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To cite this article: Carol Wogrin, Lisa F Langhaug, Charity Maruva & Nicola Willis (2019): Development and piloting of a novel, peer-led bereavement intervention for young people living with HIV in Zimbabwe, Journal of Child & Adolescent Mental Health, DOI: [10.2989/17280583.2019.1579097](https://doi.org/10.2989/17280583.2019.1579097)

To link to this article: <https://doi.org/10.2989/17280583.2019.1579097>



Published online: 24 Apr 2019.



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Development and piloting of a novel, peer-led bereavement intervention for young people living with HIV in Zimbabwe

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Background: Research emphasizes lasting psychological implications when young people are not adequately supported following close family deaths. In sub-Saharan Africa, adolescents living with HIV (ALHIV) experience multiple personal deaths along with other serious losses. ALHIV highlight that not processing their grief negatively impacts their daily lives including their ART adherence. This article describes the development and piloting of a bereavement intervention for ALHIV in Zimbabwe.

Methods: Formative research with 10 ALHIV peer counsellors (18–21 years) supported intervention development. After training, these peer counsellors facilitated a six-session bereavement intervention in 10 existing community-based ALHIV support groups. Qualitative data was collected from facilitators, ALHIV intervention participants, and their caregivers.

Results: Key themes: i) limited experience recognizing their losses; ii) lacking control over poorly understood feelings; iii) recurrent feelings of isolation, hopelessness, depression, fear, and guilt; iv) reticence to share, believing their feelings were unusual; v) shame surrounding connections felt towards their deceased. Following intervention implementation, members reported relief in learning of shared experiences, the ability to link their feelings with specific experiences and employ constructive coping strategies to address them, leading to greater emotional control.

Conclusion: Implementing high-quality grief interventions is critical when responding to the complex realities of ALHIV in sub-Saharan Africa.

Introduction

Adolescents living with HIV (ALHIV) face a myriad of challenges, ranging from physical effects of the virus, to the psychological and social implications of living with a chronic, stigmatized, health condition. In sub-Saharan Africa, this is compounded with orphaning and other losses. Increasing evidence of poor clinical and mental health outcomes in this population indicates an urgent need to further explore nonbiological factors that contribute to poor outcomes (Makadzange et al., 2015; Mokdad et al., 2016; UNAIDS 2016; UNICEF, 2016; UNICEF, 2013).

Globally, bereavement literature has broadly established that a significant number of children who experience parental death demonstrate lower self-esteem and higher rates of psychological problems than their non-bereaved counterparts (Thurman, Lockett, Nice, Spyrelis, & Taylor, 2017; Cluver, Orkin, Gardner, & Boyes, 2012; Collishaw, Gardner, Aber, & Cluver, 2016; Dowdney, 2000; Haine, Ayers, Sandler, Wolchick, & Weyer, 2003; Kaplow, Saunders, Angold, & Costello, 2010; Worden & Silverman, 1996). Bereaved adolescents living with HIV show a greater incidence of mental health problems compared with other bereaved children (Collishaw et al., 2016). A variety of factors contribute to this increased psychosocial stress experienced by ALHIV (Mavhu et al., 2013; Cluver, Gardner, & Operario, 2007).

While many bereaved adolescents improve over time, those who experience subsequent stressors such as financial burdens, disruption of routines, household mobility, family separation (especially

siblings), and lower educational attainment, are found to be at highest risk of developing long term difficulties (Thompson, Kaslow, Price, Williams, & Kingree, 1998). These risk factors pervade the lives of many children and adolescents living with HIV in sub-Saharan Africa today (Mavhu et al., 2013; Cluver et al., 2007).

Bereavement programmes have widely rested on basic constructs reflected in Worden's theory of the Tasks of Grief (Worden & Silverman, 1996). These constructs include recognizing the reality of the death, working through feelings associated with grief, adjusting to a life where the deceased is now absent, and developing an ongoing, but transformed, relationship to the deceased. While their overall conceptual framework is strong and widely used in the West, when applied to adolescents in sub-Saharan Africa, it lacks context, specifically the pervasiveness of multiple losses, and lack of a clear 'before-and-after,' — that life was one way before the death and another way after it. Instead, their life is constantly re-shaped by sequential losses, and a time before significant losses began may not be remembered. For many young people born with HIV, losses begin very early in their life, and continue to accumulate throughout their childhood and adolescence (Mavhu et al., 2013, Willis, Mavhu, Wogrin, Mutsinze, & Kagee, 2018).

Considering the pervasiveness of grief caused by multiple losses and the gravity of these losses in the lives of ALHIV in sub-Saharan Africa, urgent contextual bereavement interventions are needed for this vulnerable population. This paper describes the development of a locally adapted, theoretically based bereavement intervention for ALHIV and their caregivers in Zimbabwe (Table 1). It examines its acceptability and feasibility when integrated within an existing cadre of peer counsellors known as Community Adolescent Treatment Supporters (CATS) living with HIV1 (www.africaid-zvandiri.org) (Figure 1).

Table 1: Study objectives

Objectives of the project	Methods
Work with 10 orphaned, HIV positive adolescent peer counsellors to develop a bereavement intervention that addresses multiple losses that impact their lives.	8 sessions held biweekly to explore their loss experiences, their coping mechanisms (positive and negative), and to develop additional coping skills. Feedback from adolescent peer counsellors ensured take home crafts, written materials were limited.
Train HIV positive adolescents as peer grief counsellors (PGCs), enabling them to provide bereavement support in their community-based HIV support groups and adherence counselling sessions.	Held a four-day training to train the peer counsellors to deliver 6 bereavement support sessions (developed from the 8 sessions above) in the monthly HIV support groups they facilitate. Trainings were led by the bereavement consultant and an Africaid counselor. Two-way translation throughout the training ensured that all materials would be delivered consistently in the vernacular (Shona) across all support groups.
Pilot the bereavement support intervention in 10 community-based HIV support groups, led by the trained peer grief counsellors.	Each of the 10 trained peer grief counsellors facilitated the 6-session bereavement intervention in their community-based HIV support groups.
Support the peer grief counsellors in integrating the attention to loss and grief into the ongoing adherence counselling they provide to other HIV positive young people	Provided supervision throughout the project as the peer grief counsellors implemented the sessions, with discussion on responses of group members, their own experiences facilitating, and the implications for their ongoing adherence counselling.
Assess the feasibility and acceptability of the bereavement intervention	Qualitative data from peer grief counsellors, HIV-positive support group members, and their caregivers was used to refine the intervention, and assess its acceptability and feasibility.

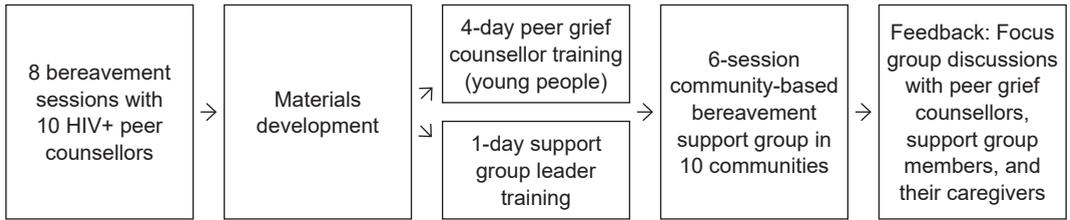


Figure 1: Flow chart describing intervention development and implementation

Methods

Intervention development

Ten orphaned and experienced peer counsellors¹ aged 18–21 years volunteered to work with a bereavement consultant (CW) to develop the bereavement intervention (males = 4; females = 6). All had contracted HIV perinatally and experienced multiple losses including deaths of significant others and non-death losses, such as separation from siblings, household disruption, and missed schooling.

Worden’s conceptual framework was adapted following observations recorded during eight sessions and follow-up discussions with peer counsellors (Table 2). A six-session bereavement intervention was developed for ALHIV; this was supported by a one-session intervention for their caregivers, designed to run concurrently with the final session for ALHIV (Table 3).

Table 2: Conceptual additions and adaptations to Worden’s conceptual model

Kept from Worden’s conceptual model	Tasks of Grief	An overview of grief. Describing personal losses. Identifying feelings and cognitions related to grief. Practicing coping strategies.
Contextual additions and adaptations		Re-establishing and/or reinforcing relational bonds with the deceased. Identifying personal emotions. Connecting feelings to behavioural responses and coping strategies. Reality of multiple losses woven throughout.
Contextual adaptations		Crafts and written materials were limited. As many live in ongoing difficult circumstances, coping strategies emphasized what can and cannot be changed, and provided techniques to cope with challenges outside their control.

Table 3: Summary of intervention sessions

Topics	Activities	
Session 1: Setting the stage, defining grief	Movement activity acknowledging shared loss experiences; <i>The Jungle Journey: Grieving and Remembering Eleanor the Elephant</i> . ² Participants started by listing general feelings experienced by others when coping with loss, and then focused on what they personally experienced.	Running throughout Guided visualisations: Satchel of loss and acknowledgement ritual
Session 2: Personal stories	Personal loss timelines; completed individually then shared with the group.	
Session 3: Exploring feelings	Activities first focused on feelings common to grief, then used a body mapping activity to move into personal feelings.	
Session 4: Feelings and coping strategies	Feelings charades; guided visualization on somatic response to feelings; overview of coping strategies generated by participants.	
Session 5: Coping strategies	Satchel of loss visualisation focused on coping and connections with the deceased; safe place guided imagery.	
Session 6: Commemoration and closing	Satchel of loss and continuing bonds; Who I am today: “My Life” CD covers.	

Training the facilitators

Following intervention development, a structured training tool was created. The 10 peer counsellors who helped develop the intervention were trained as peer grief counsellors (PGCs). Training comprised four sessions, each lasting 5 hours. Support group leaders who work with caregivers of ALHIV from the support groups were trained in one day. Importantly, **both** trainings engaged facilitators in their *own* grief *before* building their understanding of grief processes in children, and fostering their competence to facilitate specific grief-support activities and discussions in their community support groups.

Piloting the intervention

The 10 trained peer grief counsellors (PGCs) facilitated the 6-session bereavement intervention within their existing community-based HIV support groups for adolescents. Support group leaders delivered their one session to caregivers of adolescents attending the HIV support groups during a regularly scheduled quarterly support group meeting for them.

Activities included in the six-session intervention addressed topics sequentially (Table 3). The intervention began with an overview of grief. Participants then shared their own stories of loss, followed by activities to deepen their understanding of their own feelings and reactions. Coping strategies were described and then practiced. These sessions were incorporated into the regular monthly support group meetings; no one attending refused to participate.

In supervision feedback sessions, content delivery and group process were addressed. For example, one PGC had a support group member die just prior to the fourth session, which launched a discussion on how to handle deaths among support group members, a salient topic for PGCs, all of whom had experienced group member deaths.

Group size varied (9–58), reflecting different community characteristics. All groups comprised both genders, with the majority of participants aged between 10–22 years. A total of 330 adolescents participated in the bereavement sessions. Most participants missed 1 or more of the 6 sessions, with 16% attending all sessions, and 20% attending 5 sessions. This variation is reflective of general monthly variation in HIV support groups.³ At the start of each session, PGCs engaged group members to summarize earlier topics for anyone not present during previous sessions.

Assessing the feasibility and acceptability of the bereavement intervention

Initially, detailed feedback from the peer counsellors and participant observation during session delivery was used to refine the intervention. Following delivery of the 6 bereavement sessions, five focus group discussions (FGDs; $n = 27$) were conducted by an independent qualitative researcher to obtain feedback from adolescents ($n = 4$) and PGCs ($n = 1$). Support group attendance lists were used to generate a random sample to invite to the FGDs. Two FGDs included adolescents who had attended all six bereavement support group sessions. Participants in the other two FGDs had attended at least the first three sessions. Discussions lasted between 30 and 45 minutes and participants were reimbursed for their transport (US\$4 return each). Prior to the onset of the FGDs, the purpose of the discussion — to obtain their impressions of the sessions — was described to the adolescents. The voluntary nature of the discussion was explained to them; if they decided not to participate, their transport costs were still reimbursed. Moreover, the facilitator emphasized the confidential nature of the discussions, where no names were recorded; instead each participant was assigned a number. None of the adolescents invited to the discussions declined to participate. Support group leaders shared feedback they gathered from caregivers who attended their bereavement support session. The Medical Research Council of Zimbabwe reviewed this study and granted it an exemption (MRCZ/E/239).

Data analysis

FGD data was translated into English from the vernacular. All data was then analysed thematically. Data saturation was reached during the four discussions.

Results

All respondents (PGCs, adolescents, and caregivers) confirmed it was their first time to be involved in sessions specifically targeting their grief. Five main themes emerged concerning their grief experiences.

Limited experience in focusing on their losses and related feelings

Despite being a group of highly trained adolescent peer counsellors, well versed in discussing numerous aspects of their experiences of living with HIV, none could readily describe the experiences surrounding their losses. This changed following intervention exposure. One male counsellor stated, “*At first I thought this [the bereavement sessions] was nothing. But as we got into the sessions I started gaining a part of myself back*” (M3).

Participants responded enthusiastically to activities that directly identified and engaged their feelings, especially those related to loss. A guided imagery activity that used the metaphor of a backpack to help participants “unpack” and sort through their reactions to their many losses was particularly popular (Table 4: 1a). One male counsellor described his experience, “*I like thinking about all the different aspects of my experience, ... the different pockets, what’s in them*” (M1). Others concurred (see Table 4: 1a).

Table 4: Qualitative data from peer grief counsellors, adult facilitators, intervention participants, and caregivers

Ref.	Quotation
Limited experience in focusing on personal loss and related feelings	
1a	Another peer counsellor explained how using the backpack guided imagery and its related ritual helped him take stock of his past and current situation. He shared that he had always blamed his parents for passing on the virus to him and had never had a chance to grieve. The guided imagery enabled him to engage more fully in his experience of his parents and, by his report, provided a sense of relief (PGC,M3).
Wide range of emotions identified	
2a	And yet another recounted her mother warning her when she wasn't cooperating that she'd “ <i>be sorry someday</i> .” Many years later she still feels regret (PGC, F5).
2b	Others expressed their guilt and regret more simply, “ <i>I wish I'd told her I love her</i> ” (M2), or “ <i>I wish I had said goodbye</i> ” (PGC,F6).
2c	<i>I'd see other kids and their parents... I felt like I'm just alone. It made me feel jealous and angry. And to be honest, it made me feel like just going, killing myself. All the suicidal thoughts, they were overloading in my mind. I felt like doing things [other] kids wouldn't do</i> (PGC,F2).
2d	One support group leader explained, “ <i>Facilitating these sessions has also helped me overcome my own fears</i> ”, and another stated, “ <i>The module has helped me start to talk with my own family about loss and moving on; we have been struggling after losing a loved one</i> ” (SGL, F2).
Relief in learning of shared experiences	
3a	Increased awareness of their commonalities altered how they reached out and interacted with others: “ <i>It really helped me a lot ... I didn't want to share ... especially with my friends</i> ” (FGD2, F2). Another support group member explained, “ <i>I was embarrassed to talk about death... The grief sessions allowed me to talk about grief and loss; I can become open; it built my confidence</i> ” (FGD1, M3).
3b	Recognizing their shared experiences of loss emerged following the completion of a “body mapping” activity, where they identified and then shared the range of feelings they experienced. Group members repeatedly shared that ‘just knowing’ that others had lost a loved one and that they were not alone in this or the associated difficult feelings, brought them comfort. Of note, despite the energetic, upbeat, external persona of each group member, for most of the HIV positive peer counsellors, the majority of emotions reported on their maps were negative, such as feeling sad, depressed, hopeless, angry, worried, fearful, lonely, and shocked.

continued on next page

Table 4 continued: Qualitative data from peer grief counsellors, adult facilitators, intervention participants, and caregivers

Ref.	Quotation
A need for connection with the deceased	
4a	<i>"It changed the communication of those we stay with. Once we started talking to people in the house about what we were doing, that prompted information sharing"</i> (FGD1, F1).
4b	<i>"It is a good thing because I would feel much closer to my mum when I remember the times that we shared before she died"</i> (FGD3, F2).
4c	Caregivers also highlighted the importance of maintaining bonds, with one male participant stating, <i>"I feel it is important to discuss the family tree with our families before we, the elders depart from this world. This will help our children to know where to go for help and support in times of need and of joy"</i> (C6).
4d	<i>"We need to remember that these losses don't go away. When she came home with her grade 4 exam results, she seemed sad, even though she did so well. I couldn't understand. But now I think maybe she was sad because she couldn't show her [deceased] mother"</i> (C2).
An increased ability to identify feelings, connect with their present experience, and constructively respond	
5a	Referring to the backpack visualization, one intervention participant stated, <i>"I do it every now and then..., close my eyes and start picking up good memories from my bag when I start getting overwhelmed by life"</i> (PGC,F2).
5b	At the closing ritual, a female counsellor placed the stone she had earlier chosen to represent anger she was holding onto into the vase, declaring, <i>"I don't need to hold onto the anger anymore"</i> (PGC, F5).
5c	<i>"The module is crucial as it makes it easier to talk about loss and grief. We managed to identify children who were suppressing their pain after a loss and talking about it in the support group has helped them start to cope better"</i> (SGL,F3).
5d	<i>"[I] felt that our life [had ended] – but my life can continue; it allowed me the strength to move on. I am more concentrated on where I want to go. The grief sessions helped me think deeper and talk more. I became more reflective. When I talk to someone, it allows me to make better decisions"</i> (PGC,F4)
5e	One of the older adolescents who kept a diary began to write about her experience in the bereavement support group sessions, and saw longer term benefits: <i>"It improved my relationship with my step mother–writing notes in my diary improved communication with others as we talked about what I had written and learnt from the grief sessions"</i> (FGD3, F2).

Wide range of emotions identified

Repeatedly, participants spoke about guilt, mostly surrounding the common, but irrational feeling that they should have been able to prevent their parents' deaths (Table 4: 2a and 2b). One female PGC, who was aged 2 when her father died and aged 4 when her mother died, said, *"I wish I'd been empowered enough to get them to the hospital and get them tested"* (F3). Another counsellor, who was aged 5 when his mother died, stated, *"I wish I'd been able to keep her alive"* (M2).

The first session began with a children's story about grief (Henderson & McIntyre [2000], which sanctions the wide range of emotions and allows participants to explore their own varied feelings. Support group members appreciated being taught to pay more attention to their feelings and express them to others. One young person simply stated, *"if you keep them deep inside it isn't healthy"* (FGD1, F4).

Feeling sad and lonely were common emotions, often felt intensely and attributed to having a loved one die. Two counsellors spoke explicitly about feeling depressed and considering suicide (Table 4: 2c).

A female PGC (F6) shared her deep sadness resulting from consecutive losses of her mother, then her brother, and then her father. This had sparked in her a fear that she, too, would die suddenly. Once verbalized, this fear was expressed by many others.

Anger was another common emotion particularly when their deceased parents were criticized. Participants also expressed anger at their parents for passing on HIV. As one participant stated, *"I blamed my mother ..., she's the one who gave me this and now she's gone, so things are now complicated"* (FGD3, M2).

Support group leaders also reported benefitting from the training and facilitation with caregivers. In addition to realizing the importance of discussing grief and loss with young people, they felt it helped them cope with their own losses (Table 4: 2d).

Relief in learning of shared experiences

As participants became more comfortable discussing their experiences of loss and difficult life experiences, most expressed surprise when learning of similarities between themselves and their peers. Despite knowing each other reasonably well and sharing difficulties around other HIV-related aspects of their lives, for the most part, they had never shared information specific to their losses. Even factual information, such as parental deaths, was kept private, as were difficult experiences such as living in non-supportive guardian homes. One group member said with surprise, *“I always thought they [2 other group members] were better than me, but now I see they have it worse than I do”* (FGD1, F2).

Others stressed the importance of learning they weren't alone in their experience of loss (Table 4, 3a and 3b). One participant explained, *“... it helped to know more about each other so that we know that we are not the only ones who have experienced loss”* (FGD2, M4).

A need for connection with the deceased

While participants talked about missing the deceased and longing to reconnect with them, they also described messages – both blatant and subtle – that made them feel they weren't allowed to have these feelings. As stated by one female PGC, *“I'm told not to look at pictures of my mother and father because it's not good; it will cause me stress. So, I hide them in the back of my bible. Then I can look at them and others don't see”* (F2).

Participants also described avoiding talking about death at home prior to the intervention. As one participant explained, *“The adults say you are 'still too young – you would think too much' [Shona idiom for depression] if we talked about death”* (FGD3, M1). Several participants believed adults' reticence to discuss grief related to their own experiences, *“Adults don't explain to the children about death and grief, because it may start affecting their own grief and loss”* (FGD4, M2). However, following intervention exposure, young people's greater comfort in broaching the topic made these family discussions easier (Table 4: 4a).

All participants readily engaged in a ritual activity in which they placed a stone in a glass vase, speaking aloud the name of a loved one, or an experience, or memory with them. Reflecting on this ritual, participants stressed that this enabled them to remember, honour, and feel more connected to those who had died. Describing this as a pivotal moment early in the bereavement sessions, one PGC shared, *“...[these are] reminders of the ones I lost. I felt more connected... It made me feel wherever my mother was, what I lost was coming back to me. I know she's looking out for me”* (M4).

Woven throughout their discussions was an acknowledgement of feeling better after thinking about the deceased was sanctioned (Table 4: 4b). One female PGC described feeling more *“at peace”* following the bereavement sessions, stating that, *“It was almost like they were never a part of my life. But now I treasure them more”* (F3).

Following their bereavement session, caregivers also left with a new appreciation for including the deceased in family discussions (Table 4: 4c). As one caregiver explained, *“I have always avoided talking about her late parents. After this session I am going to change my approach. It is important to listen and talk”* (C4). Another caregiver shared how she now better understands the child in her care (Table 4: 4d).

An increased ability to identify feelings, connect them with present experience and constructively respond

Participants initially spoke about behaving in ways they didn't always understand, which they admitted felt confusing. Following intervention exposure, numerous group members concurred that they felt they understood themselves better and had greater control over their emotions. One male PGC described his change following intervention exposure as follows: *“I was very short tempered in the past and quick to erupt... I think it was because of things unfinished with my [deceased] father.*

But now, if I start to feel angry, I take a minute, put on music, think about it. I don't erupt" (M2). Others identified specific activities that assisted them (Table 4, example 5a and 5b).

Support group leaders who facilitated discussions with caregivers and supported PGCs believed the intervention helped them identify children suppressing their pain from loss (See Table 4, 5c) Following their bereavement session, caregivers shared that they found the focus on bereavement helpful, stating that they felt "grateful."

Finally, participants reported that focusing on their grief benefitted how they see themselves, with one participant calling it "life changing." (Table 4, example 5d and 5e).

Discussion

Bereavement plays a central role in the lives of ALHIV, however, it has not been given adequate programmatic attention, despite it being associated with their poor mental health and poor ART adherence. This paper describes the development and initial implementation of a novel bereavement intervention in Zimbabwe for ALHIV and their caregivers, and responds to the call for innovative therapies to address loss and grief in this population that lives with so many losses (Willis et al., 2014). Using a peer-to-peer model, the intervention trained HIV-positive adolescent peer counsellors to incorporate bereavement support into their existing HIV community support program. To our knowledge, there is only one other rigorous study which offers bereavement support, but it looks at young people more broadly, without a specific lens for ALHIV (Thurman, et al. 2017) who suffer greater numbers of losses which are often connected to their own HIV status.

While there is still much we need to learn regarding the role of bereavement in the lives of ALHIV, currently we can make a number of inferences. Depression and anxiety are correlated with both bereavement in children and adolescents (Cluver et al., 2012) and with poorer levels of treatment adherence (Williams et al., 2006; Reisner et al., 2009). Further, general bereavement literature has established that grief following loss of a significant person is not a unidimensional experience of missing the relationship and having to cope with its associated feelings. Rather, grief plays a role in the construction of oneself and one's world (Neimeyer, Baldwin, & Gillies, 2006). Self-concept, self-esteem, and self-efficacy are inter-related constructs that are moulded by the loss of important people (Haine et al., 2003; Servaty & Hayslip, 2001). Additionally, it has been found that self-efficacy around adherence is strongly correlated with maintaining good adherence (Johnson et al., 2007). When examined holistically, these factors suggest that addressing bereavement is critical in promoting overall wellbeing and offers significant potential in supporting improved ART adherence.

Throughout this intervention, young people and caregivers alike, reported finding benefit from addressing issues related to bereavement. Perceived social support has been found to be a strong factor in effectively coping with bereavement (Ammassari, 2002; Dopp & Cain, 2012). Adolescents described experiencing a positive shift from coping with their grief alone to feeling able to engage in conversations on loss and learning of commonalities with peers. These conversations provided them with an opportunity for social support around their losses they had previously not experienced. Many described gaining a better understanding of themselves and their emotions, and subsequently, an improved ability to cope with their challenges. Additionally, the opportunity to build or reinforce the continuing bonds with the deceased proved important, as they described a shift in their sense of self-worth, self-efficacy, and hope for the future, which they attributed to new coping skills coupled with a strengthened sense of connection.

This study emphasizes the importance of contextualizing approaches to grief support when addressing grief and loss with children living with HIV in Southern Africa. For many of them, multiple, cumulative loss permeates from young ages. This is qualitatively different from being challenged to cope with a single loss, the lens through which conceptual frameworks addressing grief were first established. Multiple losses often contribute to confusing and overwhelming experiences as described by adolescents involved in this intervention (Field, Gao, & Paderna, 2005). Consequently, activities should be oriented towards helping young people identify and process their different losses and address their unique relationship to each loss.

A second important factor relates to how children cope with trauma by cutting off from themselves and their external environment. When the perceived threat is ongoing, children will often remain in these dissociated states. While adaptive in terms of managing overwhelming fear or helplessness, this coping mechanism also comes with a price. The child is likely to act out the unprocessed feelings, of which he or she has minimal conscious understanding, which in turn, will negatively impact interpersonal relationships and foster isolation.

At the start of this intervention, a number of participants talked about feeling confused or overwhelmed. Through intervention activities, they reported being more in touch with their emotions, and having better coping skills to manage difficult feelings. Programme participants particularly liked activities that relied on their own imaginings, specifically guided imagery and visualization. They described these activities as giving them a sense of control and personal power resulting in a better developed self-understanding.

Strengths and limitations

Given the sheer numbers of children and adolescents orphaned by HIV in sub-Saharan Africa, combined with increasingly constrained resources, innovative strategies are required. Using lay cadres to provide services is a growing strategy to support vulnerable populations in resource constrained settings (Mutamba, van Ginneken, Paintain, Wandiembe, & Schellenberg, 2013; Sweetland, Belkin, & Verdelli, 2014; Callaghan, Ford, & Schneider, 2010). A Cochrane review has shown positive results when lay health workers deliver mental health interventions (van Ginneken, Tharyan, Lewin, Rao, Meera, Pian, & Patel, 2013). The engagement of peer supporters in the care of ALHIV has been recommended by WHO (WHO, 2016; WHO, 2017) and recent research suggests that peers have been effective in improving adherence, retention in care and psychosocial wellbeing among ALHIV (Willis et al., 2015)

Additionally, employing peer-to-peer approaches has been highly effective when addressing psychological needs (Repper & Carter, 2011). Peer-to-peer bereavement support models traditionally use trained adults. Building on Africaid's model of peer-to-peer work, this program was effectively implemented by ALHIV themselves, increasing outreach as well as integrating it into their existing service provision model. Adolescents were provided training, supervision, and backstopping, but ultimately were the ones who provided care. Moreover, adolescents moulded the content of the bereavement intervention. Finally, by including caregivers, we begin to respond to the WHO guidelines calling for programmes to involve caregivers in interventions for adolescents living with HIV (WHO, 2013).

There are some limitations to these findings. This intervention was implemented within a well-designed, existing, urban support group structure. Additionally, this intervention was delivered to young people already engaged in an HIV support program and with adolescents already trained and working as peer counsellors. Further testing is needed to determine training needs if starting with less skilled adolescents and in rural populations. Finally, additional research is necessary to investigate how addressing bereavement impacts on ART adherence.

As our focus turns increasingly towards adolescents living with HIV, this study opens the door for greater engagement around grief and loss in this young population.

Acknowledgements — Funding for the development and implementation of this bereavement intervention was funded by REPSSI. The authors acknowledge the enormous contribution of the community adolescent treatment supporters within Zvandiri at Africaid (www.zvandiri.org). Without their continued insistence of the importance of grief and their willingness to share deeply of themselves in this process, this programme would not have been developed. The authors also thank the young people who actively participated in the intervention and shared their impressions.

Notes

- ¹ The HIV-positive peer counsellors or Community Adolescent Treatment Supporters (CATS) were from Africaid, a non-governmental organisation headquartered in Harare, Zimbabwe (www.africaid-zvandiri.org) that uses a peer support model to provide treatment, care, support, and prevention services for children and adolescents with HIV.
- ² Michael O. Henderson & Barbara Betker McIntyre. (2000). *The Jungle Journey: Grieving and Remembering Eleanor the Elephant*. Traverse Publishing Company.
- ³ Attendance was impacted by the first three sessions being held during the school holidays, during which time some students are engaged in extra lessons, and others visited their rural home areas.

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References

- Ammassari, A., Trotta, M. P., Murri, R., Castelli, F., Narciso, P., Noto, P., ... Antinori, A. for the AdCoNA Study Group. (2002). Correlates and predictors of adherence to highly active antiretroviral therapy: Overview of published literature. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 31(Suppl 3), S123–S127. <https://doi.org/10.1097/00126334-200212153-00007>
- Barclay, T. R., Hinkin, C. H., Castellon, S. A., Mason, K. I., Reinhard, M. J., Marion, S. D., ... Durvasula, R. S. (2007). Age-associated predictors of medication adherence in HIV-positive adults: Health beliefs, self-efficacy, and neurocognitive status. *Health Psychology*, 26(1), 40–49. <https://doi.org/10.1037/0278-6133.26.1.40>
- Callaghan, M., Ford, N., & Schneider, H. (2010). A systematic review of task-shifting for HIV treatment and care in Africa. *Human Resources for Health*, 8, 18. <https://doi.org/10.1186/1478-4491-8-8>
- Cluver, L., Gardner, F., & Operario, D. (2007). Psychological distress among AIDS-orphaned children in urban South Africa. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 48(8), 755–763. <https://doi.org/10.1111/j.1469-7610.2007.01757.x>
- Cluver, L., Orkin, M., Gardner, F., & Boyes, M. E. (2012). Persisting mental health problems among AIDS-orphaned children in South Africa. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 53(4), 363–370. <https://doi.org/10.1111/j.1469-7610.2011.02459.x>
- Collishaw, S., Gardner, F., Aber, L. J., & Cluver, L. (2016). Predictors of mental health resilience in children who have been parentally bereaved by AIDS in urban South Africa. *Journal of Abnormal Child Psychology*, 44(4), 719–730. <https://doi.org/10.1007/s10802-015-0068-x>
- Dopp, A. R., & Cain, A. C. (2012). The role of peer relationships in parental bereavement during childhood and adolescence. *Death Studies*, 36(1), 41–60. <https://doi.org/10.1080/07481187.2011.573175>
- Dowdney, L. (2000). Annotation: Childhood bereavement following parental death. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 41(7), 819–830. <https://doi.org/10.1111/1469-7610.00670>
- Field, N. P., Gao, B., & Paderna, L. (2005). Continuing bonds in bereavement: An attachment theory based perspective. *Death Studies*, 29(4): 277–299. <https://doi.org/10.1080/07481180590923689>
- Haine, R. A., Ayers, T., Sandler, I., Wolchick, S. A., & Weyer, J. L. (2003). Locus of control and self-esteem as stress-moderators or stress-mediators in parentally bereaved children. *Death Studies*, 27(7), 619–640. <https://doi.org/10.1080/07481180302894>
- Harrison, L., & Harrington, R. (2001). Adolescents' bereavement experiences: Prevalence, association with depressive symptoms, and use of services. *Journal of Adolescence*, 24(2), 159–169. <https://doi.org/10.1006/jado.2001.0379>
- Henderson, M. O., & McIntyre, B. B. (2000). *The Jungle Journey: Grieving and Remembering Eleanor the Elephant*. Traverse Publishing Company.
- Johnson, M. O., Neilands, T. B., Dilworth, S., Morin, S. F., Remien, R. H., & Chesney, M. A. (2007). The role of self-efficacy in HIV treatment adherence: Validation of the HIV treatment adherence self-efficacy scale (HIV-ASES). *Journal of Behavioral Medicine*, 30(5), 359–370. <https://doi.org/10.1007/s10865-007-9118-3>
- Kaplow, J. B., Saunders, J., Angold, A., & Costello, E. J. (2010). Psychiatric symptoms in bereaved versus non-bereaved youth and young adults: A longitudinal epidemiological study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 49(11), 1145–1154. <https://doi.org/10.1016/j.jaac.2010.08.004>

- Makadzange, A. T., Higgins-Biddle, M., Chimukangara, B., Birri, R., Gordon, M., Mahlanza, T., ... Ndhlovu, C. E. (2015). Clinical, virologic, immunologic outcomes and emerging HIV drug resistance patterns in children and adolescents in public ART care in Zimbabwe. *PLoS One*, *10*(12), e0144057. <https://doi.org/10.1371/journal.pone.0144057>
- Mavhu, W., Berwick, J., Chirawu, P., Makamba, M., Copas, A., Dirawo, J., ... Cowan, F. M. (2013). Enhancing psychosocial support for HIV positive adolescents in Harare, Zimbabwe. *PLoS One*, *8*(7), e70254. <https://doi.org/10.1371/journal.pone.0070254>
- Mokdad, A. H., Forouzanfar, M. H., Daoud, F., Mokdad, A. A., El Bcheraoui, C., Moradi-Lakeh, M., ... Murray, C. J. L. (2016). Global burden of diseases, injuries, and risk factors for young people's health during 1990-2013: A systematic analysis for the Global Burden of Disease Study 2013. *Lancet*, *387*(10036), 2383–2401. [https://doi.org/10.1016/S0140-6736\(16\)00648-6](https://doi.org/10.1016/S0140-6736(16)00648-6)
- Mutamba, B. B., van Ginneken, N., Paintain, L. S., Wandiembe, S., & Schellenberg, D. (2013). Roles and effectiveness of lay community health workers in the prevention of mental, neurological and substance use disorders in low and middle-income countries: A systematic review. *BMC Health Services Research*, *13*, 412. <https://doi.org/10.1186/1472-6963-13-412>
- Neimeyer, R. A., Baldwin, S. A., & Gillies, J. (2006). Continuing bonds and reconstructing meaning: Mitigating complications in bereavement. *Death Studies*, *30*(8), 715–738. <https://doi.org/10.1080/07481180600848322>
- Reisner, S L., Mimiaga, M J., Skeer, M, Perkovich, B, Johnson, C V., & Safren, S A. (2009). A review of HIV antiretroviral adherence and intervention studies among HIV infected youth. *Topics in HIV Medicine*, *17*(1), 14–25.
- Repper, J., & Carter, T. (2011). A review of the literature on peer support in mental health services. *Journal of Mental Health (Abingdon, England)*, *20*(4), 392–411. <https://doi.org/10.3109/09638237.2011.583947>
- Servaty, H. L., & Hayslip, B., Jr. (2001). Adjustment to loss among adolescents. *Omega*, *43*(4), 311–330. <https://doi.org/10.2190/B9MH-UU5H-9CG2-RAW6>
- Sweetland, A.C., Belkin, G.S., & Verdelli, H. (2014) Measuring depression and anxiety in sub-Saharan Africa. *Depression and Anxiety*, *31*(3), 223–32. <https://doi.org/10.1002/da.22142>
- Thompson, M. P., Kaslow, N. J., Price, A. W., Williams, K., & Kingree, J. B. (1998). Role of secondary stressors in the parental death-child distress relation. *Journal of Abnormal Child Psychology*, *26*(5), 357–366. <https://doi.org/10.1023/A:1021951806281>
- Thurman, T. R., Luckett, B. G., Nice, J., Spyrelis, A., & Taylor, T. M. (2017). Effect of a bereavement support group on female adolescents' psychological health: A randomised controlled trial in South Africa. *The Lancet. Global Health*, *5*(6), e604–e614. [https://doi.org/10.1016/S2214-109X\(17\)30146-8](https://doi.org/10.1016/S2214-109X(17)30146-8)
- Van Ginneken, N., Tharyan, P., Lewin, S., Rao, G. N., Meera, S., Pian, J., & Patel, V. (2013). Nonspecialist health worker interventions for the care of mental, neurological and substance-abuse disorders in low- and middle-income countries. *Cochrane Database of Systematic Reviews*, *11*, CD009149. Retrieved from onlinelibrary.wiley.com/doi/10.1002/14651858.CD009149.pub2/abstract
- WHO. (2013). HIV and adolescents: Guidance for HIV testing and counselling and care for adolescents living with HIV. Geneva: World Health Organization. <http://www.who.int/hiv/pub/arv/arv-2016/en/>
- WHO. (2016). Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: Recommendations for a public health approach. Geneva: World Health Organisation. Retrieved from <http://www.who.int/hiv/pub/arv/arv-2016/en/>
- WHO. (2017). Policy brief: Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations, 2016 update. Geneva: World Health Organization. <https://www.who.int/hiv/pub/guidelines/keypopulations-2016/en/>
- Williams, P., Storm, D., Montepiedra, G., Nichols, S., Kammerer, B., Sirois, P., ... & Malee, K. (2006). Predictors of adherence to antiretroviral medications in children and adolescents with HIV infection. *Pediatrics*, *118*(6), e1745–e1757. <https://doi.org/10.1542/peds.2006-0493>
- Willis, N., Frewin, L., Miller, A., Dziwa, C., Mavhu, W., & Cowan, F. (2014). "My story"—HIV positive adolescents tell their story through film. *Children and Youth Services Review*, *45*, 129–136. <https://doi.org/10.1016/j.chilyouth.2014.03.029>
- Willis, N., Dziwa, C., Mawodzeke, M., Chitiyo, C., Munyohho, S., Milanzi, A., ... James, V. (2015, December). An operations research study to measure the effectiveness of the CATS service in Gokwe South District, Zimbabwe. Oral presentation at the International Conference on AIDS and STIs in Africa, Harare, Zimbabwe.
- Willis, N., Mavhu, W., Wogrin, C., Mutsinze, A., & Kagee, A. (2018). Understanding the experience and manifestation of depression in adolescents living with HIV in Harare, Zimbabwe. *PLoS One*, *13*(1), e0190423. <https://doi.org/10.1371/journal.pone.0190423>
- Worden, J. W., & Silverman, P. R. (1996). Parental death and the adjustment of school-age children. *Omega*, *33*(2), 91–102. <https://doi.org/10.2190/P77L-F6F6-5W06-NHBX>

UNAIDS. (2016). *AIDS by the numbers — AIDS is not over, but it can be*. Geneva: UNAIDS.

UNICEF. (2013). *Towards an AIDS-free generation: Children and AIDS sixth stocktaking report*. New York.

UNICEF. (2016). *For every child, end AIDS: Seventh stocktaking report, 2016*. New York: UNICEF.