

*Full Length Research Paper*

# **Mental health challenges of the lived experiences of adolescents orphaned by HIV and AIDS in South Africa**

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**Situational analysis approach was used to explore the mental health challenges of the lived experiences of adolescents aged 14 to 18 years living in South Africa who have lost their parents to HIV and AIDS. A qualitative phenomenological approach using reflective diaries was used to extract the lived experiences. Fifteen adolescents orphaned by HIV and AIDS aged between 14 to 18 years participated in the study. Eight adolescents made weekly entries for eight months and 7 of the participants brought empty diaries. Two major themes of experiences with loss and expressed emotions emerged from the reflective diaries. Experiences with loss had three subthemes of personal experience with loss, experiences with adoptive families and experiences at school. Anger, discrimination and not being told the truth were espoused from the diaries as mental health challenges. Expressed emotions included expression of anxiety, guilt, pretence, denial and hope. It became clear from these experiences and expressed emotions that adolescents orphaned by HIV and AIDS need love, caring, support and to be given hope for the future.**

**Key words:** Adolescents, lived experiences, mental health challenges, orphans, South Africa.

## **INTRODUCTION AND BACKGROUND**

South Africa has a population of approximately 47 million people (Population Report, 2007). The HIV and AIDS epidemic emerged in South Africa around 1982 and at the time the country was still battling with apartheid and the problem of HIV and AIDS was not given any urgent attention (Williams and Gouws, 2001). South Africa is currently experiencing one of the most severe AIDS epidemics in the world (Avert, 2008). The Avert report also noted that at the end of 2007, there were approximately 5.7 million South Africans living with HIV and AIDS, making this the largest HIV epidemic in the world (UNAIDS, 2008). The majority of those affected are persons between the ages of 15 and 39 years (Hartell, 2005). The highest prevalence rates are among young people, especially adolescent girls (The State of the Population Report, 2006). However, South Africa has a range of relevant policies and interventions geared towards fighting the HIV and AIDS scourge (UNAIDS, 2006).

The Economic Commission for Africa report (2007)

entitled "Impact of HIV and AIDS on gender, orphans and vulnerable children" reported that the number of orphans in Africa is increasing at a very high rate, because the AIDS pandemic targets the age group consisting of adoptive families and parents. It is estimated that 15 million children under the age of 18 have been orphaned due to AIDS, with 1.6 million of these orphans living in Sub-Saharan Africa (Avert, 2008). The Children on the Brink Report (UNICEF, 2004) suggests that 55% of all orphans are aged 12 - 17 years. This data is further supported by information from Avert (2008), which estimate that 1.4 million orphans lived in South Africa by 2007.

Adolescents orphaned to HIV and AIDS represent a population vulnerable to mental health risks. Stressors due to the loss of a loved one are highly context specific and often difficult to avoid (Fontaine and Fletcher, 2003).

Adolescents orphaned by HIV and AIDS may be more vulnerable to HIV infection than young children (UNICEF, 2004) as they are more amenable to multiple sex partners as a means of survival as they tend to take on multiple partners with the hope that the partners will support them both emotionally and financially (Tsheko, 2005). Therefore, HIV infection and the loss of guidance

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from parents are associated with additional developmental challenges (Seboni, 1997), such as poor academic performance. Psychosocial and economic distress can lead to risk-taking behaviors linked with unsafe sexual practices and substance use (Seboni, 1997).

### **Trends in orphaning**

Children on the Brink (2004) reports that the global number of children orphaned to HIV and AIDS increased from 11.5 million in 2001 to 15 million in 2003, the majority of the orphans being in Africa. Variations in Africa have also been noted (UNAIDS, 2004, 2006, 2008), with sub-Saharan Africa being the most affected. The distribution of orphaning in sub-Saharan Africa is mostly concentrated in Southern Africa, (UNAIDS, 2006). In South Africa 49% of the total population of orphans are orphaned to HIV and AIDS and this number is estimated to more than double by 2010 (UNAIDS, 2006).

### **Patterns of orphan care**

There are three general trends in orphan care, namely the gendered pattern of care, the aged pattern of care and the geographical pattern of care (UNICEF, 2004; Kuo and Operario, 2007; Thupayagale-Tshweneagae, 2008). The gendered pattern of care which is care given by females is common in many countries (UNICEF, 2004). In most countries of the world female headed families care for more orphans than male headed households (Stein, 2003). The same phenomenon is found in South Africa where 75% orphans live in households headed by females. These households have on average two orphans or more (double orphans) whereas households headed by men have only one orphan on average (single orphans) (stein, 2003).

According to the aged pattern of care, grandmothers all over the world are increasingly becoming the primary adoptive families for their grandchildren, mostly due to the HIV and AIDS pandemic (Park, 2005; Thupayagale-Tshweneagae, 2008). According to Ruiz (1999), the assumption of the parenting role by grandmothers has a major challenge of communication barrier due to the generation gap between adolescents and grand-mothers. The communication barrier results in ineffective supervision by grandmothers. Grandmothers are faced with many challenges as there is no formal income to assist them except for the social welfare benefits that covers basic amenities such as food and clothing (Thupayagale-Tshweneagae, 2008). An increasing trend in grandmothers assuming the primary care giving role has also been noticed in Southern Africa and in South Africa in particular (Matshalaga, 2004).

A noticeable number of orphans are cared for by their siblings who in most cases are female siblings aged

between 14 and 18 years (Sweat, 2003). Orphan headed families are currently on the increase in sub-Saharan Africa (Wallace et al., 2006). Germann and Siwela (2002) indicate that orphaned adolescent headed families are increasing. Also, orphan headed families are a special group prone to sexual, physical and emotional abuse, hence more financial and social attention should be geared towards this group.

According to the geographical pattern of care, the majority of orphans reside in rural areas which are less developed and have few amenities such as water, schools and health care centers (UNICEF, 2003). Most of the orphans live with their grandmothers in rural areas. This pattern is explained by the fact that HIV and AIDS disproportionately affect the poor who mostly resides in rural areas (Aspaas, 1999). A slightly different geographical pattern has been reported in South Africa where the majority of orphans were found to live in urban areas (Kuo and Operario, 2007). However, the difference between urban and rural areas has been reported to be at less than 2%.

### **Mental health challenges of adolescents**

Living with AIDS is among the most stressful of human experiences (Fontaine and Fletcher, 2003). Adolescents orphaned by AIDS are exposed to unpredictable and unfamiliar experiences (Borges et al., 2008) which is compounded and complicated by the grieving process where there is no adult guidance.

In the Southern African region, the situation is compounded by the socio-economic status of families and communities. Deaths from HIV and AIDS have affected many families and communities and have resulted in the majority of people experiencing grief, including adolescents. However, adolescents need to develop healthy patterns of grieving to cope with life's sorrows. If adolescents do not deal with their grieving process, they will be vulnerable to mental health problems and may have many anxieties about the deaths of their parents (Wolfelt, 2002). Furthermore, children who have been denied healthy grieving develop negative attitudes including difficulty in expressing emotions, hostility towards others and unnecessary guilt (Mallinson, 1999).

The adolescent is faced with striving to integrate previous roles of being young and carefree to having to deal with the emotional demands of loss with no support from parents. This may exacerbate the grieving process as the adolescent re-organize their sense of self and anxiety may set in (Goodman, 2000). Anxiety may be due to a future in which one's parents are no longer there, fear of abandonment by those in whose care adolescents are placed or an overwhelming fear of suffering and rejection.

Healthy adolescent development depends on safe and supportive environments that provide opportunities for youths to build strong and meaningful connections with

their schools, families and communities (Boeree, 2006). Being orphaned in adolescence does not provide an ideal environment and may lead to mental health problems such as depression (Erikson, 2001). Cluver and Gardner (2006) also reported that AIDS orphans exhibit post-traumatic stress disorder and psychosomatic ailments.

### Significance of the study

South Africa is one of the countries reported to have a high number of orphans. The authors found very few studies on the mental health challenges faced by orphans in South Africa (Bray, 2003; Cluver, 2003; UNICEF, 2003; UNICEF, 2004). Apart from these studies, there has been a reliance on western studies. The need to generate a knowledge base appropriate and relevant for addressing the needs of South African orphans is imperative and critical.

Although several studies have revealed the needs of orphans in South Africa, very few studies have focused on adolescents and hence their needs have been subsumed under the needs of orphaned children. Adolescents need to be recognized as a specific population with specific needs over and above those of other orphaned children.

This study will identify specific grieving and coping patterns for adolescents orphaned to AIDS and how they have experienced loss. The findings will enable the service providers to adopt a more focused perspective on addressing the needs of adolescents orphaned by HIV and AIDS.

An understanding of the mental health challenges of the lived experiences of adolescent orphans in South Africa, will provide additional unique information on their needs, which will further influence health policies relevant to them. Such an understanding can then be applied to other orphaned adolescents in South Africa and the region that share cultural and epidemic semblance.

### METHODS AND PROCEDURES

The aim of phenomenological research is to examine the meaning of life through the interpretation of the individual's lived experiences (Streubert-Speziale, 2006). A major concern of phenomenological research is to capture the totality of the human experience, with an emphasis on the meaning that social behavior has for the individual. The researchers desired to uncover the experiences of adolescents orphaned by HIV and AIDS and to discover what the adolescents need to cope with their loss and grief (Colaizzi, 1978). In accordance with phenomenological studies, the researchers utilized descriptive strategies of intuition, bracketing, analysis and description entry into diaries. Probes were used during the phenomenological interviews following what was recorded in reflective diaries to facilitate expression of the participants' lived experiences, as well as to assist them to suggest how losing their parents to HIV and AIDS could have been made more bearable and less painful (Streubert-Speziale and Carpenter, 2003).

Bracketing as a strategy was also utilized by the researchers. Researchers identified their own beliefs and assumptions and presumptions so that it did not interfere with the information given

by participants. For instance, the principal investigator had always believed that maternal grandparents are the ones who could provide for the orphans. The principal investigator was always aware of this belief but kept it from influencing the participants' stories and remained neutral throughout the data collection phase.

The researchers also read and re-read the participants descriptions and compared and contrasted their different description and noted recurring themes. After noting the recurring themes the researchers then described in detail the critical elements of being orphaned to HIV and AIDS.

A phenomenological qualitative design was used to explore the lived experiences of adolescents orphaned by HIV and AIDS through the use of reflective diaries. Reflective diaries were used to understand the lived experiences of adolescents orphaned by HIV and AIDS. Diaries are a useful tool in studying any phenomena in qualitative research (Deacon, 2000). Diaries produce a subjective knowledge of the experiences, emotions and meanings associated with the phenomena (Rosenblatt, 1995).

### Study population and setting

The target population for the study was adolescents aged 14 to 18 years who have been orphaned to HIV and AIDS and were attending a day care centre. The day care centre served as a hospice centre and a feeding and social support centre for vulnerable populations including orphans. The participants did not know their own HIV status as none of them had tested. The inclusion criteria for the research participants were as follows: (1) aged between 14 and 18 years; (2) orphaned to HIV and AIDS; (3) orphaned for more than one year; (4) attending Hospice and AIDS Awareness Centre regularly on Saturdays and (5) willing to participate in the study.

The study took place at an urban area 37 kilometers from Pretoria, the capital city of the Republic of South Africa. The center is a non-governmental organization that helps the disadvantaged populations including orphans.

### Sampling procedure

For this study, a purposive sampling technique was used to recruit research participants (Creswell, 2003). Purposive sampling is a technique in which the investigators choose the participants on a judgment of the extent to which the potential participants meet the selection criteria (Welman and Kruger, 2000). Purposeful sampling allows investigators to choose a case because it illustrates some feature or process in which the investigators are interested (Silverman, 2000). In this study, the investigators wanted to recruit adolescents who were orphaned by HIV and AIDS. The AIDS Awareness Centre was chosen as the place of study as it offers support and care to orphaned adolescents, most of who are orphaned by HIV and AIDS.

### Data collection

Reflective diaries were used to obtain the lived experiences of adolescents orphaned by HIV and AIDS. Diaries are a useful tool in studying any phenomena in qualitative research (Deacon, 2000). Diaries reflect the research participants' subjective knowledge of the experiences, emotions and meanings associated with the phenomena under study (Rosenblatt, 1995).

The research participants were given small notebooks to serve as diaries. They were then asked to record their experiences of being orphaned to HIV and AIDS in the diaries. Participants were also asked to record their thoughts, feelings and experiences during the weekly meetings at the Centre (Deacon, 2000). Participants

were given an explanation of what to record in the diaries and were asked to use pseudonyms known to the researcher only. Participants had to hand in their diaries at the end of the sixth month of data collection. The participants were reminded on a weekly basis to record their thoughts, feelings and experiences in the diaries. However, only eight participants actually wrote in their diaries, while the other seven participants handed in empty diaries. The latter group on being interviewed by the researchers reported that they did not have anything to record in their diaries. The seven participants (2 males and five females) who did not record their views further explained that it was difficult for them to write their feelings as they were still struggling to accept the death of their parents. There was no demographic difference between those who made entries and those who did not make their entries. The eight participants who made entries made on average seven entries. It was interesting to note that most of the entries were made on the weekends.

### Data analysis

Colaizzi seven steps of data analysis were used to analyze data from the diaries. The first step of Colaizzi's method is reading of transcripts. The researchers read and re-read all the participants transcripts to acquire a feel for each description in all the entries and got immersed in the way adolescents experienced death of their parents in particular how they grieved and coped with their loss. Significant meanings were extracted from the descriptions and meanings were then formulated from the statements and theme clusters were then made which led to exhaustive description. Exhaustive descriptions lent themselves to the discovery of the lived experiences of orphaned to HIV and AIDS. The researchers made a fundamental statement of the identification which was later verified by participants. There were never a time where the participants disagreed with the researchers except may be to change the wording.

### PERMISSION TO CONDUCT THE STUDY

Written consent was obtained from the Ethics Committee of Tshwane University of Technology and the Faculty Research and Innovation Committee of the Faculty of Science. Permission was also obtained from the AIDS Awareness Centre to use their premises and the adolescents in their care for the study. Written informed consent was obtained before participation in the study from the participants. Participants were given an explanation of what to write in the diaries and were asked to write pseudonyms known to the researcher only.

### ETHICAL CONSIDERATION

The researchers explained to the participants the purpose of the study and that participating in the study was voluntary. It was further stressed that those who did not want to participate in the study would not be treated any differently by the investigator and/or the Centre. The participants were further informed that they could withdraw from the study at any time if they wished to. This right was explained to the participants before they signed the consent form. The researcher further assured the participants that information obtained would not be shared with strangers or people known to participants such as family members and identifying information would be stored away so that it would not be seen by anybody at AIDS Awareness Centre. Anonymity was assured by the researcher not using the participants' names in any documentation, presentations or publications that will be developed from the study.

## FINDINGS FROM REFLECTIVE DIARIES

Findings from reflective diaries showed that death of a mother to HIV and AIDS triggers multiple anxieties in an orphaned adolescent. The stressors experienced by participants emanated from their environment in the home and school. Detailed narratives from the reflective diaries generated two themes of experience with loss and expressed emotions. Experience with loss had three sub themes of personal experience, experience with adoptive families and experience at school. The second theme of expressed emotions had two sub themes of expression of anxiety and other emotions such as anger, denial, pretence and hope.

### Personal experience

Participants reported severe pain and an extreme sense of loss. The pain experienced was reported by both the male participants (n = 3) and the female participants (n = 5). The experience of pain was better summed by the following quotes from participants: a

"I feel so much pain, is like my whole body wants to break."

"For the past two years I have been trying to ease this pain of losing both my mom and dad, I still cannot accept that both of them are gone. My life has never been the same."

"I miss them. I wish one day God will ask me what I want that will make my life better and I would say, God, if I tell you will you make this real ?. I will ask for the return of mum and dad and everything will be okay and we will be happy again."

Some of the participants reported that their lives had never been the same since their parents died. They wrote in their diaries that their youth had been taken away. They also reported having to lead false lives because they pretended to be good while, at the same time, yearning to be young and carefree.

### Experiences with adoptive families

There was a strong feeling from the participants' entries that adoptive families want to replace their deceased parents by either calling them "daughter" or "son" and by moving into the deceased parent's bedrooms. This was best described by one participant who wrote this:

"My aunt should stop calling me "daughter". I am her niece and my mother is dead. I hate it so much if my aunt refers to me as "child" as if she cares; I was a child to my mother because she cared."

Participants also wrote about how they were never told the truth about their parents' illness and not being involved in the funeral arrangements. Discrimination was also written about, as participants felt that they do household chores while adoptive families' children who are same age as themselves were allowed to play.

### Experiences at school

The participants experienced school both positively and negatively. Some participants wrote that some teachers, while trying to be kind, would give them unwanted favoritism by giving them special treatment such as asking after their welfare or giving them uniform, money for sports, and other things. Although the offerings were viewed as generous, the adolescents didn't like being singled out even among the poorer children of the class.

Classmates were reported to pass painful remarks to the participants. Some of the classmates would leave a space between them and the participants as a way of isolating them. Some classmates are reported to provoke the participants at playtime so that the participants would get angry and want to fight. Other pupils in the immediate vicinity of the comments said would laugh at them or even join the fight.

### Expressed emotions

The participants' diaries had many emotions expressed which included guilt, denial, pretence and hope. An 18 year old female participant experienced her life as not being truthful because she had to pretend to be good. She wrote this in the diary and titled it "My life at home":

"Have you ever been called an angel whereas you are not? I am forever pretending to be a nice girl staying at home, not going out like other children my age, not messing with boys. This is not me I would like to be like other girls but I have to live a lie to please my adoptive families."

Participants avoided writing that their parents died of HIV and AIDS but alluded to HIV and AIDS as either a dangerous condition or a heavy situation. Such Statements were the basis for labeling some feelings as denial. For instance, one participant avoided writing HIV and AIDS as the cause of her mother's death and wrote this:

"She was a great mother until she found herself in a heavy situation. She was living a heavy life in 2004. She was so different and I did not know what to say and do to make her feel better until she decided to commit suicide."

The same participant also expressed hope and a strong commitment to make her life better by writing that:

"I have been lonely for a long time but now I realize that everyone has their time to live and a time to die. It was my mother's time to die. I am now working hard at school and will one day become a music star and have a man of my dreams."

### Expressions of anxiety

Many participants reported feeling anxious most of the time. They reported experiencing nightmares associated with death or, at times, seeing the faces of their parents and waking up to know that it was just a dream. Sleep difficulties related to these nightmares and similar problems were associated with a lack of sleep reported by some participants.

Some participants reported being easily frightened, especially if they saw a person who resembled the deceased parent or someone who spoke like their parent. Elizabeth 16 years old wrote in her diary of experiencing anxiety and wrote this statement:

"There was this person who looked exactly like my mother and worked in a shop a long distance from my school. Every time after school I would go there just to see her. I would even call her by name with the hope that she would answer me and everything will be okay again. I did that for a long time and one day another lady asked me whether I was calling ---- (referring to my late mother.) When I nodded, she explained to me the resemblance."

### DISCUSSION

An understanding of the mental health challenges of the lived experiences of adolescent orphans in South Africa provided unique information on their expressed emotions and needs. Manser (1984) defines experience as seeing or living through an event which gives one knowledge or skill. Adolescents experience a lot of pain and rebuke from adoptive families both at school and at home. At times, participants had to repress their emotions for fear of being rebuked and blamed for not appreciating the care that adoptive families are giving them. After the death of a parent uncertainty surrounds the lives of adolescents and this is why they need to be understood, supported and accepted by the adoptive families.

Noppe and Noppe (2004) stressed that adolescent boys are prone to repress their feelings of grief and that females are more open about their grief. Adolescent males are said to be prone to internalizing their emotional distress following parental death, whereas adolescent females are open about their feelings and reach out for support from adoptive families, peers and teachers. However, the findings of this study showed that both the females and males repressed their feelings of grief and that there was no significant difference between the three

males and the five females that made entries in their diaries in the way they express their grief. Orphaned adolescents who are able to express their feelings are able to overcome negative feelings associated with parental death. Repressed feelings lead to difficulty in forming trusting relationships with adoptive families and peers. Also, a person's self worth remains low as they tend to believe they do not fit into the new family. Repression of grief may lead to the development of mental health problems (Rotheram-Borus et al., 2001).

There is an expectation that grieving will occur and that after sometime grieving will subside and those grieving will be able to move on without the presence of the loved one (Lenhart and McCourt, 200). However, those mourners who fail to adjust to the loss are said to be experiencing complicated grief (Freudenbarger and Gallanher, 1995). Orphaned adolescents who fail to adjust to parental death may develop maladaptive behaviors such as social isolation and low self esteem. Christ et al. (2003) attributes such behaviors to failure of the orphaned adolescent to control emotions or to incorporate the loss into a unified identity without fear of social ramifications.

Participants at times found it very difficult to get integrated with their peers at school after the death of their parents to HIV and AIDS, even though they played together and were friends before the parents' death. They reported that some of their school mates passed unkind remarks about their deceased parents. The response was either to fight with them or ignore them, answer back or detach from them. All these are the negative outcomes of dealing with peers. Reed (2008) emphasized that difficulty in relating to peers and adjustment at school is a normal part of grieving in the initial phase when death had just occurred. However, Sento-Pelaelo (2005) argues that peers and the school usually understand the emotions experienced by an orphaned adolescent and support her/him in their journey of grief.

The emotional pain suffered by participants needs the school, peers and adoptive families to accept orphaned adolescents without any censure. Perko and Kreigh (1988) define acceptance as a positive acknowledgement and reverence for a person. Acceptance is affirming people as they are and their right to emotional expression (Fontaine and Fletcher, 2003). In this study, adolescents described how they had wanted adoptive families and other relatives to accept them.

Discrimination was one of the behaviors that exhibited to participants that they were not accepted by their adoptive families and even some teachers at school. In some instances, the adolescents were asked to do household chores in their new families and, as a result, missed school. For example, at school, one teacher instructed a participant's classmates not to use the same eating utensils. This is another example of teachers propagating stigma and discrimination against adolescents orphaned by HIV and AIDS. In addition to this

being a painful sign of non-acceptance, it is an unfortunate weakness in a place, school, where children's resilience to face daily life situations needs to be supported (Seedat et al., 2001).

Kurdek and Fine (1994) posit that acceptance of individuals is a key factor in the control of their behavior. This perception is supported by Davis and Konishi (2000) who affirmed that acceptance of an individual is a prerequisite for successful management of the emotional behavior that they demonstrate after a death. Fontaine and Fletcher (2003) are of the opinion that if a person is not accepted they are prone to discrimination. To discriminate against a person is to reduce their present state and future potential and in the case of these orphans, cause profound pain.

Participants would like adoptive families and the communities in which they live in to show compassion about their loss. In accepting orphaned adolescents, adoptive families should address them appropriately as nieces or grandchildren and not as daughters and sons. They need to be accepted as people who have lost their parents and not viewed as people living with HIV and AIDS, as often assumed. Adoptive families can normalize these feelings by not prompting over-involvement with the orphaned adolescent, but should acknowledge the feelings expressed by adolescents in an open discussion (Rando, 1984).

Research indicates that the concept of loss develops through the interaction between cognitive maturation and personal experiences (Adah, 1996; Bluebond-Langner, 1996). Lack of emotional maturity and limited coping capabilities among adolescents may prolong their grieving process. This is compounded if the adolescent feels that they are not accepted by adoptive families (Grief Resource Foundation, 1990; Sento-Pelaelo, 2005). Bergman and Magnusson (1997) are of the opinion that a single disruptive event such as parental illness or death is part of a larger assemblage of family instability which increases the children's risk of subsequent mental health problems. Lack of acceptance may accentuate this risk (Ackerman, 1999). This assertion is supported by Forman and Davies (2003) who also affirm that lack of acceptance is one of the disruptive events that have been shown to increase the child's vulnerability to mental health problems. Furthermore, lack of acceptance may directly weaken the adolescent's emotional adjustment by affecting their coping capabilities (Forman and Davies, 2003).

Research findings have shown the importance of support after loss (Jaffe, 2003; Lyons, 2005). The single most important factor in healing from loss is having the support of other people (Rando, 1984). Knowing that people around you understand that you are grieving will make a person feel better (Yule and Williams, 1990).

The participants needed adoptive families and communities to show compassion for them as they withstood many emotions, such as crying after the

funeral. Their achievements such as being made a monitor or chosen to sing in a choir should have been recognized by their adoptive families and not ignored. Support of this type occurs when the individual giving it can ignore all the distractions and encourage someone in what they would like to do or say (Fontaine and Fletcher, 2004). Family or adoptive family support is a hallmark towards healing (Randal, 2001). Unclear messages or maintaining silence when a participant has achieved at school have been inappropriate gestures and have had a negative impact (Rando, 1984).

Truth telling was another important need espoused by participants. The research participants reported that adoptive families should be honest with them and tell them the truth about their parent/s condition in life and after death. They reported that the adoptive families did not tell them the truth from the time their parents were ill to the time of death, specifically by not mentioning the true cause of death. The participants also blamed their parents for not telling them the truth. Trust is a basic need and a firm underpinning in the development of any relationship (Erikson, 1989; Langley and Klopfer, 2005). However, it must be noted that some parents may not have told their children their diagnosis to save them from stigma and discrimination.

Truth is an essential component of a reorganized family, especially among adolescents. By not being truthful about the nature of the parents' illness, trust in the new primary caregiver was lacking from the beginning. Some adoptive families were alleged not to have allowed the participants to visit with their parents when they were very ill and were always told that the parents were getting better or would get better. Such statements gave participants hope of their parents' recovery, when truthfulness could have enabled the adolescent to better prepare for the impending death. As Rando (1984) acknowledges, the need for clear and honest communication forms the basis for an enduring relationship. Thus, not having such a relationship with the adoptive families put the newly reorganized family in jeopardy from the earliest days.

The participants further reported that after their parent(s) died they were not told the truth about their death. The death was reported in a manner that was ambiguous until the participants asked for clarification. For instance, Nell, an 18-year old male participant, was asked if he knew that his mother had been sick with TB and not actually being told that his mother had died.

Fontaine and Fletcher (2003) assert that trust is a characteristic of caring. Erikson (1989) equates trust with reliability. By not being honest and truthful with the adolescents about the circumstances surrounding the parent's illness and death, a poor foundation is established for a reorganized family in which the adolescent would have to rely on a new caregiver. Davis and Konishi (2000) alluded to the fact that being honest and truthful improves coping. Thus, lack of honesty and

trust would tend to impede the coping abilities of adolescents.

The adolescents would have liked to have been told the truth surrounding their parents' illnesses and deaths. Rando (1984) supports the notion of being truthful about the parents' illness by arguing that outlets for emotions and impulses that are appropriate for adolescents should be provided as the illness progresses. To these adolescents, it would have been better to have been allowed to visit with their sick parents to adequately prepare for their death. As it happened, the deaths came as a shock. The adolescents' beliefs about this process are supported by Rando (1984) who asserted that honesty and a rational explanation about the illness should be given as early as possible to allow the adolescent to begin the journey of grief. The participants would have also liked to have been told the true nature of their parents' illness, namely AIDS, as this would have prepared them for the potential ridicule by family members, classmates and members of the community. Some participants also stated that if they had known the truth about their parents' condition they would have asked questions about how the disease had been acquired and confirmed the diagnosis with their parents.

The other finding of the study that was interesting was the need by participants to be involved in the illness, funeral preparation and the choice of who should take them after their parents' death. The research participants reported that they were excluded from the preparation of their parents' funeral plans. Excluding young persons from the funeral arrangement is a cultural norm in most African communities (Tsheko, 2004). However, excluding adolescents from funeral plans delay their grieving process. One participant was even asked to go to school a day after her mother died so that she would not miss too much of her school work. According to Rando (1984), being excluded from the normal grieving process may cause the adolescent to not fully acknowledge the death. Rando further asserts that such acts will predispose an individual to mental health problems in future. Gardner et al. (2001), in addressing the needs of adolescents in families headed by children, emphasized the need for including them in discussions as a way of empowering them.

Involving participants in the discussion of the parents' condition and actively involving them in the funeral and burial preparation would assist them to grieve appropriately and to better cope with the loss of their parents. The active roles in which the participants felt they could have been involved included choosing a coffin, saying a eulogy and selecting songs to be sang for their parents. Including participants in the funeral arrangements would also demonstrate that the adoptive families are recognizing them as the bereaved.

The adolescents in this study needed to have hope for the future. The participants' hopes for the future should be encouraged by adoptive families and teachers alike.

Adoptive families and teachers should be able to instill hope in orphaned adolescents and encourage the further development of the hope that they have (Jeyne and Miller, 1999). The perception is that with hope, adolescents would be able to take appropriate decisions about their lives. They needed to know that they could still achieve what they wanted in life even without the presence of parents. Jane, a 17-year old female participant, expressed her hope of becoming a singer when she grows up, while Ako, a 14-year old male, expressed his hopes of doing well at school so that he could then afford to erect a tombstone for his late mother. Jevne and Miller (1999) claim that hoping for something may make a person live up to that hope. Nell, an 18-year old participant who took photographs of children playing in the field, expressed his desire to give his younger siblings the best things in life and even to build a big house someday for his family.

## Conclusion

The reflective dairies yielded data on the expressed feelings of adolescents about their loss and their eminent removal from their homes to the homes of other relatives and for some, to child headed families. The purpose of this phenomenological study was to explore the lived experiences of adolescents orphaned by HIV and AIDS. The findings of the study revealed that adolescents orphaned by HIV and AIDS need to be accepted, supported and understood as adolescents are precarious and the death of parents exacerbate it. This new information on the needs of adolescents through reflective diaries will lead to appropriate therapeutic interventions by mental health practitioners and indeed proper policy formulation to target the mental health problems of adolescents orphaned by HIV and AIDS.

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