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Institutionalised children's understanding of HIV/AIDS.

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CHAPTER 1

INTRODUCTION TO STUDY

Children's understanding of HIV/AIDS is an area that has been under-researched. Children remain a vulnerable part of the population that is affected by HIV/AIDS. One of the ways in which children are affected is the loss of parental figures to the epidemic. Present statistics indicate that there is a drastic increase in the number of AIDS orphans globally. It is predicted that by 2010, 106 million children under age 15 would have lost both their parents; 25 million of these will be HIV/AIDS orphans (UNAIDS & UNICEF, 2002).

Children are not only affected by HIV/AIDS, some are HIV positive themselves. It is estimated that by the end of 2003, 5.3 million South Africans will be infected with HIV. This was said to be the largest number of people living with HIV in a single country and it is still rising (UNAIDS, 2003). South Africa has the largest number of HIV infections in the world to date, 5.5 million (UNAIDS, 2008).

Research conducted in South Africa also shows that there is a high prevalence of the virus among children aged between 2-14 years (Shisana, 2002). These statistics show that the country is at a point where public ignorance is an unaffordable luxury. The alarmingly high percentage of HIV/AIDS affected and infected children in South Africa, necessitates more research in this area.

Aims of the study:

The focus of this research is to elicit information on how institutionalised children understand HIV/AIDS. The term 'understanding' refers to the children's own perceptions and explanations of HIV/AIDS, taking into account cognitive, emotional, and social factors.

In times where the community at large is affected by HIV, and children are said to be the most vulnerable, this study aims to explore how institutionalised children have made sense of the pandemic. These are children who may be directly or indirectly affected by HIV/AIDS. They are placed in institutions for different reason, including the loss of one or both parents to HIV/AIDS, the family's inability to take care of them, the child's HIV seropositive status, or as a result of abuse in the family. In the midst of all their experiences, children live in a time where HIV/AIDS is prominent, thus the current study seeks to investigate what HIV/AIDS means to them. The research also aims to contribute to enlarging the body of knowledge on the psychosocial impact of HIV/AIDS in South Africa. Through this, key areas for further investigation may be identified.

Rationale:

Due to the increasing inability of extended family members to look after orphans, many children are placed in institutions. As the numbers of HIV/AIDS orphans continue to rise, so does the need for researchers to look beyond how it affects adults, and take into account the children themselves. Current literature shows that studies have been conducted looking into the experience of living with and making meaning of HIV/AIDS; however, adults and adolescents have been the focus of such studies (Goldstein, 2004; Wild, 2001). Those who act as caregivers to the children argue that the children have no understanding of HIV, while others paint a gloomy picture of the impact of HIV on children (Mahlobo, 2004). The children's voices have not been heard, they have not been given enough opportunities to express how they have made sense of the pandemic. It is thus imperative that we begin to enlarge this limited knowledge.

Conducting an investigation in the area of how children understand HIV/AIDS may shed some light on the possible psychosocial impact of the pandemic on the children. Furthermore, findings from this research may be useful in guiding further research, and hopefully, in guiding the South African government policy makers in making informed decisions with regards to possible mental health interventions that may be put in place in the children's institutions.

The study aims to answer the following research question:

1.1 How do institutionalised children understand HIV/AIDS?

a. How do they understand what HIV/AIDS is?
b. How do they understand what HIV/AIDS does?
c. How do they understand themselves in relation to HIV/AIDS?
d. How do they relate HIV/AIDS to their emotional experiences?
e. How do they understand how their families/friends have been affected by HIV/AIDS?

The data collection process took place in one research site, a children's institution based in the Vaal area. It is an institution offering comprehensive services in taking care of children in need. The area it serves is characterised by unemployment, poverty, and crime. The area has both brick houses and informal housing structures. The children who live in the institution come from the entire range of people living in the area and other surrounding areas. Some of the reasons leading to the institutionalisation of children in this area include sexual abuse, physical abuse, the death of a parent, and the inability of a parent or guardian to cope with the child.

This study was influenced by research conducted by Wiener and Figuroa (1998) entitled 'Children speaking with children and families about HIV infection'. It is acknowledged in their study that the medical and social consequences of HIV/AIDS are well documented in the literature. They identified a gap in the literature regarding the experiences and perspectives of children themselves, and their research sought to look into this area. Their argument was that when HIV infected children are provided a non-threatening, safe environment with a person they can trust, they are able to share their inner world and a process of healing is facilitated.

The above-mentioned research was conducted during periods when the children were hospitalised or had hospital visits. During these periods, a child would be offered the opportunity to spend time with his/her social worker, partaking in different activities such as play, story telling, completing incomplete sentences, drawing, and writing in a workbook. Children participating in Wiener and Figueroa's study (1998) drew pictures representing how HIV looks; they spoke about how they understand HIV/AIDS and how it affects them and those around them. The children drew pictures representing how HIV appears in their bodies, sharing their experiences of living with AIDS. The current research used similar tasks in eliciting information on how institutionalised children understand HIV/AIDS, requesting participants to draw HIV/AIDS, and to draw HIV/AIDS in a person's body. Participants were also requested to tell stories and complete incomplete sentences in relation to HIV/AIDS.

The data obtained from Wiener and Figueroa's study (1998) was analysed and findings focused on emotional responses to diagnosis with HIV, recognising clinical symptoms, disclosure, advanced disease, and terminal illness. They also looked into how children are emotionally affected by having a parent who is also HIV infected, losing a parent, and some of the emotional experiences of non-infected siblings. Some of their findings are further discussed in the following chapter.

In the current study, analysis of data obtained mainly focused on institutionalised children's understanding of HIV/AIDS. Drawings of HIV/AIDS itself and drawings of HIV/AIDS in the body, showed how the children think HIV/AIDS looks like and how it affects those infected by it. Some drawings of people and families, together with the children's stories and completed sentences, gave more information in relation to their understanding of how HIV/AIDS may be related to their emotional experiences, together with the experiences of those around them. These results are discussed in detail later.

The research report has been structured as follows:

Chapter one provides background information and conceptualisation of the study, stating the purpose, aims, and rationale of the inquiry to the reader. This chapter also outlines the research questions, together with providing information on the study that the current research is influenced by.

Chapter two serves as an in-depth discussion of the literature consulted. The development of the literature review an extensive electronic search of international and national databases was conducted in order to identify relevant research published in journals, and books, as well as research reports available in tertiary institutions. The latter includes studies undertaken at Masters and PhD levels in South African tertiary institutions. The selection of material specifically applicable to children and HIV/AIDS in the Southern Africa context proved to be a challenging task. Much literature relating to other areas of the world is relevant to South Africa and sources referring to other countries were thus included in the literature review. Also, a fair amount of literature concerning children and HIV/AIDS focuses on issues to do with child-care, rights, and support. Other relevant issues discussed in literature include the impact of illness on children, together with the impact of loss/death, and institutionalisation. It was important to review developments in these areas because these areas may be related to how the subjects of this study understand HIV/AIDS.

Chapter three presents the design and method underpinning this inquiry. The chapter explains the method of data collection chosen, as well as describing the analysis of the data. Ethical considerations are also taken into account for the research process.

Chapter four presents the research results, providing a description of the general findings of this research. These findings will be presented and described in line with the task sheet as provided in appendix V, using the children's drawings throughout. Common themes that arose from the data will be mentioned, and they will be further discussed in the next chapter.

Chapter five contains a discussion of common themes from the results of the study, articulating the children's understanding of HIV/AIDS as depicted by their drawings and responses during the interviews.

Finally, in chapter six the inquiry as a whole is summarised, and the researcher reflects on the limitations of the study. Furthermore, recommendations for future research are made.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

The HIV/AIDS epidemic has been and continues to be an enormous challenge throughout the global community. Many people are infected with the disease and many others are affected by it (Gow & Desmond, 2002). HIV/AIDS has an impact on both adults and children; some of whom are infected and others are affected in a variety of ways. This paper focuses on the impact of HIV/AIDS on children, beginning with a discussion of the impact of HIV/AIDS on affected children, followed by a discussion of the impact of HIV/AIDS on infected children. The chapter then looks into how children deal with loss and how children deal with other terminal illnesses. Lastly the impact of institutionalisation on children will be discussed. The most prominent theory in relation to institutionalisation is Bowlby's attachment theory; this theory will thus be the focus of the discussion on the impact of institutionalisation on children. The paper concludes with a summary of all the discussed topics, linking the different psychosocial impacts of being institutionalised, losing a parental figure, being HIV/AIDS infected, or being affected by HIV/AIDS as a child.

It is important to note that the tendency of literature is to focus mainly on negative impacts of institutionalisation, loss in childhood, and being infected or affected by HIV. However, these negative implications are not true in all cases; a few studies note some positive factors, which will also be discussed.

2.2 HIV/AIDS Affected Children

HIV/AIDS affects many children, as social organisation is changed by this epidemic. According to Gow and Desmond (2002), all South African children will feel the impact of HIV/AIDS either directly or indirectly, in the changed manner of society in which they grow up. The high prevalence of HIV/AIDS has led to the deterioration of services, as many service providers have been lost to the pandemic. There are also high levels of stress within and outside families, and many social institutions have weakened over the years as HIV/AIDS became more prominent (Richter, Manegold, & Pather, 2004). All these factors have a direct impact on children in the world at large. Other ways in which children are affected by HIV/AIDS include the illness of caregivers within the home, the loss of one or both parents, transference to a different care-giving household, child-headed homes, increased unmet financial demands, and children with old and frail caregivers. Furthermore, children may become sexually exploited, be forced to live on the streets, become child labourers or get in trouble with the law (Jackson, 2002). The direct and indirect consequences of the pandemic are therefore formidable, and they are further discussed below.

Terminally Ill Parents

The first notable direct impact of HIV/AIDS on children is living with a terminally ill parent, one who as reached the full-blown AIDS stage. Bor and Elford (1994) argue that in effect, AIDS-related mortality of one or both parents has a devastating impact on family structure. It is stated that factors including family income, security, food, household management and the quality of care given to the children, are affected long before the death of a parent (Bor & Elfor, 1994). An ill parent is unable to go to work and earn money to assist in providing for his/her children. Furthermore, an ill parent may not have the strength to perform household duties such as cleaning, washing, and cooking. During the illness of their parents, children may have to exchange roles and become carers to their parents (Wild, 2001). These children take on household duties such as cleaning, doing the laundry, and cooking. In addition to these extra duties, they are required to meet their parent's physical and sometimes emotional needs (Jackson, 2002).

It has been found that the school performance of children who have had to care for their terminally ill parents suffer severely. This is due to irregular school attendance and an increased inability to cope with schoolwork and with home care-giving simultaneously. As a result, many young people find themselves with insufficient schooling and, thus, with poor employment prospects years after their parent's death (Bor & Elford, 1994). In addition, children undergo severe psychological trauma, as their relationships with significant figures are disrupted.

In a study conducted by Stein (2004), looking into the disclosure of a parent's HIV status to children, it was found that children who were informed of the parent's seropositive status showed significantly less anxiety as compared to children who were uninformed. It is important to recognise that while it may be beneficial to impart knowledge and information about HIV/AIDS to children, it is not sufficient, as gaining full understanding of the experience of HIV/AIDS is a gradual, unfolding journey (Stein, 2004).

Loss of Parents

One of the most striking outcomes of the AIDS epidemic in Africa is the increasing number of children left without the care of one or both parents. Statistics show that a majority of these children are in sub-Saharan Africa (UNAIDS, 2003; UNAIDS, 2006). According to research conducted in South Africa on the long-term impacts of HIV/AIDS on children, it has been postulated that by 2015, the number of orphaned children is likely to hit its highest point. It has been projected that 2 million children under the age of 15 will be maternal orphans, 3 million persons under the age of 18 will be maternal orphans, 4.7 million persons under the age of 18 will be paternal orphans (Gow & Desmond, 2002).

Richter et al (2004) states that an orphan may be defined as a child under the age of fifteen who has lost a mother (maternal orphan), a father (paternal orphan), or both parents (double orphan). Orphans affected by HIV/AIDS suffer in many areas after the

loss of their parents, including education, health, and psychosocial areas. Loudon (1998) argues that unless something is done to reinvent child care, the nation will face a gloomy future, where adults die in large numbers, and following the sight of their parents dying, children are left with nowhere to go but tented camps.

Impact on the Community

Children are dependent on adults in the family and in the community to nurture their development. The ability of adults to fulfil their duties may be reduced by HIV/AIDS. The impact on the community leads to an impact on the family, which leads to impact on children. Hunter and Williamson (in Richter et al, 2004) outlined the impact on different levels. The community is affected as those who die from HIV/AIDS related illnesses reduced skilled labour. This negatively impacts the economy, increased poverty, and causing inability to maintain infrastructure. In addition, the loss of skilled labour decreases access to services. For example, if those lost were part of the health care system, nurses, doctors, administrators, and so on, access to health care becomes difficult. This leads to elevated rates of mortality and morbidity. The inability to assemble resources for community initiatives affects individuals in the community, increasing psychological stress and breakdown.

Families are part of the community, when the community is negatively affected by HIV/AIDS, families are also affected. They suffer bereavement due to the loss of loved ones to the pandemic. In cases where those lost were breadwinners for their families, those left behind are likely to experience impoverishment, and they may lack income for health care and education. Changes in family composition and reversal of roles may cause stress and demoralisation (Richter et al., 2004). The negative consequences of HIV/AIDS on the community and families dominating in literature are shown to affect children as shown in table 1 below, based on information obtained from Richter et al., 2004, p. 9-10.

Table 1: Material and Non-Material Problems

Livelihood	Health	Education	Protection, Welfare, and Emotional Health
Loss of property Loss of inheritance Loss of shelter Loss of food security Increased poverty	Lower nutritional status Less attention when sick Less likely to be immunised Increased vulnerability to decease Less access to health services Increased vulnerability to HIV/AIDS Higher child mortality Higher exposure to opportunistic infection	Lower educational performance. Increased skipping of school. Premature termination of education. Withdrawal from school to care for others or to save costs. Fewer vocational opportunities. Traditional knowledge not passed on.	Decreased adult supervision. Decreased affection, and encouragement. Increased labour demands. Harsh treatment. Stigma. Social isolation. Forced early marriage. Sexual abuse. Exploitation. Abandonment. Institutionalisation. Grief. Depression. Antisocial and other difficult behaviour.

In summary, most children affected by HIV/AIDS are also affected by poverty. They then suffer exclusion from services such as access to good health care facilities, good education, and welfare services. Although they have constitutional rights to access such services, their rights are challenged by the vast spread of HIV/AIDS and its impact,

including the loss of staff and the high demands on resources and services to combat the spread of the epidemic (Richter et al, 2004).

Although some research has been conducted to understand the psychosocial impacts of HIV/AIDS on children, it has been argued that the social and economic impacts have overshadowed concerns about the psychological impacts (Jackson, 2002). This is said to be true in developing countries where it is difficult for existing agencies to address psychological needs as opposed to the more prominent basic needs: for example, the provision of shelter and food would be more appropriate than counselling. Those studies that have been conducted focusing on the social impacts highlighted issues such as the disruption of education, the loss of a home, working as a child, and limited access to basic services (Foster &Williamson, 2000; Jackson, 2002).

Emotional Problems

Research conducted to explore the psychosocial adjustment of uninfected children whose parents were HIV positive, had AIDS, or had died as a result of the disease, revealed the following findings: clinically elevated levels of psychological adjustment difficulties, and feelings of anxiety and depression. It was found that those children experienced more problems in school, displaying concentration problems and lower cognitive and social competence. In addition, the children were found to have higher levels of internalising problems as compared to other children, externalising problems, “acting-out” behaviour, and being less optimistic about the future (Wild, 2001).

Furthermore, it has been stated that orphaned children are likely to grow up with little sense of security and hope; as a result, they may involve themselves in criminal offences and prostitution as a means of survival (Jackson, 2002). These involvements may increase their chances of contracting HIV/AIDS.

Alternative Care

Children need to be placed in someone's care after the death of their parents. Foster and Williamson (2000) note that traditionally, orphans were absorbed into the extended family network. This has changed as the family support network has weakened over the years, resulting in many orphans not having access to immediate guardians. In some cases, one finds that biological relatives are poor or overwhelmed. Their severely strained financial resources then become a barrier, restraining them from caring for orphans. In other cases, grandparents are too old to take care of their grandchildren (Foster & Williamson, 2000).

Therefore, an alternative system of care has to be devised. One such alternative is institutionalisation. It is postulated that in the foreseeable future, neither non-governmental organizations, the state, nor donor organizations, will be able to fulfil the role of providing alternative care (Bor & Elford, 1994). Although some forms of interventions have been put in place to address this increasing need, the numbers of affected children continue to rise each year (UNAIDS, 2003).

Bor and Elford (1994) point out that urbanization has also affected the ways in which extended families organize the lives of surviving members. Unique forms of family reorganisations have emerged. An example of the new family structures is that of child-headed households, whereby children become caregivers for their younger siblings. They are faced with demands of ensuring that their siblings' financial, physical, social, and psychological needs are met (Bor & Elford, 1994). This is a huge challenge, as they also need someone to meet their own needs, since they are children themselves.

It is important for one to note that the negative outcomes discussed above are not true for all HIV/AIDS affected children, as some are absorbed into good extended family structures and other forms of supportive structures within their communities. For example, Faith Based Organisations (FBOs) offer some of the most valuable programmes in addressing the impact of HIV/AIDS on affected children. Religious bodies are an essential part of the community, providing a social network through which the needs of

vulnerable children can be met. The effectiveness of faith-based projects is attributed to the fact that compassion and care for the vulnerable is fundamental to religious doctrines. Such organisations have reached an estimated 140 000 in 6 Southern African countries, providing them with spiritual, educational, psychosocial, and material support (Richter, et al, 2004). Also, school fees waivers, payment for school uniform, and provision of food at school, are common elements of community-based support for children affected by HIV/AIDS (Richter, et al, 2004). Such forms of support provide children affected by HIV/AIDS a platform to strive for a brighter future.

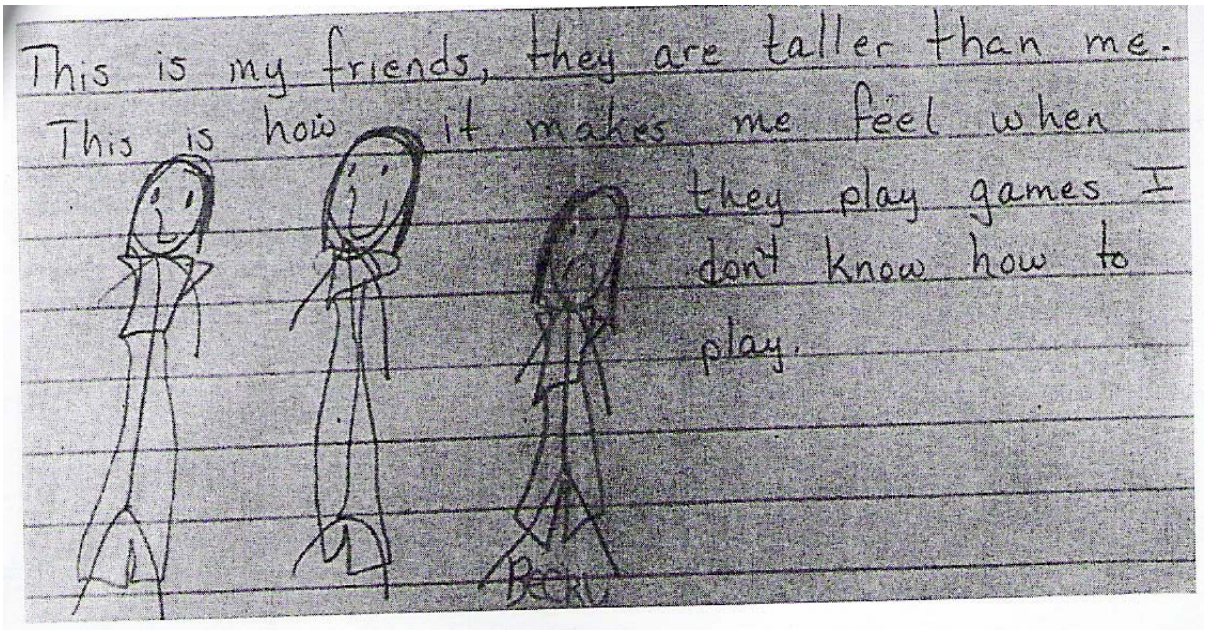
2.3 HIV/AIDS Infected Children

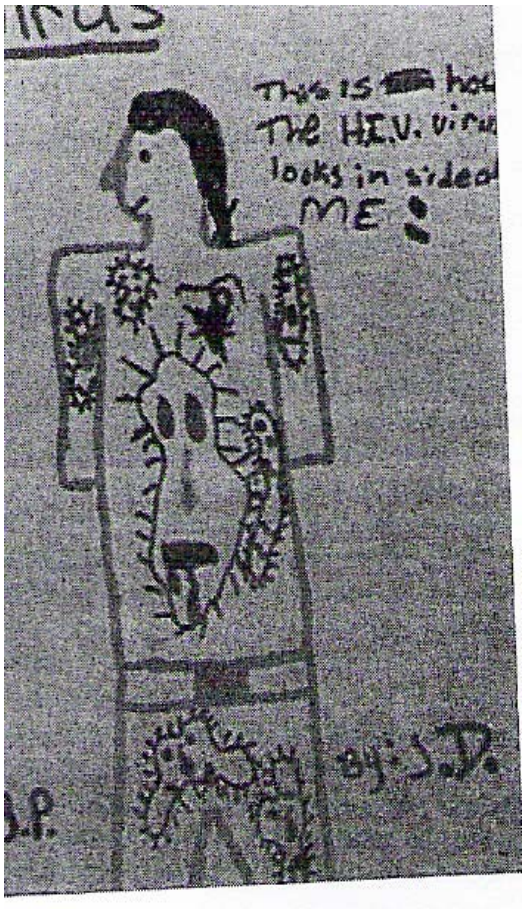
Research on HIV-infected children, like that concerning affected children, tends to focus on negative consequences. With infected children, however, the impact of HIV/AIDS is often more direct. This is the case both physically, since children experience illness and the threat of death, and psychologically. Physically, children infected with HIV/AIDS often grow up weaker and smaller than children who are not infected with HIV/AIDS. Also, in addition to taking medication, they require frequent hospitalisation for specific illnesses or infections (Wiener & Figueroa, 1998).

These hospital visits are necessary because HIV-infected children's bodies cannot fight infections as well as those of children not infected with HIV/AIDS (Ramsden, 2002). Therefore, whenever they show signs of illness, they need to receive immediate attention from their caregivers. Some of the most important signs which caregivers should be aware of include, changes in appetite, swollen glands, high temperature, coughs, breathing difficulties, skin rashes, cuts that do not heal, pain when passing urine, thrush, herpes, diarrhoea, headaches and changes in behaviour (Ramsden, 2002). HIV/AIDS infected children are subject to difficulties such as retardation in growth and development, mental retardation, regression in behaviour, psychomotor and neurological disturbances (Bor & Elford, 1994). Any infections in these children need to be discovered early and treated quickly.

One needs to be aware that some of these symptoms are quite common and even expected in children, but when it comes to an HIV infected child, one has to take extra precautions and raise levels of awareness (Yelding, 1990). Yelding (1990) argues that caring for an HIV/AIDS infected child arouses feelings of anxiety in the caregiver about the child's health. In addition, feelings of helplessness, questioning one's beliefs, and the fear of death, may be brought by the responsibility of caring for a child infected with HIV/AIDS (Bor & Elford, 1994). Carers may also become hypervigilent when caring for HIV-infected children.

Rivlin (1999) asserts that when chronic illness is part of a child's life, its effects go beyond the physical symptoms, as they filter into his/her psychosocial well-being. Several studies have shown that children with illnesses like asthma, cerebral palsy, or diabetes often feel that they are "different" from other children, and as a result, they are isolated and feel lonely (Rivlin, 1999). Similarly, Wiener & Figueroa (1998) found that HIV infected children feel that they are 'different' from other children, adding to the shame, silence and isolation that comes with an HIV positive status. The following pictures extracted from Wiener & Figueroa (1998) depict the sense of being different more strongly.

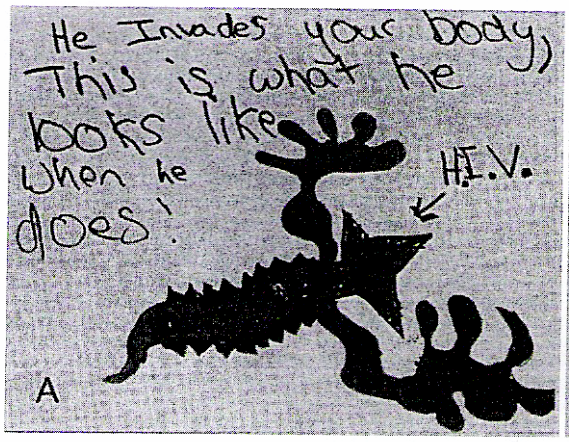


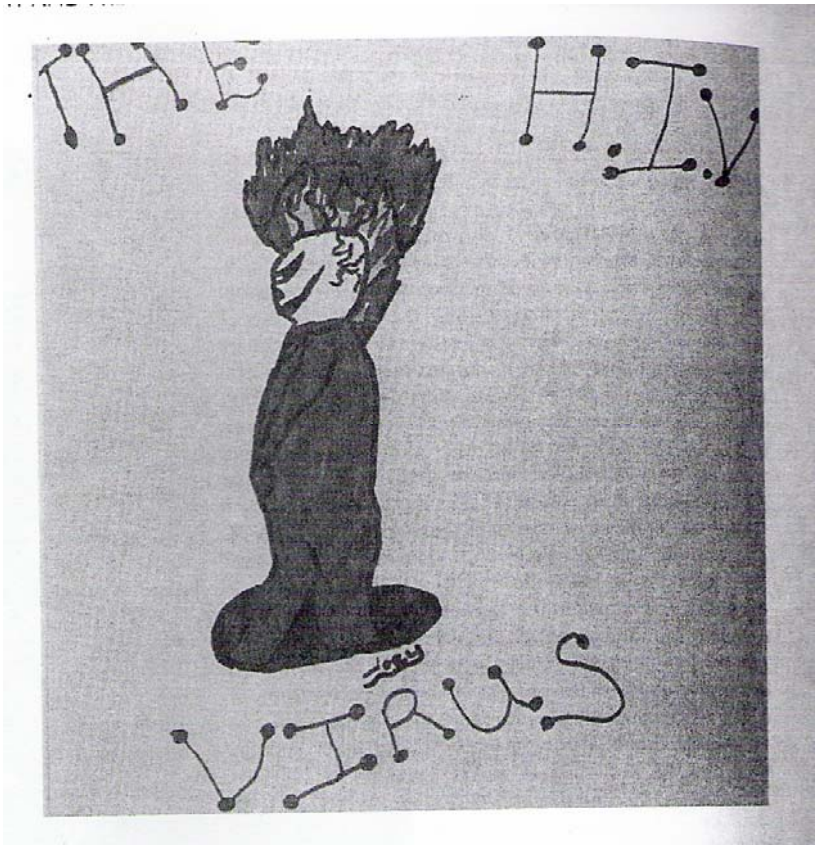


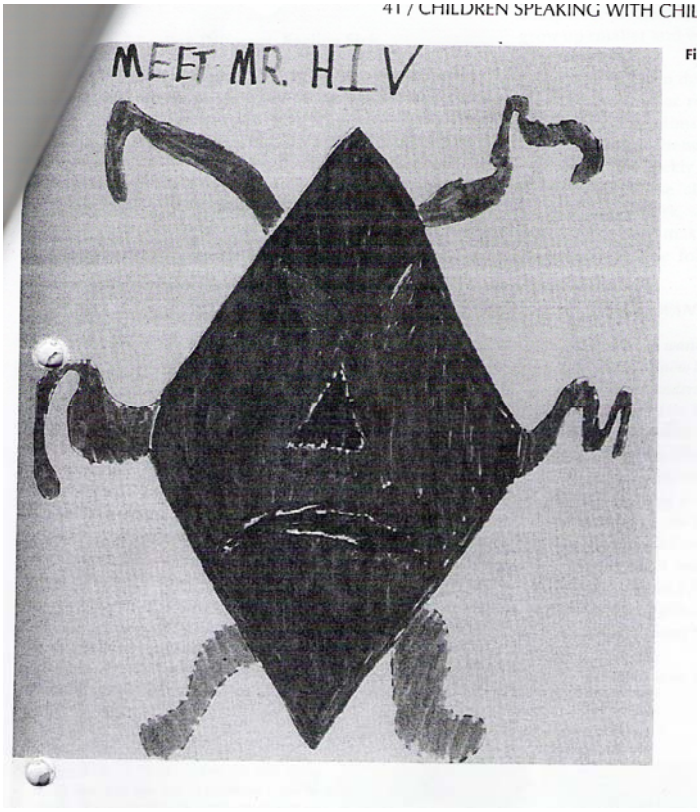
According to Wiener & Figueroa's (1998) analysis of these drawings, the figures drawn depict a sense of impotency and low self-esteem felt by HIV infected children. Furthermore, it is stated that the amount of detail used in depicting HIV/AIDS in the body shows how exposed the children feel, and this is accompanied by feelings of helplessness against HIV/AIDS.

Wiener & Figueroa (1998) suggest that children infected with HIV/AIDS, who have also lost their parents, are at a greater risk for psychological difficulties. They argue that these children tend to struggle with the ways in which they perceive themselves to be different from their peers. One of the factors adding to the children's sense of being different is the disparity in their physical appearance as compared to their healthier peers. This is demonstrated in the drawings above. The next three pictures depict how some of the

participants in the study conducted by Wiener & Figueroa (1998), imagine HIV/AIDS looks like.







Rivlin (1999) argues that as a result of the anxiety surrounding the uncertainty of the implications of HIV positive status, individuals diagnosed with HIV frequently experience psychological distress in the early stage of their infection. Individuals in the asymptomatic phase show the highest level of psychological distress. Furthermore, studies have reported that when one is notified regarding his/her HIV positive status, he/she experiences increased psychological distress (Jackson, 2002). This suggests that caregivers believe that a child who is aware of his or her HIV positive status may experience increased psychological distress as opposed to a child who is not aware of their status and its implications (Mahlobo, 2004). Empirical research is currently unavailable to prove or disprove this.

Research was conducted looking into the perceptions of health care workers on the impact of HIV/AIDS on institutionalised children (Mahlobo, 2004). According to the perceptions of health care professionals working in institutions with HIV infected and non-infected children, institutionalised children do not necessarily experience

psychological difficulties, as they are not aware of their HIV positive status. The caregivers mentioned that many children are unaware of their status because it has not been disclosed to them. The health care professionals pointed out that it is events occurring before institutionalisation and the age at which children are institutionalised that tend to have a greater impact on their psychological well-being and their formation of relationships with their caregivers (Mahlobo, 2004). More research is required in the area of children living with HIV/AIDS.

2.4 Institutionalised Children

As the current study will be investigating how institutionalised children understand HIV/AIDS, it is important to look into how institutionalised children have been understood over the years. Studies of young children in institutions often point to issues around how attachment was managed (Tomlinson, 2000). Lieberman's central argument is that the core problem for institutionalised children is the lack of trust in the reliable availability and protectiveness of the attachment figure(s) within the institutions (Lieberman, 2003). John Bowlby, who formulated attachment theory, defined attachment as the emotional bond between a parent and a child, where the child displays attachment behaviours through which proximity to the attachment figure is sought and maintained (Bornstein & Lamb, 1992; Bowlby, 1969). He proposed that understanding a child's response to the separation or loss of his/her primary caregiver allows one to understand the bond that ties him/her to that figure (Bowlby, 1969). Therefore, attachments develop through the interaction of a child and a consistently present figure, the caregiver (Papalia & Olds, 1998).

Attachment theory assumes that critical variations in the quality of one's early relationship with caregivers shape the formation of mental representations of close relationships later in life (Hook, Watts, & Cockcroft**,** 2002). This means that the nature and quality of attachment relationship formed in early childhood has implications for the nature and quality of relationships formed in later life. Therefore, each child's

development unfolds in response to the environmental influences to which he is exposed (Goldstein, Freud, & Solnit, 1980).

Children who experience emotionally available caregiving generally develop secure attachments, as the caregiver is able to respond positively to the child's signals (Papalia & Olds, 1998). When children develop secure attachments, they have a sense of themselves as competent and worthy of attention and affection. This is then internalised and generally remains for the rest of their lives. In contrast, when caregiving is inadequate, the child is likely to develop deficiencies in feelings about the self and others, and may have negative expectations regarding relationships (Zeanah, Mammen, & Lieberman 1993 in Hook et al, 2002). Therefore, insecure attachments put children at a risk of developing behavioural and social problems, poor self-esteem, and adjustment difficulties, especially when there is no improvement in the subsequent care-giving environment (Hook et al, 2002). For example, a child growing up in an environment lacking emotionally available care-giving due to the illness of parental figures, later experiencing the loss of both parents to HIV/AIDS, may be placed in an institution where the lack of emotionally available care-giving may continue. Such a child may be said to be at risk of developing behavioural and social problems.

In a study conducted by Ruddle (2001), which aimed at exploring the impact of HIV/AIDS on attachment development between HIV infected mothers and their children, it was found that HIV/AIDS does affect attachment development between a mother and her baby. It was said that the infected mother experiences feelings of guilt, anger, denial, anxiety, and stigma. These emotions adversely affected the mother-child relationship (Ruddle, 2001). However, different conclusions have been suggested in other studies, including findings that children are seen as a primary source of joy by their HIV positive parents. Other studies show that after being diagnosed as HIV positive, mothers tend to invest more in their parenting role, becoming more tolerant, involved and nurturing to their babies (Antle et al, 2001; Hutchinson, 1999; Black et al, 1994; in Long 2002).

Bor and Elford (1994) point out that infants who survive, after the loss of their mothers to HIV/AIDS, suffer from maternal deprivation. The loss of a parent may have a damaging psychological impact on a child, especially when the child witnesses the deterioration of the parent as a result of the illness (Jackson, 2002). The negative implications of the loss for a child and his/her development are compounded when the child is living with a seropositive diagnosis (Wiener & Figueroa, 1998).

According to McKay (2002), research has shown that children's emotional, developmental and spiritual needs are better met when they are in smaller, more intimate environments as compared to when they are in large institutions. This suggests that when they are in an 'intimate environment', children are more likely to bond with their primary caregivers and develop secure attachments. In contrast, children in institutions may experience difficulty in developing secure attachment relationships (McKay, 2002). However, not all institutions are lacking in intimacy, although the academic literature seems to suggest the opposite.

In a more recent study whereby attachment patterns in institutionalised South African adolescents were explored, a wide range of themes related to the attachment patterns were highlighted including rejection, abandonment, isolation and deprivation. The results of this study indicated that children who had been separated from their caregivers and placed in an institution because they were abused, neglected or maternally deprived, tended to be insecurely attached (Kats, 2003).

Some of the literature raises strong one sided opinions, as opposed to more balanced arguments, whereby different situations require different solutions. For example, Barnard (2002) states that it is better for children to remain in their homes, rather than be moved to a village or institution, where they will lose touch with their land, relatives, neighbours and the wider community. Furthermore, he argues that community care is more cost effective than institutional care, and can provide care to large numbers of children (Barnard, 2002). This suggestion may be valuable, especially when the number of orphans is increasing daily.

However, other writers have contradictory opinions. D'Agostino (2002) argues that it is more expensive to provide care for children in the community as opposed to an orphanage. Pointing out that although "experts" advocate that children should be returned to the community as opposed to staying in an institution, the community is not able to look after these children well. Furthermore, he argues that while many writers blindly assume that normal psychological development is not possible in an orphanage, this is not true in all cases, especially when children are placed in orphanages in which they are provided with adequate emotional and financial support, and where there is a stable mother figure in their home-like cottages (D'Agostino, 2002). These ideal conditions do not exist across South Africa. As a consequence of the apartheid regime, some areas in South Africa are still underprivileged (Duncan & Rock, 1997). The institutions based in these areas are therefore under-resourced as compared to those that were in areas that were not previously disadvantaged.

Similarly, MacLean (2003) found that with regard to the impact of early deprivation on child development, many studies, but not all, have been consistent in showing the negative impact of institutionalisation on all aspects of children's development (intellectual, physical, behavioural, emotional, and social). However, she argues that although institutionalisation may be presented as a risk factor for child development; it does not doom a child to psychopathology.

Colin (1996) states that one of the most widespread misconceptions about attachment theory is that a child only becomes attached to the primary caregiver. It has been shown that children develop attachments to at least one other familiar figure after the first month of being attached to the primary caregiver. This supports the suggestion that if an individual is available both physically and emotionally to the child, then an attachment bond is likely to develop. Therefore, young children may develop attachments to their caregivers in institutions (Lieberman, 2003).

Although Bowlby's theory of attachment has been useful and applied in many studies, some problems have been identified. Rose (1999) notes that males and females have increasingly become similar in terms of their duties within society, where woman are also expected to work outside their home environment. Individuals speaking from a feminist position have investigated the intense concerns of previous theorists regarding the conceptualisation of the mother-child relationship. Some of the critiques discussed by Rose (1999) include issues such as the binding of women to motherhood and domesticity; the self-interests of theorists as entrepreneurs and professionals; the classification of children from 'bad' backgrounds as pathological; the inability to change 'life-long' influences laid down in childhood; and the failure of parents to impart morality. Furthermore, issues of resilience have not been adequately addressed by the theory of attachment (Rose, 1999). According to the current author, all the above factors may be linked to the nature versus nurture debate, whereby the manner in which individuals form attachment relationships is either influenced by biological or environmental factors. One should bear in mind that attachment may be influenced by an interaction between the two factors. Similarly, institutionalised children's understanding of HIV/AIDS may be informed by an interaction between biological, psychological, and social factors related to HIV/AIDS.

2.5 Children Living with Terminal Illnesses

Although little research has been done on the impact of terminal illness in HIV/AIDS infected children, research on other diseases indicates challenges of children living with terminal illness.

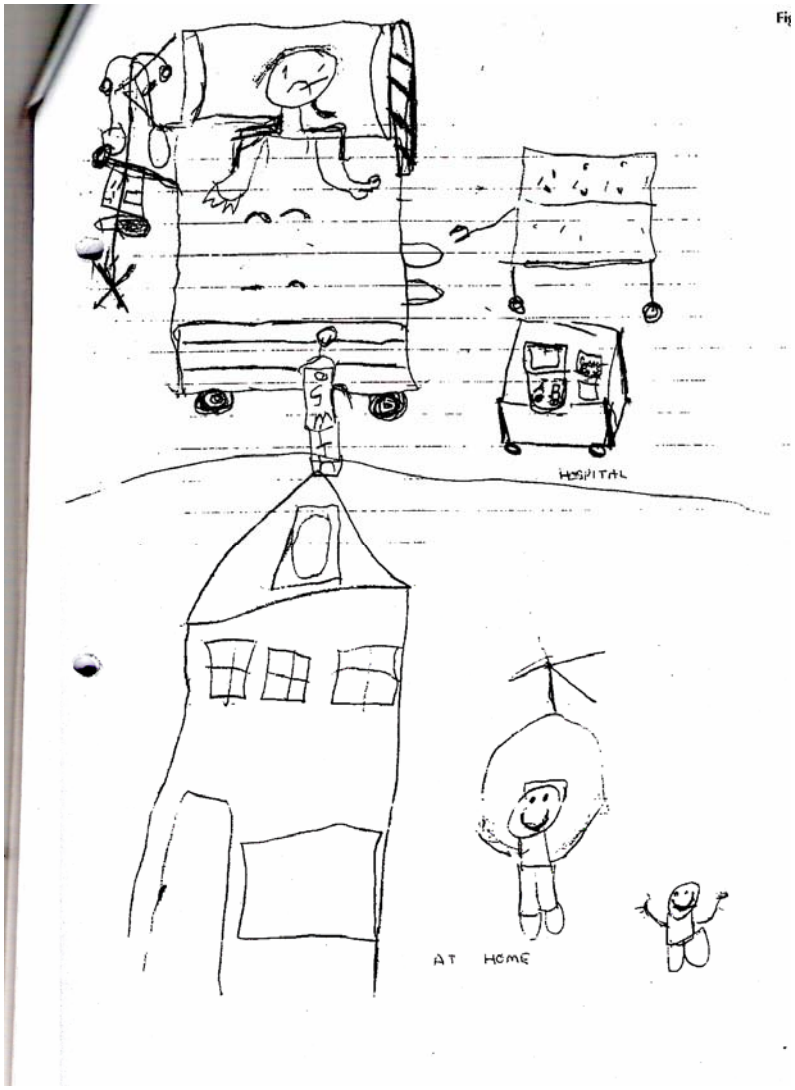
"A child's chronic illness … variable are its daily effects yet ever a threat to the child's survival, a chronic illness is inescapable. For both child and family, it is a perceptual demanding companion; a lifelong associate; a constant shadow" (Hobbs, p.62, 1985).

Examples of chronic illnesses that children may suffer from include muscular dystrophy, spina bifida, congenital heart disease, sickle cell disease, or leukemia. A child with a chronic illness stays a developing individual, needing love and care. However, the recurrent experiences that characterize the child's illness punctuate his life. The repeated medical procedures, accompanied by pain, and boredom or feelings of anxiety, may come with waiting in a clinic or at the hospital. A child may also experience feelings of anger against indifferent medical practitioners, and appreciation for those who give special care. Other recurrent experiences include lying in bed for days until the body heals, relief when the symptoms subside, the fear of death, repeated separation from caregivers and loved ones, and feeling embarrassed about being physically different from other children. Although all children experience such events occasionally, they are more present in the lives of chronically ill children (Hobbs, 1985).

During periods when a chronically ill child is free of symptoms, like any other child, the child seeks to play with other children and participate in activities that other children keep themselves busy with. Invariably, the chronic illness shapes the foundation on which friends are made, and it limits opportunities for making and keeping friends. As an adult reflecting on his childhood with a chronic illness, Covelli (as cited in Hobbs, 1985, p.77) writes that at the age of 10 "my single most persistent feeling then was of separation: other children do not take a needle. I cannot eat the same food they do. I do not feel the same as I did before. I am different".

At different stages in their lives, different children interpret their experiences of living with a chronic illness in different ways. For a toddler, who is always on the go, having a limitless desire to explore his world, illness is seen as an obstacle in the way of play. Furthermore, because of a toddler's egocentric view of causality, he may interpret illness and hospitalisation as events that he caused to happen. Mastery and success become a priority for preschool children. Chronic illness imposes a sense of failure and hinders mastery. A child at this stage may think that the chronic illness is a punishment for something bad he did. On the other hand, a child who is already in school may think that the illness is a result of contamination, and that his health will return if he follows the

doctor's orders (Hobbs, 1985). This child has developed a better understanding of cause and effect. Also, a child at this stage is more likely to notice what makes him different from children without chronic illnesses. Lastly, a chronically ill adolescent may see his body as a continuous source of embarrassment. Furthermore, his physiological limitations may hinder the desire for independence and autonomy (Hobbs, 1985). Regardless of a child's age, the presence of a chronic illness represents destruction to a 'normal' life, especially in relation to the impact of frequent hospital visits. This is a picture drawn by an HIV infected 9 year-old boy, depicting the difference between being sick in hospital and being at home.



(Wiener & Figueroa, p.739, 1998).

In hospital, the figure appears sad and hopeless. While at home, the figure appears happy and free. This implies that it is challenging for terminally ill children to cope with being in hospital, where there are different rules and regulations, and the environment is experienced as different from their homes.

Both in homes and in hospital, great efforts are placed in keeping children with chronic illnesses as well as possible. These efforts contribute to the realistic hope that their lives can be extended, and provide proof that children with chronic illnesses and those around have some measure of control. A child who is given age appropriate explanations of his illness and the importance of treatment or compliance in taking his medication is better able to accept the illness with less frustration or loss of self-esteem. The opposite is true for a child who is not told the truth about his illness and the treatment thereof (Kander, 1983). It may be challenging for families to explain to children about their illnesses.

Families of a terminally ill child face different challenges, financially, emotionally, and socially. In cases where the child becomes the main focus of attention, due to a higher demand for attention, different family members may be affected in different ways. Kander (1983), using a nuclear family to illustrate his point, argues that a mother who is overly concerned about her child may begin to feel indispensable and possessive, especially in connection with the fear of losing her child. Also, she may become more and more isolated, paying less attention to herself and other family members. As the child's father still needs to spend time with his wife, her exclusive attention on the child may make him feel resentful, guilty, and alone. The child's siblings may become jealous of him, feeling rejected and not loved by their mother. However, other families may be able to access support structures enabling them to cope better with the illness of their child.

If the negative circumstances mentioned above are true for a particular family, this negatively affects the ill child. As opposed to living in an atmosphere of unity and love in the home, the child may be getting alienation and bitterness. It can be expected that this

child, who has become the central focus for the whole family, may lose a sense of real security. This child may alienate himself from the affection and companionship of his siblings, and resist the development of a healthy independence (Kander, 1983).

Effects of chronic illness go beyond the family. They extend to the community. For example, children in a community who are not suffering from a chronic illness may refuse to play with the chronically ill child because they think his illness is contagious. This further alienates the child (Hobbs, 1985). On the other hand, the presence of a chronic illness can serve as a platform for educating the community, inspiring those without the burden of managing such an illness. These children, who did not choose to be ill, who are faced with encroaching debilitation, who know what they are going to die from, continue to live day after day as best as they can.

Despite recurrent periods of stress, many families are able to sustain themselves, some finding a greater closeness through standing by each other in difficult times. Many reports on chronic illness in children paint a bleak picture for the children and their families; however, this picture is not always a true representation of their experiences. Many families take the illness in stride, doing what needs to be done and living a life as normal as possible (Hobbs, 1985).

2.6 Children and Death

The subject of the current study, institutionalised children's understanding of HIV/AIDS, inescapably elicits issues related to children and death. It is for this reason that a section reviewing literature on children and death has been included.

Broadly, loss may be defined as a state of being deprived of someone or something that is of great value (Howarth & Leaman, 2001 in Rowling, 2003). This includes a loss of safety, familiarity, the loss of loved ones, and the loss of emotional connections. The death/loss of a significant figure has an impact on a child. It is important to bear in mind

that cognitive, social, and emotional development, all influence a child's understanding of loss and his grief reactions.

The concept of death is multidimensional and some of its aspects are more complicated for children as compared to others. Speece and Brent (in Symons-Bradbury, 2005) reviewed more than one hundred research studies investigating children's understanding of death conducted between 1930 and 1990. This review showed that for one to understand the concept of death in children, there must be an awareness of the complicated nature of death. It is for this reason that several subconcepts of death have been examined in order to understand children's understanding of death. There are four principal subconcepts of death namely universality, irreversibility, non-functionality, and causality (Symons-Bradbury, 2005).

The above concepts may be defined as follows:

Universality: a child faces the challenge of recognising that all living things eventually die, taking into account all-inclusiveness, the unpredictability, and the inevitability of death.

Irreversibility: a child recognises that death is a state from which there is no recovery, once the physical body of a living thing is dead, it can never be alive again.

Non-functionality: a child recognises the final cessation of all bodily functions.

Causality: a child is challenged to understand what it is that can or does bring about death.
(Corr, 1995b; Florian, 1985; Florian & Kravetz, 1985; Naggy, 1948; Speece & Brent, 1991; in Symons-Bradbury, 2005)

At different developmental stages in a child's life, death is understood differently. In South Africa, Symons-Bradbury (2005) conducted research on children's perception of

death from a Piagetian perspective. The participants selected for this study were between 5 to 12 years old. The researcher argued that while a few international studies on this topic already exist, it was important to look into the South African children's perspective.

The findings showed that children have a basic understanding of the death concept around the age of 7. It was also found that children between 5 and 6 have an awareness of death, however, they tend to view it as reversible (Symons-Bradbury, 2005). It was further stated that children's rate and level of engaging with and understanding of the death concept may be impacted by the high death rate as a result of a high HIV infection rate in South Africa (Symons-Bradbury, 2005). More studies explaining how children in the South African context understand death are needed, especially in relation to HIV/AIDS.

2.7 Conclusion

The HIV/AIDS pandemic has drastically increased the number of children growing up without their parents. In addition, some children are infected with the virus themselves. These children are faced with a combination of three factors, they are orphaned, they are HIV/AIDS infected/affected, and they are institutionalised. A majority of the discussed literature paints a bleak picture of the impact of HIV/AIDS on children, together with the impact of institutionalisation. As mentioned at the beginning of the chapter, most of the academic literature tends to focus more towards a gloomy and somewhat hopeless depiction of the impacts of HIV on children, together with the negative impacts of loss, terminal illness and institutionalisation. Some research findings that have been discussed tend to pathologize the children's state. Surely there is more to the experiences of the children. More research that goes beyond the pathology, into the daily lives and understandings of the children's situations, from the perspectives of the children themselves, is necessary.

One of the gaps in literature is how do children understand HIV/AIDS? What sense/meaning have they made out of the pandemic? Currently, there is no study focusing on children's understanding of HIV/AIDS within the South African context. It is pivotal that we begin to close this gap. This research is mainly seen as a foundation, it is exploratory in nature, and thus it may be understood as a step taken towards knowing which areas should be further researched in order to make a difference and contribute to the struggle against HIV/AIDS.

CHAPTER 3

METHOD

This research was conducted using a qualitative design, and it is explorative in nature. Qualitative researchers do not try to draw universal conclusions for all individuals with their findings; they rather try and provide contextual descriptions of the behaviour and development of an individual or a group (Trawick-Smith, 2003). They provide thick descriptions of aspects of research participant's lives. For instance, providing a thick description of how HIV/AIDS is understood by children within the context of an institution.

As stated previously, the method used in this research was informed by a study that was conducted in the United States of America (Wiener & Figueroa, 1998), where the experiences of HIV infected children were explored from the children's perspective. Their study is entitled 'children speaking with children and families about HIV infection'. They produced a collection of thoughts, feelings, fears, anxieties, and images revealed by 35 HIV infected and 11 HIV affected children. This research was conducted during the children's hospital visits. The children kept diaries, drew pictures, and told stories, all in relation to HIV/AIDS. Thereafter, recurrent emotional themes stemming from drawings and stories produced by the children were discussed (Wiener & Figueroa, 1998). Similarly, in the current research, institutionalised children were asked to complete some tasks that are similar to those mentioned above, including drawing pictures, telling stories in relation to their drawings, and completing incomplete sentences. While some tasks were directly related to HIV, others were not. From these,

implicit and explicit understandings of HIV/AIDS, and its relationship to self-concepts and relationships, were looked into.

3.1 Participants

Merriam (2002) states that, in conducting qualitative research, it is best to select participants from which, according to the research topic, the most can be learnt. For example, the topic 'institutionalised children's understanding of HIV/AIDS', seeks first institutionalised children. Secondly, these children must have been exposed to some information on HIV/AIDS in order for them to develop an understanding of the pandemic. Such a group of participants allows the researcher to learn relevant information in relation to the subject of the study. This particular method of involving participants is termed purposive sampling, where participants are not seen as a representative group through whom one may generalise findings, but as spokespersons for the research topic (Henning, 2004).

The institution that was approached for the purpose of this study is a Children's Village situated within a black community in the Vaal area, a township within the Gauteng Province. The name of this institution has been withheld for confidentiality purposes. The management of this institution recognises the need for such a study to be conducted, as they face issues related to HIV/AIDS and would like to be enlightened with some knowledge on how the children understand HIV/AIDS. The manager of the children's village, a qualified social worker, approached children who had been in the institution for more than a year and had been exposed to information on HIV, as there are educated in their schools and in the institution, to participate in this study. She informed them of the procedures and aims of the study, and then invited them to take part. She told the children that participation is voluntary.

12 institutionalised children were approached to become participants in the study, 11 chose to participate in the current study. Detailed and in-depth information was collected from these participants. The children were between 8 and 14 years of age, as most children at this age attend school and are able to express themselves by drawing, telling stories, and answering questions. The above-mentioned age range contributed to the heterogeneity of the study, enriching the qualitative data obtained. These participants were selected in order to explore the children's perception of HIV/AIDS.

20% of the children involved in this study are HIV infected, 40% are affected by HIV (have lost a parent or both parents to HIV/AIDS), and 40% are children who are not directly affected or infected. The sample of participants included infected, affected, and non-affected children so as to obtain a holistic view of their understanding of HIV/AIDS. The researcher decided not to exclude any child from participating based on his/her HIV status, as this would be discriminatory. Heterogeneity is seen as contributing to the richness of data obtained.

The children at the selected institution have a good psychological, social, and physiological support structure within their institution. This placed them in an environment that would able to contain issues that may have risen from this research. Taking into account the confidentiality and sensitivity involved in this study, it is important for the reader to note that the researcher will be vague with regards to information that may identify the participants in this discussion. The omitted information includes each child's historical background, name, handwriting, and HIV status; as such information is likely to compromise confidentiality.

Table 2.

Demographic Description of Participants

Participant	Age	Gender	Pseudonym
P1	13	female	Lindi
P2	13	female	Ntebo
P3	13	female	Thenji
P4	13	female	Nomsa
P5	10	male	Thabo
P6	14	male	Vusi
P7	14	male	Petru
P8	12	male	Lebo
P9	13	male	Thato
P10	10	female	Zaza
P11	9	female	Samu

Note. Total number of female participants was 6, and males were 5.
Average Age was 12.3.

3.2 Procedures

In-depth qualitative data was collected focusing on children's stories and drawings as the primary methods of communication, as these allow a non-threatening and creative approach for children to express themselves. A number of tasks were used in collecting data for the current study. The choice of data collection is motivated by its consistency with obtaining subjective information on each child's understanding of HIV/AIDS. After obtaining permission to carry out the investigation in the selected children's institution, the researcher sat in a private room in the institution with each participant. The children actively engaged in projective techniques, as they were requested to draw some pictures, and to tell stories about those pictures. These techniques included the Draw A Person (DAP), Kinetic Family Drawing (KFD), Draw a picture of someone infected with HIV/AIDS, draw a picture of HIV/AIDS itself, and completing incomplete sentences. These techniques are further discussed in the instruments section.

Data collection methods were conducted in English, Zulu, and Sotho, depending on each participant's preferred language. All participants were not English first language speakers. They did, however, display a good level of English competence and had no problem understanding the researcher's questions and task instructions. While most of the children took less than 60 minutes engaging in drawing and telling stories, including breaks to finish the research tasks, some took close to 80 minutes, but none of them went beyond this time. The children's stories were audio-recorded to ensure that they were not misquoted and that time was allocated to them completing the tasks as opposed to the researcher trying to write everything down. The interviews were transcribed and the tapes will be destroyed after the research report has been submitted and marked. Raw data is currently stored in a safe place. All data have been analysed, and a research report is written and submitted to both the University and the children's institution.

3.3 Instruments

3.3.1 Projective Techniques

The focus of the research is on eliciting information on the children's understanding of HIV/AIDS. Therefore, projective techniques were used as tools to elicit information that is either directly or indirectly related to the children's understanding of HIV/AIDS. The limitations of taking answers to questions at face value were recognised many years ago, as it has been found that people are usually unwilling or unable to provide insight into their own conditions through verbal report (Jahoda, Deutsch, & Cook, 1951). These limitations are more evident when one works with children. To overcome this challenge, projective techniques have been developed. Other advantages of using projective techniques are that minimal language skills are required when creating drawings, both conscious and unconscious may be tapped into, and the essential materials needed are pencils, an eraser, and papers (Cohen & Snerdlik, 2001). Furthermore, there are almost no limitations with regards to one's age, intelligence, or artistic skill (Machover, 1965). These factors make the use of projective techniques relevant within the context of the current study.

Projective techniques are praised for their unexploited cross-cultural utility (Cohen & Snerdlik, 2001). However, closer consideration revealed that there more cultural influence than what was originally believed, as value judgments and orientations differ. For example, in the South African context, it was found that that the Goodenough Draw-A-Man test underestimated the ability of black children (Richter, Griesel, & Wortley, 1989). Therefore, it is important to use the technique with caution, taking into account age and gender, and being cultural sensitive. Establishing the reliability and validity of projective techniques is challenging, given the fluctuating administrative conditions, the frequent complexity of the productions, and the often difficult to prove (or disprove) assumption behind the procedure (Vass, 1999 in Kats, 2003). However, projective techniques yield invaluable information, allowing individuals, especially children, to express their attitudes, needs, and conflicts (ref).

In the current study, projective techniques were not used as assessment tools. The Draw A Person and the Kinetic Family Drawing were used for three main reasons. Firstly, to see if HIV/AIDS would be spontaneously included, and if so, how it would be included. Secondly, to explore possible implicit and explicit themes that may be indirectly related to HIV/AIDS, for example sickness or loss. Lastly, to gain an understanding of the children's general emotional world, which may be of use in understanding tasks more specifically related to HIV/AIDS.

These include the task of drawing a picture or HIV/AIDS, drawing a picture of HIV/AIDS in the body, and completing incomplete sentences in relation to the subject of this study. The drawings allowed the children to express what they would not be able to express in words, looking into how they perceive HIV/AIDS looks like, and what the body of an HIV infected person looks like. The incomplete sentences allow children to express their thoughts in a non-threatening manner.

Draw A Person (DAP)

This is a procedure whereby a child is presented with a paper, pencil and eraser and given the instruction to draw a person. If necessary, it is further explained to the child to draw a whole person, not a cartoon or stick person. Thereafter, the child is asked to draw another person of the opposite gender to the first person drawn (Machover, 1968). The researcher made unobtrusive notes and comments during the drawing process. In addition, after each child had finished drawing, the researcher asked questions about the drawing. This involved asking the child to make up a story about the person drawn, as if the person were a character in a play. The questions were asked to help obtain a better understanding of what the drawing represents to each child. These were adapted from questions compiled by clinicians to elicit more information from an individual regarding his/her drawing. A copy of the questions is attached in appendix V.

The DAP may be used as an intelligence, or an emotional indicator (Cohen & Snerdlik, 2001). For the purposes of the current research, information obtained from this projective task was used as an emotional indicator, reflecting how the children see themselves and exploring whether or not HIV/AIDS features in relation to them. This helped answer the questions, how do they understand themselves in relation to HIV/AIDS, and how do they relate HIV/AIDS to their emotional experience?

The Kinetic Family Drawing (KFD)

The Kinetic Family Drawing (KFD) was designed in 1970 by Burns and Kaufman. Since then, it has been used by psychologists to assess children's perceptions of themselves, their families, and the dynamics of their family interactions. Unlike direct questions, drawings provide a less threatening manner of accessing information regarding the relationships within a child's family. With the KFD, children are given the instruction to draw a picture of their family, with each person doing something (Burns & Kaufman, 1972).

Koppitz (1968) argued that to make a meaningful psychological evaluation of any child, one needs to know how the child perceives his or her family, and his or her place within a family, in addition to the child's background and perception of self. Also, it was hypothesised that a child's feelings related to interpersonal relations and self-concept are better represented in a picture of a family with each member doing something (Burns & Kaufman, 1972). In the DAP, the self may be a manifestation of a layer presented to the outside world, a layer that may differ from a more fundamental self image. In contrast, the KFD is said to reflect an inner self as moulded by the early years of family life (Burns, 1982).

In the current study, the children were each given the instruction "draw a picture of your family, with each person doing something". After completing a drawing, the researcher asked each child to describe the drawing or tell a story about it. This assisted the researcher in analysing the drawings. One must note that although the participants of this

study are institutionalised, they too come from families. The KFD was used to see if a link between families and HIV/AIDS would spontaneously come up, to obtain information on how the children understand the direct/indirect impact of HIV/AIDS on the system of families, and how it impacts on individuals within the families.

Tasks similar to those used in Wiener & Figueroa's research

Drawing of HIV/AIDS

In Wiener and Figueroa's study (1998), children took part in drawing pictures of how the perceive HIV/AIDS looks like. Similarly, in the current study, each child was given a blank A4 page, a pencil, and an eraser and given the instruction to draw a picture of HIV/AIDS. Thereafter, she/he was asked tell a story about the drawing. This task allowed the children to put on paper what they may have not been able to express using words. allowing the researcher to extract information regarding the children's understanding of what HIV/AIDS looks like and some of the emotions that are aroused by their understanding of HIV/AIDS.

Drawing of HIV/AIDS in the body

In this task, each child was asked to draw a picture of HIV/AIDS inside someone's body. It was postulated that this task could reveal information on how the child understands what HIV/AIDS does in a person's body, and also how they understand an HIV infected person's body is affected by the virus.

After the picture had been drawn, the child was asked to complete the following sentences adapted from incomplete sentences.

What I want people to know about HIV/AIDS is_____
HIV/AIDS makes people_____
HIV/AIDS is_____

When I think about HIV_____

HIV makes people feel_____

With all the tasks, follow up questions were asked where necessary. Information relating to the children's understanding of what HIV/AIDS is, what it does, their emotional experiences in relation to HIV/AIDS, and how it affects them as individuals and those around them, arose from the different tasks.

3.4 Data analysis

Data obtained for this study were in the form of drawings and verbatim transcripts. Since the current research is qualitative in nature, data analysis should be compatible. The data was subjected to a thematic content analysis process. According to Kruger & Welman (2001), content analysis may be defined as the systematic examination of the contents of sources in order to record relative frequencies of themes and the ways in which these themes are portrayed. As outlined by Breakwell, Hammond, & Fife-Schaw, (1995), the researcher systematically examines the data, dividing it into discrete sections from which categorical themes emerged.

The process of data analysis was separated into three stages. The first stage involved eliminating material in the raw data that had no link to the research question, and would thus not make any contribution to the focus of this study. At this stage, each interview was summarised, excluding all irrelevant information from the participant's answers, drawings, and stories. The researcher sought to focus only on what is relevant to the current study.

The use of projective techniques in this study requires that the researcher use interpretation in the process of analysing the data. Taking into account that the focus of this study is to elicit information on how institutionalised children understand HIV/AIDS, interpretation of data specifically focuses on what it may elucidate regarding

understandings of HIV/AIDS. The term interpretation refers to the stage in the research process where the researcher tries to 'bring it all together', either by relating the various individual findings to an existing theory or hypothesis, or by formulating a new hypothesis that would best account for the data (Mouton, 1996). Interpretation should be done with great caution, taking into account individual differences and being culturally sensitive. Furthermore, in ensuring that interpretation for each individual case is relevant to that person's circumstances, it is beneficial to look at different drawings individually during interpretation (Mortensen, 1991). Furthermore, Clark (1995) suggests that one should discern patterns or themes from indicators arising from projective techniques in conjunction with collateral information. In the current research, themes that are explicitly or implicitly related to HIV/AIDS were extracted from all the drawings, taking into account each child's background.

In the second stage of data analysis, the researcher went through the selected information again, now grouping each participant's individual responses into conceptual clusters. This means that information focusing on a similar idea was grouped together. Thereafter, similar conceptual clusters from the different participants were grouped together, leading to the categorization and coding of data. The second stage involved going beyond what seemed relevant and moving towards identifying themes.

In the last stage of data analysis, the researcher continued to compare information across the different interviews and drawings. Following this, the frequency and manner in which particular themes are portrayed was identified. Common themes grouped together were given relevant titles. The recurrent themes from all the drawings and stories, that were explicitly or implicitly related to HIV/AIDS, were appropriately categorised and reported in chapter 4 of this research report.

3.5 Ethical considerations

Ethical considerations are fundamental requirements for any research, especially with regards to having human participants. They play a role when the researcher is recruiting

participants, subjecting them to a research procedure, and when the results of the study are obtained and released (Kruger & Welman, 2001). It is unethical for a researcher to undertake a study without the skills and training relevant for the completion of that study. A student psychologist undergoes training in making use of projective tools. The current researcher has undergone this training and is thus well equipped for the purposes of carrying out this study.

All humans are entitled to the right of privacy and being treated with respect regardless of their age, race, gender, and socio-economic status (Leedy, 1997). Garbers (1996) states that in considering ethics, the dominant question is whether the research that is conducted is fair, proper, acceptable, humane, and accountable. To ensure that ethical issues are overcome in this research, the following was done:

5.5.1 Permission

In commencing this study, permission was obtained from the University of Witwatersrand's Human Research Ethics Committee (non medical) for clearance of research involving human subjects. An application form for ethics approval was completed and signed by the researcher, her supervisor, and the head of school. This form was submitted to the ethics committee together with the research proposal. After they had discussed it, the researcher was granted permission to carry out the proposed research.

5.5.2 Consent and Assent

According to Bailey (1987, p. 409) "informed consent essentially entails making the subject fully aware of the purpose of the study, its possible dangers, and the credentials of the researchers". For this purpose, an information sheet containing all the necessary information, was given to the manager of the institution, who is the children's legal guardian. A copy of the information sheet is provided in appendix I. After reading it and obtaining clarity from the researcher where necessary, the manager of the children's institution signed two consent forms. The first was consent to participation, and the second was for permission to audio record. This informed consent form served as assurance that the procedures and aims of the study are understood.

Thereafter, the manager of the institution explained the aims and procedures of the study to the children, inviting them to participate in the study. The researcher further spoke to those children who agreed to take part. The researcher made use of the assent form attached in appendix III to invite the children to participate. Upon agreement, they gave informed assent.

5.5.3 Participating

Participation in this research was voluntary. Participants were not obliged to answer all questions; and they could ask the researcher if they wanted clarity on any question before answering it. On occasions when the children asked for clarity, the researcher provided it. Participants were informed of their right to discontinue the process if they wished. 1 child out of 12 chose to discontinue the process, reducing the number of participants to 11. Furthermore, participants were invited to take one break or more where necessary. Participants were also not deceived regarding the true nature of the study.

5.5.4 Confidentiality

Confidential information obtained from a research participant must be held in strict confidentiality by the researcher. The researcher facilitated all procedures of data collection herself. All confidential information revealed during the research process is kept in a safe place, which is only be accessed by the researcher. In order to ensure confidentiality, the names of the participants have only been made known to the researcher and her supervisor. When writing the results of the study, participants were given pseudonyms. To further ensure confidentiality, the name of the institution is not included in the research report. Also, details such as the individual participant's historical background, and their handwritings, have been excluded from the report, as such information could be used to identify the participants.

5.5.5 Risk or Benefits

Participants were informed that there would be no individual benefits obtained from taking part in the study. Also, none of the participants acquired any financial costs from partaking in the study. Counselling arrangements were made in advance with the

children's social worker to prepare for an event whereby a child would encounter emotional difficulties as a result of this study. Some of the children were referred for counselling after the study as they showed a desire to have someone to talk to about some of the challenges they face, which were not directly related to the subject of the current study.

CHAPTER 4

RESULTS

4.1 Introduction

The following section provides a description of the general findings of this research. These findings will be presented and described in line with the task sheet as provided in appendix IV, using the children's drawings throughout. Firstly, findings from the DAP will be discussed, followed by findings from the drawing of HIV/AIDS. Then, findings from the drawing of HIV in the body will be presented, followed by findings from incomplete sentences, and finally, findings from the kinetic family drawings. In presenting the findings task by task, it is hoped that the reader to get a sense of the process participants went through during the research, and how the results developed. Common themes that arose from each task in the data will be mentioned. These themes will be discussed further in chapter five. It is important to note that in both chapter 4 and chapter 5, the participant pseudonyms as indicated in chapter 3 will be used.

4.2: Findings from the DAP

Most of the information that came up from the DAP was unrelated to the subject of this study, i.e., the children's understanding of HIV/AIDS. For example, children expressed concerns about violence, the importance of keeping their environment clean, and being obedient and pleasing to adults. These factors have more to do with their individual life experiences and their experience of institutionalisation as opposed to their understanding of HIV/AIDS. These issues will be briefly illustrated below but have been largely excluded from the thematic analysis and presentation of research data for the above-mentioned reasons. Some of the findings from the DAP will be illustrated using the children's drawings below.

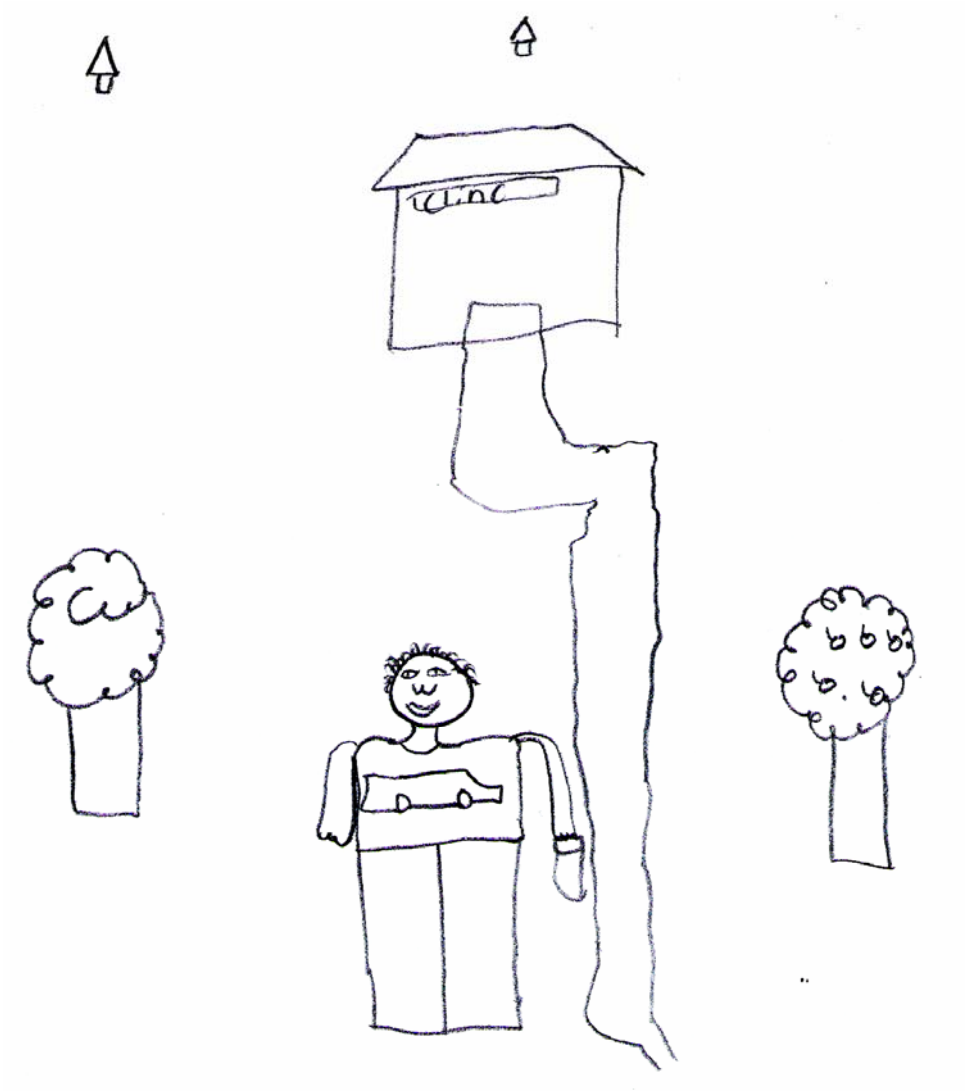


Figure 4.2.1

Figure 4.2.1 above was drawn by a young girl, Nomsa. She drew a sick person who is on his way to get medication from the clinic. In her story about the drawing, she mentioned that the figure drawn has been made ill by his neglectful parents. This suggests that the illness of her drawn person is more related to issues around abuse, neglect, and dysfunctional family life leading to institutionalisation as opposed to illness related to

HIV/AIDS. The drawing illustrates, however, preoccupations with the negative consequences of becoming ill.

Themes that were more explicitly related to the children's understanding of HIV/AIDS were found in relation to the question "When he/she is sick, what does he/she think about?"(See DAP questions in appendix IV). 5 of the 11 participants think of their own deaths when sick. Some of their responses were as follows:

"When he is sick he thinks about, maybe I could just die now" (Thabo)

"Maybe she thinks she'll die or she has AIDS" (Ntebo)

Ntebo's response shows a clear link in her understanding of the relationship between illness and HIV/AIDS, while Thabo's response draws a link between illness and death. These responses may be associated with the children's knowledge of people who died from HIV/AIDS related illnesses and other illness. References to death may be unrelated to HIV but nonetheless reflect a preoccupation with dying. Given the proximity of HIV to the lives of at least some participants, it is striking that a question concerning sickness is easily related to death. These children may feel vulnerable and are afraid that they may die when they get sick. The same child who mentioned in her female DAP that the figure will die or has AIDS when she is ill, also mentioned in her male DAP that he thinks "**that maybe he has TB, AIDS".** For this child, a clear and strong relationship between illness, HIV/AIDS and death is present.

Other children relayed a positive response to being ill, for example, obtaining help from parents and medical practitioners, or reaching out for social support. Some of their responses are as follows:

"She thinks of going to the hospital, to get better and be happy" (Nomsa**)**

"He thinks about the doctor or to tell mom that he's sick and mom will take him to the doctor" (Thato)

These children conveyed a sense of hope for healing, as opposed to hopeless regarding illness.

Another central issue reflected in the DAP concerns the loss of parental figures. For most children, concerns with the loss of a parental figure were evident in response to questions such as "what makes him/her sad? And, if she could go far away, who would she go with?" (see Appendix IV for the full list of questions asked about the DAP). One child answered that what makes her drawn person sad is "**when his parents have passed away".** Most of the children said that if they could go far away, they would choose to go with a parental figure. When Lebo was asked what makes his drawn person scared, he answered, "**When they say her father is dead".** Regarding the worries that this drawn figure has, he said, **"…when the father passed, when he died, she would always think about it"** (Lebo). The loss of parental figures was coupled with a strong desire to reunite with the parents, and fear of dying like the parents. It should be borne in mind that some of the children who took part in this study have lost their parents to AIDS. Themes of parental loss communicate an intense battle to make sense of the loss of parents and of continuing to live without them.

In summary, although most of the information obtained from the DAP was unrelated to the subject of this study, there were some responses displaying implicit and explicit themes related to understanding HIV/AIDS. The main themes extracted include the relationship between illness and death, the relationship between HIV/AIDS and illness, and the loss of parental figures.

4.3: Findings from the drawing of HIV

In this task, the children were asked to draw HIV. Their drawings represent what they perceive or imagine HIV/AIDS may look. These drawings are individually presented and described below.

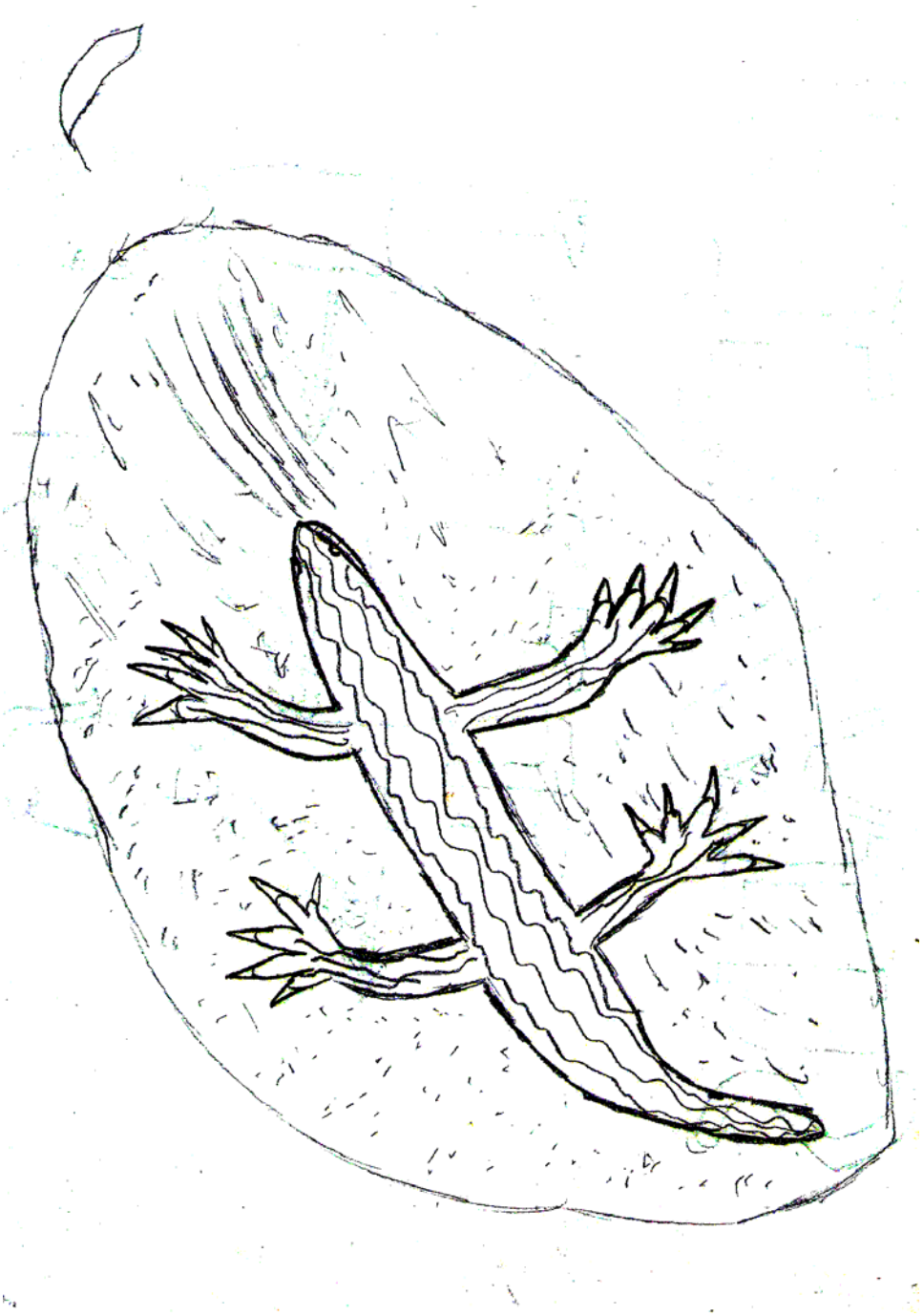


Figure 4.3.1

“ It looks like something that destroys your life…pollutes the area…all over the area. This is a lizard… When I always think of HIV/AIDS in a person’s body…something like this is spreading the virus…then the virus never dies because every 2 or 3 hours the thing spits out the virus and it gets mixed with the blood again.” (Thabo)

Thabo perceives HIV/AIDS as something that has the power to destroy an individual's life. He likens it to a lizard, a cold-blooded reptile. In his drawing, HIV has sharp claws, clenched teeth, it is big, and it seems to have a hard body. The manner in which Thabo presents HIV, suggests that he sees it as something that one should be afraid of, as dangerous and life threatening. According to Thabo, HIV/AIDS frequently releases its venom, which is the virus, inside the body of an HIV positive person. Therefore, the host is continually infected and rendered powerless, as the virus is mixed with blood every 2-3 hours.

In figure 4.3.1 above, HIV has been drawn within borders. This was similar to how other participants in the study drew the HI Virus; this suggests that they perceive HIV as contained in something. 8 out of 11 children drew the virus within borders; perhaps this is related to the children perceiving HIV as an organ that needs a host to survive. The perceived aggressive nature of HIV is illustrated in the venom and the claws in figure 4.3.1. It also comes through in figure 4.3.2 below in the form of sharp knives in the place of hands.



Figure 4.3.2

"**maybe it is a bent person, that has hair… the hands are long …when it is happy, it wants that, it should kill a lot of people. When not happy, it becomes just fine, and sits down and thinks. It is thinking that if I can kill a lot of people, how will I be, yes".** (Thenji)

Thenji has given HIV the characteristics of a human being, but somewhat deformed in that the person is bent and has very long hands. Figure 4.3.2 above shows a strange figure that has no legs, and no pupils. Again HIV/AIDS is portrayed as something one should be scared of. The participant's perception is that HIV is a person who gains happiness from killing others, and only thinks about killing other people.

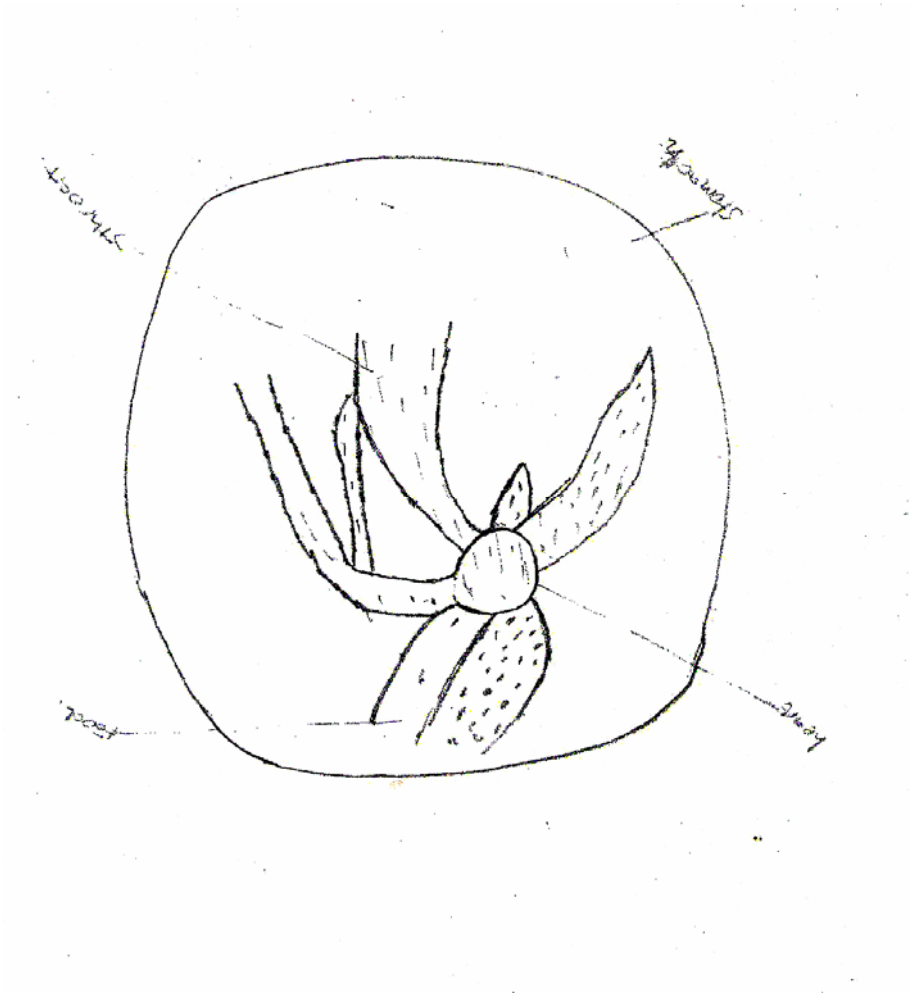


Figure 4.3.3

For Lindi, HIV/AIDS is a figure with tentacles. Some of the drawn tentacles represent feet, while one is the throat. At its centre, the figure has a heart, making it a living being. The child who drew this picture portrays HIV/AIDS as living in the stomach.

This is some of what she said about her drawing: "**This is a circle. Inside, in the small circle, it's where it's full of sores. On the sides it's red blood. Others are different. The other has changed, its like black. It goes like this, but you can't see inside that it is a heart. On this side are intestines, where the food goes in. Here it's the throat, when you cough, you feel that there is something wrong. When you cough, you feel that there is somewhere where it is painful; you can't see where it is painful. When**

you cough, spit that has blood comes out. When you cough you can't eat, food goes back, you wonder why. You eat, it doesn't go in well. Yes, you must go and sleep. And when you are always sleeping like that, the body finishes, the blankets finish you. You become thin when you sleep for a long time, when you have that illness… It always eats healthy food… you give it, but you don't know what is happening in your life…It is just there in life, how it entered, you do not know. How will it come out? You don't know." (Lindi)

For Lindi, it seems that having this virus in one's body comes with great uncertainty. It is a negative and life changing experience. It is also something that is felt but cannot be seen. It also seen as something that causes a lot of pain, and leaves an infected individual with many unanswered questions. Lindi perceives HIV/AIDS as something covered with many sores, and that some of its blood has changed colour from red to black.

The figure Lindi drew has a throat, intestines, feet, and a heart, like a human being. Bearing in mind that HIV infected individuals are encouraged to eat healthy food in order to have strength and live longer, Lindi perceives HIV/AIDS to thrive on healthy food. According to this child, it is not the person who needs the healthy food but the virus itself. While the virus is depicted as having human characteristics, an HIV positive person is portrayed as challenged in carrying out basic human functions like eating and sleeping. The figure representing HIV is seen an entity that makes living difficult, leading to feelings of uncertainty and insecurity.

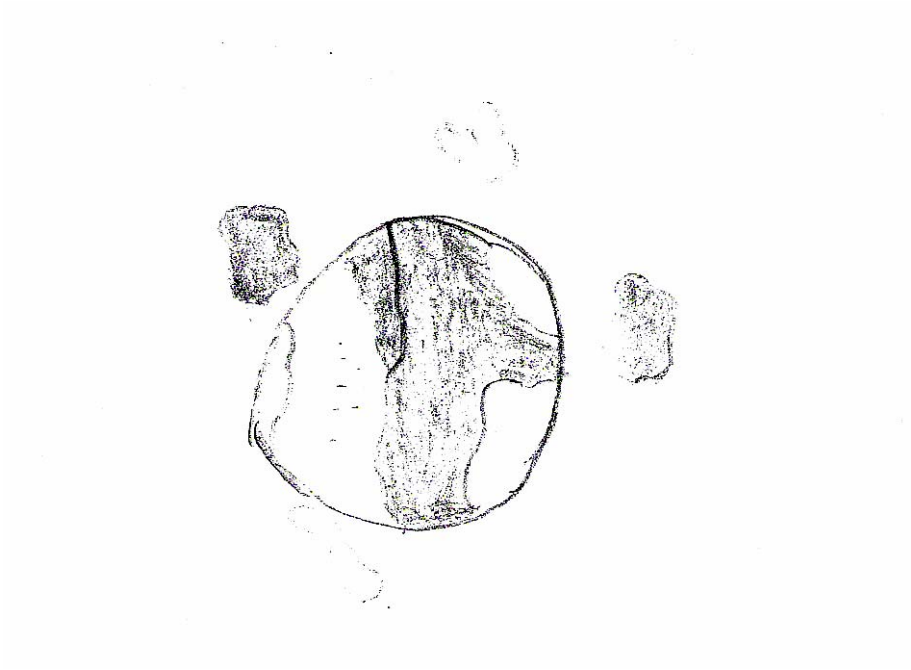


Figure 4.3.4

"…**viruses… when it ruins you everywhere in the body…** i**t starts with these things, then this… I wanted to put a colour purple…"** (Petru)

In some of the children's drawings, the uncertainty about HIV/AIDS, together with confusion about the shape it takes and how it affects an individual, was more apparent. To represent HIV/AIDS, Petru drew a big spot, surrounded by several smaller spots. Pointing at the smaller spots, he explained that is how HIV begins. Then it becomes the bigger spot. HIV is perceived as having the ability to grow, the more it grows, the more it 'ruins' the HIV positive person's body.

Pointing at the darker shaded areas, he mentioned that he wanted to use the colour purple, to show how the blood had become a different and darker colour. Similarly, Lindi spoke of red blood becoming black blood. Figure 4.3.5 below is a representation of HIV as blood with darker shaded areas.

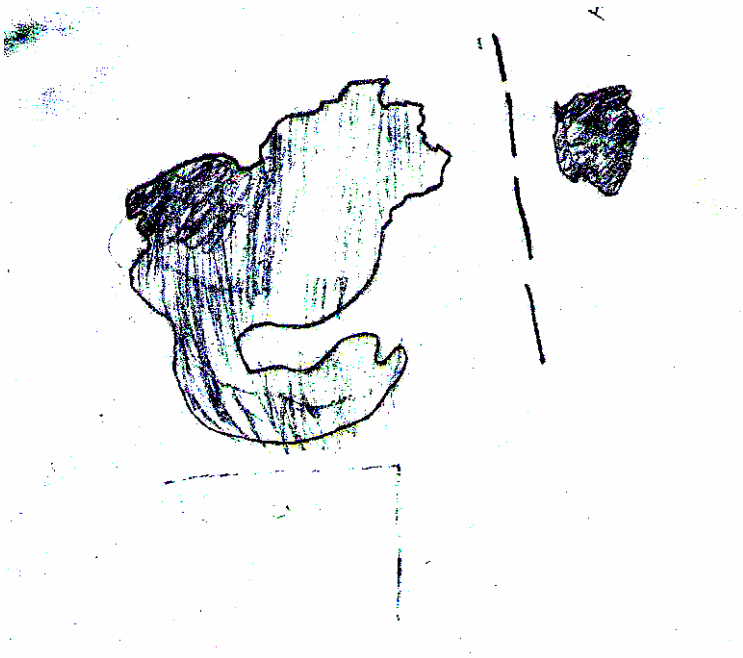


Figure 4.3.5

7 out of 11 children in this study spoke of HIV/AIDS being either contained in blood, or of HIV being like blood. There was a sense of confusion regarding whether HIV becomes a different kind of blood, or whether HIV remains a different entity from blood. In some ways, some of the children understand HIV as blood that has lost its life-giving qualities; blood that has a different and darker colour like black or purple as opposed to the normal red colour of blood. In figure 4.3.5, HIV is again portrayed as blood.

Blood, a fluid essential for the survival of humankind, is seen by some of the participants as the container of the HI virus, the enemy. As Thabo said **"it looks like something that destroys your life. Like something people say pollutes the area. This is the blood, and this is when it takes the virus out. When I always think of HIV/AIDS… in a person's body, the…something like this is spreading the virus. And I feel all the virus is getting mixed up with the person's blood, and then the virus never dies because every 2 or 3 hours the thing spits out the virus and it gets mixed with the blood again**." In other words, Thabo believes that HIV/AIDS destroys a person's life by

polluting his/her blood. Every few hours, the virus is mixed with blood. A sense of powerlessness against the virus is communicated in that blood, flowing in all human beings and essential for survival, is perceived as the tool used by the virus.

In summary, children participating in this study used different shapes to represent their understanding of HIV/AIDS. There was also confusion about what HIV/AIDS actually is and what it may look like. While some children drew from their imagination, others drew pictures based on information seen in the media. For example, one of the participants drew the red ribbon. Other children drew simple geometric shapes, and others drew spots of blood covered with sores. Although it was a challenge for them to put to paper what they think HIV/AIDS looks like, most of them managed to carry out the task. The drawings and common themes will be discussed further in Chapter 5.

4.4: Findings from the drawing of HIV in the body

9 out of 11 children drew infected figures of the same gender as themselves. All male participants drew infected males, and about 33.3 % of the females drew infected males. This resulted in 9 out of 11 of figures drawn being infected males, only two infected female figures. Another participant said, "**sleeping with boys, you must not sleep with them, maybe others have positive**" (Lindi). It seems that children partaking in this study perceive that more males than females are infected with HIV/AIDS. This section presents how children participating in this study perceive the way HIV manifests itself in the body of an HIV infected individual.

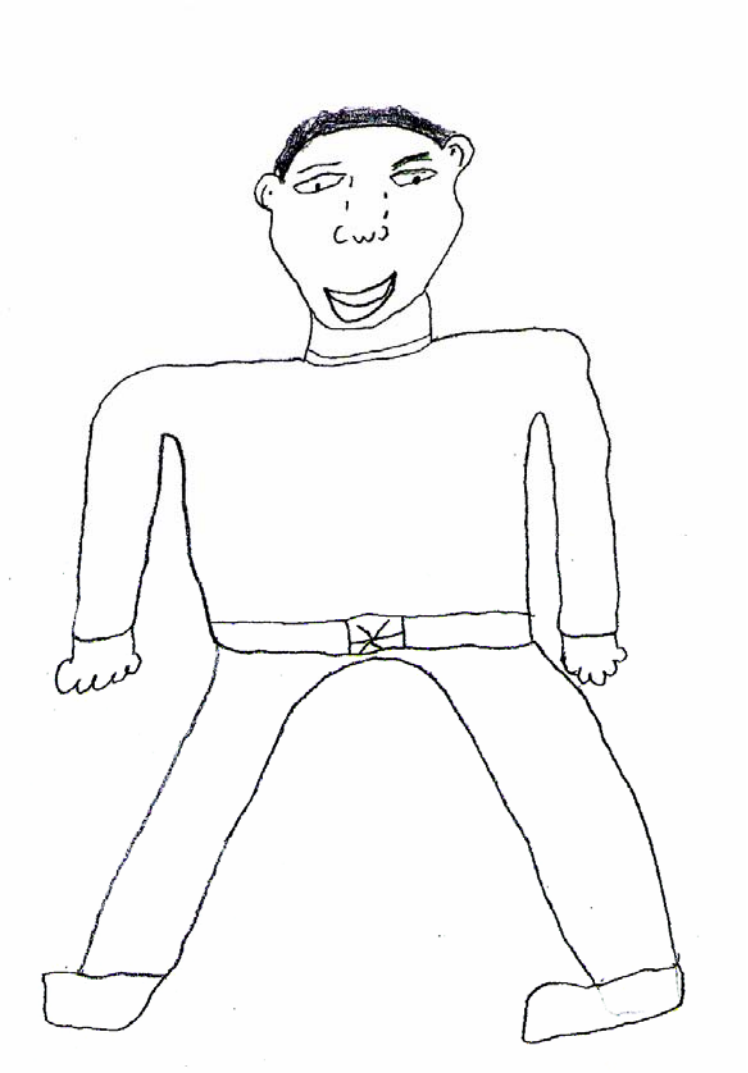


Figure 4.4.1



Figure 4.4.2

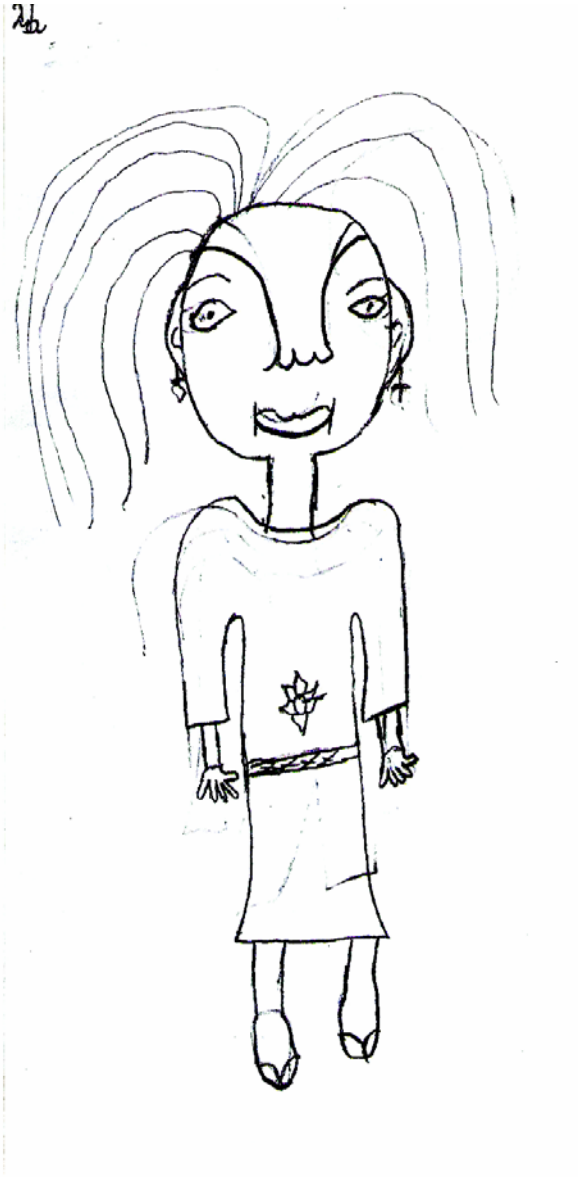


Figure 4.4.3

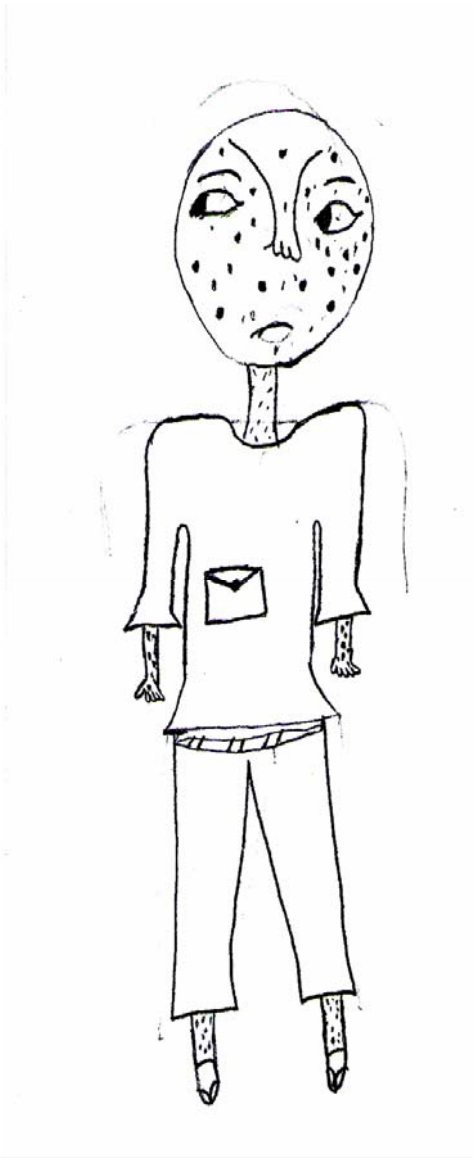


Figure 4.4.4

9 out of 11 participants portrayed observable despair in their drawings of HIV infected individuals. This is illustrated in the drawings of one male and one female participant. The male participant drew figure 4.4.1 as his DAP and figure 4.4.2 as the HIV infected individual. The female participant drew figure 4.4.3 as her DAP and figure 4.4.4 as the HIV infected individual. The differences between the DAP and the HIV infected persons drawings is striking. It depicts a strong sense of one's HIV positive status being visible and obvious to the general public. These figures also seem unhappy, vulnerable, and very ill.

Again, 9 out of 11 children drew individuals whose HIV status was visible to the public, exposing what they are ashamed of. In some drawings the body would be covered but the genitalia remained exposed. In others, the bodies had many sores, in some tears are running down their faces, while others were portrayed to have lost a lot of weight. The physiological symptoms, the stigma, the sexual transmission of the virus, and the difficult emotions that accompany HIV/AIDS are what infected individuals are unable to hide from the public, making their sero-positive status know to all. In comparison to the children's DAP figures, analysis showed that the HIV infected figures presented with feelings of sadness, inferiority, being seen as weak, not fitting in with other children, being judged and being rejected.

A minority of the children raised issues such as immobility, decreased energy levels, rebellion against standard norms, greed, and the importance of eating healthy food, and the impact of an HIV positive status on one's schooling. One of the participants said the following about her drawn HIV infected figure, "**This person, a person of HIV is slender, then then becomes thingy, becomes angry, and when when they say let's go to the clinic, he says no he is not going to the clinic, he wants to stay in the house sleeping everyday, he doesn't sit in front of the TV, always sleeping sleeping sleeping, until a person comes back from school, he is just sleeping. After that, when a person says here's some food, eat. Then he eats a lot of food, and when he finishes, then he thingy, he then goes back to the blankets again to sleep**" (Zaza). Zaza's story displays a negative perception of an HIV positive person. This person is seen as angry, rebellious, and always sleeping. It seems that the HIV positive person is perceived as lacking purpose in life, a figure that just eats and then sleeps.

The participants generally drew unattractive figures to represent HIV infected individuals. This shows the predominance of a negative perception of those infected. The most prominent themes regarding HIV infected individuals were around depression and being exposed. More drawings illustrating this will be displayed and discussed in chapter 5.

4.5: Findings from the Incomplete Sentences

There were a variety of responses to the incomplete sentences. To assist the reader in attaining a sense of how participants responded, their responses have been summarised mainly using the children's own words. While most of these answers are the children's exact words, others are paraphrased for the purpose of fitting into a tabulated format, and also for accessibility for the reader. The numbers in each column represent the number of children having a similar response, for example, 2 mean that 2 of the 11 participants had a response in that particular column.

Table I: summarized answers to incomplete sentences indicating numbers of similar responses

HIV/AIDS makes people	Sick (5)	Feel bad (1)	Sleepy always in house (1)	Thin (3)	Die (2)	Aware of it (1)	Publicly infected (1)			
HIV/AIDS is	A sick (1)	AIDS (2)	HIV positive (1)	A virus (1)	A sin, not right (2)	Disaster, ugly, killer (2)	Human…? (1)	Don't know (2)		
When I think about HIV	My life? (1)	Do I have it? (1)	Fear (1)	Suicide, death (2)	Get infected (1)	No, you can't! (1)	Danger (1)	Not supposed to do (1)	Nothing will happen (1)	Don't know (1)
HIV makes people feel	Bad (4)	Not fine (1)	Hurt (1)	Unsafe (1)	Body pain (4)	Want to infect (1)	Sick when sick (1)			
What I want people to know about HIV/AIDS is	A Virus (1)	It is not ok (1)	Not good (1)	Protect against positive boys (1)	Not sleep (1)	Take care (2)	Kill, fear inducing (2)	Alienation and destruction of life (1)	Don't know (1)	
When someone with HIV is bleeding	Don't touch blood (3)	Don't touch person (1)	Call an adult (4)	Wear gloves (3)	Feel pain (1)	Will infect others (1)	Tell him (1)	Injection (1)	Don't know (1)	
People get HIV through	Blood (3)	Helping (1)	Kissing (1)	Unsafe sex (5)	Touching (1)	Being sick (1)	Disobeying Law (1)	Don't know (1)		

People can protect themselves from getting HIV by	No blood (1)	Gloves (1)	No unsafe sex (5)	Obey instructions (4)	Don't get it (1)					
What would you say if your friend told you that he is HIV positive?	Clinic (3)	Healthy food (2)	Silence (2)	Tell teacher (1)	Ask How, when, why? (3)	Help (1)	Media (1)	Adult (1)	Don't know (1)	

The themes surfacing from the above table include the children's confusion about HIV/AIDS, what it is, what it means, how one contracts it, how HIV progresses to full blown AIDS, and how one can manage it. Only one out of eleven children said that HIV is a virus, most gave responses like HIV is a sin, a disaster, and some said they do not know what HIV is. Further confusion was shown in other responses, for example Lebo completed one sentence saying people can protect themselves from getting HIV by "**going to the clinic, they give, they check them and then they give them medicine, they sit and wait, wait, wait" (**Lebo). The manner in which Lebo responds, together with the content of his response, shows uncertainty and confusion. There was also some confusion about how one may be cured from HIV. Nomsa said People can protect themselves from getting HIV by "**going to the doctor to test, for HIV to finish, they must go to the doctor who will give them pills, and they drink the pills so that it can finish"** (Nomsa). Therefore, according to Nomsa, a person can be healed from HIV by taking some prescribed medication.

The children's understanding of HIV/AIDS seems concrete on the surface; they are able to repeat information from the media, adults, and information from their peers. For example, as shown in table I above, most participants understand that HIV can be transmitted through blood and sexual intercourse. However, there remains a sense of confusion. Other issues that came include stigma around HIV/AIDS, the different lifestyle of one who is infected, a fear for their own lives, and one's immorality being punished through infection. These themes will be elaborated on in chapter 5.

4.6: Findings from the Kinetic Family Drawing (KFD)

Drawing a picture of one's family was difficult for all the participants of this study as they are separated from their families and reside in an institution. The circumstances under which each child was removed from his/her family are unique. Similar to the DAP results; some issues which were brought up in the completion of this task were unrelated to the subject of this study. These issues have been excluded from the discussion of findings, placing focus on themes implicitly or explicitly related to the children's understanding of HIV/AIDS.

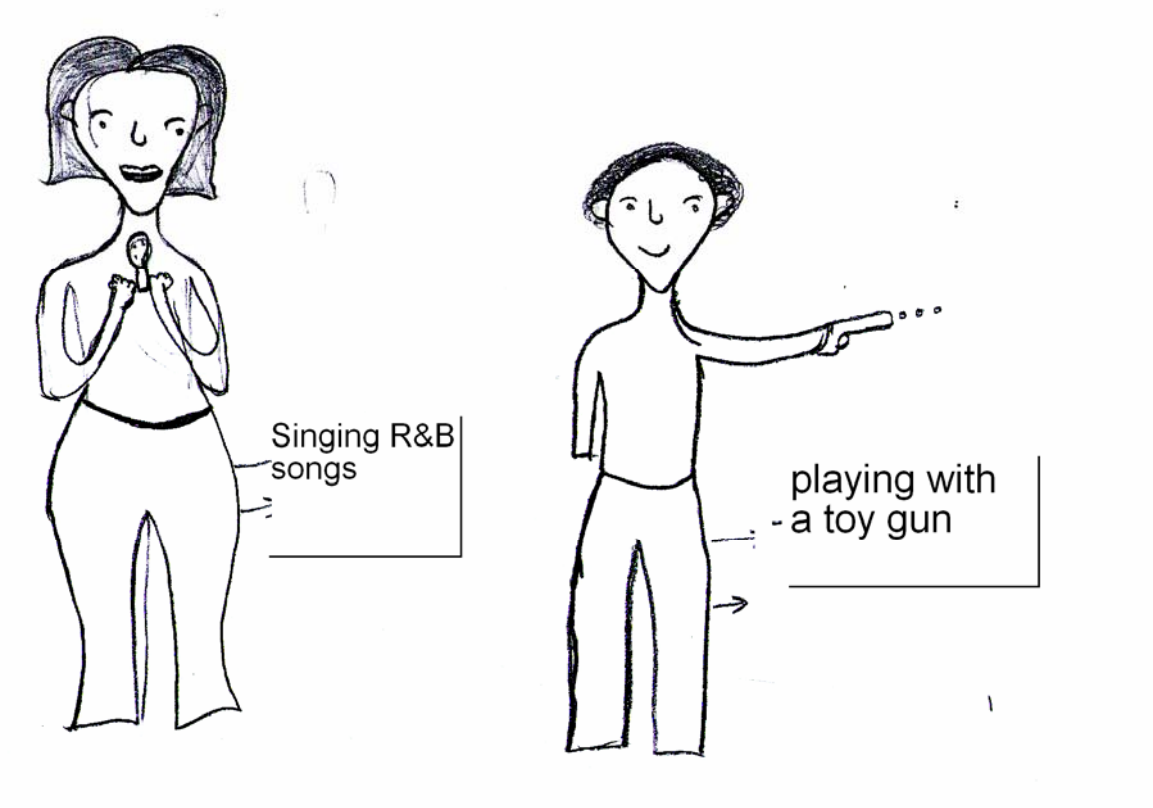


Figure 4.6.1

In the drawings of their families, most children excluded parental figures, and some excluded themselves. In figure 4.6.1 above, the participant drew a sister and brother who live alone in their home. The sister entertains herself with music, while her brother entertains himself by playing with a toy gun. Both figures do not have feet and their hands are inconspicuous. This suggests a sense of being unable to cope in their environment, lacking direction, or that they are not grounded (Burns & Kaufman, 1972). In most of the children's family drawings, concerns around children taking care of themselves due to the absence of parental figures was apparent. It seems that the participants of this research perceive that children who find themselves in such a situation are challenged. In figure 4.6.1 above, one may note that the brother and sister appear isolated, as each of them is occupied with a different activity, and none is available to meet the psychosocial needs of the other.

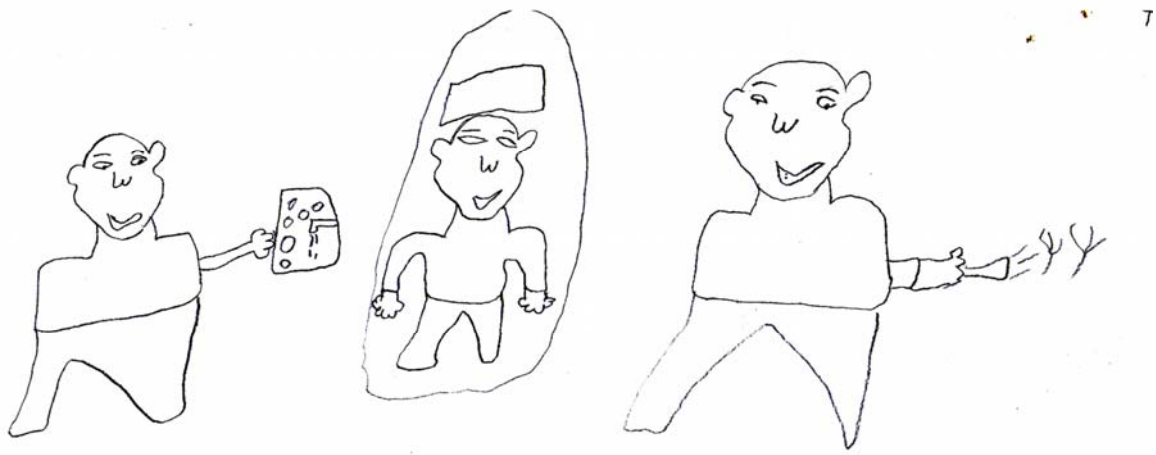


Figure 4.6.2

In contrast, figure 4.5.2 shows the participant included in his KFD together with his parents. He drew himself on the far left, his mother in the middle and his father on the right. The participant drew his mother lying in bed, separated from the family. He is washing dishes and his father is watering the garden. When another child was asked what makes her drawn person sad, she responded "**When her mother is sick and has gone to**

the hospital" (Lebo). In the drawing above, while the mother is sick in bed, the young boy carries out some household duties, different from some participants who drew themselves playing while adults take care of household duties. Such a drawing brings forth some of the issues involved in living with a terminally ill parent: the parent lies ill in bed, while the child assumes a more care-giving role.

In relation to the subject of this study, figure 4.6.1 and figure 4.6.2 highlight issues such as growing up in child headed families, living with a terminally ill parent, and some of the emotional difficulties HIV affected children may face. Other relevant Kinetic Family Drawings are presented in the next chapter, where similar themes arising from the data are discussed.

4.7 Conclusion

In summary, this chapter sought to outline and introduce the reader to the broad findings of this study, using some of the children's drawings to communicate their understanding of HIV/AIDS. These drawings are a powerful communication tool, eliciting different emotional responses and thoughts in the reader, giving a sense of how institutionalised children partaking in the current study understand HIV/AIDS. A wide variety of issues arose from the findings, including the children's understanding of HIV/AIDS in relation to death, relationships (both social and familial), and body image. There was also a sense of confusion about HIV/AIDS, together with different emotional responses such as feelings of fear and vulnerability. In the next chapter, common themes that were extracted from the research findings will be discussed, through presentation of the children's drawings and interview data.

CHAPTER 5

Common Themes

In this chapter, the common themes that came from this study will be presented, articulating the children's understanding of HIV/AIDS as depicted by their drawings and responses during the interviews. There are six major themes. The first theme is on the visibility of HIV infection, which looks at how HIV infected individuals are portrayed as being exposed or visibly infected. The second theme is the impact of HIV on relationships; this section draws on the respondents' understanding of how HIV affects relationships. The third theme is on HIV changing lives; here the manner in which participants' portrayed HIV as changing the lives of those infected is discussed. The fourth theme is on preoccupation with death and dying; which deals with the children's awareness of some issues around death. The fifth theme, confusion about HIV/AIDS, draws on the respondents' statements and drawings showing confusion about HIV/AIDS. Lastly, a theme on HIV and Morality is discussed, looking into some of the portrayed moral implications of HIV.

5.1 The Visibility of HIV Infection

A dominant theme emerging from children's perception of HIV concerns portrayals of HIV infection as being highly visible. Portrayals of infected people often include themes of being exposed to, and identifiable by, the public, and of not having the strength to prevent such exposure. The visibility of HIV/AIDS in an infected person's body came out powerfully in their drawings.



Figure 5.1.1

The above is a picture of an HIV infected woman. She has no feet and no hands, her bones are exposed and she has sores all over her body. Her face appears disfigured, and this is emphasised by the uneven placement of her eyes. Transparency is apparent in that while this figure is dressed, we can still see through her clothes (figure 5.1.1).

Another child explained, **“A person who has AIDS starts with having sores. When these sores appear, he becomes thin. Then his bones end up visible you see? And people find him disgusting. Like they don’t want to sit with him, they don’t want to play with him”** (Ntebo).

According to Ntebo, when an individual is identified as HIV positive through sores and loss of weight, rejection is experienced, as those around the infected person choose not to associate themselves with him Another participant said **“And when she** (a child) **is sick like that, she must always be in the house, but play with other children and not tell them that she is positive because they will tease her about it, and say this one I don’t want, she is not my friend, who is like this? She is positive, she will infect me.”** According to this child’s understanding, should a child’s HIV positive status be known by her peers, she is likely to be sidelined by the others children. Although she may desire to play with them, they are likely to reject her in disgust and in fear that they may become infected.

For all the participants of this study, the exposure of one’s HIV status through the presentation of the body was apparent.



Figure 5.1.2

“When you have thing, HIV, you have sores, he loses hair, he becomes sick, and then he dies” (Lebo)

Lebo’s perception of infected individuals is that they lose weight; they experience hair loss, and have sores all over the bodies. Furthermore, Lebo’s drawing of an HIV infected individual is smaller in stature in comparison to the figure first drawn, i.e., DAP figure. This was found in other drawings as well, where the DAP figures appeared bigger than HIV infected figures. In addition, some of the HIV infected figures were drawn without hands, accentuating the portrayed powerlessness.

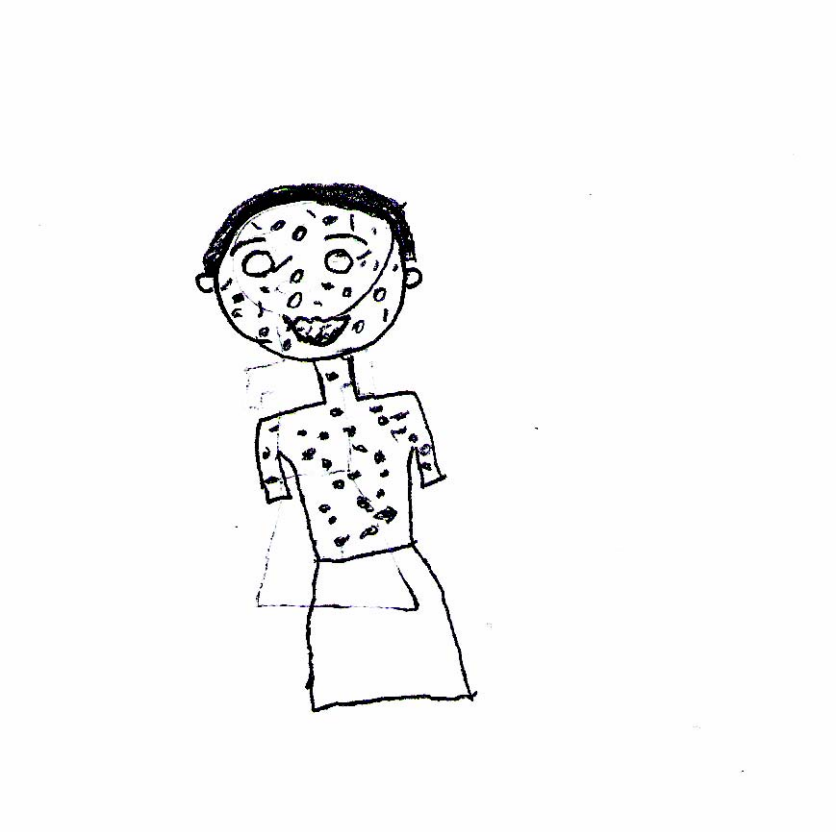


Figure 5.1.3

“This person has AIDS. He is having a lot of sores and scratches you see? Can’t walk or eat, yes, they force her to eat even at the hospital. No, she can’t, and on her face, it’s a lot of sores, you see? They have pus coming out…her mouth is wrinkled” (Thenji).

The child who drew figure 5.1.3 above portrays the body of an HIV positive individual as covered with sores and scratches. This figure has no hands, no feet, and no pupils. This figure also cannot walk or eat. For the child who drew this figure, an HIV infected person is depicted as one who has lost the ability to do what most healthy people are able to do, like walking and eating. Furthermore, drastic changes in appearance are seen as characterising an individual infected with HIV/AIDS.

Another child said the following regarding an HIV infected individual "**… people find him disgusting. Like they don't want to sit with him, they don't want to play with him"** (Ntebo).

According to this participant, HIV infected individuals are portrayed as disgusting or repulsive. Those who are non-infected would not want to associate themselves with such a person, perhaps due to fear that they may also become infected. This child assumes judgement and repulsion by others towards HIV infected people.

Similar to figure 5.1.2, some of the children drew HIV infected people with their eyes looking over their shoulders, as if embarrassed and ashamed of people knowing their status, and what people may be saying about them behind their backs. This reflects the stigma that comes with a known HIV positive status. When one of the children was asked, "what would you do if your friend told you he had HIV?" He responded by saying "**I wouldn't tell people, I would keep, hold it in me only**"(Thato). This statement displays the continued silence around HIV/AIDS.

Regarding her drawing of an HIV infected boy, one young girl said **"…he wants to kill himself…Because he is infected with HIV, and people are busy, HIV, they write HIV in the toilet…they told him to tell his parents at the hospital, he doesn't want to…because his parents won't want him, they will chase him away**" (Samu). This participant perceives an infected child as rejected and suicidal. Even though the drawn figure was advised to disclose the HIV positive status to the family, the figure chooses not to do so in fear of rejection. The figure would rather commit suicide than experience the rejection and continue to be ridiculed by other children who spread the news of his HIV positive status by writing it in toilets for others to see.

HIV infected persons are generally perceived by most participants of this study as different from others. In addition to being seen as different based on their physical appearance, some of the children believe that HIV infected individuals also feel that they are different, for example, because they are not allowed to eat the same foods as other

children. One child explained, "**you will always eat healthy food, not oil or achar, you don't eat things with too much sugar, you must eat healthy food only"** (Lindi).

Other participants spoke of the possibility of being infected by another HIV positive person as high. When Vusi was asked how HIV makes people feel, he replied, "***to feel that they have HIV, they want to infect others"*** (Vusi). Intense fear of HIV infected persons is likely to be promoted, influencing others to feel safer with being as far away as possible from one who is infected. Vusi perceives infected individuals as aiming to infect others, not wanting to be the only one infected with HIV. Children's understandings of how HIV manifests itself and affect those infected filter into how they relate with one another.

5.2 The impact of HIV on relationships



Figure 5.2.1

“I’m trying to show how you can get HIV from two friends. These 3 are friends, they got a cut and they didn’t put gloves on. The next one went for a test and also had it. So here I’m trying to say that you can get AIDS from a friend. It takes good friends, like me and my friend that even if he’s so hurt I’ll want to help him” (Thabo).

In the drawing, Thabo portrays HIV/AIDS as an arrow moving from one friend to another. This arrow moves from the stomach into the back of another, then out through the stomach again and into the back, and out through the genital with the last one. The first two figures are males, and the last is a female figure.

The above drawing and comments are a representation of how HIV has become an important factor in the children’s friendships. There is insecurity about touching and helping a friend who is hurt, in fear of becoming infected. What one should sacrifice for another friend is questioned, this may bring some limitations to how the drawn friends interact and play. It is interesting that in his comments about the drawing, Thabo implies that it takes good friends to infect each other with HIV, and that one friend would sacrifice his own health for the benefit of the other.



Figure 5.2.2

"These are two best friends, and this one is the big one, this one is the small one, he is the one who is HIV/AIDS, so this one is always worried about who likes him. Everyone now knows that he is HIV/AIDS. So now he is always, he always likes to make him feel nice and he makes him feel comfortable, like there is someone who likes me, feel like, there is someone who I am special to, that someone is special to me also, and he knows that I can always count on him when my heart is sore." (Thabo)

The child who drew figure 5.2.2 above first drew a boy on the bottom-left side of the page. This figure was sad and crying. He then erased this figure and drew two figures on the middle of the page. On the left stands the HIV infected figure, and on the right the HIV non-infected boy. The infected figure is smaller. It seems that Thabo perceives the infected figure as weaker and with a low self-esteem. On the other hand, his friend, the non-infected figure, appears to be playing the role of a saviour and comforter, from whom strength is drawn. The figures drawn are touching each other, as if reaching out for comfort.

The friend is described using positive words; it appears that he is more responsible for providing comfort in the friendship. It appears that it is important for the HIV negative friend to remain the strong and reliable one in the friendship as a constant figure of support within a judgmental environment. The HIV positive figure is worried about not being liked, highlighting issues around stigma, judgment, rejection, not belonging, and being different. The HIV negative friend is supportive and accepting. The friend makes him feel loved, special, and accepted.

When the respondent was asked where HIV is in the body of the HIV infected figure, he drew the genital area, saying this was where HIV/AIDS was situated. To this child, the genitalia represent a place where HIV resides in the body. This could be informed by the participant's knowledge of sexual transmission of HIV/AIDS.

After drawing a picture of an HIV infected individual, one of the participants, Nomsa, mentioned that "**Here, this person liked touching people's blood, he liked touching people's blood. If a friend, a small thief you see? Hit him with a fist here or on the nose I don't know, and he bleeds, and comes and does this with the hand, then the blood touches the thingy, he will be infected with HIV/AIDS"** (Nomsa). This participant also mentioned that her drawn figure "**likes saving her friends, helping them, that is why she is infected with HIV/AIDS. She likes helping them, eating with them…"** (Nomsa)**.**

Nomsa speaks of someone who became HIV positive through touching and helping people. She mentions ‘a friend’ and then changes to ‘a thief’. This may point to a conflict regarding the issue of possibly infected by a friend. It makes more sense for one to be infected as a result of a crime against him as opposed to being infected within the friendship, as a friend would not intentionally infect another. Apart from the impact of HIV within a friendship, other children spoke of the impact of HIV on relationships in general, where the HIV infected figure is alienated.

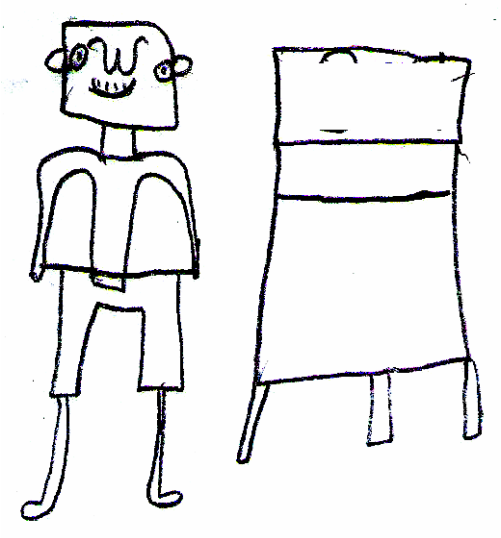


Figure 5.2.3

Figure 5.2.3 above shows an HIV infected individual who spends his time in bed. As opposed to relating to others, be it friends or family members, the drawn figure is alone in bed at most times. Another child said HIV/AIDS makes people "**to be, to be sick…always sleeping, always staying in the house"** (Samu). Similarly, other respondents portrayed HIV positive figures as isolated from relationships and activities they would have been normally engaging in, as they spend time sleeping as opposed to interacting with others. In this way, the virus is seen as limiting social interaction.

While most participants spoke of the impact of HIV on plutonic relationships, others referred to the impact of HIV on love relationships. One participant said "…**now where did I get this positive because…then she remembers that sleeping with boys, you must not sleep with them, maybe others have positive, now they infect me, now I am sick**" (Lindi). In considering sexual activity in a relationship, Lindi shows concern about the possibility of being infected with HIV. Generally, most participants perceive HIV as negatively affecting relationships.

5.3 HIV/AIDS Changing Lives



Figure 5.3.1

"Here, this person liked touching people's blood. She didn't have a house, you see it is raining and she has nowhere to go. All the people are gone, they have gone to their houses. She is the only one, she is left alone" (Nomsa).

The picture drawn by Nomsa demonstrates how the life of the figure drawn has been destroyed by HIV/AIDS. The HIV status has affected the economic status of this figure, who is now homeless. Nomsa illustrates that the figure is alone in the rain, alienated, does not have shelter, is exposed to the cold and rain, is ill and coughing, and no one is willing to help. The drawn figure is said to be suffering as a result of touching other people's blood, through which HIV was contracted.

Another child drew a picture of how he imagines HIV/AIDS looks like.

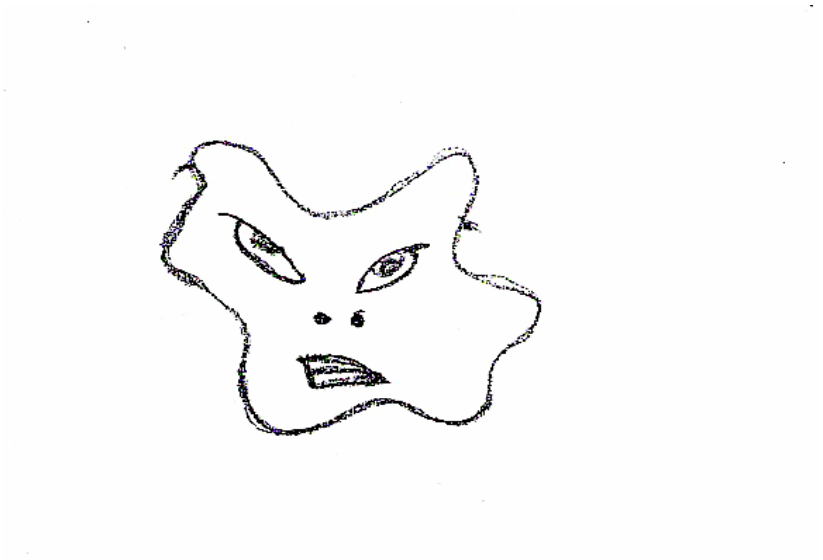


Figure 5.3.2

Figure 5.3.1 above was drawn by Thato. Thato could not tell a story about this drawing, however, he said it is a male and that it is ugly. Thato perceives HIV as something ugly. As shown in figure 5.3.3. below, HIV is also perceived as something that makes infected people ugly.



Figure 5.3.3

“This person has pimples, he even has sores in the mouth… he is not fine” (Petru).

Figure 5.3.3 shows the devastating results of being infected with HIV/AIDS on one’s appearance. The face drawn by Petru shows how an infected person’s face becomes covered with pimples and sores, one’s image is changed by HIV/AIDS. The drawn figure appears sad and hopeless, as HIV has changed his physical appearance, making the presence of the virus within the body clearly visible.

5.4 Preoccupation with Death and Dying

Themes of death were expressed by all of the respondents, both explicitly and implicitly. While some of the children spoke of their own death, others spoke of the loss of parental figures.

With regards to children thinking about their own deaths, it was striking that for some of them, the link between illness and death is strong. For example, when Thabo was asked what his drawn person (DAP) thinks about when he is sick, he answered **"When he is sick he thinks about, maybe I could just die now"** (Thabo). Another child said when sick, her drawn person "…**thinks, am I going to continue living or am I going to die?**" (Lindi). Ntebo said that when her drawn person is sick, she thinks **"…she'll die or she has AIDS**" and that her male drawn person thinks "**that maybe he has TB, AIDS**". Ntebo also said that when her drawn person is sad, **"…He thinks of many things when sad, like he could kill himself**".

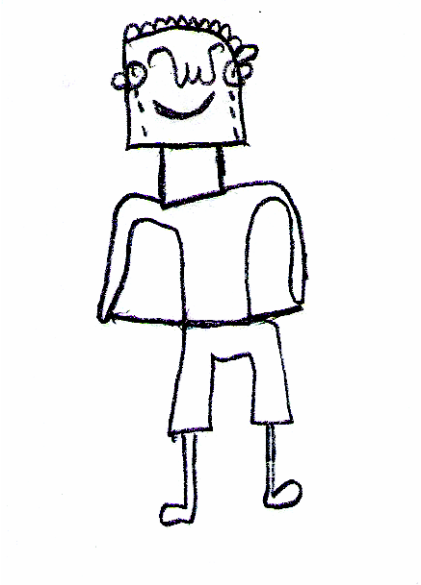


Figure 5.4.1

"He is crying because he doesn't know why HIV got into him. It is a rope, he wants to kill himself…because he is infected with HIV, and people are busy, HIV, they write HIV in the toilet…" (Samu).

According to Samu, figure 5.4.1 is carrying a rope with which he wants to kill himself because of his HIV positive status and others teasing him about it. Therefore, this figure chooses death as opposed to life with the illness. Another child mentioned that when she thinks about HIV, "…**I think about, what about my life… Like, if, like, it makes you think if I have HIV, if I have HIV/AIDS, or if I had HIV/AIDS, what was gonna happen to my life? What was I gonna do**?" (Lindi). It seems that issues around infection with HIV bring about doubt regarding one's purpose in life. In completing the incomplete sentences, Thenji mentioned that when she thinks about HIV "...**I think that I'll also die".** It appears that there is a link between HIV and death, as HIV/AIDS makes people "**to become thin, sick, and even die"** (Ntebo)**.**

Apart from the children thinking of their own deaths, preoccupations with the death of parental figures was also apparent. When Lebo was asked what worries his drawn figure (DAP) has, he answered "**He worries that his father will die, what will he do?" (**Lebo)**.** As a result of parental loss, many children drew Kinetic Family Drawings without parental figures. These were representations of children in families without parental figures, as illustrated in figure 5.4.2 below.

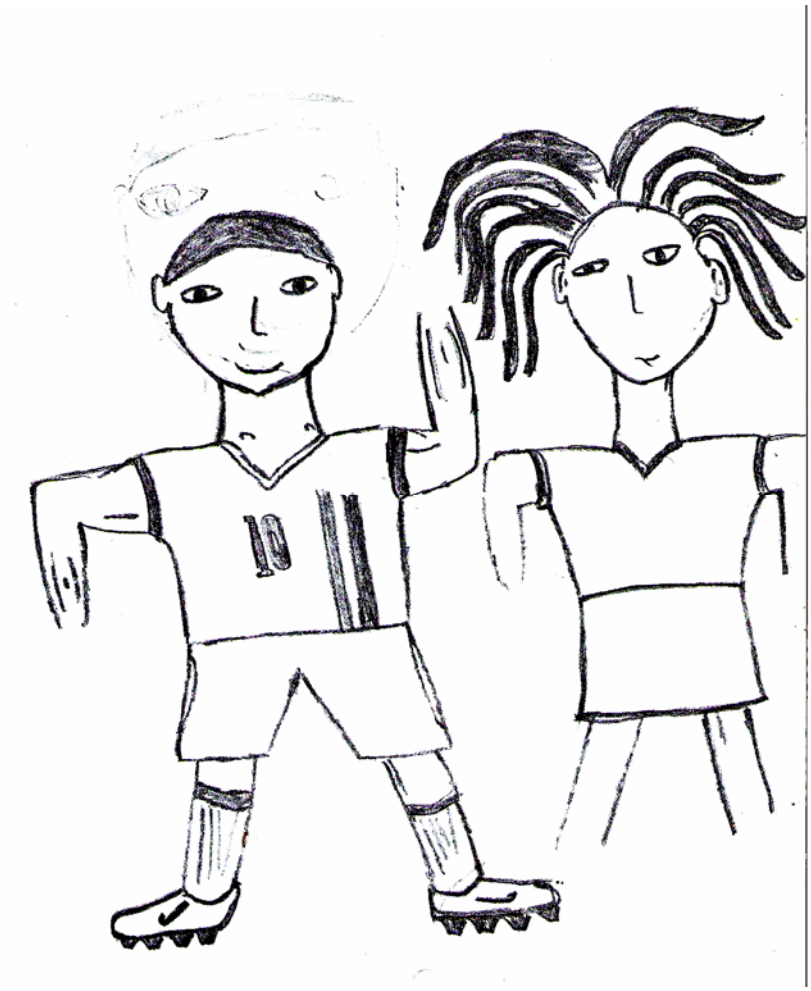


Figure 5.4.2

This picture shows a family made up of children only, the brother and sister only have each other to rely on. The figures drawn have no hands, perhaps indicating feelings of being unable to manipulate their environment. Perhaps some of the children perceive HIV affected children as vulnerable after the loss of parental figures.

5.5 Confusion about HIV/AIDS

It was challenging for the children participating in this study to express their understandings of HIV/AIDS. One should bear in mind that some of the participants of this study have probably never thought about how the HI Virus looks like, and they may have never seen it. There where points during the process of data collection where the participants would get stuck, they would not know how to respond or what to draw. At times, they admitted that they did not know, and at other times, they would make something up. In completing the incomplete sentence: "HIV/AIDS is …" Zaza paused for a while with confusion on her face, and then she responded "**I don't know"** (Zaza). Before producing a picture of HIV/AIDS, another child paused also with confusion on his face; thereafter he produced the figure 5.5.1 below.

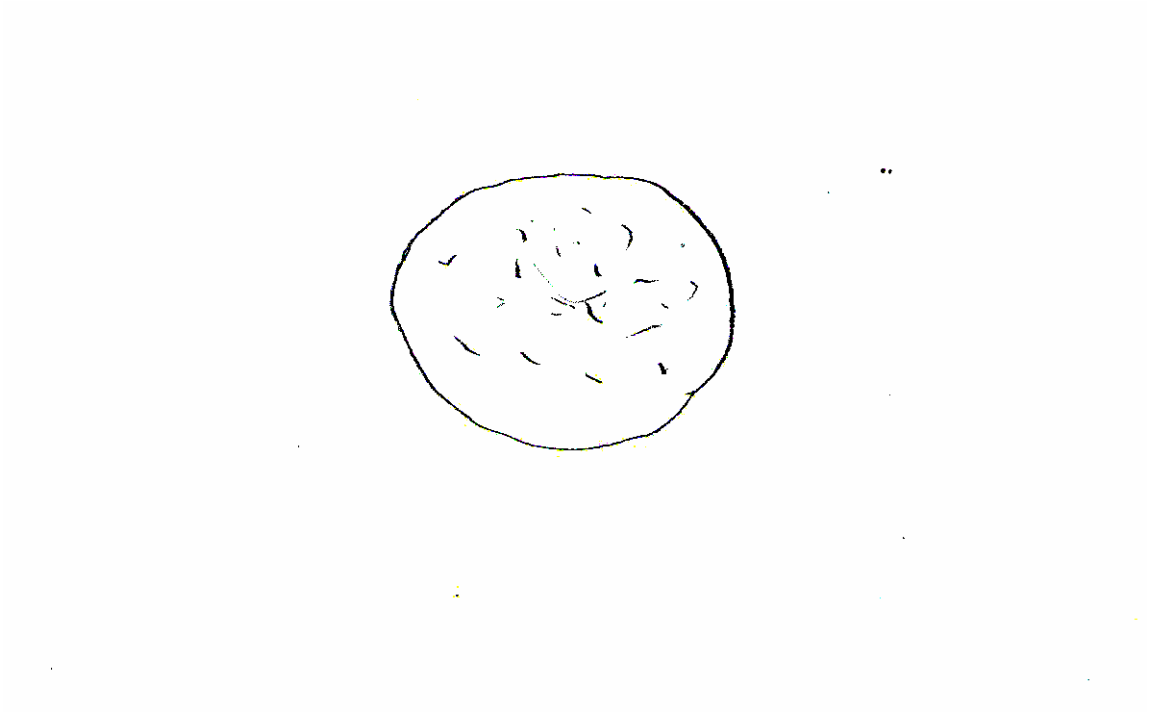


Figure 5.5.1

"… HIV, I believe it is like this… Here, it is the things of HIV only… It's HIV…It's only HIV" (Lebo).

Upon enquiry on his drawing of HIV, Lebo was unable to give a clear explanation, displaying difficulty in making sense of what HIV actually is. Finally, he said "**it's only HIV**" (Lebo). In his struggle to explain what he understands HIV to be, he became confused, and then resorted to simply stating that it is HIV.



Figure 5.5.2

"HIV haena matsho
HIV haena mahlo
HIV haena ma manto"
(Nomsa)

In English, the words in figure 5.5.2 above mean:

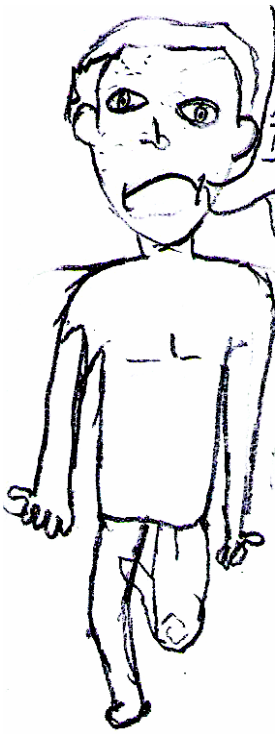
HIV does not have hands
HIV does not have eyes
HIV does not have feet

The participant further explained that "**This is blood. It's blood you see? It's this circle to…like this. I don't know how it is. Isn't it they show it on TV? They say, they ask ehm, when people are in a car, then they kiss you see? Then others touch people's blood, others … you were going out with him now you are not, he made you pregnant you see? Now they went into the school and called him and said Tshepo Mahlaku. Thingy, that Tshepo gave that paper and spoke to his male friend and**

said, why did you leave her? And he said 'if I was protecting her, I would, I would love her' you see?". (Nomsa)

Nomsa started by stating what HIV does not have, and how it is different from human beings. It seems as if while she was doing this, she was attempting to make sense of HIV and how she could best explain how she understands it. She then mentioned that it blood, seeking reassurance from the researcher by asking some questions as she continued to talk about her drawing. Then she decided to explain how she understands HIV by using information she obtained from an advertisement she saw on television. The manner in which she did this was somewhat fragmented. Again, a sense of confusion about what HIV is came through.

Figure 5.5.3



"***I am HIV & AIDS. I want somebody who can help me. I will go to the doctor, and my name is Tabo I live with my mom***"
(Vusi)

Regarding his drawings, Vusi writes, "**I am HIV & AIDS**". This suggests that when one is infected with HIV/AIDS, it becomes difficult to separate one's personal identity from

HIV/AIDS. It seems as if the person himself becomes HIV/AIDS. Similarly, a young girl who drew HIV having different body parts, including a throat mentioned that "**here it's the throat, when you cough, you feel that there is something wrong…you feel that there is somewhere where it is painful…'** (Lindi). The manner in which she expressed this suggested there was some confusion as to whether HIV was feeling pain on its throat or the human being was feeling the pain. Again there was some difficulty in separating the infected human being from the virus itself.

In addition to confusion about separating HIV from the infected individual, other children were confused about the shape of HIV and how it affects an individual.

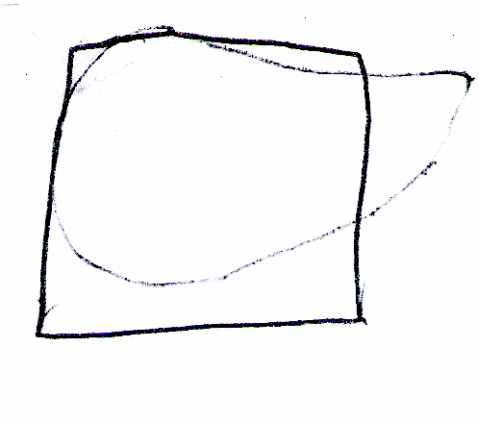


Figure 5.5.4

"**HIV is square... It is supposed to heal, but it doesn't want to heal. It wants to kill them**" (Samu)

In this instance, Samu first drew an oval shape, then she erased it (although it is still somewhat visible), drawing a square. Figure 5.5.4 is empty: although the participant gave HIV a shape, it seems she could not do more. She says HIV is supposed to heal but it wants to kill. This square does not want to heal. The connection between the square shape and the intent to kill is hard to make sense of.

The children displayed confusion about the shape of HIV/AIDS, the qualities it possesses, how it is contracted, how it could possibly be healed, and the impact it may have on an infected individual. One child mentioned that people can protect themselves from getting HIV by "**giving them pill and medication"** (Thenji), suggesting that if one is taking some medication he is protected from HIV. Another child mentioned that one may be healed from HIV/AIDS by infecting another (Lindi). Lindi also said **"…you don't know what is happening in your life…It is just there in life, how it entered, you do not know. How will it come out? You don't know**." The manner in which Lindi ends her story about her drawing of HIV displays confusion about HIV/AIDS. In addition to being confused about HIV/AIDS, other respondents placed emphasis on how infection with HIV is a result of not adhering to certain moral obligations.

5.6 HIV/AIDS and Morality

"**HIV is a sin, its thing, it's like a disaster and it's ugly"** (Ntebo).

It came up in some participant's responses that individuals were infected with HIV as a result of engaging in morally inappropriate behaviour. Ntebo labels HIV as a sin. Another child said the following: **"That when you, you do this thing that is not good, it starts bit by bit, and then you wake up infected with HIV/AIDS"** (Petru). According to Petru, HIV/AIDS is perceived as catching one off guard, like when one is asleep, only to wake up already infected with the virus. By **"this thing that is not good"**, Petru may be referring to sexual activity, but the ambiguity of his statement points to less specific notions of immorality.

Another child referred directly to sexual activity saying "**It's that when you have HIV, maybe she slept with a boy not know that boy has HIV, then she went and slept with him, but now it has entered her, and she will see herself becoming sick… you must not sleep with them, maybe others have positive and they infect me, now I am sick…"**(Lindi)**.**

In this instant, a young girl had sexual intercourse with a boy who then infected her with HIV. This leads to a sense of feeling guilty and ashamed that one has done something to deserve infection, and this gives the impression that the infection is punishment for bad behaviour. Therefore, HIV/AIDS makes people "**feel bad about themselves"** (Thabo). This child imagines that people may blame themselves for being infected and feel that they deserve to be punished.

Zaza said that people can protect themselves from getting HIV by refraining from sexual activity. "**They they they do, they do not sleep with boys who have HIV"** (Zaza). It is assumed that those who uphold good moral behaviour do not engage in sexual intercourse at a young age.

Another child drew a picture raising HIV/AIDS awareness



Figure 5.6.1

"This is a picture to show like, don't, protect yourself from HIV. This is a girl who shows that she has HIV/AIDS. This picture of mine can protect a person from HIV, because of, many people, it's that they want children because of the grant money, yes… Then they make babies, and others get infected with HIV. And the babies die" (Ntebo).

The drawn figure above represents an infected HIV activist, raising awareness and encouraging open communication about HIV. The story told about the figure highlights the issue of poverty in relation to HIV/AIDS, and people, women in particular, engaging in unsafe sex in order to conceive children, through which they may access funds from the government in the form of grant. According to Ntebo, engaging in this puts one at risk of being infected with the virus, and places lives in danger as the "babies die".

The children displayed an awareness of safe sex as a more acceptable practise, like Thenji mentioned; people get HIV "**if they sleep without using a condom."** Thenji continued to say that if her friend told her he had HIV, the first question she would ask is **"how did you get it?"** suggesting that the friend might have done something wrong or bad to get infected.

Apart from issues around sexuality, the use of drugs and alcohol also came up. One child mentioned that with her HIV infected figure, HIV "**got in while he was smoking drugs**" (Samu). She continued to say her HIV infected figure "…**is thin, he doesn't want to sleep on the bed, when he sleeps he is busy … he doesn't want to sleep. They reprimand him, and he likes drinking alcohol… Then he drinks beer, and again he smokes**" (Samu). According to Samu, the HIV infected individual is perceived to possess negative characteristics such as stubbornness, lack of discipline, and substance abuse.

As those infected are portrayed as having done something bad to become infected with HIV, those who are non-infected are portrayed as preferring not to spend time with those infected. Generally, a negative perception of HIV in relation to morality was portrayed.

5.7 Conclusion

Most of the participants in this study showed an understanding of some information the media, their teachers, peers, and the public in general regarding how one can become infected with HIV/AIDS, and how one can prevent this from happening. For example, one child explained that people get HIV through "**touching a person's blood, and the person who is touching the other person's blood has a cut on his hand, and you get it by kissing someone who has sores on his mouth and you get it from unsafe sex"** (Thabo). He also explained that people can protect themselves from getting HIV by "**not touching another person's blood and by not having unsafe sex"** (Thabo).

When asked what he would say if a friend told him that he is HIV positive, he responded "**I'll say its fine even if you have HIV/AIDS I'll still be your friend. I won't worry because at school they say it wont do anything if you are friends**". He continued to say that "a**t the home they don't talk about it",** it being HIV/AIDS. This issue of HIV is discussed at school, and children are encouraged to interact with one another regardless of another's HIV positive status. The education on HIV/AIDS attempts to address stigma in relation to HIV/AIDS. On the surface, children are shown how one can live positively with HIV/AIDS, as illustrated in figure 5.6.1 above, where the HIV infected individual is smiling while raising awareness on HIV/AIDS. Underneath the surface, the children pick up on the fear and uncertainty surrounding the issue of HIV. What they pick up on seems to influence their understanding of HIV/AIDS more than the message of living positively with HIV/AIDS.

CHAPTER 6

DISCUSSION

This chapter will discuss the research findings and it will be attempting to answer the research questions. The discussion is divided into four sections, drawn from the research questions indicated in the introduction in this research report. The titles are as follows: institutionalised children's understanding of what HIV/AIDS is, institutionalised children's understanding of what HIV/AIDS does, institutionalised children's understanding of themselves in relation to HIV/AIDS and how do they relate HIV/AIDS to their emotional experiences, and, institutionalised children's understanding of how their families/friends have been affected by HIV/AIDS. The chapter will also articulate the research findings in relation to existing literature, highlighting noticeable findings not reflecting dominant aspects of the literature. Finally, limitations of the study together with implication for further research will be outlined.

Institutionalised children's understanding of what HIV/AIDS is

The drawings of HIV/AIDS suggest that institutionalised children participating in this study understand HIV/AIDS as something that has the power to destroy life. It is seen as scary, ugly, and dangerous. While most participants referred to HIV as a killer, others referred to it as a disaster, and others said HIV is a sin. Such an understanding of HIV by children is not reflected in literature. This implies that there is a gap in literature.

HIV was also understood by other respondents to possess some characteristics of a human being, like walking, thinking, and eating. Although the virus is seen as somewhat similar to human beings, it also has different and mysterious characteristics, like that of being felt but not seen. For example, it was said that one of the HIV infected drawn figures could feel HIV when coughing but could not see it. This was accompanied by a feeling of discomfort.

Similar to the participant's of Wiener and Figueroa's (1998) study, children in the current study understand that HIV is a virus. The children displayed an understanding of HIV as a virus contained in something. For most participant's, it is understood that HIV is contained in blood, however, there was some confusion regarding whether HIV is in blood or if it becomes a different kind of blood, characterised by a different and darker colour like purple or black.

A sense of being confused and having unanswered questions about what HIV is was also apparent. For example, confusion about shape of HIV/AIDS was displayed. Perhaps this shows that most children participating in this study have not been exposed to the real shape of HIV/AIDS. They had to draw from their imagination and based on the information they have obtained from the media, educators, peers, and others. Some of the responses showing a sense of confusion about what HIV is included the response that HIV is AIDS, another participant said HIV is HIV positive. Perhaps for some children HIV/AIDS is what it is; it cannot be explained further. Finally, a minority of participants said they do not know what HIV/AIDS is, either they could not explain, or they were choosing not to engage with the concept, or they truly do not understand what HIV/AIDS is. This shows that children need some help in understanding HIV/AIDS better.

Institutionalised children's understanding of what HIV/AIDS does

Children participating in the study understand HIV/AIDS as something that destroys lives, causes pain, and gains pleasure from killing. For one child, HIV/AIDS lives in the stomach, where it eats healthy food that is intended to nourish an infected person's body. HIV/AIDS is understood as having the power to take over an individual's life, leading to negative consequences. For example, it makes itself visible on the infected person's body, changing physical appearance/body image. The body looks very ill, as it is covered with sores. The children's drawings also raised factors of weight loss, hair loss, decreased energy levels, and immobility, as an infected person spends his/her time sleeping.

HIV/AIDS is understood to ruin a person's body as it spreads and multiplies in the body of an infected figure. Being infected with the virus is seen as life changing and bearing negative consequences. Jackson (2002) highlights some of the ways children's lives have been changed due to the epidemic. He argues that HIV affected children are likely to experience homelessness (Jackson, 2002). Similarly, one of the respondents drew a figure that had become homeless as a result of the figure's HIV positive status.

These consequences that come with HIV are no only physical, but also emotional. Those infected are perceived to experience the following emotions: insecurity, uncertainty, fear, vulnerability, and sadness. Despair is portrayed in the drawings of infected figures. The loss of happiness is shown by tears running down an infected figure's face. These figures are also understood as rejected and judged by those around them, seeing them as weak and sometimes perceiving them to be disgusting. In turn, the infected figures feel inferior, isolated, and that they do not belong. These feelings are similar to those spoken of by HIV infected children participating in Wiener and Figueroa's study (1998).

There were other characteristics understood to be present in the lives of HIV infected figures, which are not spoken of in literature. These include rebellion, laziness and greed. For example, HIV infected figures were understood to be rebellious in refusing to take medication or to go to the clinic. These figures were understood to be lazy as they spend all their time sleeping. And finally, they were perceived as greed, as they just eat and eat but are never seen as meeting the needs of another.

Institutionalised children's understanding of themselves in relation to HIV/AIDS and how they relate HIV/AIDS to their emotional experiences

The findings of this study showed that participating institutionalised children see themselves as vulnerable in relation to HIV/AIDS, wondering about the possibility of being/becoming infected themselves. Those already infected worried more about the negative consequences of being infected, while those affected together with those

participants who were neither infected nor directly affected, worried about becoming infected with the virus. The children seem to understand themselves as those at risk and therefore displayed a need to be careful. For example, some were horrified to even think about HIV/AIDS, saying 'No, you can't!', as if thinking about HIV/AIDS could also put one at risk of becoming infected. This need to be careful could be shown in being judgmental and avoiding those known to be infected.

In contrast, a few participants displayed that they are not afraid of HIV infected figures and that they were assured that nothing bad would happen if they thought about HIV/AIDS. As opposed to being judgemental, some participants spoke of being loving and supportive of those infected, willing to risk one's own life or health in order to help an infected figure.

Institutionalised children's understanding of how their families and friends have been affected by HIV/AIDS

Most information on the impact of HIV on families and friends as understood by the children was not as explicit as those understandings already discussed. However, it was striking that most children related illness to death, and some related illness directly to HIV/AIDS. Similar to dominant findings in literature (Jackson, 2002; UNAIDS, 2002; UNAIDS, 2006), where HIV/AIDS is spoken of as having increased the rate of mortality and consequently increasing the number of orphans, children participating in this study showed concern about the loss of parental figures and concern about children living in families where parental figures are absent. These concerns are related to the impact of HIV/AIDS and also to the institutionalised children's personal experiences.

Bearing in mind that some of the participants have lost parents to HIV/AIDS, issues related to the challenges faced by children living with terminally ill parents also came through. In-depth analysis of figures drawn by one child who had also lost parents to HIV/AIDS revealed features of depression. According to Pizzo and Wilfert (1998), the

negative implications of the loss for a child and his/her development are compounded when the child is living with a seropositive diagnosis. It seems that for one of the participants of this study, this postulation may be true.

HIV/AIDS was not only seen as affecting individuals in the family, but also filtering into friendships. On one hand, some children spoke of their drawn figures as rejecting others based on their HIV positive status. On the other hand, other children spoke of being supporting and non-judgemental, willing to put their own lives at risk in order to maintain a good friendship with another infected figure.

Conclusion

This study sought to investigate how institutionalised children understand HIV/AIDS. The findings showed that the children understand that HIV is a virus. They also displayed an understanding of the different modes of transmission, such as sexual intercourse, mother to child, and touching another's blood while one is hurt. The children also displayed an understanding of how a person can protect him/herself from becoming infected. They mentioned protected sex, wearing gloves when helping someone who is infected, and calling an adult to assist when another child is bleeding. The information they shared shows that they have been educated about HIV/AIDS. However, there were gaps identified in their understanding of HIV/AIDS. These gaps were in the form of confusion about HIV/AIDS, incorrect information about HIV/AIDS, and the dominance of negative implications of HIV/AIDS, linked to issues of stigma. A need to address these issues appeared.

LIMITATIONS AND IMPLICATIONS FOR FURTHER RESEARCH

This section will outline the limitations of this research from the perspective of the researcher. From these limitations, implications for further research will be drawn.

- Firstly, the major limitation of this research was that it was based on the perceptions of different individuals. While some of the participants were HIV infected, others were affected and others were neither infected nor affected. Perceptions are largely subjective and therefore, the reliability of the findings may be questionable. A bigger sample may thus be considered for further research.

- Furthermore, these results may not be generalised to other institutionalised children across South Africa, as they were only based on the perceptions of a few children, living in one institution. However, as this was a qualitative research with an explorative motive, concerns regarding the sample size were secondary to obtaining rich data with regards to the participant's perceptions.

- The use of the DAP and KFD did not yield much information related to HIV/AIDS, perhaps there are other techniques through which spontaneous information on understanding of HIV/AIDS may be used in further research.

- Although the data collected was rich in content, due to the limited scope of this paper; the discussion mainly focused on factors that were directly connected to the children's understandings of HIV/AIDS, other themes may be elaborated on in future research.

- Although information on how children infected with HIV understand HIV/AIDS, as compared to children who are affected and children who are neither infected or affected was present, such information was excluded for confidentiality reasons. This was limiting in that some interpretations could not be included in the report, as they did not make sense without the participant's background information. Perhaps in future research, means of protecting the participants identity but still being able to use some historical information together with revealing their HIV status, can be identified and used.

The following questions may be answered through further research:

- What is informing the children's understandings of HIV/AIDS?

- How does the way they understand HIV/AIDS influences their behaviour?

- How can they be assisted to have a better understanding, with less fear and gloom in the subject of HIV/AIDS?

- What can be done to assist the children to respond appropriately to education about HIV/AIDS?

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APPENDICES

Appendix I: Subject Information Sheet



Tel: 072-458-0428
Email: vales777@yahoo.com

Dear Manager

My name is Bongiwe Mahlobo, and I am conducting research for the purposes of obtaining a Masters degree at the University of the Witwatersrand. My study aims to explore how institutionalised children understand HIV/AIDS. I would like to invite you to participate in this study by allowing the children living in your institution to participate.

Participation in this research will entail the children drawing and telling stories as a means of expressing themselves. They will be asked to draw a picture of a person, a picture of a family, a picture of HIV, and a picture representing HIV in the body. They will then be requested to tell a story in relation to each picture. With your permission, I would also like to record the stories that the children will share with me. The tapes and transcripts will not be seen or heard by other people at any time, and will only be processed by my supervisor and I. The tapes will be destroyed after transcription, and the transcripts will be stored in a safe. Some of the children's drawings, without identifying information, will be included in the research report.

Participation is voluntary; therefore, no child may be forced to participate. Also, no person will be advantaged or disadvantaged in any way for choosing to participate or not to participate in the study. All of the responses will be kept confidential, and no information that could identify the children will be included in the research report. The children may refuse to answer any questions they would prefer not to. You may also choose to withdraw the children from the study at any point.

If you choose to allow for the children's participation in the study, please fill in your details on the form below. Your approval for participation in this study would be greatly appreciated. This research will contribute both to a larger body of knowledge on the psychosocial impacts of HIV/AIDS on children. This may help to inform the development of relevant intervention strategies within institutions.

A summary of the results will be made.
For further information, please contact me on the number provided above.

Kind Regards

Bongiwe Mahlobo

Appendix II: Consent Forms

Participation Consent Form

I _____ consent to the participation of the following children in the study conducted by Bongiwe Mahlobo on exploring how institutionalised children understand HIV/AIDS.

1.
2.
3.
4.
5.
6.
7.
8.
9.
10.

I understand that:

- Participation is voluntary.
- The children may refuse to answer any questions they would prefer not to.
- The children may be withdrawn from the study at any time.
- No information that may identify the children will be included in the research report, and their responses will remain confidential.

Signed _____

Audio-Recording Consent form

I _____ consent the recording of the following children's responses in the study conducted by Bongiwe Mahlobo on exploring how institutionalised children understand HIV/AIDS.

1.
2.
3.
4.
5.
6.
7.
8.
9.
10.

I understand that:

- The tapes and transcripts will be processed by the researcher and her supervisor only.
- All tape recordings will be destroyed after the research process is complete.
- No identifying information will be used in the transcripts or the research report.

Signature: _____

Appendix III: Letter of Assent and Assent Form



Tel: 072-458-0428
Email: vales777@yahoo.com

Hello

My name is Bongiwe Mahlobo, and I am a psychology student doing research on children who stay in an orphanage. I would like you to take part in my study.

If you choose to take part, I will ask you to draw some simple pictures and tell me stories regarding those pictures. These pictures and stories will help me understand what is important to you and also what HIV/AIDS means to you. With your permission, I would also like to record the stories that you tell me so that I can listen to them after we have met. I will be the only one who listens to the tapes and I will keep them in a safe place so that no one else listens to them. When I finish with my study, I will destroy the tapes. Thereafter, I will write a report on what I found. I would like to include some of your pictures in my report.
To protect your identity, I will not include your names or any information that would allow someone to know that I spoke to you. You are not forced to take part in my study. If you choose to participate, you can change your mind about it at any time. Also, you may refuse to answer any questions you do not want to. If you have any questions, you are free to ask me. If you choose to participate, please fill in your name on the form below.

Yours sincerely
Bongiwe Mahlobo

Assent Form

I _____ agree to take part in the study conducted by Bongiwe Mahlobo on exploring how children living in an institution understand HIV/AIDS. I understand that:

- I am not forced to participate
- I may refuse to answer any questions I do not want to.
- I can stop at any time
- My name will not be in the report so that people cannot know that I said what is written.

Signed _____

Appendix IV: Task Sheet

Draw A Person (DAP)

- Present a child with a paper, pencil and eraser and ask him/her to draw a person. This should be a whole person, not a cartoon or stick person. Thereafter, the child is asked to draw another person of the opposite gender to the first person drawn
- The researcher will make unobtrusive notes and comments during the drawing process.
- After the child has finished drawing, the researcher will ask questions about the drawing.

What is his/her name?

How old is he/she?

What does he/she like?

What does he/she hate?

Does he/she have friends?

What does he/she like about her home?

What doesn't he/she like about her home?

What doesn't he/she like at school?

What does he/she like at school?

If he/she could change one thing in his/her life, what would it be?

What makes him/her angry?

And what does he/she do when she is angry?

What makes him/her happy?

If he/she had three wishes, what would he/she wish for?

What makes him/her sad?

What does he/she do when he/she is sad?

What makes him/her scared?

If he/she could go far away, who would he/she go with?

What worries does he/she have?

When he/she is sick, what does he/she think about?

Tasks similar to those used in Wiener & Figueroa's research

A. Drawing of HIV/AIDS

- Ask the child to draw a picture of HIV/AIDS.
- Ask the child to tell you a story about the drawing

B. Drawing of HIV/AIDS in the body

- Ask a child to draw a picture of HIV/AIDS inside someone's body.
- Ask the child to complete the following sentences in relation to the picture
    - HIV/AIDS makes people
    - HIV/AIDS is
    - When I think about HIV
    - When someone with HIV is bleeding
    - HIV makes people feel
    - What I want people to know about HIV/AIDS is
    - People get HIV through
    - People can protect themselves from getting HIV by
    - What would you say if your friend told you that he is HIV positive?

The Kinetic Family Drawing (KFD)

- Present a child with a paper place horizontally, a pencil and an eraser.
- Ask the child to draw a picture of their family, with each person doing something.
- After completing a drawing, the researcher will ask each child to tell a story about the drawing.

With all the tasks, follow up questions will be asked where necessary.

Appendix V: Ethics Clearance Certificate