

EXPERIENCES OF ADOLESCENTS WHO LOST A PARENT TO AIDS IN THE WESTERN CAPE, SOUTH AFRICA: A QUALITATIVE STUDY

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Abstract

Background: AIDS related deaths of parents have resulted in large numbers of children being orphaned. Adolescence, a particularly vulnerable period in a child's developmental life is characterised by uncertainties, role confusion and identity crises. This stage becomes even more complex when adolescents lose their parents through AIDS. The purpose of this qualitative study was to explore the experiences of adolescents who have lost their parents through AIDS.

Methods: In-depth interviews were conducted with 8 adolescents between 14-17 years old who had lost a parent to AIDS. A thematic analysis of the transcripts was performed.

Results: Some of these adolescents had to grow up quickly, so as to engage in parental roles before they were of appropriate age. The participants had to endure multiple stresses. The maternal grandparents were seen as the most suitable support compared to the paternal grandparents.

Conclusions: 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. Trauma counselling should be afforded to adolescents who lost their parents due to AIDS. Interventions are urgently needed that are suitable to the local context and that address bereavement as well as other issues that affect the day-to-day lives of these adolescents. Additional studies are needed to identify factors that promote resilience among these adolescents and the role of paternal family in caring for adolescent orphans.

Keywords: Adolescents, care-giving experiences, HIV/AIDS, orphans, South Africa, Qualitative methodology, thematic analysis, socio-cultural effects

Background

Orphaning caused by HIV/AIDS is an increasing and chronic problem affecting developing countries throughout the world and the AIDS epidemic has created more than 15 million orphans worldwide (Van Dyk, 2008). Studies suggest that parental death rates among AIDS orphans are between 2.5 and 3.5 times higher than those of children with parents (Van Dyk, 2008). Furthermore, over half of all orphans under the age of 18 years are adolescents aged between 12 and 17 years (Thupayagale-Tshweneagae & Mokomane, 2013). Statistics SA (2013) reported that the total number of persons living with HIV in South Africa increased from an estimated 4 million in 2002 to 5, 26 million by 2013 and sub-Saharan Africa accounted for 90% of the estimated 16.6 million global AIDS orphans in 2009 (UNAIDS, 2010). In South Africa alone an estimated 2.2 million children, 12% of all the children under the age of 18 years, have lost both parents to HIV/AIDS (Van Dyk, 2008; UNAIDS 2010).

Overall, orphaned and vulnerable adolescents often lack role models and social support systems vital to healthy development, particularly in relation to education and livelihoods (UNICEF, 2002). The social and environmental contexts of adolescents in South Africa are clearly impacted by poverty and the extent of the HIV epidemic, which have a complex impact on adolescent grief. AIDS-related deaths shape children's and adolescent's expressions of grief which are formed in and around feelings of avoidance, shame, stigma, fear and guilt (Richter, 2004). Furthermore, children who have lost a parent(s) due to AIDS or have a parent who is

living with HIV endure the loss of parental support and nurturing and may experience a great deal of stress, anxiety, depression and despair (Smart, 2003; Richter, 2004; Van Der Heijden & Swartz, 2010). In addition, siblings may be divided among several households within the extended family (Foster & German 2002) who at times is over-whelmed by the magnitude of the burden of caring for orphaned children. Foster & German (2002) add that relatives and neighbours who have agreed to take care of the orphans sometimes contribute to their despair by taking their properties or inheritance and leaving them more vulnerable to exploitation.

The reality of AIDS in the family is that children are often caring for the sick and assuming adult responsibilities before they are ready to do so (Smart, 2000; Steffenson, 2002). Van Dyk (2008) reported that children who take care of their sick parents may be faced with the trauma of nursing and watching their parents die of AIDS. Although there may be external help, children are not emotionally equipped to deal with the role of being a caregiver (Van Dyk, 2008). Children affected by AIDS start grieving in anticipation long before the death of a parent and often experience multiple losses after the death of their parents (UNAIDS, 2000). They may find themselves caught up in inheritance squabbles, which minimizes the time for the child to grieve the loss of a parent.

Studies have shown that an increasing number of AIDS orphans who grow up without parental support and supervision become victims of poverty, school drop outs (Schönteich, 2000; Richter, 2004). This means that these

adolescents are also at an added risk of sexual exploitation and coercion (Osborn, 2007). There is also evidence that adolescents orphaned by AIDS represent a population vulnerable to mental health risks (Thupayagale-Tshwenegae, Wright, & Hoffmann, 2010). Higher rates of depression and anxiety, stigma and less optimism about the future have been reported among children orphaned by AIDS as compared with non-orphans (Richter 2004; Li, Naar-King, Barnett,

Stanton, Fang & Thurston, 2008; Weismann, Orvaschel & Padian, 2008).

Clearly, adolescents affected by the HIV/AIDS status of their parents tend to have multiple challenges. It is necessary therefore to understand the experiences of these adolescents so applicable interventions and programmes are developed to improve their quality of life. This study therefore explored the experiences of adolescents who had experienced the loss of a parent to AIDS.

Methods

Participants

Purposive sampling was conducted via an Non-Governmental Organisation (NGO), which renders foster care and therapeutic services to HIV and AIDS orphans within the Gugulethu, Western Cape community. Study eligibility criteria consisted of: 1) death of one or both parents from AIDS; 2) aged between 14 and 17 years; 3) had to reside in Gugulethu; 4) be on the foster care database of the NGO; 5)

either be under the supervision of maternal or paternal grandparents, aunts and even family friends and 6) able to communicate in either English or isiXhosa. Participants were recruited and interviewed until data saturation had been reached. A total of twelve participants were selected. Three participants, however, decided to withdraw (without providing a reason) during the interview process, leaving a final sample of nine participants.

Procedure

Data were collected in the following way: At the start all the participants in the study were informed about the study and that participation was voluntary. They were also informed that they could withdraw at any time. Upon their agreement to participate in the study, in-depth interviews were conducted in a child friendly interview room for approximately an hour and

a half. Permission to record the interview was also granted by all the participants. Trust between the interviewer and the interviewee was established by ensuring that the interview process was kept conversational. All the interviews were conducted in isiXhosa, they were then translated into English by a language expert.

Data analysis

The data was analysed by means of thematic analysis. All recordings were transcribed verbatim. Pauses, hesitations as well as unclear speech were indicated. Transcripts of the interviews were carefully read, and

patterns and themes were identified. This information was then converted into different codes. Similarities, differences, and contradictions emerged which resulted into sub-themes.

Ethics considerations

Ethics clearance was provided by the Senate Research Committee, at the University of the Western Cape and permission to conduct the study was provided by the leadership of the NGO. Participation in the study was totally voluntary and participants were not obligated to participate. Their request to withdraw at any time was respected. Confidentiality was ensured by not using the participants' name; participants were each requested to provide a pseudo-name that they would like to be

referred to. Verbal and written informed consent were granted by both the foster parents/guardians and the participants. Debriefing was arranged with registered professionals, counselors and social workers at the NGO. All the relevant information about the participants was stored and kept confidential in a safe place. The transcripts and recordings were locked up in a cupboard at all times and were only available to the researcher and the colleague who assisted with the translations from isiXhosa to English.

Results

Table 1 presents the biographic information of each participant as indicated in table 1. All participants provided pseudonyms for the purpose of anonymity.

Table 1: Biographic information of participants

Participant	Gender	Age	Language	Family/siblings	Reside	Relationship with father	Financial dependence
Thembile	M	15	IsiXhosa	Single parent family	Maternal Grandparents	None	Grandparents
Mbali	F	16	IsiXhosa	Older brother	Maternal Aunt, Uncle, brother & 3 cousins	None	Aunt, Uncle
Noluthando	F	17	IsiXhosa	Brother & sister	Siblings	None	Herself
Yoliswa	F	15	IsiXhosa	Maternal grandmother, aunt, uncle & 3 cousins	Maternal grandmother, aunt, uncle & 3 cousins	None	Maternal family
Prude	F	15	IsiXhosa	Brother	Maternal family	None	Maternal family
Felicia	F	17	IsiXhosa	Sister & brother	Maternal family	None	Maternal family
Thando	M	15	IsiXhosa	Twin sister	Maternal grandmother, aunt, uncle, nieces, nephews & twin sister	None	Maternal family
Linda	F	15	IsiXhosa	Siblings	Siblings	None	Elder sibling
Sinoxolo	M	16	IsiXhosa	Two siblings staying	Paternal uncle & aunt	Deceased	Paternal family

				with paternal aunt	& two children		
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Seven themes with accompanying sub-themes emerged from the interviews.

Challenges

Cultural or traditional practices/norms

Cultural or traditional practices/norms are an area that participants had identified as being a challenge. It was seen to 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 was not discussed and from the responses of the adolescents it was apparent that some of the children were never granted the opportunity to hear from their own parents regarding their HIV status. The following response highlight this:

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. Nobody helped me after I was told the news I was told to take the news as a man after that I was told that I can go and play in the yard [Thembile, male, 15]

The period of adolescent development is naturally a difficult time for many of the participants. The added loss of a parent was often too much for such an adolescent 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 excerpts below highlight the pain that was experienced by some participants:

I was heart broken, 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 [Noluthando, female, 17]

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 [Mbalu, female, 16]

I did not cry I was just shocked and the tears could not come out. I only cried after a month that she was buried [Felicia, female, 17]

Some participants experienced negative treatment from some of their family members who believed that their HIV positive parents had brought a curse to their family. The following statement was heard:

She [paternal grandmother] said that my mother, my two twin sisters and I had brought a curse to the family [Thando, male, 15]

Feelings of security, protection, soothing, comfort and help was seen as missing but needed by some of the participants. Many of the adolescents described watching their parents' physical suffering as something that they would never be able to forget. The following accounts by participants expressed this:

I did not believe that she had left me I still had hope that she was going to come back from hospital, until the wake and my mother was the only one not in the house [Yoliswa, female, 15]

It breaks my heart to see how people with HIV/AIDS are suffering, and I know from that, that my mother also suffered a lot [Thando, male, 15]

Socio economic effects

Most of the participants lived with their maternal grandparents, siblings, family friends and few with paternal family. The lack of income had resulted in some of these

adolescents being deprived of education, as caregivers often did not have funds to send them to school. Participants shared the following:

When I was staying with my paternal family I used to be sent home for not paying school fees [Thando, male, 15]

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 [Noluthando, female, 17]

Taking on the adult/caregiver role

Some participants reported that through losing a parent (s) through AIDS they become heads of their families and had to care for their

younger siblings. Female participants faced responsibility for more general house chores, care for the sick and younger children.

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 [Linda, female, 15]

I love my brother and sister very much. I talk to them, do their washing and assist them with their homework [Noluthando, female, 17]

Experience with caregivers with loss of a parent

Despite the devastating effects of death due to AIDS most of the participants still found the family living arrangements to be the best. Most of the participants were living with family members and majority of them had been

residing at these residents since their birth. However it was clear that after the death of their parents adolescents viewed their caregivers in different ways. Both positive and negative inputs were given by participants about caregivers.

(a) Experience of positive caregiving

Most of the participants were cared for by grandparents with maternal grandparents often identified as the most loving and kind caregivers. Aunts, siblings, mother's friends and lastly followed by the paternal family were also identified as caregivers by the participants. The children in this study felt that maternal families played the most important role in supporting them. The type of support mentioned by the participants included physical, material and emotional needs being catered for by their caregivers. Positive support experienced with their caregivers is highlighted in the following excerpts:

I regard my grandmother and grandfather as my parents. They are the ones who buy me anything that I want. They pay my school fees and clothes like these Takkies (shoes) I am wearing [Thembile, male, 15]

When there is not enough food in the house my grandmother will rather give my sister and I the food and stay without than to starve us [Thando, male, 15]

(b) Experience of negative caregiving

Although some adolescents had supportive environments created by extended family members, not all had the same experience. Some participants experienced exclusion, isolation, loneliness, stigma and discrimination from many of their caregivers. These negative experiences and/or maltreatment that were encountered by some of the adolescents are indicated below:

My second eldest aunt is the one who evicted me from my maternal home. When under the influence of alcohol she used to say that I am not contributing towards food so she will not dish me food. I never knew when she is going to dish me hence I decided not to eat her food [Felicia, female, 17]

My 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 [Thando, male, 15]

Loss of a reliable and caring support system

It was evident that the adolescents in the study had lost a support system that played a significant role in their lives. Their experiences and the stage they were in, led to feelings of insecurity, shame, depression, anxiety, a lack of self-worth and at times, feeling isolated. All participants included examples of how they

coped with and responded to challenges including losing a parent (s) to AIDS. Participants identified various sources of support from people who supported them. For some it was a few different people, while others had one significant supporter. Support structures included, family and community, teacher(s) and welfare organizations. The following examples were given:

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. [Participant 8]

My friends at school would share some of their lunch with me. [Participant 3]

Participants reported that they are often faced with lack of support from their biological fathers, either before they were even born, or after the death of their mothers. Support from their fathers, was usually in the form of material, affectionate or financial measures. The following results were heard:

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. [Felecia, female, 17]

This statement was supported by another participant:

My father deserted my twin sister and me and went to live with his new family in other province. He has never come to visit us; we do not even know if he is still alive as he went to stay in another place with his new wife (frowns) [Thando, male, 15]

Because we were struggling I gave my father, our baby sister (who was born HIV positive), 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, my father and his family took back everything that they bought for my baby sister, including her school uniform [Noluthando, female, 17]

Participants related strong bonds with their mothers. The lack in relationship with their father is illustrated below:

There were no activities that we did with my father although he was the one alive [Thando, male, 15]

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 [Linda, female, 15]

Participants likewise recalled that, life-skills programmes that are taught at their schools are effective. It helped strengthen the relationships of the teachers with the adolescents. Some educators were seen as an effective support system by some participants, while others saw them as (rude and unkind). The statements below indicated this:

Teachers at my school treat children well, they are the ones who identified my sister and me and referred us to the aftercare [Thando, male, 15]

My 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 [Felecia, female, 17]

Children treat each other well; maybe it is because in our life orientation class we are taught of HIV/AIDS and how to treat people infected and affected by HIV/AIDS [Noluthando, female, 17]

Discussion

The loss of a parent or both parents brings about immediate change in the lives, roles and responsibilities of AIDS orphans (de Witt & Lessing, 2010). Moreover, AIDS orphans were led to prematurely assume adult roles and responsibilities within their household as they cared for their ill parents and siblings. Many of the adolescents in the current study described difficult experiences associated with being caregivers to their ill parents, watching their parent (s) deteriorate and ultimately the death of a parent (s). On the other hand, for many of the adolescents within the study, not being told what the cause of illness and death was more detrimental and stressful to them. Interestingly, Thupayagele-Tsheneagae & Benedict (2013) found that, even though, in instances where

adolescents are aware of the cause of illness of death they opted not to disclose in order to keep the memory of their parents free from the stigma of AIDS. This too was stressful on the adolescent and would lead to future mental health issues.

Furthermore, adolescent orphans in the study, also felt dejected by their extended families, their community and the organizations purported to be supporting them. In some instances relatives do not necessarily want to take these adolescents but feel obligated to care for them (Thupayagele-Tsheneagae & Benedict, 2013). This led to AIDS-orphans experiencing the loss of educational opportunities, support, food security, health care, economic stability and property as a result of parental illness and death (Ishikawa,

Pridmore, Carr-Hill, & Chaimuangdee, 2010; Lalthapersad-Pillay, 2008; Deacon & Stephney, 2007).

The adolescents in the study perceived the support from paternal families as mostly negative as the lack of support from the paternal families was highlighted. Maternal grandparents were seen as the most suitable support, even though at times they had ill health of their own. These findings are supported by Thupayagele-Tsheneagae & Benedict (2013) whose participants felt that their grandmothers were their source of encouragement. 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. In addition, the emotive reactions; shock, anger and denial of losing a parent was so severe that participants reacted in different ways. However the study of Thupayagele-Tsheneagae & Benedict (2013) reported that adolescents who lost a

Conclusions

The experience of losing a parent or becoming an orphan due to AIDS is a dynamic process marked by several difficulties and challenges for adolescents. The implications of impending parental death due to HIV related illnesses herald the onset of several struggles including poverty, lost educational opportunities, living with extended family systems marked by difficulty, potential exploitation within their homes and culturally specific forms of stigma related to their loss making these youth extremely vulnerable.

parent or parents to Aids felt more comfortable speaking to adolescents that have experienced the same kind of loss. Feelings of emptiness and anger was felt, when participants spoke of other children, sharing activities with their parents, while they are not able to do so. The extended family at large was considered as the most suitable institution to take the care of these children.

Adolescents, reported differently, on their school, welfare services and the churches. Overall, the feedback regarding these institutions was satisfactory. Religious sectors needed to be more open and vigilant about responding to HIV/AIDS as the adolescents did not know much about what the church was doing in-terms of raising awareness. The findings cannot be generalized to other groups of people as this study had a very small sample and participants were from one race group who had either lost one or both parents due to AIDS, and the experiences of other races and non-orphans are not represented in this study.

The results of this study 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 thus recommended: that the capability of the grandmothers to take care of these children must be continuously assessed by social workers. It is also important that Welfare organizations continue to capacitate the caregivers, as it seems the most available caregivers are the elderly. 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. Trauma counselling should be freely

accessible for all children/adolescent who experienced parental loss due to AIDS. Health care workers and social workers should encourage parents to disclose their status to their children as this may minimize the trauma they will experience. Parents should be educated in order to make children knowledgeable about their extended family and their possible future caregivers, in preparation for their dying. Diminishing the

shame and stigma around an AIDS-related death is an urgent requirement for vulnerable children and adolescents who will have a lot to cope with once a parent or caregiver dies, while they may likely be feeling the need to hide their emotions. Therefore, adolescents may be able to respond with more resilience when grief arrives, if the culturalized confinements attached to death are sensitively challenged.

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