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THE PSYCHOSOCIAL NEEDS OF TEENAGERS ORPHANED BY HIV AND AIDS: A QUALITATIVE STUDY IN KWAZULU-NATAL

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ABSTRACT

Dealing with HIV, AIDS, parental illness and death are realities many South African teenagers have to face. Understanding the experiences of such teenagers provides a vital ingress into the complexities of the HIV and AIDS epidemic as a social phenomenon. The objective of this study was to describe the psychosocial needs of orphans aged 13-15 years. In-depth interviews were conducted with a purposeful sample of teenaged orphans in KwaZulu-Natal. Findings reveal that these teenagers were confronted with drastic changes before and after the deaths of their parents. Several losses were experienced, such as the loss of a parent, the loss of friends, the loss of a home, an inheritance and a childhood. The care experience of the teenagers differed. Whereas some caregivers provided some of the needs of the teenagers, unmet psychosocial needs and poor care were reported.

Key words: HIV status, HIV and AIDS, orphans, psychosocial needs, social support, teenagers, trauma

INTRODUCTION

UNICEF, UNAIDS and US PEPFAR (2006) report that at the end of the year 2005, about 12% (12 million) of all orphans in sub-Saharan Africa were due to AIDS-related mortality. Brookes, Shisana and Richter (2004) estimate that 24,0% of South African teenagers in the 15-18 year age group have lost one or both parents due to HIV and AIDS. Research shows that orphans face many psychosocial challenges that involve the lack of parent-family cohesion and poor acceptance into the new families they join (Harms, Jack, Ssebunnya and Kizza, 2010). They also face social problems, such as the lack of supportive peer groups and role models, stigma and other risks in their immediate environment (Thurman, Brown, Richter, Maharaj and Magnani, 2006). Psychosocial problems that affect children orphaned due to AIDS-related causes start at the illness of the parents and continue well after their death. Orphans, typically, suffer higher levels of anxiety, depression and anger (UNICEF, 2006; Makame, Ani and Grantham-McGregor, 2002).

Müller, Sen and Nsubuga (1999) report that increased risk of malnutrition, inadequate shelter, lack of clothing and interrupted schooling are commonly cited as the consequences of the death of wage-earning adults in AIDS-affected households. Whereas these problems relate to material provisions for orphans, Kalala, Yamba and Simasiku (2002) point out that if the psychosocial needs of orphans remain unmet, meeting their material needs has little impact on their welfare.

Research on the psychosocial needs of orphans and vulnerable children has generated much knowledge on the topic (see Cluver, Gardner and Operario, 2007; Kidman, Petrow and Heymann, 2007; Shisana and Louw, 2006; Simbayi, Kleintjes, Ngomane, Tabane, Mfecane and Davids, 2006). Thurman et al. (2006) explore the sexual risk behaviours of teenaged orphans in South Africa.

In our review of literature, we discovered that there is a paucity of South African studies that focus primarily on the psychosocial needs of teenaged orphans. Moreover, we envisaged this study as a child-centred approach to understanding the experience of HIV and AIDS-induced orphanhood. Our assumption was that children and teenagers need to be taken seriously as social agents who actively construct their own social worlds. This means that we are interested in the teenage interviewees' own interpretations of their experiences and of the meaning that these interpretations have in their lives. We regarded the teenagers as competent informants in the sense that they have their own stories that will help us better understand the issue of

psychosocial needs of teenagers orphaned by HIV and AIDS. To this end the objective of this study was to describe the psychosocial needs of orphans aged 13-15 years in KwaZulu-Natal by generating their personal stories and accounts.

METHOD

Research design

A qualitative approach in the form of narrative work was used to gauge the orphans' experiences before and after the deaths of their parent(s). This approach was chosen to fit the researchers' view that experience is a storied phenomenon. We regarded our interviewees as persons who lived lives as orphaned youth and were thus competent to tell, retell and relive the storied experience of teenaged orphanhood. The chosen approach enabled the researchers to gain insights into the relationships, complexity of interactions and the psychosocial needs of teenaged orphans. Connelly and Clandinin (2006:375) set the parameters of narrative inquiry as follows:

“People shape their daily lives by stories of who they and others are and as they interpret their past in terms of these stories. Story, in the current idiom, is a portal through which a person enters the world and by which their experience of the world is interpreted and made personally meaningful. Narrative inquiry, the study of experience as story, then, is first and foremost a way of thinking about experience. Narrative inquiry as a methodology entails a view of the phenomenon. To use narrative inquiry methodology is to adopt a particular view of experience as phenomenon under study.”

Study setting

The study was conducted in Indlovu village in the Umkhanyakude district of KwaZulu-Natal, South Africa. The village comprises 970 housing units and the majority of the population is black African and IsiZulu-speaking.

Study participants

Volunteer participants were selected using purposive sampling from orphans affected by HIV and AIDS and cared for and supported by a local non-governmental organisation (NGO) called Inkanyezi Yokusa Mina Nawe. To be orphaned in the context of this study, refers to a state in which the interviewee is a person under the age of 18 who has lost either one or both

parents due to HIV and AIDS-related causes (please see the actual age parameters set as inclusion criteria below). At the time of the study, Inkanyezi Yokusa Mina Nawe cared for 177 orphans of whom 49 were between the ages of 13 and 15 years. In recruiting interviewees, the researchers did not differentiate between double orphans (those who have lost both parents), maternal orphans (those who have lost a mother) or paternal orphans (those who have lost their fathers). Eventually five volunteer interviewees were selected which included three double orphans and two maternal orphans.

The interviewee recruitment and selection strategies were purposefully employed as the NGO was able to offer psychological support to the participants after the conclusion of data-gathering (a major ethical consideration in this study). The inclusion criteria set were that the participants had to be older than 12 years of age and younger than 16 years of age, that they were orphaned due to AIDS-related causes, that they received support from the NGO, that they assented to be interviewed and that a legal guardian consented to their participation in the research.

Permissions and informed consent

Prior to the commencement of the interviews, written permission and approval to conduct the study was granted by the Research Ethics Committee of the University of South Africa (UNISA), the South African Department of Social Development's Hlabisa Region and Inkanyezi Yokusa Mina Nawe.

Research participants were recruited in their households by the researchers with the assistance of the volunteers from Inkanyezi Yokusa Mina Nawe. Informed consent forms were given to the guardian of each recruited participant to sign after the objectives of the study had been explained to them. The teenagers were given informed assent forms to sign. In each recruited case, the objectives of the study, what participation entailed, that voluntary participation was asked for, how the data were to be generated, analysed and written up were explained in IsiZulu. The two researchers whose home language is IsiZulu conducted all the pre-interview briefings, the informed consent and assent negotiation, all of the interviews and the post-interview debriefings.

Data collection activities

The researchers used a semi-structured interview schedule which was developed out of a review of literature on teenagers and orphans. In-depth

interviews were conducted in August 2008 by the researchers using the interview guide. More than one interview was conducted with each participant until data-analysis revealed the saturation of themes. All interviews were conducted in IsiZulu and recorded on an audiotape with the assent of the teenagers and the consent of their legal guardians.

Data analysis

The audio-recorded interviews were transcribed verbatim and translated into English. Stories were re-written to form chronological sequences and patterns of experiences. The analysis commenced with reading and rereading the transcribed interviews, field notes and research journal. The rich and extensive data of storied lived experience were subjected to two rounds of analysis. The first round was aimed at identifying major themes in the data. The collated raw material was then subjected to a first round of coding of themes in the data. The first level coding was guided by the organising concepts gleaned from the review of the literature and from a thorough reading of the transcripts.

In the second round, the aim was to condense the themes to reveal a number of key, insightful storylines that emerged from the stories. This second round of coding meant that the first-level codes were collapsed into broader themes through the detection of related patterns and sub-themes in the information. The researchers independently coded and checked the coded transcripts in order to increase the dependability of the emergent findings. Themes that emerged from the informants' stories were pieced together to form a comprehensive picture of their collective experience.

RESULTS

Brief profiles of the research participants, an overview of the results and emerging themes

To help contextualise the findings of this study, some biographical information on the participants is presented in Table 1 on the following page. It shows how female relatives (aunts, grandmothers or older female siblings) became the primary caregivers of these children during their parents' illnesses and after their deaths. It struck the researchers that all of the participants reported that they did not have sound relationships with their fathers even before HIV and AIDS affected their households.

Table 1: Biographical information on the participants

Parti- pants	Gender	Age	Education level	Orphan type	Primary caregiver
1	Male	13	Grade 5	Double orphan	Maternal aunt
2	Male	15	Grade 8	Double orphan	Maternal aunt
3	Female	13	Grade 8	Maternal orphan	Sister (also a minor)
4	Female	15	Grade 9	Double orphan	Maternal grandmother
5	Female	13	Grade 7	Maternal orphan	Maternal grandmother

Another striking observation during all of the encounters with the research participants was their apparent lack of excitement about their youthfulness. Kamper and Badenhorst (2010) mention that an outward future-orientation is a prominent trait among deprived and underprivileged teenagers. A recurrent entry in all our fieldwork notes was that although all of our teenage interviewees were able to express a future career aspiration, none of them gave concrete examples of things that they really liked about their lives, or things that they were looking forward to. Instead, the narrations were beset with reflections on the harshness of a life characterised by mourning and bereavement. Another common thread that ran through all the narrations was multifaceted lives exposed to different types and levels of trauma from young ages so that all of the respondents retold how they were robbed of a carefree childhood. They were faced early on with the multiple losses of significant members of their families, and were sent to different households. These experiences contributed to their feelings of being uprooted from their original families.

The narrative analysis revealed five themes related to psychosocial needs, namely (1) disclosure about HIV in the family; (2) the social and physical needs experienced by orphans; (3) needs arising from relocation and changed household living arrangements; (4) emotional trauma and abuse and (5) attempts at nurturing resilience and fostering hope. Findings in terms of each of these themes are discussed on the following pages.

Disclosure about the parents' HIV-status

All of the research participants reported that their parents did not disclose information about their illnesses to them. This was narrated as a deep regret because it denied them the opportunity to discuss their parents' health with them before they passed away. They felt that such openness would have enabled them to better cope with their parents' illness and death. They also reported that they harboured unanswered questions about the deaths of their parents, for example:

I did not have any information about my father's illness [pause]... except that I was told by my aunt that he was ill. I was young and I could not probe further because my father was not staying with me... I would have loved to have known more about his illness but nobody said anything about it. As for my mother...I only know that she was suffering from headaches and my aunt took care of her when she was ill (Participant #1).

Most participants expressed the opinion that although they would have preferred to know the truth about their parent's conditions, they were too young to ask their elders questions. In traditional Zulu households, young children are not supposed to confront elders, even if the matter at hand may impact negatively on the child. The lack of information about their parent's illnesses triggered further doubt, for example:

I started asking myself that, could it be HIV-related death? I answered myself.... no, it can't be. I asked all these questions with no answers and who was going to give me those answers? I guess those are the questions I will always have throughout the rest of my life without getting answers for (Participant #2).

I know I am not supposed to diagnose my mother with this disease but from what I was taught about the symptoms of AIDS, I think my mother was suffering from it. I did not think like this when she was ill because I did not know about the symptoms then but now I do (Participant #5).

I trusted my mother a lot but I wonder if she told me everything about her illness. Since TB [tuberculosis] is curable if you treat it, why did my mother die? Unfortunately I can't ask anyone but this question is always coming up in my mind (Participant #3).

Painful memories surfaced in the narrations of parents suffering from obscure symptoms that seemed to persist over time without having a clear diagnosis or label for what they were suffering from. This inability to discuss their parents' condition caused feelings of fear and isolation in these young people.

The silence about HIV and AIDS persisted for most of them even after the deaths of their parents. Therefore, the non-disclosure of the parental status remained an unfulfilled need. This is an important finding as research from Western countries seems to indicate that parental disclosures of HIV status were less emphasised by orphans and tended to lead to an increase in behavioural problems for the children involved or a deterioration in the parent-child relationship (Shaffer, Jones, Kotchick, Forehand and the Family Health Project Research Group, 2001).

Social and physical needs

Research participants spoke with longing of things that they had possessed when their parent/s were still alive which they have to do without. At the same time, however, the participants were appreciative of the efforts by their extended/foster families to provide for them, even though this was not enough, for example:

It is very painful that other children are getting everything they like and I am not. My aunt is trying everything to provide what I need but the gap still remains. It would have been better if my mother was still alive because my aunt would not be struggling to raise me. As much as my aunt loves me, she cannot replace my biological mother. I was very happy when my mother was still alive because she used to love me so much and provided everything I asked from her (Participant #1).

I was living a good life when my mother was alive but now, life is no longer the same as before. I was getting everything I needed; she was buying me the full set of [school] uniforms, which I don't have now. Now I have one skirt instead of two; I don't have a school tie; I have old shoes (Participant #3).

The type of idealised reporting demonstrated in the vignettes here about how much better the interviewees' lives were prior to the impact of HIV and AIDS on their households was not unique to this study. This has been found in studies among orphans in Zimbabwe where the interviewees clearly distinguished between their quality of life when their parents were still alive, when they became sick and when they eventually died (HSRC, BRTI, NIHR and FACT, 2006). Deepening household poverty (which started when the parents became too ill to work and continued due to the additional care burden on their new foster households) resulted in two respondents dropping out of sports teams because there was nobody to supply sports attire. Four of the participants referred to a painful loss of privacy since the dwellings were not big enough to accommodate all of the household members and they had to share small bedrooms with the children in their foster families.

Relocation and changed living arrangements

The narrations revealed that after the death of their primary caregivers radical changes took place in the lives of the teenage orphans. Some were taken in by foster or extended families and this compelled them to relocate from their original dwelling places to a new area of residence. Such changes included a change of school. Not all the interviewees shared the same experiences in their relocations as for some the moves were within the same community, but for the majority the move was over a bigger geographical distance within the same province.

UNAIDS (2002) reports that this re-distribution of orphans to different households, involving relocation away from schools and friends, is a common occurrence, obligating the teenagers to cultivate new friendships, and learn to deal with different teachers in a new setting. Madhavan (2004) distinguishes between voluntary fostering and crisis fostering where the former refers to traditional informal fosterage and the latter to fostering done in response to a crisis — mostly death of biological parents or economic hardship. It was clear from the interviewees' retelling of their relocations that they all formed part of crisis fostering which often precluded careful planning and consultation about how this would impact on the children and their schooling.

Participants reported that they were forced to migrate from their original dwelling places to either join households where their ill/dying parent(s) were cared for, or to new foster or extended households. In some cases, this meant more than one move in a short period. This uprooting to new, unfamiliar places was reported as a traumatic experience. It is important to note that during all of these changes, the children experienced several painful events, namely serious parental illness, parental death and the relocation of the household. Their receiving environments (new homes) were often not ready to deal with these children's stress and trauma, for example:

Unfortunately, I did not have a choice to stay at Ingwavuma because my mother was ill here [Mtubatuba] so I had to come. At Ingwavuma, I was sharing a big house with my cousin but here I feel very squashed and it is unusual to me. I should not complain or say too much; at least my aunt loves me (Participant #1).

The impact of moving to a foster family situation presented challenges to these young people, which included leaving behind the memories of a place where they grown up; leaving friends behind; sometimes even dropping out of school. The children thus became strangers in their new households and

the new areas to which they were forced to move. Participants did not initiate, or favour, the move to the new foster households but they felt obliged to do so, because the family had decided to distribute the children in that way. It is common practice in rural Africa for children to be reallocated in this way, so that the care-burden of orphans and vulnerable children is distributed across various households (Howard, Phillips, Matinhure, Goodman, McCurdy and Johnson, 2006). Participant #3 said:

After my mother's funeral, the family had a meeting in our [the children's] absence and decided that I should go and stay with my aunt since I was the youngest. This was difficult for me because I was not consulted, I was just forced to go and stay with her... if I was consulted I would have preferred to stay here where my mother was staying [grandmother's house] before she died.

Trauma, financial exploitation and abuse

Losing a parent is emotionally taxing, but some of the research participants suffered the additional ordeal of emotional trauma or abuse by some of their new caregivers. Some of them lost their inheritance which would have been of some financial value to them. Participants told of the emotional trauma they suffered at the hands of their caregivers who took their belongings and sold them bit by bit to passersby, for example:

My relationship with my grandmother is not good because she did not take good care of my father's belongings. She did not give me the money she got from selling my father's belongings, and the money that came from my father's employer (Participant #2).

Some foster parents also took useful documents, including the identity documents and death certificates and hid them. Foster and Mafuka (1997) found that orphans are vulnerable to financial exploitation, which includes the misappropriation of inheritance monies, homes, and property by surviving adult relatives. African customary law is often cited by family members as justification for disenfranchising orphans and widows from property and inheritance (Mwenda, Mumba and Mvula-Mwenda, 2005). This practice, referred to as "property-grabbing" undermines the livelihood of orphans already severely compromised by the death of parents (Gilborn, Nyonyintono, Kabumbuli and Jagwe-Wadda, 2001). A number of researchers (Izumi, 2006a and 2006b; Rose, 2006 and 2005; Drimie, 2002; Nyambedha, Wandibba and Aagaard-Hansen, 2001) comment on the inability of orphaned children in Africa to protect their property and inheritance rights against

usurpations by relatives and others. These researchers note that such violations of orphans' property and inheritance rights are routinely ignored by other researchers and commentators who regard the fluidity of property and inheritance rights and the influence of traditional and customary law on such issues as a normal part of life in Africa instead of emphasising the devastating impact of such violations. Rose (2006:2) states:

“In view of how little attention children's property and inheritance rights have received, as well as how little is known about violations of these rights, it is no wonder that the governments of Southern and East Africa have not already fully protected such rights within legislation.... Those people who deny children their property and inheritance rights commonly argue that customary law supports their own rights to inherit and/or use the property of the children's parents. They maintain that the rules of customary inheritance stipulate that the property of deceased adults should be distributed within the extended family, or they maintain that the rules of customary inheritance require that adult guardians of children decide how inherited property should be distributed or earned property should be used.”

Some participants became the victims of verbal and emotional abuse at the hands of the caregivers. Frequent emotional outbursts witnessed by these children were a source of deep pain for the participants, for example:

My aunt shouts at us [interviewee and her twin sister] and she tells us that she will chase us to go back where we belong. When we tell our grandmother, she just keeps quiet and when we tell our father, he normally tells us that he will take us so that we could stay with him. Sometimes my father asks my aunt about this matter and she says we are lying... I am very confused, I do not know what to do now because I always wanted to go and stay with my father but I know that my mother did not want me to stay with my father (Participant #5).

Is there a chance to nurture resilience and restore hope?

The story of our five teenage orphans is incomplete if we do not include their own reflections on the possibility for resilience and hope. As indicated at the start of our discussion of the findings, the retelling of their lived experiences as children affected most deeply by HIV and AIDS was dominated by sadness and little enthusiasm for future expectations. Nonetheless all five interviewees were beneficiaries of the services provided by Inkanyezi Yokusa Mina Nawe. In terms of their experiences of their interactions with the organisation, the interviewees noted that they were able to fulfil their

basic needs. They considered the role played by this organisation as vital in helping them restore some sense of purpose and confidence in life.

Participant #1, for example said:

I feel so different ever since I started associating with Inkanyezi Yokusa Mina Nawe. They give us food, clothes, and life lessons. When I visit that place, I meet other children who are in the same situation as I am, and we talk and share common issues with one another. This has really helped me a lot and I think other children feel the same way.

Participant #2 said:

Apart from the support I get from my aunt, Inkanyezi Yokusa has done wonders in my life. They have given me the life orientation training and life skills that I would never have received.

Participant 3 told the researchers how she received support from school friends and her church:

When I am feeling sad about something, I confide to my school friends, but if I miss my mother I do not talk to my friends but I prefer going to church for prayers. I am afraid of talking about my mother with my friends because they would ask me questions that I am not ready to answer about my mother.

Although the findings should be treated with some circumspection due to the small sample size and the possibility of some acquiescence responding in answering questions about the safety net provided by the NGO, the evidence adduced in this study demonstrates that the safety nets provided by such organisations are important to teenagers. It has already been mentioned that the narrations of the five teenagers in the study lacked general optimism about their future. At the same time, however, their stories revealed that, through the support they received from the NGO and their church, they were able to find some hope and nurture resilience, albeit only in the notion of shared experiences with other vulnerable youth.

DISCUSSION

For the participants in our study, the memories of their parents' disease progression and deaths were traumatic. Caregivers in foster or extended families provided shelter and clothing, but this was often insufficient. Reported problems included insufficient space, resulting lack of privacy, not having new clothes, not having a full school uniform and not having sport

clothes. The deprivation of inheritance by caregivers was cited as a challenge.

It was found that the inability to discuss their parents' condition caused feelings of fear and vulnerability in the participants. The psychosocial needs presented in this study includes the lack of disclosure of parental HIV status; the breakdown of the original family unit; the lack of parental guidance, love, care, and acceptance in the new families that take them in; and the lack of the kind of support that would help orphans adjust to new environments without their parents. Many of the interviewees expressed their appreciation for the affection and support they received from their caretakers, the NGO and the church, regarding this as a major contribution to their personal growth and development. Richter, Foster and Sherr (2006) also report that the sense of belonging and hope that is nurtured in these relationships (with caregivers, friends, and fellow churchgoers) enables children to cope better with hardships.

The impact of HIV and AIDS on the family unit will be felt for decades to come. This requires urgent attention from all involved, including families; communities; schools; churches; NGOs; local government; and the international community. The selectivity of the sample limits the conclusions that can be drawn from this study. However, it provided valuable insights into the psychosocial needs of teenage orphans and the important role that stakeholders can play in funding or supporting the psychosocial services provided to teenage orphans.

In terms of implications for policy, the study's findings suggest that social protection measures for teenage orphans should respond to their unique risks and vulnerabilities. Targeted social protection interventions for teenage orphans should include economic protection in the form of income transfers, educational provision, improved access to social services including grants and protection against property grabbing. Richter (2008:2), for example comments:

“AIDS activism has increased access to ARV treatment. Now, in the same way, we must improve the ability of people to claim social protection entitlements. Social protection packages are affordable. The International Labour Organization has estimated the cost of a small universal old-age pension; universal primary education, free primary health and child benefit payments as between 1.5 to 4.5% of GDP for low-income African countries.”

Such interventions should also include psychosocial protection in the form of improved access to counselling services (Devereux and Sabates-Wheeler, 2004; Foster, 2005; Sabates-Wheeler and Waite, 2004).

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