

# Grieving experiences amongst adolescents orphaned by AIDS: Analysis from event history calendars

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Mental health is an essential component of adolescent health and wellbeing. Mental health practitioners assess adolescents' mental health status to identify possible issues that may lead to mental health problems. However, very few of the tools used to assess the mental health status of adolescents include assessment for grieving and coping patterns. The current tools used for assessing an individual's mental health are lengthy and not comprehensive. The purpose of this study was to assess grieving patterns of adolescents orphaned by AIDS and to appraise the usefulness of an event history calendar as an assessment tool for identifying grieving experiences, in order to guide and support these adolescents through the grieving process. One hundred and two adolescents aged 14–18 years, who had been orphaned by AIDS, completed an event history calendar, reviewed it with the researcher and reported their perceptions of it. Thematic analysis of the event history calendar content revealed that it is an effective, time-efficient, adolescent-friendly tool that facilitated identification and discussion of the orphaned adolescents' grieving patterns. Crying, isolation, silence and violent outbursts were the main grieving patterns reported by adolescents orphaned by AIDS. The researcher recommends use of the event history calendar for identification of orphaned adolescents' grieving experiences. Early identification would enable mental health practitioners to support them in order to prevent the occurrence of mental illness due to maladaptive grieving.

## Introduction

Several instruments, including the Inventory of Complicated Grief, the Pathological Grief Questionnaire and the Texas Inventory of Grief have been used by mental health professionals to identify grief (Yi Wen & Gustafson 2004:11). In most African countries, grief assessment is not included in health assessment forms (Mayeya *et al.* 2004:65). Furthermore, international instruments used in the assessment of grief might not be applicable to adolescents orphaned by AIDS in South Africa. Therefore, it would be useful to use an event history calendar for grief assessment.

Grief is understood to be an incorporation of diverse psychological (affective, cognitive, social, behavioural) and physical (physiological, somatic) manifestations, the overt expression of which varies between and within cultures (Li *et al.* 2008:148). Affective manifestations include depression and despair, dejection, anxiety, guilt, anger, hostility and loneliness. Cognitive manifestations include pre-occupation with the deceased, low self-esteem, self-reproach, helplessness, hopelessness, a sense of unreality, and problems with memory and concentration. Behavioural and social manifestations include agitation, crying, fatigue and social withdrawal (Stroebe, Stroebe & Schut 2000:11).

According to the report entitled 'Adolescents orphaned and vulnerable in the time of HIV and AIDS' (2005), there are more than 15 million children who are orphaned largely because of AIDS, with 55% of all orphans being adolescents under the age of eighteen (Gallo 2006, Center for Disease Control 2006 & Collishaw *et al.* 2010). The Economic Commission for Africa (ECA) report (2006), entitled 'Impact of HIV and AIDS on gender, orphans and vulnerable children' alludes to the fact that the number of orphans in Africa is increasing rapidly, because the AIDS pandemic targets the age group consisting of caregivers, and parents. The ECA report also noted that 43.4 million orphans were living in Africa at the end of 2003 and that the number was projected to increase to 50 million by 2010 and would largely be due to AIDS. These AIDS orphans are robbed of their parent's care, support and socialisation, representing a 'skipped generation' (Economic Commission for Africa 2004:17).

## Problem statement

Currently in South Africa and other African countries, assessment for grieving experiences is not a standard procedure when doing a mental health assessment. This omission might be due to the

lengthy mental health assessment forms, which are not age-specific, used in mental health institutions and wellness centres. The use of an event history calendar has been found to be a user-friendly way to assess adolescent sexual risk history (Martyn & Belli 2002:270; Martyn & Martin 2003:213; Stafford 2006:16), and might be an ideal tool for assessing the grieving experiences of adolescents orphaned by AIDS in South Africa.

### Grief

Grief is defined as sorrow and the emotional suffering caused by loss (Neimeyer 2001:3). A more useful understanding of grief lies in the assumption that grief is larger than sorrow (Moules *et al.* 2004:100). Sorrow is an overwhelming sadness, an emotion that is enclosed within grief. However, grief is as much the celebration of the lost person as it is the surrendering of the lost person to memory. Within grief, there are aspects of intense sadness, but intense sadness over the loss can end, yet grief can remain and be experienced over time (Moules *et al.* 2004:100). Grief is a biological experience (Sacks 2001:219) as well as an emotional, spiritual and cognitive one. As a result, grief becomes a continuing experience, sometimes abating, sometimes distressing, but always a present part of the life of a person who has experienced a loss (Moules *et al.* 2004:100).

Grief is an individual's subjective response to the loss of a person, object or concept that is highly valued (Stuart & Laraia 2001:860). It comprises all the emotions and sensations that accompany the loss of someone or something dear to you (Leavy 2005:1). It is an emotional component of the bereavement process. Furthermore, it includes specific emotions and behaviours in response to loss, such as depression, loneliness, yearning and searching for the deceased (Demmer 2004:294). According to Goodman (2002:296), the loss of a close relative to death not only affects individuals at a physical level but also in the realisation that the person who died will miss out on future milestones. For an adolescent, if it is a parent who died, the knowledge that the parent will not see you graduate, marry and have your first child might make the loss unbearable (Abebe & Aase 2007:2060).

Many theorists have tried to explain the phenomenon of grief. Sigmund Freud, John Bowlby and Elizabeth Kübler-Ross are some of the prominent theorists who have developed an understanding of the grieving process. All these theorists acknowledge the enormous pain and suffering that the bereaved individual experiences (Krueger 2006:4). They have also established that after a period varying from six months to five years the process of grieving can move toward acceptance.

TABLE 1: Bowlby's four stages of grief their characteristics.

Stages	Stage characteristics
Numbing	This lasts a few hours to a week. It may be interrupted by outbursts of extremely intense distress or anger.
Yearning and searching	The bereaved person searches for the lost person, a search which can last for months or even years.
Disorganisation and despair	The person has recognised the loss and may feel hopeless about the future and withdraw from others.
Reorganisation	The person begins to come to terms with the loss and plans to move forward.

Source: Adapted from Bowlby (1988:85)

Freud (1917) viewed grief as a normal reaction to loss and believed that grief does not require any intervention as it has to take its normal course, unless severe reactions, including lowered self-esteem, occur. Bowlby's grief theory (Bowlby 1973) identified four stages of grief (Table 1).

According to Kübler-Ross, the emotional responses of bereaved individuals might revolve around the anger and bargaining stages. Tsheko (2006:8) agrees with this assertion and notes that for adolescents who have lost their parents due to AIDS, their emotional responses are most likely to revolve around the anger and testing phases as they question why their parents died and not other people's parents.

Whilst the above theorists have made important contributions to our understanding of grief, a number of emerging theorists are re-examining the traditional theories. Two of these emerging theorists are Bonanno and Kaltman, as quoted by Adolfsson & Larsson (2010:202), who contend that as the grieving process unfolds, bereaved individuals will begin to consider the meaning of their lives; these are subjective meanings that are associated with interpersonal loss and manifest themselves in a continuum. Furthermore, Moules *et al.* (2004:99) view grief as an ongoing experience that is not resolvable, but is eminently liveable.

Moules *et al.* (2004:100) assert that society only recognises grief in an individual when it becomes problematic. Often, there are cultural expectations that a grieving individual should get over the loss and not continue feeling grief for an extended period (Moules *et al.* 2004:100). As a result of these cultural expectations, grieving individuals learn to hide their grief from the public and internalise it. It is this internalisation of grief that pathologises the experience of grief, leading to withdrawal, isolation and depression (Moules *et al.* 2004:101). Only during this stage may society realise that the individual is not coping.

Demmer (2004:294) points out that those individuals who grieve for an AIDS death confront many issues that may complicate their grieving process. Such issues may include the HIV status of the bereaved individual, multiple losses and inadequate social support. Demmer (2004:294) also contends that children or adolescents who lose their parents to AIDS will suffer prolonged grief and are likely to develop psychiatric problems. This assertion is further supported by Stuart and Laraia (2001:756), who report that children who have experienced repetitive losses begin to anticipate the future with grief. Van Dyk (2003:275) describes the difficulties that AIDS orphans encounter during the grieving process. Most of these children may struggle to come to terms

with the reality of being orphaned and experience the loss of parental care and physical and social protection.

The grieving process for an adolescent orphaned by AIDS may be prolonged because of lack of social support, especially if it is the mother who died and the surviving next of kin are also grieving over the loss of their spouse or child (Harms *et al.* 2010:6). In African communities, it will even be compounded by the fact that children are socially conditioned to hide their feelings. Also, more attention is often given to the grieving adult than to the grieving children (Tsheko 2006:15). Lack of support and poor communication patterns may later lead adolescents to develop adjustment disorders (Van Dyk 2003:275).

### Event history calendar

An event calendar approach is an interviewing method in which the more memorable events serve as cues to help the participant remember other life events (Martyn & Belli 2002:270). Calendar interviewing is designed to retrospectively collect reports about the course of one's life (Arbor 2006:16). According to Martyn and Belli (2002:270), event history calendars are used to collect data about events and life transitions over short and long periods of time. When using calendar interviewing, the researcher allows flexible interviewing to maximise the validity of the data (Martyn & Belli 2002:273). However Yi, Lori and Martyn (2008:467) caution that the flexibility used in calendar methods does

not mean that the interviewer is free to ask questions outside the event calendar. In the calendar methodology, separate timelines for each of the areas of interest to the study are used (Arbor 2006:17).

Available literature on the clinical use of event history calendars is only limited to adolescent risk factors and does not address grief assessment. Event history calendars have been found to improve data on sexual histories compared to traditional methods that assessed sexual histories of adolescents (Yi, Lori & Martyn 2008:469). This was the premise on which the researcher based the adoption of the event history calendar to assess grief amongst adolescents orphaned by AIDS. The event history calendar was adopted and modified to include concepts relevant to grief (Table 2a & Table 2b).

**Instructions:** Fill in your experiences or age under the years mentioned. For instance, if you are 18 now it means in 2002 you were 13, so you put 13 in 2002.

### Definition of key concepts

**Adolescence:** This refers to the transition from childhood to adulthood, which is marked by distinct biological, cognitive, and socio-cultural changes (Collishaw *et al.* 2010:886). According to Desmond *et al.* (2002:35), the *Constitution of the Republic of South Africa (Act 108 of 1996)* regards any person from 0 to 18 years as still a child. However, for the purpose

**TABLE 2a:** A sample of the event history calendar completed by a participant.

Measurements	Year					
	2004	2005	2006	2007	2008	2009
Age	16	17	18	19	20	21
Goals in life	-	-	-	-	Look after my siblings	Study hard and make my mum proud
Family (Tick if live with)	-	Mum, dad and siblings	Dad and siblings	Grandmother and siblings	Grandmother and siblings	Grandmother and siblings
Role models	-	Dad	Dad	Dad	Dad	Dad
Significant events	-	-	Death of my mother	Death of my father	Inability to go to school	Being sponsored for further studies by a Spar manager
Substance use	-	-	-	-	-	-
Alcohol	-	-	-	-	-	-
Marijuana	-	-	-	-	-	-
Others (name)	-	-	-	Sniffed glue	Sniffed glue	-

Source: Adapted from Martyn (2005)

**TABLE 2b:** A sample of the event history calendar completed by a participant.

Measurements	Year					
	2004	2005	2006	2007	2008	2009
Friends	Tim	Tim	Tim	Fred	Fred	Tim and Paul
Partners (put initials)	-	-	-	-	-	-
Grieving patterns	-	-	Crying, Isolation	Blaming God, dad and mum	Anger outbursts	Talked it out with my friends and grandmother
Coping strategies	-	-	-	-	-	Work hard at school
Emotions expressed	-	-	Anger	Anger, hatred	Anger	Anger at times
Expression of anger towards	-	-	At parents and God	-	-	-
Feelings of blame towards	-	-	The world	-	-	-
Experience of anxiety	-	-	-	-	-	-
Any episodes of depression	-	-	-	-	-	-
Careless indulgence in sex	-	-	-	-	-	-

Source: Adapted from Martyn (2005)

of this study, adolescents will refer to middle adolescents, which are persons aged 14–18 years.

**AIDS:** This refers to a collection of diseases that result from infection with HIV (Lyons 2005:3).

**Grieving:** Grieving is a process of expressing sorrow and the emotional suffering caused by loss (Neimeyer 2001:3).

**Orphan:** A child (0–18 years) who has lost a parent (UNICEF 2004:9). In this study, orphans refer to middle adolescents aged 14–18 years who have lost at least one parent (mother or father) to AIDS-related diseases.

### Research objective

The objective of this study was to assess the grieving patterns of adolescents orphaned by AIDS.

### Significance of the study

The purpose of this study is to contribute to a more effective way of assessing grieving experiences amongst adolescents orphaned by AIDS. The adoption of an event history calendar to assess grieving experiences would allow for early detection of maladaptive grieving patterns and hence appropriate and immediate mental health intervention.

## Research methods and design

### Design

The study utilised the descriptive mixed methods of the event history calendar and open interviews with fifteen participants based on the contents of the event history calendar to obtain data about the grieving experiences of adolescents orphaned by AIDS.

### Sampling

The study was part of a larger study aimed at developing a peer-based mental health support programme for adolescents orphaned by AIDS. The participants were one hundred and two adolescents orphaned by AIDS, aged 14–18 years, selected by purposive sampling. Adolescents were eligible if they identified themselves as being orphaned by AIDS, spoke Setswana and English, and were regular attendees at the AIDS Awareness Centre in the Gauteng Province of South Africa. Participating adolescents could read and write.

### Materials

A sample of the event history calendar that could have been completed by any participant, but does not reflect the responses of any specific participant (Table 1).

### Data collection procedure

Data was collected as part of a large study between January, 2008 and December 2008. The researcher interviewed the participants, using the event history calendar to elicit

information on grieving experiences, year of parents' death, role models and how they have affected the adolescents' grieving experiences, significant events in the participants' lives, and with whom they lived. Participants completed the event history calendar and this took each participant about 10 minutes. The interviews then followed for another 60–90 minutes, using the event history calendar data as a guide to facilitate the discussions. Participants' views on the use of the event history calendar were then elicited on how it influenced recall and discussion of their grieving experiences. After every interview the researcher debriefed the adolescents and recorded field notes.

Explanation of the use of cues to aid recall was given to participants by the researcher. The history questions were designed to aid recall and report any grieving experience that the participant used or was still using, for instance, statements such as, 'I am interested to know about any special event in your life and its association with the way you grieved'. 'What are your most significant events in your life?' 'What were your reactions at the announcement of your parent's death?' or 'Have these reactions changed over time?' The participants were requested to indicate pseudonyms only and to hand the calendars back to the researcher individually. Some of the participants asked to take the calendars home and to return them at the next meeting and that was accepted. After the participants had completed their event history calendar, the researcher interviewed each participant individually and allowed him and/or her to think aloud about what he and/or she had written.

### Data analysis

The Statistical Package for the Social Sciences (SPSS), version 11.0 (SPSS, Chicago), was used to analyse quantitative data. Descriptive statistics were used to summarise the sample demographics and grieving experiences obtained from the event history calendars. Frequencies were also used to evaluate the features of the event history calendars.

Thematic analysis was carried out using Colaizzi's (1978) seven steps of data analysis as described by Polit and Beck (2008:524). The first step of the data analysis entailed the researcher reading and re-reading all the participants' calendars and transcripts from the audio-taped interviews to acquire a sense of the way the adolescents expressed their grieving experiences.

### Study setting

The study took place at an AIDS Awareness Centre, run by a non-governmental organisation in an urban area 35 km from Pretoria, the government seat of the Republic of South Africa. The facility serves as a day-care and hospice centre for terminally ill persons, their families, people living with HIV and AIDS and orphans, including AIDS orphans. At the time of the study there were 250 orphans and of those 150 were orphaned by AIDS.

## Ethical considerations

The Ethics Committee of Tshwane University of Technology and the Faculty Research and Innovation Committee of the Faculty of Science granted the researcher permission to conduct the study. In addition, the data collection was undertaken in line with the principles of ethical research involving human subjects. These principles include special attention to communicating the aims of the study, and the rights of people participating in the research, written informed consent, and confidentiality. It was explained and emphasised to the participants that participating in the study was voluntary, and that those who did not want to participate would not be treated any differently by the researcher or the staff at the AIDS awareness centre. The participants were informed that they could withdraw from the study at any time if they so wished without incurring any negative consequence whatsoever. The participants were assured that the researcher was the only one who would have access to information obtained from participants. Finally, written signed informed consent was obtained from participants and a signed assent obtained from their guardians.

## Trustworthiness

The criteria for measuring trustworthiness of data followed the strategy of credibility as established by Lincoln and Guba (1985:112). Credibility of the data analysis was confirmed by member checking and peer checking techniques. In member checking, a summary of the interview was discussed with each participant and it was confirmed that the researcher was representing his and/or her ideas correctly. For peer checking, the coder and the researcher coded independently. Disagreements were discussed and clarified until consensus was reached.

## Reliability and validity

Three adolescents orphaned by AIDS were given an event history calendar to complete before it was given to participants in the study. These three adolescents were excluded from the study. Some terms such as role model and significant event were explained.

## Results

The findings of the study were divided into the divisions from the event history calendar.

### Demographic data

The ages of the adolescent participants ranged from 14 to 18 years old, and their mean age was 16 years: 64.7% ( $n = 66$ ) of the participants were females and 35% ( $n = 36$ ) were males; 53.3% ( $n = 54$ ) were in grade 8 and 26.5% ( $n = 27$ ) were in grade 10 at the time of the study; 66.6% ( $n = 68$ ) lived with their grandmothers, whilst 3% ( $n = 3$ ) lived with aunts and 13.7% ( $n = 14$ ) lived with their siblings.

### Role models

Sixty per cent ( $n = 61$ ) of the research participants named parents as role models, whilst 20% ( $n = 20$ ) named political leaders and 13.7% ( $n = 14$ ) named world celebrities as their role models. Seven participants reported that they had no role models. World celebrities referred to international and local actors as well as international and local sports icons. Very few participants named teachers and relatives other than their parents as role models.

### Significant events

For 80% ( $n = 82$ ) of the participants, significant events included the dates of their parents' deaths and the anniversary of their parents' deaths. Other significant events prior to the death of their parents included occasions when gifts had been received, such as bicycles, cell phones or even beds. Significant events after the death of the parents included the emptiness of their own birthdays and other personal achievements, such as passing examinations, being selected as a class monitor or being chosen to sing in a choir.

Such significant events were recalled consistently by the participants. This finding is supported by reports that the value systems of every family are disrupted by the death of a parent (Arbor 2006:17).

### Use of tobacco and other substances and careless indulgence in sex

Two-thirds (66.6%,  $n = 68$ ) of the participants did not use any tobacco or any other substances. The other third (33.3%,  $n = 34$ ), however, did occasionally smoke cigarettes and drink beer with their peers. Most (86.6%,  $n = 88$ ) of the participants had not had any sexual encounters. Of the fourteen who had, one was raped by a family member who lived in the same compound. Thirteen girls who had had a sexual experience did so around the time of the one-year anniversary of their parents' death.

### Grieving experiences

The research participants identified various behaviours associated with grieving. Their descriptions of the actions associated with grieving behaviours are reflected (Table 3).

Experiences of grieving by adolescents orphaned by AIDS, included crying, angry outbursts, fighting, suicidal ideation, isolation and silence. Verbally abusing those who wanted to help was mentioned by two participants. Some of the participants reported that they had cried as a way of grieving

TABLE 3: Grieving and coping patterns used by adolescents orphaned by AIDS.

Behaviours associated with grieving	Actions associated with coping behaviours
Crying	Carefree attitude
Fighting	Professional Counselling
Isolation	Expressing feelings to caregivers and friends
Silence	Giving up on life by pretending it does not matter
Suicidal ideation	Indulgence in food
	Reading a book on death and dying
	Working hard at school
	Singing

for their parents. They explained that crying had relieved the emotional stress but that it did not take away the emotional pain. The participants also noted that when told about the deaths of their parents it was as if the world had ended, whilst others experienced emotional numbing. One of them explained this in the following way:

'I could not feel anything. There was no emotion. I looked at people and did not see them until I asked them what it was that they had just said.'

One participant said she had blamed those who wanted to help her. She asked one teacher, who had been a friend of her parents as well as a neighbour, why she was still alive and yet her mother was dead. She became very angry with those who said that everything would be okay. One participant explained her resentment when she reported that a teacher who had known her parents asked her and her siblings to contact him any time they were in need. She responded to the teacher in the following way: 'You should have died so that my dad would look after your children.'

The participants also indicated that their relatives should have allowed them to choose coffins for their deceased parents and to say or write a eulogy; these rituals would have helped them to deal with their grief. Some participants said that nobody really cared about them in the days after their parents' death, as they were asked to make tea for those coming to offer condolences; only their friends really cared. Thus, the grief of the adolescents was not recognised at the time of the funeral. Not only were they excluded from any participation in the service, but they were expected to play the role of 'host' at the gathering afterwards.

## Emotions associated with grieving experiences

### Expressed emotions

The most commonly expressed emotion was anger. The research participants were angry towards their deceased parents, themselves, God and caregivers. Blame and hatred were also indicated: the blame was mostly directed towards God. Other participants blamed their parents for dying.

### Expression of anxiety

The participants reported that they had experienced anxiety through nightmares, the inability to sleep and becoming easily frightened. Some participants mentioned experiencing palpitations, especially when seeing a person who resembled the deceased parent. Sweating of hands was also mentioned amongst the signs of anxiety experienced.

## Discussion

Mental health practitioners may want to use the event history calendar to assess the grieving patterns of adolescents orphaned by AIDS. Assessment of the grieving patterns would enable both the nurse and the adolescent to proceed towards preventive measures such as preventive and supportive counselling.

According to the findings of the event history calendar, the majority of the participants indicated that their parents were their role models. Young people can choose their role models from any context, including their peers. According to Zur (2010), adolescents choose their parents and teachers because a parent, especially the mother, embodies certain values in the adolescents which are expanded at school (Zur 2010). Celebrities serve as role models because their lives seem easy, without any pain (Chazan 2002:160).

Tobacco, substance use and careless indulgence in sex were also indicated by over sixty-six percent of adolescents as an experience with grieving. Adolescent orphans have been associated with careless indulgence in sex and substance use (Lebotse 2004:20). Orphaned adolescent girls are reported to be vulnerable to sexual exploitation and are found to indulge in sex earlier than non-orphaned adolescents (Lebotse 2004:23). This finding negates what has been reported in research that the majority of orphaned adolescents indulge in sexual encounters early after their parents' death, as in this study only 14% of the participants had indulged in sexual encounters.

Behaviours and actions used by the study participants demonstrated that individuals do grieve differently, and that grief is individual (Fontaine & Fletcher 2004:457). The individualisation of grieving experiences and expression of grief varies between individuals and cultures (Li *et al.* (2008:148).

Anger and anxiety were emotions associated with the grieving experiences from the event history calendar. Anger after the death of parents can snowball, making everyone around the grieving person resentful and angry with them (Moules *et al.* 2004:102). When a person loses a close family member, they get angry with anyone or anything that has been associated with the deceased person. This may be the reason why some participants were angry with God, caregivers and even the deceased parent (Leavy 2005:2).

Sleep problems, especially insomnia, are common amongst adolescents following the death of a parent. Insomnia has been linked to poor daytime functioning of an adolescent (Melhem 2008:404). Nightmares are also a common occurrence that may accentuate mental health problems. Depression and post-traumatic stress disorder have been linked to sleep problems following the death of a parent (Melhem 2008:404). All these expressions are associated with maladaptive grieving experiences (Sento-Pelaelo 2005:85).

The data that emerged from the event history calendar is a demonstration of its usefulness in assessing grieving experiences.

## Limitations of the study

It should be noted that the research findings of this project are based on a purposive sample. The sample was primarily drawn from a community centre that supports AIDS-related

orphans, who might have experienced similar or different grieving experiences.

## Recommendations

This study has provided baseline data upon which future research that looks at the assessment of grieving experiences with event history calendars can be built. Adoption of the modified event history calendar to identify grieving experiences with adolescent orphans is highly recommended for timely intervention and prevention of mental illness.

## Conclusion

This study is an initial effort to assess grieving experiences amongst orphaned adolescents using an event history calendar. The use of the event history calendar as tool to identify grieving experiences has implications for mental health practitioners in mental health institutions including wellness clinics.

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## Competing interests

There are no competing interests in this study.

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