The role of elderly carers in HIV prevention and care; the perspectives of older adults in underprivileged communities in South Africa

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Abstract: In many societies, the elderly take on the enormous role of being the caregivers of sick family members. Little is known about the context in which they provide HIV/AIDS-related care, and their role as caregivers is most often not documented. This study conducted interviews with 31 elderly carers to explore their care-giving activities in relation to adult children with AIDS-related illness, and to examine their perceived role in HIV prevention and management in rural communities in Mpumalanga Province, South Africa. The findings indicate that older adults who assume the natural role of caring for sick adult children live in multigenerational households. Key caring activities include the provision of physical and hygiene care, financial and emotional support, and health and nutritional care. Besides the physical caring activities, the elderly carers play a critical role in the prevention of HIV. They promoted condom use, encouraged HIV testing, and spoke openly about the HIV status of their sick adult children. Their critical role in administering antiretroviral treatment (ART) and encouraging adherence demonstrates a comprehensive understanding of the importance of adherence and the complex ART regimen. The findings underscore the need to train and incorporate older adults into adherence programmes to facilitate their role as long-term adherence partners. They are also an essential vehicle to reduce stigma and discrimination in their communities.

ABOUT THE AUTHORS

Dr Makhosazane Ntuli, was a Public Health doctoral candidate when the project from which this data is derived was conducted. For her doctoral study, she developed an HIV and AIDS educational programme for older adults to meet their needs as they care for sick family members. The premise for developing the programme was the need to involve older persons in the prevention and management of HIV and AIDS. Currently, she is a technical advisor at the Health Systems Trust, not-for-profit organisation that supports the transformation of the health system in South Africa. She continues to advocate for the acknowledgment of the crucial role of the elderly in HIV prevention.

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PUBLIC INTEREST STATEMENT

In many societies in sub-Saharan Africa, the elderly play a critical role in helping families cope with the HIV and AIDS epidemic. However, the context in which the elderly provide HIV- and AIDS-related care is often ignored in HIV prevention programmes. This paper outlines the caring activities performed by elderly carers to their very ill adult children and their positive contribution towards the HIV and AIDS programme. We found that most of the elderly carers lived in extended family households, and used their old age pensions to perform caregiving activities. They accompanied the sick to the clinic, administered medication, fed the sick when the disease progressed, and provided hygiene care. They played a crucial role in HIV prevention, they encouraged HIV testing, promoted condom use, and served as adherence partners. The caregiving role of elderly carers is critical and they should be involved in programmes to reduce the HIV/AIDS.
1. Introduction

In most developing countries, where institutional care facilities are lacking, the health care services offer significant but limited care and support to those with AIDS-related illness, leaving the bulk of the work to the families (Knodel & Zimmer, 2007). The caring for people living with HIV (PLHIV) is increasingly dependent on social networks, and the family network is the first point of call as the basic social unit (Mbereko et al., 2019). Research suggests that in a population severely affected by HIV, the elderly are important providers of care to their HIV-infected adult children and their orphaned children (Ssengonzi, 2007). Older adults have provided an alternative support network outside the health facility since the beginning of the HIV and AIDS pandemic (Knodel & VanLandingham, 2002) and have been in the forefront in the care of sick people (Knodel & Zimmer, 2007; Ssengonzi, 2009). Thus, in most societies in sub-Saharan Africa (SSA) the older adults care and support family members, orphans, and adult children with AIDS-related illnesses (Knodel & VanLandingham, 2002; Ssengonzi, 2009).

In South Africa most of the households with an HIV and AIDS individual have older persons who eventually take up the role of caring for the sick adult child, due to the multigenerational living arrangement in which 85% of people above 60 years old live (Hosegood & Timaeus, 2005; McKinnon et al., 2013; Ralston et al., 2015). This living arrangement has resulted in the older adults taking responsibility for providing care to their adult children sick with AIDS-related illness (Knodel & Zimmer, 2007; Ssengonzi, 2009). The clustering of HIV infection in households has led to older adults caring for multiple individuals, either concurrently or sequentially (Small et al., 2019; Ssengonzi, 2009). Multiple care experiences of older adults may arise from the lack of institutional care facilities for PLHIV and AIDS (Chepngenno-Langat, 2014). Research has shown that beyond being heads of multigenerational households, older adults assume the role of caring for sick adult children willingly as a normative practice and derive satisfaction from their caregiving roles (Brown & Brown, 2014; Chepngenno-Langat, 2014).

Various studies have reported that older adults undertake crucial and numerous care giving roles (Knodel, 2012; Nyirenda et al., 2015; Ssengonzi, 2009). The extent of caregiving includes meeting the patient’s physical and hygiene needs, administering medications, and assisting the sick to access health facilities. Hygiene care ranges from doing laundry to bathing, turning, and lifting the sick adult child. Some caregiving tasks are labour-intensive and associated with physical strain among older adults. Such activities include assisting the sick adult out of bed to use the toilet, which may be a pit latrine outside the house, in rural societies (Knodel & Zimmer, 2007; Nyirenda et al., 2015; Tanyi et al., 2018). Older adults also provide psychological support (Knodel et al., 2010b; Skovdal et al., 2011), they give encouragement, calm the sick, chat with them, and offer kind words, particularly in the later stages of the illness (Boon et al, 2010b; Knodel, 2012; Knodel et al., 2001).

In most poor and rural communities, co-residence is also often associated with the provision of financial support. Thus, the care that older adults provide to their sick adult children extends to the financial support required to meet their needs (Moyer & Igonya, 2014; Schatz & Ogunmefun, 2007). In South Africa older adults use their pension social grants to provide financial support and care for all the needs of their sick adult family members (Munthree & Maharaj, 2010; Nyirenda et al., 2015). People with AIDS-related illness need specialised care and money for transport to the health facilities (Mbereko et al., 2019; Nyirenda et al., 2015; Tanyi et al., 2018). In addition, the elderly carers provide nutritional care for the sick as well as other members of the household and incur extra costs to meet the dietary requirements of the sick (Munthree & Maharaj, 2010; Nyirenda et al., 2015; Ssengonzi, 2009).
Besides the provision of physical and psychosocial care, the researchers suggest that older adults have a great potential to contribute to the control of the HIV and AIDS epidemic. They educate others about common HIV risk factors and stress the need to reduce risk behaviours (Knodel et al., 2006; Williams et al., 2008). They have emotional reasons for motivating their adult children against risky behaviour, encouraging HIV testing and counselling, and ensuring that those infected with HIV seek and comply with ART (Knodel & Zimmer, 2007). Older adults are excellently positioned to be the treatment partners for their HIV-positive adult children, grandchildren and family members (Skovdal et al., 2011). Most adult children on long-term ART have a living parent, and many live with their parents in multigenerational households. Older adults play supportive roles in ART adherence. They remind family members to take their ART medication and to go for ART refills, and they take them to their appointments. They are dedicated to ensuring that their sick adult children adhere to ART (Knodel, 2012; Skovdal et al., 2011; Williams et al., 2008).

Notwithstanding that HIV and AIDS has had a significant negative impact on older adults in SSA, it is essential not to view them only as victims of HIV and AIDS. Growing attention is being paid to the positive effects of caregiving might have on older carers (Brown & Brown, 2014). Additionally, there is value in exploring their knowledge of HIV/AIDS, how they contribute to fighting the HIV epidemic in their households and communities, and how society can utilise their wisdom in caring for those sick with AIDS-related illnesses. The unique potential of the elderly parents of HIV-infected adults to assist with ART adherence has received almost no attention. Yet the researchers maintain that elderly parents are unmatched in ensuring the well-being of their adult children (Masquillier et al., 2014; Williams et al., 2008). They consistently play the care and support roles amidst various challenges such as limited knowledge, a lack of skills, limited financial resources, and a lack of social and emotional support (Knodel & Zimmer, 2007; Knodel et al., 2006).

Sub-Saharan Africa has experienced the greatest impact of the HIV and AIDS pandemic, and the older adults have taken on the enormous role of being the caregivers of the ill family members and orphans (Lekalakala-Makgele, 2011; Njororai & Njororai, 2013; Ssengonzi, 2009). In rural households, older adults have disproportionately burdensome role as the care-givers of terminally ill adult children, who often migrate to rural areas for care (Munthree & Maharaj, 2010; Nyirenda et al., 2015). The care provided by older adults is an important public health issue (Chepkenego-Langat & Evandrou, 2013), and in an HIV-endemic context, the caregiving they provide remain critical (Schatz & Seeley, 2015). However, the older adults have been largely ignored and little is known about the context in which they provide HIV- and AIDS-related care to adult children and grandchildren in South Africa. Their role as caregivers is most often not properly examined, analysed and documented (Njororai & Njororai, 2013). This paper highlights the caring role of older adults for their very ill adult children and examines how they perceive their role in responding to HIV prevention and treatment in their households and communities.

In SSA older caregivers will continue to provide care to PLHIV and AIDS due to the inability of the healthcare systems to provide the care needs of PLHIV (Chepkenego-Langat & Evandrou, 2013). There is a need to enhance the contribution of elderly caregivers through incorporating them within the continuum of care for effective HIV and AIDS management (Chepkenego-Langat, 2014).

2. Methods

2.1. Study design
The purpose of the main study from which this paper emanates was to develop an HIV and AIDS educational programme for older adults to meet their needs as they care for sick family members with AIDS-related illnesses. The research study was conducted between June and August 2016. The research utilised a mixed-method study design which is described in detail elsewhere (Ntuli & Madiba, 2019). Previous papers on this project highlighted aspects of the burden of caring such as physical exertion, the emotional toll, and the impact of limited resources on performing care. This
paper presents data on the care giving role of older persons and their perceived roles in the prevention of the spread of HIV.

2.2. Setting and recruitment
The research population consisted of persons aged 60 years and above who presented at the health facilities to collect chronic medication. The participants were recruited from 12 primary health facilities via purposive sampling. The participants were selected if they answered yes to indicate that they had taken care of an adult child with an AIDS-related illness, were in a sane state of mental health, and were themselves not too critically ill to answer questions. Data collection was ceased after 31 older persons had been interviewed, as the recruitment was guided by data saturation. Saturation was considered to have been achieved once the interviews were not generating any new information, when no new information was being contributed to the understanding of the caring role of older persons (Gentles et al., 2015). The health facilities were located in Thembisile Hani sub-district of Mpumalanga Province in South Africa. The sub-district is approximately 75 km northeast of Pretoria and is predominantly rural with high levels of poverty, poor education, unemployment, and limited infrastructure.

2.3. Data collection
The lead investigator and trained fieldworkers used a semi-structured interview guide to interview the participants. They asked open-ended questions pertaining to such matters as the day-to-day caring activities that they carried out for the sick child, the duration of their caring for the sick child, the outcome of the illness, their perceptions of the role of older adults in preventing the spread of HIV, and how older adults could be assisted to play a role in the prevention of HIV. The interview guide allowed for probing and follow-up questions to encourage the participants to express their experiences and perspectives in detail. Each interview was audio-taped with the consent of the participants, was conducted in the local language, and lasted for about 60 minutes. All interviews were conducted in a room separate from the main facilities of the clinic to ensure privacy. Signed informed consent was obtained from all participants prior to data collection. The participants were informed about the voluntary nature of the study and were assured of confidentiality and anonymity of the process.

Ethical clearance for this study was obtained from the Sefako Makgatho Health Sciences University Research Ethics Committee [SMUREC/H/259/2015: PG], and the Mpumalanga Provincial Department of Health and the Nkangala Health District.

2.4. Data analysis
All interviews were transcribed verbatim in the local language, translated into English, and uploaded into NVivo 10, which is qualitative data analysis software (QSR International, Melbourne, Australia). The English transcripts were carefully checked for the accuracy of the translations by the lead investigator, who is fluent in both languages. The authors adopted thematic analysis, using an inductive approach (Braun & Clarke, 2006). Analysis began with a careful reading of a few transcripts independently, to familiarize the authors with the data and identify initial emerging codes. These codes were used to develop a codebook, and the emerging themes were discussed until the authors reached consensus about their definitions. This led to the finalisation of the codebook. The codes were then grouped into categories, and emerging themes across the transcripts were identified. Final themes were decided upon by agreement between the authors.

To facilitate rigour and the credibility of the findings of the study, we used a number of strategies: we interviewed the participants in the local language, transcribed the interviews verbatim, and spent time in the field to familiarise ourselves with the study context. Both authors were involved in the analysis and interpretation of data, to reduce investigator bias (Denzin, 2012).
3. Results

3.1. Description of the study sample
The participants were from multigenerational households, and most were the sole caregivers for their sick children. All of them had cared for at least one adult child, four cared for two, and one had cared for three sick adults. The mean age of the sick adult care recipients was 33.3 years, the range being 20–52 years. The length of care was 6–24 months, and 24 of the recipients of care had died. Of the 31 elderly carers who were interviewed, all but one were female. They were aged between 62 and 82 years, most (19) of them were aged between 62 and 69 years, and almost half (15) had no formal schooling. At the time of the interviews, five of them were living with 9 to 12 household members, 19 had 8 children, and only 1 participant was living alone. Almost all (27) were on treatment for hypertension and had visited the clinic to collect their chronic medication. Twelve of those with hypertension were also talking medication for diabetes mellitus (Table 1).

3.2. Themes
Two main themes with sub-themes emerged from the analysis of the care giving activities and the perceived role in HIV prevention, as outlined in Figure 1.

3.2.1. Care giving activities
The interviews revealed that after the participants committed to caring for the sick adult children they performed the caring activities and took the task upon themselves as their parental responsibility.

| Variables                              | Categories          | Frequency. | Percentage |
|----------------------------------------|---------------------|------------|------------|
| Age categories                         | 62–69               | 19         | 61.3       |
|                                        | 70–82               | 12         | 38.7       |
| Education status                       | No formal schooling | 15         | 48.4       |
|                                        | Primary education   | 13         | 41.9       |
|                                        | Secondary education | 3          | 9.7        |
| Number of people in the household      | 1–5 people          | 22         | 73.3       |
|                                        | > 5 people          | 8          | 26.7       |
| Age category of the adult care recipients | 20–30 years       | 10         | 32.3       |
|                                        | 31–35 years         | 5          | 16.1       |
|                                        | 36–52 years         | 8          | 25.8       |
|                                        | Do not know         | 8          | 25.8       |
| Sex of the adult care recipients       | Female              | 21         | 70         |
|                                        | Male                | 9          | 30         |
| Number of adult care recipients        | 1                   | 26         | 83.87      |
|                                        | 2                   | 4          | 12.9       |
|                                        | 3                   | 1          | 3.23       |
| Duration of the care for the sick adult children | Less than a year | 15         | 48.4       |
|                                        | 1–2 years           | 6          | 19.4       |
|                                        | > 2 years           | 7          | 25.8       |
|                                        | Do not remember    | 2          | 6.4        |
| Outcome of the care for the sick adult children | Died               | 24         | 80.0       |
|                                        | Alive               | 6          | 20.0       |
3.2.1.1. Physical hygiene and care. They performed a variety of physical and personal hygiene care activities ranging from bathing and clothing, turning, supporting or carrying those they were caring for to and from the toilet, which in many instances was outside the house.

I bathed him, dressed him, and did everything for him. I used to carry him piggyback and put him on the couch in the living room and switch on the TV for him. When the time comes for him to sleep, I would help him to his room. I would pick him up and put him on the bed. (75 year-old parent.)

Sometimes he had a running tummy and then you will have to help clean them up.

Sometimes they vomit and you also have to clean them. (76 year-old parent.)

Their illnesses incapacitated the sick children to the extent that they became incontinent of urine and stools.

When he soiled himself I would wash his clothing and linen > I never slept day and night, eyi ..., it was extremely difficult. (66 year-old parent.)

Because he was already messing himself we even make the bucket toilet for him inside his room, so that when he is done I can take it out and dispose of the contents. (73 year-old parent.)

3.2.1.2. Emotional support. The elderly carers played a critical role in providing emotional support to their sick adult children as part of their caring role. They provided encouragement, instilled hope, boosted their morale, became the pillar of strength for the children, and gave them unconditional love. They showed vast, extraordinary tenderness in caring for their children.

I would do what she could not do for herself ... I would sing for her and read the word of God. I would feed, bath and left her to sleep and went outside. The time for meals was 12h00. I would come again and stay with my child, chatted, played, joked with her and even kissed her. She would look at me, I would sing for her until she fell asleep and I would leave her. (65 year-old parent.)

3.2.1.3. Encouraging adherence to ART. Over and above the physical care activity, the elderly carers also accompanied their adult children to the clinic when they were unwell, to screen for HIV, for routinely scheduled follow-up, and to collect their ART medication. Their narratives indicated that they supported and supervised their adult children to take their medication and to adhere to the strict follow-up care by health care workers.

I said to him this is not the end of the road and that he must keep on taking the treatment that they gave him. I took care of him from then and he became much better. He then said
to me he was healed and that he was not going to go to the clinic again for the treatment. I discouraged him from stopping to take the treatment and I explained that once you start with the treatment it is for the rest of your life. (69 year-old parent.)

The elderly carers got worried when their children failed to adhere to ART. They took it upon themselves to administer it and observed that their sick children took the treatment to ensure adherence. Their children’s failure to comply with treatment became stressful for the elderly carers.

He went to the clinic regularly to collect his treatment but when he got back, he put them in the box. When I saw the box, it was full. He only started taking the pills when I started giving it to him. (64 year-old parent.)

My child did not want to eat. He did not want his pills ... I had to force him to eat and drink his pills. If I did not ensure that he took his pills, he would not take them. I was worried that he would not get better if he did not eat or drink his pills. (60 year-old parent.)

The elderly carers had confidence in the ARTs and believed that they would improve their children’s health and the quality of their lives. Failure to comply with treatment became stressful to the elderly carers. They had observed many others in the neighbourhood who were on the verge of dying but had recovered, gained weight and looked better.

My child was fat but lost weight, yoo! [My goodness!] She was like a stick ... But, those that listen get well. My uncle had one and when I looked at her, I would get scared but now she is beautiful. She took these things [ART]. I also saw my neighbour’s child; today he has gained weight and is looking good. I so wish that mine also endured and be like this one ... My child would be alive. (73 year-old parent.)

The elderly carers acquired a lot of experience on how to support their children to adhere to ART. They even developed counselling skills, which they used to support their children, and planned to use these skills in future to encourage others to take their medication.

Actually I am at ease and I am brave, because I have seen this thing [HIV] and how it is. Even if a child comes to me and says that ‘Gogo I have HIV’, I will be able to sit them down and tell them to use these things [ART] appropriately. I will tell them just as we drink pills for high blood, they need to take their pills properly and not mix them with things they are not supposed to. (66 year-old parent.)

3.2.1.4. Nutritional care and feeding. The feeding and nutrition task performed by the elderly carers consisted of various activities. They ensured that the sick child got good nutritious food, procured the food, prepared the meals, and fed their children when they could not eat by themselves. Their narratives indicate that they understood the importance of eating healthy nutritious food before taking ART as well as for the general well-being of the sick person. The elderly carers got worried if their children did not want to eat or had a poor appetite, or vomited after their meal. They bought special nutritious foods just to ensure that their children ate before taking the ARTs.

I worried and ensured that she got all what she wanted. Sometimes she would eat a little bit and I wished she could have eaten more than that. (70 year-old parent.)

I had to force him to eat ... I was worried because he would not get better if he did not eat ... When I fed him with soft porridge, he did not like it, so I bought him Morvite [a nutritional supplement] and he would eat it for one day. On the other days he would not eat. When he ate he would become alright. (60 year-old parent.)

I would even buy this special mealie meal of theirs and make soft porridge for her. (70 year-old parent.)
I tried to feed him porridge in the morning and then gave him his pills and kept on feeding him porridge when he had poor appetite. (73 year-old parent.)

3.2.2. Perceived role in HIV prevention
The elderly carers said that they wished to engage in activities to combat the HIV and AIDS epidemic, and suggested various roles they could play in doing so. They wished to be able to educate people and create awareness about HIV, encourage HIV testing and counselling, and promote the use of condoms to prevent the spread of HIV.

3.2.2.1. HIV awareness and education. They described the perceived role they would like to play in the prevention of the spread of HIV as that of education and awareness creation in their households, churches, and neighborhoods.

We can assist by talking about this disease [HIV] at churches and in the community and the social workers should speak about it and how to prevent it and also to consult local health facilities. (65 year-old parent.)

The role that I would have to play is to sit down with young people in the community and talk to them. (70 year-old parent.)

We should teach the youth that if you are a girl you only sleep with one man and if you are a boy you sleep with one girl. (Elderly parent of unknown age.)

Some said that they already had a role to play in the prevention of the spread of HIV, and spoke openly in churches and neighborhoods so that others could benefit from their experience. They also indicated a desire to go to the clinic and ask to be given an opportunity to talk to the young people about HIV/AIDS.

I told everybody that my son was HIV-positive ... I did not hide it ... until he passed on. One day when I was in church, I stood up and told the people about my child's status and asked them for prayers. (69 year-old parent.)

They wanted to be vehicles for counselling and encouraging the youth and desired to be taught about HIV to enhance their already existing potential in counselling. They further alluded to the need for older people to be included in HIV programmes.

It would help if older people can be taught about HIV and be used to broadcast in community radio. (Elderly parent of unknown age.)

I would like us to be involved in the talks about HIV and AIDS. People talk alone, but not with older people. They don’t talk with us about HIV/AIDS. That is why I am saying let us take this opportunity and talk about HIV. (70 year-old parent.)

The role that I would play would be to sit down with them [young people] and tell them that there are lots of diseases out there. (76 year-old parent.)

3.2.2.2. Encouraging HIV testing and counselling. Caring for their adult children sick with AIDS-related illnesses exposed the elderly carers to first-hand knowledge about HIV and AIDS. As a result, they believed in and encouraged HIV testing for their adult children and others in the neighbourhood so that they would know their HIV status and could be treated timeously with ART.

When they told me that XXX had developed boils under his armpit, I told him to go to get his blood tested because there are many illnesses out there. (64 year-old parent.)
So, before a girl decides to sleep with a boy she must go first to a doctor; let me say both of them, they must go to a doctor for HIV testing. Then the doctor will tell them if they are HIV-negative. (67 year-old parent.) 

3.2.2.3. Promoting the use of condoms. The participants were strongly convinced that the use of condoms is the best way of preventing the spread of HIV. They accepted that young people engage in sexual activities. They indicated that they would urge their children to protect themselves from HIV when they engage in sexual intercourse.

We say to our children; if you have multiple partners then it is better to use condoms. (69 year-old parent.) 

Our children do not tell us when they get partners. They run to sex instead of running to the clinic but still even if they can go to clinic for contraceptives you find that one of them is sleeping around and might infect the partner. It is better if they can use protection or condoms. (63 year-old parent.) 

I tell them that if you go flesh to flesh, you will get HIV. The condom will prevent that the disease to gets to you. (70 year-old parent.) 

Some of the participants indicated that when they had attended chronic reviews at the clinic they would bring condoms home and place them where their adult children could see them in an effort to encourage them to use condoms.

We must warn our children about HIV and tell them to be safe. When I come here at the clinic I take some condoms home and put them where they can see them. (60 year-old parent.) 

I wish to protect them from being infected. I take condoms home when I visit the clinic. But I don't know if they use them or not. (67 year-old parent.)

4. Discussion
The study was conducted in the context of the popularly held view that the elderly are a forgotten group in HIV and AIDS programmes which address HIV prevention and management, and that their contributions are unrecognised. Yet, elderly carers play a pivotal role in caring for their sick adult children and other family members affected by HIV and AIDS (Knodel & Zimmer, 2007; Sengonzi, 2009). In practice, elderly carers are the ones who accompany the sick to the health facilities, stay with them when they are hospitalised, administer the prescribed medication at home, and generally act as the primary caregivers (Chepnogo-Langat & Evandrou, 2013; Knodel et al., 2010b; Schatz, 2007; Williams et al., 2008).

Consistent with past research, the majority of the participants in this study were females, were over 70 years of age, and were the sole care providers for their adult children with AIDS-related illnesses (Schatz, 2007; Sengonzi, 2009). The participants performed various caring activities, ranging from the physical activities of daily life to hygiene care, financial support, emotional support, and health care. They ensured that the necessary health facility check-up visits actually took place and that there was adherence to ART. The care giving activities observed in this study have been reported in previous studies elsewhere (Boon et al., 2010a; Knodel et al., 2011; Nyirenda et al., 2012; Schatz, 2007; Singo et al., 2015).

Elderly carers recounted that they had played a critical role in providing emotional support to their sick adult children. The study found that giving unconditional love, regardless of the nature of the illness of their children, came naturally to them, and they instilled hope in them and supported them until death. Consistent with past studies, the participants had tried different methods of boosting the mental state of their children. They provided encouragement, tried to relieve their pain and anxiety, and helped them to have a peaceful death (Saengtienchai & Knodel, 2001; Sefasi, 2010).
The study observed that the key caring task of the participants was the provision of assistance with health care and ensuring that the sick visited the health facilities when they needed medical attention, such as routinely scheduled ART refills. They accompanied their children to the clinic, as has been reported in other studies (Knodel et al., 2010a; Saengtienchai & Knodel, 2001). As reported elsewhere, the participants administered and monitored the ART to support adherence. They encouraged the sick children to adhere to ART even when they resisted the treatment and insisted that they abide by the schedule of follow-up visits to health facilities (Knodel et al., 2010b; Williams et al., 2008). Those who had witnessed the positive effects of ART in other cases believed that if their children had managed to adhere to their treatment they would have lived, just as they had seen many others survive AIDS-related illness in the community and on television.

As reported in previous research, the participants believed in the effectiveness of ART and were able to make sense of the complex medical regimes, despite their age and low literacy levels (Williams et al., 2008). They demonstrated a comprehensive understanding of the importance of adherence to ART and the complex regimen, following the counselling they received from the healthcare workers they interacted with in the health facilities. The observations in this study and those of others underscore the need to equip older adults with the knowledge and skills to do the task efficiently. This could be achieved through proper training and incorporating them into adherence programmes to facilitate their role as long-term adherence partners (Knodel et al., 2010a; Williams et al., 2008).

The participants provided the nutrition essential to the success of ART treatments (Williams et al., 2008). This study found that they had a good understanding of the importance of good nutrition, and thus ensured that their sick children had nutritious meals. The task of nutritional care included buying and preparing food and catering for the special food preferences of the sick. Moreover, as their sick children became too weak to eat on their own, they needed specialised food. This suggested that extra efforts had to be made and extra financial resources spent, particularly in view of the fact that the provision of nutritional needs extended to other household members as well.

Consistent with past observations, elderly carers for sick adult children play an important role in encouraging HIV testing (Knodel & Zimmer, 2007; Williams et al., 2008). Their narratives revealed that they encouraged and supported their sick children to test and to access treatment. The study also documented the desire of the participants to be involved in the prevention of HIV transmission, to advocate early HIV testing, and to promote the use of condoms to curtail the spread of HIV in their communities. Research suggests that the elderly in many settings in SSA have the potential to influence their adult children to avoid risky behaviours. Our findings as well as those of others suggest the need for alternative approaches to providing HIV and AIDS education (Small, 2009; Williams et al., 2008), coupled with HIV education campaigns, to facilitate the elderly in matters of HIV and AIDS (Knodel & Zimmer, 2007).

The elderly are considered key resources in combating some of the effects of the HIV and AIDS pandemic (Chepngeno-Langat & Evandrou, 2013; Njororai & Njororai, 2013). The study is in support of this view. We established that the participants play a crucial role in families, church, and communities in speaking about HIV and its prevention, as well as in providing support to individuals and families affected by HIV and AIDS. These observations suggest that the elderly could be an essential vehicle to promote disclosure and prevent stigma and discrimination in their households and communities. They spoke about HIV in church, despite HIV being a taboo topic, which implies that they can break this silence. This highlights the need to involve the elderly in strategies to mitigate stigma and discrimination (Knodel et al., 2010b).

Unsurprisingly, researchers suggest that elderly carers could be utilised as an available committed community resource in the prevention of HIV and AIDS (Saengtienchai & Knodel, 2001; Small, 2009). Although the study established that the elderly carers spoke openly about sexual
behaviours with adults and grandchildren, the elderly carers in this study acknowledged their lack of HIV skills and knowledge. They expressed the need to be equipped with counselling skills to assist them in their undertaking to contribute to the prevention of the spread of HIV. The need for training could be used as a basis to integrate them in HIV prevention programs. In the African society, the elderly are highly revered and their opinions valued, engaging them in HIV prevention has a potential for success. Lastly, the role of the elderly in the care of AIDS orphaned children put them in an opportune position to influence early HIV testing and condom use among the youth.

The study setting limits the ability to generalize the findings to other elderly carers in urban settings since this study was conducted in one municipality a rural setting.

5. Conclusion
The findings of the study are that the participants performed care giving activities, provided financial and emotional support, health care and their nutritional needs for the sick and other family members in their multigenerational households. The frequent need to transport the sick to and from health facilities and the inability to provide adequate food were the most pressing challenges for them.

Beyond the normal caring role, the participants encouraged ART adherence, promoted condom use, encouraged HIV testing, and spoke openly about the HIV status of their adult children to prevent the transmission of HIV and AIDS.

It is imperative that the National Department of Health and HIV program developers take cognisant of the role that the elderly carers play in HIV related treatment and prevention to develop and implement HIV-related training programmes for the elderly. This could be achieved at both programming, community levels, these interventions should be integrated into the health promotion and education offered by the health care providers in primary health care facilities. The elderly could be utilized to provide HIV related health promotion and education to patients. They could also be an essential vehicle to promote disclosure and reduce stigma and discrimination in their communities by integrating these topics in the health promotion and education sessions. Additionally, with proper training and empowerment, the elderly could be formally utilised to support and supervise adherence to ART by family members living with HIV. The study established that they performed this role successfully; still, it is important that the training provide sufficient information and skills to enable them to carry out this role effectively.

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MN and SM conceptualized and designed the study. MN conducted the study and collected data. MN and SM analysed the data. MN prepared the first draft of the paper SM revised the manuscript. All authors approved the final draft.

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