REFLECTIONS ON THE CHALLENGES FACED BY ELDERLY AFRICAN WOMEN IN CARING FOR THE ORPHANS LEFT BEHIND BY THEIR ADULT CHILDREN WHO DIED OF AIDS-RELATED ILLNESS.

Thozamile Qubuda (MPhil)
Cornelie Groenewald (DPhil)

Abstract

In South Africa, AIDS patients are increasingly cared for at home by women in their traditional role of family caregiver. The number of parents assuming care for their adult children infected with HIV and with AIDS-related illness is increasing and this affects parents negatively. The objectives of this study were for these elderly women to reflect on the challenges faced by them while caring for the orphans left behind by their adult children who have died of AIDS-related illnesses. A phenomenological orientation has been used, since the aim was to explore subjective meanings, experiences and interpretations. Lived experiences of 10 elderly African women, who were taking care of their grandchildren, were investigated. Carers struggled with the physical impact of this disease; there was a clear nexus between the carers' coping capacity and the PLWHAs' physical health. As the PLWHAs' health declined, carers' coping skills were put to the test.

Keywords: Caregiver; experiences; person living with HIV and AIDS; family; Gugulethu.

Introduction

The caregiver's role has changed - and physical and emotional preparation for the death of a loved one is no longer routine. Today, the focus and overall experience of informal caregiving has shifted, and there is a dearth of contemporary research on the experience and rewards of informal caregiving (Smith, 1996). In the third decade of the HIV and AIDS epidemic, the South African health care system still grapples with a disease that may exist for generations. HIV and AIDS remains a relevant issue for the fields of social science, health care and other human service fields. Since the beginning of the HIV and AIDS epidemic, informal caregiving has emerged as a critical component of the health delivery system for HIV-positive clients (London, et al., 2001). This study examined the reflections of elderly women to determine the challenges faced by them while caring for the orphans left behind by their adult children who have died of AIDS-related illness.

Methods

Hermeneutic phenomenology is an appropriate method for this research, enabling the phenomena of life's experiences to be structurally and systematically analysed, thereby allowing in-depth interpretation of these lived experiences. The aim is to '...construct an animating, evocative description in textual form of human actions, as we have met with them in the life-world' (van Manes, 1990, p. 19). The purpose of this form of research '...is to act as an advocate in progressing human life, by increasing its thoughtfulness and sensitivity to situations' (van Manes, 1990, p. 21).

On examining possible research methods, the main concern was to choose a methodology that would provide a framework within which the research question could be meaningfully addressed. The study adopted a qualitative research approach. Within this approach a phenomenological orientation was accepted since the objectives were to explore subjective meanings and experiences from the respondents' points of view.

Setting and participants

A convenience sample of isiXhosa-speaking elderly women over the age of 60 years, who were caring for
children and/or grandchildren as a result of HIV or AIDS, participated in this study. No detailed population statistics were available from which a probability sample could be drawn as the research was conducted in a setting with limited resources. I was unable to select a random probability sample due to the nature of the study and had to settle for a convenience sample with elderly women who were associated with a local non-governmental organisation and partner in the study in order to include as many older caregivers as possible. However, through a snowball effect, other elderly women in the community and friends of the non-governmental organisation became aware of the study and were interested in participating.

The women were also approached by community health workers and were invited to participate in the study, if they matched the inclusion criteria. As the community health workers, all employed by non-governmental organisations, had thorough knowledge of the area and were acquainted with the caregivers; they were able to approach all elderly women that were eligible to be interviewed. All of the participants had been involved in taking care of a relative living with HIV and AIDS and had been caring for children who had been orphaned by their parents' deaths.

Data collection
Data was collected by structured, in-depth, face-to-face interviews. The purpose of this approach was to elicit the participants' perspectives with as little probing as possible. This specificity assisted in (a) gaining further information, (b) testing preliminary findings, and (c) looking for commonalities and differences in the participants' stories (May, 1998). Interviews lasted approximately 45 minutes. Observational field notes (Lincoln and Cuba, 1985; Boyd, 1993) and theoretical memoranda and diagrams (Strauss and Corbin, 1990) were also used during data collection to ensure a more accurate and thorough recollection of the circumstances surrounding the interview and participants' experience.

Data analysis
To analyse the rich wealth of data generated by the in-depth interviews, however, it was necessary for the researcher, being inexperienced in phenomenological analysis, to follow a set of guidelines. These guidelines were provided by Hyrner (1985) and Giorgi (2005) who felt a need existed to provide guidelines to researchers who did not have enough philosophical background to know what "being true to the phenomenon" meant in relation to concrete research methods (Hycner, 1985:280).

Constant-comparative analysis (Strauss and Corbin, 1990; Cherlin, 1983), a process of constantly comparing the data for similarities and differences, guided data analysis, thus capturing all potentially relevant aspects of the data as soon as they were received. Transcription and analysis of the interviews began immediately following the first interview and were preceded by analysing the transcribed interviews line by line, highlighting important ideas and themes. Each theme was coded and recoded using Ethnographic computer programme (Seidel, 2008).

Ethical Considerations
The study was submitted for ethical review by the Research Ethics Committee: Human Research (HUMANIORA), Stellenbosch University. Participation was completely voluntary and the anonymity of the participants was ensured. The participants were informed of their right to withdraw from the study at any stage. All of the participants signed a consent form before they were interviewed, stating that they were participating willingly and gave permission for the use of the information for publications and for audio-recording of the interviews. The information given by the participants during the interviews was treated as confidential and the anonymity of the participants was a priority. All of the personal details were removed from the transcriptions. The recordings, transcriptions and notes of the interviews were locked away in the offices and electronic copies were saved on a password-protected computer.

Results and discussion
(NB: All names are pseudonyms)
Through the process of interpretative analysis three main themes arose. These themes were (1) Challenges experienced by elderly African women in caring for AIDS-orphaned grandchildren, (2) Grief responses and coping strategies, and (3) Support systems available to assist elderly African women caregivers in caring for AIDS orphans.
The challenges experienced by elderly women
Most participating elderly women experienced stress relating to caring for their grandchildren, which specifically included unexpected pressure (for example, financial constraints) and transitional problems of becoming primary caregivers (for example, child management problems). These stressors impacted directly on the grandmothers’ own emotional needs. The major challenges facing these grandmothers in their caregiving role will be discussed.

Unemployment makes it difficult to provide care
Mrs Bethiwe, a 65 year old female caregiver, had these comments:

“i have been asking my granddaughter to look for a job so as to assist me, the financial burden was becoming too much, she refuse to leave school, and i just keep quiet.”

The difficulties induced by poverty proved to be a major challenge to most elderly women, exacerbating their struggle to send their grandchildren to school. This is consistent with Nyamukapa and Gregson’s (2005) study which found markedly low primary school completion rates among children in Zimbabwe who had lost their parents.

Difficulties in accessing governmental child grant
The study further reveals that all of the elderly women complained about lack of access to government social grants. For most of these elderly women ignorance was a major problem. Some grandmothers were not even aware of the existence of government assistance that could be obtained through the Department of Social Development. This ignorance seemed to be as a result of the lack of dissemination of information to these elderly caregivers. Many of them did not possess radios, let alone televisions, and, for those who knew about the availability of government assistance, corruption and bribery hindered their efforts to obtain assistance. The latter group complained that the officials responsible for the distribution of these funds often put their own relatives first, even if they were not eligible for funding. This was best described by a67-year-old female caregiver, Mrs Nanthi, when she said

“My son, there is a lot of corruption in this government, people benefit only by knowing someone in the government; we poor people have nowhere to go but just [have] to wait.”

In addition to the above, a further problem related to delays in accessing government child grants arose for those who were on the lists. Some participants hinted that they would spend days visiting the Department of Social Development offices in vain, only to be told that their funds had not yet been cleared, or simply that their files had gone missing. The repeated visits ended up depleting the little funds they had for taxi fare often forcing them to abandon their requests for social grants. For those with missing files, no clear explanation was provided and. most probably because of a lack of knowledge regarding legal procedures to challenge the situation, most elderly women would not and could not take any further action.

Another problem experienced by these elderly women was the absence of birth certificates for the orphaned grandchildren. Elderly women often found it difficult to register the orphans for assistance without such crucial certificates, and obtaining a birth certificate, when no supporting documents were available entailed finding witnesses to prove a biological connection with the orphans. To make matters worse, in most cases contact had been lost with the orphans’ fathers after the death of the wife. Often, as explained by the participants, there was no contact between the in-laws after parental deaths.

Physical constraints
Most grandmother-caregivers reported experiencing health problems, either from re-parenting at an old age or because of the stress suffered as a result of losing a child or children to AIDS. This is consistent with Olshovski et al.’s (1999) finding that, owing to the stress of caregiving, elderly women’s health risks may increase to a level higher than those dictated by age alone. A 60 year-old female caregiver (Mrs Lulama’s) reflected on her difficulties and revealed how her health had deteriorated due to caring for her orphaned grandchildren:

“My whole body aches, especially on the knees and the back, it’s sometimes difficult to lift heavy objects.”
This highlighted physical exhaustion as a challenge among elderly caregivers because their bodies were no longer resilient. Other complaints relating to physical constraints included the experience of pain in the side due to the hard work involved in catering to the orphans’ needs, while for some visual and hearing impairments were the highest concern. Two of the participants had difficulty in hearing and during the interviews I had to raise my voice in order for them to understand what I was saying. As mentioned earlier, one participant relied on her orphaned grandchild, without whose assistance she would not be able to cope, since her vision was badly impaired. On the day of our interview, this elderly woman had received word that the paternal grandmother of her orphaned grandchild had passed away.

Lack of support from extended families
The majority of maternal grandmothers were confronted by a lack of support from the extended families of the orphans of whom they were taking care. A 64 year-old female caregiver (Mrs Bonke’s) had this to say:

“The father of this child is not supporting him, we haven’t heard from him and his family, they did not even come to the funeral of my daughter to pay their last respects and now rumour says that he is also very sick.”

The lack of contact between the two families often left the elderly women with no one to turn to for assistance. To worsen matters, the whereabouts of some of the orphans’ fathers were not known. This aggravated the elderly women’s situation as they had no one to turn to in times of crisis, for instance in endeavouring to obtain birth certificates for the orphans.

Another challenge faced by the elderly women was that of the children adjusting to a new life. For most participants it remained a big challenge to bond with the orphans who had grown up with their biological parents. A 60 year-old female caregiver (Mrs Wongani who was HIV positive) asked:

“How will they care for themselves when I am gone? There is no one to look after them when I am gone, my husband died long ago, I am unable to give them everything as their parents did?”

In such instances, elderly women found it especially difficult to cope with their role as caregivers. Participants stated that some of these orphaned grandchildren found it difficult to perform some household duties to help their grandparents. The elderly women, however, had to ensure that their grandchildren adjusted to their new circumstances.

Depletion of resources
Resources were also a major problem faced by these elderly women. Most of the food available was not good for people living with HIV and AIDS.

A 64-year-old female caregiver (Mrs Phethani) stated:

“I have sold everything I have including my chickens and few goats back at home in the Eastern Cape, I have nothing left, and I am just living on hand-outs from my neighbours.”

Few of the elderly women possessed livestock and so most of the households were poverty stricken. Therefore caring for their ill children worsened the situation and the subsequent care of their orphaned grandchildren compounded the problem. As noted previously, drought worsens the legacy.

Additionally, and as noted by Matshaleta (2004), one of the biggest identified problems was the dietary needs of HIV patients. When these patients are discharged from hospital, a special diet is usually recommended, which contains a list of preferred food items whose nutritional value, according to the hospital staff, will assist the patient in the recovery process.

Grief responses and coping strategies
Grief and trauma
Elderly caregivers experienced considerable distress, due in no small part to having lost one or more adult children to HIV and AIDS. Many of the elderly women told personal stories about hardship, sorrow and the determination to make life bearable for themselves and the orphans in their care. They spoke of their difficulties in coping with the emotional toll of HIV and AIDS, and said talking about the feelings caused by the loss of their children was like “opening an old wound”.

52
These and other personal testimonies lent a powerful context to the pain felt by older caregivers, emotional stress that is exacerbated by poverty, fear for the future and the overwhelming burden of caring for the many orphans and vulnerable children (OVC) who join the households. Mrs Bethiwe had these comments:

“...The first one to die was his brother, later followed by his sisters. I nursed all my children when they were sick, all three of them (she cried and the interviewer allowed her to vent). This sickness kills a person horribly; it sucks all his blood out. I was so hurt, I nearly died. I had some terrible pains on the back of my neck, but I managed to come out of that and called upon God to carry me. I cried my heart out— I had to cry.”

Mrs Mokwena also expressed the pain of caring for her late children, her HIV grandson and her immunocompromised granddaughter through the following quote:

“[After burying these children] I was sick because I nursed them throughout their illness until I realised that there is nothing that I can do. I took Tumi (her grandson) to the doctor because he was ill, he is HIV positive. I make sure that every month I take this child to the doctor. I hope they find a cure for AIDS soon. Tumi and this other girl (her granddaughter) are very weak and they are a bit slow. I think this girl might be infected by the virus as well.”

Grandparents battling their own grief and trauma are faced with the difficult task of providing psychosocial support to the grief-stricken OVCs who join the household. A study conducted by Ciacherty (2008) on children living with grandmothers in north western Tanzania, found that most of the children who participated in the study had lost both parents. A 65-year-old female caregiver (Mrs Moni) made this observation:

“Each morning revives sad memories and the reality of your losses and burdens, and to face the poor orphans, how emotionally draining it is.”

This quotation by a participant best described the extent to which a bereaved mother can be affected in terms of grieving for a deceased child and it was found to be a common scenario in most households.

In this regard, religion plays an important role and can be a significant source of support for the family (Mayers, 2002).

**Despair and grief**

A 64-year-old female caregiver (Mrs Phethani) remarked,

“I do not know why he has left his children to me; I have no strength and money to look after these orphans.”

These words can best describe how Mrs Phethani felt at the time of the interview, even though her son had died some time ago. Mrs Phethani found the questions extremely painful to answer and, upon entering her gate, she would begin sobbing because these questions about her late children opened up her wounds afresh. This actually made my research journey difficult as I evoked sorrowful emotions in some grandmothers by intruding in sensitive areas of their lives. Mrs Phethani lamented the deaths of her children and stated that every time the orphans return from school, tears roll down her cheeks, because she wonders why their parents died, leaving the children to struggle in her care.

**Risk of being infected**

Since most of the participating elderly women provide the care for their terminally ill children, they raised concerns about the possibility of themselves being infected with HIV. In addition, some of the grandchildren in their care were infected. The idea of putting on gloves as a safety measure was not understood or accepted by most of these elderly women. These precautionary measures were viewed as a sign of shunning or discriminating against the sick members of the family. Further, even if these elderly women accepted the implementation of these precautionary measures, gloves were not easily available, and, when they were available they too expensive for everyday use.

In cases where elderly women were not sure of the child or children's HIV status, having these children tested was usually perceived as unacceptable. A further obstacle experienced by elderly women was how to administer the ARVs due to the time compliance.
Support systems available to assist elderly women-caregivers in caring for orphans due to AIDS

Available support systems
As indicated by previous investigations (see Matshalaga, 2004; Winston, 2006), a growing concern raised by participating elderly women was how to meet the financial needs of the children in their care. This responsibility became overwhelming if there was more than one grandchild to rear. These elderly women indicated a need for education and assistance in identifying additional sources of income. Given the personal toll that accompanies parenting by grandparents, many grandmothers reported a need for support and interventions tailored to their unique needs.

Increased uncertainty about the future
The most stressful aspect of caregiving, according to participants, was the increased uncertainty about the future. A common statement raised by various elderly women was;

"I do not know what will happen to these orphans if I die."

For many, there were no contingency plans in place and therefore they kept on worrying. The fear of an uncertain future took on an added intensity because most elderly women were socially isolated and, often, had no one to confide in or with whom they could share their predicament. This caused them to believe that this caregiving role at an advanced age, and under difficult circumstances, would send them to an early grave, but not as early as that of their children. Clearly there was neither active anticipation of dying nor any meaningful planning, which, according to Erikson (1982), is an attribute of old age.

Discussion
Elderly women are caring for orphaned grandchildren under difficult circumstances; they are committed to the caregiving role despite the hardships they are encountering. Some extended family and community members are always very supportive of orphan care, although not on a regular basis, but only biological family members offer assistance. The Home Based Care programme specifically addresses the care of orphans, but does not adequately meet all the challenges and needs of these orphans. There is not enough psycho-social support for the elderly women as caregivers and for the orphans in their care. The women and children are still in the process of mourning their losses, yet they receive little or no social support. These elderly women are worried about the future of orphaned grandchildren but there are no contingency plans in place for most households. Elderly women experienced ill health due to the death of their children, or their health has deteriorated due to their loss and the subsequent care of the orphans. Noteworthy, though, is the fact that most of these grandmothers have little, and very often no, knowledge about AIDS due to illiteracy.

Recommendations
It is recommended that counselling be offered to elderly grandmother-caregivers and AIDS orphans to assist with their feelings of bereavement and their sense of loss. The grandmothers need to understand the bereavement process that they are going through as most of them do not have knowledge about HIV and AIDS. Bereavement, according to UNICEF (2002), refers to a sense of loss and the grief and mourning processes that accompany it. Counselling will be necessary to avert the situation and provide grandmothers with the emotional base from which to face their new realities and be able to care for their bereaved grandchildren. It is also recommended that there be proper HIV and AIDS awareness campaigns at community level to avoid stigmatisation of affected families, so that the community is receptive to caregivers. Trauma counselling following the deaths of their children, is necessary, as it is clear that grandmothers need assistance in dealing with the stress of their unexpected and assumed status. Thus interventions should be made at community level so that they feel less alienated and more capable of coping with the demands of parenting the second time around. Despite the need for counselling, it should be considered that not all townships have HBC workers and training and dispatching them to different rural areas can be problematic.

Methodological limitation of the study
The present study was one that was exploratory and used a purposive sampling method. Consistent with the nature of purposive sampling, there was no intention or purpose to generalise any of the findings. However, the inherent limitations of using a
purposive sample are the possible restricted range of the sample and the lack of diversity among study participants. As stated, these findings cannot be generalised to other studies, but they add contextual depth to the meaning of caregiving for this sample. The participants comprised a small, purposive sample for phenomenological inquiry.

Another limitation of this qualitative study was the small sample size (n = 10). This study was based on a voluntary, non-random sample. The participants were limited to elderly African female caregivers of PLWHAs who were residing at a hospice in Gugulethu, Western Cape, at the time of the interviews. Therefore a limitation of this research might be the restrictions related to generalising this study to other groups such as individuals suffering with cancer, stroke, Alzheimer’s disease and other maladies.

Although generalisation was not the intended goal of this study, the researcher was concerned about transferability of the findings of the study (Lincoln & Guba, 1985). By way of detailed, rich descriptions, as well as in-depth information regarding the context and background of the study, it was anticipated that knowledge generated from this research could be appraised for its applicability and applied appropriately in other contexts.

Recommendations for future research
More research is needed to understand further and quantify the extent to which the elderly women are providing care for their dependants, as well as how they are affected by their care responsibilities. More specifically, future research should include theoretical constructs from behaviour change theories, such as attitudes, self-efficacy, social norms and knowledge with respect to caring, to explain and understand the behaviour of elderly women as providers of care.

Conclusion
This study highlights the expanding changing role of elderly women and their responsibilities and challenges as care-givers of children and grandchildren as a result of HIV and AIDS. Elderly women fulfill a wide range of responsibilities with a minimum of resources, assistance and support and suffer major economic, psychological and social consequences as a result.

References


software), Colorado Springs, Colorado: Qualitative Research.


