AIDS Care

Psychological and Socio-medical Aspects of AIDS/HIV

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/caic20

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To cite this article: Clare Kyomuhendo , Alice Boateng & F. Akosua Agyemang (2020): Experiences of elderly women caring for people living with HIV and AIDS in Masindi District, Uganda, AIDS Care, DOI: 10.1080/09540121.2020.1832191

To link to this article: https://doi.org/10.1080/09540121.2020.1832191

Published online: 14 Oct 2020.

AIDS CARE
https://doi.org/10.1080/09540121.2020.1832191

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Experiences of elderly women caring for people living with HIV and AIDS in Masindi District, Uganda

Clare Kyomuhendo [a], Alice Boateng[b] and F. Akosua Agyemang[b]

[a]Bugema University, Kampala, Uganda; [b]Department of Social Work, University of Ghana, Legon, Accra

ABSTRACT

HIV/AIDS prevalence among adults aged 15–49 is increasingly affecting elderly women as caregivers. This study explored the experiences of elderly women caring for people living with HIV/AIDS in Masindi District, Uganda. Employing qualitative methods, 24 participants (18 elderly women caregivers and 6 key informants) were purposively selected. Data was collected from in-depth face-to-face interviews and analysed thematically. Findings revealed that participants performed numerous roles, resulting in economic, psychological, social and physical challenges. Coping strategies employed are problem and emotion-focused. Elderly women caring for HIV/AIDS persons will benefit from direct intervention and support services.

ARTICLE HISTORY
Received 26 January 2020
Accepted 29 September 2020

KEYWORDS
Caregiving roles; coping strategies; elderly women caregivers; HIV/AIDS; stigma

Introduction

Poverty and powerlessness characterise old age in developing countries where most elderly lack savings/pension (Beales, 2000; Choudhary, 2013), thus depending on their children's support. However, high HIV/AIDS prevalence is weakening this support (Kautz et al., 2010).

Globally, 36.7 million people were living with HIV/AIDS (PLWHAs) in 2016. In Sub-Saharan Africa, HIV/AIDS effects are higher with 4.2% infected adults, and Uganda with 6.5% among working ages 15–49 (UNAIDS, 2016, 2017; WHO, 2017).

Consequently, African families are left in a crisis, posing caregiving burdens on elderly women since caregiving is considered their traditional role (Kipp et al., 2006; Seeley et al., 2009).

Masindi District HIV trend

Masindi District records increased HIV prevalence. The 2006 HIV rate was 7.7%, and in 2011, 8–8.2% in mid- and south-western districts, including Masindi. Although 6.9% decline happened in 2014, Masindi District Local Government (MDLG) in 2015 noted 8.2% HIV rate higher than the national prevalence (Ministry of Health, 2010; Muzoora, 2006; UNAIDS, 2014). In Mid-Western Region containing seven districts (Masindi, Hoima, Kibaale, Kiboga, Kiryandongo, Kyankwanzi and Buliisa), Masindi ranks high with 10.6%. Moreover, the 2016 January–March Masindi District HIV/AIDS bulletin records 23,729 PLWHAs, increasing the care demands.

Care for AIDS is unlike other diseases, as it is long time. Hence, predisposes elderly caregivers to multiple vulnerabilities. Extensive research on HIV/AIDS and elderly caregiving in Uganda exist. However, little is known about elderly women caring for PLWHAs in Masindi District, Uganda, which motivated this study.

Methods

Research design and participants

Qualitative research design was employed. Twenty-four participants were purposively recruited, including 18 elderly women caregivers and 6 key informants (3 counsellors and 1 counselling coordinator from The Aids Support Organization (TASO), and 2 nurses from Masindi hospital). The caregivers were 60+ years, giving care to: (1) HIV/AIDS children aged 3–17; (2) HIV/AIDS adults aged 18 or more, and (3) both age groups.

Data collection and analysis

Study approvals were obtained from TASO Research Ethics Committee, Uganda, and the Ethics Committee for Humanities, University of Ghana. Through head of ART clinic – Masindi hospital and counselling coordinator – TASO, participants were recruited. An

CONTACT Clare Kyomuhendo clare.kyomuhendo@gmail.com Bugema University, P.O. Box 6529, Kampala, Uganda Clare Kyomuhendo

informational session was done, and their consent sought before the study. Two interview guides in Runyoro (the local language) and English were used to conduct in-depth interviews. Interviews were audio recorded, lasting between 40 and 90 minutes. All caregivers were interviewed in Runyoro and Key informants in English.

Data were analysed thematically by transcription into text format, data segmentation into categories, data labelling based on objectives, themes development, data description using participants' quotations, and data analysis by comparing findings with the literature.

The Runyoro interviews were first transcribed verbatim into Runyoro transcripts which were later translated into English. After transcription, an interpreter knowledgeable in both languages was employed to listen to the recoded interviews and read through the transcripts to check for data inconsistencies.

Results

Demographic characteristics of elderly women caregivers

Majority of the caregivers (twelve) were aged 60–74, four (75–84) and two (85 and above). Ten had primary education, one (vocational training), one (nursing training) and six (no education). Ten were self-employed, six unemployed and two were retired. Eight cared for grandchildren, five (biological children), three (biological children and grandchildren), one (in law) and one (niece). Nine cared for persons aged 18 and above, seven for persons aged 3–17, while two cared for both age groups. Four elderly caregivers were HIV positive and on antiretroviral therapy.

Caregiving roles

The caregivers provided nursing/health-related care by accompanying relatives to hospitals, managing/treating wounds and administering medications:

> … I set an alarm at every 7:00 am and 7:00 pm. when it rings; I leave whatever I am doing and give him drugs … (Caregiver of 13-year-old grandchild)

An informant supported:

> They are drug companions (someone always available to help clients whenever taking drugs). Their roles include reminding clients of time, encouraging them … coming for drugs when the client can't come on appointment. (Key informant, TASO)

Psychosocial care by advising, encouraging and spending time with PLWHAs was noted. Also, care for orphans by providing basic needs plus education occurred.

The elderly provided physical care to their bedridden, too weak or young relatives. This included cooking/feeding, bathing, washing and dressing.

Challenges faced

Economic challenges

Elderly caregivers expressed that the overwhelming needs and expenditures resulted into financial depletion and poverty:

> I have become poorer, hence begging for transport money … Some give and others ignore … upon reaching the hospital, she asks for bread. (Caregiver of 12-year-old niece)

An informant noted:

> Caregivers spend much on transport as they can't walk and clinics are far, and buy drugs lacking in hospitals … some patients stay long bed ridden which increases expenditure. (Key informant, Masindi Hospital)

Limited housing and sleeping materials were expressed. Again, financial challenges influenced withdrawing grandchildren from school; besides transport difficulties, thus missing clinic appointments.

Social/psychological challenges

Caregiving affected participants' mobility. Additionally, stigma made caregivers fear disclosing their relatives' HIV status.

Psychologically, worries; fear and hopelessness were experienced as relatives' health deteriorated. Furthermore, the long hospital waiting hours stressed the caregivers:

> I feel hopeless. She has been my only source of support, the apple of my eye … who will take care of me? (Caregiver of 44-year-old daughter)

An informant affirmed:

> Psychologically, they lose hope … They question themselves why their family because HIV has a trend that, when you get one family member infected, there's a likelihood of getting another. (Key informant, TASO)

Health, physical and nutritional challenges

Participants experienced physical ailments like chest pains, backache and sleepless nights due to caregiving activities. Others lacked gloves and disinfectants, thus afraid of contracting HIV and opportunistic infections like Tuberculosis (TB). Nutritionally, food insufficiency and unbalanced diets were expressed.

Coping strategies adopted

Problem-focused coping

Ten of the 18 participants (55.6%) sought support from family, friends and community. When support failed, they borrowed money or sold land to raise finances:

> I begged and got tired; until we started selling our land … Some of us go for loans. (Caregiver of 47-year-old son and 21-year-old grandchild)

Four participants (22.2%) adjusted time by waking up early, to perform the overwhelming caregiving roles.

Furthermore, participants adopted confrontative strategy to deal with negative reactions from people stigmatizing their relatives:

> They were beating my grandchildren whenever they went to play and I warned them … (Caregiver of 33-year-old daughter and 2 HIV/AIDS ill grandchildren)

Emotion-focused coping strategies

Although caregiving was difficult, the elderly accepted the role to help their relatives. Also, three caregivers (16.7%) used positive reappraisal by developing a positive mind, and hoping for relatives' improvement.

Fourteen caregivers (77.8%) adopted spiritual expressions like prayer and trust in God. However, spiritual expressions by seeking treatment from traditional healers occurred due to thoughts that relatives suffered from witchcraft.

Caregivers used actions like withdrawal from people by isolating, and avoiding visitations to shield their sick relatives from people they felt insecure around.

Negative emotion-focused coping strategies

Two caregivers (11.1%) adopted negative emotion coping of suicide attempt and alcohol abuse with hopes of solving their challenges:

> … I have hated myself and life. I had even decided to commit suicide to rest from this suffering. (Caregiver of 60-year-old daughter)

> When worries are too much, I take waragi (local brew). (Caregiver of 6-year-old grandchild)

Discussion

Findings revealed caregivers for PLWHAs perform roles like physical activities, psychosocial, nursing/health-related care, etc. After their relative's death, orphans were cared for (Evans & Thomas, 2009; Hawkins, 2019; Waliser et al., 2002).

The economic challenges resulted from insufficient income and high expenditure. This increased poverty; poor housing/sleeping materials; grandchildren's withdrawal from school and missing clinic appointments (Fauk et al., 2017; Knodel et al., 2003; Nala-Preusker, 2014).

Social and psychological challenges resulted from demanding roles; witnessing relatives' health deterioration and long hospital waiting hours. HIV/AIDS stigma disrupted caregivers' social lives (Jones, 2012; Ssengonzi, 2007).

Health wise, caregivers lacked gloves and disinfectants, which would lead to infection as some relatives had a double infection of HIV/AIDS and TB. Nutritionally, food insufficiency was expressed. The reported physical ailments (chest and leg pain, backache, sleep loss) resulted from stressful roles (Amoateng et al., 2015; Munthree & Maharaj, 2010).

The caregivers adopted problem-solving strategies of: seeking support, time adjustment, confrontation and borrowing money/selling land. Emotion-focused coping included: role acceptance, positive reappraisal, avoidance and spirituality (trusting God and traditional healers). However, some adopted negative emotion-focused coping of alcoholism and attempting suicide (Fauk et al., 2017; Kasiram & Hölscher, 2015; Nankwanga et al., 2009; Ssengonzi, 2007).

Limitations include: the used sample size limits generalisation. Regarding the back and forth translation of original responses from Runyoro to English, some data might have been lost as finding the exact meanings of some words in either language was sometimes difficult. To counter this challenge, closest equivalent English words were used to replace those that could not be translated directly from the local language.

Conclusively, elderly caregivers for PLWHAs need attention, by Ugandan government allocating a budget/policy offering financial support. Also, agencies/donors could provide direct interventions including food, beddings and housing to caregivers in limited resource settings.

Disclosure statement

No potential conflict of interest was reported by the author(s).

ORCID

Clare Kyomuhendo http://orcid.org/0000-0002-0552-9603

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