

Chapter One

1.1 Aim

This research aims to explore the experiences of adolescents living with HIV and AIDS.

1.2 Rationale

HIV and AIDS were first perceived of as major problems impacting on multiple levels of human functioning just over two decades ago. Initially the enormity of the challenge to combat HIV and AIDS was underestimated, but the realization of its devastating effects has become all too evident world wide, especially in Sub Saharan Africa (Van Dyk, 2001). South Africa has the fastest growing HIV and AIDS rate, with the highest prevalence being among young people (15-24 years) especially females (Foster & Germann, 2002; Hoosen & Collins, 2004). The Lancet (2003) states that there are almost 5 million HIV infected people in South Africa, approximately 1000 AIDS related deaths a day, and an estimated one and a half million children becoming orphans by the year 2010 (Lancet, 2003). These figures clearly indicate that HIV and AIDS is a crisis with major psychosocial implications that impact on every member of society, with women and children being particularly vulnerable to suffering the consequences of the disease (Goldstein, Pretorius & Stuart, 2003; Müller & Pienaar, 2004). In order to understand the nature of HIV and AIDS and its psychological, physiological and social implications,

ongoing and extensive research is required in connection with all vulnerable groups.

The focus of the majority of research involving HIV and AIDS is three fold. Firstly it focuses on the physiological, economical and medical implications associated with HIV and AIDS (Bartos & McDonald, 2000; Cameron, 2006; Lancet, 2003; Robins, 2006). Secondly, research explores the effects of HIV and AIDS in marginalised groups (Goldstein, et al, 2003; Müller & Pienaar, 2004). Thirdly, it examines the psychological and emotional implications of HIV and AIDS, particularly within adult population groups, namely people who are older than eighteen years (Cameron, 2006; Roth & Nelson, 1997). It is apparent from contemporary research that HIV and AIDS have the greatest impact on the poor and manifest in gender discrimination, poverty, stigma and abuse (Boonzaier & de la Rey, 2003; Hoosen & Collins, 2004).

The highest proportion of HIV deaths is in the twenty to thirty age group, which means that many of the people who have died of AIDS, may well have contracted HIV during their adolescent years, often through unprotected sex or through rape (Campbell, Foulis, Maimane & Sibiya, 2005; Foster, 2006; Richter & Swart-Kruger, 1995). The second highest mortality rate falls within the thirty to forty age group, indicating that children and adolescence are at great risk of being orphaned as many of

their parents fall into the latter high risk category (Foster, 2006). This combination of risk factors makes adolescents particularly vulnerable to the pandemic. Given the reality that the rate of infection amongst adolescents is very high, (Campbell et al, 2005; Ungvarski & Flaskerud, 1999) it is vital that their physical and psychological needs be met in order to enable them to cope with the consequences of living with HIV and AIDS (Hubley, 2002; Johnson, Schierhout, Steinberg, Russell, Hall & Morgan, 2004; Van Dyk, 2001). An examination of current literature reveals that very little research has been done in connection with adolescents' psychological and emotional functioning within the context of HIV and AIDS (Cluver & Gardner, 2007). It appears as if adolescents are marginalized and their voices remain silent in contemporary research. It is essential for this neglect to be redressed as voicing their stories may well help them to make sense of their life journeys, and it may help the scientific community implement appropriate interventions for them.

1.3 Literature Review

1.3.1 Introduction

People living with HIV and AIDS are forced to confront numerous emotional and social challenges as the disease has the potential to impact on multiple levels of functioning (Cohen & Abramowitz, 1990). What further exacerbates the difficulties associated with HIV and AIDS is the

belief that only ‘evil’ people are infected with the disease (Campbell, 2003; Campbell, et al, 2005). As a result affected or infected individuals are often reluctant to disclose their or their loved one’s status (Cameron, 2006; Goldstein et al, 2003). Stigma and rejection not only impacts on adults but children as well (Drew, Makufa & Foster, 1998; Freeman & Nkomo, 2006). In addition HIV and AIDS undermines the very foundations of family life and consequently children impacted on by the disease are confronted with numerous life changing challenges and difficulties which are age specific in that children are generally ill equipped to take care of their own financial and emotional needs (Domek, 2006; Drew et al, 1998; Freeman & Nkomo, 2006).

The following Literature Review will firstly define the term ‘Living with HIV and AIDS’ as it is used within the context of this research. This will be followed by an in depth discussion of stigma and poverty on all people living with the disease. After this discussion the focus will be specifically on children and adolescents. Key points to be discussed will be the role of extended families, child-headed households, street children and places of safety. The psychological implications of HIV and AIDS within the context of childhood will follow this discussion. This section will be concluded by focussing specifically on adolescence, identity and HIV and AIDS.

For the purpose of this research art, poetry and story telling were used to enable the adolescents to tell their stories. Consequently the Literature review will conclude with a discussion of the therapeutic validity of poetry, story telling and art making.

1.3.2 Defining the term ‘Living with HIV and AIDS’

In this research, the term “Living with HIV and AIDS” will be used to refer to people who belong in one of more of the following categories:

- a) People who are HIV positive and are thus infected by HIV
- b) Those who have been diagnosed with full blown AIDS, and
- c) Those who have either lost a family member or close ally as a result of HIV or AIDS related causes and/or
- d) People who have a family member or close ally who is currently HIV positive or has been diagnosed with AIDS.

The term ‘Living with HIV and AIDS’ characterizes a survival positive that emphasizes the continuation of life. It therefore, focuses on survival and, by implication, has less negative connotations.

1.3.3 Factors exacerbating the impact of HIV and AIDS

1.3.3.1 Stigma

Every person living with HIV and AIDS belongs to a community. A community’s construction of meaning around the nature of HIV largely

determines the impact that being HIV positive will have on the psychological well being of the infected person and their immediate as well as extended family (Goldstein et al, 2003; Müller & Pienaar, 2004; Roth & Nelson, 1997).

People who are diagnosed HIV positive are often subjected to stigmatization by society, which in turn rebounds on their family members (Campbell et al, 2005; Skinner & Mfecane, 2005). In addition to external stigma attached to HIV, Cameron (2006) argues that those infected also suffer from internalized stigmatization which leads to feelings of being dirty, reprehensible and unlovable. Children who are HIV positive are subjected to the same negative responses, which can severely undermine their concept of self (Campbell et al, 2005).

HIV is associated with sexual promiscuity, and as such generates a great deal of moral judgment and blame (Campbell et al, 2005; Müller & Pienaar, 2004). Infected individuals are often perceived of as being responsible for their plight and therefore not deserving of sympathy. This perception is generalised to children as well (Campbell et al, 2005; Skinner & Mfecane, 2004). Adolescents who have contracted the disease as a result of unprotected sex are often perceived of as being evil and are at risk of being rejected by their communities, including their parents and family (Campbell et al, 2005). Judgment is not based on objective

information around the nature of the virus as fear generated by the knowledge that HIV is not curable exacerbates the situation (Cameron, 2006; Campbell et al, 2005). People living with HIV and/or AIDS of all ages are generally subjected to humiliation and rejection due to these perceptions (Campbell et al, 2005; Crewe, 1992; Schlebusch & Cassidy, 1995; Van Dyk, 2001).

Research indicates that women are more likely to be tested and to reveal their status, and as a result women are often perceived of as being the cause of HIV and AIDS (Campbell, et al, 2005; Le Marcis & Ebrahim-Valley, 2005; Van Dyk, 2001). Belief that women are responsible has led to many women and their children being driven out of communities (Le Marcis & Ebrahim-Valley, 2005; Letlaka-Rennert Luswazi, Skinner & Mfecane, 2004). Marginalisation of women impacts on children who have even less status than their mothers. Furthermore, if mothers have HIV, children are at risk of being orphaned, which increases their vulnerability (Cluver & Gardner, 2007; Letlaka-Rennert et al, 1997).

1.3.3.2 Poverty

HIV is often associated with poverty and although it is not a disease that is restricted to the poor, it does have a greater negative impact on the poor, especially when the primary bread winner is infected (Letlaka-Rennert et al, 1997). Within the context of rural areas in Sub-Saharan

Africa, grandmothers often take care of children while parents seek employment in cities. When a parent returns home due to infection the financial burden on the family is substantially increased (Andrews, Skinner & Zuma, 2006; Foster, 2006). Furthermore, in the final stages of AIDS, the infected person requires full-time care that is psychologically and physically exacting for those entrusted with this task (Van Dyk, 2001). When a child is the primary caregiver, he/she is often unable to cope with the dual task of running the home, and completing his/her education (Andrews et al, 2005; Foster, 2006). Children are not emotionally equipped or developmentally mature enough to handle these exacting demands and the impact on 'normal' functioning, such as being able to focus on education and social interaction with peers, is profound (Andrews et al, 2005; Van Dyk, 2001). As a result, children who find themselves in this situation often drop out of school. Lack of education puts them at greater risk socially and economically (Hubley, 2002; Johnson et al, 2004; Van Dyk, 2001). In addition the stress of watching a parent dying increases the risk of depression in the young care givers (Andrews et al, 2005).

Stigma, poverty, and abuse all serve to intensify the negative impact of HIV on the lives of infected people, but in particular on children who are emotionally and financially dependent on adult support (Le Marcis &

Ebrahim-Vally, 2005; Müller & Pienaar, 2004). Living with HIV and AIDS affects children and adolescents on all levels of functioning.

1.3.4 Children and adolescents

Given the high AIDS mortality rate in Sub Saharan Africa it is evident that children living in poor and marginalised communities are at greater risk of losing both their parents (Foster, 2006; Foster & Germann, 2002; Lancet, 2003). When this happens children either end up in extended families, in child-headed households, on the streets or in places of safety (Cluver & Gardner, 2007; Foster 2006; Foster & Germann, 2002).

1.3.4.1 Extended families

HIV and AIDS related deaths have exerted an enormous impact on the extended family, which invariably feels obligated to take care of orphaned children (Foster, 2006). Extended families have generally borne the brunt of caring for HIV orphans, and this to a certain extent has masked the very real problem regarding the alarming increase in HIV orphans (Domek, 2006; Foster 2006). Research has indicated that in recent years the extended family system has become weakened. Factors that have contributed to this observation include the increasing number of orphans requiring care, the decreasing number of prime-age care givers, and systemic changes such as migrant labour and education. This perceived weakening of the system means that more children are ending

up in child-headed households or as street children (Foster, 2006; Foster & Germann, 2002). Even when children are incorporated into extended family systems, their orphan status makes them vulnerable to abuse. Research has shown that orphaned children are regularly removed from schools in order to work for their extended families. Illiteracy puts them at greater risk of being abused economically and physically (Foster 2006). In some instances the extended family does not want to take care of AIDS orphans, as they fear repercussions from the community (Campbell et al, 2005; Van Dyk, 2001). When no other alternatives are available, grandparents who are subsisting on meagre pensions and have few resources at their disposal are expected to take care of children (Freeman & Nkomo, 2006). When grandparents die, the children are compelled to look after themselves (Drew et al, 1998; Schlebusch & Cassidy, 1995).

1.3.4.2 Child-headed households

Orphans who have no adult support system generally end up looking after themselves with the oldest child becoming parentalised. Children in child-headed households are open to multiple levels of abuse (Andrews et al, 2006; Foster, 2006; Sowell, 2007). Firstly with no parental figure to protect their rights, they are vulnerable to being physically and sexually abused (Andrews et al, 2006; Freeman & Nkomo, 2006; Foster, 2006). The incidence of rape amongst children living in child-headed households is extremely high (Andrews et al, 2006; Cluver & Gardner, 2007; Richter &

Swart-Kruger, 1995). Furthermore, the parentalised adolescent or child is unable to continue with his/her schooling due to added domestic responsibilities. The adolescent is then at risk of being exploited within the context of child labour and furthermore has fewer career options at his/her disposal (Foster 2006; Snel, 2003).

1.3.4.3 Street children

Orphans who are unable to survive in their communities may be lured to cities, where they hope to have access to more resources. These children set up homes and communities on the streets where they establish their own cultural norms (Richter & Swart-Kruger, 1995, Sowell, 2000). They are considered more vulnerable than most adolescents of becoming HIV infected because sexual experimentation and drug abuse is considered the norm (Richter & Swart-Kruger, 1995). Furthermore, they are cut off from normal HIV educational sources such as schools and families where they could obtain valuable information regarding HIV infection. Health and safe sex practices are secondary to their survival needs which are a priority (Richter & Swart-Kruger, 1995). Survival is often dependent on begging and stealing (Richter & Swart-Kruger, 1995; Sowell, 2000). In order to survive, many children are lured into prostitution by unscrupulous adults, a phenomenon that impacts on boys and girls (Richter & Swart-Kruger, 1995). Life on the streets is harsh as street children face the ongoing risk of being raped, abducted and physically

abused. Street children invariably receive no education, and have no adult role models to teach them life skills (Richter & Swart-Kruger, 1995; Sowell, 2000). They constitute a lost generation with very little hope of improving their lot without adult intervention (Richter & Swart- Kruger, 1995; Snell, 2003; Sowell, 2000).

1.3.4.4 Places of safety

Places of safety are considered a last resort in the care of orphaned and vulnerable children. Many children prefer to live in child-headed households if extended families are unable to take care of them (Cluver & Gardner, 2007; Foster, 2006; Foster & Germann, 2002). However, because of increased numbers of orphans and the concomitant pressure exerted on the extended families, many children are being abandoned and subsequently placed in care centres (Foster, 2006; Foster & Germann, 2002). Informal care centres are being opened on a regular basis but these are generally poorly run by untrained care-givers (Freeman & Nkomo, 2006). This puts the children at greater risk of being physically and sexually abused (Foster, 2006; Freeman & Nkomo, 2006). Research indicates that most children in large care centres get their physiological needs met. However, in most instances their psychological and emotional needs are secondary (Drew et al, 1998). Craig and Richter-Strydom (1983, as cited in Louw et al, 1998 p 407) point out that according to research, early sexual activity is more prevalent in lower socio-economic groups,

especially where adolescents are in crowded living conditions with non family members. Furthermore, children who are orphaned and lack personal involvement with an adult role model are more likely to engage in sexual activity at an early age (Cohen & Abromowitz, 1990; Richter & Swart-Kruger, 1995). Consequently, adolescents living with HIV and AIDS, who are living in care centres, are at greater risk of engaging in risky behaviour. Furthermore, care centres uproot children from their communities and add to their feelings of isolation and alienation (Cluver & Gardener, 2007). Children resent being labelled 'orphans' due to the fact that, in many communities, the label has negative connotations. Children placed in care often feel that they are defined by their orphan status, which translates into being unwanted and rejected (Cluver & Gardner, 2007). Thus it can be argued that children living with HIV and AIDS in care centres live with a doubly negative stigma which may well have a negative impact on their sense of self.

1.3.4.5 Psychological implications

There is a body of research examining the nature of interventions aimed at educating adolescents in terms of HIV and AIDS (Campbell, 2003; Campbell & McPhail, 2002; Van Dyk, 2001). However, very little research exists that investigates the psychological implications of children and adolescents living with HIV and AIDS (Cluver & Gardner, 2007; Strydom & Raath, 2005). Domek (2006) points out that the

psychological well-being of children living with HIV and AIDS is severely compromised. HIV positive children experience a variety of complex feelings involving shame, humiliation, anger, loneliness, confusion, depression and fear (Strydom & Raath, 2005). HIV positive adolescents and children are at risk of experiencing clinical anxiety and depression due to 'recurrent and cumulative' losses (Cluver & Gardner, 2007; Strydom & Raath, 2005). Cumulative losses include death of parents, loss of health, loss of homes, living in poverty, violence, sexual abuse, and confronting their own mortality. With the advent of antiretroviral treatment, many children are surviving and consequently entering adolescence with serious mental health problems (Domek, 2006; Strydom & Raath, 2005).

Adolescents who are not infected but are living with the consequences of HIV and AIDS are equally challenged. They have to confront a deep sense of abandonment due to the illness and subsequent death of a parent/parents and/or the rejection of their community. This is particularly applicable to adolescents who are living in deprived and poverty stricken communities (Campbell et al, 2005; Foster, 2006; Foster & Germann, 2002). Furthermore, they invariably confront educational and psycho-social problems all of which have the potential to impact on their mental health (Campbell et al, 2005; Domek, 2006; Foster, 2006; Foster & Germann, 2002; Sowell, 2000). Given the reality that these adolescents

are at greater risk of being infected with HIV (Campbell et al, 2005; Ungvarski & Flaskerud, 1999) it is essential that their physical and psychological needs be met in order to enhance their daily functioning, and ultimately, their quality of life (Domek, 2006; Hubley, 2002; Strydom & Raath, 2005; Van Dyk, 2001).

Adolescence is a particularly vulnerable period of development. In order to fully understand the threat that HIV and AIDS pose to normal development, it is essential to examine adolescents' developmental context as well (Domek, 2006).

1.3.4.6 Adolescence, identity and HIV and AIDS

Adolescence is a period in development that forms a bridge between childhood and adulthood. The onset of adolescence is between the ages of eleven and thirteen and ends between the ages of seventeen and twenty-one. However, the specific onset and ending of adolescence is largely dependent on cultural and individual perceptions (Louw, van Ede & Louw, 1998). Adolescence is generally demarcated by physiological and psychological changes that occur within a socio-cultural context. Therefore how adolescence is perceived and the impact it has on the individual is context specific (Campbell et al, 2005; Louw et al, 1998).

Erikson (1963) posited that human development occurred in predictable phases throughout the life-span (Erikson, 1963). Accordingly Erikson conceptualised eight invariant developmental phases namely the Trust vs Mistrust stage, the Autonomy vs Shame and Doubt stage, the Initiative vs Guilt stage, the Identity vs Role Confusion stage, the Intimacy vs Isolation stage, the Generativity vs Self-Absorption and Stagnation stage, and the Ego Integrity vs Despair stage (Erikson, 1963). Each of these stages is characterised by a specific developmental crisis that ideally requires resolution, but whether or not resolution is achieved does not impede the process itself which, as has been mentioned, is biologically driven (Crain, 1992; Erikson, 1963). According to Erikson (1963) the interactive process between societal and environmental demands leads to a stage specific developmental crisis. A ‘crisis’ is a developmental challenge that arises within the context of the individual’s interaction with his/her society. It is thus evident that Erikson (1963) perceived development as being driven by a dynamic interaction between a predetermined ground plan which is biologically based and the context in which an individual finds him/herself (Crain, 1992; Erikson, 1963). Erikson posits that positive resolution of each stage’s developmental crisis leads to a strengthening of the ego whereas failure to do so leads to regression (Crain, 1992; De Carlo, 2005; Erikson, 1963; Ryckman, 1985).

In the adolescent phase of development, the crisis that needs to be resolved is identity versus role confusion, with resolution leading to fidelity. Erikson (1963) posited that fidelity can only be achieved through the successful integration of all the former crises into the ego. The adolescent needs to be trusted and valued by his/her family and society, in order to develop meaningful independence (Erikson, 1963). Along with the positive aspects of the past, the adolescent is also required to resolve guilt feelings around perceived and actual past failures. This ultimately leads to a future focus involving a career (Crain, 1992; De Carlo, 2005; Erikson, 1963; Ryckman, 1985).

Adolescents who are unable to resolve the developmental crisis of identity versus role confusion are more likely to form a 'negative identity' which may lead to an over identification with anti-social groups, gangs and negative role models (De Carlo, 2005; Erikson, 1963; Ryckman, 1985). Role diffusion often manifests with higher levels of aggression and in many instances, adolescents who are unable to form an individual identity reject groups that offer social support and choose instead to embrace destructive and life threatening patterns of behaviour (Campbell et al, 2005; De Carlo, 2005). Adolescents who feel that life has no meaning and that they personally have no future become more vulnerable to both mental and physical illness. In addition, they are more susceptible

to substance abuse and suicide (De Carlo, 2005; Hüsler, Blakeney, & Werlen, 2005).

An application of the above theory to adolescents living with HIV and AIDS clearly highlights the enormous challenge faced by these youngsters as HIV and AIDS impacts on every level of their functioning. Their social support systems within the family and the broader community are severely disrupted, their sense of self-worth and meaning is undermined, their health and well-being is challenged on every level, and often their schooling is disrupted, thereby limiting perceived career opportunities (Richter & Swart-Kruger, 1995; Snell, 2003). In many instances adolescents living with HIV and AIDS find themselves in foreign environments, among strangers and this further exacerbates the problem (Johnson et al, 2004; Le Marcis & Ebrahim-Vally, 2005; Skinner & Mfecane, 2004; Van Dyk, 2001). Adolescents who fail to perceive the potential of the future are at greater risk of engaging in unprotected sex, alcohol and drug abuse and other life- threatening activities (Hüsler et al, 2005; Richter & Swart-Kruger, 1995). A lack of purpose and meaning also increases the risk of suicide (Hüsler et al, 2005; Richter & Swart- Kruger, 1995).

Self-identity is often tied in with body concept, and the physical threat related to HIV can severely undermine the adolescent's self-concept

(Cohen & Abromowitz, 1990; Strydom & Raath, 2005). The highest proportion of HIV deaths is in the twenty to thirty age group, which means that many of the people who have died of AIDS, may well have contracted HIV during their adolescent years, often through unprotected sex or rape (Ungvarski & Flaskerud, 1999). The integrity of the body is central to a sense of self and in rape, this integrity is violated. Murphy (1998) argues that after sexual abuse, the abuse becomes ‘embodied’ giving the sexual abuse survivor the problem of living with an internal abused self, while at the same time living with the fear around a dangerous and threatening world. Many adolescents who are HIV positive have contracted the virus due to rape and sexual abuse (Richter & Swart-Kruger, 1995; Snell, 2003). In addition many of the adolescents who are currently infected may well have contracted the virus at birth. However transmission at birth has decreased dramatically since the availability of Nevirapine (Domek, 2006).

Adolescents are also required to develop gender role identity, which in turn is tied in with self-concept. In order to facilitate the process of gender identity, adolescents need to engage in interaction with peers from the opposite sex (Louw et al, 1998; Waddell, 1998). Given the physiological changes related to adolescence and the innate desire to establish interaction with the opposite gender, adolescents are propelled into sexual interaction that challenges them on many levels, particularly

within the context of HIV (Campbell et al, 2005; Snell, 2003). Adolescent's bravado and perception of invincibility adds to their vulnerability as they often believe that they are exempt from being infected (Foster 2006).

There are millions of adolescents living with HIV and AIDS and therefore the question raised is how they cope with the reality of this illness (Andrews et al, 2006; Domek, 2006). Sowell (2002) sounds a warning that adolescents living with the consequences of HIV and AIDS may well be entering early adulthood 'uneducated, poorly socialized and potentially alienated'. This is a reality that should not be ignored. It is time to give adolescents living with HIV and AIDS a voice that needs to be heard if suitable and sustainable interventions are to be implemented. Being enabled to voice their stories will help adolescents to make sense of their life journeys. Furthermore, communicating a personal story either verbally or non-verbally has therapeutic value as it helps to externalize pain and make sense of confusing life events (Müller & Pienaar, 2004; Roth & Nelson, 1997).

Developmentally, adolescents are often reluctant to engage in direct communication concerning their thoughts and feelings (Louw et al, 1998), thus it can be argued that creative alternatives to traditional therapies are needed in order to give adolescents living with HIV and AIDS a 'voice.'

The two alternative therapies used in this research are art therapy and narrative therapy. Within an African context, story telling is a culturally acceptable mode of communication (Miller; 1979). Art making transcends cultural barriers and is a universally acceptable form of communication (Wood, 1984).

1.3.5 Cultural validity - Africa's tradition of story telling

The tradition of story telling is an intrinsic part of the diverse cultural groups that make up the African continent. In Africa, stories and legends focusing on the origins of good and evil, the creation of man and the reason for life abound (Miller, 1979; Panford, Myaney, Amoah & Aidoo, 2001). These fascinating stories reveal a great deal about their societies of origin and how various cultures not only view themselves, but also forces beyond human control. These myths and legends survived orally, emphasizing the importance of a narrative tradition in African culture (Miller, 1979). In addition to the oral transmission of cultural knowledge, there is a rich tradition of art and crafts used to enhance the oral process. Cultural artefacts such as masks, drums, figures and mythological creatures were used as a visual stimulus for the community involved in the story telling process. These artefacts have continued to provide a rich source of cultural information to this day (Panford et al, 2001).

Societies that are dependent on oral tradition have virtually disappeared. However the interest in oral accounts of history has recently received increased scholarly attention. Ross (1991) states that although anthropologists argue that oral history is only significant if it spans at least two generations, he believes that the shared stories in any community are part of collective history making – thus it can be argued that the narratives of all members of a community are significant (Müller & Pienaar, 2004).

The oral tradition has died out to a certain extent. However individuals' and communities' narratives of identity continue to play an important role in data collection particularly in a qualitative approach to psychological research (Müller & Pienaar, 2004; Roth & Nelson, 1997). Relevant data is generally collected through interviews, which in essence constitute aspects of the community's collective oral history. This point is verified if one analyses the qualitative studies related to community's construction of meaning in connection with HIV and AIDS (Le Marcis & Ebrahim-Vally, 2005; Roth & Nelson, 1997).

1.3.6 The therapeutic validity of art therapy

Art therapy is a term that defines a diverse collection of practices, which are firmly based on a foundation of psychotherapeutic principles and in turn reflect the therapist's belief in the healing power of the art making

process (Dalley, 1987; Henzell, 1989; Wood, 1987). The process in itself involves a transactional relationship between the client and the therapist, with the art image being the mediator (Arguile, 1992; Birtchnell, 1987, Henzell, 1989; Wood, 1987). Clients often find it easier to relate to the therapist non-verbally and in the process- the image, which is a personal statement, provides a springboard for analysis and discussion (Birtchnell, 1987; Dalley, 1987).

The inability to verbalize feelings is a typical characteristic of adolescence (Arguile, 1992; Louw et al, 1998) which is further complicated by language barriers. The language barrier is a major issue, especially in rural communities. It is within this context that art therapy is valuable as art making is a universal language that transcends racial and cultural barriers (Dalley, 1987; Wood, 1987).

In art therapy, aesthetic appeal is of little significance – it is the process that is significant as well as the image (Arguile, 1992; Dalley, 1987; Henzell, 1989). The psychodynamic approach, which focuses on bringing unconscious feelings to a conscious level and thereafter exploring these feelings, holds true for art therapy as well. However, in this instance, the symbolism and metaphor inherent in the image adds depth to the process (Schaverien, 1987; Weir, 1987).

HIV, AIDS and poverty have severely undermined the relationship between mother and child that is so important in healthy development (Richter & Swart-Kruger, 1995). It can be argued that the art making process may prove to be invaluable in assisting children to come to terms with the disruption of normal parent/child interaction. In addition the art making process can provide the children with a vehicle for telling their stories. It is not the role of the art therapist to force the person to disclose his/her feelings. The art therapist, along with the room and the process provides a safe place where the feelings can be contained until the client is able to verbalize thoughts around the creative process (Birtchnell, 1987; Dalley, 1987; Wood, 1987).

Art making and mark making, such as symbolic patterns, are innate to all ethnic groupings and as such, all children are able to engage in the process of image making. In addition, the process is directly linked to symbolization. Even in the beginning stages of art making, the child who scribbles is in the process of symbolization (Matthews, 1986; Murphy, 1998). The child has a symbolic relationship with all his/her images, which corresponds to and mirrors his/her relationship with the world (Matthews, 1986, Murphy, 1998; Schaverien, 1987; Wood, 1987). Art therapy taps into this relationship in order to allow the child to explore his/her reality (Dalley, 1987; Schaverien, 1987).

1.4 Research focus

This research examines art images, poetry and narratives created by adolescents living with the disease in order to explore the question “What are adolescents’ experiences of living with HIV and AIDS?” It is believed that this will be a small step in the right direction in terms of filling the void in current literature with regards to the emotional and psychological impact of HIV and AIDS on adolescents.

Chapter Two: Methodology

2.1 Sample

Adolescents from two care centres catering for the needs of vulnerable and orphaned children were invited to participate. Both care centres are situated in central Johannesburg. Home One houses orphaned and abandoned children and is currently in the process of registering as a Non-Governmental Organisation. Home Two is a registered Non-Governmental Organisation catering for the needs of HIV positive mothers and their children.

Twenty eight adolescents from the two care centres participated in the intervention. Of these, 16 participants were girls and 12 were boys. Nine of the girls and 6 of the boys live in Home Two. The participants were all in school and ranged in age from thirteen to eighteen years of age. Two groups were run in each of the participating homes. It was decided to separate the two groups as developmentally early adolescence is characterised by greater emotional and psychological upheaval than later adolescence (Erikson, 1963; Louw et al, 1998). Furthermore, adolescents who are on the cusp of adulthood are confronting different emotional and developmental issues to adolescents who are in their early teens (Erikson, 1963; Louw et al, 1998).

The researcher was invited to conduct a therapeutic intervention in both care centres. In Home One, all the adolescents were required to attend the intervention, while in Home Two, adolescents attended on a voluntary basis. However, all participating adolescents were asked if their work could be used for research purposes prior to the intervention being implemented. Work was only used if permission was granted to do so.

The adolescents had the following experiences in common:

- They are living in a place of safety
- The majority have lost one or more parents as a result of HIV and AIDS
- A number of them are HIV positive

2.2 Data collecting process

The therapeutic intervention that was used in this research, was structured around art making, story telling and poetry, and was designed to enable adolescents living with HIV and AIDS to tell their stories. Some of the participants consented to have their stories taped. The ensuing interviews were unstructured and questions were guided by the content of the adolescents' stories. At the conclusion of the intervention, the work generated by the adolescents was photographed.

Throughout the intervention, process notes were written. These notes contain analysis of non-verbal and verbal communication during the intervention and were used to enhance an understanding of the adolescents' stories.

2.3 Structure

Part One

Part One combined a number of exercises geared towards facilitating the process as follows:

Firstly it was structured around the theme of “An African Journey of Courage”. The theme was chosen because adolescents often find it extremely difficult to share their feelings and experiences (Louw et al, 1998). Furthermore, it requires courage to tell one's story, especially when the story is characterised by many painful and difficult memories that previously have not been spoken about. Accordingly, the focus of Part One was on enabling the participants to feel comfortable and safe enough to express their feelings and thoughts around living with HIV and AIDS.

‘An African Journey of Courage’

The exploration of the theme of courage in the first session, aimed to empower the adolescents to tell their stories as they perceive them. The

emphasis was on courage to narrate what life has been like without feeling obligated to alter their experiences in any way.

Week One: Treasure chest of courage

The process was started with each participant being given an unused, unassembled shoe box. After assembling their boxes, the participants were invited to decorate them in a way that would reflect their uniqueness. A variety of art materials were provided such as ribbons, beads, shells, magazines, sequins, glitter and feathers. Each participant was invited to explain how the box reflected an aspect of his/her story.

A box was used as it can be symbolic of being contained. In a therapeutic encounter it is important to provide the participants with a sense of being contained (Dalley, 1987; Waddell, 1998; Weir, 1987; Wood, 1987)). According to the 'Bionian' approach, in a good relationship between mother and child, the child is able to project his or her anxieties into the mother and the mother is able to hold these and contain them. The mother makes sense of the difficult feelings projected into her and then projects them back into the child in a more manageable form (O'Shaughnessy, 1992; Riesenbergn Malcolm, 1992; Waddell, 1998). Within the therapeutic relationship, the therapist assumes the role of 'the thinking mother' and in holding the client's unmanageable feelings, she enables the client to feel contained throughout the sharing process (O'Shaughnessy, 1992;

Riesenberg Malcolm, 1992; Waddell, 1998). In this intervention, the participants created boxes that in turn could be perceived of as symbolic of the therapist's containing function (Dalley, 1987; Weir, 1987). Furthermore, in creating the box as a reflection of their own stories, the box may well be seen as a projection of self, as well as a projection of the therapist (Dally, 1987; Schaverien, 1987). The boxes were placed in a locked room for safe keeping. This emphasised that what they had created is worth being looked after which in turn had the potential to become symbolic of their individual importance and need for self care and containment (Schaverien, 1987; Wood, 1987).

Week 2: African figure

The adolescents were presented with a variety of waste materials such as newspaper, scrap material, buttons, lace, ribbon and so on. Each participant was invited to create a human figure. Waste material was an important aspect of the process, as the images created not only reflected individuality, but also transformed what was throwaway into something of value. The group verbally explored the transformation that had occurred.

Week 3: African talking stick

In this session the tradition of story telling within an African context was discussed. The participants were given examples of the traditional use of visual prompts to enhance the process of story telling. It was pointed out

that in their case, they would be using their figure and an ‘African Talking Stick’ as a visual prompt. The ‘African Talking Stick’ was a concept formulated by the researcher as a symbolic representation of the visual prompts that were used by traditional story tellers. The adolescents were invited to decorate their sticks in order to make them unique. A variety of materials were used such as glitter, ribbon, beads, sequins and wool. The discussion focused on how the talking stick linked to the uniqueness of their individual stories. The positive and negative power of words was explored. Discussion focused on the importance of feeling safe in order to tell one’s story. The talking stick was placed alongside the figure as a symbol of containment during the process of telling their stories.

Week 4: Image of courage

The participants were each given a photograph of themselves. The photographs were placed in the boxes. In this way a visual link was established between the figure, the talking stick and the individual participants. Furthermore the photographs highlighted the uniqueness of each member of the group. As a symbolic ending to Part One, each participant was invited to make a personal gift out of beads. The boxes were locked away for safe keeping, as the art images can be perceived as an extension of the Self, and therefore because the images were being

safely contained (Dalley, 1987, Weir, 1987), the participants could feel contained until they met for the second part of the intervention.

Part Two

Week six to eleven: My story

Part Two started with a summary of the initial process. During this phase of the intervention, participants were encouraged to tell their stories in a mode of their choice, which included writing, poetry, art making or oral story telling. In many instances the adolescents had never been given the opportunity to tell their stories and therefore, Part One formed an important foundation to Part Two.

Five two-hour sessions were allocated to this section of the intervention. The participants were provided with a variety of art materials, which they were free to utilise. These incorporated both traditional art materials such as paint and pencil crayons, as well as other objects such as waste material.

Research suggests that the choice of medium and mode of expression may be directly related to unconscious processes and can thus provide valuable insight into the adolescent's perceptions of self (Dalley, 1987; Birtchnell, 1987).

Week Twelve: Group posters

At the start of the intervention, participants named their groups in order to establish a group identity. In the final session, the groups made a poster. The presentation and content of the posters was decided on through a process of group negotiation and participation. The posters were used to explore their identity within the context of the home. A photograph of the adolescents and their final poster was given to each member of the individual groups.

Taped narratives

At the conclusion of the final session participants were invited to tell their stories. Those who chose to tell their stories were given the choice to have them taped. If permission was given, the taped stories were transcribed and used for documentation purposes.

2.4 Data collection

The data was collected within a Participatory Action Research Paradigm (PAR). According to Babbie & Mouton (2001) PAR is closely aligned to Action Research. However, the primary difference is that participation is implied in Action Research but is a pre-requisite in PAR. Both Action Research and PAR follow the same cyclical process when collecting data which involves “diagnosing a problem situation, planning action steps, and implementing and evaluating outcomes” (Babbie & Mouton, p 63). The researcher identified that many of the adolescents had not been given

the opportunity to talk about their experiences and the impact that living with HIV and AIDS has had on their lives, or had found it extremely difficult to do so despite having access to therapeutic support. Consequently, the primary aim of the intervention was to empower the adolescents to tell their stories as and how they chose to tell them. The research was thus based on a foundation of implementing an intervention which was entirely dependent on the participation of the adolescents. Subsequent to the intervention the outcomes were evaluated in order to provide a holistic understanding of how the adolescents have experienced living with HIV and AIDS.

In order for the data to be valid, it was essential for the participants to feel that they were under no obligation to engage with the process, despite the fact that for some, participation was not voluntary. It was made clear from the outset, that adolescents who were compelled to be in the process had the choice to participate or not in that they could either engage with the process or merely observe what the other adolescents were doing. It was evident that this choice in itself was incentive enough for the participants who consequently all chose to actively engage with the process and to have their stories used for research purposes. For many of the participants, particularly in Home One, this was the first time that they had been given the opportunity to tell their stories and this appeared

to give the adolescents a sense of ownership of the process and how and what they chose to reveal.

Puttergill (2003, p 85) states that the ‘methods that enable the researcher to explore the more subjective and intuitive dimensions of knowing are the best methods of generating qualitative data’. Qualitative research enables the researcher to enter into the realm of the person’s everyday experience. However, a qualitative approach does not automatically give the researcher access to data. The key to successful qualitative research ultimately lies in the relationship between the researcher and the persons being researched. What is revealed is based on trust, listening and openness to experiencing the world of the people involved. Generally qualitative researchers enter the field with no specific hypothesis in mind in order to allow the context of the interaction to generate the issues to be researched. The context is vitally important if one is to understand the reality of the people being researched (Flick, 1998; Puttergill, 2003). The intervention used to collect data for the proposed research met the above criteria.

2.5 Data Analysis

A thematic content analysis of the art images, narratives, poetry and interviews was conducted using the Interpretative Phenomenological Analysis (IPA) method. IPA focuses on people as ‘self-interpreting

beings' (Taylor, 1985, as cited in Smith & Eatough, 2007, p 36). The central aim of IPA is to examine how people engage in meaning making in order to make sense of their lived experience. The focus is on individual perceptions of reality. Furthermore, IPA is concerned with the impact of big issues on individual lives either at a particular critical point or on an ongoing basis. IPA maintains that events of this nature have a profound impact on how people perceive themselves and their identities (Smith & Eatough, 2007).

IPA acknowledges that analysis is impacted on by the researcher's subjective response to data. However it emphasises that the researcher needs to utilise a meticulous analytical processes that enables him/her to retain the authenticity of the participants' narratives. The researcher is required to extrapolate dominant themes from the narratives which reflect the participants' unique as well as common characteristics (Smith & Eatough, 2007). There are close similarities between this approach and Content Analysis. Content Analysis also emphasises close analysis and categorization but includes additional steps that enable the researcher to measure reliability of generated categories (Devlin, 2006). Within the context of this research, the majority of the data used were taken from direct quotes. In addition, at the end of each session, participants reflected on what they had created and how it related to their life stories.

All information generated was recorded and used in conjunction with an analysis of art images and written data.

In order to collate verbal and visual data, a structured process, including the following steps, was utilised:

1. An initial close detailed examination of collected data which enabled the researcher to become familiar with what was communicated. This familiarity enabled the researcher to gain a holistic understanding of what the participants were aiming to communicate and established a foundation on which further analysis could be grounded (Devlin, 2006; Smith & Eatough, 2007). Within the context of this research, the researcher was actively involved with the participants throughout the process and consequently was able to identify themes and sub-themes as and when they emerged. After the intervention, notes collected during the process were combined with written and recorded information to ensure that the authenticity of the stories would not be lost.
2. The researcher identified themes which were organised into clusters. Identified themes were linked back to initial data in order to create a condensed list of reflected themes (Devlin, 2006; Smith & Eatough, 2007).

3. After further refinement of themes, commonalities and differences were identified (Smith & Eatough, 2007). Common themes provided the springboard for further analysis and refinement (Devlin, 2006).
4. At this point an operational definition for each category was formulated (Devlin, 2006).
5. Subthemes were organised under identified super-ordinate themes (Smith & Eatough, 2007).

The entire process was checked against the participant's ideas as according to IPA and Content Analysis, it is essential that these are not lost in the researcher's interpretation (Devlin, 2006, Smith & Eatough, 2007).

Kelly (1999), points out that if qualitative research is to be reliable, the researcher needs to distance him/herself from the interaction in order to examine data from an insider and outsiders' perspective. This process is termed *distanciation*. *Distanciation* highlights the 'subjective and contextual limits of understanding' (Kelly, 1999, p 421). In many respects, aspects of the context which are not explicit become evident when one stands back in order to examine it from the outside. Often what is created reveals more than the intention of the original creator. This additional analysis of texts (as well as images with regards to this research) increases understanding of the reflected experiences of

individuals as well as the relevance of these experiences in a broader context. In essence the researchers' distancing enables him/her to examine data more critically in order to give it greater reliability (Kelly, 1999). This proved to be challenging as working with vulnerable adolescents makes the objective analysis of information particularly difficult. The intervention took place over 12 weeks and consequently the adolescents identified quite strongly with the researcher and enjoyed the individual attention they received. In addition, when life stories are told and personalities emerge, it is extremely difficult to choose which stories and quotes to include and which to exclude. Consequently the researcher found maintaining objectivity in the selection of quotes and images to illustrate themes extremely difficult. This difficulty clearly highlighted the important role of the supervisor in helping to minimise the impact of subjectivity in the selection of data and the analysis of images.

The researcher followed the following steps in order to ensure that she was able to Distance herself prior to proceeding with analysis.

1. Analysis of collected data was started twelve months after the intervention.
2. The researcher conducted no further workshops with the participants during this period.

3. Three researchers were asked to code the research and in the reliability check the themes that came up were similar across all raters.

As has been previously mentioned, given the nature of the intervention as well as the content of the stories told, it was extremely difficult for the researcher to Distanciate herself. The participants' vulnerability, courage and determination to survive made the objective analysis of stories, poetry and art images a challenging experience which required constant monitoring.

2.6 Analysis of images

Within the context of art therapy, the image is seen as a projection of unconscious anxieties (Dalley, 1987; Birtchnell, 1987), The validity of this assumption has been subjected to extensive research in particular within the context of Projective Drawings (Blau, 1991; Koppitz, 1968; Ogden, 1984). Several studies have validated the identification of emotional and psychological indicators in human figure drawings as well as in tree and house drawings (Blau, 1991; Koppitz, 1968; Ogden, 1984).

In order to analyse the art images for this research, a combination of the assessment criterion listed in Blau (1991), Koppitz (1968) and Ogden (1984) was utilised. An application of these approaches provided valuable

insight into the emotional and psychological impact that living with HIV and AIDS has on adolescents. All of the above theorists did extensive research on the identification of emotional and psychological indicators in children and adolescents art images (Blau, 1991; Koppitz, 1968; Ogden, 1994). The researcher utilised these findings in order to ensure that images were approached as objectively as possible. Utilising validated approaches to the analysis of art images gives validity to the findings related to the non-verbal communication of the adolescents (Blau, 1991; Koppitz, 1968; Ogden, 1994).

The aim of utilising a combination of multiple approaches was to provide a holistic, idiographic and realistic picture of the reality of adolescents living with HIV and AIDS in their own words.

Chapter Three: Research findings and Discussion

3.1 Introduction

Through the mediums of art, writing and poetry the participants in this research have poignantly voiced the reality of living with HIV and AIDS. Although as individuals their stories have unique qualities, common experiences bind them together, namely HIV and AIDS, Poverty, Stigma, Loss and Resilience. Within the context of this research it was evident that living with HIV and AIDS and its interaction with poverty and stigma laid the foundation for the subsequent experiences of surviving loss associated with living in a care centre. The stories highlight how the interaction between living in a care centre and living with HIV and AIDS has profoundly impacted on the adolescents' perceptions of themselves and the world they live in. Within the five core experiences sub-themes emerged, which in some instances were common to the majority, but in others were shared by only a few of the adolescents, such as sexual and emotional abuse, suicide ideation and depression. However despite the differences it was evident that for individual participants, all their experiences were central to their self-concepts, their desire for normality and their determination to survive.

The analysis of collected data reveals that the adolescents have been living with the reality of HIV and AIDS for many years and this intervention may well have been the first opportunity that they have had,

or utilised, to voice how the disease has coloured their experiences, both prior to their admission to the care centres and currently. Consequently this discussion is structured sequentially. The quotes, art images and poetry related to their earliest experiences of HIV and AIDS will be the focus of the first part of the discussion. This will be followed by an analysis of the adolescents' experiences in the care centres in relation to their past experiences and their future hopes. It will be pointed out how the twin challenges of coping with HIV and AIDS and living in a care centre has impacted on multiple levels of the adolescents functioning. Winnicott's theoretical understanding of the impact that living in an 'orphanage' has on children will be used to provide a conceptual framework that will provide insight into the emotional and psychological challenges that these young people are and will continue to face. This chapter will conclude with a discussion of the way in which the adolescents have managed to make sense of their worlds despite their numerous difficulties. Quotes and art images have been selected in order to give 'voice' to the adolescents' shared and in some instances unique experiences.

3.2 HIV and AIDS and Poverty

It is evident from research conducted within the field of HIV and AIDS that people who are living in poor communities are more susceptible to the HIV virus and to the consequent repercussions of stigma and

alienation associated with the disease (Andrews et al, 2006; Foster, 2006; Foster & Germann, 2002). Poverty was central to the experiences of all the adolescents who participated in this research. Research suggests that when one or more family members are infected with HIV, family income drops substantially (Andrews et al, 2006; Foster 2006). The reduction in income impacts directly on children whose health, academic achievement and emotional well being is severely compromised (Andrews et al, 2006; Drew et al, 1998; Foster, 2006). This reality is evident in the following quotes:

Neo age 13: “My father died in 2004 then I lived with my mother and then she died and then I live with my three brothers and then we did not eat for 3 days we did not have food to eat and then my brother say he wan the place for me and my sisters an he bring us here so that we must get a future” (sic).

Lindiwe age 18: “When my father get a job he started to get Sick in 2003 and he stert to go to hospital, and it sow hart to my mother she stat to find a job and father died. After my father died mather start ta get Sick to. She was wick and not happy to see in Bragwanath and they sen her to Sebokeng hospital when she die” (sic).

The above quotes highlight the reality that when one parent is infected with the disease there is the strong possibility that the second parent will also be infected (Foster, 2006) consequently in Sub-Saharan Africa where the HIV pandemic is at its most virulent, children are particularly at risk of loosing both parents (Andrews et al, 2006; Drew et al, 1998; Foster, 2006). In addition the quote illustrates parental illness and death invariably leaves children with the daunting task of having to survive with limited resources (Drew et al, 1998, Freeman & Nkomo, 2006).

Mosiua age 15: “My mom was Sick and I’ve young sisters and no one work my mom she just get the pension of the children....it was too hard ” (sic).

Mosiua’s quote emphasises how mothers living with HIV and AIDS are faced with the daunting task of coping with their deteriorating health while at the same time trying to meet the physical and emotional needs of their children (Andrews et al, 2006; Foster 2006; van Dyk, 2001). As is evident from this quote, many people infected with the disease are unable to work and consequently their and their children’s health and well being is compromised (Andrews et al, 2006; Foster 2006).

The following quote illustrates how difficult it is for children living with poverty as a consequence of parental illness, to carry on functioning

normally. In addition Siphiwe's quote highlights the reality that if grandparents are alive they are often the first to offer support for their ailing children and their offspring (Drew et al, 1998).

Siphiwe age 13: "I don't have a father and gramma and granfa so I came here befor this I was all weys in the school sees the children eating nice food But me I was not eatin in the school" (sic).

In many instances, young adolescents' schooling is prematurely curtailed in order for the child to take care of the household demands (Andrews et al, 2006; Foster, 2006; Van Dyk, 2001). These children are often expected to meet the needs of the ailing parent, and to take care of younger siblings (Andrews et al, 2006; Foster, 2006). The lack of education has serious implications on the young person's future career opportunities thereby increasing their vulnerability (Domek, 2006; Johnson et al, 2004; Van Dyk, 2001). The majority of the participants in this research struggle academically and it could well be argued that their schooling and ability to achieve their potential was severely undermined by the experience of living with HIV and AIDS and poverty. The following quote poignantly captures just how difficult this reality is for children:

Mosiua age 15: “Like ehhe...my mom was sick, she sick the full time she was sick and I remember at grade seven I even leave the school.....My mom was very sick..... It was too hard for me” (sic).

3.2.1 Witnessing the dying process

In addition to experiencing the gradual erosion of their lives due to HIV and AIDS, many of the adolescents witnessed their parents dying. The adolescents whose mothers died prior to their placement in the care centres found the dying process far more traumatic than those who were in the safe confines of the care centre when their mothers died. An AIDS related death is generally extremely traumatic to experience and to witness. Firstly the person does not die of AIDS but dies as a result of the opportunistic diseases that attack the body due to the break down of the immune system (van Dyk, 2001). Death is often slow and is generally accompanied by extremely painful symptoms such as mouth ulcers, headaches, difficulty with swallowing, vomiting, diarrhoea and excruciating pain when touched (Hubley, 2002; van Dyk, 2001). From the stories of adolescents who were able to talk about their mothers’ and or fathers’ deaths, it was evident that the experiences haunt them and in many instances have left them with guilt at not being able to relieve their parents’ pain. In addition some of the adolescents found their parent’s painful death so traumatic that they reflected a deep sense of guilt around

not being ‘good enough’ children. The traumatic nature of this experience is captured in the following quotes:

Mosiua age 15 : “..... my mom.....died in a bad way died in a bad way that she was sick and she died at home and I was there looking at her” (sic).

Nkosinathi age 16: “I saw her..... she was sick. She had bad things happening to her. I tried..... I tried to help her because she couldn’t eat” (sic).

The simplicity of the above quotes captures the sense of hopelessness and helplessness that Mosiua and Nkosinathi experienced as each witnessed his mother’s painful death.

For 12 of the 13 adolescents living in Home One, namely the care centre for orphaned and abandoned children, the death of their parents marked a dramatic change in their lives. They were forced to leave their homes and their communities and in many instances were separated from siblings who were sent to grandparents or extended families. It was evident that these adolescents were given very little time to grieve their loss and in addition were not given the opportunity to talk about their altered circumstances. Consequently it appears as if they are still locked in the

grieving process. The following quotes reflect the deep sense of loss still experienced by the affected adolescent:

Lungile age 18: “And my mother died and they brough me to the care center in 2003 it was so hart for me and I was crying” (sic).

Samuel age 13: “I went to school with my bike and when I coame back I find that my mother is daed I started to cry when they grave him I was so sad But I told my self that only God know” (sic).

Themvikile age 16: “In 2003 I had no where to stay. My mother was dead so I live in a children’s home” (sic).

3.2.2 Grandparents

The question thus raised is why these adolescents end up in care centres and not with their extended families as traditionally in Africa, extended families have taken care of orphaned children (Foster, 2006; Foster & Germann, 2002). Research has shown that as a result of the increasing number of orphans in many families this option is no longer viable (Domek, 2006; Foster 2006; Foster & Germann, 2002). There are two reasons for this decline in the support of extended families: firstly many families are no longer able to survive the additional cost of orphaned

children and secondly due to the stigma associated with the disease families are reluctant to take children in (Campbell et al, 2005).

None of the adolescents who participated in this research mentioned living with uncles and aunts, but several had previously been cared for by grandparents or have siblings who are in the care of grandparents. Within the context of this research it was evident that grandmothers have been called upon to carry the burden of orphaned children. This was particularly evident in Home One. In Home Two, namely the care centre catering for mothers and children, grandparents did not feature in the stories. This difference may well be due to the reality that the children arrived at the care centre with their mothers and so grandmothers were not called upon to take care of them. In terms of five of the adolescents in Home One, they were sent to the care centre when the grandparents were no longer able to cope with the financial demands, became too frail or ill to care for the children, or died.

The following quotes highlight the important role of grandparents in coping with the increasing number of orphans (Freeman & Nkomo, 2006). In addition they point to the financial implications related to taking care of orphaned children and the extent to which poverty undermines the grandparents/grandmothers' ability to do so:

Lungile age 18: “In the Freestate my grandmother.....no one is helping my grandmother. Even now my grandmother she suffer for the children to get a food cause she only get a grant the end of the month” (sic).

Maisha age 13: “When I was yang I was staying in bedrooms I was staying with my granmother & granfather my granfather Past away in 2003 I staying with my granmother and my granmother the strak hight at her so she want to the hopetals so I came her on 2004 and on 2005 my granmother past away until today” (sic).

3.2.3 Loss of homes and family possessions

In the process of relocating to the care centres all of the adolescents who participated in this research lost their homes and their communities. Twelve of the adolescents arrived at the care centres with their destitute mothers, while the remainder were placed in care as their safety had been compromised as a result of parental death. Some of the participants’ parents owned their homes, but these adolescents were unable to lay claim to their family possessions as is evident in the following quote:

Lindiwe age 17: “When I.. I went back to see the house I didn’t find the house anymore because the people are stealing all the things but I still like this house cause it’s where I was staying. It’s where I was with my

family.... sharing all the hopes, laughing together. We were happy to be in this house but there's no more this house" (sic).

Lindiwe's experience draws attention to the vulnerability of children being exploited and abused when they are orphaned (Drew et al, 1998). Lindiwe and her siblings were unable to protect their possessions and lost everything with the death of their parents. The 28 adolescents in the respective care centres all arrived with virtually no possessions thus emphasising the complex nature of loss experienced by adolescents living with HIV and AIDS (Campbell et al, 2005; Foster, 2006).

One of the participants was living on the streets prior to his placement in a care centre. When his parents died he was looked after by a family member, but due to ongoing abuse, he ran away from home and ended up living on the streets. However, it is evident in the following poem that not having a secure home and parental support was particularly lonely and challenging for him:

What would you do,
If you had no place to call home,
If you had no place to call home
If no one loved you (sic).

Jacob age 15: Appendix B: 2

Loosing their homes had a profound impact on the adolescents who participated in this research as was evident in the spontaneous inclusion of their homes in their narratives. The following drawing by Mosiuoa captured the sense of loss experienced by the adolescents and also highlights how for many their homes became symbolic of the extensive losses that they have experienced as a result of living with HIV and AIDS.

Mosiuoa age 15: Appendix A: 1

Mosiuoa identifies his home by including the street number on the door thereby giving it a context. When Mosiuoa first drew his home, he excluded the tap on the side of the house. Towards the end of the intervention he returned to his original drawing and added the tap, running water and bucket. In art and dream images water is often seen as being symbolic of the unconscious (Weir, 1987). In addition, Jung did extensive research with regards to archetypal images and a bucket may be seen as a universal symbol of a container (Jung, 1952). It can thus be argued that this is a symbolic representation of the experience he had of sharing originally unexpressed thoughts and feelings concerning the loss of his mother and his home (the water) and having them heard in a safe and containing space (bucket). Although he was able to start the process of telling his story he still felt vulnerable. The floating bucket is a visual

symbol of this vulnerability. If the bucket falls over, its contents (his emotions) will spill out and be uncontained.

It is interesting to note that distortions in the house visually reinforce his feelings of exclusion and isolation. The windows are too high which prohibits anyone from seeing into or out of the house. In addition intruders are kept out of the house with secure burglar guards. A drawing of a house is seen as a representation of self and consequently this drawing captures Mosiuoa's feelings of loss and isolation (Ogden, 1998). No one can see the deep sadness and loss he is experiencing (the high windows) and likewise he is struggling to express these feelings in order to come to terms with his loss. He is symbolically locked into a grieving space.

Simon, whose work is discussed below, was unable to express his feelings of loss and loneliness verbally and chose instead to draw images that reflected what he was feeling. It was evident that for Simon and many of the other participants who struggled to talk about their experiences, drawing provided them with a less threatening avenue of expression.

Simon age 13: Appendix A: 2

The house looks face like with the windows resembling eyes, doors resembling nostrils and the roof a hat. In addition the oblong shape in

front creates the impression of a screaming mouth, whose pain is unheard. The inclusion of a father and children jammed into the front seat of the car adds to the poignancy. Simon includes a table and chairs below an apple tree. No one is sitting at the table, which adds to the feelings of loss and loneliness that this image generates.

Simon age 13: Appendix A: 3

There is a strong similarity between the house and this self portrait. The cap on Simon's head is similar to the cap on the house thus creating a visual link between this sorrowful self portrait and the symbolic self portrait of the screaming house. His crossed arm may be seen as a reflection of his efforts to contain his grief. The drawing is unstable with one leg shorter than the other, reflecting the instability and uncertainty that Simon has experienced since his mother's death (Koppitz, 1968; Ogden, 1984).

3.2.4 Loss of siblings

Along with the death of parents and in some instances grandparents or due to the mothers' HIV status and ill health, the adolescents were forced to confront additional losses as they were relocated to the care centres. Ten of the 28 participants were separated from siblings. Separation was generally due to family members being able to accommodate only some of the children. For one adolescent who is quoted below, the separation was

based on a difficult choice that she had to make between a potential education and living with her grandmother and siblings.

Lungile age 18: “In the Freestate my grandmother.....no one is helping my grandmother, so it’s only my grandmother. They give him.....like they help, they help him sometimes.....not every day...you see So if I can go there I won...I know I won’t be able to go to school cause there’s no money” (sic).

In reflecting on her decision not to live with her grandmother Lungile said: “I have a difficult time because sometimes I miss them a lot I miss them a lot but there’s nothing I can do” (sic).

Lungile’s words capture the ambivalent feelings that she was experiencing with regards to her decision to leave her family. Part of the ambivalence appears to be guilt related to the knowledge that siblings who are left behind continue to face financial difficulties. In addition the choice that Lungile had to make to live in the care centre was not an easy one. She was compelled to make this decision because she knew that if she lived with her grandmother, she would not be able to attend school which highlights that despite the difficulties she was facing, she was able to hold onto hope. Lungile believes that education is the key to a brighter future and in order to achieve this she is prepared to sacrifice being with

her family. Her hope is that she will be able to return home empowered to support her family financially and emotionally.

3.2.5 Loss of childhood

Living with HIV and its consequences led to four of the adolescents being compelled to assume adult responsibilities that they found emotionally and physically exacting.

Jacob was one of the adolescents who had experienced a great deal of emotional and physical deprivation and consequently he struggled to interact with the adults or adolescents in his care centre. He viewed all their overtures of friendship with suspicion and consequently found himself increasingly alienated from the other adolescents. The following poem reflects his deep sense of loss with regards to his parents. Furthermore it poignantly captures how lonely and alienated he felt when he was living on the streets:

Where were you- when I was born
When I grew up
When I lived on the streets
When things fell apart.
Where were you when I needed you most?
When I cried and struggled.

Where were you?” (sic).

Jacob age 15

Jacob: Appendix A: 4

During the course of the intervention Jacob attempted to commit suicide and was consequently hospitalised. After Jacob was released from hospital he created an ostrich out of egg boxes as a symbol of the way he was feeling.

Jacob explained that ostriches are brave birds which are able to protect themselves against danger and like the ostrich he has to protect himself. Jacob struggled to complete this image and found that the eye kept falling off and the legs were too weak to hold it up. He ruefully commented that perhaps this was symbolic of his situation. He is unable to see properly and finds it difficult to stand on his own two feet that is why he tried to take his own life. Jacob placed his ostrich in a special box, pointing out that the ostrich would have to remain in ‘hospital.’ He added that he would complete the ostrich once he felt strong enough to do so.

3.2.6 Vulnerability to abuse

Due to parental illness, several of the adolescents were neglected both physically and emotionally. In the case of two of the adolescents, the absence of parental support and supervision translated into sexual abuse.

Jacob was abducted and sodomised while Thembikile was raped and then kidnapped. Mosiuoa, a third adolescent was exploited by a local gang and consequently drawn into illegal activities.

Mosiuoa age 15: “I go with the gangster. I doing bad things and my mom she always tell me I better leave that” (sic).

Mosiuoa was struggling to survive at the time and was consequently extremely vulnerable as he longed to belong. His mother was too ill to meet his needs for nurturance and consequently he attempted to fill the void in his life by associating with the gang members. He continues to live with the guilt.

Thembikile age 16: “And I was about to close the room and he knocked again and I opened the door and he came in the room and he asked me where is my mother, and then he like asking me when is my mother coming an I said I don’t know and he started to touch in my private parts and then he raped me. I didn’t tell my mum because I was scared that we wouldn’t have a place to stay because he was going to say we must go so I just kept quiet. I didn’t know that he was HIV” (sic).

Thembikile has experienced multiple levels of abuse and neglect. She was raped and abducted. She lived with her abductors for several years until

her HIV status started impacting on her ability to work as a domestic help. While in captivity she did not attend school and this has severely compromised her scholastic performance. Themvikile struggles with depression, anger, guilt, loneliness and isolation.

3.2.7 The impact of stigma on coping with loss

It is patently evident that when their mothers and/or fathers were infected with the HIV virus, the adolescents' lives changed dramatically. The majority experienced the primary loss of a parent/parents, as well as additional losses of family and communities. It appears as if most had little or no opportunity to work through their dramatically altered realities prior to being admitted to the care centres. Society generally finds it extremely difficult to confront the reality of death and often the topic is avoided at all costs. Kübler-Ross (2001) points out that people who are terminally ill invariably have their physical needs met, but discussing the reality of impending death is often avoided. Consequently many dying people are denied the opportunity to voice their fears and concerns regarding death. This in turn impacts on children, as they too are denied the opportunity to discuss their own or their parents' impending death. Silence around the reality of death, inevitably results in the dying person as well as his/her immediate family feeling isolated and alone in their grief (Kübler-Ross, 2001). The 'conspiracy of silence'

surrounding death invariably exacerbates the grieving process. Sharing pain with others makes it that much more bearable (Kübler-Ross, 2001).

This ‘conspiracy of silence’ is particularly applicable to HIV and AIDS. The main factor contributing to this silence is stigma. HIV and AIDS unlike most other diseases which are life threatening is directly linked to sexual activity and assumed promiscuity and therefore is considered justifiable punishment (Goldstein et al, 2003). Research has shown that even within the context of health professionals, infected individuals bear the brunt of social judgement (Schlebusch & Cassidy, 1995; Van Dyk, 2001). Disclosure often results in social isolation and victimization by communities as well as in many instances, family members (Campbell et al 2005; Goldstein et al, 2003; Schlebusch & Cassidy, 1995). Consequently, non-disclosure is seen as the most viable option. Even when patients are dying as a result of opportunistic diseases associated with full blown AIDS, the disease itself is seldom mentioned (Cameron, 2006; van Dyk, 2001).

Within the context of this research, the adolescents whose parent/parents have died as a result of the disease have been left with a heritage of silence and are unable to talk about the cause of their parents’ deaths and the impact that it has had on their own lives. This conspiracy of silence is

also applicable to adolescents whose mothers or fathers are infected with the HIV virus but are still alive.

In Home Two, the adolescents are free to talk about their mothers' status and for the majority mothers' deaths, as it is open knowledge within the safe confines of the community. However it is interesting to note, that even in this accepting environment the adolescents did not mention HIV and AIDS as the cause of their mothers' deaths.

Josephine age 17: "Mom because I'm here she caused all my problems" (sic).

In the above quote Josephine touches on the reality that she and her siblings are in the care centre because of her mother's HIV status but does not specifically mention the disease.

Nkosinathi age 16: "I think I was twelve years old then (when he and his family arrived at the care centre). I moved here because we did not have a place to live" (sic).

Nkosinathi does not mention that the central reason for their move to the care centre was that his mother was rejected by her community as a result of her HIV status.

Only one adolescent, Themvikile age 16 who is also HIV positive verbalised the reality that her mother died of HIV in a poem that she wrote about the disease (Appendix B:1).

3.3 Living in a Care Centre

Within the context of this research it is evident that living with HIV and AIDS has profoundly impacted on the adolescents' experiences. However, in the analysis of data, it is apparent that an additional factor which has impacted on their experiences either positively or negatively is living in a care centre. In order to make sense of these findings, the work of Winnicott (1958; 1969; 1984) will be used as he conducted extensive research with children living in care centres. His research (Winnicott, 1958) clearly illustrates the profound impact that living in a care centre can have on the lives of children. As has been pointed out in the analysis of data thus far, adolescents living with HIV and AIDS have experienced multiple levels of deprivation as a result of poverty, stigma and living with HIV and AIDS. In addition to these experiences the adolescents have suffered the additional deprivation of their homes and the nurturing care of their mothers. Winnicott's (1958) research focuses on the impact of this double deprivation of homes and mothers on the lives of children living in care centres. He worked extensively with deprived children and in the process posited that understanding the effect of the environment changes that the children are subjected to is essential for understanding

developmental difficulties confronting children in care centres (Winnicott, 1958).

Firstly, Winnicott (1984) maintained that if children have had a ‘good enough’ experience of mothering in infancy and childhood, then being placed in a care centre becomes that much more daunting. He posited that children, who have experienced good bonding with their mothers and then find themselves in care centres, are more likely to develop anti-social tendencies. He therefore emphasised the importance of ascertaining the amount of normal emotional development that was made possible in the beginning by a good-enough environment, and to assess when the deprivation began and the damage done by the deprivation (Winnicott, 1984).

Winnicott (1984) identifies six categories that are useful in determining the beginning and extent of deprivation. For Winnicott (1984) the most important category to be considered is “Ordinary good home, broken by accident to one or both parents.” It appears as if this category is applicable to several of the participants. HIV and AIDS was the ‘accident’ that deprived them of their homes and their environments. Their stories and poems reflect poignancy and longing with regards to lost mothers, who in many respects symbolise multiple layers of loss such as homes, education, friends and family. Winnicott (1984) hypothesises that

children in this category possibly could have experienced good parenting in infancy which may well have laid the foundations for mental health. He further explains that the “deprivation is secondary and supervenes on health” (Winnicott, 1984, p.178). Accordingly, children in this category are more likely to be able to respond to good experience and a caring environment because they had previously experienced a good-enough family life and may therefore be able to respond positively to experiences that resonate with what has been internalised (Winnicott, 1984). However, children in this category are at high risk if confronted with an overly hostile or alien environment. Consequently Winnicott (1984) maintained that children who have had ‘good-enough’ experiences of mothering in childhood or infancy are more likely to benefit from being placed in foster care.

The participants in this research bear testimony to the reality that in Sub Saharan Africa, because of the devastating impact of the HIV and AIDS pandemic on women and children (Cameron, 2006; Goldstein et al, 2003; Müller & Pienaar, 2004; Roth & Nelson, 1997) and its consequent disruption of family life, many children are being placed in care centres despite the risk (Domek, 2006; Foster 2006; Foster & Germann, 2002). It is evident that this is a proverbial “Catch 22” situation as the alternatives of living in child-headed households and/or on the streets are equally, if not more ‘high risk’ (Andrews et al, 2006; Cluver & Gardner, 2007;

Richter & Swart-Kruger, 1995) particularly when children are challenged by the consequences of poverty as well (Boonzaier & de la Rey, 2003; Hoosen & Collins, 2004; Letlaka-Rennert et al, 1997). In addition, research has shown that many children who are in foster care with extended families are not necessarily in nurturing environments (Foster, 2006; Foster & Germann, 2002). However, the research that has been conducted with regards to living with extended families does emphasise that it is possibly a more palatable alternative for a child than a care centre (Foster 2006).

The reality that living with a family unit, no matter how poor, is a better alternative appears to explain why grandparents have had such a profound impact on the lives of several of the participants in this research. Grandmothers in particular have taken on the nurturing role of parent after children have been orphaned thereby providing the children with extended experiences of a 'good-enough' environment. However, it is evident that given the important role these grandparents play, when they are no longer able to care for the children due to poverty, ill health or death, the loss is acutely felt and may result in exacerbating the mourning process and the deep sense of loss. Furthermore, it can be argued that the children experience double loss after being in the care of family and then being compelled to enter a children's home.

According to Winnicott (1984) when children are deprived of parental care and their ‘good-enough’ environments, in order to survive, they develop defensive organisation. Winnicott (1984) posited that an examination of these defences will reveal the extent of the deprivation and the potential risk to the child. A common defence for deprived children is splitting of the personality. According to Winnicott (1984) this splitting is particularly evident in children who are overly compliant and eager to please. These children present a “shop-window or out-turned half, built up on a basis of compliance, and the main part of the self containing all the spontaneity is kept secret” (Winnicott, 1984 p. 165). Some of the adolescents who participated in this research appeared to have adopted this defence. This was particularly evident in Home One, which is more formally structured. For example adolescents who presented as helpful and co-operative and who were perceived by management to be ‘shining examples’ for the ‘defiant’ children, often revealed angry and confused feelings in their art work or writing which was incongruent with their demeanour as is evident in the following art image:

Noluthando age 18: Appendix A: 5

Noluthando drew this image of herself standing in the door of her home. The front of the house has no windows, and the door appears to be crushing her. The black lines surrounding the figure add to the

aggression. A feeling of instability is reflected in the wavy line delineating the entrance to her home. Noluthando found it difficult to express her anger and generally presented with a genteel facade of compliance. Research conducted within the field of art therapy highlights that an art image often holds and reflects unconscious and repressed feelings and is particularly useful in understanding adolescents who are unable to or unwilling to reflect negative feelings (Schaverien, 1987; Wood, 1987), as was the case with Noluthando.

If children's defences against anger become so entrenched that they lose their identities in the process and the 'false self' is perceived as the real self, then Winnicott (1984) posits they are in greater danger of becoming mentally ill, than the child who outwardly and openly reflects his/her rage. Consequently it appears as if Noluthando's genteel compliance may well be putting her at risk.

Three of the adolescents who participated in this research found reflecting their anger so difficult that they manifested with severe depression and consequently attempted to commit suicide. The anger, depression and confusion that led to these attempts are captured in the following poem and art image created by Josephine:

Confusion

Spilling out

Blocking my life

Not controllable – painful

Josephine age 17

Josephine: Appendix A: 6

This abstract drawing was created by Josephine to compliment the above poem. The jagged, dark, dense lines with a predominance of diagonals emphasize the extent of Josephine's anger and confusion as she struggles to come to terms with her mother's HIV status and the reality of being in a care centre.

Winnicott (1984; 1965) posited that angry and defiant children are in reality hopeful children and have greater potential to heal and resolve many of their inner conflicts if they are provided with consistent, nurturing yet firm boundaries (Winnicott, 1984). From the following examples of art images and quotes it is evident that many of the adolescents are still extremely angry at the deprivation that they have been forced to experience:

Mosiua age 15: “I just try to be like other children, to play but I don’t know how...ehh I just..I just become angry. When a person talk to me now I’m angry...I don’t know what to dojeesh I just loose hope” (sic).

The above quote illustrates just how difficult Mosiua finds it to manage his angry and hopeless feelings, and his inability to understand his complex emotional response to the world. In addition it reflects his longing to be like other children thereby reflecting just how alienated and isolated he is feeling.

Thembikile, the 16 year old who has experienced multiple levels of abuse is overwhelmed with anger and finds her negative feelings difficult to manage. In addition to the losses she has endured, she is facing the reality of her own impending death as due to ongoing AIDS related illnesses, her health is extremely fragile. Her anger often translates into self destructive behaviour. She has attempted to kill herself and at times stops taking her antiretroviral medication thus further compromising her health and putting herself at greater risk of succumbing to the opportunistic diseases associated with AIDS.

The following extract from a poem that Thembikile wrote reflects her anger at having to live with HIV and AIDS.

HIV/AIDS you are not fair! – you have no mercy at all !!!!!!!

You took my mother just like that!

I HATE YOU! (sic).

Thembikile: Appendix B:1

Thembikile: Appendix A: 7

Thembikile's struggle with angry and often uncontained feelings is reflected in this self portrait. This image is very masculine in character reflecting Thembikile's ambivalence with regards to her sexuality. She mentioned that she would like to be a boy as boys are not as vulnerable to sexual abuse. The figure is poorly integrated with stunted arms and an enlarged head. The stunted arms are indicative of Thembikile's struggle to connect to others. Unresolved anger is reflected in the bared teeth. The eyes are unseeing and are placed at the side of the head reinforcing a lack of integration. The neck is hardly visible and the head enlarged which is indicative of impulsivity (Koppitz, 1968; Ogden, 1984).

During the intervention there was evidence of antisocial behaviour. For example mid intervention, in Home One, the room in which the art images were stored was broken into and some of the art work was destroyed. In addition some of the items were stolen. Theft is in fact a common occurrence in Home One and to a lesser extent in Home Two. On face value these actions may be considered indicative of mal-adjustment and a

lack of resilience, but an alternative ‘Winnicottian’ approach is equally valid.

Winnicott (1965) posits that anger and destructive behaviour in institutionalised children is a sign of hope in that the child is able to perceive the clash between what is conceivable and what is reality and reacts to this perceived clash (Gomez, 1997; Winnicott, 1958, Winnicott, 1965). The realisation of an environmental failure to meet his/her needs may result in the child ‘attacking’ the environment in anger (Winnicott, 1965). According to Winnicott (1958), the anger is indicative of the innate drive to survive against all odds. Thus if one takes Winnicott’s (1965; 1984) understanding of anger and the antisocial tendency into account, then it may be said that the high levels of anger reflected amongst the participants in this research is a reflection of hope and in many respects resilience. Winnicott posits that the anti-social tendency often manifest with destructive acts which is the child’s attempt to communicate not only anger, but also a plea for strong parenting from an adult who can contain and control the child’s emotional chaos without responding punitively (Gomez, 1997; Winnicott, 1958; Winnicott, 1965).

Winnicott’s (1984) understanding of the difficulties experienced by children living in ‘homes’ appears to be particularly relevant to adolescents living in Home One which is a traditional ‘institution’ where

children are housed in a large building that lacks the intimacy that Home Two has. Consequently the adolescents who are in the larger institution appear to be less settled and angrier. In Home One, the acts of aggression and destructive behaviour are far more severe than they are in Home Two.

Winnicott (1984) posits that large formal care centres are more suitable for children who have never experienced a 'good-enough' environment and are consequently suffering from severe deprivation. He asserts that in a 'hostel type' environment, there is less personal touch with children and, in order for the establishment to operate, a more impersonal and dictatorial environment is provided. Winnicott (1984) posits that severely deprived children who have never experienced a 'good enough environment' are more likely to be contained in a home of this nature. However, given the high levels of anger and the reflection of hope that is evident in the poetry, writing and art images of these adolescents it appears as if the majority of them have experienced a 'good enough' environment at some point in their lives, and therefore a nurturing and less rigid approach to caring for these adolescents who are living with HIV and AIDS appears to be essential for their mental health.

Home Two is structured less rigidly than the homes that were prevalent when Winnicott conducted his research (Winnicott, 1984) and consequently it appears as if the levels of deprivation identified by

Winnicott (1984) are not as applicable to Home Two as they are to Home One. A factor which appears to have impacted on the adolescents' ability to adapt and thrive within the context of a care centre may be due to the fact that the majority arrived with their mothers. Consequently their mothers were available to help them to cope with living in their new environments. In addition, when their mother's did succumb to AIDS, the adolescents concerned were able to turn to caring and familiar care givers who understand their difficulties. Furthermore, the adolescents are provided with firm boundaries but at the same time they are clearly important members of the community and as such the majority of the adolescents in this home appear to feel valued.

The impact of this more informal and nurturing environment is evident in the following quotes:

Thembikile age 16: "I am happy cause I get everything that I want, they pay for my school fees, they buy me some clothing and I thank God that I'm still alive and I thank ..I thank Gillian that she suffer....she suffered me I think that time.... that time when she is giving me a second chance" (sic).

Naledi age 17: “I thank Nikki especially when I.....when I go through any difficult things she’s always she’s always there for me. She’s like my mother she’s always there for me” (sic).

Nkosinathi age 17: “Here at the home it is like a family cause they take care of us and look after us” (sic).

The nurturing environment reflected in Home Two appears to have helped the adolescents who have lost their mothers subsequent to their placement in the home, to work through the grieving process more effectively as is reflected in the following quote:

Nkosinathi age 16: “I think then I am lonely. If you don’t have a mother then there is no one to look after you. But here I have friends and people who look after me” (Sic)

It thus appears as if the environmental deprivation that Winnicott identified in relation to children in what he termed ‘institutions’ is less applicable to adolescents who are in smaller care centres with numerous adult care givers who are able to identify with their experiences and provide them with emotional and psychological support (Gomez, 1997; Winnicott, 1984). This however does not imply that the adolescents do not struggle with their context; it merely suggests that the children have a

better chance of maintaining their mental health and ultimately overcoming difficulties, because the smaller more intimate environment is more nurturing. Winnicott (1984) posits that treatment of deprived and delinquent children should ideally aim at enabling the child to relinquish his/her anti-social defences and allow him/her the experience of being cared for in a way that would facilitate new growth on a basis of trust. It can be argued that Home Two in particular may well be meeting this criterion required for a 'good-enough' environment

3.3.1 Guilt

Within the context of this research it was evident that guilt and feelings of self loathing went hand in hand with feelings of anger that characterises deprived children (Winnicott, 1965) as is reflected in several of the stories, poetry and art images. This is particularly evident in the following quote:

Mosiuoa age 15: "Mother is a special person on earth by me I didn't respect I always do bad stuff on people eg stealing, cheating and lie people came to my mom and tell her that your son is doing that and that so my mother was always streased because other they tell her that they will kill me. I think she was angry for me..... I wish she can forgive me.....I wish she can forgive me.....for all that I don" (sic).

A week after writing these words, Mosiuoa tore them out of his book, washed them, scrunched them into a ball and threw them away. This process can be interpreted as an attempt to project his negative feelings into the visual image and consequently to destroy them (Dalley, 1987; Schaverien, 1987; Weir, 1987).

Mosiuoa was deeply attached to his mother. After the death of his father his mother became ill with the disease and he was compelled to look after the family, a task that he was ill equipped to cope with. In order to escape from the daily anguish of watching his family fall apart, he joined a gang. He continues to live with guilt and consequently is struggling to work through his losses.

Mosiuoa: Appendix A: 8

These feelings of guilt are reinforced in this self portrait. Mosiuoa has excluded facial details, thereby reinforcing his feelings of alienation and loss of self. The exclusion of feet highlights his feelings of instability and insecurity. The hands behind his back indicate feelings of guilt (Ogden, 1998).

Noluthando age 18: Appendix A: 5

Hidden hands are indicative of guilt whereas cut off feet are is a sign of emotional vulnerability (Ogden, 1984). Noluthando wore a mask of

genteel friendliness and verbally communicated that she was content and resolved, but this picture highlights the reality that she may be struggling with anger and associated guilt.

Sibusiso age 14: Appendix A: 9

In this drawing Sibusiso reflects his guilt by cutting off his hands. The cigarette in his mouth and cross around his neck, as well as the exclusion of legs all emphasise the ambivalent feelings that Sibusiso was struggling to cope with.

3.3.2 Bargaining

Kübler-Ross (2001) points out that in coming to terms with grief and loss, individuals generally tend to bargain with God in an effort to ward off future perceived threats of loss. When a parent dies prematurely, or when a sibling dies remaining family members are likely to become aware of their own vulnerability (Kübler-Ross, 2001). The dead parent in essence symbolises the frailty of life and because of the social stigma attached to HIV and AIDS, guilt and punishment (Goldstein et al, 2003).

In order to cope with their loss and fear related to living with HIV and AIDS, many of the adolescents attempted to bargain with God. Bargaining was reflected in the belief that if they tow the line and behave, then they

will be 'blessed' with a long life and by implication protection from the same fate as their parent/s.

Samuel age 13: "I think god he will Forgive all your sins mum I am still love you so much We still mees you as your children mum I want to know how you die is that day mum I think you will go to heaven My mum can you pry and ask Lord to give us a Long Long life and after that will do right thing in our lives and I want to see you again my mum" (sic).

Lungile age 18: "I hope everyone will repent cause I know that its not me but others as well that be in my situation" (sic).

Josephine age 17 found it difficult to reconcile her ambivalent feelings related to her mother. After writing a particularly critical poem about her current situation and her mother's role in it, she included the following statement:

"I still love you because I don't want to loose you" (sic).

This quote reflects fear that if she acknowledges her anger her mother may die and consequently she punctuates her poem with a positive statement almost as if this will protect her mother from succumbing to AIDS.

3.3.3 Depression

Six of the 28 adolescents reflected high levels of depression and anger accompanied by self-destructive behaviour. Three of the adolescents had attempted suicide prior to the intervention while one overdosed during the intervention. All the attempts appeared to be cries for help as the adolescents involved found it difficult to express their feelings of loss and alienation.

The following poem written by Jacob, one of the adolescents who attempted to commit suicide captures the ambivalent feelings that he confronts on a daily basis.

Life is RED.

It is full of Danger.

It has got taste.

Bitter and Sweet.

It makes me feel 'hopeless'

I'm scared of Life" (sic).

Jacob age15.

Life for Jacob has been 'bitter' but he longs for it to be 'sweet'. However, he fears life and often reflected the belief that he will die young.

In the following quote it is evident that Mosiuoa, like Jacob, has experienced a great deal of trauma and also suffers from periods of disillusionment and hopelessness as he confronts the pain of loss.

Mosiuoa age 15: “I end up loosing hope cause all the things I try nothing work out” (sic).

Thembikile’s childhood which was characterised by sexual, emotional and physical abuse has left her deeply traumatised. She often feels that life is too difficult to cope with and consequently sinks into deep states of depression. Thembikile’s quote indicates that despite experiencing periods of deep depression, at times she is able to reach out to the people in the community who care about her and give her support.

Thembikile’s age 16: “I did think of killing myself but if you talk you get help somewhere” (sic).

3.3.4 Acceptance

The adolescents whose mothers died subsequent to their placement in the home appeared to have managed to work through their losses more effectively than those who were orphaned prior to placement. Nkosinathi lost his mother after he had been placed in the care centre. Consequently he was surrounded by supportive friends. The following quote reflects his

fear of loss prior to his arrival as he was aware of his as well as his mother's HIV positive status. His mother was extremely ill when they arrived at the care centre and he believed that once she died he would be abandoned.

Nkosinathi age 16: "I think then I am lonely. If you don't have a mother then there is no one to look after you. But then I come here and here I have friends and people who look after me" (sic)

Joshua age 14: Appendix A: 10

In this drawing Joshua visually illustrates his belief that in learning to accept the past, healing occurs. In discussing this drawing he stated that the eye symbolises how he perceives the world. The torn veins and blood show the pain of his past. The colours blue and green which symbolise healing are repairing the damage and slowly the wounded part of the eye will decrease. He added that what helps him is to allow the light of hope to enter his life. Joshua pointed out that education and the relationships that he has built with the people in the care centre form the foundation of his hope.

3.3.5 Search for identity

Geographical locality and social interaction are important in helping to define identity (Erikson, 1963) and consequently losing everything that

had previously defined them resulted in the majority of the participants having to go through a process of redefining themselves. Part of the process of identity formation is a sense of belonging (De Carlo, 2005; Erikson, 1963; Louw et al, 1998) and these young people were required to establish new relationships and new significant connections in order to feel part of their new contexts. Adolescents who were traumatised prior to placement found the process particularly daunting.

Josephine age 17: Appendix A: 11

In this drawing Josephine has split the page into two distinctive halves. She pointed out that the top half reflects the part of her that is white. The colours in this section are brighter because she feels that this side of who she is gives her strength. The lower half is in sombre, aggressive colours because she hates this aspect of her identity. The floating heart is split in two thereby symbolising the identity confusion that Josephine is experiencing. She pointed out that her heart is being torn apart as she struggles to find her identity. Josephine added that she is caught between anger and depression as is reflected in the colours of the heart. The red section reflects her anger at not being white, and the blue section is symbolic of her hopelessness, because she knows she will always be black. An attempt to deny the reality of her black identity appears to exacerbate Josephine's depression and suicide ideation.

Jacob age 15: Appendix A: 12

The African Talking Stick represents my true African culture. It reminds me that I'm an African and that I'm a South African. I feel protected on the South African soil because it's the land where I was born. It also symbolises the culture and the origin of myself" (sic).

Jacob had lost touch with his family when he lived on the streets and had consequently defined himself by his 'street child' status. When he arrived in the care centre he hated being referred to as a 'street child' and worked hard at rediscovering his roots in order to find out where he belonged and how he perceived his future.

Solomon age 14: "The sweet lovely lady my mother used to be a traditional healer and her sister used to be a traditional healer and mountain healer. Each and every day her sister came and fetched her and they will go and dig to get the medicine which they will give to those sick people" (sic).

Solomon was one of the adolescents who found it extremely difficult to settle down in the care centre. He resented living in the centre as he felt that it stripped him of his African identity. He found it particularly difficult to manage his anger and was constantly engaged in aggressive and defiant behaviour.

3.3.5.1 Identity and HIV and AIDS

Three of the adolescents who participated in this research are infected with the HIV virus, and consequently part of the challenge of their search for identity is incorporating this reality into how they perceive themselves, without defining who they are entirely in relation to the disease. Living in an environment that accepts HIV as part of life has enabled the three adolescents who are infected with the disease to find meaning through talking about the disease and acknowledging it as part of who they are.

Jabu age 15: “These days young people are engaged a lot to sex. Some people are not educated about HIV/AIDS. As a young people we should speak out about us being surrounded by HIV/AIDS. We want that older people hear (Listen) to what we have to say. We want to educate young people about HIV/AIDS. We want a brighter future for old and new generations” (sic).

Thembikile age 18: “I would like to tell other HIV children that even if what’s happened to them they must just talk because talking it helps....it’s helping because you might say things and you think no one can help you but maybe when you talk and share your stories and that is helping” (sic).

3.3.6 Need for normality

The 28 participants in this research clearly indicated that they would like to be perceived as normal adolescents. Part of the desire for normality is related to living in a care centre and being labelled orphans. The care centres provide them with security and meet their instrumental needs, but despite this the majority yearn to be in normal families with normal homes. The break down of their family structures and their life in a care centre sets them apart from other adolescents and appears to add to their feelings of loss and alienation.

Mosiua age 15: “And then others when the month end, they just go to their moms and she gives them money or their moms come here..... I see them walking with their moms.....it becomes so hard for me” (sic).

This quote indicates that the loss of his mother left Mosiua feeling alienated and different. For him, normality means living with a family in a home and the constant reminder that he would never be able to return home or see his mother left him feeling overwhelmed with grief and at times unbearable anger.

Tshidi age 16: Appendix A: 13

In this portrait of herself, Tshidi has created an image of a fashionable, teenager with all the necessary gear. She pointed out that if she was

living with a normal family that is how she would dress. Tshidi added that she would spend her day shopping at the mall and would meet her friends to go to ‘movies.’ For Tshidi, being in a home with unlimited freedom symbolises the normality she desires.

For the HIV positive adolescents who participated in this research, antiretroviral treatment has played an important role in enabling them to feel normal and at the same time hopeful of a better future as is evident in the following quotes:

Nkosinathi age 15: “Antiretrovirals help me a lot. I feel like I am....I am like a normal person... just like any other boy who does not have HIV” (sic).

Themvikile age 16: “I still get Sick sometimes but not as much....not as much cause now I am on medicine..... on the antiretrovirals. I can able to go to school. I think that is why they have given me a second chance” (sic).

Jabu age 15: “To keep strong and live for a long time I need to take some medication (antiretrovirals) eat healthy food and exercise” (sic).

3.4 Hope and Resilience

Hope, characterised by a belief in the future despite the often extremely challenging events that one is called upon to cope with, is perhaps best embodied in the concept resilience. The majority of the participants in this research reflected high levels of resilience and a belief in their own strength to break free from the spiral of poverty and illness that has characterised their lives to date.

Lungile age 18: “I want be a lawyer and a social worker but now I didn’t finish the school.... because at the centre they took me to college they say I’m too old but now I want to.... want to go finish my school and be what I want to be so that I can help my sisters and my family” (sic).

Naledi age 16: Appendix A: 15

“The feathers tell me that one day I will be free and I will fly. I have courage. The colours show me that I have had sad times but now I have hope” (sic).

Naledi acknowledges that life has been difficult but it is evident that she still believes that life can be different. Her faith in a brighter future enables her to carry on functioning. She works hard at school and is determined to do well so that she can live an independent and functional life when she leaves the care centre.

Mosiua age 15: “I can wish to be...to be wise and to have the strength to just.....I know that my past will be always part of me but just to try forget and live for now....to live to help my brothers and my sisters” (sic).

Mosiua’s awareness of his siblings’ needs and the consequent desire to help them has enabled him to hang onto hope despite the reality that he experiences many dark and lonely moments and is plagued by feelings of guilt.

3.4.1 Hope for a better future

A driving force and subtheme of hope in the lives of these adolescents is the desire to achieve a good education and to break free from poverty. In Home Two, adolescents who work hard and are able to achieve academically are rewarded with bursaries. Some of the adolescents who have been unable to achieve either due to gaps in schooling or learning difficulties have been sent to skills based schools, and consequently have been enabled to hold onto their dreams. This care centre has been up and running for several years, and management is actively involved in encouraging the adolescents to set and achieve future orientated goals. Home One is in its infant stages and adolescents are only supported financially until they leave school.

Mosiua age 15: “Uhh it’s like I love music. I can be happy if I can....if I can see myself as a musician or a DJ so that I can help my sisters.”

Mosiua has identified his passion and has linked it to a brighter future. He also reflects an ongoing concern for his siblings who are living with relatives. He holds onto the hope that when he becomes independent he will be able to unite his family.

Nkosinathi age 15: “At first I want to be an artist but now I’m not doing it. I..... now I want to be a businessman or a welder. I want a welding business or to bring people from the airport to their places” (sic).

Like Mosiua, Nkosinathi has identified his strengths. He is currently in a good skills based school that is very supportive. Consequently he believes that he can establish himself in a career that will sustain him. The care centre he is in provides the adolescents with a great deal of encouragement to follow their realistic dreams. This does translate into financial assistance in order to do so. The knowledge that he is backed by a supportive community has freed Nkosinathi to dream of a future and to hold onto hope.

Lungile age 18: “I wanted to go to school and to finish and I wanted to be a lawyer between lawyer and social worker. I didn’t finish the school and

I'm going back to the location getting a job and end up getting the children, forgetting, drinking, doing wrong things. I don't want that. I want to learn more" (sic).

Lungile has missed a great deal of schooling and struggles academically, however she holds onto her dream of becoming a lawyer or a doctor. Her dreams in many respects have helped her to survive the reality of her extremely difficult childhood and her life in a care centre.

3.4.2 Faith

Home One is Christian based and consequently the 14 adolescents in this group discussed their faith freely and openly. For them their faith is an integral part of hope. In addition in both care centres several of the adolescents included crosses in their drawings thereby symbolising the central role of faith in helping to enhance their resilience.

Nosipho age 14: "My figure it an angel. It can fly. I want to fly like my angel. The angel remind me that I am special to God who love me" (sic).

Adolescents living in care centres often feel that they are unloved and abandoned. Nosipho's belief that despite her feelings of abandonment, God loves her has enabled her to adapt to her altered circumstances.

Noluthando Age 18: Appendix A: 14

My box has lots of yellow feathers yellow show happiness. The box is a nest..... my nest is God. I am like a bird..... I need to be in God's nest" (sic).

Noluthando's faith has enabled her to feel contained. She pointed out that when she feels alone, she remembers that she is in God's hands.

Maki age 18: "I know God more than before because I didn't know God but now I know God. I learn lot of things. I learn how to work with people, talk to people and I ... I met some people you know and now I can go and sing in the church and I'm blessed for that" (sic).

Maki was able to cope with her pain due to her strong belief that she could turn to her God for help in times of need. In addition her faith has enabled her to connect to a caring and supportive community that has helped enhance her self-worth.

Kethukhule age 15: "I wish good thing to my family and I even pray for them that God may help us, to get through this situation we are in" (sic).

Prayer has helped Kethukhule to cope with the loss of her siblings and feelings of guilt related to the difficult circumstances they are living in. In many respects her faith is keeping her hope alive.

The analysis of data reveals that the adolescents who participated in this research draw on past and present experiences in order to enable them to cope with the reality of living with HIV and AIDS. The road that they have travelled has not been easy and certainly appears to have challenged them on every level of their functioning. However, despite the at times daunting experiences that they have confronted, it is evident that the majority have managed to hold onto hope and consequently are gradually finding meaning within their new contexts.

Chapter Four: Conclusion

This research aimed to explore the experiences of adolescents living with HIV and AIDS. The research data revealed that institutionalised adolescents who have been directly impacted on by the disease are compelled to confront numerous life changing and emotionally demanding circumstances that have the potential to undermine their development. However it was patently evident that despite these extremely demanding contextual challenges, these young people have developed the ability to draw on inner and external resources in order to continue functioning.

The experiences of these adolescents, supports current research which highlights the impact that poverty and stigma exerts on individuals affected by HIV and AIDS (Andrews et al, 2006; Cameron, 2006; Campbell et al, 2005; Goldstein et al, 2003; Müller & Pienaar, 2004). Furthermore it emphasises the reality that vast numbers of young people in Sub Saharan Africa are growing up without the nurturance of parents. This research concurs with previous research which points that if society does not take responsibility for caring for the adolescents who are living with the consequences of the disease we face the prospect of coping with a dislocated and 'lost generation' of adolescents who have grown up parentless, not because of political ideologies but because of societal indifference to the suffering of those living with HIV and AIDS, stigma and in many instances poverty (Andrews et al, 2006; Foster, 2006; Richter & Swart-Kruger, 1994). The research highlights the reality that

adolescents whose voices have remained largely unheard need to be taken cognisance of.

Within the context of this research it is evident that despite the numerous difficulties and losses that the adolescents have experienced, they are able to hold onto hope and continue to believe that the future can be better. These positive feelings in no way diminish the reality that adolescents who are living in impoverished environments are at higher risk of having their development undermined as a consequence of the disease (Andrews et al, 2006; Cluver & Gardner, 2007; Drew et al, 1998; Richter & Swart-Kruger, 1995; Schlebusch & Cassidy, 1995;).

The combination of stigma and poverty coloured many of the experiences discussed in this research. Unfortunately stigma remains the single most debilitating factor within the context of HIV and AIDS as it alienates families from each other, results in people being driven out of communities (Goldstein et al, 2003; Müller & Pienaar, 2004; Roth & Nelson, 1997), and individuals not being tested timeously (Cameron; 2006). As is pointed out by Cameron (2006) it is time for society as a whole to work together to challenge unfounded assumption and judgemental attitudes with regards to HIV and AIDS.

4.1 Strength

The researcher was involved with both communities over an extended period and therefore was able to establish a foundation of trust with the participants. The intervention was interactive and practical and consequently the participants were able to utilise both verbal and non-verbal modes of communication in order to express thoughts and feelings around living with HIV and AIDS. Adolescents who found it difficult to express themselves verbally as a result of language restrictions were given the opportunity to do so using art. As a result the data is rich and varied.

4.2 Limitations

The research was completed retrospectively in that permission from an academic institution to use collected data was only granted after the intervention was completed. Prior to the onset of the intervention, the researcher hypothesised that data generated would provide valuable insight into adolescents' experiences of living with HIV and AIDS. Consequently both institutions were approached for written permission and participants were informed of the possibility that their work could be used for research. The care centres and the adolescents were presented with written documents which clearly outlined the intent of the researcher. Data were only collected after all involved had agreed that the

researcher could do so. Whether or not this impacted on the quality of the collected data is not ascertainable.

The participants in this research are living in institutions and therefore some of their experiences may be very different to those of adolescents living with HIV and AIDS who have remained in their communities. Research indicates that children living in institutions do experience high levels of alienation and dislocation (Foster 2006; Winnicott, 1984) and therefore it may be argued that some of the experiences may well be related to living in care centres rather than being unique to HIV and AIDS.

Stigma proved to be a major challenge particularly in the Home One. In this home the children did not openly discuss how their parents had died and consequently, the decision to include individual adolescents work was based on the knowledge that both parents had died as a result of illness within a few months of each other and that family members were unable to take them in as a result of family resources being depleted by the large number of children within that family being orphaned. An additional criterion used for inclusion was if parental deaths were linked to opportunistic diseases associated with full blown AIDS. Within the context of HIV and AIDS, stigma is an ongoing problem (Cameron, 2006; Goldstein et al, 2003; Müller & Pienaar, 2004; Roth & Nelson, 1997).

Disclosure is voluntary and when individuals succumb to opportunistic diseases, the opportunistic diseases such as Tuberculoses are listed as the cause of death. Accurate data with regards to the actual number of HIV infected people is consequently difficult to ascertain (Cameron, 2006).

Only three of the adolescents who participated in this research are infected with the HIV virus, therefore the research focuses primarily on the experiences of adolescents who have been affected by parental death rather than having their health compromised as a result of the disease. It was therefore not within the scope of this research to adequately explore how being infected with HIV impacts on adolescents' experiences. The three adolescents have access to antiretroviral medication and are in an accepting environment and therefore their perceptions of being HIV positive may not be reflective of the experiences of adolescents who are infected and have remained within their communities. An additional factor which may have influenced the input of the three adolescents who are positive is that they were included in the group of adolescents who are not infected. Logistically it was not possible to separate them.

4.3 Recommendations

In the process of conducting this research it became evident that children who are living with HIV and AIDS are particularly vulnerable to abuse (Campbell et al, 2005; Freeman & Nkomo, 2006; Richter & Swart-Kruger,

1995). When these children arrive in care centres they have often survived many traumatic and challenging experiences. In order to facilitate future mental health, the care centres are thus challenged to provide a 'good enough' nurturing environment. As a society this is a challenge that needs to be met in that the community as a whole should provide care centres with positive support and input to enable them to provide a 'good enough' environment. For example, volunteer care givers could act as parental role models for adolescents. However, given the vulnerability of these children, the care givers would have to be prepared to commit themselves to such a programme on a long term basis. Home Two where the children appear to be more settled has such a programme in place. Research with regards to the impact that this type of intervention is having on the children could prove to be invaluable.

The availability of antiretroviral medication has resulted in an increasing number of HIV positive adolescents and children regaining their health with a consequent increased life expectancy (Domek, 2006). These children are entering adulthood with a unique set of circumstances which will colour their self-perceptions and their experiences (Domek, 2006). It is therefore important to conduct extensive research with regards to the physical and psychological implications of antiretroviral medication on children and adolescents infected with the virus.

Within the context of this research it became evident that contextual variations influence how living with HIV and AIDS is perceived. Research that focuses on the positive and negative impact of differing contexts on adolescents' ability to adapt and cope with the difficulties of living with HIV and AIDS is essential. Contexts have the potential to undermine or enhance individual functioning. Research can inform interventions that could enable adolescents and children to remain within their communities as it appears as if being removed and placed in institutions may not be the best alternative (Domek, 2006; Foster, 2006). In order to validate this hypothesis, research contrasting the experiences of adolescents in communities, in child-headed households, in foster care and in institutions could prove invaluable.

References

- Andrews, G. Skinner, D. & Zuma, K. (2006). Epidemiology of health and vulnerability among children orphaned and made vulnerable by HIV/AIDS in Sub-Saharan Africa. *AIDS Care*, 18(3): 269-276.
- Arguile, 1992, R. (1992). Art Therapy with children and adolescents. In D. Waller & A. Gilroy (Eds.). *Art Therapy: A Handbook* (pp. 140-154). Buckingham: Open University Press.
- Babbie, E. & Mouton, J. (2005). *The practice of social research*. Cape Town: Oxford University Press.
- Bartos, M. & Mc Donald, K. (2000). *AIDS Care*, 12(3): 299-306.
- Birtchnell. J. (1987). Art therapy as a form of psychotherapy. In T. Dalley (Ed.). *Art As Therapy: An introduction to the use of art as a therapeutic technique* (pp. 30-44). London: Routledge.
- Blau, T. H. (1991). *The Draw-A-Person Test: a summary of Commonly Utilized Interpretive Features*. Florida: Psychological Seminars, INC.

- Boonzaier, F. & de la Rey, C. (2004). Women Abuse: The construction of gender in women and men's narratives of violence. *South African Journal of Psychology*, 34(3): 443-463.
- Cameron, E. (2006). Normalising Testing – Normalising AIDS. *The Southern African Catholic Quarterly*, 270(5-6): 53-56.
- Campbell, C. (2003). *Letting them die: Why HIV prevention programmes often fail*. Oxford: James Currey.
- Campbell, C., Foulis, C. A., Maimane, S. & Sibiya, Z. (2005). "I have an Evil Child in my House": Stigma and HIV/AIDS management in a South African Community. *American Journal of Public Health*; 95(5): 808-816.
- Campbell, C & Mac Phail, C. (2002). Peer education, gender and the development of critical consciousness: Participatory HIV prevention by South African youth. *Social Science and Medicine*, 55(2): 331-345.
- Cluver, L. & Gardner, F. (2007). Risk and protective factors for psychological well-being of children orphaned by AIDS in Cape Town: a qualitative study of children and caregivers' perspectives. *AIDS Care*, 19 (3): 318-325.

- Cohen, J. & Abramowitz, S. (1990). AIDS Attacks the Self: A Self-Psychological Exploration of the Psychodynamic Consequences of AIDS. *Progressive Self-Psychology*, (6):157-171.
- Crain, W. C. (1992). *Theories of Development*. New Jersey: Prentice Hall.
- Crewe, M (1992). *AIDS in South Africa: The Myth and the Reality*. London: Penguin.
- Dalley, T. (1987). Art as therapy: some new perspectives. In T. Dalley, C. Case, J Schaverien, F Weir, D. Halliday, P. N. Hall and D. Waller. (Eds.). *Images of Art Therapy: New developments in theory and practice* (pp.1-35). London: Routledge.
- De Carlo, A (2005). Identity Matters: A new Intervention Threshold for Social Work Practitioners Working with African American Adolescents. *Child and Adolescent Social Work Journal*, 22 (1): 35-55.
- Devlin, A. S. (2006). *Research Methods: Planning, Conducting and Presenting Research*. United States: Thomson Wadsworth.

- Domek, G. J. (2006). Social consequences of antiretroviral therapy: preparing for the unexpected futures of HIV-positive children. In *Lancet*, 367, (9519): 167-169.
- Drew, R. S., Makufa, C. & Foster, G. (1998). Strategies for providing care and support to children orphaned by AIDS. *AIDS Care*, 10(Supplement 1): 9-15.
- Erikson, E. H. (1963). *Childhood and Society*. New York: W. W. Norton & Company.
- Flick, U. (1998). *An Introduction to Qualitative Research*. London: Sage.
- Foster, G. (2006). Children who live in communities affected by AIDS. In *Lancet*, 367 (9511): 489.
- Foster, G. & Germann, S. (2002). In M. Essex, S. Boup, P. Kanki, R. Marlink, & S. D. Tlou (Eds.). *AIDS in Africa*. New York: Kluwer Academic.
- Freeman, M. & Nkomo, N. (2006). Guardianship of orphans and vulnerable children. A survey of current and prospective South African caregivers. *AIDS Care*, 18(4): 302-310.

- Goldstein, N., Pretorius, H.G., & Stuart, A.D. (2003). The Social Construction of HIV/AIDS. *Health SA Gesondheid*, 8(2): 14-22.
- Gomez, L. (1997). An introduction to object relations. Bristol: Arrowsmith.
- Henzell, J. Art, psychotherapy, and symbol systems (1989). In T. Dalley (Ed.). *Art As Therapy: An introduction to the use of art as a therapeutic technique* (pp. 15-29). London: Routledge.
- Hoosen, S. & Collins, A. (2004). Sex, sexuality and Sickness: Discourse of gender and HIV/AIDS among KwaZulu-Natal women. *South African Journal of Psychology*, 34(3): 487-505.
- Hubley, J. (2002). *Treatment Management: The AIDS Handbook. A Guide to the Understanding of AIDS and HIV*. Oxford: Macmillan.
- Hüsler, G., Blakeney, R & Werlen, E. (2005). Adolescent Risk: The Co-Occurrence of Illness, Suicidality, and Substance Use. *Journal of Youth and Adolescence*, 34(6): 547-557.

Johnson, S., Schierhout, G., Steinberg, M., Russell, B., Hall, K. & Morgan, J. (2004). AIDS in the Household. Health and Development Africa: Social Surveys Memory Box Project. *AIDS and Society Research Unit, UCT*. 203-216.

Jung, C. G. (1952). Individual Dream Symbolism in Relation to Alchemy. In C. G. Jung. *Dreams*. London: Routledge.

Kelly, K. (1999). Calling it a day: reaching conclusions in qualitative research. In M Terre Blanche and K. Durrheim (Eds.). *Research in Practice: Applied Methods for the Social Sciences* (pp. 421-437). Cape Town: UCT Press.

Koppitz, E.M. (1968). *Psychological Evaluation of Children's Human Figure Drawings*. New York: The Psychological Corporation.

Kübler-Ross, E. (2001). *Living with Death and Dying*. Channel Islands: Guernsey.

Lancet. London: Aug 16, 2003. 362(9383):501.

- Le Marcis, F. & Ebrahim-Vally, R. (2005). People living with HIV and AIDS in everyday conditions of township life in South Africa: between structural constraint and individual tactics. *Journal of Social aspects of HIV/AIDS*, 2(1): 217-235.
- Letlaka-Rennert, K., Luswazi, P., Helms, J. & Zea, M. (1997). Does the womanist identity model predict aspects of psychological functioning in black South African women? *South African Journal of Psychology*. 27(4): 236-243.
- Louw, D. A., van Ede, D.M, and Louw, A. E. (1998). *Human Development*. Cape Town: Kagiso.
- Matthews, J. (1986). Children's Early Representations. *Inscape*. Winter 1986, 12-17.
- Miller, P. (1979). *Myths and Legends of Southern Africa*. Cape Town: ABC Press.
- Müller, J.C. & Pienaar, S. (2004). Stories about care: Women in a historically disadvantaged community infected and /or affected by HIV/AIDS. *HTS*, 60(3): 1029-1046.

- Murphy, J. (1998). Art Therapy with Sexually Abused Children and Young People. *Inscape*, 3(1): 10-16.
- O'Shaughnessy, E. (1992). Psychosis: not thinking in a bizarre world. In R. Anderson (Ed). *Clinical Lectures on Klein and Bion* (pp. 89-101). London: Routledge.
- Ogden, D.P. (1984). *Psychodiagnostics and Personality Assessment: A Handbook: Second Edition*. Los Angeles: Western Psychological Services.
- Panford, S., Nyaney, M. O., Amoah, S. O., Aidoo, N. G. (2001). Using Folk media in HIV/AIDS prevention in rural Ghana. *American Journal of Public Health*, 91(10) 1559-1562.
- Puttergill, C.H. (2000). *Research in the Social Sciences*. Pretoria: University of South Africa.
- Richter, L. & Swart-Kruger, J. (1995). AIDS-risk among street children and youth: implications for intervention. *South African Journal of Psychology*, 25(1): 31-37.

- Riesenberg Malcolm, R. (1992). As if: the phenomenon of not learning. In R. Anderson (Ed). *Clinical Lectures on Klein and Bion* (pp.114-125). London: Routledge.
- Robins, S. (2006). From “Right” to “Ritual”: AIDS Activism in South Africa. *American Anthropologist*. 108(2): 312-324.
- Ross, M. B. (1991). *Remembering the Personal Past – Descriptions of Autobiographical Memory*. New York: Oxford University Press.
- Roth, N. L. & Nelson, M. S. (1997). HIV diagnosis rituals and identity narratives. *AIDS Care*, 9(2): 161-179.
- Ryckman, R. M. (1985). *Theories of Personality Development* (4th Ed). California: Brooks/Cole.
- Schaverien, J. (1987). The scapegoat and the talisman: transference in art therapy. In T. Dalley, C. Case, J Schaverien, F Weir, D. Halliday, P N. Hall and D. Waller (Eds.). *Images of Art Therapy: New developments in theory and practice* (pp.74-108). London: Routledge.

- Schlebusch, L. & Cassidy, M. (1995). Stress, social support and biopsychosocial dynamics in HIV-AIDS. *South African Journal of Psychology*, 25(1): 27-29.
- Skinner, D. & Mfecane, S. (2004). Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa. *Journal of Social aspects of HIV/AIDS*, 1(3): 157-163.
- Smith, J. A. & Eatough, V. E. (2007). Interpretative phenomenological analysis. In E. Lyons & A. Coyle (Eds.) *Analysing Qualitative Data in Psychology* (pp. 35 – 50). London: Sage.
- Snell, C. L. (2003). Commercial Sexual Exploitation of Youth in South Africa. *The Journal of Negro Education*, 72(4): 506-514.
- Sowell, R. L. PhD, RN, FAAN (2000). AIDS Orphans: The Cost of Doing Nothing. *Journal of the Association of Nurses in AIDS care*, 11(6): 15-16.
- Strydom, H. & Raath, H. (2005). The psychosocial needs of adolescents affected by HIV/AIDS: A South African study. *International Social Work*, 48(5): 569-580.

- Ungvarski, P. & Flaskerud, J. (1999.). *A Guide to Primary Care Management*. Pennsylvania: Saunders Company.
- Van Dyk, A. (2001). *HIV/AIDS Care & Counselling: A Multidisciplinary Approach*. Cape Town: Maskew Miller.
- Waddell, M. (1998). *Inside Lives Psychoanalysis and the Growth of the Personality*. New York: Routledge.
- Waller, D. & Gilroy, A. (1992). Introduction. In D. Waller & A. Gilroy (Eds.). *Art Therapy: A Handbook* (pp. 3-24). Buckingham: Open University Press.
- Weir, F. (1997). The role of symbolic expression in its relation to art therapy: a Kleinian approach. In T. Dalley, C. Case, J Schaverien, F Weir, D. Halliday, P N. Hall and D. Waller. (Eds.). *Images of Art Therapy: New developments in theory and practice* (pp. 109-127). London: Routledge.
- Winnicott, D. W. (1958). The Antisocial Tendency. In *Collected Papers*. London: Tavistock Publications.

Winnicott, D. W. (1965). *The Family and Individual Development*.
London: Tavistock Publications.

Winnicott, D. W. (1984). *Deprivation and Delinquency*. London:
Routledge.

Wood, A. (1984). The child and art therapy: a psychodynamic viewpoint.
In T. Dalley (Ed.). *Art as Therapy: An introduction to the use of art as
a therapeutic technique* (pp. 62-81). London: Routledge.

Appendix A



A: 1 Mosiuoa



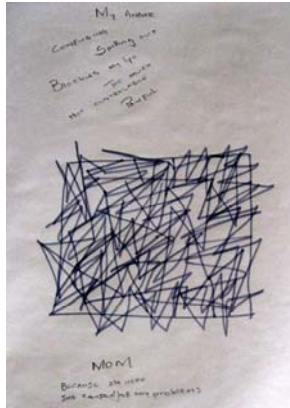
A: 2 Simon

A: 3 Simon



A: 4 Jacob

A: 5 Noluthando



A: 6 Josephine



A:7 Themvikile



A: 8 Mosiuoa



A: 9 Sibusiso



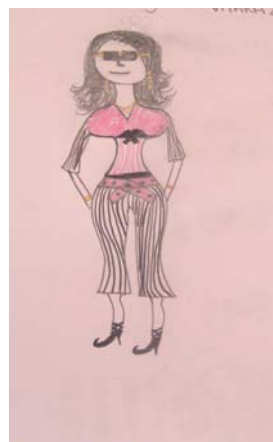
A: 10: Joshua



A: 11: Josephine



A: 12 Jacob



A: 13 Tshidi



A: 14: Naledi



A: 15: Noluthando

Appendix B

1. An Orphan lets her heart speak

HIV/AIDS

Do you think you are right?

Do you think you are fair to me?

Why do you choose to make us suffer?

Can you see that now I have no mother because of you?

Did you think about that before you took my lovely mother?

HIV/AIDS you are not fair! – you have no mercy at all !!!!!!!

You took my mother just like that!

I HATE YOU!

HIV/AIDS where do you come from?

Who sent you to take out parents?

Are you going to give me the love that my mother was giving to me?

Do you know how many orphans there are in the world because of YOU?

HIV/AIDS because YOU took my mother.....

Where are my rights?

Who's going to protect my rights.....? (Sic)

Thembikile age 16

2. What Would You Do?

What would you do,

If you had no hope,

If you had no place

to call home

If no one loved you.

What would you do,

If you lived in the streets

If you had no friends

and relatives (sic).

Jacob age 15

3. Wake Up

Young people don't play with fire, coz life is too short

You only have one life to live and live wisely.

Never quit when things don't go your way 'coz'

Quitters never win and winners NEVER QUIT.

You were born a winner not a loser.

Recognise your failure SYMPTOMS and get RID of them.

Don't let anyone stand in your way.

Take charge of your life and move on.

Learn to take risks and accept life's challenges

Remember Life is a journey and not a DESTINATION so LIVE WISELY!
(sic).

Jacob Age 15

Appendix C

C: 1 University Research Clearance Certificate