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Authors

Matovu, Schola

Dawson-Rose, Carol

Weiss, Sandra

et al.

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“Thoughts Can Kill You”: Characterization of Mental Health Symptoms by Ugandan Grandparent–Caregivers in the HIV/AIDS Era

Schola Matovu, PhD, RN^a, Carol Dawson-Rose, PhD, RN, FAAN^b, Sandra Weiss, PhD, RN, FAAN^b, and Margaret Wallhagen, PhD, RN, GNP-BC, AGSF, FGSA FAAN^a

^aDepartment of Physiological Nursing, School of Nursing, University of California–San Francisco, San Francisco, California, USA

^bDepartment of Community Health Systems, University of California–San Francisco, San Francisco, California, USA

Abstract

Studies of caregiving provided to HIV/AIDS orphans by sub-Saharan African grandparents have found that it has physical, financial, and emotional consequences. Our study extended this research by identifying and characterizing the symptoms experienced by Ugandan grandparent–caregivers, particularly as related to the caregiving role, loss and grief. Grounded theory methodology was used to conduct and analyze audio-recorded, semi-structured interviews with 32 grandparents. Findings revealed a cluster of biopsychosocial distress symptoms, especially anguish (driven by traumatic anxiety and disbelief), depression, and somatic symptoms that were linked primarily to psychological distress. The impact of cultural practices and beliefs on these symptoms was also identified. Results have implications for public health, research, and policy changes needed to alleviate symptoms of biopsychosocial distress among Uganda grandparent-caregivers.

Background and significance

Caring for a loved one may be stressful and could have adverse health outcomes for the caregiver. The experience of caring, or caregiving, has been studied in many contexts, but primarily in relation to the stress experienced when the caregiver and care recipient are either of the same generation or only a single generation apart (Chou, 2000; Davidhizar, Bechtel, & Woodring, 2000; DesRoches et al., 2002; Grinstead, Leder, Jensen, & Bond, 2003). However, the HIV/AIDS pandemic has focused attention on a significant group of caregivers—grandparents—caring for orphaned grandchildren who themselves may be infected with HIV (Drah, 2014; Grobler & Roos, 2012; Kanya & Poindexter, 2009; Ssengonzi, 2009). Although the financial and physical burden of this caregiving has been

CONTACT Schola Matovu, Schola.Matovu@ucsf.edu, Department of Physiological Nursing, School of Nursing, University of California–San Francisco, 2 Koret Way, San Francisco, California 94143, USA.

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moderately explored in the existing literature, health outcomes, particularly those related to mental health, remain understudied in sub-Saharan Africa.

Mental disorders account for 10% of the assessed disease burden in sub-Saharan Africa, and yet countries in this low-resourced region lack comprehensive legislation as well as the financial capability and workforce capacity to promote the mental health of their vulnerable populations (World Health Organization [WHO] & Columbia University, 2016). According to the 2006 *WHO-AIMS¹ Report on Mental Health in Uganda*, Uganda's Ministry of Health allocated only 1% of its national health care expenditure to mental health, and most of this expenditure was for treatment of psychiatric disorders (WHO, 2006). Consequently, the presumably less obvious and elusive symptoms of other mental health problems associated with the caregiving role, such as depression and anxiety, often go undetected. In addition, the insufficient to non-existent resources dedicated to research that promotes mental health in this setting further limit our understanding of culturally nuanced manifestations of mental health disorders and their respective etiologies.

The WHO (2014) has defined *mental health* as “a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community” (para. 1). Based on that definition alone, it is clear that the majority of individuals in sub-Saharan Africa—who are born, live, and age in poverty-stricken environments with numerous socioeconomic disparities—are at high risk for chronic poor mental health. A search of the literature on mental health and overall psychosocial well-being of older grandparent-caregivers in the sub-Saharan African region yielded very few studies.

A limited number of studies have investigated the mental health of adult caregivers younger than 50 years of age (Abasiubong, Emem, Olawale, & Udobang, 2011; Skeen, Tomlinson, Macedo, Croome, & Sherr, 2014) or other samples that comprised both young and older caregivers (Kagotho & Ssewamala, 2012; Kuo, Operario, & Cluver, 2012). These studies have revealed evidence of varying levels of stress, depression, and suicidal ideations, among other mental health problems. However, studies focusing exclusively on the mental health of older adults (50 years of age or older) are limited. The paucity of knowledge for this sub-Saharan African older adult age group contrasts markedly with the wealth of knowledge in western countries that have studied this population more comprehensively (Hayslip & Kaminski, 2005; Kelley, Whitley, Sipe, & Yorker, 2000; Musil, Warner, Zauszniewski, Wykle, & Standing, 2009; Winston, 2003).

Some of the Western studies reported that HIV/AIDS intensified the experience of stigmatization, isolation, and shame among caregivers of people living with the disease (Winston, 2003). However, out of various debilitating mental disorders, depression in particular has been reported to cause a great burden on older adults, especially those who are caregivers to family members (McKinney, Oh, & Sibille, 2012; Musil et al., 2009; Prina, Deeg, Brayne, Beekman, & Huisman, 2012). Data compiled by the WHO reinforce the

¹Assessment Instrument for Mental Health Systems.

impact of depression as the leading cause of disability globally (WHO & Columbia University, 2016).

A few Ugandan studies have investigated depression in the general population (Johnson, Mayanja, Bangirana, & Kizito, 2009; Okello & Musisi, 2006; Okello & Neema, 2007) but not specifically among grandparent-caregivers. Johnson et al. (2009) interviewed a young Ugandan cohort (18–29 years) to explore diverse views on the etiology, sociocultural meanings, and medical treatment of depression. Their study, along with Okello and Neema (2007), are among the few studies that highlighted the importance of acknowledging and exploring diverse explanatory models in understanding mental disorders such as depression in this setting. However, a significant gap in knowledge remains in the general understanding of mental health as a state of well-being in sub-Saharan Africa, particularly in Uganda. In particular, there is a critical need for culturally grounded research to understand the mental health challenges faced by older caregivers of children affected by HIV/AIDS. Our study attempted to address this gap. Results from such studies may contribute to the research on caregiving and also underpin the development of programs that may enhance the psychosocial well-being in this population.

Methods

Design and objective

The present qualitative study used grounded theory methodology (Charmaz, 2006; Strauss & Corbin, 1990). The overarching objective of our study was to gain an understanding of the caregiving experiences and mental health of Ugandan grandparents, 50 years of age and older, who provide primary care for their grandchildren affected by HIV/AIDS. However, the purpose of the analysis described in this manuscript was to characterize the mental health symptoms experienced by our participants, particularly those related to the caregiving role, loss, and grief.

Sample, recruitment, and setting

To be eligible for participation in the study, individuals had to be (a) 50 years of age or older, (b) grandparents who had cared for children affected by HIV/AIDS for at least 6 months, and (c) Luganda-speaking (commonly spoken in Uganda and the primary investigator's native language). Also refer to Table 1 for other participant demographic characteristics. In order 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. These settings included regions that, historically, have been the most affected by the HIV/AIDS epidemic.

As described in our prior publication (Matovu & Wallhagen, 2018), we initially approached local elected government officials and informed them of the purpose of the study. These leaders then informed potential participants about the study and gave interested grandparents information on how to contact the primary investigator for eligibility screening. To avoid potential coercion, none of the participants were directly approached by the primary investigator about participating in the study.

Procedures

Data collection—Research approval was obtained from the Institutional Review Board of the University of California–San Francisco Committee on Human Research, the Makerere University College of Health Sciences, and the Uganda National Council for Science and Technology. Data were collected using semi-structured, in-person interviews, each lasting 60–90 min. To detect symptoms suggestive of poor mental health and/or psychosocial well-being and to optimize assessment of sociocultural factors underlying an individual’s symptom experience, the Cultural Formulation Interview (CFI) of the *Diagnostic and Statistical Manual of Mental Disorders* (APA, 2013) was used to inform the initial interview guide. Consistent with grounded theory methodology (Charmaz, 2006; Strauss & Corbin, 1990), the interview guide evolved throughout the data collection process to include new categories.

To illustrate, when participants were initially asked to “Describe what your experience has been like as a result of losing multiple children to AIDS,” some participants could not describe their experiences beyond “it feels badly” or responses such as “I am having a lot of thoughts.” To further unravel the meaning of these brief descriptions, the primary investigator prompted participants with follow-up questions for them to relate the “bad feeling” experienced with common illnesses such as malaria and asked them how they would differentiate those related to the loss experience. Additional prompts such as “Tell me more” or “Repeat back” were also used to allow for clear elucidation of the nature and impact of their “thoughts.” A combination of these interview techniques gave participants an expressive breakthrough with their descriptions that revealed themes related to their concerns and sadness about losing valuable relationships; worries about how they would continue supporting their families without resources; and disbelief at having lost almost all their children. These emerging themes were then used in posing additional interview questions to explore the emergent salient categories such as *Social support* that collectively informed the developing substantive theory that explained the overall caregiving and symptom experiences.

Data were collected via audio recording of interviews. The primary investigator (first author) made careful observations of events, interactions, and participant non-verbal cues during the interview sessions and took elaborate field notes, some of which were transcribed for later analysis and/or memoing (Charmaz, 2006; Strauss & Corbin, 1990). Thirty-two one-time interviews and three follow-up interviews were obtained, translated, and transcribed by the primary investigator, who is fluent in Luganda and possesses “the linguistic competence and [...] knowledge of the people under study,” (Birbili, 2000). Finally, when the study’s overall objective was achieved and there was no further emergence of new salient categories and subcategories—a point of theoretical saturation (Glaser & Strauss, 1967; Strauss & Corbin, 1990)—data collection was concluded.

Data analysis—Audio interviews were transcribed and entered into Atlas-Ti software, which manages qualitative data analysis. Consistent with grounded theory methods, transcribed narratives were read line-by-line, followed by initial, focused, and axial coding performed to deconstruct the data and identify salient “codes”—clusters or units of meaning

that represent the participant's reality (Charmaz, 2006; Strauss & Corbin, 1990). Through constant comparison (Charmaz, 2006) between and within new and previous interviews, salient codes were identified by their frequent occurrence in the narratives.

Subcategories, categories, complex concepts, and transcribed fieldnotes were further developed and enriched using reflexive and analytic "memoing" to (a) enable the researcher's self-reflection on the emerging categories, participants, and/or social worlds, and (b) pose "questions, musings or speculations" (Creswell, 2007, p. 290). Transcribed fieldnotes of observations made during data collection, such as crying or silence, were also coded, analyzed, and later used to inform the emerging subcategories, categories, and explanatory model. These analytic procedures were all performed following non-linear or non-sequential and iterative or systematic and repetitive steps, to detect new themes emerging from the data (Charmaz, 2006; Strauss & Corbin, 1990).

In addition, we ensured rigor by utilizing a combination of methodological approaches that included theoretical sensitivity, saturation, triangulation, memoing, and reflexivity, as described by Charmaz (2006) and Strauss and Corbin (1990). For instance, we used data triangulation by recruiting from both rural and urban settings to compare participants' experiences; and ensured theoretical sensitivity by carefully examining each interview for new and salient emerging themes before deciding to end data collection when saturation was achieved. Although the primary investigator performed the initial analysis, a team of four senior researchers, and a writing group of doctoral students further analyzed the data to ensure methodological rigor.

Findings

This study was not focused on identifying the presence of mental illness but rather to qualitatively characterize mental health symptoms as reported by the participants. Results revealed specific psychological and physical symptoms experienced by caregivers as well as antecedents or causative factors underlying these symptoms as reported by participants. We begin by providing a brief overview of these antecedents, although symptoms are the primary focus of our results.

Antecedents

Findings revealed two key antecedents that underpinned the participants' mental health symptom experience: (a) perceived caregiver burden related to chronic social and economic challenges; and (b) losses—such as death or disappearance of adult children, spouses, and other family members and the depletion of tangible resources—as well as the subsequent experiences of grief and bereavement.

Perceived caregiver burden—Central to the cumulative stressful events and demands perceived by our study participants was caregiver burden. As a result of multiple factors that include HIV-related or other death or disappearance of adult children, grandparents had to take an active role in the physical, financial, and emotional well-being of their grandchildren. The majority of participants were most worried about how to cope with the burden of caring for grandchildren without the resources and social network necessary for

fulfilling this duty. Additionally, many of these grandparents reported emotional distress that was magnified by multiple other factors, including (a) their orphaned grandchildren being infected with HIV, (b) their grandchildren's disrespectful or uncooperative behavior, (c) a lack of financial resources to maintain a household and to provide for the family's basic needs (e.g., education and health care expenses), (d) disputes with family members, and (e) other socioeconomic stressors (e.g., unemployment, lack of education, exposure to traumatic civil wars, and displacement due to those wars).

Loss, grieving, and bereavement—Researchers such as Zisook and Shear (2009) have deduced that *grief* is the “emotional, cognitive, functional and behavioral response” to *bereavement*, or “the fact of loss” experienced after the death of a loved one (p. 67). The majority of the study participants had lost adult children or spouses in the distant past, while others reported losses within months, weeks, and even days of the interview. Despite the passage of time, these grandparents, especially those who had experienced multiple losses, described both immediate and chronic responses to their grief.

The grandparents described *anticipatory* grief as they nursed their loved ones through often extended periods of illnesses to the final stages of death. This finding supports those of Winston (2003) who reported on the experiences of anticipatory grief among grandmothers who had to cope with their adult children's illnesses and those who endured additional and similar experiences with their grandchildren being infected with HIV. Following the anticipatory grief, they noted *acute* grief characterized by intensive psychological pain in the early aftermath of the loss of their loved ones (Zisook & Shear, 2009). In addition or subsequent to distress caused by devastating loss to death, grandparent—caregivers also described non-death-related dimensions of loss, such as forfeiture of property, as reported in our prior publication (Matovu & Wallhagen, 2018). Overall, although loss seemed more devastating than caregiver burden as causes of distress, both varied in magnitude and elicited a continuum of similar psychological and associated physical symptoms of distress.

Characterization of mental health symptoms

Psychological symptoms

Based on the antecedents of mental health symptoms discussed above, participants reported two primary psychological symptoms. First, participants recounted visceral reactions of anguish and traumatic anxiety in the acute stages of grief in response to the death of their adult children. Their narratives contained vivid details of the intensity and persistent nature of this anguish—a testament to the traumatic impact of these losses on their well-being:

I took him [son] into the hospital myself.... [O]ne hand was supporting him so he wouldn't fall and the other hand held my cane to support me [H]e abruptly popped up in bed and almost fell off the bed I quickly grabbed him mid-air and he right away died in my arms So, I tried to call out for help and the *basawo* [medical personnel] came in and helped me straighten him up in the bed and turned to me and asked, “so what can we wrap him in?” I took off my *gomesi* [traditional dress] and gave it to them So they wrapped him up. I walked home like a mad

woman; I couldn't even find my way back home That was five years ago He was about 40 years old. (1Mask)

Additionally, participants reported feelings of disbelief at having lost almost all their children, which was described by some as losing their children "completely":

The thoughts were mainly about completely losing all my family. All my children that would have otherwise helped me out are completely gone! I remained with no one to help me or to run to. So those were the thoughts that consumed me. (7Bus)

Other participants reported constant worrying or "thinking a lot":

You think of how they all went ... all your children! You think about the diseases that took them and the way that they died. And so that is what you think about until you can't think any more. I think a lot. (1Mask)

I was very hurt because losing that many children was such a tragedy! I still feel the same way today. The hurt does not end at the funeral but it continues and the thoughts are quite many! (1Bus)

For grandparents who had lost multiple children or family members, the recurring traumatic losses seemed to be much more detrimental, especially in cases in which these losses occurred in close proximity: "I had a lot of thoughts especially after losing five people in only one year! Three brothers, my daughter and my husband died, all in one year!" (7Bus).

Likely, the recurrent grief and bereavement that these caregivers reported could lead to unresolved grief and other subsequent disorders, such as persistent complex bereavement disorder. The American Psychological Association (APA) characterizes persistent complex bereavement disorder as a frequent experience of significantly severe grief that is unresolved at least 12 months after death of a loved one or beyond cultural norms of grief responses (APA, 2017). Customarily, the bereavement process is a shared experience among the Baganda that starts with days of mourning as family and neighbors view the deceased's body and perform cultural and religious rituals such as choosing the heir to the lost loved one and praying (Seeley, 2014). However, the social network to provide such emotional and financial support and fulfill these cultural ceremonies was not readily available, with implications for persistence or worsening of their mental health symptoms related to unresolved grief.

As evidenced by our participants' responses, depressive symptoms were also prominent. For example,

[T]here was a year I got a lot of sadness.... My heart started getting weak and I wanted to kill myself and get out of this world. I didn't have anyone to assist me. There was no food at home, no money; I wanted the children to go to school ... so many things. We all looked terrible in the home. I went to one of the ladies in the village crying and she got up and gave me a bar of soap and said, "You need to go home and clean up because you look so bad." I was tired of everything and all the heart was telling me was to die. I asked myself what I did in this world not to have anyone to help me out. [Silent]. (2Luw)*

Besides exhibiting suicidal thoughts, participant 2Luw* also revealed that two of her adult children and one of her grandchildren had mental illnesses with cognitive disabilities. This evident family history of mental illness, along with the possible biological or genetic implications, supports the argument that in the presence of social, environmental, or physiological stressors, grandparent 2Luw* could be at even greater risk for significant mental health problems.

Overall, participants expressed an emotional state of general unhappiness, hopelessness, feeling overwhelmed with responsibility and emotions, irritability, regret, denial, anger, disappointment, and frequent crying that is consistent with depressive symptoms. It is well recognized that cumulative and chronic stress, if not well-managed, can lead to mental illnesses such as depression and anxiety (APA, 2017). Although the current study did not aim to identify mental illnesses per se, many participants reported symptoms related to depression, psychological distress, anxiety, and even post-traumatic stress disorder as characterized in DSM-5 (APA, 2013).

Informed by the Cultural Formulation Interview of the DSM IV (APA, 2013), probes were initially used to ascertain the participants' cultural perspectives on the meaning, cause, and symptoms of perceived loss-related and other cultural concepts of their perceived distress. The majority of grandparents understood that the experience of grief was a normal response to loss. However, some were further distressed by the belief that their families' misfortune, suffering, and loss were due to witchcraft that was cast onto them by disgruntled relatives or neighbors:

He [son] was [bewitched] by his auntie who did something wrong to him and so he got really [mentally ill] I believe she took his cloth and did something with it that caused him to become [mentally ill]. I don't know what she did with the cloth but it looks like she took it to a gravesite. This problem [spell] is really in the family ... my entire family is destroyed without any kind of progress. My [co-wife] also started bewitching me and so I was in a lot of pain and fear for my life.
(4Luw)*

While for some grandparent–caregivers, these beliefs exacerbated distress, these traditional practices also offered an alternative and causative explanation of illness and death—an explanation that allowed them to cope with their losses and other hardships. Without access to mental health services, some participants resort to seeking advice and treatment from traditional healers:

At times I go to someone [traditional healer] who might give me advice on what is going on, or herbs, you know, to stop the illness. Sometimes the thoughts decrease and I feel better after knowing what is going on, other times you can't do anything about it. (20Luw)

As illustrated by participant 20Luw, this indigenous belief system may seem to promote help-seeking behavior. Okello and Musisi (2006) corroborated that these beliefs offer culturally appropriate explanatory models of mental disorders otherwise described as *eByekika*—that is, clan illnesses—among the Baganda tribe to which the majority of the current study participants belonged. However, Johnson et al. (2009) have conceptualized

these clan illnesses as psychotic depression and related “illnesses of thought” linked to unipolar depression.

Physical symptoms

In addition to the psychological symptoms described above, grandparent–caregivers frequently reported physical symptoms that included cardiac symptoms described as heart palpitations or irregular heart rate, shortness of breath, muscular and skeletal pains, and gastrointestinal symptoms such as peptic ulcers. For instance, when prompted to describe the meaning, intensity, or location of physical symptoms, participants made statements such as:

My heart beats a lot as if I am startled and I get very weak. It’s been now three years and it would beat so fast that in the middle of a conversation with someone, I can’t even talk at some moments and instead make gestures At times I tend to suddenly get startled without any reason and then start feeling a throbbing in my chest. Just like you react to a caterpillar and jump suddenly, then I start feeling the throbbing in the chest. m(27Luw)*

I frequently get a feeling as if a *huge insect* enters here [gestures towards mid-chest] and then it spreads and I get the cough. It does go away and then return ... but it is different each time. Other times I hear as if someone is walking behind me but when I look back, there isn’t anyone there. It is like hearing your heart beating in your ears. (4Kit)

Additionally, participants reported somatizations, such as chills, general body weakness and aches, insomnia, and loss of appetite. Considering that most of the grandparents had never been clinically diagnosed with the reported physical symptoms and had limited-to-no health literacy, they generally related these physical symptoms to either poor aging and/or other comorbidities. Strikingly, however, they also perceived the symptoms as caused by psychological distress:

Actually, I do have a heart problem ... I think it was caused by my child’s death. I was really affected and my heart started beating very fast. I constantly feel that way. (2Mask)

It is very hard because you can’t sleep and can’t eat. You think about the one that died first, the one that died second, and the third, up to the fifth. How can you sleep? Losing a child is the worst thing that could happen to you. So you stay up all night until dawn.... You know how it is with us old people; we can’t sleep anyway so all you do is think about all those children that you have lost and stay in constant pain. You can’t forget the first one that died years ago just because it has been a while ... [Y]ou remember all of them as vividly. Or you are reminded by pictures or their stored personal items. (1Kit)

Ultimately, although our study participants did not explicitly characterize their mental health symptoms as “illness” or “disease,” they understood the impact of this magnitude of distress on their overall health, as explained by participant 1Kit:

You have no peace left but are strengthened by those who are still with you. And if you don’t have anyone, you die prematurely; the thoughts can kill you. You can see

one losing weight and yet they deny being sick but those thoughts can kill you. Someone could worry so much and become as thin as a stick without any apparent problems but all due to that worry.

Discussion

Findings of this study revealed that the symptom experience reported by the grandparent–caregivers was biopsychosocial in nature. Admittedly, some participants may have had certain chronic comorbidities rather than any clear association between their psychological and physical symptoms. However, for most participants, the perceived association between their mental and physical symptoms is a unique finding that has not been previously reported in the existing grandparent-caregiving research in Uganda. Nonetheless, it has been extensively studied in Western caregiving (Minkler, Roe, & Price, 1992; Musil et al., 2009; Whitley & Fuller-Thomson, 2018) and other chronic stress-related literature (Glaser, Sheridan, Malarkey, MacCallum, & Kiecolt-Glaser, 2000; Weiss, Haber, Horowitz, Stuart, & Wolfe, 2009).

As a case in point, researchers, such as McEwen and Stellar (1993), have indeed attributed physical illness such as arthritis, cardiovascular disease, diabetes, and other biologic and behavioral responses to psychological distress through a process of “allostatic load” (McEwen, 2003; McEwen & Stellar, 1993). Allostatic load has been defined by McEwen and Stellar as “the wear and tear on the body” that results from repeated, chronic stress. In the presence of social, environmental, or physiological stressors, the Hypothalamic–Pituitary–Adrenal Axis triggers a stress response that includes hyperactivity of the corticotropin releasing factor, which research indicates is a contributor to mental illnesses such as depression and anxiety (Keller et al., 2017; Kemeny, 2003). In addition, the sympathetic nervous system is triggered to produce hormones such as epinephrine from the adrenal medulla, which can lead to physiological responses such as increased blood pressure and blood glucose levels and decreased blood flow to the gastrointestinal system (Goldstein, 1987; Weiss et al., 2009). Thus, reported psychological and physical symptoms could potentially be related to the brain’s stress response system.

Additionally, conceptual definitions of the types of distress found in our study have been explored. For example, Ridner (2004) defined concepts that describe human response to illness or life challenges, including distress, psychological distress, biological distress, and stress. Ridner (2004) analyzed and defined *psychological distress* as a “unique discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary or permanent, to the person” and *biological distress* as “potentially harmful physiological changes that occur in the human body in response to a stressor” (p. 539). Ridner’s definition of general *distress* is a “non-specific, biological or emotional response to a demand or stressor that is harmful to the individual” (p. 539).

Although these delineations of the various forms of distress are critical to research, they fail to capture the complexity of their experiential coexistence. Furthermore, these conceptual definitions seem not to acknowledge the external “worlds” or social environments as

potentially contributing to the perceived mental and physical state of being. Based on the premises of symbolic interactionism (Blumer, 1969), a theory that underpinned our grounded theory study, it is crucial to emphasize the role of the external *social worlds* and how those may interact with an individual's cognitive faculties to determine physical and behavioral symptom manifestation. This is particularly critical to the better understanding of the nature, severity, and cultural experience of distress symptoms. These philosophical underpinnings further inform decisions on research methods and measurement tools that are needed to appropriately investigate and operationalize concepts and inform interventions. Therefore, considering that participants' characterization of distress was biopsychosocial in nature, we defined it as biopsychosocial distress, a symptom cluster continuum of unpleasant and potentially harmful physical and psychological responses to particular stressors or a combination of stressful life events or demands within their social environment.

Ultimately, the perceived biopsychosocial distress symptoms, if left untreated, could potentially exacerbate preexistent problems or trigger a myriad of new physical, neurologic, and mental health problems such as posttraumatic stress disorders, major depression, anxiety, persistent complex bereavement disorder, and other stressor-related disorders (APA, 2013). This risk is particularly high when the symptoms are chronic, especially as related to unresolved grief and/or recurrent forms of losses or if daily demands persist. Although our findings ultimately revealed a comprehensive characterization of biopsychosocial distress symptoms, more studies are needed for further exploration of the symptom experiences and related causative factors in this population. Such research is critical to the identification of effective coping strategies and interventions needed to diagnose and manage poor health outcomes among Ugandan grandparent-caregivers.

Limitations and strengths

Transferability of this study cannot be assumed because of the small sample size. In addition, we used a widely established snowball sampling technique (Wasserman & Faust, 1994) that may have increased the potential for certain sociodemographic characteristics not representative of all grandparents in that region or nationally. However, our study was strengthened by the thick descriptions of participants' symptom experiences that provided a deeper and broader understanding of the cultural and social factors underpinning the phenomenon. This approach was crucial in exploring the participants' experience and its impact on their biopsychosocial well-being and mental health, particularly in the sub-Saharan Africa setting where these topics are understudied and therefore poorly understood.

Conclusion

The grandparents interviewed for our study helped us to get a broad understanding of the mental and physical health implications of caring for grandchildren in the HIV/AIDS era. The dearth of knowledge identified in this study's literature review indicates that more research is needed to better understand the mental, physical, and psychosocial well-being of Ugandan grandparent-caregivers. The WHO's new comprehensive *Mental Health Action Plan 2013–2020* (WHO, 2013), which includes objectives on providing universal,

integrative, and responsive mental health and community-based social care services as well as increasing research in mental health, is a step in the right direction.

Our findings can be used to inform public health, research, policy, and multilateral initiatives and interventions. Such interventions can include family-centered care plans, childcare and respite care, and psychosocial interventions similar to crisis and grief counseling, public health initiatives—among other social services needed to improve the mental health and psychosocial well-being of these older adults. Additionally, tangible assistance with basic needs such as food and clothing is needed to alleviate ongoing social and economic stressors that create significant caregiver burden. Our findings also indicate that strengthening of social support networks within the grandparents' community is warranted. Additionally, professional guidance is recommended, such as therapy and other ongoing initiatives to promote coping behaviors to manage their emotions, to “let go” of their negative thoughts that may cause depression, or to find meaning in their new caregiving roles.

Where mental illness may be prevalent, caution should be exercised to avoid transplanting treatment modalities practiced in other cultures without the use of tools or approach modifications that are culturally sensitive and concordant. For instance, cultural relativism (Baghrarian & Carter, 2017) should be applied to (a) investigate normative ways in which loss and grief are manifested, (b) identify effective coping strategies needed to deal with loss and caregiver burden, and (c) find an effective balance between formal, traditional, and religious practices as they relate to general health and cultural experience of distress symptoms.

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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/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)