying ourselves

I used to enjoy playing with other kids anytime I was done with everything I was supposed to do in the house. After that I'll go back to the house and be with my mom.

**LIFE AFTER THE MOTHER'S ILLNESS**

I was shocked, I was shocked when I heard of my mother's HIV/AIDS's illness

She told me herself. She called us (she and her sister), she sat us down and told us she was HIV positive. I felt so sad.

Life became so difficult. Some people stopped visiting our house. Even I couldn't go outside the house anymore.

The family was not getting along anymore. They started mentioning things about my mother. They stopped coming to our house. Only few family members came. Even her friends stopped coming to our house just to say we've heard that so and so is sick.

I did not feel right because I have, I have, I have told these people before and now I felt so bad when they came across me in the street. They did not even take notice of me like they used to. The situation has affected my life in the community as I used to have friends like I have friends now. I love my friends.

My friends stopped coming to visit me. Their mothers told them about my mother's situation as they themselves used to be my mother's friends and knew about her status. Thus we did not get along anymore. We could not interact anymore in the community.

When my friends rejected me I felt so hurt because it was obvious they were judging me

At school I did not attend so well any more because I sometimes did not have money to buy food for lunch, and I was not used to that.

Nothing changed with regards to the happy times I used to spend with my mother. It is all still the same.

My wish is to become Peer Operator. I chose that because I like interacting with many people of different backgrounds in different organizations.

## **Participant No. 2 (14 yrs)**

### **LIFE BEFORE THE MOTHER'S ILLNESS**

I cannot remember how life used to be with her because I did not stay with her. I used to stay with my father in Hout Bay.

### **LIFE AFTER THE MOTHER'S ILLNESS.**

When I first discovered that my mom was HIV positive my heart was broken, I could not believe it. But now I'm enjoying, and my mom is enjoying her life. She is taking her medicines. She is laughing about it to the people. She does not care about the fact that she is HIV positive.

My mom told me about her HIV status herself. She told me over the phone. But first time I heard I could not believe it because my mom was pregnant with my small brother. So then my small brother also got this from her pregnancy. When she phoned me I was in Hout Bay with my father and she was in Khayelitsha.

Life at home was not very good. My mom could not even want to go outside because she was thinking the people will see her. She did not want to tell anybody. She just told her family and her children. So my big sister told my mom she must tell the people about it, she can forget about it and take her medicines.

She said...., she listen to my big sister, she took her medicines. She is no longer scared to tell the people about her status

My mom's situation did affect my life. My heart was broken. My mom was living with her sister. My uncle, when he saw my mom going to the toilet. He would do bad things. He would wait for my mom to come out of the toilet, and then he would take a toilet paper and wipe off the toilet even though there was nothing to wipe off. I could not tell my mom when I saw my uncle doing that. But then I told my heart to tell my mom so that she can know that. When I told my mom her heart was broken. I told her no...., she must not try...., and my mom went like (making gestures showing that it has to stop). My uncle stopped doing what he was doing.

Even the spoon, even when my mom eats with a spoon. My uncle said she must have one spoon to use.

My mom then bought a house. Then I went to stay with my mommy and to look after her.

I watch the time for her to take her medicine. I must make her food before she take her medicine. I must sort out her bed to make it comfortable for her to sleep. After that I can go to play outside.

The situation has affected me, but when I'm at school I have to forget that to concentrate on my books because I was thinking I was going to fail this year, but I did not fail.

It has affected me badly in the community but I survived to hear that my mom is feeling better.

I survive just to be with my mom. When I go to play I'm not scared to tell the people that my mom is sick of HIV/AIDS. When she goes to the clinic, I'm not going to school; I go with her to the clinic. So I feel better.

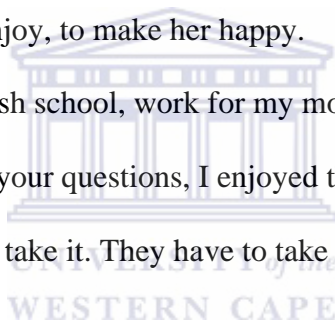
They react good when I tell them (about her mother status) because they are nice friends.

Sometimes my mom is sick. I'm going to spend the weekend with my family, with my father.

Sometimes I stay with my mom. Sometimes I do cooking with my mom, helping her in the kitchen. So I just want her to enjoy, to make her happy.

I wish that I may be able to finish school, work for my mom, and take care of my mom.

Thank you (the researcher) for your questions, I enjoyed them. Just for those (children) who their mothers have HIV they have to take it. They have to take care of their mothers and enjoy it.



### **Participant No. 3 (13 yrs)**

#### **LIFE BEFORE THE MOTHER'S ILLNESS**

Life was not good. For a long time she did not say anything. Only when I was about ten she then told me she was HIV/AIDS positive.

She used to cough a lot, when I asked she would say she is fine, that she does not have anything.

The after sometimes, when she was really sick, she then told.

It used to be nice before she got weaker. We used to play games together. I used to enjoy a certain game about writing names in the blocks according to specific alphabets.

I used to enjoy watching her singing and dancing.



Our happy time together was not that long because she used to leave, go to work and we would only see each other later in the evening.

I used to enjoy spending more time playing with other children, but I also had to pay attention to my school work.

### **LIFE AFTER THE MOTHER'S ILLNESS.**

I cried when I discovered that my mom is HIV positive, after that I could not say a word to her, for about a week I could not engage in a conversation with her.

When I first discovered about her HIV/AIDS status, it was when I went to the hospital to take the tooth out. I went with her. There I heard her mentioning that she needed to fetch ARV's. I already knew at that point in time that ARV's were for people with AIDS. I asked her why she has never told me before about her HIV/AIDS status and she said she did not want to hurt my feelings.

I was fine afterwards. I told her that I did not like how she never told me rightly that she was HIV/AIDS positive. She apologized.

At home it was not nice at all, I was always thinking about this thing of hers.

At school it has affected me just a bit; my performance is not that bad. In the community it has not affected me at all. My friends have not changed towards me. More so as some of them have HIV positive mothers like 'so and so' (referring to one of the participants she came with).

We do speak and that's nice yes, however I do get that feeling that she's not exactly what I expect of her, but she will remain my mother and nothing will change that.

Our happy times together have changed; however, we do still play games together.

I don't like the fact that she is now drinking, but when I tell her about it she tells me that it is her money she is spending on alcohol.

My wish is to become a nurse in future. I would give HIV/AIDS people ARV Treatment. I would also give some advice top HIV/AIDS parents that they should not drink alcohol because by drinking they really hurt their children emotionally. I know it because my mom is doing it to me.

**Participant No.4 (15 yrs)**

**LIFE BEFORE THE MOTHER'S ILLNESS.**

We were happy, she used to give us anything we wanted, she'll go to work, just work-work, and come back home and bring us something that could make us happy, something like food.

I used to make her coffee when she came back from work. And maybe she says I must wash her feet and I'll wash them.

My mother and I used to play cards, play cards and enjoy ourselves.

She cooked very nice food, whenever I asked for anything she would just make a plan for me to get it.

We used to spend lot of time together with my brothers. We would go to the beach, from ten to four. We would have plenty food and play.

I love playing with other children, but most of the time I like spending at home because there's lots of skollies out there and I don't like that.

**LIFE AFTER MOTHER'S ILLNESS**

At first I was sad. I did not know how do I, how can I talk about that. I was shocked because I hear other people say if you have HIV/AIDS you gonna die. And now that made me sad. But my mother tried to make me understand that HIV/AIDS is not just killing people. Only if you are not taking treatment then it will make you die.

I was happy because after I heard about her status she told me, No Vuyo, don't worry I'm gonna be alright. I'm gonna try my best to make you to be strong and accept that.

When she disclosed, she tried to sit down with us at home. But she does not talk to me because I'm the elder one with my brothers. Others don't stay at home. They stay in Gugulethu. Ann took time to make me understand, but I have tried, I have tried yeah. I told my brothers and sisters that we will be fine.

My life is bad now, the things I want at school I don't have, I cannot afford all the things they want at school. My mom would just say "I'm gonna try my level best to get everything you want, I'll go and look for money, I'll ask my brothers to help, I'll tell them we don't have money to buy food" and so forth. And that make me feel bad.

My mom tries to support me but she cannot afford many things like school fees, and new clothes. My friends, they always buy new clothes and when I talk to my mom she would just say "No Vuyo, I don't have money, but I will try all my best". She would make all these promises.

I feel bad and I told myself that okay, so my mother always tell lies to me, always, always; "I'll buy this and that for you". She lies to me.

I tried to speak to her about it, I asked her "Mom, why do you always tell me you gonna bring-bring me something, something? No, Vuyo you know at home we don't have money to buy food".

And I try to understand but always she promises me anything I ask her to bring me. Always she promises me that. I understand that at home we are suffering and all that, but always promising me that really make me feel bad.

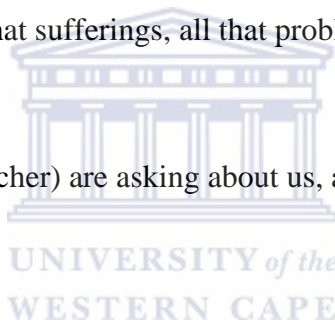
It would make it better if she was not making promises because I will know that she cannot afford it.

I don't think my life at school has been affected because I try my...., after she told me about her .....,status I understand a lot, and she always comfort me. Maybe something happen to me outside and I talk to her she tell me okay, what I must do. But now I'm fine at school. I always do my schoolwork and I don't have any problem. My school performance is perfect.

Most of the time she is not at home. She is at her sister's place. She spends most of the time there with her. Sometimes it makes me feel happy, but other times it makes me feel bad because most of the time she is not at home. Other time I go to her sister and share these things with her. Her sister will try to comfort me and she will give me her own money to buy food because at home we don't have money to buy enough food. After school as soon as I get home I go to her.

I can wish for..., at home, all that sufferings, all that problems must go away, and get all what we want.

All these things you (the researcher) are asking about us, are you gonna make our situations positive?



### **Participant No. 5 (14 yrs)**

#### **LIFE BEFORE THE MOTHER'S ILLNESS**

Life was not good. My mother was sick and she was not right. For a long time she was not aware she had HIV/AIDS. Eventually she went to Karl Bremmer Hospital, and that's where she found out she was HIV/AIDS positive.

We used to spend time together, just have happy moment together.

We joked together, played together.

She loved singing, and made jokes about how they do things at church.

We used to spend the whole day together, enjoying each other's company.

I would play with other children for about an hour and go back to the house. I used to enjoy that.

### **LIFE AFTER THE MOTHER'S ILLNESS.**

It was difficult; I thought she will die early.

My mom told me herself. She called me and my sister and told us she is HIV/AIDS positive.

I felt very bad. She was crying as she was telling us.

It is fine; we are still together as a family. However, her situation does hurt me, because she cannot work as she used to. At times she does not have money for our school fees. And sometimes I think about it so bad that it affects my sleep.

There is an older sister at home who helps out with groceries, and her (mother) own sister also helps out.

Sometimes I have to leave early at school because my mother would be very sick. My school performance dropped. When I write tests my mind is always preoccupied with my mom's conditions.

My life in the community has not changed because my friends in the community are not aware of my mom's HIV/AIDS status.

My mom and I currently spend very little time together.

I wish I can wake her up so that we can engage in the conversation, and that she would at least try to speak, but speak a little bit and fall asleep again. I wish she can stand up, get better and be well with her health.

**Participant No. 6 (14yrs)**

**LIFE BEFORE THE MOTHER'S ILLNESS**

Life was good, we were fine. I did not stay with my mom. She lived at Makhaza with my stepfather and my two little sisters. And I lived at Site-C with my grand mother. We used to see each other. We would have good times. She would tell me fairytales. I used to enjoy that. During holidays I would visit her in Makhaza.

I used to enjoy watching her cooking. She cooked very nice food.

When she visits us in Site-C we used to spend half a day together, and then she will go back to Makhaza.

It was nice to stay with my grandmother. She also told me bedtime stories before I go to sleep. I enjoyed that as it also helps me to fall asleep very quick.

**LIFE AFTER THE MOTHER'S ILLNESS**

It was so painful when I discovered about my mom HIV/AIDS status. I thought she will leave me. But as time went by, I realized that AIDS does not kill when a person manage herself very well by treating it, and visiting the clinic.

My mom disclosed her HIV/AIDS status herself. She first called me and sat me down. We first played some cards games and then she told me. After that she called my two sisters in and told them as well. She was very calm. I felt so bad. But when she finished telling me, she also explained more about what HIV/AIDS is to give me a better understanding.

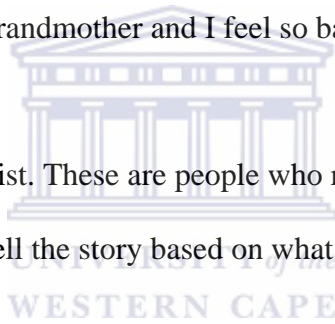
My mom used to be so quiet. She would close herself in her room and would not speak to me when I visited her in Makhaza. But now the situation became better than it used to be.

My grandmother and I have accepted my mom 'situation. My grandmother understands because when my mom disclosed she also explained to her more about HIV/AIDS. My grandmother said to my mom that she is still her child and nothing will ever change that.

My mom 'situation has not affected me at school. I have realized that when I passed all my tests. In the community people treat us very well because they know that AIDS does not just infect a person. They don't gossip about us, they know that what my mom has she did not choose to have. I now stay with my mother, so I get to spend more time with her.

When my mom gets sick, my grandmother and I feel so bad, that's because we really love my mom.

I wish to become an Archeologist. These are people who research about things that happened long time ago. They dig bones and tell the story based on what happened with regards to those bones.



**APPENDIX 6**

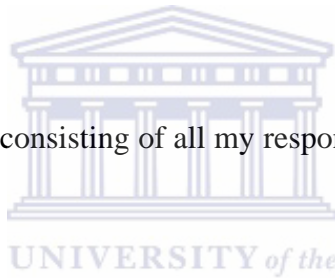
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**PARTICIPANT'S APPROVAL OF DATA VALIDITY**

**Title of Research Project: The experiences of adolescents living in households with mothers who are HIV/AIDS positive**



I have read the data transcripts consisting of all my responses and I declare the information therein valid.

The study has been described to me in a language that I understood and I freely and voluntarily agreed to participate. My questions about the study were answered. It was explained to me that my identity will not be disclosed. The interview sessions created a warm and caring atmosphere and I felt comfortable to answer all the questions. Throughout the process, I was aware that I can withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Participant's name.....

Participant's signature.....

Date.....

Student's name: Tsweleng M.P

Student number: 9408943



Programme: MA Child & Family Studies

