Published in final edited form as:
Afr J AIDS Res. 2011 June 14; 10(1): 15–24. doi:10.2989/16085906.2011.575544.

Bereavement among South African adolescents following a sibling's death from AIDS

Craig Demmer[*] and **Nina Rothschild**
Lehman College of the City University of New York, 250 Bedford Park Boulevard West, Bronx, New York 10468, United States

Abstract

While increasing attention has been paid in recent years to studying the impact of parental death from AIDS on children, we know little about how a sibling's death from AIDS affects children. In this qualitative descriptive study, 11 in-depth interviews were conducted by trained social workers with adolescents who had lost a sibling to AIDS, in KwaZulu-Natal Province, South Africa. The average time since the sibling's death was 18 months. These adolescents had been actively involved in caring for their sick sibling, yet they received inadequate emotional support from any source both before and after the sibling's death. HIV/AIDS stigma as well as the family's daily struggle to survive caused these adolescents to keep their feelings and their grief to themselves. Despite the trauma of losing a beloved sibling and the hardships of their environment, they demonstrated remarkable fortitude as well as concern for others. More research is needed on the issue of sibling bereavement associated with AIDS, and interventions that address the multiple needs of these vulnerable young people need to be developed.

Keywords

children and youths; grief; HIV/AIDS; psychological aspects; qualitative research; sibling loss

Introduction

The HIV epidemic continues to have a devastating impact on the people of South Africa. Besides having the largest number of people living with HIV in the world, AIDS remains the leading cause of death in the country (UNAIDS, 2009). In 2007 there were approximately 5.7 million people living with HIV in South Africa, and about 350 000 people died of AIDS in that year alone (UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance, 2008). The total number of new HIV infections in 2009 was estimated to be 413 000, with KwaZulu-Natal continuing to be the most-affected province in South Africa (Statistics South Africa, 2009). The failure of successive governments to respond quickly and effectively to the epidemic has been widely debated and is said to have resulted in the needless AIDS-related deaths of many children and adults (Epstein, 2007). For the period 2002–2005, it was estimated that more than 330 000 premature deaths could have been prevented if the government had provided timely access to antiretroviral (ARV) drugs for people in need of them (Chigwedere, Seage, Gruskin, Lee & Essex, 2008).

---

[*] Corresponding author: craig.demmer@lehman.cuny.edu.
The authors — Craig Demmer is a professor and Nina Rothschild is an adjunct instructor in the Department of Health Sciences at Lehman College of the City University of New York.

Given the vast scale of the HIV epidemic in South Africa, many young people have to contend with sorrow and loss at an early age. While it is impossible to determine how many young people in the country have lost a brother or sister to AIDS, population statistics on HIV/AIDS prevalence and mortality suggest that they represent a large group. In the 1980s and early 1990s, when there were few effective treatments available for HIV and when AIDS-related mortality was high worldwide, a vast body of literature emerged in the West which focused largely on the bereavement experiences of white, educated, gay men who had lost partners and friends to AIDS (Martin, 1988; Martin & Dean, 1993; Kemeny & Dean, 1995; Summers, Zisook, Atkinson, Sciolla, Whitehall, Brown, Patterson & Grant, 1995). The experiences of individuals who lost a sibling to AIDS have been largely overlooked in the published literature, not only in the West but in the African context as well. While there have been few studies on adults that lose a sibling to AIDS, even less is known about young people who have lost a brother or sister to AIDS. In South Africa, there is little discussion about AIDS deaths and infrequent acknowledgement of AIDS as the cause of death when attending someone's funeral (Riffe & Fouche, 2007).

The purpose of this article is to describe the bereavement experiences of a sample of adolescents in KwaZulu-Natal Province, South Africa, who lost a sibling to AIDS. The objective of the study was to explore how adolescents cope with the loss of a sibling to AIDS, to determine the daily stresses they face, and to assess what types of support may be available to them. It is expected that these findings will fill a gap in the literature since little is known about the experiences of young people who have lost a sibling to AIDS in South Africa as well as in other resource-limited countries. Understanding the experiences of these adolescents can help inform supportive interventions for this population group.

Based on what is known about the impact of AIDS-related loss on individuals in the South African context, it is possible that young people who have lost a sibling to AIDS may be at risk for various health and psychological problems. A national survey of mental health among South African adults showed that there was a strong association between knowing someone who died of AIDS in the previous 12 months and depression, anxiety and substance abuse disorders (Myer, Seedat, Stein, Moomal & Williams, 2009). Findings from a qualitative study of adults who had lost a loved one to AIDS in KwaZulu-Natal showed that a number of stresses compounded their grief, including stigma, lack of support and poverty (Demmer, 2007). Research on children in Cape Town who had lost a parent to AIDS showed elevated psychological problems, including depression, post-traumatic stress, problems with peers, and conduct problems (Cluver, Gardner & Operario, 2009).

The sibling relationship is unique in that, unlike the parent/child relationship, the relationship is a relatively equal one and is likely to last longer over a lifetime (Robinson & Mahon, 1997). Davies (1993) suggested that that there are three essential features of sibling bereavement. The first critical feature is shared family attributes, such as shared experiences and history between the deceased and the surviving sibling. The second feature is physical separation between the two by virtue of death, and the third feature of sibling bereavement is a change in the externally defined role of the surviving sibling (e.g. being in charge of wrapping up the affairs of the deceased sibling; fulfilling the roles of the deceased sibling).

Kurland (2003) identified several themes in interviews with adolescents who had lost siblings to non-AIDS causes, including: initial reactions of profound surprise together with refusal to accept the truth; a very intimate and romanticised connection to the dead brother or sister; nurturing and sheltering behaviours for each other among the surviving siblings; lack of comprehension of the reason for the death; and, more intimate connections to family members in the aftermath of the sibling's death. Furthermore, an enduring connection to the dead sibling and to religious faith appeared to ease grieving among these siblings.

Robinson (2001) conducted the first study on bereavement among adults who had lost a sibling to AIDS and found an association between the level of closeness of the surviving sibling with the deceased and the intensity of grief. In that sample from the United States no connection was found between the time since the sibling died and the intensity of grief. Due to the stigma associated with AIDS, these adults reported difficulty divulging the cause of death to others and they contemplated various possible outcomes prior to deciding how they would inform other individuals that their sibling had died from AIDS (Robinson, 2002). In their analysis of a personal narrative of losing an adult brother to AIDS, Eaves, McQuiston & Miles (2005) observed that the grieving process included reflections on the experience of caregiving, coming to terms with the terminal nature of the illness and death, and dealing with the uncertainty, regret and fear of disclosure.

In South Africa, the task of mourning is made more difficult for children who have lost a sibling to AIDS because of the highly stigmatised nature of the disease in the country. In a study of high school students in the North West Province, 64.1% believed that HIV-positive pupils should not be allowed in their school, 58.7% agreed that AIDS patients should be forced to place their names on a list in order that other people could be protected, 55.5% indicated that pregnant women who tested HIV-positive should be forced to have an abortion, 46.5% believed that AIDS was a punishment from God, and 42.3% were sceptical about having a meal with an HIV-infected person (Strydom, 2003).

Sibling-bereaved children may not receive the social support they need due to AIDS stigma and they may be forced to keep the nature of their sibling’s death a secret and thus may hide their grief. In one of the few studies considering the effect on social support on children whose parent was infected with HIV or had died of AIDS, Lee, Detels, Rotheram-Borus & Duan (2007) found that those who had more social-support providers reported significantly lower levels of depression and fewer conduct problems over a two-year period.

In resource-limited countries where high levels of HIV/AIDS stigma coexist with low levels of support (both formal and informal), it is likely that young people who have lost a sibling to AIDS will be particularly vulnerable. Besides dealing with the psychological impact of losing a sibling to AIDS, children also have to deal with other stresses in their daily life which may or not be related to the death of their sibling. A number of studies have demonstrated the negative effects of AIDS-related illness and death on the household. Studies in South Africa have shown that households are often crippled financially as AIDS impacts the household over a long period of time, from when the family member becomes ill until long after their death (Gow & Desmond, 2002; Strydom & Raath, 2005). Longitudinal studies of households have shown that households with an HIV-infected member tend to be larger, poorer, and have lower levels of employment among the members than do unaffected households; additionally, income and household expenditure continue to decline over time for these households (Bachmann & Booysen, 2003 and 2004). The costs to poor households affected by AIDS, especially medical and funeral costs, are often outstripped by the available resources (Ewing, 2002; Bachmann & Booysen, 2003).

Because of finances having been directed toward caring for the sibling and the cost of the funeral together with the possible loss of income if the sibling was older and working, surviving siblings may find that there is less money available for food and clothing and for their education. We know from studies of children who have lost parents to AIDS that many children are more often absent from school or have to leave school because of a lack of funds in the household (Andrews, Skinner & Zuma, 2006; Mishra, Arnold, Otieno, Cross & Hong, 2007). Girls in households impacted by AIDS are more likely to be withdrawn from school earlier than boys are (Bhargava, 2005).

Given the number of children and young people in South Africa who have lost a brother or sister to AIDS, and considering the possible long-term effects of this loss, we need to better understand their experiences.

Methods

A qualitative descriptive approach was used to explore South African adolescents' lived experiences of losing a sibling to AIDS (cf. Sandelowski, 2000). A variety of methods are used in qualitative research and among these methods in-depth interviews hold the greatest appeal as they can explore the participants' perceptions, beliefs, and experiences in their own words and can reveal new areas not anticipated at the beginning of the study (Britten, 2006).

Study participants

To be eligible for the study, participants had to be adolescents who had lost a sibling to AIDS. Purposive sampling was used to select participants with a range of experiences (see Ulin, Robinson, Tolley & McNeill, 2002). Several local community-based organisations served as gatekeepers for locating participants, as this is particularly recommended when conducting research with vulnerable families (Horowitz, Ladden & Moriarity, 2002). The characteristics of the participants are summarised in Table 1. The age range of the participants was 12 to 18 years and most were females. The average age of the deceased siblings was 20 years old and the average time since the death of the sibling was 18 months. Eight of the deceased siblings were females and three were males.

Procedures

This study was approved by the institutional review boards of the University of KwaZulu-

Natal (South Africa) and Lehman College (United States). Data collection took place in 2008 and 2009. The participants were recruited and interviewed until it was determined that no new themes emerged from the analyses (i.e. a state of theoretical saturation was reached) (Strauss & Corbin, 1998). A total of 11 adolescents were interviewed. This sample size is deemed appropriate for qualitative interviews (McCracken, 1988; Creswell, 1998). Informed assent was obtained from each adolescent.

The research was performed using semi-structured interviews with the participants. All interviews were scheduled at a time and place convenient for the participants. Some interviews were conducted in an office of a local community organisation and some were conducted in the participant's home. In all instances, the participant was interviewed in private with the interviewer; family members were not present during the interview.

The interviews were conducted by bilingual (Zulu/English) social workers. A senior member of the research team in South Africa (a social worker with expertise in qualitative research) was responsible for preparing the field staff to conduct these interviews. An interview guide was developed based on a review of the existing literature on AIDS-related bereavement, through consultation with professionals in KwaZulu-Natal working with children and families affected by HIV or AIDS, as well as based on the first author's research experience investigating AIDS-related bereavement among adults in South Africa (Demmer, 2007). The purpose of the interview guide was to ensure that all relevant topics were covered in the interviews. All interviews were conducted in a conversational manner and questions were not always asked in the same order or manner. The overriding purpose of the interviews was to explore what the participants felt about losing a sibling to AIDS and for them to describe how their lives had been impacted by this loss.

The importance of establishing trust with the participants was reinforced among the interviewers as was the need for the voices of the participants to be heard and for the interviewer to be aware of their own feelings and prejudices (Oskowitz & Meulenberg-Buskens, 1997). The suggestions of Horowitz *et al*. (2002) were followed by communicating the relevance of the study to the participants, making the data-collection process as user-friendly as possible, stressing that all views and perspectives were welcomed, and providing appropriate reimbursement to the participants. Being mindful that the interview process could be stressful or even traumatic for these adolescents, the interviewers solicited feedback from them about how they were feeling as a result of the interview, and referrals to local mental health resources were made whenever necessary. Interviews typically lasted one hour. Each participant was interviewed once. In acknowledgement of their contribution to the study, each participant was paid R70 (approximately US$10) after completing the interview.

All interviews were conducted in Zulu and recorded. They were transcribed verbatim and translated into English. The accuracy of translations was verified independently by a consultant who was bilingual (Zulu/English).

Data analysis

The transcripts were the primary data for analysis. The data were analysed using qualitative content analysis. Qualitative content analysis was deemed suitable for generating descriptive themes that converged with the study objective of describing the experiences of bereaved adolescents in KwaZulu-Natal. Qualitative content analysis is the analysis strategy of choice in qualitative descriptive studies (Morgan, 1993; Sandelowski, 2000; Krippendorf, 2008).

Transcripts of the interviews were carefully read and reread, line by line. The data were first analysed using inductive, open coding; key sentences and concepts were highlighted and coded. In the next stage, the initial themes were identified and grouped into domains. Patterns, variations and concepts were identified. Themes that emerged most frequently across the transcripts were identified. Following the coding procedures outlined by Strauss & Corbin (1998), phenomena were grouped into categories of like meaning and the contents of the categories were compared between and within transcripts. Coding themes were developed based upon the constructs from the interview guide, as well as on the basis of the interview transcripts. New emergent themes were identified and incorporated in the coding process. The transcripts were re-coded if either a new code was developed or an existing code was revised. The transcripts were coded and analysed by the first author. After careful and repeated examination of the transcripts, categories of analysis were developed and defined. There was a continuous process of collecting data and comparing data with the previously coded data. During the coding process, we actively searched for variations to increase the validity of the findings (see Maxwell, 1996). The qualitative software program NVivo8 was used to code and facilitate the analysis of the transcripts of the interviews. Software programs such as this facilitate hierarchical or 'tree-like' coding and analysis of large amounts of text across multiple themes (Richards, 2002). Deductive and inductive codes were developed and applied to the data using NVivo8. To ensure trustworthiness (Lincoln & Guba, 1985), coding, themes, and key findings were discussed by the research team until consensus was reached. To enhance the credibility of the data analysis, full descriptions of the experiences of the participants were used to support the themes identified. Furthermore, the research team members independently reviewed the categories and themes generated. Only codes and themes that achieved consensus were included.

Findings

Six main themes emerged from the data analysis and are presented below.

Dealing with a sibling's sickness

The participants were aware that their sibling was sick for while, but they usually did not know the cause of the illness until just before the sibling died. The participants acknowledged that they had little knowledge about HIV and AIDS during this period and had not known any other people with the disease. In a few cases the sick sibling informed the participant directly about their diagnosis, but most participants found out either through a parent or by overhearing a conversation:

> *'I heard my parents talking inside the house. After they realised I have heard what they did not intend me to hear, they asked me to move out of the room'* (participant 4).

One participant was told by his grandmother a week after the funeral that his brother had died of AIDS. Watching their sibling deteriorate was a confusing and frightening experience, especially when the sibling was admitted to the hospital and the hospitalisations became more frequent and longer. It was rare for an adult or professional to sit down with the participant and explain what was going on with their sibling or to talk to them about how they were feeling. The following quotes illustrate what participants felt when their sibling was in the hospital:

> *'It was pleasing to see him…but it was sad when we were leaving because my mother would cry and then all of us would cry'* (participant 4).

> *'She was in and out of the hospital. She was using diapers and vomiting blood…. It was hurting because sometimes she would not be able to speak but she would point what she wants until she cries. Sometimes we could not see what she wants and we all cried'* (participant 8).

> *'It was painful. I couldn't take the pain of seeing her in the hospital and I will cry a lot'* (participant 9).

When the sibling was at home, most participants had been involved in caregiving. Some would spend all their time after school watching over their sibling and some had to miss school because there was no one else to look after their sibling. They helped with bathing their sibling, washing their clothes and dressing them, going to the clinic to pick up medications and assisting them with taking the medications. While most accepted responsibility for caring for their sibling and did so without complaining, they nevertheless felt the burden placed on them:

> *'I had to arrange things that he will need during the day before I go to school and I used to be a little late at school because of him…I lost some time for school and had to repeat a grade'* (participant 2).

> *'I was very upset, lost weight, always crying, and sometimes asked myself why this is happening to me?'* (participant 10)

Most of the participants were aware of the severity of the sibling's illness and several remembered worrying that the sibling could die soon:

> *'His situation got worse and I realised he was not going to live long'* (participant 4).

> *'Sometimes we were not able to see her because she was in the intensive care unit. It was difficult because it showed that the hopes of her life were diminishing'* (participant 8).

Reaction to the sibling’s death

The participants learned about their sibling’s death in various ways. Some had been told by their mother when they got home from school. Two participants picked up the phone at home and were the first to be informed by the hospital that the sibling had died. In some instances, the sibling had died at home:

> *‘We woke up in the morning and we find out that he was dead’* (participant 6).
>
> *‘When I came back from school I did not see her in her room; I saw the way the situation was and it became clear to me what had happened. I locked myself in my room and wept’* (participant 7).
>
> *‘In fact she passed on while we were sitting and chatting as if she was not ill. My grandmother is the one who noticed that something was not right…. We rushed her to hospital where on arrival she was certified dead’* (participant 8).

The participants had reacted with shock upon hearing that their sibling had died. They felt that they were not prepared for their death:

> *‘I did not believe mom when she relayed the message. I was shocked because I had expected her to feel better and to return to school as planned the following year…. Hey! I have never cried like I cried that day. I had so much pain’* (participant 1).
>
> *‘It was like someone had ripped my heart out. I was not aware that she was about to die. I had thought she was going to come back like she normally did [crying]’* (participant 3).
>
> *‘I was shocked and I dropped the phone and cried. I never thought it could happen so soon’* (participant 5).

Most participants had attended their sibling’s funeral; one participant said she did not go to the cemetery because she was afraid and still could not believe her sibling had died. After the funeral, most participants refused to attend other funerals in the future as it was too painful for them. The participants acutely mourned the loss of their siblings. All of the participants were younger than the siblings that had died and they had looked up to them. They also missed having someone they could confide in:

> *‘There are many girls at home, but she was the one closest to me as I could talk to her about my problems and difficulties…I was just left with no one to talk to’* (participant 3).
>
> *‘We were very close. She was a loving person and had patience’* (participant 7).

Before getting sick, the sibling had typically assumed many of the roles of a parent and the participants had relied on their sibling not only for emotional support:

> *‘He used to assist by buying food and also help with my school things that I needed’* (participant 4).
>
> *‘My sister loved us and she was doing everything for us: cooking, washing, fetching water and so on…. It was a very difficult time indeed because my sister was the one who was giving me the money for transport to school’* (participant 8).

Finding someone else to fill this void was difficult. The participants commonly described their sibling as ‘kind,’ ‘sympathetic’ and ‘helpful.’ But it was the loss of someone who they could confide in and someone who would encourage them that was most deeply felt. One male participant stated that what he missed most about his 21-year-old brother was the advice he used to give him and how his brother was the mediator in family quarrels. Although they had friends, the participants still felt lonely. Losing a sibling was a devastating experience for these young people and talking about their sibling opened up old wounds. Even though it had been some time since their sibling died, they still felt like they would reappear.

Some participants gained comfort from their faith and viewed the church as their ‘second family.’ A couple of participants were involved in church youth groups. There was no evidence that the participants felt rage and frustration at the seeming unfairness of their sibling’s suffering and early death. Faith provided a measure of solace to some. One participant stated:

> *‘The church does assist because I am always aware that God is around all the time. Right now as I talk to you I feel better. Things may be different tomorrow, but if I pray about that, the situation changes for the better. Even if I do not see the change immediately, within days I will see that — all because I prayed’* (participant 10).

In general, the participants bottled up their feelings and preferred not to dwell on their loss. For the male participants in particular, an effort was made to not show emotions or cry in front of others. One female explained how she coped with her grief:

> *‘I just go into my room, take out my diary and write my thoughts. I also look at the photos where I am with her and I also write her a letter. Sometimes I sing the songs she liked and pray’* (participant 7).

The participants set aside their pain as they did not want to make their other siblings feel depressed or sad. One participant remarked that she preferred to not dwell on her pain and that her energy was better spent on helping her surviving siblings. The participants did not express a lot of anger because of having to deal with a sick sibling or frustration because a considerable amount of family attention was directed to the sick sibling or annoyance because family life was put on hold. Rather, many of them seemed to have internal reserves of strength and were able to capitalise on those resources in order to remain afloat.

Since their sibling’s death, the participants kept busy each day. When they were not doing school work, they engaged in fun activities like playing soccer or hanging out with friends. For both the male and female participants, household chores took up a lot of time, providing focus and a sense of stability for them as well as a feeling of contributing to the household.

The participants took pride in their ability to help their sibling during their illness and wished to develop their caregiving skills in the future. Because of their own experience, they felt that they could be of assistance to other young people who have lost a sibling to AIDS. Several participants expressed a desire to become a nurse, doctor or social worker and they wanted to do whatever they could to help people affected by HIV. The experience had deepened their sensitivity and compassion for others and inspired them to work in a helping profession as a legacy to their deceased sibling.

The adolescents’ views about stigma

The participants voiced strong feelings about the stigma surrounding their sibling’s illness. When asked by others what his brother died of, one male participant usually answered that it had been an accident or some other illness. When asked why he did not tell the truth, he replied:

> *‘I fear that they will ask more questions and I may not have the answer, or they will think my brother got AIDS…through promiscuity’* (participant 2).

Some participants explained that they concealed the nature of their sibling’s illness for fear of being shamed and embarrassed in their community. They mentioned being hurt by the callousness of people who seemed to exhibit no sympathy or sensitivity for people with HIV or AIDS. Some participants pointed out the hypocrisy of people who gossiped and whispered about others who they suspected had HIV while hiding their own HIV status:

> *'What hurt me was to see his friends…spreading that he was sick because of HIV. The problem was that they never mentioned that they are also infected'* (participant 4).

The stigma of HIV caused the participants to feel isolated and alienated. They felt that they had to battle the situation on their own, receiving limited or no support from a larger community that seemed hostile or insensitive. They could not understand why people in the community rebuffed and rejected people with HIV or AIDS, making their situation even more painful and humiliating.

At school, most participants reported that their teachers were unaware that their sibling had been sick. In the few cases when teachers knew, they had not inquired as to the cause of the sickness and the participants were mostly reluctant to confide in their teachers. This secrecy continued even with their friends. When asked if any of his friends knew anything about his brother, one participant said: *'Yes they know, although they do not know the whole story of how he died'* (participant 6).

Even after the loss of their sibling from AIDS, the secrecy around the disease persisted. Some other members of the extended family had died after the sibling's death, but when asked if they knew whether these family members had also died of AIDS, most of the participants said they did not know and that no one talked about it. One participant reported that she had another sister who was HIV-positive, and one participant reported that the 3-year-old niece of her deceased sister was HIV-positive — yet the subject of HIV and AIDS continued to be avoided.

Relationships with family members

The size and composition of the household in which each participant lived varied greatly. The household sizes ranged from three to 15 members. There was a mixture of grandparents, parents, foster parents, or older siblings who were the heads of the various households. Only one participant lived with both parents. One participant lived with her two older brothers; one lived with her grandparents and her five siblings; seven participants lived with their mother and siblings; and one participant and her siblings lived with foster parents. For the most part, the father had abandoned the family. It was not uncommon for siblings to have different fathers. It was often left to the mother or grandmother to manage the household and to take care of the family. The participants reported that they were close to their primary caretaker, who was usually their mother, grandmother or foster mother:

> *'You always need the support and care of a parent as your friends may not know everything in life, and yet your mom has experience and has been on this earth longer'* (participant 1).
>
> *'My mother is the one who tries for all of us, and she brings everyone and everything together for the family'* (participant 3).

They largely felt that they could count on their primary caretaker for support, but they were mindful of how overex-tended their primary caretakers were, and they did not want to burden them further. The participants did not talk about their fathers very much since many had not seen their father in many years. They generally did not harbour much anger toward their father who had essentially abandoned them. Because of the large size of many of the households and the multiple demands placed on each family member on a daily basis, the participants tended to become surrogate parents to their younger surviving siblings or they viewed their older siblings as a surrogate parent for themselves. This seemed to be a natural family dynamic and the expectation was that everyone helped out no matter what their age. Four female participants had each lost a sister to AIDS who had also left behind a child who they were now each helping to take care of. Sometimes another sibling was mentioned as causing the family trouble because of personality issues or a tendency to drink, but on the whole family conflict was not often mentioned by the participants.

A couple of participants indicated that their mother was somewhat overprotective and was constantly reminding them to live a ‘clean life’ and to not get into trouble. At the same time, the participants wished to be a good role model for their surviving siblings, especially the younger ones. And, as they got older, they were pleased that they were more often included in family decisions.

Living in poverty

Each participant lived in a household where money was in short supply and it was a daily struggle to provide for everyone. The participants were acutely aware of the lack of resources in their family and they wished they could be of more help, but most were still in school and jobs were scarce anyway. The burden of supporting the household often fell on the mother, grandmother or foster parent since the father/s of the children in the household were largely absent. There were few sources of income in each household. Most families subsisted on a child-support grant or old-age grant or money from the primary caretaker’s job. Few of the adolescents’ primary caretakers were employed. Some people in the household did odd jobs, sold produce or crafts, or braided hair, but the income was irregular and meagre. Occasionally, a neighbour or friend helped out, but most people they knew were in a similar situation. The following quotes illustrate the worry about money that the participants shared:

> *‘I have too many family problems especially that have to do with money’* (participant 3).
>
> *‘What I can say is that the life at home is getting more and more poor, because there is only one working and she is far. Sometimes months pass by without her sending us money…. It is only my mother who assists because she gets social grants of two young children of my brother’* (participant 4).

Thus, multiple family members were forced to survive on paltry reserves. In the past, some of the families had depended on the sibling for money before he or she died, and the family felt not only the emotional impact of their loss but the financial one as well:

> *‘Yes, it was very hard, mostly because he was the breadwinner at home. Now we are surviving by collecting bread at the Crisis Centre. No one is working at home. My mother is doing some temporary jobs from the neighbourhood, but it is not enough to support us’* (participant 6).

Finding enough food for everyone in the household was a constant challenge and weighed heavily on the participants’ minds:

> *‘At home we cook once or not at all because we do not have enough, so that makes me find life very hard’* (participant 6).

Several participants talked about how their deceased sibling had helped pay for their transportation to school or their school fees and now that burden fell on their overwhelmed mother or grandmother. This created guilt as well as sadness that they would not be able to achieve their goals of going to university once they had completed school. It was difficult enough to find money so that they could complete high school, let alone further their education. It was hard for the participants to be hopeful for the future when there seemed to be no way out of their predicament. Merely subsisting from one day to the next was the priority.

Sources of support

The primary sources of support for the adolescents were the mother or grandmother and maybe a friend. A few participants reported that they knew other children who had lost a sibling to AIDS and this created a special bond between them as each understood what the other was going through. Some participants worried that they would lose their close friends as they grew older and moved away and got jobs. They related that some teachers were aware that the participant had lost a sibling, but were unaware that it had been due to AIDS. Teachers in general were not viewed as a source of support.

Although mothers and friends could be counted on for support, the participants noted that dwelling on their grief was not encouraged within the family. When they talked about their deceased sibling, the conversation was quickly steered toward happy memories:

> *'At home we do not talk about heartache and pain or sadness. We simply talk about things that she used to say, but nothing about matters of the heart and soul'* (participant 3).

Some participants said that they kept their feelings to themselves because other people would not understand and that some would even laugh and make fun of them. One participant complained that whenever her family talked about her brother, she and her siblings were told to go outside and play, thus excluding them from sharing memories of her brother.

There was also a concern with upsetting other people with their grief. Even if people encouraged them to talk about their grief, the adolescents worried about the pain they would feel themselves as a result of such disclosure. So the degree to which they were able to share their grief was truncated. One participant explained:

> *'Sometimes I just talk to my boyfriend, but I sometimes am unable to talk about my sister's nature of her illness. I do not want to bring sadness when we are together. He does not know that I sometimes have these moments, especially missing my sister'* (participant 3).

None of the participants had received counselling and when asked if they would be interested in obtaining individual counselling, only two expressed an interest. However, there was more enthusiasm for a support group for young people who had lost a sibling to AIDS. Although one participant worried that she would not feel comfortable talking with strangers, most felt that a support group would be helpful. As further evidence of their altruistic nature, they emphasized how they could be of assistance to other teens in such a group versus how others could help them. In addition to sharing stories and showing other teens how to care for a sick sibling, the participants suggested that it would be important for there also to be fun activities in such a group (e.g. games, sports, or staging a play).

Discussion

This study explores the experiences of South African adolescents who lost a sibling to AIDS. In this small sample we found high levels of altruism, patience and perseverance among the participants. This is particularly notable considering the circumstances in which these young people lived and the lack of support and resources available to them. They had taken an active role in caring for their sibling at home before they died and they did so with little complaint even though it disrupted their school work and left little time to be a regular adolescent and to socialise with friends. While it was expected that they would be involved in caring for the sibling along with other family members, they received little acknowledgement for this. When their sibling was hospitalised, no professional had sat down with them to explain what was happening. At home as well, there was little discussion about what was happening to their sibling so they were largely left uninformed about the sibling's illness and prognosis. Family members (particularly the adolescent's mother) were commonly overwhelmed by the person's illness and distracted with the demands and stresses of living in an environment plagued by poverty, and this may partly explain why the participant's needs had been overlooked.

The stigma surrounding HIV and AIDS made caring for their sibling and coping with their sickness and subsequent death much more difficult for the participants. The task of helping children care for a sibling with HIV, as well as helping them cope with their grief, is a challenging one for medical and social service providers because of issues around disclosure and the need to respect the family's feelings and fears about HIV and AIDS. A family may not want a child or adolescent to know that their sibling has AIDS, so the provider is then limited in terms of what kinds of information to offer them. Nevertheless, what is clear from our interviews with these adolescents is that they required more emotional support from professionals as they grappled with the stresses associated with caring for a very sick sibling.

The participants indicated that they would have liked more emotional support at home as well. Even though the adolescents were able to identify a close family member (usually their mother or grandmother) who they could talk to, they wished they had more people who they could rely on for support. In some instances, the family imposed clear rules about its willingness to talk about the deceased sibling and what could be discussed and how often. Generally, there was reluctance among members of the household to talk about the deceased sibling, perhaps because they were afraid of upsetting everyone else. The focus was on occasionally sharing happy memories — but to not do it too often. The participants felt they were given a clear message in their family not to dwell on their grief and instead to direct their energy toward helping care for surviving siblings, doing their chores, and concentrating on school work so they could get a job in the future.

Many of the participants experienced acute grief and sorrow and felt isolated and not able to share their anguish. As they grieved, these young people were acutely aware of the shame associated with HIV and AIDS in their community. Rather than being able to turn to external resources for comfort and support, many of these young people felt that they could not confide in or derive consolation and reassurance from family members, neighbours, or community members because of stigma. In their study of children who lost parents to AIDS, Nkomo, Freeman & Skinner (2009) found that parental death was deeply troubling and led to feelings of sorrow and bereavement and a tendency to allocate responsibility for the death to other individuals. The major emotional trials experienced by these children included a sense of vanished youth and identity, a feeling of neglect and desertion, anxiety about their daily existence, and concerns about coping. They also found that for some children in the study the negative comments and conduct of people in the community intensified those feelings. Although the young people in the present study did not allocate responsibility for their losses to others, they did articulate intense feelings of sadness and yearning and they too found the reactions of others (sometimes even family members) off-putting.

The burdens confronting the participants were substantial. Finding money for school fees and putting food on the table was a challenge for their primary caretakers, particularly because jobs were scarce and there were many dependents in some of the households. For most of these young people the possibility of escaping poverty seemed unlikely. To help those affected by HIV and AIDS in South Africa, Campbell, Nair & Maimane (2007) suggest that greater emphasis on strengthening the capacity of communities is needed; strategies for this could include: increasing information and fundamental skills and competencies, developing common spaces for conversation and analytical thinking, enhancing a feeling of communal possession of the situation and encouragement for activity, focusing on local assets and reserves, putting to work current formal and casual systems and associations, and constructing affiliations between groups on the margins and stronger external players.

Despite extreme poverty and a dearth of external resources, the adolescents in this study demonstrated resilience and found ways to cope with their grief. They took pleasure in remembering certain characteristics of their deceased siblings, such as their jokes or the warmth and comfort and love they provided, and they summoned the strength to go on. They were able to avoid peer pressure (e.g. to become pregnant) and retained hope for a better future for themselves. How these young people were able to surmount so many obstacles and continue to function relatively well is not completely clear. Their emotional resourcefulness and relative hardiness may be in part a product of their youth. Also, the daily battle to survive in impoverished circumstances may have superseded their sorrow and forced these young people to focus on more urgent needs besides their grief (Demmer, 2007). In many respects they had single-handedly confronted their pain, seen the worst that life has to offer, and decided that they would not be paralysed by their grief: they felt they had no choice but to move on. Perhaps the fact that in every case the surviving sibling seemed to have deeply cared about his or her brother or sister was helpful to their coping. The relationships they described seemed to be not fraught with the burden of animosity and ambivalence and jealousy which so often characterise sibling relationships, but rather they were characterised by a deep and abiding love. The memory of the sibling somehow sustained them and served as a source of strength.

Although the young people in this study had sufficient strength to persevere in the face of extreme hardship and loss, some of them did express an interest in talking with someone in the future, either individually or in a group, about their experiences. Many other young South Africans in similar situations may benefit from appropriate mental health services for their grief. The current system of mental health care, however, may not be equipped to address their needs. In their analysis of the public mental health system in South Africa, Lund, Kleintjes, Kakuma & Flisher (2010) reported that while significant changes have occurred within mental health policy and law in South Africa, serious problems remain, including substantial disparities from province to province, a dearth of solid data for preparing services and remedying inequities, ongoing domination of psychiatric hospitals for the delivery of mental health care, and considerable unaddressed needs for psychological treatment services.

Further studies are needed to examine the impact of a loss of a sibling to AIDS on children and young people in South Africa as well as how to better address the needs of this group. Obtaining input directly from young people, such as the ones in this study, regarding how to best address their psychological needs, would be helpful.

Limitations

The study has several limitations. First, as a qualitative study it was not intended to provide information that is representative of all adolescents in South Africa who have lost a sibling to AIDS. Second, we found it very challenging to recruit adolescents who were willing to participate in the research due to the stigma and secrecy surrounding HIV and AIDS in South African society. We would have liked to conduct more than one interview session with each participant as that would have enabled us to explore sub-themes more thoroughly and to better explain similarities as well as discrepancies among some of the findings. Third, due to the wide range in ages of the adolescents and the challenges associated with interviewing adolescents in general, there were variations in the ability of the participants to express themselves which affected the quality of the data and prevented a deeper analysis of the themes. Fourth, although the adolescents were interviewed separately, they were accompanied by a family member when they were interviewed at the local community organisation or else there were family members present at home if they were interviewed in their home. The participants might have been hesitant to discuss certain issues or to discuss them in depth knowing that there were family members nearby. Fifth, the majority of the adolescents interviewed were females and it would have been worthwhile to have been able to recruit and interview more males. Despite these limitations, this study is the first to provide preliminary data on the experiences of adolescents who are grieving the loss of a sibling to AIDS in South Africa.

Acknowledgments

The study was funded by the National Institute of Nursing Research (Grant No. 1R21NR010423A). We are most grateful for this funding. We are also grateful to the individuals who agreed to participate in the study.

References

Andrews G, Skinner D, Zuma K. Epidemiology of health and vulnerability among children orphaned and made vulnerable by HIV/AIDS in sub-Saharan Africa. AIDS Care. 2006; 18(3):269–276. [PubMed: 16546789]

Bachmann MO, Booysen FLR. Health and economic impact of HIV/AIDS on South African households: a cohort study. BMC Public Health. 2003; 3(14) [published online].

Bachmann MO, Booysen FLR. Relationships between HIV/AIDS, income, and expenditure over time in deprived South African households. AIDS Care. 2004; 16(7):817–827. [PubMed: 15385236]

Bhargava A. AIDS epidemic and the psychological well-being and school participation of Ethiopian orphans. Psychology, Health and Medicine. 2005; 10(3):263–275.

Britten, N. Qualitative interviews. In: Pope, C.; Mays, N., editors. Qualitative Research in Health Care. 3. Malden, Massachusetts: Blackwell; 2006.

Campbell C, Nair Y, Maimane S. Building contexts that support effective community responses to HIV/AIDS: a South African case study. American Journal of Community Psychology. 2007; 39(3/4):347–363. [PubMed: 17447133]

Chigwedere P, Seage G, Gruskin S, Lee T, Essex M. Estimating the lost benefits of antiretroviral drug use in South Africa. Journal of Acquired Immune Deficiency Syndromes. 2008; 49(4):410–415. [PubMed: 19186354]

Cluver L, Gardner F, Operario D. Poverty and psychological health among AIDS-orphaned children in Cape Town, South Africa. AIDS Care. 2009; 21(6):732–741. [PubMed: 19806489]

Creswell, JW. Qualitative Inquiry and Research Design: Choosing among Five Traditions. Thousand Oaks, California: Sage; 1998.

Davies B. Sibling bereavement: research-based guidelines for nurses. Seminars in Oncology Nursing. 1993; 9:107–113. [PubMed: 8506421]

Demmer C. Grief is a luxury: AIDS-related loss among the poor in South Africa. Illness, Crisis and Loss. 2007; 15(1):39–51.

Eaves YD, McQuiston C, Miles MS. Coming to terms with adult sibling grief: when a brother dies from AIDS. Journal of Hospice and Palliative Nursing. 2005; 7(3):139–149.

Epstein, H. The Invisible Cure: Africa, the West, and the Fight against AIDS. New York: Farrar, Straus and Giroux; 2007.

Ewing, D. Welfare. In: Gow, J.; Desmond, C., editors. Impacts and Interventions: The HIV/AIDS Epidemic and the Children of South Africa. Pietermaritzburg, South Africa: University of Natal Press; 2002.

Gow, J.; Desmond, C. Households. In: Gow, J.; Desmond, C., editors. Impacts and Interventions: The HIV/AIDS Epidemic and the Children of South Africa. Pietermaritzburg, South Africa: University of Natal Press; 2002.

Horowitz JA, Ladden MD, Moriarity HJ. Methodological challenges in research with vulnerable families. Journal of Family Nursing. 2002; 8(4):315–333.

Kemeny ME, Dean L. Effects of AIDS-related bereavement on HIV progression among New York City gay men. AIDS Education and Prevention. 1995; 7:36–47. [PubMed: 8664097]

Krippendorf, K. Content Analysis: An Introduction to its Methodology. Thousand Oaks, California: Sage; 2008.

Kurland L. A qualitative analysis of sibling loss by sudden death during adolescence (San Diego, California, Alliant International University). Dissertation Abstracts International: Section B: The Sciences and Engineering. 2003; 64(5-B):2392.

Lee SJ, Detels R, Rotheram-Borus MJ, Duan N. The effect of social support on mental and behavioral outcomes among adolescents with parents with HIV/AIDS. American Journal of Public Health. 2007; 97(10):1820–1826. [PubMed: 17463374]

Lincoln, Y.; Guba, E. Naturalistic Inquiry. New York: Sage; 1985.

Lund C, Kleintjes S, Kakuma R, Flisher AJ. Public-sector mental health systems in South Africa: inter-provincial comparisons and policy implications. Social Psychiatry and Psychiatric Epidemiology. 2010; 45(3):393–404. [PubMed: 19506789]

Martin JL. Psychological consequences of AIDS-related bereavement among gay men. Journal of Consulting and Clinical Psychology. 1988; 56(6):856–862. [PubMed: 3204195]

Martin JL, Dean L. Effects of AIDS-related bereavement and HIV-related illness on psychological distress among gay men: a 7-year longitudinal study, 1985–1991. Journal of Consulting and Clinical Psychology. 1993; 61(1):94–103. [PubMed: 8450113]

Maxwell, JA. Qualitative Research Design: An Interactive Approach. Thousand Oaks, California: Sage; 1996.

McCracken, G. The Long Interview. Newbury Park, California: Sage; 1988.

Mishra V, Arnold F, Otieno F, Cross A, Hong R. Education and nutritional status of orphans and children of HIV-infected parents in Kenya. AIDS Education and Prevention. 2007; 19(5):383–395. [PubMed: 17967109]

Morgan DL. Qualitative content analysis: a guide to paths not taken. Qualitative Health Research. 1993; 3:112–121. [PubMed: 8457790]

Myer L, Seedat S, Stein DJ, Moomal H, Williams DR. The mental health impact of AIDS-related mortality in South Africa: a national study. Journal of Epidemiology and Community Health. 2009; 63(4):293–298. [PubMed: 19074926]

Nkomo N, Freeman M, Skinner D. Experiences of children heading households in the wake of the human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) epidemic in South Africa. Vulnerable Children and Youth Studies. 2009; 4(3):255–263.

Oskowitz B, Meulenberg-Buskens I. Preparing researchers for a qualitative investigation of a particularly sensitive nature: reflections from the field. South African Journal of Psychology. 1997; 27(2):83–88.

Richards L. Rigorous, rapid, reliable, and qualitative? Computing in qualitative method. American Journal of Health Behavior. 2002; 26(6):425–430. [PubMed: 12437017]

Riffe H, Fouche C. Does anyone die from AIDS in South Africa? Journal of HIV/AIDS and Social Services. 2007; 6(4):23–35.

Robinson LA. Adult grief reactions following a sibling's death from AIDS. Journal of the Association of Nurses in AIDS Care. 2001; 12(2):25–32. [PubMed: 11296728]

Robinson LA. Disclosure after a sibling's death from AIDS. Community Health. 2002; 25(1):22–31.

Robinson L, Mahon MM. Sibling bereavement: a concept analysis. Death Studies. 1997; 21(5):477–499. [PubMed: 10175164]

Sandelowski M. Whatever happened to qualitative description? Research in Nursing and Health. 2000; 23:334–340. [PubMed: 10940958]

Statistics South Africa. Statistical Release 0302. Pretoria, South Africa: Statistics South Africa; 2009. Mid-Year Population Estimates, 2009.

Strauss, A.; Corbin, J. Basics of Qualitative Research. Thousand Oaks, California: Sage; 1998.

Strydom H. HIV/AIDS and South African adolescents: attitudes and information needs. Social Work/ Maatskaplike Werk. 2003; 39(1):59–72.

Strydom H, Raath H. The psychosocial needs of adolescents affected by HIV/AIDS: a South African study. International Social Work. 2005; 48(5):569–580.

Summers J, Zisook S, Atkinson JH, Sciolla A, Whitehall W, Brown S, Patterson T, Grant I. Psychiatric morbidity associated with acquired immune deficiency syndrome-related grief resolution. Journal of Nervous and Mental Disease. 1995; 183(6):384–389. [PubMed: 7798087]

Ulin, PR.; Robinson, ET.; Tolley, EE.; McNeill, ET., editors. Qualitative Methods: A Field Guide for Applied Research in Sexual and Reproductive Health. Triangle Park, North Carolina: Family Health International; 2002.

UNAIDS. AIDS Epidemic Update 2009. Geneva: UNAIDS; 2009.

UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance. Epidemiological Fact Sheet on HIV and AIDS: Core Data on Epidemiology and Response — South Africa. 2008 Update. Geneva: UNAIDS/WHO; 2008.

Table 1

Characteristics of the participants (*n* = 11 adolescents)

Characteristics	***n***
Age (years):	
≤13	1
14–15	1
16–17	7
>17	2
Males	3
Females	8
HIV status unknown	11
Average number of people in household	7