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Health challenges of elderly people caring for children orphaned by AIDS in a community setting in South Africa

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Abstract

The HIV epidemic has resulted in the death of many people in their reproductive years, leaving behind orphans who are sometimes cared for by their elderly relatives despite the feebleness of their aging bodies. The purpose of the study was to explore and describe the health challenges of elderly people caring for children orphaned by AIDS. This research was conducted as a qualitative phenomenological exploratory, descriptive, and contextual study, conducted in the Mafikeng Municipality of North-West province in South Africa. Data were collected from December 2011 to February 2012 through individual face-to-face interviews and field notes. Elderly people's health challenges in caring for children orphaned by AIDS centred on physical, psycho-emotional, economic and, psychosocial constraints, linked to re-parenting at an old age or because of losing their own children and relatives to AIDS. They experienced physical exhaustion as a challenge of caring for the children orphaned by AIDS as the capacity of their bodies was now reduced and they also had to meet the physical, emotion and spiritual needs of the orphans as well as providing them with food, clothing and shelter. Lack of sleep, dizziness, elevated blood pressure, low glucose levels and asthmatic attacks were also aggravated by contemplating how to fend for these children or owing to the fact that the orphans were very stubborn and took the elderly for granted. This study afforded an understanding of the health challenges elderly people experience in caring for children orphaned by AIDS. The study also recommended some of the interventions that can assist elderly people in this role they play of caring. Based on the findings, it can be deduced that on top of health challenges they face, they are obliged to deal with the added burden of caring for orphaned children by AIDS.

Keywords: Elderly people, challenges, care giver, community.

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Introduction

The human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) are a worldwide problem; the AIDS epidemic has caused a substantial increase in mortality among adults of reproductive age (Blacker, 2004; Porter & Zaba, 2004; Alpaslan & Mabutho, 2005), hence creating a generation of orphans with parents being wiped out in the prime of their life. In the wake of HIV/AIDS, elderly people find themselves taking on the responsibility of caring for AIDS orphans, despite the feebleness of their aging

bodies (Ntozi, 1997; Bray, 2003; Nyambedha, Wandibba & Aagaard-Hansen, 2003; Oburu & Palmérus, 2005; Ssengonzi, 2007; Ice, Zidron & Juma, 2008; Ice, Yogo, Heh & Juma, 2010). It has been well documented in the literature what the impact on elderly people caring for orphaned children may be, such as chronic stress which contributes to ill-health and is particularly known to have an impact on the cardiovascular, immunological, gastro-intestinal and endocrine system (Sapolsky, Armanini, Packan & Tombaugh, 1987; Vladimir, 1993; Sapolsky, 1999; Nhongo, 2004; Ice et al., 2008; Hlabyago & Ogunbanjo, 2009).

The AIDS epidemic has affected every aspect of life in Africa, from people's livelihoods to the capacities of societies (Alpaslan & Mabutho, 2005), creating a generation of orphans whose parents have died. Observations from this study further show that most infected partners die in succession; that is, when one parent dies of AIDS, the other is also often living with AIDS and dies shortly thereafter, leaving the children as orphans and creating a parenting crisis in most societies, including South Africa. It has been estimated by AVERT (2010) that, there are between 1.5 and 3 million AIDS orphans where one or both parents are deceased in South Africa, and it is further estimated that the HIV/AIDS epidemic has created half of the country's orphans. This large number of people who die of AIDS-related illnesses leaves behind vulnerable age groups, the very old and the very young – the former having to become parents again despite the feebleness of their bodies.

According to a study by Ice et al. (2010), care-giving has potential to impact on the health of the elderly through economic stressors and/or psychosocial stressors. Thus study further reveals that if care-giving is primarily being experienced as an economic stressor, one might expect that health would be impacted through a general depletion of resources available to purchase food and maintain health. Fewer resources available for food would act to decrease food choices, limiting nutritional value and overall food intake. Similarly, a decrease in resources available for health maintenance can result in caregivers accessing fewer and poorer health services (Sauerborn, Adams & Hien, 1996; Donovan & Massingue, 2007; Maruapula & Chapman-Novakofski, 2007). Elders may delay seeking treatment, resulting in more advanced disease (Jones, 1997; Russel, 2004). Furthermore, under-nutrition can lead to poor health outcomes. Here one would expect to see a decline in body mass index and other indicators of body fat, a decrease in haemoglobin, possibly a decline in glucose, and poorer physiological health, i.e. more infections, lower energy, and undiagnosed and treated chronic disease.

It is therefore evident that there is a growing number of elderly people taking on the responsibility of caring for AIDS orphans in South Africa, with attendant health challenges of their own, as may be observed from the literature (Bradshaw, Johnson, Schneider, Bourne & Dorrington, 2002). Although a

number of studies have been done with regard to the health challenges of the elderly worldwide and in South Africa, no study is available on elderly people caring for AIDS orphans in Mafikeng district in North West province. The role of the elderly people in this setting and similar situations deserves further exploration as AIDS continues to claim the lives of their children, leading to an increase in the number of orphans, hence causing a possible additional burden to their health. Most reports cannot be generalised to the South African population because of the differences in culture, type of support available in the community, the setting and so on.

Based on this, the main objectives of the study were therefore to explore and describe the health challenges of elderly people caring for children orphaned by AIDS in North West province, as well as determining the support needs of elderly people in fulfilling their role as carers for grandchildren orphaned by AIDS. This qualitative study attempted to contribute to the current knowledge base regarding elderly people's health challenges and their role of caring for or parenting children orphaned by AIDS, by exploring the topic in relation to elderly people in a specific rural setting.

One of the limitations of this study is that the sample of participants selected comprised elderly people from just one district. HIV-affected families living in rural areas may not be representative of such families in the rest of the country. A large sample size selected randomly from more than one village in a similar situation would thus have allowed for more generalisable results. However, given the sensitive nature of the study, the sample size was limited. In addition, the relatively small sample size in this study made the research feasible. Given limited finances and owing to the fact that it takes time to build trust with participants, it would have been difficult to achieve this within the time available if a larger sample had been selected.

Framework

Tronto's (1993) ethics of care framework in relation to the study's findings on the health challenges of elderly people caring for AIDS orphans was used, where good care consists of holistic practices involving four phases: caring about, taking care of, care-giving, and care receiving. Tronto's ethics of care framework can serve as a guide to pinpoint issues and challenges in the caring process and relationships by raising questions related to the elements of care. These are identified as: attentiveness, responsibility, competence and responsiveness. The context of care includes power, privilege and adequacy (Tronto, 1993).

Methodology

This study was designed as a qualitative phenomenological exploratory, descriptive and contextual study, conducted in the Mafikeng Municipality of North West province from villages around the area. The purpose of the study was to explore and describe the health challenges of elderly people caring for children orphaned by AIDS, as well as determining the support needs of elderly people in fulfilling their role as carers for these children. The population of the study included elderly people caring for children orphaned by AIDS on a full-time basis in Mafikeng Municipality, North West province, South Africa, and data were collected during the period December 2011 to February 2012 through individual face-to-face interviews and field notes. Selection of participants was through a purposive sampling approach. The targeted sample size was 10 to 12 participants due to the nature of the study and the fact that not many of these elderly people were willing to participate.

Individual interviews were conducted in Setswana as this was the participants' language; the interviews were audio-taped in an environment convenient to the participants, e.g. their home. These were phenomenological interviews and data were collected until saturation was reached. The aim of phenomenological inquiry is to explore greater depth of meaning from the elderly people of what it is like for them caring for children orphaned by AIDS (Burns & Grove, 2005). The questions were piloted with five participants who were also included in the actual study. The research question derived from the purpose of the study was 'What are the health challenges you experience as a result of you caring for the child orphaned by AIDS?'

The views of each participant were transcribed verbatim from the recordings, translated from Setswana into English and analyzed (Creswell, 1994) to ensure trustworthiness through the assistance of a professional translator and an independent coder using an open coding system. The intention of the analysis was to organise the data into meaningful individualised interpretations or frameworks that describe the phenomenon under study (Burns & Grove, 2005). Individual analysis of the transcriptions was done and categories were formed to allow the researcher to identify similarities, differences and relationships. The developed categories were then grouped into themes.

Ethical clearance for the study was obtained from the Ethical Committee of the University of the Western Cape and research was conducted in accordance with the ethical and professional guidelines specified by the South African Nursing Council. Ethical considerations pertaining to research were observed continuously during the research process, such as confidentiality, anonymity and privacy, and pseudonyms were used instead of participants' real names. Participants gave consent to participate in the research study through verbal and

written consent, and participation was free and voluntary. The nature and intention of the study was explained to participants in their language of choice, and that there was no harmful procedure involved. Lincoln and Guba's criteria (1985) for trustworthiness were applied and all four strategies were addressed: credibility, confirmability, transferability and dependability.

Results

Table 1 shows the biographical information of the 10 participants, including the number of children they lost to AIDS and the number of orphans they care for. The names included are not their real names.

Table 1: Biographical information of participants caring for AIDS orphans

Names	Age in years	Marital status	Gender	Number of deceased children	Number of orphans cared for
Mmatsepo	72	Window	Female	2	4
Nuku	62	Married	Female	1	3
Keneilwe	74	Window	Female	2	2
Mpho	74	Married	Female	1	1
Modiegi	61	Single	Female	2	3
Lerato	78	Window	Female	3	5
Tsholofelo	64	Married	Female	3	8
Mmapule	60	Divorced	Female	1	1
Segametsi	65	Divorced	Female	2	2
Leina	73	Widowed	Female	2	2

Data collection and analysis identified four categories of health challenges experienced by elderly people caring for children orphaned by AIDS: (1) physical constraints (2) psycho-emotional constraints (3) economic constraints and (4), psychosocial constraints. These are presented together with the themes and sub-themes in Table 2.

Table 2: Categories and themes

Categories	Themes/sub-themes
1 Physical constrains	1.1 Chronic health
2 Psycho-emotional constraints	2.1 Depression and coping 2.2 Increased uncertainty about the future 2.3 Risk of being infected
3 Economic constraints	3.1 Demands exceeding resources

Discussion

Physical constraints

According to a study conducted by Joslin and Brouard (1995), the time demands of child-rearing can preclude giving attention to the caregivers' own health, resulting in missed medical appointments and exacerbation of chronic conditions. As Tsholofelo, a 64-year-old married woman, reported:

I did not have high blood pressure problems until my husband and I started looking after these orphaned children a few years ago. I find myself worrying excessively about them. My heart starts to beat fast, I have dizzy spells and headaches and when I get to the clinic my blood pressure is elevated and the nursing sisters have to ask me to sleep at the clinic for some time until my blood pressure has gone down.

Psycho-emotional constraints

Depression and coping

Depression can be an extremely difficult and prolonged condition, where feelings of tiredness, loss of energy and low self-esteem are common (Kaufman, 1995). Joslin and Harrison (1998) and Van Dyk (2001) argue that elderly caregivers of AIDS orphans experience physical and emotional health-related illnesses that impact on their psychological well-being. Elderly people often complain about problems such as depression, stress and burn-out, feelings of inadequacy, helplessness, guilt and loss of self-esteem and confidence (Van Dyk, 2001). This was found to be true of the elderly people in the present data collected, as they sometimes put the needs of the orphans before theirs, more especially the health needs of the orphans. This situation was worsened by the young ages of the orphans in their care, which may suggest that many of these elderly people may continue to be caregivers until they reach late adulthood.

In addition, a study by Joslin and Harrison (2002) found that the stress related to the raising of HIV-affected and orphaned children might precipitate or aggravate chronic conditions in elderly people. In this study Leina (73 years old and widowed) reported that:

I am raising two children orphaned children by AIDS; one is a teenager who is very stubborn and difficult to discipline. She is actually pregnant as we speak; it really frustrates me most of the time as these kids take me for granted when I try and discipline them.

During old age there is much sorrow to cope with and some despair must be acknowledged, which will be much worse among caregivers who are confronted with various pressures (Joslin & Harrison, 2002).

Increased uncertainty about the future and lack of support from extended families

According to the study the most precipitating state and the most stressful aspect of care-giving was the uncertainty raised by several of the elderly people. This is reported by one grandparent as follows: "I do not know what will happen to these orphans if I die, more especially because other extended family members are not willing to give any form of assistance or even look after some of the orphans." Erikson and Kivnick (1986) stated that during old age there is a clear sense that death's door is open and not so far away. Some of the elderly people were confronted by a lack of support by the extended families of the orphans they were taking care of, as stated by Mmatsepo (72 years old and widow):

The father of the youngest orphan actually demands a share of the Child Grant of R250 that the child receives monthly and this really breaks my heart, because it's really nothing much. I sometimes wish I could die due to the problems and demands I face and as the result of lack of support from other extended families.

This is consistent with Schafer (2000), who argues that a person needs a network of social support during a crisis. The lack of contact between the two families often left the elderly people with no one to look to for assistance. This aggravated the elderly people's health as they had no one to turn to in times of crisis (Schafer, 2000). These elderly people usually face strong material, emotional and psychological constraints and receive little external support (Guest, 2001).

Risk of being infected

Mpho is a 61-year-old married woman, and she and her 64-year-old husband have lost two children to AIDS. She noted: "We look after one child orphaned by AIDS who is infected by HIV and we fear the possibility of being infected with HIV too. This child is always sick and does not seem to be thriving well." A study by Kuo and Operariob (2010) reveals that some of the participants reported being worried about exposing themselves to the virus while they looked after the children, so much so that they were living in persistent fear. According to the findings of the current study, some of the elderly people were already infected with HIV.

Economic constraints

According to Paul (1989), stress is experienced when the personal and situational demands exceed resources. The researcher's findings reveal that most of the elderly people reported having difficulties in paying for school fees, medical costs, buying clothing, food, school uniforms and books for the AIDS orphans under their care, as their pension monies were not enough to cater for all these needs. Nuku (62 years old and married) reported as follows:

Two of the AIDS orphans under our care have even dropped out of school due to finances; they have looked for jobs to assist with footing the bills. My husband and I don't know what to do regarding our situation, as we feel that they have been traumatised by the loss of their parent."

At the time of the interviews all of the participants were pensioners. The pension they receive is very little to provide for the children's basic needs including provision of food, clothes, school fees and medical expenses. This is consistent with findings that revealed that most of the time elderly people are unable to provide for the basic needs of these orphans with their pensions (Strydom, Thebe & Wessels, 2009).

Difficulties in accessing government aid

The interviews also reveal that all of the elderly people complained about lack of access to Child Grants for AIDS orphans and government aid. All of them had applied for assistance but have been waiting, some for two to three years, as Tsholofelo reported: "My husband and I applied for grants for AIDS orphans at the Department of Social Welfare, but have been waiting for almost two years now for them." The elderly people who had already applied for aid to assist in caring for AIDS orphans reported a delay from the Social Welfare offices; whenever they followed up they were informed that it was still being processed. "We actually have given up hope owing to this delay," reported Tsholofelo.

Unemployment

At the time of the interviews most of the participants were unemployed and others were pensioners. Those receiving a pension reported that it is very little to provide for the children's basic needs, including provision of food, clothes, school fees and medical expenses. This is consistent with findings that revealed that most elderly people are unable to provide for the basic needs of these orphans from their pensions (Strydom et al., 2009).

Psycho-social constraints

Glick, Weiss and Parkes (1974) found that generally a person may require more than a year to come to terms with grief. Gerdes, Moore, Ochse and van Ede (1988) observes that grief has come to be recognised and allied with a range of negative feelings, which are part of general emotional turmoil. Mmatsepo indicated that:

I constantly have feelings of wishing to die, because I don't know how I can ever look after all these AIDS orphans. My son, who was assisting me build my house, has passed on also due to the disease and lack of support with these children. Life is really unfair to have taken the only help I had away from me. These constant worries really cause me sleepless nights.

Elderly people may as a result of the negative feelings become angry and blame fate, self, others and God for the loss of a loved one (Gerdes, 1988).

Effects of Child discipline on the health of the elderly people

Difficulties and stress in adapting to the new parenting role between the elderly and their grandchildren, and lack of understanding between children and elderly people due to the generation gap, was reported to be a common problem by HelpAge International (2005) and Oburu and Palmerus (2005). These findings are consistent with what Segametsi (65 years old and divorced) had to say:

I am looking after two teenage girls orphaned by AIDS. They are very stubborn and don't listen when being reprimanded about their behaviours. I feel very frustrated most of the time. They come home very late at night and I fear that they too will get infected with the disease or even end up getting pregnant.

Conclusion

The findings of this study highlight the health challenges of elderly people caring for children orphaned by AIDS, either due to re-parenting at an old age or as a result of losing children and relatives to AIDS. The elderly experienced physical exhaustion as a challenge of caring for children orphaned by AIDS, since the capacity of their bodies is now reduced, and they have to meet the physical, emotional and spiritual needs of the children as well as providing them with food, clothing and shelter. Lack of sleep, dizziness, elevated blood pressure, low glucose levels and asthma were also aggravated by either contemplating how to fend for these children or owing to the fact that the orphans were very stubborn and took the elderly people for granted.

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