Role Reversal of Elderly Caregivers for People Living with HIV and AIDS in Uganda: A Case study of Masindi District

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Abstract

African nations are progressing in healthcare, yet HIV/AIDS remains a concern in adults aged 15-49, who are crucial to the workforce. Amidst fragmented family care system, the elderly women care for the sick family members and orphaned grandchildren. This study investigated the role reversal of Elderly Women Caring for People with HIV/AIDS in Masindi District, Uganda. Using qualitative methods, in-depth interviews were conducted on purposefully recruited 18 elderly women caregivers and 6 key informants from The Aids Support Organization (TASO) and Masindi Hospital. The results showed that when caring for dependent adult sick children and young orphaned grandchildren living with HIV, the elderly caregivers repeated most tasks they had previously performed for their children when they were still young, resulting in role reversal. This dynamic resulted into caregivers' emotional burnout. Addressing the elderly caregivers' unique needs in HIV/AIDS care policies is crucial for their psychological well-being amidst shifting socio-cultural expectations.

Key words: Role reversal; Elderly Women; Caregivers; People Living with HIV/AIDS; Uganda Masindi District

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Introduction

Families served as an organising factor in the traditional African setting, providing structure to relationships, duties, and behaviour that was passed down from one generation to the next (Mtshali, 2016). Reciprocity was essential, and parents frequently invested in their children's health, education, and general well-being with the hope that their offspring would take care of them when they grew older (Nhongo, 2004; Saengtienchai & Knodel 2001; Williams & Tumwekwase 2001). Proverbs like "When your elders take care of you while you cut your teeth, you must in turn take care of them while they are losing theirs" (Apt, 1996, p. 22) are cultural expressions of this worldview that serve as a constant reminder to kids of these expectations (Mtshali, 2016). Therefore, traditionally, having children served as both a financial resource and a safeguard against old age (old age assets), and the number of children one had determined the level of support expected (Nhongo, 2004). Extended family took in and looked for the elderly (Kimuna & Makiwane, 2007).

The expectations of children to care for their old parents have been challenged by a number of challenges in the modern era. African societies have seen significant shifts in the responsibilities that older people play within families throughout time (Kosse, 2012; Nhongo, 2004). There has been a reversal in roles, with older people contrary to African tradition becoming the sole caregivers and breadwinners to the younger generations (Kimuna & Makiwane, 2007; Tanga, 2008). Although factors like unemployment, formal education, and a modern way of life, among others contribute in the change of roles played by older people, HIV/AIDS has currently exacerbated this role reversal experiences in the affected communities (Lekalakala-Mokgele, 2011; Nhongo, 2004). In Sub-Saharan Africa (SSA), 4.2% of the traditionally productive adults who are parents and breadwinners aged 15–49 are infected with HIV, with Uganda recording 6.5% (UNAIDS, 2016, 2017; WHO, 2017; Schatz & Ogunmefun 2007). Furthermore, in SSA, HIV-related causes of deaths in 2022 were estimated to be about 380,000 (WHO, 2024). This destabilises the established traditional support system for the elderly (Schatz 2007).

Due to the AIDS epidemic, elderly parents are seen changing roles by assuming the responsibility of providing full support, and care for their adult children with HIV/AIDS, and as surrogate parents of their orphaned grandchildren (Munthree & Maharaj, 2010; Nala- preukeser, 2014; Ainsworth & Dayton, 2003; Fouad, 2004; Bock & Johnson, 2008). This is due to

circumstances like spousal abandonment of the HIV infected adult child, or the necessity of providing care as the HIV/AIDS adult child's mother; and living together in a family home prior to the illness's onset (Nala- preukeser, 2014; Tarimo, Kohi, & Outwater, 2009). Moreover, many adults with AIDS-related illnesses return to their parents' homes when they can no longer manage independently, placing the parents in the role of primary caregivers (Ntozi, 2001). This situation often imposes significant physical, economic, and social burdens on the elderly, who may already be impoverished and not ready for this new responsibility (Nhongo, 2002). This leaves the older parents with challenges to overcome despite their incapability, which negatively impacts their health and well-being (Phetlhu &Watson, 2014).

Also, due to the HIV/AIDS pandemic, the elderly have been increasingly involved in filling the gap left by other population groups, by caring and upbringing their grandchildren (Bigbee et al., 2010), the situation which Nhongo (2004) terms as 'Africa's Newest Mothers', due to the new roles adopted at an old age. In SSA, 11.5 million children were orphaned due to AIDS in 2020 (UNICEF, 2021), of which most orphans are living with grandparents (UNICEF 2003). With this, the elderly become responsible for the economic, psychological and social support, food, clothing and school fees of these orphans (Kosse, 2012; Nhongo, 2002). This conflicts the traditional expectation role that older peoples are to guide their families and communities. For instance, the elderly traditionally played vital roles within their communities, including fostering social cohesion and transmitting cultural norms, values, and knowledge across generations. They served as custodians of tradition, preserving ancestral knowledge and ensuring its continuity from older to younger members of society (Nhongo, 2004).

A significant body of evidence above support the view that HIV/AIDS pandemic over the years has altered the roles of older people in the affected communities by taking on parenting responsibilities again after children have been raised, which requires many older people to readjust (Bullock, 2004). Unfortunately, in many African countries, these roles are performed without support (Nhongo, 2004). Also, available studies fail to recognize that death and loss from HIV/AIDS have the women's positions in many societies as many now assume the role of breadwinners, a role traditionally held by men (Iwelunmor & Airhihenbuwa, 2012). Moreover, there is a great deal of literature on HIV/AIDS and its impact on the orphans (Hill et al., 2008; Nyasani et al., 2009) but limited data exists on the role reversal of older people who provide care

to adult children with HIV/AIDS and subsequently orphaned grandchildren (Mtshali, 2016; Bohman et al., 2007; Bullock, 2004; Kimuna and Makiwane, 2007; Nyasani et al., 2009). Furthermore, because of strongly deep-rooted gender and sociocultural norms, women have historically been assigned the duty of caregivers (Kimuna and Makiwane, 2007).

Due to the dearth of literature on the role reversal experienced by older persons due to HIV/AIDS pandemic in Africa, this study aims at offering insights into the experiences and adjustments that older women in Masindi District, a rural community of Uganda make as they transition from the role of a parent and a grandparent into the role of sole caregivers for their adult children in reproductive age groups as well as their grandchildren. This will provide an avenue of the government of Uganda as well as other African countries grappling with the effects of HIV/AIDS pandemic to put in place interventions that are culturally relevant to support older people providing intergenerational care amidst family disruptions and missing generations.

The Care Burden of Older people

Due to the mortality of younger generations from HIV/AIDS, most African nations are experiencing a rapid transformation in the structure and roles of families. Elderly people suffer when young adults pass away since it not only takes away their lives but also the resources invested in them. The growing number of orphaned children is another effect of HIV/AIDS (Kimuna & Makiwane, 2007; Chazan, 2008). When they would have rested, elderly people in HIV/AIDS-affected nations take on the role of primary caregivers for their adult children who are HIV-positive and their orphaned grandchildren (Chitaka, 2012; Seeley et al., 2009; Musil et al., 2009; Schatz & Gibert, 2014). This results into the reorganization of existing family structures (Lindsey et al., 2003). Unfortunately, older people peform this role when facing hardship and when themselves are in need of support (Kimuna & Makiwane, 2007; Nhongo, 2004). Therefore, the major effect HIV/AIDS on population ageing is the burden placed on older people in terms of filling the gap left by other population groups in providing care and support to other family members (Moore & Henry, 2005).

In addition, more elderly parents are finding it difficult to deal with the various effects that HIV and AIDS have on their households, communities, and families (Nala-Preusker, 2014). For instance, HIV/AIDS has a catastrophic financial burden because it is an extremely costly condition in Africa, requiring, among other things, that the afflicted person be given a well-balanced diet

and pay for medical treatment. Poor living conditions and an economy dependent on cash are the results of this (Kyomuhendo et al., 2021; Moore & Henry, 2005). Furthermore, because they frequently lack energy and are unemployed, the majority of older carers are less likely to have a steady source of income to support them in their job as carers (Chitaka, 2012). Older people struggle to provide for themselves and their dependents when they have no means of support. When they do make some money, they frequently deny themselves the little they get in order to feed the family, which puts them at risk for food deprivation (Mtshali, 2016).

Furthermore, when older people are stigmatized due to having a relative infected with HIV/AIDS, it affects them psychologically and socially (Kyomuhendo et al., 2021). Again, their psychological wellbeing is worsened especially when they witness the health of their relatives deteriorating (Jones, 2012; Ssengonzi, 2007). With limited resources and support, older persons are ill-prepared to provide this level of care, and emotional consequences in the form of stress, sadness, tension, and worries are unavoidable (Boon et al., 2010). Additionally, most older persons are increasingly experiencing non-communicable diseases, like diabetes, hypertension, high blood pressure, among other chronic illnesses (Kyomuhendo & Adeola, 2021). Therefore, the burden of caring for adult children infected with HIV/AIDS and later orphaned grandchildren is heightened by their own ailing health (Mtshali, 2016). This is because activities involved in care like lifting, washing, bathing, among others results into physical ailments like chest pain, leg pain, backache, among others which makes the role stressful (Kyomuhendo et al., 2021; Amoateng et al., 2015; Munthree & Maharaj, 2010).

Older people and Intergenerational Care Support within the African Family

According to Bohman et al. (2009), "to be old" in African languages denotes knowledge and wisdom. Because of this, elder people have historically played a significant role as cultural ambassadors and have been in charge of mentoring and counselling younger family members. Once more, their responsibility was to guide their families' and communities' rites and ceremonies in order to guarantee their continued existence (Nhongo, 2004). In addition, the majority of African communities integrated and looked after elderly individuals within extended families (Kimuna and Makiwane, 2007). But the family, a crucial institution, is under attack, endangering both its continued existence and its ability to take on the burden of providing care (Mtshali, 2016; Moore & Henry, 2005). HIV/AIDS is disrupting family structures by transferring the burden and pattern

of tasks on the aged family members, who are either unfit to carry them out or believe they had fulfilled their obligations (Bohman et al., 2007; Nyasani et al., 2009; Petros, 2010). Again, HIV can infect several family members and multiple generations at once, thus restricting the economic streams that older Africans usually rely on for assistance (Moore & Henry, 2005). Again, the disruption caused by the AIDS epidemic at the family level is that the lives of young adults in the prime are lost. This changes family structures with increasing older people-headed and "skipped-generation" households (Alpha KM Kosse, 2012). This places older people at the forefront of the epidemic as caregivers.

Moreover, it is customary for members of the extended family to collaborate in order to care for ill family members (Lekalakala-Mokgele, 2011). In contrast to the support that comes from the extended family, the problem of HIV/AIDS confidentiality limits the number of individuals who may offer care (Nhongo, 2004). This is not the same as the past, when helping needy families may involve the entire community (Kosse, 2012). As HIV/AIDS robs families of young adults, particularly those between the ages of 15 and 49 (UNAIDS, 2012), it is become more difficult to provide the necessary assistance to all those in the society who require it. Therefore, elderly people are on the front lines of caregiving during this AIDS crisis, a phenomenon some authors have dubbed "role reversal" or "change in roles." This is from being provided and cared for by the younger generation, to being the sole care providers for the younger generation (Ainsworth & Dayton 2003; Kakooza, 2004; Kakooza & Kimuna, 2006; Kimuna & Makiwane, 2007; Nala-Preusker, 2014). Again, family care may be restricted as a result of refusals to offer care owing to financial hardship, obligations at work, or stigma, which lessens the ability to meet the needs of their members (Moore & Henry, 2005).

Besides, HIV/AIDS is changing demographics, and household structures as a result of missing generations (Kakooza & Kimuna, 2006). Currently, elderly women are increasingly heading households and caring for AIDS orphans, which make them primary breadwinners. For example, study findings by Kimuna and Makiwane (2007) indicate that nearly 76% of the participants were the sole breadwinners in the households that included more than one generation. It is worthy to acknowledge that under such circumstances, older people provide care not only to their biological children, but also to extended family members such as siblings, grandchildren, and sons-or daughters-in-law (Chepngeno-Langat, 2008). This varied nature of relationships among

caregivers and care recipients make older people‘s role clear, as not only the heads of their immediate family, but also the extended family network, whose responsibility is not only limited to social roles but also includes a financial commitment (Iwelunmor & Airhihenbuwa, 2012).

The loss of income and support due to HIV/AIDS places a significant strain on multi-generational households, where older women's pensions often become essential for both crisis situations and daily subsistence (Schatz & Ogunmefun, 2007; Nyasani et al., 2009). Kimuna and Makiwane (2007) note that older family members, primarily women, bear the financial burden of caregiving, including medical expenses, basic necessities like food and utilities, and funeral costs, often utilizing their pensions to cover these expenses. Moreover, Munthree and Maharaj (2010) found that grandparents caring for grandchildren have to meet various needs such as education, healthcare, and basic necessities, which younger relatives would typically fulfill if they were available or in good health (Kakooza & Kimuna, 2006; Knodel & Im-Em, 2004).

Limitations

The fact that the translation from Runyoro to English was not exact may have affected the study's findings. However, the researcher tried to use the closest words that accurately expressed the thoughts of the individuals. Again, a translator who was fluent in both languages was also hired to listen to the recorded interviews and go over the translated transcripts in order to reduce any discrepancies in the data.

Materials and methods

Research design and participants

There have been previous descriptions of the study's population, setting, and data collection methods (Kyomuhendo et al., 2021; Kyomuhendo et al., 2021). Briefly, this is a qualitative sub-study that is part of a bigger study about the "Experiences of Elderly Women Caring for People with HIV/AIDS in Masindi District, Uganda." In this study, a qualitative approach was chosen because it enables direct communication between the researchers and participants, allowing them to gather data through direct observation of participant behaviour and actions (Creswell, 2014). This enables in making clear the meanings that people or groups attribute to social or human

problems (Creswell, 2009). Employing purposive sampling technique to select the study participants, data were collected from in-depth face-to-face interviews with 18 elderly women caregivers (60 years or more) and 6 key informants (from The Aids Support Organization (TASO) and Masindi Hospital). In totality, 24 participants were used in this study as by then no more new information was being obtained from the participants' responses to the interview questions.

The elderly caregivers for persons with HIV/AIDS were residents in Masindi district providing care to children with HIV/AIDS of less than 18 years, adults with HIV/AIDS of 18 years and above, or caring for both children and adults in the given age groups. Assuming a role of a sole caregiver at an age of 60+ years to totally dependent adult sick children could cause an emotional and economic toll to the caregivers as at this age the older parents expect to rest and be taken care of by their adult children due to the deteriorating health that come with ageing. Studying the role reversal experiences aimed at understanding the meaning the elderly caregivers gave to the unexpected role they performed of giving care to adults infected with HIV/AIDS, who are instead supposed to be caring for them in their old age, as it is expected in traditional African society. Key informants included the counselors, social support department officer from TASO and nurses from Masindi Hospital was that they must have worked with HIV/AIDS related cases for a period of one year or more. Their selection was based on their experience through interactions when working with caregivers in providing services to their sick persons, and their knowledge on how the epidemic affects these caregivers. Both the caregivers and the key informants were to be fluent in either English or Runyoro (the local language).

Data collection and analysis

Data were collected from TASO– Masindi branch and Masindi Hospital situated in Masindi district, Uganda. The study sites were selected because Masindi Hospital (public owned) and TASO (NGO) partner and network in providing services to persons living with HIV/AIDS and their families. They were reliable for getting participants who could provide the best information for the study. Also, a representation from the two agencies (public and private) would provide at least a balanced view of key informants about the experiences of elderly caregivers for persons with HIV/AIDS and how effective their intervention and support services are in meeting caregivers' needs and their families. This was to help identify the gaps in services, hence creating room for improvement and the involvement of the government and other stakeholders to support.

Data collection and analysis procedures

Before commencing with the study, ethical clearances were obtained from the AIDS support organisation research ethics committee and the University of Ghana Ethics Committee for Humanities. Permissions to collect data from the two study sites were sought and granted, after which the in-charge ART clinic at and a counselor at Masindi hospital and TASO respectively helped in identifying the participants. The purpose of the study was explained to the participants to enable them to voluntarily accept to be part of the study. Additionally, confidentiality was highly considered in this study by holding the interviews at places comfortable to the participants to ensure privacy including homes and private rooms for elderly caregivers and offices for key informants. Again, in reporting the findings, accrual names of the participants were concealed. The interviews were conducted in both English and the native spoken language (Runyoro) and this was based on what the participants were comfortable with. The interviews lasted for a minimum of forty minutes and a maximum of ninety minutes. Also, permission to audio record the interviews was sought and granted by the participants. The audio recordings were transcribed from audio to a text format using Microsoft word processor and analyzed thematically. This was supported by rapid assessment of summaries from the field notes.

Findings

Socio-demographic characteristics of respondents

The elderly caregivers' age distribution indicated that twelve of the respondents were ranging within the young-old category of 60–74 years, while four were in the middle old category (75 to 84 years) and two were the oldest old (85 and above). Eight of the caregivers were providing care for their grandchildren, five were providing care for biological children, three were providing care for both biological children and grandchildren simultaneously, one was providing care to an in law, and the last participant provided care to a niece. Half of the caregivers (nine) provided care for HIV/ AIDS adults aged 18 or more, seven provided care for HIV/AIDS children aged 3–17, while two provided care for both age groups. Concerning the number of people in the **household**, eleven caregivers were living with 5-10 people, while five had 1-4 people, and two had more than 11 people. Most of the caregivers (seven) were the breadwinners of their households, five indicated

to have combined support from various people, four indicated children, one noted grandchildren as the breadwinners, and the last participant indicated the spouse as the breadwinner.

The Role Reversal Experienced by Elderly Women when Caring for Adult Children with HIV/AIDS

In relation to the African traditional setting, the study found that the participants' cultural expectations of having their adult children to take care of them in old age had been altered by the HIV/AIDS pandemic. Participants noted that they had always wished to have a free life, enjoying provisions and care from their children in old age, which was not the case. They had to take on new roles of being full-time caregivers to their HIV/AIDS adult children, who were the breadwinners before illness. In their own voices, they expressed:

> *… Children are like a bank for us in our old age like this, where they have to provide all the support to you. So I as an 86 aged mother, when I start providing the same support I provided to her when she was still young and dependent, such as looking for her food to eat, paying for her needs, persuading and sometimes forcing her to take medicine, it is different from what I expected and this grieves my heart (Caregiver 4, taking care of 60-year-old daughter).*
>
> *I hoped to get care, comfort and provisions from my child in my old age. When she fell ill, I started experiencing deep loneliness and fear within me because I may have nobody to do all those things for me. Seeing what I am going through, I cry a lot when I am alone… I imagine how I will be able to face life without her. Can I even manage to face the responsibilities of caring for my sick grandchildren alone? (Caregiver 15, taking care of 33-year-old daughter and 2 HIV/AIDS ill grandchildren).*

A key informant commented on providing full-time care responsibilities to adult sick children:

> *… So, the time these elderly parents would have been resting, when these roles are being carried out by their older children, they are like beginning afresh some roles they did some time back. That is what disturbs most of them. Some tell us when we go for home visits, "when I see my neighbors' children bringing them this and that, these are washing, and*

those are cooking for them, I feel bad, because in my case, it is me to wash for these children, to cook for them, and so on and so forth" (Key informant 2, TASO).

From the above, it is clear that with the HIV/AIDS illness of the participants' adult children, all the dreams and expectations of good life and care from their children are not fulfilled, as they have to repeat the roles they had done earlier for their children when they were still young. This was emotionally and physically draining to the elderly caregivers.

The elderly women experienced a change in roles due to the overwhelming responsibility of caring for adult sick children. The elderly caregivers noted that they were now heads of their households and thus were responsible for providing physical and financial support, planning, among others, which was very challenging with regard to their age and deteriorating health. Some participants recounted:

... I am also responsible for heading my household which includes planning for them and being a primary breadwinner, as it is comprised of my adult sick child and young grandchildren (Caregiver 1, taking care of 34-year-old daughter).

I now have to look for food to feed the whole of this family because we have to survive. No resting even at this age. The activities I provided to my child when was young I am repeating them even now that she is 44. Is it not a shame for me in the community? (*Caregiver 3, taking care of 44-year-old daughter*).

Some key informants had this to comment in support for the change of roles of the elderly women caregivers:

Their roles change in many ways. For example as elderly parents, they are supposed to be resting at those years. However because of taking care of their sick children, they are forced to do some roles like preparing food, before preparing even they have to look for the food itself. For those taking care of adult children who are bed ridden, they feed the person like a baby, wash their clothes, bath them, which are much for these old people (Key informant 6, Masindi hospital).

And they look for money to help in providing care, in things like buying them what they want, paying for their transport to the hospital, since the patients are weak, and they cannot walk, and the distance from their homes to the hospital may be far. Now because they are old and some don't work, they try to do what they can so that they get money to look after their patients (Key informant 5, Masindi Hospital).

Care for Orphaned Grandchildren and role reversal

The study found that the elderly women also had to care for the children of their adult children who ended up dying from the disease. Hence, they become the main source of support for these new members in the home. The elderly women expressed playing child-rearing roles where they provided for the basic needs of their orphaned grandchildren, including meeting their educational, physical, and spiritual needs. Moreover in order for the elderly caregiver to ensure that their grandchildren are well kept, they had to wake up very early to perform their roles. They indicated in the following narratives:

As old as you see him, his mother had never enrolled him in school, and now when I started staying with him, I took him to school and he has been promoted to primary two… So, my daily life starts early so that I get ready my grandchild, dressed, and fed for school. … I ensure that his personal hygiene and spirituality is good (Caregiver 6, taking care of 10 year-old HIV/AIDS ill grandchild).

Another thing is that I take care of his educational needs by helping him to do homework and I have to be going to his school for meetings and sometimes just to check how he is performing (Caregiver 14, taking care of 13 year-old HIV/AIDS ill grandchild).

A key informant added on the caregivers' new role of caring and supporting orphaned grandchildren:

…of course, taking up those other responsibilities of the young ones. Because if I am a mother and I get sick or I die, obviously it is my parent who takes on those responsibilities of caring for grandchildren. So, the responsibilities shift to the old women. They provide the

basics, even if it is buying books for these children to go to school, still it is them (Key informant 1, TASO).

More so, the most challenging role for these elderly women while attending to their orphaned grandchildren who were also infected with HIV was the financial aspect involved in meeting the required basic needs. Being of age and hence could not be economically active as before, the participants had to live from hand to mouth. When the in the worst situation, the elderly caregivers had to ensure that at least the needs of the infected grandchild are met while the rest the grandchildren with the caregiver inclusive are denied including dropping out of school. The caregivers lamented:

When I get one thousand shillings, I buy for him a glass of sugar, soap and other things he requires as a sick child (Caregiver 6, taking care of 10 year-old HIV/AIDS ill grandchild).

…I also find it hard to meet the education needs of these grandchildren. That is why the two have already dropped out of school moreover in primary six. Now it is only this sick child remaining in school, and she requires scholastic materials which I have not yet got and the term is almost beginning. Her uniform is also old and she keeps asking for the new one which we have not yet got (Caregiver 10, taking care of 7 year-old HIV/AIDS ill grandchild).

Playing a role of a sole caregiver and source of support to the orphaned grandchildren living with HIV after spending much time and resources while caring for their parents before dying could explain the poverty experienced by the participants. In amidst the current dwindling extended family support as opposed to the olden days, older persons are cleft overwhelmed by the burden of care shouldered alone.

Emotional experiences of caring for/ losing an adult suffering from HIV/AIDS

Worry

Being a primary caregiver of an adult HIV/AIDS sick child left the elderly women worried especially when they observed their children's health deteriorating. To the participants, seeing their adult children lying helplessly bed ridden or paralyzed meant they would be long-term caregivers and hence their wishes of having their children care for them in their old age being a dream:

I feel worried, because as a parent, I feel bad seeing my child's physical health declining and lying helpless in the bed. This comes especially when I am doing activities like bathing her, changing her positions, which makes her like a very young child (*Caregiver 3, taking care of 44-year-old daughter*).

I ask myself a lot of questions that why me? I wish God had left her legs not paralyzed. She could have continued doing her other activities and may be supporting me in one way or the other, but now see (Caregiver 1, taking care of 34-year-old daughter).

A key informant confirmed:

Definitely, their mind is always under pressure. Hmm they cannot look far. Like most of every parent, a child is hope. But if she sees hers is getting drugs which will not end, lifetime treatment, and she knows it doesn't heal, anytime this person will die, they are tortured psychologically…(Key informant 4, TASO).

Worry among the elderly women caregivers resulted from knowing that their children's health condition was lifelong as well as observing the health of those children depreciate.

Fear

The elderly women expressed fear of losing their source of support. This was especially for those participants whose adult sick child was the only breadwinner. This made the elderly parents see their future full of suffering. Furthermore, the elderly women caregivers with deteriorating health were afraid of not having responsible children in the future who would provide them a befitting burial as a parent when they die. This fear was aggravated particularly when the caregiver had lost other adult children to HIV/AIDS as lamented:

I get afraid because the child who has been providing me support has fallen totally sick... I see myself as a person who will suffer the rest of my life. What pains me is seeing my children leave me, now who will bury me? (Cries)… (Caregiver 1, taking care of 34-year-old daughter).

I am being disturbed now than before since I have developed sight problem... The one who could have attended to me is here sick and cannot do much. It is me rather

who is taking care of her. The rest of the children do not care and even are very far in other places (cries) (Caregiver 4, taking care of 60-year-old daughter).

One of the key informants had this to comments on the caregivers' fear:

… All the time they keep on thinking on their clients. They fear that when their daughter or son dies, who will take care of them? So, most of them suffer from depression (Key informant 5, Masindi Hospital).

The elderly women caregivers further had fear of the unknown and this was concerning what would happen to the little children of their care recipients in case they died. The lack of resources to take care of the young children who would be orphaned made the participants stressed. Again, the nature of the sickness the care recipient was suffering from and the stigma associated with it left the elderly women questioning themselves how the community would treat their household.

... You think of the disease the person is suffering from as it does not cure and then you look at the young children who will be left behind, what you will tell them what happened to their parents if they are no more. You see this fear in your heart also comes in of thinking what will be said about me and my children, and many things like that (Caregiver 15, taking care of 33-year-old daughter and 2 HIV/AIDS ill grandchildren).

… while providing care to your adult child you get very depressed. You know he/she is going to die. You look at the number of children being left behind without support for them. You again look at the money and time being wasted on this patient, an all these combinations stress you (Caregiver 8, taking care of 20-year-old HIV/AIDS ill grandchild).

What mostly brought fear among the elderly women caregivers was knowing that they might spend the rest of their old age as destitute without support and care from their children. Again, their inability to take care of the orphaned grandchildren alone without resources or extended family support increased fear among the aged parents.

Hopelessness

Hopelessness was portrayed by the elderly women who faced a double tragedy of losing multiple children to HIV/AIDS pandemic, as well as being the primary caregivers of

orphaned grandchildren of which some had been infected with the disease. When the aged parents remembered the caregiving roles, they had provided for a long time that did not yield any gain coupled with the gradual fading of their dreams and plans of having invested in their children for future support caused pain among the participants. In their own voices, they noted:

> *You cannot imagine the pain one goes through. For my case, the pain of providing care and burying eight children has affected me… (Caregiver 8, taking care of 20-year-old HIV/AIDS ill grandchild).*

> *The truth is that it hurts as you see that all the kind of life you dreamt of having when old is all shut down. For my case, out of the 12 children I had, four are dead by the same cause. We go through a lot when raising and educating them. So when they grow and we see them working, we have hopes that our days of toil are going to end. As they start supporting us with the small things they get, we become happy and proud of them. Now as you are planning, such disease comes in, robbing them away and you go back to scratch while taking care of the children left behind (Caregiver 13, taking care of 13-year-old HIV/AIDS ill grandchild).*

> A key informant added:

> *… They also share with us that the experience they go through is very stress full. They lament that "instead of my children taking care of me, they have all died and I have gone back to the olden days when I was giving birth, because I am taking care of the young orphaned grandchildren, who are also HIV positive. So, I have to spend sleepless nights when the child is sick, I have to give all the attention the child needs from a parent, the time I have to rest I have to look for food," and so on and so forth (Key informant 2, TASO).*

Discussion

Findings established that elderly women experienced role reversal when caring for adult children with HIV/AIDS. Role reversal as noted by participants occurred because they had always expected and wished to have a free life, enjoying provisions and care from their children in old age, which was not the case. The findings indicate that the elderly caregivers have now taken on full-time care responsibilities to their totally dependent HIV/AIDS adult children. Thus, repeating the roles they

had earlier on performed for their children when they were still young; such as providing the physical and financial care, material support, among others. This agrees with studies by Nhongo (2004); Saengtienchai and Knodel (2001); Williams and Tumwekwase (2001) that, parents' investment in the health, education, and well-being of their children often were based on the expectation that children will care for them in their old age. It is also in agreement with studies by Munthree and Maharaj (2010); Nala- preukeser (2014) and Kosse(2012) that, due to the AIDS epidemic, parents are forced to assume the responsibility of providing full support and care for their adult children with HIV/AIDS, where the elderly often provides economic, psychological and social support.

Furthermore, the participants' role reversal experiences continued even after the death of their care recipients by solely caring and supporting the orphaned grandchildren as previously noted by (Nyasani et al., 2009; Mduduzi Nkosinathi Gladwin Mtshali , 2016). In the current study, the elderly caregivers were noted to provide all the basic needs of their orphaned grandchildren including education, which came with a financial obligation as they had to enroll these grandchildren to school, provide the scholastic materials, and also help them do their homework. This role also forced them to wake up early to prepare their grandchildren for school, administer medication to them etc. This supports a study by Nhongo (2004) that, older people play a key role of bringing up children, the world's future capital, where they provide the physical, economic, and social support. Also, it agrees with Hawkins' (2013) study that caregivers' daily lives started early to get ready their grandchildren dressed, fed for school, and given medication. In communities greatly affected by HIV/AIDS pandemic, most family structures are disrupted as young able bodied working adults are lost leading to increased older people-headed and "skipped-generation" households (Alpha KM Kosse, 2012). This explains why in the current study older people were at the forefront of the epidemic as caregivers for both their adult children and totally dependent young grandchildren who were mostly HIV positive. This role was performed with limited or no resources as well as lacking extended family support care support (Kimuna & Makiwane, 2007; Nhongo, 2004).

Further evidence in the study indicated that caring or losing an adult child suffering from HIV/AIDS emotionally drained the participants. Watching their adult children suffer with a lifetime disease and subsequently having their health depreciate, fear of losing their only available

and reliable source of support increased varying emotional strains onto the elderly caregivers (Kyomuhendo et al., 2021; Jones, 2012). For elderly caregivers who had lost multiple adult children to HIV/AIDS, fear of the unknown concerning how they will end their life in old age, as well as how to care for orphaned grandchildren made them hopeless (AMI R. MOORE AND DOUG HENRY, 2005; Mduduzi Nkosinathi Gladwin Mtshali, 2016). According to Boon et al. (2010), with limited resources and support, older persons are not well equipped to engage in this extent of caregiving, and emotional consequences such as stress, sadness, tension, and worries are inevitable.

Conclusion

As shown by the findings of the study, elderly women caregivers experience role reversal when caring for their totally dependent adult children with HIV/AIDS. This is because they are forced to provide full-time care and also repeat some of the roles they had earlier done for these adult sick children when they were young. This situation makes the life of elderly parents miserable, as the adult children who are meant to serve as an economic security and also care for them in their old age are very weak and cannot support. Moreover, another phase of role reversal is experienced when caring for young or orphaned grandchildren who are left in the care of the elderly women, some of whom are HIV positive without any other source of support. This makes the aged parents repeat the child rearing roles, which could have been performed by their adult children, would they have lived or been in good health. The knowledge of the elderly women that they would potentially be long term caregivers to multiple generations simultaneously solely in a time they are meant to rest increased bitterness and regret among the participants.

Recommendations for Practice and Policy

Older people caring for their adult children living with HIV/AIDS are not equipped with skills to effectively cope with the burden of care assumed unexpectedly in old age. Moreover, support is rarely forthcoming from their families, communities, the government and other stakeholders to support them in the caregiving role shouldered, which results in emotional trauma. In order to ensure that the informal and formal care sectors cooperate in the struggle to fight HIV/AIDS pandemic, a holistic and integrated approach involving the unique needs of the elderly caregivers

is needed. This will help in ensuring that their psychological, and physiological wellbeing are promoted as they care for their adult children with HIV/AIDS in amidst their diminishing socio-cultural expectations

Participants in the study expressed their concern about education for grandchildren with HIV/AIDS in their care, since they were unable to meet the school requirements, such as uniforms, books, among others; thus, withdrawing their grandchildren from school. The researcher thus recommends that the Ministry of Education should provide or exempt orphaned children due to HIV/AIDS from such requirements, so as to help build an educated future human resource base for the country, by maintaining such children in school, and providing for their needs. This will relieve the elderly caregivers from the stress of meeting the educational needs and the pain of seeing their grandchildren drop out of school.

Again, as the number of people living with HIV/ AIDS increase, the Ugandan government, both at the central and local level, and various NGOs need to include elderly caregivers in policy development and program planning, on issues affecting them. Understanding the experiences of elderly caregivers in the informal sector is crucial in the formulation of practical policies/programs to ensure that they are working to meet their caregiving needs.

Direction for Future research

There is paucity of research on how HIV/AIDS has altered the role of older people as household heads and sole caregivers of their HIV/AIDS infected and affected family members. Because of this, there remains a gap in understanding the structural contexts as well as the collective norms and expectations that constitute and shape informal (family) care. Therefore, more studies are needed in HIV/AIDS affected African communities to help understand and appreciate the role of older people in the contemporary African informal care sector in times of crisis when social and family institutions are dwindling. Understanding the experiences and concerns of these caregivers should ultimately inform national and international programs to better account for African families in their own policies for care.

Also, the study targeted only elderly women caregivers, thus lacking male's perspectives on lived experience as caregivers to persons with HIV/AIDS. Therefore, future researchers can include

male caregivers to share their experiences since men also participate both in the informal caregiving. This will help improve the caregiving roles of elderly persons to PLWHA.

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