



## Research article

## Support services available for elderly women caring for people living with HIV and AIDS in Masindi District, Uganda

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## ABSTRACT

In sub-Saharan Africa, HIV/AIDS remains a big challenge and a leading cause of death among young adults, its main productive human resource. Hence, increasing the demand for care and support services by the epidemic infected and affected people. As a result, elderly persons, especially women are burdened to provide care and support; amidst disintegrated family support system and the inability of public and private sectors to adequately address their needs. The current qualitative study examined the support services available for elderly women caring for people living with HIV/AIDS in Masindi district, Uganda. A purposive sampling method was used to recruit 24 participants. In-depth interviews were conducted with 18 elderly women caregivers and 6 key informants. Findings indicated that the elderly women caregivers were at least receiving support from two major sectors; including the informal (family, friends, neighbors, religious and community groups) and formal (The Aids Support Organisation- Taso and the government) support systems. However, this support was not consistent and efficient for optimal caregiving. Therefore, more needs to be done by making both the informal and formal support systems fully available for elderly caregivers for HIV/AIDS people, thus, benefiting from direct intervention and support services to help meet their care needs.

## 1. Introduction

HIV/AIDS epidemic has caused devastating effects across the globe. WHO (2017) reveals that Sub-Saharan Africa is more affected with 1 in every 25 grown-ups living with HIV. In 2016, East and Southern Africa had approximately 19.4 million people living with HIV, while Uganda had 6.5 % HIV rate (UNAIDS, 2017). Caring for people living with HIV/AIDS (PLWHA) is demanding, and families play a pivotal role in providing long-term care (Wacharasin and Homchampa, 2008). In many developing countries, caregiving takes place in extremely limited conditions at home where access to formal health care system is inadequate due to poverty (Kipp et al., 2006). Depending on the care intensity, caregivers for PLWHA face unique challenges and demands, while having little government and NGO support (Pallangyo and Mayers, 2009; Nala-Preusker, 2014) (see Tables 1 and 2).

Caring/managing PLWHA, reducing and controlling the prevalence/spread of HIV have been major concerns. Hence, sub-Saharan African countries with Uganda inclusive have adopted numerous health and HIV care policies. Osafo et al. (2017) note that these policies are likely to have

caused major impacts on home based care for PLWHA, thus more up to date studies required. Uganda for instance has implemented two health policy and care reforms. The 2010 ministry of health shifting from vertical (stand-alone) HIV care programme to integrating HIV services into general health systems (Zakumumpa et al., 2018; Uganda Aids Commission (UAC), 2016). This aims at reducing the costs of HIV care and treatment services, meet the growing needs of PLWHA, and further ART coverage. However, the ability of Uganda's government to sustain these services remains uncertain as clear long term plans for HIV care lack, after international funding has reduced (Kakaire et al., 2016). Secondly, the ministry of health adopted the 2015 WHO recommendation that all people diagnosed as HIV positive should be enrolled on antiretroviral therapy irrespective of their CD4 counts (WHO, 2015).

Furthermore, Uganda's ministry of health, as well as other sectors, have developed particular standards and guidelines on the continuum of Counseling and Testing (HCT), prevention, treatment, and care, as well as Orphan and Vulnerable Children (OVC). These standards may be required in the future for monitoring and assessing service availability, accessibility, quality, and utilization (Ministry of Health (MOH), 2016).

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**Table 1.** Socio demographic characteristics of elderly women caregivers.

| Background Characteristic | Frequency (N) | Percentage (%) |
|---------------------------|---------------|----------------|
| <b>Age</b>                |               |                |
| 60–74                     | 12            | 66.7           |
| 75–84                     | 4             | 22.2           |
| 85+                       | 2             | 11.1           |
| <b>Education</b>          |               |                |
| No Education              | 6             | 33.3           |
| Primary                   | 10            | 55.6           |
| Vocation                  | 1             | 5.6            |
| Nursing Institution       | 1             | 5.6            |
| <b>Marital status</b>     |               |                |
| Married                   | 7             | 38.9           |
| Single                    | 3             | 16.7           |
| Widowed                   | 4             | 22.2           |
| Separated                 | 4             | 22.2           |
| <b>Number of children</b> |               |                |
| No Child                  | 1             | 5.6            |
| 1-5 Children              | 9             | 50.0           |
| 6-10 Children             | 8             | 44.4           |
| <b>Religion</b>           |               |                |
| Christian                 | 16            | 88.9           |
| Muslim                    | 2             | 11.1           |
| <b>Employment status</b>  |               |                |
| Unemployed                | 6             | 33.3           |
| Self-employed             | 10            | 55.6           |
| Retired                   | 2             | 11.1           |
| <b>Bread winner</b>       |               |                |
| Elderly Caregiver         | 7             | 38.9           |
| Children                  | 4             | 22.2           |
| Grandchildren             | 1             | 5.6            |
| Spouse                    | 1             | 5.6            |
| Combined Support          | 5             | 27.8           |

Source: Field Data, 2018.

**Table 2.** Socio demographic characteristics of key informants.

| Background Characteristic                      | Frequency (N) | Percentage (%) |
|--|---------------|----------------|
| <b>Sex</b>                                     |               |                |
| Male   | 1             | 16.7           |
| Female   | 5             | 83.3           |
| <b>Education</b>                               |               |                |
| Basic Certificate                              | 1             | 16.7           |
| Diploma  | 2             | 33.3           |
| Degree   | 3             | 50             |
| <b>Employment</b>                              |               |                |
| Counsellors                                    | 3             | 50             |
| Counselling coordinator/social support officer | 1             | 16.7           |
| Nurses   | 2             | 33.3           |
| <b>Employment Sector</b>                       |               |                |
| Private sector/NGO                             | 4             | 66.7           |
| Government/Hospital                            | 2             | 33.3           |
| <b>Working Experience</b>                      |               |                |
| 4–13 years                                     | 2             | 33.3           |
| 6–12 years                                     | 4             | 66.7           |

Source: Field Data, 2018.

In 2006 for example, the Uganda's Ministry of Education and Sports developed a policy and guidelines document on HIV/AIDS as a response to the Government of Uganda's requirement that each sector had to

develop a sector specific policy consistent with and which responded to the national overarching policy on HIV/AIDS and the national strategic plan. This document highlighted the measures and standards of HIV

treatment and care where all education institutions were to put in place measures for supporting learners, who may be HIV positive including referral for ART and management. Still under treatment and care, the education and sports sector was to create linkages and networks with significant government institutions, accredited civil society organizations and other partners in order to enable accessibility to HIV/AIDS treatment including ART, treatment of opportunistic infections plus other linked services. Also, the capacity of health facilities within education institutions was to be strengthened to either provide some or all the above treatment or to collaborate with the providers of such treatment to ensure adherence to treatment through follow up, or make sure that treatment is provided under supervision of a qualified health worker, while learners are at school (Ministry of Education and Sports (MOES), 2006).

Another important element that the 2006 Uganda's Ministry of Education and Sports document speaks about is the social support. Under this category, the Ministry of Education and Sports was to ensure that measures were put in place to assist students and learners, including OVCs, who were unable to attend school regularly or learn effectively due to HIV/AIDS (including remedial classes); schools and other education institutions were also to be encouraged to keep regular contact with parents, guardians, and local community leaders to ensure, psychosocial support, social protection and a supportive environment for such learners; the Ministry of Education and Sports was also to encourage and support school-based innovations aimed at supporting OVCs in gaining access to scholastic materials and other fundamental necessities, and schools were to collect, retain, and routinely update data on the number and status of OVCs in their schools (MOES, 2006).

The Uganda national HIV and AIDS policy developed in 2011 also has numerous standards and guidelines towards providing the needed services for persons infected with HIV and their caregivers. The policy strives to reduce the negative health consequences of HIV and AIDS by providing adequate medication, care, and support to all HIV-positive and HIV-affected people. This is accomplished by forming partnerships with the government, Civil Society Organizations (CSOs), Faith-based Organizations (FBOs), PLHIV networks, and others to provide treatment and care; developing a referral system between facility-based and community-based care; and establishing a referral system between facility-based and community/home-based care; supplying drugs for treating opportunistic infections and for reversing the progression of HIV disease and AIDS, including anti-retroviral (ARVs); and addressing nutritional and dietary needs of persons infected and impacted by HIV and AIDS. Furthermore, infected individuals and their families must be assisted in coping with the social, psychosocial, and economic effects of HIV and AIDS through appropriate interventions, as well as encouraged to participate in development efforts. Within their respective means, the government, civil society, communities, and households will share responsibility for assisting HIV-positive and HIV-affected people. And in order to reduce HIV vulnerability and promote equal access to impact mitigation services, the policy states that caring for children and young people affected by HIV and AIDS would be a collaborative effort involving the government, civil society, communities, parents, and guardians. The government and its partners will assist the promotion and execution of the policy and strategy for orphans and other vulnerable children (OVC) (UAC, 2011).

Moreover in 2016, the Uganda's Ministry of Health clearly stipulated the guidelines for prevention and treatment of HIV in the country. Under the section of care and support for People Living with HIV (PLHIV), the document mentions of a minimum care package that should be offered to all people living with HIV upon enrollment and during their entire time in HIV care. This care package is made of 10 service areas including: Clinical evaluation and monitoring of all HIV-infected people to ascertain WHO clinical stage of disease and exclude comorbidities; Antiretroviral Therapy initiation at the earliest opportunity in all people with confirmed HIV infection, regardless of clinical stage or CD4 cell count; Nutrition services by conducting nutrition assessment, counselling and support (NACS); opportunistic infection screening, prevention, and management;

screening and treatment of Co-morbidities; sexual & reproductive health services; adherence counseling by doing adherence preparation, monitoring, and support; psychosocial support & palliative care; and positive health, dignity, and prevention. Also, other prevention services are noted which involve providing immunizations according to the national immunizations schedule, educating and promoting the use of Insecticide Treated Mosquito Nets (ITNs) and educating and promoting the use of safe water, sanitation and hygiene practices (MOH, 2016).

Still in 2016, the Ministry of Health developed the national HIV testing services policy and implementation guidelines for HIV testing services including those at communities and Home based HIV Counseling and testing (HBHCT). Community HIV testing services aim to serve especially priority populations that otherwise would not attend facility based HTS. The services are to be offered in homes, social gatherings, education establishments and at workplaces. On the other hand, HBHCT is to be implemented through door-to-door testing for all consenting individuals, couples or families in a specified geographic area and index client contact tracing and testing that is offered to households with a consenting known HIV positive person or an active or suspected TB patient (index client) (MOH, 2016).

Although such and other health policy measures, standards as well as guidelines are established to improve HIV care in Uganda, their effective implementation across all regions in the country remains a question of concern. Additionally, there is little understanding on how these policies impact families providing the home based care. This is profound because Tanga (2008) notes collapsed social networks in high HIV/AIDS prevalence regions, despite the pressure of supporting orphans and PLWHA.

Also, regardless of above measures and standards of HIV care, some key issues and challenges have been recorded over the years to be confronting the fight as well as provision of support services for people infected and affected by HIV/AIDS in Uganda. These include reduced international funding to support HIV care; stock outs of key items including test kits, STI drugs and other supplies; limited funding for comprehensive Social and Behavioural Change Communication (SBCC) despite the low HIV/AIDS comprehensive knowledge; and lack of common technical programming guidelines for SBCC that would inform systematic monitoring and evaluation of such interventions. Also, reported are persistent human capacity gaps in terms of skills and numbers in implementing partner agencies; inadequate coverage of comprehensive combination prevention interventions; limited comprehensive knowledge of HIV/AIDS in that in some areas, there are still misconceptions about the causes of AIDS; and care and treatment gaps (retention and adherence especially among infants, adolescents and mothers to care due to weak follow-up systems, leading to loss of clients at all levels) (Kakaire et al., 2016; UAC, 2015).

The above situation may not be different from Masindi District Uganda, where PLWHA increased from 15,015 in 2015 to 23,729 in 2016 (MDLG, 2015; Masindi District HIV/AIDS bulletin, 2016). This raises the need for care and support services by PLWHA and their families, hence necessary to know how various caregivers are able to sustain HIV care. This study therefore explored the support services available for elderly women caring for people living with HIV/AIDS in Masindi district, Uganda.

## 2. Materials and methods

### 2.1. Research design

The setting of the study, population and collection data procedures have been described elsewhere (Kyomuhendo et al., 2020). Concisely, this is a qualitative sub-study within a larger research project on the "Experiences of Elderly Women Caring for People with HIV/AIDS in Masindi District, Uganda". A qualitative research design was appropriate because it enables the study to take place in a natural setting where participants experience the problem (Creswell, 2014). Using a qualitative design enhanced exploring sensitive issues and revealing through stories

the lived experiences and support services elderly women caring for PLWHA have.

## 2.2. Participants and study sites

A sample of 24 participants was recruited, comprising 18 elderly women caregivers of 60 years and above and 6 key informants (4 TASO officials and 2 Masindi hospital nurses). This is because according to Creswell (2009), an ideal sample size for a qualitative study should range from 5-25 participants to reach saturation. Thus, data collection from participants ended at 24 because saturation had been achieved, as no new additional data were being found. This was observed during the interviews, when the researcher began to hear the same comments as expressed in previous data even after asking probing questions. Furthermore, by using small sample sizes, the researcher is committed to discovery through the use of multiple ways of understanding. It is also possible for the researcher to use more than one method (e.g. interviews and observations) (Speziale and Carpenter, 2003).

The elderly had a caregiving experience of minimum six months, caring for children (3–17 years), adults (18 years and above), and both children and adults living with HIV/AIDS. The selection of 60 years and above elderly was because they are in a period when they are less productive and physically waning. Therefore, caregiving roles assumed at this age could come with other challenges if appropriate support lacks. Hence, the researchers wanted to understand the support services the elderly have to effectively provide care. Key informants had a one year minimum working experience with PLWHA and their caregivers, and were interviewed to ascertain their knowledge on interventions/support services available for elderly caregivers of PLWHA.

The study was conducted in Masindi district, located in Mid-Western Uganda, 216 km North West of Kampala, Uganda's capital City (Masindi District Local Government (MDLG), 2015). TASO– Masindi branch and Masindi Hospital were the study sites. Masindi Hospital is government-owned and partners with TASO (situated within the hospital) to provide HIV services (Otago, 2013; UMOH, 2016). TASO is an indigenous NGO founded in 1987 to pioneer HIV/AIDS response in Uganda. In particular, TASO Masindi branch establishment followed a 2004 baseline survey carried out in Bunyoro region, which showed the district having fewer AIDS service organizations yet with high HIV prevalence. The center offers counseling, medical care, social support, community mobilization and AIDS education, among others. Unlike other centers, TASO Masindi offers HIV Counseling and testing (VCT) in communities due to limited VCT services in the region (TASO, 2015).

These study sites were selected because they partner/network in providing services to PLWHA and their families, thus, reliable for getting participants with suitable information. Also, a representation from two agencies (public and private) would provide balanced information on how effective their intervention/support services are in meeting the elderly caregivers' needs. Hence, helping to identify service gaps and creating room for improvement.

## 2.3. Data collection and analysis procedures

The study was approved by TASO Research Ethics Committee, Uganda (Protocol # TASOREC/70/17-UG-REC-009) and the Ethics Committee for Humanities, University of Ghana, Legon (Protocol # ECH 070/17–18). Before commencing the data collection, the program manager at TASO–Masindi branch and the Masindi Hospital administrator were contacted, and permission obtained to conduct research with them. Afterwards, the researchers were introduced to the head of ART clinic at Masindi hospital and a counselor at TASO, who introduced eligible elderly women caregivers. An informational session was done to share details about the study. Key informants (nurses and counselors) were selected through head of departments, who identified people knowledgeable and experienced in working with PLWHA. All participants were

allowed to voluntarily make informed consents to participate in the study.

The researchers used an interview guide to solicit participants' information through one-on-one interview. Open-ended questions were used to obtain data, which enabled researchers' interaction and probing for more information from the participants. The interview guides were developed by the researchers in both English and Runyoro (local language), and interviews were conducted in both languages basing on participant's preference. With participants' permission, oral interviews were audio recorded, complemented with notes taking, and lasted for approximately 40 min to 1 h 30 min.

After collecting the data, it was transcribed into text format, through repeated playing of the audio recorder to make meaning of the information. Interviews conducted in Runyoro were translated into English and the researchers ensured content preservation. Data were coded basing on the study objective, which helped to develop various themes described in presenting the findings. The researchers described the data using participants' multiple viewpoints and synonyms were used to conceal their identities.

## 3. Findings

### 3.1. Demographics

The elderly women caregivers' ages ranged from 60 to above 85. However, majority (twelve) were young-old (60–74 years) as opposed to four (75–84 years) and two (85 and above years). The highest educational background of the caregivers was vocational and nursing trainings (Two), primary (ten), and no formal education (six). Seven were married, four widowed, four separated, and three never married. Nine caregivers had 1-5 children, eight had 6-10 children, and one had no child. Their religions were Christian (sixteen) and Muslim (two). Ten caregivers were self-employed, particularly engaged in petty trading. Six were unemployed and two retired. Most participants (seven) were household breadwinners, five had combined support from others, four indicated children, one noted grandchildren, and the last participant indicated spouse as the breadwinner.

Key informants interviewed were made up of one male and five females. Three of them had degree certificate, two had diploma and one had a basic certificate. Of the six, three of them were counsellors, one a counselling coordinator/social support officer and two were nurses. Four of them worked in a private sector/Non-governmental organisation with a working experience of about six to twelve years; and two worked in a government hospital with a working experience of four to thirteen years.

### 3.2. Informal support systems

Findings of this study show that participants had various forms of informal arrangements to support them when providing care for their relatives living with HIV. This included support from their family members, friends, neighbors, as well as religious and community groups. Support from these sources were noted to help in reducing the care needs which the elderly caregivers were faced with.

*Support from family members.* Majority of the participants shared their experiences of receiving support from their family members, of which children were mostly mentioned. This support from children was especially financially, materially (inform of foodstuffs and clothes), and socially (visitation). In the long run, the caregivers were relieved from some of the care burdens experienced. Some participants who received family support expressed:

*From my children, I get support in terms of money, material things like foodstuffs and clothes... They usually call to check how our day went and of course once in a while, come and visit (Caregiver 14, taking care of 13-year-old grandchild).*

... Another one is in form of social support by visiting and staying with me to provide company. When you have people around you, loneliness and burden of providing care is reduced (Caregiver 5, taking care of 6-year-old grandchild).

However, some participants lamented not receiving any family support which made their caregiving experience challenging. This is because these specific caregivers were finding it hard to meet their care needs. Some of the reasons highlighted for lack of family support was attributed to being neglected by their children as well as the poverty situation of their children which made it difficult for them to support their elderly parents. One participant recounted:

...My family has not supported me in anything, and when you ask for their support they will tell you they have a lot of challenges and problems to solve. So you even get ashamed to keep asking (Caregiver 15, taking care of 33-year-old daughter and 2 HIV/AIDS ill grandchildren).

A key informant confirmed on the elderly caregivers' lack of family support:

They generally have issues; some of them don't get support from the "so called children" who have brought the kids to them... (Key informant 6, Masindi hospital).

**Support from friends and neighbors.** Despite of the poverty situation faced by some households, other participants reported some instances of receiving support from friends and neighbors. This was in form of food items, financial and social support especially visitation, which helped in reducing the caregivers' burdens. Also, the visitation was reported to strengthen their relationship as the elderly caregivers and their HIV/AIDS care recipients felt still loved by their friends and neighbors. Friends in particular were noted to be helpful in providing financial support in terms of lending some money to the elderly caregivers when approached as well as providing emotional/psychological support by providing comfort and advice. One elderly woman caregiver noted:

...my neighbors are very good to me. Like that man there, he usually comforts us, you see him coming or sending children to bring us food when he has harvested. He shares with us everything he harvests. Friends have also been by my side and I run to them when I need to borrow money, or speak to them for comfort and advice when faced with a challenge. I do not know if I could have managed without them (Caregiver 15, taking care of 33-year-old daughter and 2 HIV/AIDS ill grandchildren).

**Support from religious groups.** Churches were noted to be supportive to the elderly women caregivers and their relatives infected or affected with HIV/AIDS. From the findings, spiritual; material (e.g. household items such as soap, salt, and sugar); and social support (visitation) were reported to be received from churches regardless of whether the participants were or were not active church members or other organized church groups. The spiritual support mentioned was inform of prayers which helped to keep the caregivers and their care recipients at peace and with hope/trust in God amidst the challenges and sickness. On the other hand, visitation enhanced a spirit of togetherness. Some churches were also noted to have welfare policies for vulnerable church members. Although not specifically for the elderly, they benefited from these policies because of their church membership. Some participant commented as follows regarding support the church support they got:

From the church, I get household items like soap, salt, matchbox, and money. This is given to all vulnerable people in the church of which I am one... (Caregiver 8, taking care of 20-year-old grandchild).

There is a church group called "Katwesengerenze" where I am a member. This is a spiritual group which moves to households of its members to pray with them, support them when they are in a problem like death, sick family member, and so on. In this group, we share testimonies and encourage our

members in challenges. Unfortunately, I stopped joining them because I have to be home, though they still support me... (Caregiver 12, taking care of 8-year-old grandchild).

**Support from community groups.** Community groups especially saving groups and charity organizations were cited to provide services that helped the elderly to care for their PLWHA. Also, individual community members were said to be visiting and providing food items. From the findings, it was also noted that participants who belong to associations in the community have emotional, economic, and social support, which help them to cope, due to connections with various people, as compared to those who do not join any association. In their voices, some elderly women caregivers noted:

Community members once in a while come to check on us, how we are doing, and sometimes they bring us food items since most of us here are farmers... (Caregiver 4, taking care of 60-year-old daughter).

I am in the support group community known as "Twekambe", which is for children with disability. He is a beneficiary because he has a learning disability. They gave us a she-goat and even come to treat it (Caregiver 13, taking care of 13-year-old grandchild).

However, some participants explained that being an active group member required payment of fees, of which money was lacking hence being a challenge. Also, the full-time care which was required of them limited their time to attend meetings. Thus, leaving the groups in order to reduce on the pressure from external sources which could hinder them from providing effective care. One of the caregivers echoed:

I was in a group, but I left last year because I could not manage balancing going for meeting and providing care... Another challenge was the money for depositing every week, which I failed sometimes to raise, so I quit (Caregiver 5, taking care of 6-year-old grandchild).

### 3.3. Formal support systems

Caregivers received services from two major organized arrangements which included the Non-governmental organization (TASO), and the government. Support from the government was mainly from the public district hospital and from the public schools which provide free education to the orphaned and vulnerable children.

#### 3.3.1. Support from non-governmental organizations (TASO)

The Aids Support Organization (TASO) was mostly mentioned by the participants to provide support for persons living with HIV/AIDS who received HIV care under the organization. This support in the long run benefitted either directly or indirectly the family members of the PLWHA. Also, although some services received from TASO were not directly benefiting the elderly as caregivers, they at least reduced their caregiving burdens experienced. The intervention/support received included: counselling, sensitization on HIV/AIDS, material and support to Orphaned and Vulnerable children (OVCs), free treatment, and home visits.

**Counselling.** Most participants acknowledged being often counseled by the counselors from TASO on every clinic visit when accompanying their care recipients. Additionally it was found that the counseling services were extended to a household level when the counselors went for home visits to make a follow up on how their clients were doing. This was recognized to create a cordial relationship between the counselors and the caregivers, as well as an opportunity for the participants to open up on the caregiving burdens encountered. Thus, counseling services from TASO helped the elderly caregivers in coping with the psychological/emotional challenges of caregiving faced. The narrations below summarize responses regarding counseling services elderly caregivers receive from TASO:

*I receive counseling on every visit I go. Counselors make sure they have talked to me or I tell them what is bothering me and they advise accordingly. When I consult them of anything about the disease, they open up freely and explain to the level of my understanding (Caregiver 14, taking care of 13-year-old grandchild)*

*... And of course, providing us with counseling services for free. When the counselors come for a home visit, they will talk to you, give you advice, and also encourage you (Caregiver 7, taking care of 18-year-old grandchild).*

On this account, key informants from TASO emphasized the provision of counseling services to HIV/AIDS clients and their caregivers:

*TASO provides counseling services to the caregivers and persons living with HIV/AIDS. We also try to build rapport with them so that they may open up when talking to them, which helps in identifying some issues that need attention (Key informant 2, TASO).*

*... We offer them counseling services to deal with the emotional challenges they face or may face in the future (Key informant 3, TASO).*

**Provision of information and education about HIV/AIDS.** It emerged from the findings that TASO counsellors and medical personnel provided the participants information and education about HIV/AIDS both at the health facility and during home visits. Specifically, the elderly women caregivers mentioned being taught on how to provide good care for their people living with HIV/AIDS; the modes of HIV transmission and prevention, and how to provide good nutrition. This information provided helped the elderly women caregivers learn how to provide care without infecting themselves with HIV, in addition to changing the wrong mindset they had on the ways how HIV is spread or prevented. Information on nutrition also helped the caregivers learn how to give a well-balanced diet to their relatives living with HIV/AIDS, hence, a door step towards drug adherence. One of the participants narrated:

*TASO educates us about HIV/AIDS, especially, about how to avoid contracting the infection. This has erased some misconceptions which I had about HIV/AIDS, thus, improving my caregiving roles (Caregiver 18, taking care of 47-year-old son and 21-year-old grandchild).*

A key informant added on how TASO provided sensitizations on HIV:

*We give them information on how best they can provide care for PLWHA ... there is a problem of myths by these elderly people, and most of them are not educated. If we don't give them the information, they are not going to offer the best service to these people. So we give them the information both at the health facility and at home, when conducting home visits (Key informant 1, TASO).*

**Free medical treatment.** From TASO, participants also received free HIV/AIDS treatment and other medical services for their care recipients. The free treatment from the participants' responses included not only ARVs, but also to other illnesses of their care recipients such as coughing and malaria treatment. This was noted to have been beneficial in reducing the medical expenses incurred when providing care. The caregivers stated:

*The free medication it provides has improved our health and they even treat other diseases which are not HIV related as long as you are their client (Caregiver 10, taking care of 7-year-old grandchild).*

*TASO gives free medication to this child. They told us that if she gets sick, we should not buy any medicine but take her to the offices for the doctors to treat her (Caregiver 7, taking care of 18-year-old grandchild).*

A key informant from TASO narrated the following in support of the free treatment and other medical services the elderly caregivers received for their clients:

*We give them free medication related to HIV/AIDS, and also treatment to any other sickness, such as malaria, cough, flu, and many others (Key informant 1, TASO).*

**Linkages and referrals services.** There are instances that the services needed by the elderly caregivers for their clients are not in existence at TASO as an organization, but rather are available in other organizations or bigger health care facilities. Therefore, it was found that when required services are not available at TASO, linkages and referrals are enacted. This helps the caregivers to get their care recipients' services from other service providers without many challenges. Thus, reducing the burden of providing care as noted:

*We also refer them to other service providers as long as we see that the services one needs we cannot offer them at the center. They may include legal aid, referral to big hospitals, and other agencies (Key informant 2, TASO).*

**Material support.** TASO as an organization provided services beyond the medical realm. That is, since some of the people they served lived in poverty and sometimes with little or no support from relatives, support in form of clothes and food were provided depending on the needs assessment made. The material support which was received by the elderly caregivers helped reduce their caregiving needs and improve clients' wellbeing. A participant described:

*TASO was giving her food items and powdered milk. Recently, she was given a 6 inched brand new mattress and a blanket. At least now she has a comfortable place to sleep on (Caregiver 11, taking care of 21-year-old grandchild).*

On the account of material support in form of nutritional support, a key informant indicated:

*We carry out nutrition assessment and if we find those who need to be supported, we normally give them some food supplements provided by USAID... but this is limited to clients who are diagnosed and found malnourished (Key informant 3, TASO).*

**Home visits.** TASO furthermore carried out home visits, to check clients' health, and also monitor how caregivers perform their roles. During home visits, HBHCT (Home Based HIV Counseling and Testing) services, which include voluntary testing are extended to the caregivers and other household members. This helps them know their HIV status and also continue providing care without fear. Some caregiver disclosed:

*Counselors from TASO usually come to check how their boy (client) is doing. This motivates us to continue providing care (Caregiver 9, taking care of 10-year-old grandchild)*

*They even come and visit her at home to check on how she is doing, how she is taking her medicine, and even advise us on what to do if at all we have challenges (Caregiver 7, taking care of 18-year-old grandchild).*

One of the key informants also explained how home visits is scheduled in the organization's work plan

*We do home visits. It is within our work plan to do home visit follow ups, more especially when we identify children with high viral load, and we target those families... (Key informant 3, TASO).*

Another key informant narrated how home visits enables them to provide Home Based HIV Counseling and Testing (HBHCT) services to the caregivers and other consenting household members:

*We extend to them HBHCT service. We prioritize this to our clients' homes, since there is a considerable risk in homes which have HIV/AIDS history. Some of these caregivers were exposed long ago and they have not had an opportunity to test... We therefore help them to know their status and when found positive, we enroll them on care (Key informant 1, TASO).*

### 3.3.2. Support from the government

This theme addresses the intervention/support services the elderly caregivers received mainly from the public district hospital as well as free public schools inform of universal primary education (UPE) and universal secondary education (USE). The support services in summary included: free medication, sensitization, counseling, pension benefit, and free education to their HIV/AIDS orphaned grandchildren.

*Free medical services.* Most participants noted getting free medical services from the hospital for both their family members living with HIV/AIDS and other household members. However, it was reported that the hospital services are not always the best due to lack of some prescribed drugs, thus necessitating the caregivers to buy them. This in the end increased the out of pocket expenditure. Moreover, this whole situation was hard for some poor elderly caregivers who could not afford the cost of such medicines in the pharmacies. Participants revealed in their own words:

*We get free ARVs from the government hospital where she gets her ART from. However, when some other drugs are missing like for appetite, blood, and so on, we are required to buy them, which is slightly expensive (Caregiver 17, taking care of 30-year-old sister in law).*

*My whole household is treated at our government hospital and everything is free, though sometimes their services are not all that good, but nothing to do since we can't afford going to the private hospitals (Caregiver 4, taking care of 60-year-old daughter).*

*Information on HIV/AIDS.* Participants received information on HIV/AIDS and care whenever they visited the hospital or on local radio stations during health programs. The information mentioned was on how best to provide care, nutrition and its relevance to adherence, among others. Also noted was the free counseling services received from the nurses. These helped the caregivers deal with emotional challenges, together with knowing what to do when providing care for people living with HIV. However, these services were not provided at a home based level as home visits for clients living with HIV/AIDS were not being carried out by the hospital staff during the time of the study. One of the elderly woman caregiver narrated:

*When we come to the hospital, the nurses give us information on how to best care for PLWHA. They also provide counseling which is helpful because sometimes you come with a lot of things running on your mind (Caregiver 1, taking care of 34-year-old daughter).*

One of the key informants confirmed on how the nurses did their best to provide the necessary information to the caregivers both on media and during hospital visit:

*... our side is to give them information. We do our best to provide it on radio stations, those who come with their clients here we tell them the importance of nutrition and adherence (Key informant 6, Masindi Hospital).*

Another key informant expounded on the necessity of the counselling services the nurses provide during ART clinic days:

*Usually, we give them on-going counseling, because if you don't continue counseling them, they forget and can't fulfill their duties properly (Key informant 5, Masindi Hospital)*

*Retirement packages.* From the study, the results showed that only two caregivers benefited from the government's pension scheme due to retirement. This money helped meet the cost of some basic needs, thus, depending less on their family support than those who are not on pension. In their own voices the participants explained:

*I do get my retirement benefit every month though it is small to meet the increasing needs I have at hand ... It is very helpful in meeting the needs required in providing care such as medication, transportation, buying food for the house hold, among others (Caregiver 3, taking care of 44-year-old daughter).*

*I do receive my pension from the government. With that at least I am able to meet some of the basic needs (Caregiver 17, taking care of 30-year-old sister in law).*

However, most caregivers expressed helplessness as they had been in the informal sector. Hence, being financially incapacitated as they were not pension beneficiaries or on other form of government subsidy. This made the caregiving situation hard for the elderly caregivers as they had to depend fully on their family support or sometimes on philanthropy benevolence from the neighbors, friends, churches and community. Moreover, this support was in most cases insufficient and inconsistent. Also, sometimes the elderly caregivers together with their care recipients felt being an added burden to other people which could affect them psychologically.

In a summary, one of the elder caregivers lamented:

*I have never received any thing from the government. Even, I have never heard our local leaders telling us of any services available for us (Caregiver 11, taking care of 21-year-old grandchild).*

*Free education services.* In order to reduce the illiteracy rates in Uganda, as well as increase the number of pupil/student enrollment and retention in schools, the government introduced free primary and secondary education for all, which is provided by government owned education institutions. Hence from the findings, it is pointed out by the participants that they received free education for their orphaned grandchildren, which reduced their economic burden of paying schools fees. However, the elderly caregivers mentioned that they had to meet some out of pocket costs like examination fee, and also provide all scholastic materials required such as book, school uniforms, among others.

One of the participants reported on how she received free education services and how this saved her from the burden of paying school fees

*... The government provides us with free education for our grandchildren. ... So we as the elderly poor people are saved from straining ourselves with looking for school fees (Caregiver 5, taking care of 6-year-old grandchild).*

Another participant narrated on how the out of pocket cost incurred becomes challenging for those taking care of many orphaned and vulnerable grandchildren:

*Even though we are told the education is free, we are being asked money for exams, or this and that. Sometimes if you are having more than five grandchildren you suffer because the money goes high. Still, we have to buy uniforms, books, and other things needed, without which children are chased from school (Caregiver 13, taking care of 13-year-old grandchild).*

### 3.4. Barriers for effective HIV service delivery

*Insufficient support from the government and NGOs.* From the findings, it was narrated that the intervention/support services in place both from the government and NGOs were not efficient for participants' optimal caregiving roles, as enough had not been done to support the elderly caregivers and their care recipients. This is because caring for people infected and affected by HIV required long term care, which came with increased financial expenditure (e.g. on transportation for hospital visits, nutrition, and other medication); increased psychosocial challenges (due to stigma, pressure from the amount of care required, reduced social interaction, etc.) among other factors. At the same time, support from informal arrangements was not reliable which left the elderly caregivers in a dilemma on how to sustain the care they provided. One of the participants summarized:

*The support we receive is not enough to efficiently sustain us in undertaking this important caregiving task. This leaves us in a situation where our personal needs are neglected. That is why sometimes an elderly caregiver can end up dying before the care recipient due to stress (Caregiver 16, taking care of 40-year-old daughter).*

Key informants also agreed that the intervention and support services in place were not efficient for the elderly caregivers' optimal caregiving roles. They remarked:

*...the support they receive is so meager and sometimes we don't reach everyone... (Key informant 4, TASO).*

*They are given some basic materials like books and children's school fees. However, this support has a limited coverage as anyone who is outside the central division does not benefit (Key informant 6, Masindi Hospital).*

*We live in a limited resource setting where we can't give it all and thus prioritize the clients, since most of our support comes from donors... We are given targets prioritizing a given activity, and hence compromise some activities. Also, the number is very overwhelming, that we may not reach out to everyone or all the homes because HIV burden has almost hit every home. So, we look out for those who are more vulnerable (Key informant 1, TASO).*

**Ineffective home based care providers.** Findings indicated that some elderly caregivers failed to administer drugs as recommended, especially to the HIV/AIDS infected grandchildren. They were also noted being forgetful in providing clients with drugs in the right time, besides missing clinic appointments. Also, the service providers noted that the elderly caregivers failed to control their adolescent grandchildren living with HIV. It was revealed that the elderly grandmothers pampered their grandchildren and failed to command them to take drugs. All these factors were considered to have impacted adherence which also made the recovery process difficult despite the good efforts out in by the health care providers to provide treatment as noted:

*There are some roles in which the caregivers are not effective, more especially when it comes to adherence to treatment. We have children who are taking their drugs twice a day, and the time should be uniform to ensure consistency. But for most elderly caregivers, time is a big challenge, and therefore sometimes not particular on the time these children are given drugs... They even forget the days of appointment, since it is the appointment systems that we use for our clients (Key informant 2, TASO).*

*Sometimes they are not authoritative enough to command the children to take drugs. In the long run, the children do not adhere well, their viral load shoots high and even their health deteriorates. That is why we are having high viral loads among children and adolescents being cared for by the elderly (Key informant 1, TASO).*

However, the interventions/support services received from TASO (NGO) and Masindi Hospital (Government) helped alleviate some challenges the elderly faced as caregivers. A participant expressed feeling satisfied with her caregiving role after seeing her grandchild's health improve due to treatment:

*I am happy with how the boy is coping with ARVs. Nowadays, he never gets sick as he used to be... Before starting treatment, he used to have wounds, malaria, cough, weight loss, and so on but they all disappeared. You can also see his looks. You can't tell that he is infected with HIV (Caregiver 13, taking care of 13-year-old grandchild).*

### 3.5. Discussion of findings

This study explored the support services available for elderly women caring for PLWHA. Current findings indicate that elderly caregivers receive informal support (family, friends, neighbors, religious/community group), which provide financial, material, social and emotional support. This supports [Amoateng et al. \(2015\)](#) and [Maradik Harris and Kim \(2014\)](#) who showed similar support sources for elderly caregivers. However, the family system is not effective as it used to be in supporting the elderly, hence, most caregivers found it hard to meet their care needs. This is because most children are unable to support their elderly parents due to financial inadequacy.

Under formal support systems, TASO (an NGO) and the Government were mentioned. TASO provided the caregivers services like counseling, sensitization on HIV/AIDS, free treatment, linkages/referrals and home visits. This confirms [Ntozi and Nakayiwa's \(1999\)](#) Ugandan study that NGOs such as TASO provide counseling and treatment services in a culturally appropriate manner. It also supports [Hodge and Roby's \(2010\)](#) study in Uganda, where participants received counseling, food, and medicine from TASO.

From the government, the elderly caregivers received free medication, grandchildren's education, pension, sensitization, and counseling services. Similar findings have been reported by [Knodel and Saengtienchai \(2005\)](#) in Thailand. However, participants indicated that even though their grandchildren's education was free, they paid some fee requirements and provided scholastic materials, which was challenging. This confirms [Kakooza and Kimuna \(2006\)](#) that the Ugandan government through the Ministry of Education does not provide other required fees like development fund, equipment fees, school uniforms, and books. Again, authors emphasize that the elderly caregivers' inability to afford such items made the children not enrolled in schools. Also, caregivers reported that sometimes drugs for their PLWHA lacked in the hospital, thus, buying them expensively.

Welfare programs/policies specifically for elderly caregivers for PLWHA were lacking in the district. This made caregiving burdensome as most elderly were not on pension scheme and at the same time not beneficiaries of the Senior Citizens Grants (SCG). This supports [Osafo et al. \(2017\)](#) that, there is no social protection policy for Home-based caregivers in Uganda. The authors add that the piloting of the Senior Citizens Grants (SCG) in six districts can be targeted to include senior citizens engaged in home-based care for PLWHA.

Even with the NGOs and government's interventions/support, some barriers were highlighted to hinder effective service delivery for optimal caregiving. These included: inadequate support for the elderly and their PLWHA due to donor's priority and limited coverage; forgetfulness to administer HIV/AIDS infected grandchildren drugs; missing clinic appointments; and failure to control adolescent grandchildren. These impacted drug adherences negatively. This support [Jones \(2012\)](#); [Urassa et al. \(2018\)](#); [Ugwu and Eneh \(2013\)](#), who reported similar findings.

Nonetheless, both government and NGOs played key roles in supporting the elderly to care for PLWHA. Participants reported positive experiences like satisfaction due to PLWHA's health improvement, after receiving services. This confirms [Bejane \(2012\)](#) that service providers were seen as lifesavers after care recipients were seen having an improvement in their health.

## 4. Conclusion

Although elderly caregivers for PLWHA receive some form of support services from the informal and formal systems, this support is not consistent and efficient for optimal caregiving. Therefore, more needs to be done by making both the informal and formal support systems fully available for elderly caregivers to help in meeting their care needs.

## 5. Recommendations

From the findings, indications show there being no welfare program specifically for elderly caregivers of PLWHA in Uganda. This made caregiving burdensome, since they experience numerous challenges when caring for their PLWHA. Also, at the time the study was conducted, Uganda had introduced a welfare program for elderly persons known as the Senior Citizens Grants (SCG), which was still effected in only few targeted districts and Masindi was not inclusive. Moreover, this program does not include elderly persons engaged in home-based care for PLWHA. Based on these, researchers recommend the Ugandan government to expand the Senior Citizens Grants (SCG) to include elderly women caregivers engaged in home-based care, or design a new policy targeting elderly caregivers of PLWHA and their families.



Findings revealed the government hospital not making home visits to monitor how their HIV/AIDS clients are managing with the disease. Also, drugs were sometimes lacking at the facility, hence the caregivers buying them costly from the pharmacies. Researchers recommend that there should be improvement in health care services by the Ministry of Health in collaboration with other HIV/AIDS service providers, to promote community based health care, and home visits to follow up PLWHA under the elderly's care. Additionally, enough drugs should be stocked in hospitals to avoid the elderly from spending. These efforts combined can reduce drug adherence deficiencies high reported among PLWHA.

The government and NGOs should establish community support networks targeting elderly caregivers for PLWHA, to provide social, emotional, material, financial and spiritual assistance.

## Declarations

### Author contribution statement

Clare Kyomuhendo: Conceived and designed the experiments; Performed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.

Alice Boateng, F. Akosua Agyemang: Conceived and designed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data.

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### Data availability statement

Data will be made available on request.

### Declaration of interests statement

The authors declare no conflict of interest.

### Additional information

No additional information is available for this paper.

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