

I don't want to talk about that disease [meaning HIV/AIDS].


When asked to substantiate on his response he said:

Today I do not have a mother or a father all because of it [AIDS].

Yoliswa who was born with the HIV virus regarded it as a disease that children get from their pregnant mothers. The following excerpt illustrates this:

You see if a woman is pregnant and does not take ARVs [Antiretroviral tablets] while pregnant she will give birth to a HIV positive child.

As they were defining this disease and observed their parents health deteriorating and not being able to work, who had an aunt who died of AIDS, shares the following



It is a disease that makes you very weak, you can't breathe, and other people must clean you and feed you just like my father's late sister.

4.3.2 Section B: Challenges before and after parental loss

- Socio-cultural effects of culture to AIDS orphans
- Socio economic status of orphaned children
- The right to be a child and thus become transformed into caregivers.

4.3.2.1 Challenges

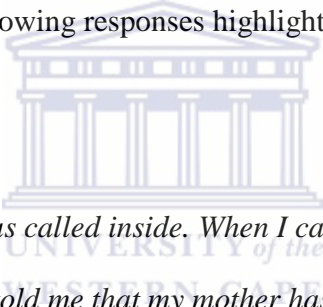
AIDS affects individuals and families in their most productive years and leads to poor economic performance. The AIDS pandemic has caused the loss of productive and often well educated adults, a loss not only for the country but especially for families that lose economically productive breadwinners (Aspaas, 1999). Research reports that many AIDS orphans experience orphan hood way before the death of their parents due to the different challenges that they face,(UNAIDS,2000). Cross (2001) reported that the death of a parent meant the loss of the household's only cash income stream and hits to the point of cash-flow crisis resulted from extended illness ending in death and funeral needs. The following sub-themes in supporting this theme are presented as follows:

Socio – cultural effects of culture on AIDS orphans

Nord (1997) reported that the death of a family member to AIDS–related death poses a cultural social arrangement as the bereaved are forced to recognise the social loss, while communities simultaneously deny the presence of the HIV/AIDS pandemic. Children should be informed and involved when there is someone ill so as to help you share your sorrow, ignoring them may leave them with feelings of sorrow and guilt (Kubler-Ross, 1985). Credo Mutwa a traditional healer known to have cared for AIDS orphans in Children First (2000) notes that children are more intelligent than credit that adults want to give them, hence they can be told about HIV/AIDS. Children First (2000) reported that if a death occurs in a family and it is hidden from children, they can come and confront you for it. It needs to be understood that funerals are for the family. Kubler-Ross (1985) informs that cultural, religious and local customs need to be respected; in addition

Kubler-Ross (1985) believes that families and communities should grant children and mostly adolescence the opportunity to pay their last respect to their loved ones in a dignified manner. Culture is one of the areas that have either played a positive or a negative role in the lives of the AIDS orphans and their family relations. Within the African culture, death is a topic that is not discussed with children. Deacon *et al.* (2007) states that the reluctance of caregivers to discuss death and illness with minors in fear of stigmatization and discrimination can result in parents not preparing their children for their death. From the responses of the participants it was apparent that some of the children were never granted the opportunity to hear from their own parents regarding their HIV/AIDS status. The following responses highlight this:

Thembile states that:



I was playing outside when I was called inside. When I came in, there were people from next door and the one old man told me that my mother has passed away and from now I must stay in the house until after the funeral.

When asked who helped him to deal with the news Thembile, responded by saying:

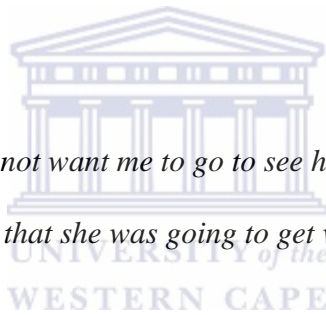
Nobody helped me after I was told the news I was told [people in the house] to take the news as a man after that I was told that I can go and play in the yard.

Kubler-Ross (1985) states that families have a tendency to avoid sharing the truth about the death of a loved one and rationalize that telling them will upset them or that they are too young to be able to cope with the crises. Kubler-Ross (1985) adds that losing a loved one is so much of a tragedy hence it is important to allow people to express their

emotions rather than suppressing them. Culture also played a negative part in this case because as shown in this excerpt the child was not prepared for the news. According to the African custom Xhosa to be precise, death is not something that is discussed with children as they are perceived not to understand it. Hence this child was just told as news he heard to hear and accept at face value. Deng *et al.*, (2007) reports that lack of knowledge, existing culture, social and religious norms, values and beliefs may impact on families and communities. In so doing society suppressed the child's feelings and concluded that they were irrelevant and under the circumstances they were not to be considered. This occurs even when the parent is terminally ill.

Mbali says:

They [family members] did not want me to go to see her at the hospital when she was very ill they always told me that she was going to get well.



Noluthando, in supporting Mbali, reported:

My aunt told me not to go and visit my mother at the hospital, I must see to my siblings.

Even though this made her feel on the other hand reasonable as she thought she was going to make her mother proud when she returns from hospital. She was not aware that the next news was to inform her of her mother's death. Kubler-Ross (1985) highlighted that grief and fear when allowed to be expressed and shared in childhood can prevent much future heartache. Nord (1997), Kubler-Ross and Stedeford (1984) concur that adolescence naturally is a difficult time of development and an added loss of a parent is often too much for such a youngster to endure hence it would be appropriate to listen to

them and allow them to express their feelings whether it is guilt, anger or plain sadness. The excerpt below highlights the pain that was experienced by Noluthando. She longed to visit her terminally ill mother but at the same time had to consider the well being of her siblings in order to make her mother happy.

I was heartbroken, I always wished if I could see her but my siblings had to be important so that when she comes back [from hospital] she can see that I have looked well after them.

The cultural rituals in some families are complex that children sometimes have to guess for themselves that there is a crisis in the family. Kubler-Ross (1985) states that families have a tendency to avoid sharing the truth about the death of a loved one and rationalize that telling them will upset them or that they are too young to be able to cope with the crises. This is presented by Yoliswa in the following excerpt:

When I got back from school the furniture was put outside and immediately I knew that she had passed away [crying].

Mbali who has a similar experience reports the following:

She was very sick; my grandmother decided that my brother and I are not going to the hospital again until my mother was better. She convinced us that the ward sister has informed her that children are not allowed in the ward where my mother was in.

Prude continues,

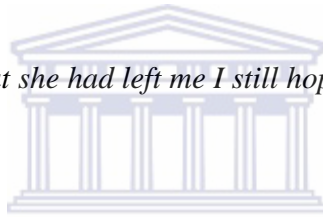
The following day she told us that the hospital has phoned to report that my mother had passed away.

Thembile adds:

I thought it was a joke (shaking his head). I was playing outside with my friends, and then called inside. When I came in there were people from next door and the one old man told me that my mother has passed away and from now I must stay in the house until after the funeral.

When asked how he responded to the news Thembile reports:

I cried, I did not believe that she had left me I still hoped that she was going to come back



When asked who helped him to deal with the loss of his/her parent Thembile reports:

Nobody helped me after I was told the news I was told to take the news as a man and go and play in the yard.

Family friends that share their condolences tend to focus on the adults without realising the pain the children are undergoing. When Mbali was asked how she reacted then when the news was conveyed to her:

I cried and they [the people in the house] told me don't be ridiculous, you have seen your mother suffering now the Lord has taken her to her home.

Van Dyk (2008) highlighted that bereavement is triggered by the sense of loss that occurs when one loses something or someone to which one has become attached to.

This separation or loss initiates a process of grief. Nord (1997) defines grief as a peculiar amalgam of anxiety, anger, pain and despair following the experience of what is feared to be irretrievable loss of a loved one the responses of the above participants highlights this experience

Sinoxolo in addition to this reported the following,

I was angry because they did not want me to go to hospital with them and yet my mother used to go with my siblings and me.

Some of these children have experienced negative treatment from some of their family members who believed that HIV positive parents had brought a curse to their family. Walker *et al.*, (2004) state that South African society is characterized by cultural complexity and difference, this can be reflected in many ways that health and disease are understood. Van Dyk (2008) in supporting Walker *et al.*, (2004) reflects that a person with AIDS may fully understand the immediate cause for his/her illness as the virus but will still seek traditional healers opinion. Witchcraft is believed to be the causal factor in HIV transmission, however van Dyk (2008) notes that while people may believe that the cause of AIDS is witchcraft, counselors, social workers and health care workers should stress the immediate cause of HIV/AIDS as a germ which is sexually transmitted

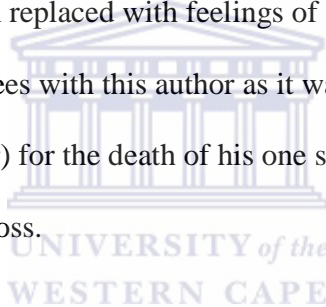
Thando shares the following

She [paternal grandmother] said that my mother, my two twin sisters and I had brought a curse to the family.

Walker *et al.*, (2004) reported that belief systems impact directly on how we understand and respond to illness. Thando, one of the participants whose sibling died very young, believes that the health condition of his mother resulted in the death of his sibling as his mother was not able to care for them due to her own ill health. He explains this as follows:

She [meaning mother] was not able to care for us hence my one sibling [twin] died [frown].

In the case of Thando, Kubler-Ross (1987) states that when the stage of denial cannot be maintained any longer it is then replaced with feelings of anger, rage, envy and resentment. The researcher agrees with this author as it was clear that there was an element of (blaming his mother) for the death of his one sibling. His facial expression showed the anger towards the loss.



Kubler- Ross (1985) states that many families especially in the areas where old customs are still alive friends, family, grandparents and neighbours will come together and give the family support. Kubler-Ross (1985) continues by saying, this gives that family and friends a chance to actively participate in the healing of the pain, however the challenge with the bereaved starts when all the family and friends are gone as one have to face the reality. One of the African customs is to support family members during the bereavement this lasts until the day of the funeral. Thereafter all family members go back to their destinations and you are left alone to start grieving with no one realising what this loss has done to you as a person. It was clear that some of these children had experienced that gap in their lives as they highlighted the loneliness that was in the house after the funeral

an. All the participants' highlight the support of the family members during this period the following excerpt has highlighted what Prude shared:

Everyone was supportive during that week [before the funeral], that made me not to feel her absence much but as weeks goes I realised that she was gone.

Thando, who has experienced all forms of abuse from his paternal family, shared some of his experience:

My [paternal] grandmother and my stepmother treated my sister and me very badly. After the death of my mother and my other twin my grandmother decided to take my remaining twin and I and go and throw us by the riverside.

Deng *et al.* (2007), in supporting the above statement, state, that one of the common forms of stigma are gossip verbal abuse and name-calling. Walker *et al.*, (2004) highlighted that AIDS is greatly feared and popular beliefs can result in stigma and discrimination. Walker *et al.*, (2004) continues by saying that in some communities the transition of HIV is associated with the transgression of sexual taboos, health is associated with cleanliness and moral hygiene and disease is seen as the outcome of forbidden exchanges and even witchcraft. It is then not surprising that these children, together with their mother were seen as a curse for the family. What was also surprising is the fact that this mother was just as cruel to her own daughter as well, as Thando conveys on the following excerpt:

My paternal grandmother treated her only daughter my paternal aunt bad. She used to swear at her and never assisted her when she was sick.

When asked how he felt when he saw his aunt encountering the same experience they endured:

I used to be hurt as she was the only person who cared for us and treated us well.

The participants expressed their pain and suffering at seeing their parents who were at one stage their support system being broken down by the HIV virus and they were unable to assist them. Erikson (1980) defines adolescence as role confusion developmental stage meaning at this stage parental support is of outmost importance. This was not so with these children as they had to count on each other or other family members Deng *et al.*, (2007) states that in South Africa social isolation is a major manifestation of stigma. People refuse to discuss their disease and children who are affected with HIV are often ostracised by their peers and society.

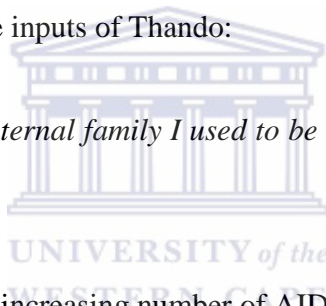
Socio-economic status of orphaned children

South Africa is known to have the highest number of people infected with the HIV virus. This has resulted in the country losing many economic active citizens at a young age that could still be a good resource to the country's economy. This costs the government via the administration of different state grants. Heymann and Kidman (2008) states that families who are already economically marginalised prior to the AIDS related crisis are at the risk of not being able to meet the basic needs of the AIDS orphans.

Most of the participants currently live with their maternal grandparents, siblings, family friends and paternal family. Most of the caregivers depended either on Old Aged pension or Disability Grants. Both are received from the Government of South Africa, which is

R1010 per grant per month. Amoateng and Heaton (2007) states that, in South Africa social assistance is provided in the form of different grants namely the old aged grant, disability grant, care dependency grant, a foster child grant, a child support grant and grants in aid and social relief of stress. As stated in the previous discussion, AIDS is removing the breadwinners and caregivers in large numbers from families, and resulting in the elderly and minors fending for them. Although section (29) (1) (a) of the Bill of Rights (1996) states that every child has a right to education, the lack of income has resulted in some of these children being deprived of education. In most cases this is due to the fact that caregivers often do not have funds to send these children to school. The following excerpt illustrates the inputs of Thando:

When I was staying with my paternal family I used to be sent home for not paying school fees.



Van Dyk (2008) argues that an increasing number of AIDS orphans who grow up without parental support and supervision becomes victims of poverty and subsequently engage in criminal activities and prostitution so as to earn a living. Noluthando highlighted that due to her level of poverty she decided to leave school.

This year I decided not to go back to school as my school shoes were torn and there was no one to buy me school shoes.

This does not mean that the problem was solved. It could have been the beginning of the problem. Noluthando could get a nutritious meal at school and now that it's not there, she had to look for alternative ways of surviving. Research has indicated that the girl child during this stage is more vulnerable to many forms of sexual abuse as their sex organs

begin to enlarge Papalia *et al.*, (2008). This can result in unsafe behaviours of some of the teenagers (Papalia *et al.*, 2008)

Williams (2000) reported that caregivers experience financial pressure as they are expected to clothe, feed, educate, love and support AIDS orphans. This can be difficult as in most cases caregivers are unemployed and dependent on state grants. The limited income from the caregivers thus prevents them from providing what the participants would need, despite the fact that the caregivers will be trying their best with their limited funds and resources. In most cases this often means that the lifestyles of the participants will change.

Thembile reported this:

When I asked her [his mother] something she never used to say it is expensive like the “Nike Takies” unlike my grandparents when I ask something expensive they say they cannot afford it however will buy me something cheaper.

Amoateng *et al.*, (2007) state that information available on the social and economic impact of HIV/AIDS on families and children in South Africa is very little, this epidemic represents a major challenge to the state given the alarming rate in which individuals are infected. The participants reported that biological parents and (mostly mothers) have played a significant role in ensuring that their basic needs are met, even though their health was deteriorating. The following excerpts highlight what Yoliswa presented:

It was my mother as she was working and when she lost her job due to ill health she got a [disability] grant.

In supporting this statement Mbali added the following inputs:

When my father got ill my mother continued to work until her health deteriorated.

According to Cross (2001) many poor families are sliding deeper into poverty due to HIV/AIDS. She continues by saying that some of the most regular financial needs of the households with unsupported dependants are food, clothing for the children, school expenses, and medical expenses. At times parents had to jeopardise their values and dignity and start doing businesses that can put the lives of their children in danger, and mostly the girl child, for their survival. Noluthando reports the following in supporting this view:

My mother started a shebeen, as she was unemployed and struggling in order to be able to buy us food and clothes. When her health deteriorated she stopped the shebeen and this meant that we had to struggle again however the [disability] grant helped her to buy us food.

Mbali who has had the experience of staying with another HIV positive family member reported the following,

My aunt who is HIV positive is the one who buys us food and pays the electricity and water

Prude added that:

My aunt died in 2003 because of AIDS, she used to buy us food and clothes.

Yoliswa pointed out that:

My grandmother buys us food mostly on ALPAY [pension] days.

It was clear that maternal grandmothers were the primary caregivers to the AIDS orphans. This view is also supported by Aspaas (1999) who states that:

Owing to the loss of adults between the economically productive ages of 15 – 45 [due to AIDS –related deaths], an increasing number of orphans are relying on elderly relatives who may lack sufficient resources both mental and physical to provide for them.

In supporting Aspaas (1999), Kelso (1994) reported that elderly women regularly assume the role of caregivers following the death of their children and their spouses. These are left to look after the children that are left behind hence AIDS is known as the “Grandmothers” Disease in most of the African countries. It has been clear that if the grandmother does not inherit these children. It then becomes the role of an aunt and in most cases maternal aunts and family friends as it has been highlighted in the above excerpts.

The right to be children: Transforming into caregivers and breadwinners

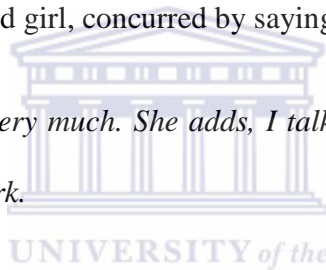
UNICEF (2003) reported that the newest number of children orphaned by HIV/AIDS is alarming and they represent a segment of those affected by HIV and AIDS. The newest phenomenon emerging in Southern Africa is that of child-headed households, in which the eldest orphan becomes the parent as no relative, can or will (Kelso, 1994). Amoateng and Heaton (2007) state that information available on social and economic impact of AIDS on families and children is scanty. Deng *et al.*, (2007) states that marginalised

groups such as the poor, ethnic and racial minorities and particularly single woman are more vulnerable to HIV/AIDS-related stigma and discrimination. Gannon (1994) reported that children who have lost their parents through HIV/AIDS become heads of their families and have to care for their younger siblings. Children especially girls face more general house chores, care for the sick and younger children. The following excerpt highlights the response of Linda in support of this statement:

I regard my eldest sister as my parent as she is the person who buys me food, clothes, pays my school fees and buys me anything I want when she can.

Noluthando a seventeen year old girl, concurred by saying:

I love my brother and sister very much. She adds, I talk to them, do their washing and assist them with their home work.



The death of a parent is devastating, especially when there are children who still need to be taken care of and are left behind. Nord (1997) reported that illness and death within the family draw attention and energy away from the needs of children. One of the participants Linda concurs by saying:

I think my mother's illness did impact on her parenting role as she was not able to cook for us as her children.

This theme also highlights the parental role taken by these children in caring for their own parents, mostly because no one else supported them. In responding to this Linda reported the following:

Let me say she was not able to care for us instead we had to care for her.

Steffenson (2002), Nord (1997) and Smart (2000) agree that the reality of AIDS in a family is that children are caring for the sick resuming adult responsibilities before they are ready to do so. Nord (1997) continues by saying being an AIDS orphan or having a parent dying of AIDS might impact on some adolescents who might be themselves struggling with this transitional stage while having to care for parents and siblings. The following quotation from Noluthando who is 17 years old reports:

We later decided to do the house chores ourselves as she was getting tired quickly.

4.3.2.3 Section C: - Coping strategies adopted by adolescents who have lost their parents through HIV/AIDS

- Available support resources
 - Family and community support
 - HIV and education
 - Health care systems
 - Private welfare organisations
 - Religious institutions

Coping strategies

Deng *et al.*, (2007) states that in some cultures it is customary to throw away the belongings of the dead however in some families' people still kept some valuable

mementos as keepsakes. These children highlighted family bonds as a strong coping mechanism and celebrations brought their family and extended family closer. The family values that were built among these children help them to cope with the loss of their parents strong. Sinxolo in this excerpt:

Every night before we go to bed my father used to ask us to gather for the evening prayer and every morning early my father used to wake us up for prayer.

He adds

At times you would be half asleep but you had no choice but to wake up for the prayers (He smiles)

The separation of siblings result in children blaming themselves for the illness and death of a parent and for their misfortune (Smart, 2003) Gouws and Kruger (2004) reported that too much stress in the life of an adolescent may exert a depressing influence on the young person's self-esteem. While this can be true and can make nuclear families more vulnerable during times of crises, it is also true that these families can strengthen their emotional support that is needed during crisis times as they need each other (Bezuidenhout, 2004). Thus, it is important not to separate siblings from one another during death of parents as they can be a good support for each other (Richter *et al.* 2004). Sinxolo who is separated by distance with his siblings relates

I see them every December holiday. You know what, at the time when I went to my mothers funeral [Eastern Cape] he [baby brother] would cry and ask for my mother (he keeps quiet looks as if he is going to cry) I did not know what to say I would just cuddle

him and try to comfort him. I must say though now that he is growing he is not asking her any more but he just gets excited to see me and want to sleep with me.

He continues:

My other brother is very quiet he does not talk much but when I am at home [Eastern Cape] I accompany him to the fields to fetch the cattle. He gets so excited when he sees me. You know when I go to the homelands I bring them something nice like the “Yogetta”.

Amoateng *et al.*, (2007) reports that taking care of an AIDS-sick person is not only an emotional strain but also a major strain on households. The love and care that some of the families have for each other kept some of the families strong and close to each other even though they were affected by the strain of having to cope with a sick family member this love was at times carried over to the children. The following statement supports this:

My uncle used to come and chat with my mother and I when he comes from work mostly on Fridays and weekends when he had a drink;

She continues

I think he was worried about losing his sister. He used to say; “Is jy all right my ma se kind” meanings are you all right my sister.

Mbali, in relating part of her traditional family customs that helped her to cope with the loss of her mother, highlights the following:

During Xmas and Easter my maternal uncles and aunts, my nieces and nephews let me say the whole family we wake up early in the morning and we visit the graves of our grandparents including my mother’s grave.

Yoliswa adds that her grandmother wanted them to celebrate every birthday at their house. During these occasions all the family members come together at their home (maternal house).

Prude who had a very close relationship with her mother shares the following

When I remember the good things we used to do together sometimes when I watch the family videos I get happy

Thembile shares the following

I have my mother's photo that I hang in my bedroom; I look at it every day mostly when my aunt has hit me

Linda shares

My sister [who is a Rastafarian] would go with me to her stall to sell veggies and keep me busy.

Linda adds that when asked what she did then when it dawned that her mother was gone:

I decided not to think about her but it is not easy.

Available support resources

UNICEF (2003) states that HIV and AIDS on children raises the risk that more children will fall through the cracks and face barriers in accessing education, health care and other basic services. The emotional pressure on children affected by HIV and AIDS can be devastating as they at times suffer from isolation, loss of self-esteem, depression and

anxiety. UNICEF (2003) recommends that the best way to protect children orphaned by HIV and AIDS is through placing them in the care of relatives and extended family members in their own community. Most of the Government Departments are strengthening their policies and strategies aimed at addressing the issue of HIV and AIDS. The following sub-themes will illustrate the different support systems highlighted under the theme support systems available to assist AIDS orphans.

Family and community support

Family is very important in all cultures and is no difference in this study. Hence the researcher had to explore the support systems that participants have. Social support, which is rooted in family and community members, is defined by Amoateng *et al.*, (2007) as the instrumental, educational social and psychological assistance actually provided to a person. The support that these children received from the different family members made them to feel more secure in their community. Amoateng *et al.*, (2007) reported that taking care of an AIDS-sick person is not only an emotional strain but also a major strain on households. The love and care that some of the families have for each other kept some of the families strong and close to each other, even though they were affected by the stress of having to cope with a sick family member. This love was at times carried over to the children concerned. The following statement supports this:

Linda shares:

My uncle used to come and chat with my mother when he comes from work mostly on Fridays and weekends when he had a drink;

She continues:

I think he was worried about losing his sister. He used to say; “Is jy all right my ma se kind” meanings are you okay my sister.

Sinoxolo who is geographically separated from his siblings appeared to be a great trustworthy support for his sibling relates the following

I see them every December holiday. You know what, at the time when I went to my mothers funeral [Eastern Cape] he would cry and ask for my mother (Sinoxolo, keeps quiet looks as if he is going to cry) I did not know what to say I would just cuddle him and try to comfort him. I must say though now that he is growing he is not asking her any more but he just gets excited to see me and want to sleep with me.

He continues:

My other brother is very quiet he does not talk much but when I am at home [Eastern Cape] I accompany him to the fields to fetch the cattle. He gets so excited when he sees me. You know when I go to the homelands I bring them something nice like the “Yougetta”.

Friends were identified as a support. However, it was evident that these children were not comfortable in discussing their parent’s status with them. The following excerpts illustrate this:

Mbali, who also had an experience of being raised by an aunt who was HIV positive, shares the following:

I have friends they know that my mother has died but I have never shared the cause of her death with them.

Prude said:

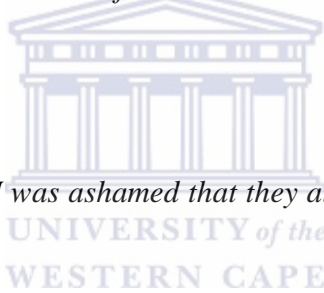
I told her that my mother was ill. I did not tell her that she had HIV. She then came with her mother to visit my mother. My mother told her mother about my mother's status. We are still friends.

Noluthando highlights:

My friends at school would share some of their lunch with me.

She continues:

I left school this year because I was ashamed that they always shared their food with me and I had nothing to offer them.



Thembile said:

I do not have best friends but the friends that I have did not treat me bad maybe it is because they did not know.

Thando reports

I have friends whom I attend with the aftercare classes at Siyaphambili, we play together but we never speak about our parents.

Yoliswa who was born HIV positive shares

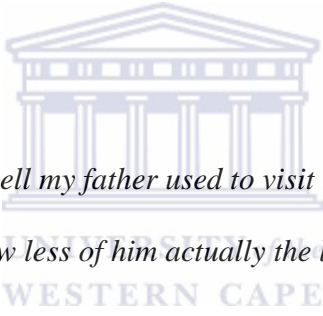
My friends are nice, we play together but I have never shared with them my HIV status

Felicia shares her experience

My classmate called me names and I was angry and I hit her badly

The Bill of Rights section 28 (1)(b) states that every child has a right to family care or parental care, However, AIDS orphans have reported that they are often faced with lack of support from their biological father's, either before they were even born, or after the death of their mothers. This support can be material, affectionate or financial. The following excerpts illustrate this:

Felicia shared this:



When my mother was still well my father used to visit us and buy me anything I want.
When my mother got ill I saw less of him actually the last time I saw him was on the day of my mother's funeral.

This statement is supported by one of the participants Thando, who related the following ordeal regarding his father. His father deserted him and his twin sister and went to live with his new family in Gauteng:

He has never come to visit us; we do not even know if he is still alive as he went to stay in Gauteng with his new wife (frowns).

It was evident through the frowning that even although he had no power over the desertion, he was not happy. It could be he was missing his father as the only parent

that was alive, or wanted to know whether he was still alive. The case of this participant was interesting and sad as his father deserted them.

Mbali reported that:

She [my mother] told me that he [my father] was a student from Namibia who came to study here in South Africa, at the end of the year went back. I don't know whether he knew that she was pregnant when he left, as I do not know him and his siblings.

To which Noluthando, whose younger sister was born HIV positive, reported that:

Because we were struggling I gave him [father of baby sister] permission to look after her, at least she was going to be well cared for. When my aunt came to stay with us she decided to go and fetch her. They [him and his family] took back everything that they [had] bought [for] her including her school uniform.

Participants related strong bonds with their mothers. However it was clear that the gap between them and their fathers was bigger than one had envisaged. The inputs from these participants illustrate this:

Thando shared this:

There were no activities that we did with my father although he was the one alive.

Linda, who was removed from her paternal home to live with her siblings at her maternal home due to her father's misuse of alcohol, conveyed the following

I used to be hurt by the fact that he did not come to visit me but my mother used to say he is under the influence of alcohol.

The extended family throughout the Sub-Saharan Africa is traditionally known to create a safety net to orphaned relatives. Museveni (cited in Aspaas reports of 1999) states that, traditionally at the death of parents, children are sent to live with another member of the extended family. This is, however, changing as the challenge of absorbing the ever-increasing number of children in households with limited resources suppresses in many instances the material ability of these households, regardless of the willingness or desire to help (Aspaas, 1999). Kaseke & Gumbo (2001) suggests that the harsh economic environment makes it difficult for members of the extended family to support their needy relatives. This, at times, could be one of the reasons why some extended families desert their traditional responsibilities. The following excerpts highlight some of these concerns:

My father had two sisters, the last time I saw them was in 1999 at my father's funeral.

In some cases caregivers, who were very supportive in their own way, however now being unemployed they could not assist financially. This is stated in the following excerpt,

Mbali shares:

Most of my uncles [maternal] do not work, so they are not able to assist my aunt financially.

In other cases in spite of the minimal financial resources, caregivers did not show as much affection as they could, as illustrated below:

Noluthando shares:

We are struggling there are some days that my siblings and I would go to bed with out food. Sometimes my uncle would come with a bun chow and will eat it in front of us, sometimes when he has had enough will give my brother a left over piece.

HIV and Education

The Commonwealth Secretariat (2001) reported that schools are one of the most important ways of reaching out to youth before they begin sexual activities. The constitution of South Africa says that no child should be discriminated against, treated unfairly or harassed at school because of their HIV status or because somebody in their family is HIV positive. The life-skills programmes that are taught at the different local schools are seen as an effective resource by the adolescents. These also strengthen the relationships of the teachers with the adolescents. Hence educators are reflected as an effective support system by some of the participants, while others see them as (rude and unkind). The following statements support this:

Thembile shared this:

Some teachers are kind some swear at you and call you stupid dog (frowning).

The facial expression of this participant was clear that he was not happy with the behaviour of some of the teachers. It could be that the teacher was not aware of this child's experience i.e. why he was not coping and regarded as a problem child who is misbehaving, and yet he could be crying out for love. The following excerpts highlights a different picture regarding the behaviour of the teachers and this is presented in the following excerpts:

Thando shared:

Teachers at my school treat children well, they are the ones who identified my sister and me and referred us to the aftercare.

Mbali adds:

Teachers at my school treats children well I haven't heard of any child treated badly at my school.

Felicia highlighted this:

Teachers do listen to the problems of children but I don't think children talk to teachers about their problems.

She continues:

My class mate called me names and I was angry I hit her badly that my class teacher reprimanded me and told me to come with my parent the next day. My maternal aunt came with me and she explained my teacher my problem. My teacher was very sympathetic. He arranged that I see a school psychologist so as to receive counseling.

There seems to be more support in terms of nutritious foods at primary school level, compared to high school level. This was highlighted by some of the responses of the participants:

Thembile says:

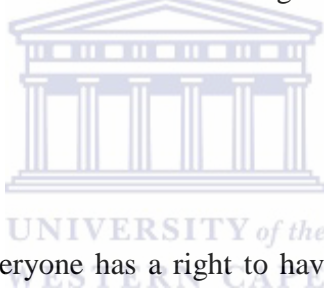
At primary we used to get bread and milk shake but here at high school we getting nothing.

Children also appear to treat each other with respect and dignity as highlighted by excerpt:

Noluthando shares:

Children treat each other well; maybe it is because in our life orientation class we are thought of HIV/AIDS and how to treat people infected and affected by HIV/AIDS.

The above excerpt also shows that the school is regarded as a place that educates the participants of HIV/AIDS.



Health Care Systems

The Constitution states that everyone has a right to have access to health care services including reproductive health. The United Nations Convention on the Rights of the Child says every child has a right to enjoyment of the highest attainable standard of health and to facilities for treatment of illness and rehabilitation of health. It is then the Government's role to ensure that no child is deprived of his/ her right to access health care services. The treatment received from nurses is seen as both negative and positive by the participants. This has been reflected in some of the statements made:

Thando shared:

Some of the nurses listen to you and some shouts at you.

He continued by saying:

When I first came to Cape Town because the clinics are at a walking distance compared to the rural areas, I wanted to know more about the disease that killed my mother and my twin sister, the nurse at the local clinic shouted me asking what I am going to do with the information, because I am too young.

Prude highlighted the following:

Kind nurses always help me when I require information for my HIV/AIDS school projects.

Yoliswa simply said:

I think she [mother] was treated well at the clinics but at the hospital [-----] I don't think they looked well after her; she was always wet or crying in pain when we visited her.



Welfare Services

The Department of Social Development and the funded welfare organisation such as Ikamva Labantu, Cape Town Child Welfare Society and Siyaphambili Orphan Village within the Western Cape are reflected as systems that support the orphans and their families in assisting them with the different grants and other material goods: This is reflected in the following experts':

Thando shared:

Our teacher wrote us a letter that we had to take to the social worker together with my grandmother for her to assist us with a [foster care] grant.

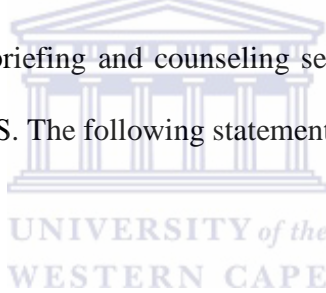
Linda shared:

She depended on the [disability] grant so I would just not tell her about the school excursions.

She continues by saying that:

The little grant money she received was for food, her medication and hiring a taxi when she goes to the doctor.

In supporting the above statement, Amoateng *et al.*, (2007) states that HIV/AIDS affected households spend a third of their income on medical care. Social workers were seen as a support system in offering debriefing and counseling services to children who had lost their parents through HIV/AIDS. The following statement highlights this:



Linda shared the following:

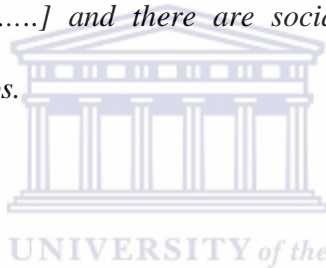
I used to cry mostly when I think of my mother. My sister then took me to the social worker at the local welfare offices and explained her [social worker] about the death of our parents. She [social worker] used to sit with me and talk comforting words and say I could cry as much as I like I am going to be fine. She [social worker] also helped me to get a school fees discount at my school. She explained to my school principal that I depend financially on my sister.

De Jong (2003) states that there is a growing determination among communities, NGOs, government departments and other stakeholders that more must be done in supporting families of victims HIV/AIDS. De Jong continues by saying that in 2001 the UN General

Assembly Special Session included the signing of a Declaration of commitment by Governments in empowering stakeholders, global and National. There are also Private Welfare organisations (PWOs) that appear to assist these orphans by providing the much needed support systems for example, Cape Town Child Welfare Society, Ikamva Labantu and Siyaphambili Orphan Village. These are identified as organisations that the Department of Social Development is buying services from as illustrated in the following excerpts,

Thando shares:

I attend the aftercare at [.....] and there are social workers that assist us with homework and take us on camps.



He continues:

They give us clothes and vegetables that are donated to the village.

Thembile just said:

She [social worker] invites me to workshops and outings organised for orphan children.

Yoliswa simply said:

At [.....] they teach us life skills and educational talks on HIV/AIDS.

Mbali added:

If you are feeling down [.....] (social worker) talks to you and most of the time you feel better

Religious Institutions

According to the Commonwealth Secretariat (2001) religious groups, particularly the Christian churches, have led the way in caring for the individuals infected and affected with HIV/AIDS. In 1997 a religious group called inter-faith was developed in Lusaka. These groups put their faith and doctrines aside and promoted a united front against HIV/AIDS. The Methodist Church of Southern Africa in their Revised HIV and AIDS Strategy and Implementation Plan (2006) states that to respond to the challenge of HIV and AIDS, the churches must be transformed in the face of HIV and AIDS crisis in order that they may become a force for bringing healing and hope to all affected by HIV/AIDS. The children had mixed feelings regarding the support they were receiving from their churches. In some of the churches ministers are not open about the HIV pandemic, while in some churches they were communicating openly about it. The following experts are the example of these:

Thando shares:

In my church I only know about my sister and me. One never hears about any talks regarding HIV/AIDS or other people who have had this experience.

Felicia highlighted:

Every Sunday there is a speaker who talks about HIV and AIDS, she continues to say we have a candle light day and children are also given a slot to share the good memories about their parents if you are strong enough.

The Methodist Church of Southern Africa in their Revised Strategy and Implementation plan (2006) notes that a support programme for people living with AIDS must include the provision for basic needs, as the body needs certain food substances to remain healthy and to be able to successfully fight against HIV. One of the participants who were asked about the kind of support he receives from his church reported that his church (Anglican Church) supports his family with food parcels. The following expert highlights this:

Thembile shared:

I do not know but our church brings us food parcels regularly.

4.4 Conclusion

This chapter has attempted to explain the findings of this study. This was presented in seven themes. These themes are divided in two sections whereby the first section is presenting the experience prior to parental death. The last section is each theme had sub themes that accompanied it. The following chapter will be focusing on the summary, recommendations and conclusion

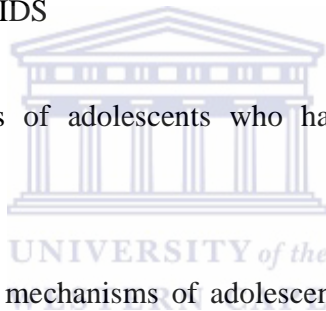
Chapter Five: Conclusion and Recommendations

5.1 Introduction

In this final chapter central issues of the findings are presented, followed by the recommendations.

This study aimed at exploring the subjective experiences of adolescents who had lost their parents through HIV/AIDS. Furthermore, the study's objectives were to:

- Understand and Describe the experiences of adolescents who have lost their parents, through HIV/AIDS
- Explore the challenges of adolescents who have lost their parents through, HIV/AIDS
- Understand the coping mechanisms of adolescents who have lost their parents, through HIV/AIDS



5.2 Central issues

The participants in this study were clients of the Ikamva Labantu project that renders foster care services within the Gugulethu community. The participants provided information regarding their experiences of losing a parent to HIV/AIDS, before and after the death of the parent. Different themes emerged during the analysis of the data, as was discussed in the previous chapter. Central and overarching issues are considered to be challenges, experiences of post-parental loss and available support resources.

5.3 Experience of participants after parental loss

Paternal families were perceived by these adolescents as mostly negative. The treatment they received was regarded as brutal by most of the participants. The participants did highlight elements of abuse within the maternal family but they were more dominant at the paternal side. The maternal grandparents were seen as the most suitable support, even though at times they experienced their own ill health. When asked whom do they regard as a parent in the absence of their biological parents, it was easy for the participants to identify with their maternal grandparents as mother and father compared to the paternal grandparents. Based on the inputs of the participants, this then concerns the researcher as it looks like paternal grandparents are not very much involved when it comes to the care of their sons children. Most of the participants highlighted minimal or no interest by their fathers in their well being after the death of their mothers.

It appears that shock, anger and denial of losing a parent was so severe that participants reacted in differing ways. Some still cried when they shared their experience about their parents. There was a significant level of anger shared as the participants described HIV/AIDS. There was a significant feeling of emptiness highlighted by the participants when other children share current activities they do with their parents, while they are not able to. This resulted in them missing them dearly.

5.4 Challenges

In looking at this theme it was clear that some of these children had to grow up quickly, so as to engage in parental roles before they were at the appropriate age. It was evident that there are cultural rituals that impeded their understanding of death. The fact that they

were used to having access to different material support, e.g. attending good schools and suddenly finding themselves in a situation which was unbearable for some of them to understand. This resulted in them having to compromise so as to understand their new life style. It was clear that there was significant, pain as some of the participants shared their experience. Research concurs that children who lose parents due to HIV/AIDS undergoes a significant level of stress and pain.

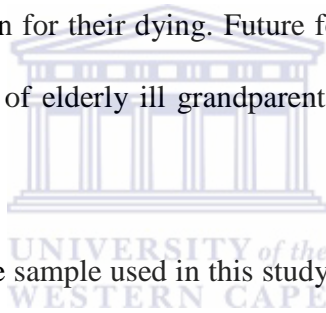
5.5 Coping strategies

It was clear that even though there was an element of negativity when it came to some of the family members such as fathers, uncles and aunts, but still the family and friends at large stood out as a very good support system. The extended family at large is still regarded as the most suitable institution to take the care of these children. The school, the health services, welfare services and the churches were perceived in different ways however in overall the feedback regarding these institutions was satisfactory. Participants in some of the areas made recommendations mostly in the health sector that the health workers be more sympathetic to the victims of HIV/AIDS and their families. It was also clear that the religious sector need to be more open and vigilant about responding to HIV/AIDS as the children did not know much about what the church was doing in-terms of awareness.

5.6 Recommendations

Based on the findings the following recommendations are made. The capability of the grandmothers to take care of these children must be continuously assessed by social workers. It is important that Welfare organisations continue to capacitate the caregivers,

as it seems the most available caregivers are elderly people. When placing these children into foster care it is important to consider close relatives or members of the community that these children are familiar with (compared to strangers). Awareness programmes should be initiated by Welfare organisations. Men to be educated and sensitised regarding the trauma caused by them, abandoning their children. Trauma counseling should be afforded to all the adolescents who lost their parents, due to HIV/AIDS. Health care workers and social workers should encourage parents to disclose their status to their children as this may minimise the trauma that they go under. Parents should be educated in order to make children knowledgeable about their extended family and their possible future caregivers, in preparation for their dying. Future foster care placement in the case where children are in the care of elderly ill grandparents. The establishment of support groups for adolescent orphans.



The researcher is aware that the sample used in this study does not represent the diversity of the Western Cape. The area does not represent the demographics of the entire province. However it is intended that this study, though a tip of the iceberg will be able to contribute to the work of social workers and all those who work in the field of children and families. It is then recommended:

- That research focusing on the experiences of the adolescents be placed on the agenda for future research, and may be replicated on a larger scale.
- A research on the relationship of HIV/AIDS adolescent orphans and Welfare professional can also be a topic to be considered.

- A topic on the experience of caregivers caring for adolescent HIV/AIDS orphans can also be considered for future research.
- The role of paternal family in caring for adolescent orphans

5.7 Limitations of the Study

The researcher viewed the following as limitations in this study. The topic is sensitive and the interview guide contained questions that were sensitive for the participants. The total sample of participants was twelve however only nine finally agreed to participate in the study. Some of the participants might have felt intimidated by the topic, and hence three withdrew from the study. As permission was requested from the caregivers they might also have been intimidated by the study. This could have influenced the feelings for some of the participants. Due to stigma relating to HIV and AIDS and experiences by HIV positive people, their families could have influenced some of the participants not disclosing their full experiences. Gugulethu is vast with the highest HIV/AIDS cases in the Western Province. The small sample size does not represent the whole of Gugulethu. Although the researcher attempted to select the participants from most of the settlements in the area, this was not possible. Therefore, the findings are not able to be generalised to all orphans living in Gugulethu.

5.8 Summary

In summary, there is partial commitment from the biological fathers to take responsibility of caring for their children (mostly after the death of the partners). Orphan children miss their parents and the activities they used to do together. The extended family is still seen

as the most suitable institution to be able to care for AIDS orphans. Culture as an institution is seen as impacting, both positively and negatively in the lives of the orphaned adolescents to HIV/AIDS. Most of the orphans were not prepared for the death of their parents thus leaving them with a lot of unanswered questions. The elderly grandparents are committed to the care of the orphaned children, despite their financial challenges and their health status. The school is seen as an institution that provides support to the orphaned adolescents. The health sector is seen as an institution that needs to be more child-friendly. There needs to be more openness and transparency at churches, regarding HIV/AIDS.

5.9 Conclusion

This chapter presented a summary of the findings, conclusion and recommendations. A public presentation will be made to the Department of Social Development, Welfare Organisations rendering services to Children and Families as well as interested parties such as community leaders, church leaders and Health professionals so as to share the findings. The researcher hopes that this report will bring value to the Gugulethu community.

REFERENCES

Amoateng, A.Y. & Heaton, T.B. (2007). Families and households in post –apartheid South Africa: Socio- demographic perspectives. Child, Youth, Family and Social Development Research Programme. HSRC.

Alpaslan, N. & Mabutho, S.L. (2005). The Experience of elderly grandmother caregivers and AIDS orphans. *Social Work / Maatskaplike Werk*. 41(3)276 – 295.

Altschuler, J. & Dale, B. (1999). *On Being an III Parent*. The Tavistock Clinic, London. Sage Publications

Arkava, M.I & Lane, T.A. (1983). *Beginning Social Work Research*. Boston

Aspaas, H.R. (1999). AIDS orphans in Uganda; Geographical and gender interpretations of household resources. *Social Science Journal* (On line), Vol. 36, No. 2, p.22 Available: (Accessed 04 November 2003).

AVERT (2008) HIV/AIDS in South Africa.

<http://www.avert.org/aidssouthafrica.htm> (Accessed 25 October 2008)

Babbie, E. & Mouton, J. (2001). *The practice of social research*. Oxford, New York, Oxford University Press.

Bannister, P., Burman, E., Parker, I., & Tindali, C. (1994). *Qualitative methods in Psychology: A research guide*. Buckingham: Open University Press.

Baylies. C., (2000) AIDS Sexuality and Gender in Africa. Perspectives on gender and AIDS in Africa. Chapter 1 p1-24.

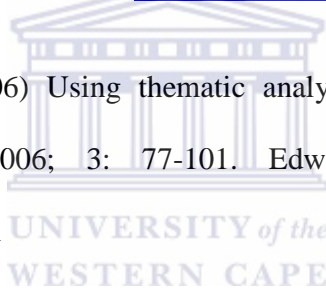
Becker, C. (1992). Living. An Introduction to phenomenology. USA: Sage

Bezuidenhout, F.J. (2004). A Reader on Selected Social Issues. Fourth Ed. Van Schaik Publishers S.A.

Bogdan, R.C. & Biklen, S.K. (1992). Qualitative Research for Education: an introduction theory and methods. Boston, London, Sydney and Toronto: Allyn & Bacon, Inc.

Bonsire, L. (2001). Youth Against AIDS: www.worldvoices.org/aids/

Braun, V. & Clarke V. (2006) Using thematic analysis in psychology. Qualitative Research in Psychology 2006; 3: 77-101. Edward Arnold Publishers Ltd: www.QualResearchPsych.com



Brenner, M. (1985) Intensive Interviewing. in M. Brenner, J. Brown and D. Canter (Eds), The Research Interview: Uses and approaches (pp.147-161). London: Academic

Cerbone, D.R. (2006) Understanding Phenomenology. Series Editor Jack Reynolds

City of Cape Town, (2002). Socio Economic Profile of the Western Cape. Cape Town

Children's ACT, 2005 (ACT (38 of 2005) Government Printers. S.A

Child Care ACT, 1983(ACT 74 OF 1983) Government Printers. South Africa

Cleiren, M.P.H.D., (1993). Bereavement and Adaptation: A comparative study of the aftermath of death. Washington: Hemisphere

Collins Concise Dictionary, (1999) Glasgow: Harper Collins

Colman, O.A. (2001). Dictionary of Psychology. New York: Oxford University Press.

Common Wealth Secretariat (2001). A Commonwealth Response to a global Health Challenge. Marlborough House: London.

Constitution of the Republic of South Africa, (1996) Act 108 of 1996. Pretoria, S.A. : Government Printers.

Creswell, J. W. (1994). Research Design: Qualitative and Quantitative Approaches. Thousand Oaks, London: Sage Publications.

Cross, C. (2001). Sinking Deeper Down: HIV/AIDS as an economic shock to rival households. *Society in Transition*, Vol. 32 (1) p 133-147.

Crotty, M. (1996). Phenomenology and Nursing Research, Churchill Livingstone, Melbourne, Australia.

Croyer, (2001) cited in Poku, N.K. (2005) AIDS in Africa. How the Poor are Dying, Malden, USA

Cullinan, K., (2000). Memory Boxes. South African Memory Box Association. Joko@pvas.co.za . <http://www.health-e.org.za/view.php3?id=20000927> (accessed on 10/17/00)

Cluver, L. & Gardner, F. (2006). The psychological well being of children orphaned by AIDS in Cape Town, South Africa. *Annals of General Hospital. Psychiatry* v.1-3. Published on line 2006 July 19.doi: 10.1186/1744-859x-5-8. BioMed Central Ltd.

Dawes, A. (2002). *Sexual Offences against Children in South Africa*. Children's Institute. University of Cape Town.

Deacon, H. & Stephney, I. (2007). *HIV/AIDS, Stigma and children. A literature review*. HSRC Press. South Africa

De Jong, J., (2003). *Making an Impact in HIV/AIDS: NGO Experiences of scaling up*. ITDG Publishing. Southampton Row, London.

Demmer, C. 2004. Loss and Grief following the death of a patient with AIDS. *Social Work*. 40(3): 294-315

Dempsey, P. (2000). *Using Nursing Research*. New York, Philadelphia.

Deng, R., L. J., Sringeriyuang, L., and Zhang K., (2007). Drug abuse, HIV/AIDS and Stigma in a Dai community in Yunnan, China. Vol. (64) p1560-1571.

Denzin, F. & Lincoln, S. (2008). *Handbook of Qualitative Research Method*. London Sage Publications.

Denzin, N.K., & Lincoln, Y.S. (2000). *Hand book of Qualitative Research*. Second Edition. London Sage Publications. Thousand Oaks

Department of Health (1998). *Youth in South Africa Bear A Terrible Burden-HIV/AIDS*.

Department of Health (2006). *Republic of South Africa: Progress Report on Declaration of Commitment on HIV and AIDS*

Department of Social Development, (2003). National Guidelines for Social Services to Children Infected and Affected by HIV/AIDS. Pretoria National Department of Social Development.

De Vos, A.S.; Strydom, H., Fouché, C.B., Poggenpoel, M., & Schurink, E. W. (1998). Research at Grassroots: A premier for the Caring Professions. 2nd Ed Pretoria: Van Schiack Publishers.

De Vos, A.S, Strydom, H., Fouché C.B., & Delpont C.S.L., (2005). Research at Grassroots, For the Social Science and Human Professions 3rd Ed. Van Schiack Pub.

Dolores, C., & Tongco, D. C. (2007). Purposive Sampling as a tool for informant selection. Ethobotany Research and Applications 5: 147-158

Dorrington, R., Bradshaw, D. & Budlender, D. (2002). HIV/AIDS profile in the provinces of South Africa. Indicators for 2002. Centre for Actuarial Research, Medical Research Council and the Actuarial Society of South Africa.

Dube, M. W., (2001) HIV/AIDS and the curriculum methods of interpreting HIV/AIDS in Theological Programmes. World Council of Churches. S.A.

Durkin, K., (1995). Developmental Social Psychology -From Infancy to Old Age. Cambridge: Blackwell Publishers Inc.

Dwivedi, K.N., (1999). Group work with children and adolescents. London: Jessica Kingsley Publishers.

Dworkin, S. H., & Kaufer, D. (1995). Social services and bereavement in the lesbian and gay community. *Journal of Gay and Lesbian Social Services*, 2(3/4), 41 -60 Cited in Nord (1997)

Edelston, K. (1988) *Countdown to Doomsday AIDS*. Media House Publications

Everatt, D. (1994) *Creating a future, Youth policy for South Africa*. CASE and JEP, Ravan Press S.A..

Ewing, D. (2000). Where love is the only therapy. *Children First*. Volume4, number 31, June-July.1998

Erikson, E. H. (1968). *Identify Youth Crisis*. New York: W.W. Norton.

Erikson, E.H. (1959). Nord, D. (1997). *Multiple AIDS- related loss. A handbook for understanding and surviving a perpetual fall*. Taylor and Francis, Washington D.C.

Erikson, E. H. (1980). *Identify and life cycle*. New York: W.W. Norton

Filliher, F., (2005) *Interpretivism and the Pursuit Research Legitimation: An Integrated Approach to Single Case Design*. *The Electronic Journal of Business Research Methodology* Volume 3 Issue 2, (123-132).

Foster, G. & Williamson, J., (2000) *A review of the current literature of the impact of HIV/AIDS on children in sub-Saharan Africa*. *AIDS*, 14(Suppl.3): S275 – S284)

Foster, G., (1997). *Children rearing children: A study of child-headed households*. Paper presented at the conference on the socio-demographic impact of AIDS in Africa, held 3-6 February 1997. International Union for the Scientific Study of population: Durban.

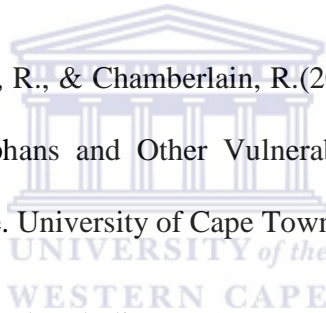
Foster, G., & German, S., (2000). The orphans Crisis (Draft). In Essex (Ed) AIDS in Africa.

Francis, E., (2001) Humanitarian Action. Sub-Saharan African Region information on HIV/AIDS. UNDP.

Frederickson, S., & Kanabus, A., (2004). Children on the Brink. A joint report of new orphan estimates and Framework for Actions. UNAIDS, UNICEF/ USAID.

Gannon, G. (1994). Children and Youth at risk of HIV/AIDS. Issues of Residential Care Community Perspectives. National Association of Child Care Workers NACCWCT.S.A.

Giese, S., Meintjies, H., Croke, R., & Chamberlain, R.(2003).Health and Social Services to Address the Needs of Orphans and Other Vulnerable Children in the context of HIV/AIDS. Children's Institute. University of Cape Town



Gilborn, L., Nyonyiton, R., Kabumbuli, R., & Jagwe-Wadda, G. (2001). Making a difference for children affected by AIDS: Baseline findings from operations research in Uganda, The population Council.

Golafshani, N., (2003) Understanding Reliability and Validity in Qualitative Research. The Qualitative Report Volume 8 no(4), 597 – 603.

Gouws, E., & Kruger (1994).Adolescent Development. An educational perspective. Pretoria: Butterworths

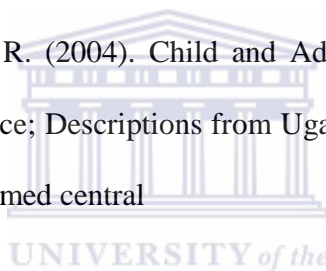
Gray, D.E., (2005) Doing Research in the real world. London. Sage Publications

Gregory, D., and Longman, A. (1992), Mothers suffering: Sons who died of AIDS. *Qualitative Health Research*, Vol2 no3, pp.334-357

Grossmann, R. (1984) *Phenomenology and Existentialism. An introduction.* Edmund Husserl, Martin Heidegger, Jean –Paul Sartre. Routledge and Kegan Paul. Mass.02108, USA

Harber, M. (1998) *Developing a community- based AIDS orphan project: A South African Case study.* ATTIC. Conference on raising the Orphan Generation. Paper No1. Pietermaritzburg.

Harms, S., Jack, S. & Kizza, R. (2004). *Child and Adolescent psychiatry and mental health. The orphaning experience; Descriptions from Ugandan adolescents who have lost parents to HIV/AIDS.* UK Pub med central



Harvey, R.D. (2001). *Individual differences in the phenomenological impact of social stigma* , *journal of social psychology* 141(2): 174 – 189)

Heidegger, M. (1962). *Being and time, a translation of Seinund Zet* by John Macquire and Edward Robinson. New York: Harper Publishers

Hein, S. F. & Austin, W. J., (2001). *Empirical and Hermeneutic approaches to phenomenological research in psychology: A comparison.* *Psychological methods*, 6, 3-17

Heymann, J. & Kidman, R. (2008) Weaving a tighter safety net: How communities can support families in the context of the AIDS pandemic. Institute for Health and Social Policy. Issue Brief 111.

Hope, (2001). Cited in Poku, N.K. (2005). AIDS in Africa. How the Poor are dying. Malden, MA 02148, USA

Hunter, S. & Williamson, J. (2000). Children on the Brink. Executive Summary. Updated Estimates and Recommendations for Interventions. United States Agency for International Development

Husserl, E. in Spiegelberg, H. (1976). The Phenomenological Movement: A Historical introduction. Vol. 2, Martinus Nijhoff, The Hague

Intergrated Development Plan, (2004). City of Cape Town. Cape Town

Jackson, S., Rodriguez-Tome, H. (1993). Adolescence and its social worlds. Lawrence Erlbaum Associates Publishers

Jaffe, M. L. (1998). Adolescence John Wiley and Sons, Inc.

Jennings, J.L. (1986). Husserl revisited: The forgotten distinction between psychology and phenomenology. American Psychologist, 41, 1231 - 1240

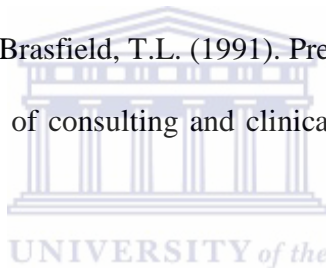
Jogunosimi, J. (2001). Advocates for the Youth: The HIV/AIDS Pandemic among youth in Sub-Sahara Africa .200m Street, NW. Suite 750, and Washington DC.E-mail: questions@advocatesforyouth.org.

Kaseke, E. & Gumbo, P., (2001). The AIDS Crisis and Orphan Care in Zimbabwe. *Social Work*, Vol. 37 (1) p 53-58.

Kelliher, F. (2005). Interpretivism and the Pursuit of Research Legitimation: An Intergrated Approach to single Case Design. *The Electronic Journal of Business Research Methodology*. Volume 3 Issue 2, pp 123 -132.

Kelso, B. J. (1994). Orphans of the storm, *Africa Report*, Vol. 39, no.1 p5 Available: Ebscohost: Academic search premier Item: AN9406080336 [accessed 04 November 2003].

Kelly, J. A., Lawrence, J. S. & Brasfield, T.L. (1991). Predictors of vulnerability to AIDS risk behaviour relapse. *Journal of consulting and clinical Psychology*. Vol 59 no 1, pp. 163 – 166.



Kelly J.A., (2001). The Impact of HIV/AIDS on the Rights of children to education: Paper presented at the SADC/EU Seminar on the rights of children in a world with HIV/AIDS. Harare

Kersten, F. (1982). Edmund Husserl. Ideas pertaining to a pure phenomenology and to a phenomenological philosophy. Martinus Nijhoff publishers

Kiragu, D. (2002). Addressing the susceptibility of Youth to HIV/AIDS infection. Paper presented at the International Policymakers Conference on HIV/AIDS. Track 1A: knowledge and behaviour change. New Delhi, India 11 – 12 May 2002. www.csakenya.org/pdfs/vct-report- PageMaker. PDF. [Accessed on 20 October 2007]

Kirk, J. & Miller, M. (1986). Reliability and Validity in qualitative research. Sage University paper series on qualitative research methods, No.1. Newbury Park, California: Sage Publications.

Kluckow, (2004) cited in Van Dyk, A. (2008) HIV/AIDS Care and Counseling. A multidisciplinary approach 4th edition. Maskew Miller Longman Ltd Cape Town

Kock, (1995), cited in Paley, J. (1997), Husserl, phenomenology and nursing, Journal of Advanced Nursing, Vol 26, pp.187 – 193.

Kohlberg (1978). cited in Van Dyk, A. (2008) HIV/AIDS Care and Counseling. A multidisciplinary approach 4th edition. Maskew Miller Longman Ltd Cape Town

Kubler-Ross, E. (1985). On Children and Death. A touching and inspired work about how children and their parents can and do cope with death. Macmillan Publishing Company, New York.

Kubler-Ross, E. (1987) On death and dying. Macmillan Publishing Company, New York.

Lacity, M.C. & Johnson, M.A. (1994). Understanding Qualitative Data: a framework of text analysis methods. Journal of Management Information Systems/Fall1994. pp.137 – 155.

Leclerc-Madlala, S. (1997). Infect one, infect all: Zulu youth response to the HIV/AIDS epidemic in South Africa.

Leedy, P.D., (1997) Practical Research: Planning and design. 6th Ed Columbus, Ohio: Prentice Hall

Lincon & Gumba (1985) cited in De Vos, A.S, Strydom, H., Fouché C.B., and Delport C.S.L., (2005). Research at Grassroots, For the Social Science and Human Professions 3rd Ed. Van Schiack Pub.

Lynch, V.J. (2000) HIV/AIDS at year 2000.A Source Book for Social Workers. Boston Collage

Louw

Louw, D.R. Darleen, D.R., & Orr, M., (2001). HIV/AIDS: Care and Support of Affected and Infected Learners. A guide for Educators. Department of Health South Africa.

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

Maj, M. (1991) Psychological problems of families and health workers dealing with people infected with Human Immunodeficiency Virus 1, Act Psychiatric Scandinavia, vol. 83, no 3 pp.161 - 168

Mapp, T. (2008) Understanding phenomenology the lived experience. Research and Education. British Journal of Midwifery, May 2008. Vol. 16 no 5 (308 – 311)

Marcus, T. (1999). Wo! Zaphela Izingane. Living and Dying with AIDS. Blesston Printing Johannesburg.

Marshall & Rossman (1999) cited in De Vos, A.S, Strydom, H., Fouché C.B., and Delport C.S.L., (2005). Research at Grassroots, For the Social Science and Human Professions 3rd Ed. Van Schiack Pub.

May, L. (1993). *Qualitative Research*, London Sage Publications.

McKerrow, N. (1994). When children are orphaned by AIDS. *Positive Outlook* Vol. 1(4), pp. 8-9.

Meintjies, H. & Giese, S. (2003) Addressing the impact of HIV/AIDS on children in South Africa. *Priorities for funders and Development Agencies*. Children's Institute. UCT. Rondebosch

Meintjies, H., & Giese, S. (2004) Addressing the impact of HIV/AIDS on children in South Africa. *Priorities for Funders and Development Agencies*: Children Institute. U.C.T. S.A.

Meintjies, H., Hall, K., Marera, D. & Boule. (2010). *AIDS Care* 01, 10 Vol.22; (1): 40 - 49.



Metcalf, L. (2001). *Youth and HIV/AIDS*: www.stopglobalaids.org

Miles, M. B. & Huberman, A.M. (1994). *Qualitative data analysis: an expanded sourcebook*, second edition. Sage Publications

Milton, J., (2000). The Social spread of HIV/AIDS in South Africa. *Journal of association of nurses in AIDS Care*, 11(4): 17-26

Morris, A.L. (1995). *Listening to older adult learners: the experience of using assistive technology in task performance and home modification*. Blacksburg, VA: Virginia Tech

Myers, M.D. (1997). *Qualitative Research in Information Systems*. *MIS Quarterly*, 21(2), 241 -242.

Mouton, J. (2001). How to succeed in your Master's & Doctoral Studies. A South African Guide and Research Book. Van Dyk Publishers.

Munro, I. (2002). The Lived experience of Gay Men caring for others with HIV/AIDS: living, loving and dying in the era of HIV/AIDS. Submitted in fulfillment of the requirements for the degree of Doctor of Philosophy. School of Nursing Deakin University.

Murphy, D., Johnston-Roberts, K. & Hoffman, D. (2003). Regrets and advice from mothers who have disclosed their HIV+ serostatus to their young children. *Journal of child and Family Studies* 12(3): 307-318.

Museveni cited in Aspaas, H.R., (1999). AIDS orphans in Uganda; Geographical and gender interpretations of household resources. *Social Science Journal* (On line), Vol. 36, No. 2, p.22. [Accessed 04 November 2003].

National Programme of Action for Children in South Africa. The Presidency, (2001). *Children in 2001 .A Report on the state of the nation's children*. Office on the rights of children .The door communications.

Newman, W. L. (1997). *Social Research Methods: Qualitative and Quantitative Approaches*. Boston: Allyn and Bacon.

Ng'weshemi, J.; Boerman T. & Schapink D. (1997). *HIV prevention AIDS care in Africa. A district level approach*. Royal Tropical Institute, Nederland.

Neill, J., (2006). Analysis of Professional literature Class 6: Qualitative Research
Accessed on 2009/06/09 from:

Nord, D. (1997). Multiple AIDS- related loss. A handbook for understanding and
surviving a perpetual fall. Taylor and Francis, Washington D.C.

Norman, A., Kadiyala, S. & Chopra, M. (2005). Placing HIV-positive Mothers at the
Centre of planning for Orphans and Vulnerable Children: A Case Study of South Africa.
MRC. S.A.

Paley, J. (1997). Husserl, Phenomenology and nursing. A journal of advanced nursing,
vol. 26. pp.187 - 193

Papalia, D. E., Olds, S. W. & Feldman R.D. (2008) A child's world. Infancy through
adolescence Eleventh Edition McGraw-Hill International Edition

Parker, W. & Aggleton S. (2002). On the move: The response of public transport
commuters to HIV/AIDS in South Africa, Department of Health: S.A.

Parkes, C. M. (1970). The first year of bereavement: A longitudinal study of the reactions
of London widows to the death of their husbands, Psychiatry, vol.33, pp. 444 – 467

Parry, J.K. (1989) Social Work Practice with Terminally Ill. Haworth Press

Patton, M. Q. (1990). Qualitative evaluation and research methods 2nd Ed. London: Sage
Publications.

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

Perkel, A.K. (1992). *The mindspace of AIDS: Dynamics of transmission*. Cape Town:

Piaget (1950) cited in Papalia, D. E., Olds, S. W. & Feldman R.D. (2008) *A child's world. Infancy through adolescence Eleventh Edition McGraw-Hill International Edition*

Poku, N.K. (2005) *AIDS in Africa. How the Poor are Dying*. Malden, MA 02148, USA

Potter, J. & Wetherell, M. (1987). *Discourse and social psychology: beyond attitudes and behaviour*. London: Sage Publications.

Pretorius, H.G., Goldstein, N. & Stuart, A.D. (2005). *Meaning-Making of a group of South Africans in their experience of living with HIV: A Phenomenological Study*. *Health S.A.* Vol. 10 No.1

Rau, A. (2002). *combating child labour and HIV/AIDS in Sub-Sahara Africa. A review of policies, Programs, and projects in South Africa, The United Republic of Tanzania, and Zambia to identify good practice*. Printed in France.

Ray, M. A. (1994) in Morse, J.M. eds. (1994). *Critical issues in Qualitative research methods*. Sage Publications, Thousand Oaks

Richter, L. Manegold, J. & Pather, R. (2004). *Family and community interventions for children affected by AIDS*. Cape Town : HSRC Press.

Robertson, M., & Donaldson, M., (2003). *Family murder, the child victims*. <http://www.csvr.org.za/articles/artfamur.htm>. [Accessed on 2003.10.15]

Ross, E., & Deverell, A. (2004). *Psychosocial approaches to health, illness and disability: a reader for health care professionals*. Pretoria: Van Schaik Publishers.

Rossmann (1999) cited in De Vos, A.S, Strydom, H., Fouché C.B., and Delpont C.S.L., (2005). *Research at Grassroots, For the Social Science and Human Professions* 3rd Ed. Van Schiack Pub.

Rubin, H. J. & Rubin, I. S. (1995). *Qualitative Interviewing: The art of hearing data*. London .

Rubin, A. & Babbie, E., (1997). *Research Methods for Social Work*. USA: Brooks/Cole Publishers

SAHARA, (2004). *Journal of Social Aspects of HIV/AIDS*. Vol. 1 NO.2 August 2004

Seaberg, J.R. (1998). Utilising sampling procedures. In Grinnell, R. M. *Social Work Research and Evaluation*. Third Edition, Itasca, IL: Peacock

Shaffer, A., Johns, D., Kotchick, B., Foreland, R., & The Family Health Project Research Group. (2001). Telling the children: Disclosure of maternal HIV Infection and its effects on child psychosocial adjustment. *Journal of Child and Family studies*. 10 (3): 301-313.

Shank, G. (2006) Six alternatives to mixed methods in qualitative research. *Qualitative Research in Psychology*; Vol.3: 346 – 356.

Shisana, O., and Simbayi, L., (2002). *Nelson Mandela / HSRC Study of HIV/AIDS: South African National HIV Prevalence, Behavioural Risks and Mass Media. Household Survey*. Cape Town: HSRC Press.

Shisana, O., Rehle, T., Simbayi, L.C. & Parker, W. (2005). South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey. Cape Town. HSRC Press.

Shisana, O., Rehle, T. Simbayi, L.C. & Zuma, K. (2009). AIDS among older children and adolescents in Southern Africa. United Nations Plaza, New York. USA

Simon –Meyer, J. (1998). Children in distress best practice response to children affected by the HIV/AIDS epidemic.

Slot-Nielson, J. (2004). Realising the rights of children growing up in child-headed households. A guide to laws, policies, and social advocacy. Creda Communications

Smart, R. (2000). Children living with HIV/AIDS in South Africa. A Rapid Appraisal. A NACTT Project. Save the children.

Smart, R. (2003). Policies for orphan and vulnerable children: A framework for moving ahead. Policy project, USAID. Washington DC.

Silverman, D. (2001) Interpreting Qualitative Data. Methods for analysing talk Text and Interactions. Second Ed. Sage Publications

Spiegelberg, H. (1978). Doing Phenomenology: Essays on and in Phenomenology. Martinus Nijhoff. Hague

Spiegelberg, H. (1976). The Phenomenological Movement: A Historical introduction. Vol. No.1. Martinus Nijhoff, The Hague

National Strategic Action Plan (2007) HIV/AIDS and STI Strategic Action Plan for South Africa 2007 – 2011. Pretoria.

Straus, A. and Corbin, J., (1998) Basics of Qualitative Research, London: Sage Publishers

Stedeford, A. (1988). Facing Death. Patients, families and professionals. Heinemann Professional Publishing Ltd.

Steinberg et al., (2002) cited in Poku, N.K. (2005). AIDS in Africa. How the Poor are dying. Malden, USA

Steffenson, E.A. MPH. (2002). South African youth's knowledge, attitudes and practices: Potential implications for the AIDS epidemic.<http://www.kff.org/>

Terminology Committee for Social Work, (1995). New Dictionary of Social Work Cape Town: Bookbinders.

Todres, L. (2005). Clarifying the life-world: descriptive phenomenology. Qualitative research in health care journal (104 -145) England: Open University Press.

Tongo, D. C. (2007). Purposive Sampling as a tool for informant selection. Ethobotany Research and Applications 5: 147-158

UNAIDS, (1998). Force for Change: World AIDS Campaign with young people: World AIDS Campaign Brief Paper. Geneva.

UNAIDS, (1999). Listen, Learn, Live! World AIDS Campaign with Children and Young People: Geneva. AIDS Epidemic update. UNAIDS (2000). *Report on global HIV/AIDS epidemic 1211 Geneva 27 Switzerland.*

UNAIDS, (2000). A matter of life and death. South African Journal, 4(12), 3. Robertson AIDS Action Group.

UNAIDS, (2002). A conceptual framework and basics for Action: HIV/AIDS Stigma and Discrimination. Geneva: UNAIDS

UNAIDS, (2005). New Report presents three scenarios for AIDS in Africa by 2025. UNAIDS

UNAIDS, (2008). Report on the Global AIDS epidemic. Geneva: UNAIDS

UNICEF (2003) The Impact of HIV/AIDS on children. A paper presented at 3rd meeting of the African Committee of Experts on the rights and Welfare of the Child. Ethiopia: Addis Ababa

UNICEF (2007) Africa's Orphaned Generations. For Every Child Health, Education, Equality, Protection. Advanced Humanity

Van Dyk, A. (2001). HIV/AIDS Care and Counseling a Multidisciplinary Approach 2nd Ed., Maskew Miller Longman Group.

Van Dyk, A. (2003). HIV/AIDS Care and Counseling: A Multidisciplinary Approach 2nd Edition Pretoria: Pearson Education South Africa

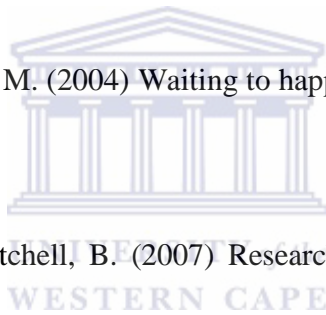
Van Dyk, A. (2008) HIV/AIDS Care and Counseling. A multidisciplinary approach 4th Ed. Pearson Education S.A.

Van Manen, M. (1990). Researching lived experience: Human science for an action sensitive pedagogy. The Althouse press, Canada

Van Praag, E. (1995). The Continuum of care: Lessons from developing countries. *International AIDS Society Newsletter*, 3, 11-13.

Vika, G. M. (2006) Revised HIV and AIDS Strategy and Implementation Plan. The Methodist Church of Southern Africa.

Walker, L., Reid, G. & Cornel, M. (2004) Waiting to happen. HIV/AIDS in South Africa. University of Witwatersrand



Welman, C. Kruger, F. & Mitchell, B. (2007) Research Methodology 3rd Ed. Oxford University Press S.A.

Whiteside, A. & Sunter, C. (2000). AIDS: The challenge for South Africa. Cape Town

Williams, M. J. (1988). Gay men as Buddies to persons living with AIDS and ARC, *Smith College studies in Social Work*, vol.59, no1, pp.38 – 52

Williamson, J. (2004). What can we do to make a difference? Situation Analysis concerning children and Families affected by AIDS. Displaced children and orphans. Funds of USAID.

Williamson, J. (2002). Strategic Action for Children and Families Affected by AIDS: USAID.

Wolfet, A., (1987). Helping children cope with grief. Indiana: Accelerated Development Inc.

World Health Organisation (WHO) (2004). The Weekly Epidemiological Records No 47 and 48, November – December; UNDP: Human Development Report.

Wong, G. & Jevne, R. E. (1997) Patient hope: Exploring the interactions between physicians and HIV seropositive individuals', *Qualitative Health Research* vol.7, no1, pp.32-56.

Wyse, D. (2004) *Childhood Studies: An introduction* Blackwell Publishing



Appendix 1: Request for permission to conduct a Study

Request for permission to conduct a Study

The Director Ikamva Labantu
Woodstock
Cape Town

Dear Sir/ Madam

RE: Requesting permission to conduct a Research Study with the clients of your organisation.

I am currently a Master's student, in the Child and Family Studies Programme, Social Work Department at the University of the Western Cape. My thesis is, **An Explorative Study on the Experiences of Adolescents who have lost their parents to HIV/AIDS.**

The study will focus on adolescents who have lost parents through the HIV/AIDS pandemic. They will have to reside in Gugulethu, and will have to be part of your foster care programme; they will have to be willing to participate in the interviews. Should you grant me permission, a follow up meeting will be arranged with the foster parents so as to arrange a meeting with them and explain the purpose of the study. The results of the study will be made available to you before any information is published.

I shall appreciate if you and your management will favourably consider my request.

Thanking you in advance

N. W. Somtsewu (Mrs.)
MA. Child & Family Studies Student
University of the Western Cape

APPENDIX 2: Consent form

Consent form

I..... (Caregiver) hereby give consent that my (grandchild, niece, nephew, sister, brother, or friend's child Participate in the research study entitled: **An explorative Study on the Experience of adolescents who have lost their parents through HIV/AIDS.**

It has been explained to me that a mini-thesis in partial fulfillment of requirements for a Master's degree in Child and Family Studies will be submitted to the Social Work Department at the University of the Western Cape.

The purpose of the research was explained to me as the caregiver. I am informed that all the information regarding my child will be kept anonymous. I was informed that under no condition will the participant be forced to participate, and the caregiver has the right not to allow his/her child to participate in the exercise. However the contribution that the participation of my child will make for the development of future policies regarding orphaned adolescents was also explained.

The researcher has informed me that should there be a need for my child to be sent for counseling due to him/her feeling distressed, such service will be arranged at no cost.

Signature of Guardian: Date:

Signature of Researcher: Date:

Appendix 3: Assent form

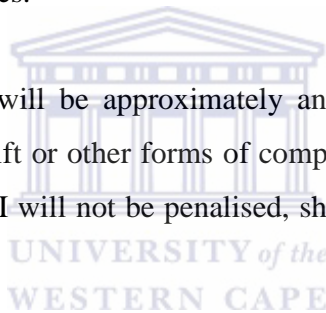
Assent form

I (Participant), hereby declare that

I shall participate out of my own free will in the interview, as the purpose of the study has been explained to me. I am prepared to cooperate by sharing my life experience and be honest at all times.

I understand that my identity will be kept anonymous at all times. I understand that after the mini-theses have been compiled all the tapes and transcripts will be erased so as to ensure confidentiality at all times.

I agree to the interview that will be approximately an hour. I understand that I will receive no form of payment, gift or other forms of compensation for my participation in the interview. I am aware that I will not be penalised, should I choose to withdraw from the interview.



I am aware that the topics to be discussed are about how the experience of losing my parents has affected me. I am aware that due to the nature of the sensitivity of this topic that I might be upset and emotional. I am aware that the Researcher will arrange counseling for me should I should I require it at no cost.

Signed aton this

Signature of participant.....

Signature of researcher

Appendix 4: Interview guide:

Interview guide:

1. BACKGROUND INFORMATION:

Ukulungiselela le-ngxoxo ndicela undixelele igama lakho kunye negama ongathanda ndikubize ngalo kwesi sicatshulwa.

For the perpose of this study can you please give me a name that you would like me to call you?

Mingaphi Iminyaka yakho yobudala?

How old are you?

Ukweliphi ibanga esikolweni?

In which grade are you at school?

Unexesha elingakanani ufunda kweli-banga?

How long are you in this grade?

Unexesha elingakanani uhlala kwelikhaya uhlala kulo ngoku?

How long are you residing at your current home?

Misebenzi mini oyenzayo akhaya?

What type of chores are you doing at home?

Ungena kweliphi ibandla/inkozo/icawa?

To which congregation do you belong?

2. FAMILY RELATIONS:

Ubuhlobo ngokweFemeli

2.1. I would like us now to do what I call a family tree. Do you know what a family tree is? If not I explain.

Ndifuna senze lento kuthwa ngumNombo wefemeli, uyawazi umnombo wefeli? ukuba akundiva ndizakukuchazela banzi.

2.2. Who do you regard as a parent close to you in the family? Why is it so? Ngowuphi uMzali ocinga ukuba nguyena osondele kuwe efemelini yakho? kutheni kunjalo?

- 2.3. Tell me about your relationship with your mother and father?
Khawundixelele bunjani ubuhlobo phakathi kwakho noMama kwakunye noTata wakho?
- 2.4. What kind of activities did you use to do with your parent(s)? (probe)
Misebenzi mini obuthi uyenze nabazali bakho?
- 2.5. Can you please share who your father's siblings and your mother's siblings are?
Ndicela ukhe undichazele ukuba ngobani abantakwabo Tata kwakunye noMama wakho?
- 2.6. Can you talk about the relationship between you and your aunt and uncles you have told me about?
Ungakhe undixelele ngokuba bunjani ubuhlobo phakathi kwakho noMakazi bakho kwakunye noMalume bakho obundinike bona?
- 2.7. Do you live with any one of them? (Probe)
Ingaba uhlala nomnye wabo?
- 2.8. What is it like growing up under the care of relatives? (Probe)
Uva njani/kunjani ukukhulela phantsi kwenkathalelo yezizalwana zakho?
- 2.9. How many children did your parents have, and what are their ages and gender?
Bangaphi abanye abantwana bakokwenu ngaphandle kwak kubazali bakho?
Zingaphi iintombi, emangaphi amakhwenkwe, mingaphi iminyaka yabo?
- 2.10. Describe your relationship with each of relationship siblings? (probe)
Ungakhe undichazele banzi ngobuhlobo phakathi kwakho nabantakwenu?

3. PARENT CHILD RELATIONS AND PARENTS DEATH:

Ubuhlobo bomzali nomntwana kwakunye nokusweleka kwabazali:

- 3.1. Can you please share your relationship with your mother? (Probe)
Ungakhe undibalisele ngonxulumelwano/ngobuhlobo phakathi kwakho noMama wakho.
- 3.2. How did you find out about your mother/ father's HIV/AIDS status? (Probe)
Ufumanise/uve njani ukuba uMama/ uTata wakho ugula yintsholongwane yeNgculaza/kaGawulayo?
- 3.3. How did you cope with your mother/ father's HIV/AIDS status? (Probe)
Uye wamelana njani nalemeko yokuba umzali wakho ugula yiNtsholongwane yeNgculaza/kaGawulayo?
- 3.4. How did your mother/ father's illness impact on his/her parenting role? (Probe)
Indima yobuzali iye yaphazamiseka njani ngexesha ebegula yintsholongwane yeNgculaza/kaGawulayo uMzali wakho?
- 3.5. How often did your mother/ father express their love to you as the child?
Ebelibonakalisa kangaphi, njani uthando lwakhe uMama/uTata wakho kuwe njengoMntwana wakhe?
- 3.6. How did you cope seeing your parent in pain? (Probe)
Uye wamelana njani nemeko yokubona umzali wakho esezintlungwini?
- 3.7. How did you react when you were told that your mother/ father had died? (Probe)
Uye wenzani usakuxelwa ukuba uMama /uTata wakho uswelekile?
- 3.8. What was the reason for you to react that way? (Probe)
Ibiyintoni na isizathu sokuba wenze ngolohlobo/ngalondlela?

- 3.9. Was there any particular person who helped you emotionally to deal with the death of your mother/father? (Probe)
Ingaba kubekho Mntu na oye wakululeka ngokwasengqondweni kwintlungu obukuyo yokushiya ngumzali?
- 3.10. Who is the person who looked after your mother/ father during his/ her illness?
Ngubani na uMntu obejongana nomzali wakho ngexesha lokugula kwakhe yintsholongwane kaGawulayo?
- 3.11. With whom were you staying at the time of your mother/father's death and in what province?
Ngelixesha uMama/uTata wakho aswelekayo ubuhlala nabani na? kweliphi iPhondo?

4. EDUCATIONAL EXPERIENCE

Amava ngokweMfundo/eSikolweni



- 4.1. How was your education affected by your parent(s) illness? (Probe)
Ingaba imfundo yakho yaphazamiseka njani kukugula komzali wakho?
- 4.2. Did you ever have to stay out of school because you had to care for your ill parent(s)? (Probe)
Wakhe wahlala awaya esikolweni kuba kwakufuneka wonge umzali wakho?
- 4.3. Have you ever not been able to pay school fees because of the illness/death of your mother/father? (Probe)
Ubukhe wakwimeko apho ungakwaziyo ukuhlawula iimali zesikolo ngenxa yokugula nokusweleka koMzali wakho?

- 4.4. Did you receive food from the school feeding scheme? (Probe)
Ubukufumana ukutya kwinkxaso yokudla efunyanwa ngabantwana esikolweni/abangathathi ntweni?
- 4.5. In your opinion, how do teachers and other children treat children who have lost parents through AIDS at your school? (Probe)
Kokwakho ukucinga/nokubona ingaba abantwana abazinkedama ngenxa kaGawulayo baphatheka njani esikolweni sakho?
- 4.6. Do teachers listen to the problems of children who have lost their parents through AIDS? (Probe)
Ingaba abafundisi ntsapho/ootishala bayazimamela iingxaki abathi bahlangabezane nazo abantwana abaswelekelwe ngabazali ngenxa kaGawulayo?
- 4.7. What kind of support do teachers give to children who have lost parents through HIV/AIDS?
Loluphi uhlobo lwenkxaso/loncedo oluthi lunikwe ngabafundisi ntsapho kubantwana abazinkedama ngenxa kaGawulayo?

5. HEALTH EXPERIENCE

Amava ngokwezempilo

- 5.1. How often did your mother/father have to attend the local clinics and hospitals? (Probe)
Umzali wakho wayeqhele ukuya kangaphi kumaZiko oonyango nasesiBhedlele (Clinics and Hospitals)?
- 5.2. How can you describe the treatment your parent(s) received at the local clinics including the medication administration? (Probe)
Ungakhe undichazele banzi ngempatheko umzali wakho ebethi ayifumana esiBhedlele naseKliniki kwakunye nendlela ebenikezwa ngayo amayeza akhe?

- 5.3. How are children who have lost their parents through AIDS treated at the local clinics? (Probe)
Abantwana abaswlekelwe ngabazali ngenxa kaGawulayo ingaba baphatheka njani kwikliniki yasekuhlaleni?
- 5.3. What do you think are the reasons for children your age to normal go to the local clinics? (Probe)
Ucinga ukuba yintoni izizathu ezibangela abantwana abakobu budala bakho baye ezikliniki ezisekuhlaleni.?
- 5.4. Can you share some of your experiences when you attend the local clinics to ask about HIV/AIDS or perhaps contraceptives? (Probe)
Ungakhe wabelane nam ngamava akho xa ubukhe waya ekliniki esekuhlaleni nokubuza ngentsholongwane yesandulela sengculazi kunye noGawulayo okanye ngamayeza okuthithela?

6. RELIGIOUS EXPERIENCE:

Amava ngokwaseNkozweni/Ecaweni

- 6.1. Are there any projects or programs at your church run for children who have lost their parents through HIV/AIDS? (Probe)
Ingaba enkonzweni/ecaweni yakho zikhona akhona amahlelo ezenzelwe abantwana abathe bashiywa ngabazali ngenxa kaGawulayo?
- 6.2. How does the congregation treat children who have lost parents through HIV/AIDS? (Probe)
Ibandla/inkozo yakho libaphatha njani abantwana abathe bashiywa ngabazali nganxa kaGawulayo?

7. ECONOMIC PRESSURE

Ubunzima ngokwesezimalini.

- 7.1. Who supported you financially before your mother/father became ill? (Probe)
Phambi kokuba uMama okanye uTata wakho agule ngubani obekuxhasa ngokwasemalini?
- 7.2.1 Who supported you during his/her illness? (Probe)
Ngubani oye wakuxhasa ngethuba lokugula loMzali wakho?
- 7.3 . How did the illness and death of your mother/father affect your family's financial situation? (Probe)
Ingaba ukugula nokusweleka komzali wakho kwayichaphazela njani imeko yezemali efemelini/ ekhaya?
- 7.3.1 After the death of your parent(s) who provided for your basic needs like food, clothes and shelter? (Probe)
Emva kokusweleka komzali wakho, ngubani owathi wajongana neemfuno zakho ezinjengokuba ufumane ukutya,impahl kwanendawo yokuhlala?
- 7.3.2 What was this person(s) doing that makes you feel that they are /were responsible for your basic needs? (Probe)
Wayesenza ntoni loMntu eyathi yabangela uzive eluthathele kuye uxanduva lokuba ufumane ukutya, impahla kwakunye nendawo yokuhlala?

4. SOURCE OF SUPPORT:

Iziko/umthombo wenxhaso

- 4.1. Who are the people that helped you deal with the illness of your parents? What did they do to support you? (Probe)
Ngobani abantu abathi bakunceda ukukomeleza ukuba umelane nokugula komzali wakho, Benzani ukuxhasa wena?
- 4.2. How did the people that you lived with (at home) treat you when they heard that your mother/ father have AIDS? (Probe)
Baye bakuphatha njani abantu ohlala nabo ekhaya bakuva ukuba uMzali wakho unentsholongwane kaGawulayo?
- 4.3. I would like you to tell me who your friends are? How long have you been friends? Why have you chosen the above mentioned as your friends? (Probe)
Ungakhe undixelele ukuba ngobani abahlobo bakho? Lixesha elingakanani bengabahlobo bakho? Kwakutheni ukuze ukhethe bona njengabahlobo bakho?
- 4.4. Can you describe any changes in your relationships with your friends during their illness and after their death? (Probe)
Ungakhe undichazele banzi ngentshintsho ezathi zenzeka bakathi kwakho nabahlobo bakho malunga nobuhlobo benu ngexesha lokugula nokusweleka koMzali wakho?
- 4.5. Besides your friends and family who else helped you deal with the death of your mother/father; was there a nurse, a social worker, psychologist, or a teacher who helped you? (Probe)
Ngaphandle kweFemeli nezihlobo zakho ngubani omnye owathi wakunceda ukuba womelele umelane nokusweleka koMzali wakho kwaba balandelayo ingaba yaba nguMongikazi, nguNontlalontle, uMntu ojongana nabantu ngokwasengqondweni okanye umfundisi ntsapho?

- 4.6.** Can you please share with me what this person has done for you to help you deal with the death of your parent(s)? (Probe)

Ungakhe undichazele ukuba wenza ntoni lomntu kuwe ukuncedana nawe ukuba womelele umelane nokusweleka koMzali wakho?

- 4.7.** Do you know of any organisations in your community that supports children who have lost parents through HIV/AIDS? (Probe)

Ingaba unolwazi lwemizi enikezela iinkonzo ekuhlaleni ethi ixhase abantwana abaswelekelwe ngabazali ngenxa kaGawulayo?

