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Loss as Experienced by Ugandan Grandparent-Caregivers of Children Affected by HIV/AIDS

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Abstract

Despite increasing numbers of studies investigating grandparent-caregivers of children orphaned by HIV/AIDS in sub-Saharan Africa, research on their mental and physical health remains inadequate. We provide a qualitative account of the nature, extent, and relationships among multiple variations of loss emerging from 32 interviews with Ugandan grandparent-caregivers of grandchildren affected by HIV/AIDS. Regardless the type or nature of the loss, participants expressed physical, emotional, and financial distress as a result. This cumulative loss and subsequent grief could potentially be associated with mental and physical health problems. Research to further explore the concept of loss among this vulnerable population is recommended.

Keywords

HIV/AIDS; loss; Ugandan grandparent-caregivers

There is a growing body of research on grandparental caregiving provided to children orphaned by HIV/AIDS in sub-Saharan Africa (Clark, 2006; Kasedde, Doyle, Seeley, & Ross, 2014; Grobler & Roos, 2012; Merli & Palloni, 2006; Rutakumwa, Zalwango, Richards, & Seeley, 2015). Data from these studies suggest that older adults are caring for households impacted by the HIV/AIDS epidemic without adequate resources. Several of these studies report on the physical, psychosocial, and financial burdens experienced, while a few identify coping strategies described by the grandparent-caregivers. However, the experiences of loss, particularly loss created by the HIV epidemic, have not been extensively investigated. Some studies reported singular incidents of loss in relation to the caregiving experience, but studies examining the concept of loss as it pertains to Ugandan grandparent-caregivers in the HIV era are woefully rare.

Review of the literature revealed that a few researchers have attempted to address the HIV/AIDS-related interpersonal losses experienced by this aging population. For instance, Seeley (2014) recounts the impact of HIV/AIDS on Ugandan lives over the last three decades and provides anecdotes of grandparents' loss experiences resulting from HIV/AIDS-related deaths. Also, Demmer (2010) explored the impact of AIDS-related loss on the well-being of women and their subsequent attitudes and experiences of losing young children to AIDS. In

addition, Western scientists such as Miltenberger, Hayslip, Harris, and Kaminski (2004) examined the societal perception of loss as a concept with regard to custodial grandparents, but the grandparents' self-perception of loss was not examined.

Other studies have investigated loss as it pertains to overall mental health (Baker, Procter, & Gibbons, 2009), Alzheimer's disease, and dementia (Collins, Liken, King, & Kokinakis, 1993; Sanders, Morano, & Saltz, 2003). However, no studies were found that examined dimensions of loss experienced by grandparent-caregivers in the sub-Saharan setting, particularly in Uganda. Findings from the present study address this deficit in the research by presenting a qualitative account of the nature, extent, and relationships among multiple types of losses experienced by grandparent-caregivers of children largely impacted by HIV/AIDS in sub-Saharan Africa.

METHODS

Methodology and purpose

The study was conducted using grounded theory (Charmaz, 2009; Strauss & Corbin, 1990), a qualitative methodology underpinned by the sociological theory of symbolic interactionism. This methodology allowed us to systematically and reiteratively navigate data collection and analysis procedures in a nonlinear manner, an approach that is considered most effective in qualitative research (Charmaz, 2009; Strauss & Corbin, 1990). Additionally, by using theoretical sampling (Glaser & Strauss, 1967), line-by-line constant comparison of new and older transcribed data to identify emerging salient categories, and inclusion of new concepts in subsequent interviews, we were able to achieve the purpose of the study. In this study, we sought to understand the experiences and mental health of Ugandan grandparents 50 years of age and older who provide primary care for their grandchildren affected by HIV/AIDS. The current manuscript focuses on the ways in which the experience of loss was described by the participants and the impact these experiences had on their lives.

Sample

To participate in the study, individuals had to be Luganda-speaking grandparents 50 years of age or older who had been caregivers for children affected by HIV/AIDS for at least 6 months (see Table 1 for participant characteristics). Luganda is the most commonly spoken language in Uganda and the primary researcher's native language. To facilitate recruitment of participants that could best inform the research question, local council leaders were initially apprised of the study. They, in turn, agreed to identify and contact individuals in their villages who met the inclusion criteria. Potential participants then contacted the primary researcher to be screened for eligibility. Snowball and purposive-sampling techniques were used to select participants and obtain responses relevant to the research question.

Recruitment, Approval, and Setting

Approval to conduct the study was obtained from the Institutional Review Board of the University of California, San Francisco Committee on Human Research and Makerere

University College of Health Sciences. Administrative clearance was obtained from the Uganda National Council for Science and Technology. Participants were recruited from four general population settings, including regions that, historically, have been most affected by the HIV/AIDS epidemic. To provide the study with richer narratives that could represent the diversified perspectives and experiences of grandparents, participants were recruited from both rural (i.e., Masaka and Luwero) and urban (i.e., Kampala and Busia) areas. Interviews were performed at sites convenient to the participants—homes, neighboring schools, and community centers.

Data Collection

Data were collected using a qualitative interview guide with semistructured questions, such as, “How has your experience as a grandparent-caregiver been?” These questions were followed by prompts and probes, such as, “Tell me more,” or repeating back to expand understandings and follow up on newly identified themes. Each participant was interviewed on one or two occasions for 60–90 min. Congruent qualitative grounded theory methods (Charmaz, 2009; Strauss & Corbin, 1990), digital audio recorders, field notes, memos, and photographic observations of relevant household activities or living conditions were used to capture and contextualize the interviews. Thirty-two one-time interviews and three follow-up interviews were obtained, translated, and transcribed by the primary researcher (first author) who is fluent in Luganda. Data collection was completed after theoretical saturation was reached and no new data could be extracted from the interviews.

Data Analysis

Analysis of the transcribed data used grounded theory methods and Atlas-Ti, a software program that facilitates systematic analysis of qualitative data. Transcribed narratives were read line-by-line and open, axial, and selective coding were performed to deconstruct the data and identify salient “codes”—clusters or units of meaning that represent the participant’s reality. Both reflexive and analytic memoing were used frequently to (a) enable the researcher’s self-reflection on the emerging categories, participants, and their social worlds, and (b) pose “questions, musings or speculations” (Creswell, 2007, p. 290). These memos were then used to analyze developing and complex concepts that seemed to be particularly salient during coding or other levels of analysis. Thus, both coding and memoing followed an iterative and nonlinear process. Additionally, transcripts were reviewed by researchers (co-authors) familiar with the study, with categories and themes discussed and refined to capture the intent of the interviews.

FINDINGS: DIMENSIONS OF LOSS

After experiencing a crisis or a myriad of unfortunate occurrences, participants stated that they experienced a loss, void, or sense of something missing that impacted their lives at a physical, social, or emotional level. Although loss was often associated with the death of a loved one, participants reported similar deprivation and emotional distress in relation to other types of experiences. Thus, while participants may not have explicitly referred to this deprivation or distress as “loss,” we analytically inferred that this experience of missing possession, service, convenience, or other entity was a form of loss. This analytic decision is

based on Shives's (2008) description of loss as "a condition whereby an individual experiences deprivation of, or complete lack of, something that was previously present" (p. 76).

All of the participants had experienced some form of loss—temporary or permanent, moderate or extraordinary, anticipatory or fait accompli. We identified relationships between these dimensions of loss as being either *primary*—an initial inaccessibility or deprivation of a valued possession or person or other entity—or *secondary*—losses that came as a result of a cascading of events after or concomitant with the primary loss. Specific types of losses were then identified under these two dimensions as described in the subsequent sections of this manuscript. Notably, the types of loss described by study participants were not mutually exclusive (i.e., any type of loss could co-occur with any other type of loss).

Primary Losses

Loss of Self—Participants frequently referred to experiences that can be described as a "loss of self." Most grandparent-caregivers, particularly grandmothers, described this experience of loss of self as (a) a decline in functional abilities, health, or quality of life, or (b) diminishing self-identity and self-image. These older adults attributed these declines to normal aging. Participants believed that this primary loss of their youth and vitality had led to other types of loss, such as loss of identity, independence, attractiveness, options, perceived control of body, or external function. Understandably, primary aging, determined by inherent or hereditary influences, is considered a normal process in any similar cohort (Shives, 2008). However, many of the grandparent-caregivers were prematurely aged by the harsh, often traumatic and unfortunate circumstances of their lives. This premature aging further inhibited their thriving or even their performance of the basic activities of daily life. For these older adults, the principal day-to-day objective was survival. In some instances, grandparents reported the loss of self as a decline in energy and an inability to perform daily activities or specific jobs that would more adequately support their families and carry out their caregiving role. For example,

I am weaker now. ... If you send the child to do a chore that you would otherwise have done yourself and they don't, it saddens me to look at the [task] undone and yet I am too weak to do it myself. So that makes me feel sick inside. You may ask [a grandchild] to wash your clothes and he says, "I will wash them tomorrow," and of course he never does. (6Mask)

In addition, some of the participants described a loss of their youth that further hindered them from leaving abusive or unhappy marriages and seeking desirable companionships: "Let me tell you something, my child-... finding another companion can only be possible if you still look good and are still young ... all that is gone" (6Mask). Notably, the loss of self could also be considered secondary. For example, loss of adult children or family members may lead to a qualitative diminishing of the grandparent-caregivers' view or recollection of their history. Ultimately, as they mourn the loss of their family members, some participants could not avoid reflecting on and worrying about the loss of their own lives or mortality and the impact of their eventual death on the lives of their grandchildren. For example, "I am pained by those children. If they don't get any schooling, how are they going to be in life? If

I die, especially since my health worries me, what will happen to those children? They are still young” (2Kit).

Loss of Adult Children and Grandchildren—Grandparent-caregivers described experiences of loss of adult children as a result of death from any of multiple causes, but in most instances, death was due to HIV/AIDS. Although some grandparents reported having lost their children as toddlers or preadolescents, the majority lost adult children who were in the age range of 20–45 years, which corresponds to the age range of the demographic most affected by the HIV/AIDS epidemic in Uganda, 15–49 years (Joint United Nations Programme on HIV/AIDS, 2016). In describing their experiences burying their adult children, most of the participants expressed the unbearable anguish endured by parents who bury their children in contravention of the perceived natural order—in which, normally, grandparents are buried by their adult children. For example,

[As] a parent and an elder, you would wish to die before your children. ... It is so painful for a parent to bury one child after another. ... I should have died first and left the children behind. ... See, I don't have many people [friends or family] to leave behind. ... I am left alone, what can I do? (2Kit)

This loss is particularly devastating to some because it is not just the demise of immediate family members, but of a lineage and heritage. For example, as an only child who was orphaned as a child and had to grow up with relatives who did not embrace her as kin, participant 5Mask lamented about what having, then losing, her children meant:

Having my own children made me so happy. One would be my brother, the other my father, my mother. ... It is like I created the [relationships] that I never had. But then I lost all of them and remained all alone as I was before. (5Mask)

In addition to this loss, participants reported the experience of losing children who had disappeared without a trace. For example,

He [one of the sons] also went off with soldiers [army] and I don't hear from him. He left when he was very young and we looked for him everywhere but couldn't find him. The next thing I heard was that he was seen in [another town]. Since then, there was no trace of him. I haven't heard from him since. (6Kit)

As reported by this grandmother, some adult children migrated to other towns or countries, motivated mostly by a lack of financial stability and a desire to seek better opportunities elsewhere. Many communicated with their families only sporadically or not at all. Often, grandparent-caregivers lost all contact with their adult children. When adult children went missing without a trace, affected grandparent-caregivers lacked closure or finality and were instead chronically distressed by the mystery surrounding the child's disappearance. Not only did these grandparent-caregivers mourn the disappearance of their adult children, but also, at times, perceived the sporadic communication or lack of communication as deliberate abandonment of their children's parenting responsibilities. For example,

[My son] left. I hear he is in [another district] now. ... It has now been seven years without seeing him ... and I have no way of finding him ... and he never calls up to this day. He doesn't even know what is happening with the children. The girl is in

[another district]. I don't hear from her either. ... She also just abandoned the child and left. ... Her child is about four years now. (3Bus-Grandfather)

Alternatively, other participants expressed anticipatory loss of grandchildren to the paternal family when they got older. For example,

You may raise a child and they grow up to become good people, however, they quickly begin realizing that the other [paternal] side is the main family and forget that you, the grandmother, are the one that raised them. That is a very big problem because they may then begin looking at you as a nonrelative now that they have their other kin to go to, so all your efforts go to waste. ... This child would grow up and take care of me but instead they just leave you all alone. ... They don't look back and remember the grandmother that raised them. (7Bus)

Like 7Bus, grandparent-caregivers often dreamed of being taken care of in return for their child-rearing efforts and sacrifices, yet realized this would be lost if the adult grandchildren were reclaimed by their "primary" family. Some participants had actually experienced this loss with older grandchildren. This abandonment and loss—whether potential (i.e., anticipatory) or *fait accompli*—was, for most of these older adults, intensely distressing and saddening.

Loss Of Spouses—In addition to the aforementioned losses, participants also reported losses of spouses as a result of death or other causes, such as separation, divorce, or the gradual emotional disconnection and dysfunction of their marriages. All participants interviewed were either widowed, separated, or in undesirable polygamous families.

I was married for about twelve years or so and had about seven children. [My] husband ... was convinced to go into the army to Somalia; and he died there. I never heard from him until I heard that he had died. I don't even know what year or when he died. (2Bus)

Because 2bus was uncertain her husband had died, she was left in a state of unresolved grief. For others, however, the loss of a spouse created a complex void. While initially describing themselves as married, some, on further prompting, revealed they were actually widowed: "I have been married for 23years ... to the same man who died ... he died in 1998" (5Bus).

As revealed by this participant, this status of widowhood, especially among the grandmothers (in contrast to the grandfathers), resulted in a loss of option to remarry because remarriage would have been considered culturally abominable by their children, in-laws, or other extended family members. Some were, in fact, interested in remarrying; however, their desire was superseded by the expectation that, out of respect for the deceased spouse, they would maintain their widowhood. For example, "I could get married again but ... my friend, I don't want to take that chance. ... Things are complicated. Mmmm [silence]. But if I do, wouldn't the children be upset?" (4Luw)*; and "I didn't want to get married again. ... First of all, my husband [ex-husband, remarried and living elsewhere] is nearby and you can't get someone else in his home" (2Mask).

In addition to death as a cause of terminated marriage, some participants reported that spouses had overtly divorced or separated from them or had abandoned their marriages and disappeared without notice. For example,

The most painful thing is that the person you would have called your companion cannot even take you to the hospital when you are ill at night and yet he has the money. Through all the illness and lack of necessities in the household, he insists that he doesn't have the money. Even when I moan and cry in pain, he does not say, "My dear, what is the problem? Let me take you for treatment," or "Here is the money for your treatment." I wonder how he can turn on me at this stage in my life when I need him to provide for the family. ... He does not come back home at times because he is with his other wives and if he does, he comes in at 2:00 a.m. He is enjoying his life and that hurts so much because there is nothing I can do. (6Mask)

Because of the marital problems that this participant experienced, she was emotionally disconnected from her husband, who had other wives and families. This loss of marital connection was frequently reported—particularly by grandmothers. As a result of their marital disconnection, most of these grandmothers had decided to never remarry.

Besides the emotional impact of marital problems expressed by participants such as 6Mask above, others expressed a loss of a partner and co-parent with whom they shared the caregiving responsibilities. After relying on their spouses for many years, marriage dissolution often left these older adults disappointed, frustrated, and without support. For example,

The other problem is that of not having a man because if it is the two of you, you put your heads together and see what to do. But now, not having a man, not having a supporter, you don't have anything. ... I am just surviving. (4Bus)

For most of the grandmothers, this type of pragmatic loss of husband as partner was particularly challenging and distressing. This is especially true in Ugandan households, where husbands are typically solely responsible for the family's financial support, while wives are the family's homemakers. Accordingly, the loss of a husband often necessitated a restructuring of family roles and the requirement that the grandmother partake in jobs outside the home, jobs that in many instances were viewed as untraditional and inappropriate for women. Since most of these women married as young teenagers and had depended on their husbands for support throughout their adult life, the loss of their spouses was a devastating hardship. Moreover, the hardships of marital loss were often exacerbated by other stressors, waning health, and aging.

Secondary Losses

LOSS OF RESOURCES—In addition to primary losses, the large majority of our study participants were further distressed by the loss of resources in the form of either property or financial savings. Hobfoll (1989) corroborates that loss, particularly as related to depletion or disappearance of resources, can heighten perceived psychological stress and impact one's mental health. He described resources as "those objects, personal characteristics, conditions,

or energies that are valued by the individual or that serve as a means for attainment of these objects, personal characteristics, conditions, or energies” (p. 14).

For the majority of both rural- and urban-dwelling participants, the most valuable form of resource or asset is land, from which they grow food, sell produce, raise animals, and construct homes without any restrictions from landlords. Other forms of resources may include small business assets, such as a retail shop. In the course of nursing their loved ones, usually over long periods of time, many of these older adults deplete all of the resources available to them. With the loss of spouses, this experience is further complicated by family disputes in which other extended family divide up or abrogate land ownership and take property belonging to the deceased husband, leaving the grandmothers without any assets to survive on. For example,

My husband had left me in a good place, with my own plot. But my son [his heir] sold my land ... and went on to buy his own. He called and said, “Mother, I am going to build you a house and give you the grandchildren to stay with you,” but he never did. (1Mask)

My father-in-law had given us a piece of land in 2010, he [deceased husband] started selling it off, claiming that he would use that money to start a business for us. Instead, he got another woman and spent all the land money on her before he died. (4Luw)*

LOSS OF THE “SAFETY NET”—In addition to discrete losses created by a death or disappearance of a loved one, many grandparent-caregivers reported cumulative losses that we refer to as the loss of a “safety net” that included both physical assets and a social network of friends, relatives, and immediate family members. Within a collectivistic cultural context, as exists in Uganda, in which family and community serve as resources for survival, loss of that safety net can be detrimental. In combination with inadequate social services, loss of their personal safety net impacted the grandparents’ personal well-being and that of their grandchildren. In the narratives of these older adults, the idea of being “the only one left to care for the grandchildren” was a recurrent theme—an expression of frustration and despair that was exacerbated by the vitiation of their social network. For example,

What makes me sad is that most of my supportive people have died. At some point ... my [niece’s] husband fell sick too. ... He eventually died in October 2012. He used to take care of me and would take us out to have a good time. And in December 2012, my husband died and thereafter, my son died in January 2013. Before I would heal from all that pain, I had to bury my niece in March 2013. That one was the hardest for me to take because she was my mother and my father. She is the one that bought everything for me that I needed. Even when she was sick, she would send me money. ... So when she died, I died too. ... She left me with a lot of sadness and poverty and I can barely take care of her children. Her family took all her belongings. (4Luw)*

Loss of the social network was partly the result of weakening or disintegration of intergenerational ties or lineage, which left some grandparents without the safety net of their kin. This loss was particularly evident as a result of failed marriages, loss of employment, or

migration of relatives. Cumulative losses eventually hindered communication or other contact that would otherwise have facilitated the grandparents' support-seeking efforts.

LOSS OF "THE DREAM"—A consequence of a loss of safety net and tangible resources was a gradual disintegration of ambitions—dreams of what life could have been. In their conditions of chronic poverty, our participants' unemployment and lack of government and other supportive social services eventuated in a lack of formal pension, retirement plan, and savings. Indeed, the only practicable investment for these older adults was in their children's and grandchildren's education and success in life. Accordingly, if the grandparent-caregivers' surviving adult children and grandchildren failed to provide for them, their dreams of security and of benefiting from their family were for naught. If the surviving adult children died, the grandparents' hope for security died with them. For example, participant 7Kit explained the dilemma and regret of loss after she had invested in her children's education:

But when I think about my children that way, I fail to eat. I think about the one that was a teacher and say, I wouldn't be working today if she was alive. The same with the doctor. ... Even in his death bed, he would give me the money and say, "Here you go, mom, I know how much money you spend on household expenses." [silence]. (7Kit)

DISCUSSION

Whether a grandparent-caregiver's loss was isolated or collective, the repercussions of this deprivation are adverse, often extensive, and can potentially affect (or can be associated with) psychosocial, mental, and physical health. Current research has focused on individual experiences of loss, particularly as related to death of loved ones. However, in contrast with the death of a loved one, which may elicit an urgent and supportive response from others, other types of losses discussed in this paper may not elicit as much attention and concern for those impacted.

For example, in Uganda and most cultures, family and friends rally around those that have lost their loved ones and may offer emotional and tangible support during those difficult circumstances. Unfortunately, such traditional practices might not be exercised with other types of loss, such as those discussed in this paper, that could potentially have the same or even worse impact on the affected individuals. Besides, the cumulative impact of the multiple dimensions of loss may not be considered as impactful to the grandparent-caregivers' well-being. Therefore, increasing public awareness of the dimensions and types of loss, as well as the fact that individuals can experience multiple visible and invisible losses at the same time, is critical. Public awareness of these variations of loss may elicit improvement in interpersonal relationships and provision of both tangible and emotional support to grandparent-caregivers from the surviving social network.

Similar to the nature and multiplicity of loss, the approaches used by grandparent-caregivers to mitigate the various types of loss may also differ. For example, participants may attempt to cope with the death of their adult children by focusing on the satisfaction derived from caring for their grandchildren. However, other kinds of loss, such as loss of resources,

cannot be so readily adapted to counteract the cumulative perceived loss, especially in underresourced settings. Therefore, it is critical that research focuses on a holistic approach to studying loss to further increase awareness among policy, research, health, and other stakeholders. This awareness is crucial in facilitating availability of and access to social services, such as crisis interventions and counseling, to this population.

CONCLUSION

Our study findings have uniquely contributed to a broader understanding of the concept of loss beyond a person-oriented focus to a socially meaningful experience of loss, with emphasis on the nature and multitude of these losses. Although our study didn't aim to investigate the impact or severity of each dimension or type of loss, that limitation could impede the design and implementation of effective and targeted interventions needed to mitigate the most preeminent type of loss. However, the study was strengthened by its ability to initiate a conversation geared toward understanding the concept of loss as experienced by Ugandan grandparent-caregivers. In turn, this understanding may broaden our knowledge of the cultural dimensions of loss—how loss is perceived, experienced, and dealt with—and may inform us about differences in similar experience across various ethnic groups.

Although our purposive sampling attempted to recruit equal numbers of men and women, the final sample was overwhelmingly female. This is congruent with findings from the literature reviewed prior to initiating our study. These samples also included more grandmothers than grandfathers. In the current study, this gender discrepancy is most likely due to the pre-existing cultural and gender roles in which Baganda women, who were the majority of our participants, have tended to shoulder the hands-on care for their family members, while men assume responsibilities outside the home (MacNeil, 1996). Although each of the five male participants reported some dimension of loss, our study findings may be limited by the reflection of mostly female perspectives on the overall caregiving experience and the related dimensions of loss. However, this is also a strength in that it highlights the vulnerability of women as it pertains to the various dimensions of loss related to widowhood, separation, and divorce, which could inform actions and interventions such as those geared towards women empowerment.

Finally, our findings could inform studies that may need to investigate how the various dimensions of loss may individually or collectively affect grandparent-caregivers' physical and mental health. For instance, although our study did not aim to explore causal relationships between dimensions of loss and their impact of the health of the participants, similar studies on grandparent-caregivers have reported poor health outcomes such as depression as a result of lost or decreased social support (Musil, 1998). Therefore, future studies are needed to compare or determine which dimensions of loss might be of higher significance in impacting the health of grandparent-caregivers, or even explain synergetic or additive relationships among the various elements of loss. Other studies that investigate social perception of the various dimensions of loss, particularly as experienced by grandfathers, may also be needed to fully understand this social phenomenon and improve the psychosocial well-being of grandparent-caregivers.

Biographies

Schola Matovu completed her PhD at the University of California-San Francisco, where she is currently training as a postdoctoral research scholar to further advance her research agenda. Both personal and professional experiences have prepared Dr. Matovu for her current research interest in the mental health and psychosocial well-being of older grandparent-caregivers for children who are affected by HIV/AIDS in Uganda. Her long-term goal is to continue studying ways to promote the overall quality of life and well-being of older adults, particularly those with caregiving responsibilities.

Margaret Wallhagen is a professor of gerontological nursing, and director of the UCSF/John A. Hartford Center of Gerontological Nursing Excellence and Senior Nurse Scholar for the San Francisco Veterans Administration Quality Scholars program. Her research and publications focus especially on how older individuals and their families manage chronic illnesses as well as changes that occur with age. For the last several decades, she has focused especially on the impact of hearing loss on the individual and family across multiple settings.

REFERENCES

- Baker AEZ, Procter N, & Gibbons T (2009). Dimensions of loss from mental illness. *The Journal of Sociology & Social Welfare*, 36 (4), 25–52.
- Charmaz K (2009). Shifting the grounds: Constructivist grounded theory methods for the twenty-first century. In Morse J, Stern P, Corbin J, Bowers B, Charmaz K, & Clarke A (Eds.), *Developing grounded theory: The second generation* (pp. 127–154). Walnut Creek, CA: Left Coast Press.
- Clark SJ (2006). Demographic impacts of the HIV epidemic and consequences of population-wide treatment of HIV for the elderly: Results from microsimulation. In Cohen B & Menken J (Eds.), *Aging in Sub-Saharan Africa: Recommendations for furthering research* (pp. 91–116). Washington: National Academies Press.
- Collins C, Likien S, King S, & Kokinakis C (1993). Loss and grief among dementia caregivers. *Qualitative Health Research*, 3, 236–253. doi:10.1177/104973239300300206
- Creswell JW (2007). *Qualitative inquiry & research design* (2nd ed.). Thousand Oaks, CA: Sage.
- Demmer C (2010). Experiences of women who have lost young children to AIDS in KwaZulu-Natal, South Africa: A qualitative study. *Journal of the International AIDS Society*, 13, 50. doi: 10.1186/1758-2652-13-50 [PubMed: 21143929]
- Glaser BG, & Strauss AL (1967). *The discovery of grounded theory*. Chicago: Aldine.
- Grobler H, & Roos V (2012). Psychosocial experiences of coloured grandmothers who care for their grandchildren: Implications for intergenerational relations. Paper presented at the 30th International Congress of Psychology, 22–27–July, Cape Town.
- Hobfoll SE (1989). Conservation of resources. A new attempt at conceptualizing stress. *The American Psychologist*, 44, 513–524. doi:10.1037/0003-066X.44.3.513 [PubMed: 2648906]
- Joint United Nations Programme on HIV/AIDS (2016). Fact Sheet November 2016. Retrieved from http://www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_en.pdf
- Kasedde S, Doyle AM, Seeley JA, & Ross DA (2014). They are not always a burden: Older people and child fostering in Uganda during the HIV epidemic. *Social Science Medicine*, 113, 161–168. doi: 10.1016/j.socscimed.2014.05.002 [PubMed: 24880658]
- M. CM (1998). Health, stress, coping, and social support in grandmother caregivers. *Health Care for Women International*, 19, 441–455. doi:10.1080/073993398246205 [PubMed: 9849191]
- MacNeil JM (1996). Use of culture care theory with Baganda women as AIDS caregivers. *Journal of Transcultural Nursing*, 7, 14. doi:10.1177/104365969600700204 [PubMed: 8974412]

- Merli M,G, & Palloni A (2006). The HIV/AIDS epidemic, kin relations, living arrangements and the African elderly in South Africa In Cohen B & Menken J (Eds.), *Aging in sub-Saharan Africa: Recommendations for furthering research* (pp. 4–1, 4–50). Washington, DC: National Academies Press.
- Miltenberger P, Hayslip B, Harris B, & Kaminski P (2004). Perceptions of the losses experienced by custodial grandfathers. *Omega - Journal of Death and Dying*, 48, 245–262. doi:10.2190/ARUD-1PJD-MBJY-N76N
- Rutakumwa R, Zalwango F, Richards E, & Seeley J (2015). Exploring the care relationship between grandparents/older carers and children infected with HIV in south-western Uganda: Implications for care for both the children and their older carers. *International Journal of Environmental Research and Public Health*, 12, 2120–2134. doi:10.3390/ijerph120202120 [PubMed: 25689350]
- Sanders S, Morano C, & Corley CS (2003). The expression of loss and grief among male caregivers of individuals with Alzheimer disease. *Journal of Gerontological Social Work*, 39, 3–18. doi:10.1300/J083v39n04_02
- Seeley J (2014). *HIV and East Africa: Thirty years in the shadow of an epidemic*. Abingdon-on-Thomas, UK: Routledge.
- Shives LR (2008). *Psychiatric-mental health nursing* (7th ed.). Philadelphia: Lippincott, Williams & Wilkins.
- Strauss A, & Corbin J (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.

TABLE 1.Demographic characteristics of study participants ($N=32$).

	Characteristics	<i>n</i> (%)
Gender	Women	27 (84.4)
	Men	5 (15.6)
Age in years (mean: 63.13):	50–59	14 (43.8)
	60–69	9 (28.1)
	70–79	5 (15.6)
	80–89	3 (9.4)
	90–99	1 (3.1)
Marital status	Married	9 (28.1)
	Monogamous	6 (66.7)
	Polygamous	3 (33.3)
	Divorced or separated	5 (15.6)
	Widowed	18 (56.3)
Level of education	Primary School	9 (28.1)
	Secondary School	1 (3.1)
	No education	22 (68.8)
Employment	Self employed	4 (12.5)
	Day laborer	12 (37.5)
	No employment	16 (50)
Setting	Rural	12 (37.5)
	Urban	20 (62.5)