Poverty and food insecurity survival mechanisms for older persons with and without HIV/AIDS in a rural setting South Western Uganda.

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Abstract

We explored poverty and food insecurity among older persons living with HIV/AIDS (OPLHA) in a rural setting in central Uganda using individual interviews with individuals aged 60 and over. Our conceptual framework provides a lens for how food insecurity and HIV are connected through a complex interplay between bidirectional pathways including nutritional, mental health, and behavioural factors at the community, household and individual levels. Participants' narratives revealed that key factors in food security, and thus survival, among OPLHA include familial and social networks, informal labor as a means of income generation, and subsistence farming providing goods to exchange.The findings provide insight into the interconnectedness of older persons' food security with the available their health and access to help, and their livelihoods. We conclude that interventions are required to address the gaps in access to food, particularly among older persons in ill or ailing health.

Introduction:

Older people in Uganda face extreme levels of poverty and a heavy caregiving burden (Kasedde, Doyle, Seeley, & Ross, 2014; Kuteesa, Seeley, Cumming, & Negin, 2012; SCHATZ, SEELEY, NEGIN, & MUGISHA, 2017; Seeley, Wolff, Kabunga, Tumwekwase, & Grosskurth, 2009). In addition to diseases of aging, there are also now a significant number of older persons in Uganda living with HIV due to new infections at older ages and individuals living longer on antiretroviral treatment (ART) (Bakanda et al., 2011; Mills et al., 2011). There is existing research on the impact of food insecurity on adherence to ART in Uganda (Emenyonu et al., 2009; Nzabona, Ntozi, & Rutaremwa, 2016; Tsai et al., 2011; Tuller et al., 2010; Weiser, Palar, Frongillo, Tsai, & Kumbakumba, 2014). Yet, there is little information on older persons' coping strategies to deal with general poverty and food insecurity, or the ways that competing factors including HIV care, non-communicable disease management, and caregiving burdens impact their ability to cope.

The HIV/AIDS epidemic has affected older people in Uganda in different ways than their younger counterparts both indirectly and directly. Since the onset of the HIV epidemic, older people in Uganda have played a major role mostly in the provision of care to children orphaned by HIV/AIDS and provision of care to both children and adults with HIV/AIDS infection (J. Mugisha et al., 2013; Ssengonzi, 2007). Even with the introduction of ART, older people play a significant role in caring for children on ART and ensuring that these children adhere to treatment (Rwamahe Rutakumwa, Zalwango, Richards, & Seeley, 2015). On the other hand, older people themselves may be infected with HIV/AIDS and may also themselves need care (J. O. Mugisha, Schatz, Seeley, & Kowal, 2015). At the same time, chronic non-communicable diseases are increasing in Uganda, with older persons bearing the brunt of this emerging epidemic (J. O. Mugisha et al., 2016; Nyirenda et al., 2013; Scholten et al., 2011). Older persons, however, may not have sufficient resources – money or food – to address their multiple health care and caregiving needs.

Food insecurity has been defined as the limited or uncertain availability of nutritionally adequate, safe foods, or the inability to acquire personally acceptable foods in socially acceptable ways (Normén et al., 2005). In Uganda, food insecurity remains a problem, especially among the older persons who have to provide food for themselves and others they care for (Kakooza & Kimuna, 2006; Ssengonzi, 2007). In one study conducted in Mbarara in western Uganda, the prevalence of severe food insecurity was 38% and was more prevalent among women than men (Tsai et al., 2011). Within East Africa, food insecurity has been shown to worsen with increasing age and is more common in people affected by HIV/AIDS (Nagata et al., 2012). In Uganda, food insecurity may be worse in older persons since most of them may not have land where to grow their own food crops. The practice in this study setting is for people who do not have their own land is to borrow land and use it to grow food (RP Rutakumwa, Bukenya, Tumwekwase, Ssembajja, & Seeley, 2017). Even when land is borrowed, some form of payment in form of money or foodstuffs has to be paid to the landowner, which may not be feasible for older persons.

Older people in Uganda face extreme levels of poverty (Najjumba-Mulindwa, 2003; Okidi & Mugambe, 2002). Factors that have been attributed to chronic poverty among older people in

Uganda include ill health which increases with ageing, unemployment, lack of capital to start business, lack of support, caring for orphans due to HIV/AIDS and lack of savings and assets (Najjumba-Mulindwa, 2003; Seeley, 2008; Ssengonzi, 2007; Williams, 2003). Poverty and food insecurity are interrelated in that when people are very poor, they may not be able to have enough food for consumption.

In addition to consequences like malnutrition and ill health (Vozoris & Tarasuk, 2003), food insecurity contributes to non-adherence to ART (Palermo, Rawat, Weiser, & Kadiyala, 2013; Weiser et al., 2014; Young, Wheeler, McCoy, & Weiser, 2014). Various mechanisms under which this happens include: ART increases appetite and leads to intolerable hunger, side effects of ART are worsened in the absence of food, some participants may skip doses if they do not have enough food, competing demands between costs of food and medical expenses may lead people to default on treatment (Weiser et al., 2010). The cycle continues as insufficient food negatively impacts health and wellbeing, contributing to under production and poverty.

In the past, within most of the Ugandan setting, the main coping strategy for poverty and food insecurity was through help from the extended family . However, with the impact of HIV/AIDS on the families and with more young men moving away from villages to urban centres to look for employment, it is unclear how older people affected by HIV/AIDS cope with the issues of food insecurity and poverty. It is also not clear what roles informal social support networks play in enabling older people to cope. Since the social assistance grants for empowerment of older people in Uganda are only at a pilot level and do not yet cover all older people in Uganda (Merttens et al., 2016; Niño-Zarazúa, Barrientos, Hulme, & Hickey, 2010), it becomes important to explore how older people in Uganda cope with these two issues of food insecurity and poverty.

Through in-depth interviews (IDI) with older men and women this paper examines coping mechanisms related to food insecurity and poverty for three categories of older Ugandans those living with HIV and on ART, those living with HIV but not yet on ART, and those not living with HIV.

Conceptual Framework

Our research is guided by the work of Weiser et al. (2011). Weiser et al. (2011) developed a framework that illustrates how food insecurity and HIV are connected through a complex interplay between several bidirectional pathways (nutritional, mental health, behavioural, community, household and individual level pathways). In applying their framework to our study, we adapted their model to better reflect the context and population of our study. For example, at the community level, the original model has three distinct structural drivers: ecological, economic, and social factors. The most salient of these for our research are the economic factors, in particular poverty and its relationship with food insecurity survival mechanisms.

At the household level, Weiser et al. (2011) categorize food insecurity as perpetuated through nutritional, mental health, and behavioural pathways. Our research focuses on the behavioural pathways that influences the adoption of positive or mal-adaptive coping strategies. At the individual level, we identified two important components that further illustrate the relationship

between poverty and food insecurity survival mechanisms: nutritional pathways, and HIV progression and co-morbidity. Nutritional pathways are influenced by food insecurity (lack of affordability and quantity of food available); and it is at the individual level where decision making about food intake takes place. The relationship between co-morbidities and HIV progression complete the framework. Given the aim of our research, this modified conceptual framework enables us to outline the experiences of older people living with or without HIV in relation to food insecurity and their survival mechanisms.

Methods:

Study setting

Data for this study were collected from people aged 60 years and over who were recruited from Kalungu district in rural Southwest Uganda. Most of the older people recruited for this study participate in the ongoing general population cohort (GPC) study (Asiki et al., 2013). The population of the study area mainly practice subsistence farming and produce small quantities of coffee for selling. The main food crops produced include bananas, maize, beans and cassava. Because of seasonal changes and emergence of new crop diseases, especially coffee wilt and banana weevil, coffee and banana crops are failing. A small proportion of the population also rear pigs, goats, cows and poultry, mainly to get products for eating and then sell the surplus. Over 50% of the population is aged less than 15 years. However, the population of those aged 50 years and above has continued to increase and presently is around 3000 within the GPC cohort. Most of the households have small pieces of land (less than 5 acres) with very few landowners with sizable acres of land. However, some people are landless. The road infrastructure within the study area is not well developed and most of the roads are slippery in the rainy season. The most common form of transport is by small motorcycles commonly referred to as “boda boda”. In addition to using them for transporting merchandise, they are also used to transport sick people to health facilities.

Within the study setting, there are two pubic health care facilities at a health centre level three (Droti, 2014) and two big private health care facilities, one of which is run by the MRC/UVRI and LSHTM Uganda research Unit. At public health care facilities and at the MRC health care facility, all services are free. Treatment of people infected with HIV with combination antiretroviral therapy (cART) within the study setting commenced in 2004. Currently there are three health facilities within the study setting that provide ART to patients in need. About 250 (out of 3000) older people (50+) are receiving treatment with antiretroviral drugs from health facilities within the study setting. Since the introduction of ART in Uganda, ART treatment guidelines have changed and currently, the test and treat policy is being implemented. However, not all the people who test HIV positive are started on ART immediately because of some issues (Gardner, McLees, Steiner, Del Rio, & Burman, 2011).

Participant sampling

Three Health facilities in the study setting that provide ART to people infected with HIV/AIDS were approached in August 2016 for lists of older people (50-plus) accessing HIV services at these facilities. These lists included older persons who were already on ART and older people

who were living with HIV but had not yet initiated ART. In addition, we made use of a list of HIV negative older people who were participating in the ongoing HIV surveillance studies within the GPC. After stratifying by three categories (HIV+ on ART, HIV+ not on ART, HIV-), we randomly selected 20 participants in each category to interviewed. Six of those listed as HIV+ not on ART, had initiated on ART by the time of interview. Thus, this paper was draws on interviews with 26 older persons living with HIV on ART, 14 older persons living with HIV but waiting to be initiated on ART and 20 older persons who were HIV negative.

Data collection

The study was cleared by the Uganda Virus Research Institute Research and Ethics Committee and the Uganda National Council for Science and Technology. Prior to interviews, an information sheet with all details about the study was read to the study participants. All participants gave written/thumb printed consent. Data were collected through in-depth interviews using a semi-structured interview guide. The guide explored themes related to (1) participants' experience of HIV and ART; (2) overall wellbeing and quality of life; (3) social support networks; and (4) engagement with the health system. Respondents initiated on ART additionally self-reported their ART adherence, as well as barriers and facilitators to access, and treatment and medication adherence. Interviews lasted 1-2 hours, and were conducted by one of two members of the field team skilled in qualitative interviewing. All individual interviews were conducted at the participants' homes. Interviews were audio recorded and summaries for the interviews were made immediately after the interview without listening to the recorded script.

Data analysis

The field team had regular debriefing sessions with the project leader and PI during the data collection period to discuss the progress and outline impressions. Summaries of each audio recording, as well as full transcripts were completed for each interview. Adopting the thematic content analysis approach (Aronson, 1995), we inductively developed themes and analyzed patterns emerging from the data. Emerging from the theme of overall wellbeing and quality of life, were issues related to food security and poverty and how older people cope with these issues. Within the theme of social support networks, participants discussed issues related to poverty and coping strategies for food and poverty related issues. The research team (1) repeatedly read the summaries and transcripts to become familiar with the data, (2) coded the data by identifying key issues and recurrent themes related to food security issues and poverty and coping mechanisms by study participants, and (3) organised the themes into categories. The codes and themes were based on participants' accounts of food insecurity, poverty coping mechanisms and how these are related to ART adherence. The data analysis was done manually.

Results:

The aim of this study was to explore poverty and food insecurity mechanisms for older persons affected by HIV/AIDS in a rural setting in South Western Uganda. Analysis of the data revealed two overarching themes and several subthemes. In what follows, we explore the themes titled food insecurity survival mechanisms its related subthemes.

Food Insecurity Survival Mechanisms

Familial and Social Networks as a Source of Survival

Numerous participants discussed a myriad of ways in which familial and social networks operates as a source of survival in their lives. For example, one participant stated,

> *If manage to get what to eat today, in the evening I can decide to go to a friend to ask for something to eat say cassava. When I have my money, I buy food and when am not having, I go to my friends and they borrow me food since am a widow. I can't sleep with hunger when I have the friends. Some give me the food and they tell me to go and dig for them after. (Female aged 70; on ART)*

Not only does this participants' narrative illustrate how she uses familial networks in her time of need, her admission also illustrates one of the many ways participants strategize to help lessen experiences of food insecurity. In addition to the excerpt above, one participant discussed how her children helped her.

> *If I need support for food, I have my friends whom I go to. I send my children to them. When I don't have energy to move, I tell the children to go and ask for any kind of food from my friends be it matooke or cassava. When my son buys a bunch of matooke, he comes here and removes for me two clusters of matooke and he also takes the remaining two for his family. (Female aged 70; on ART)*

Likewise, a male participant on ART explained how his family was a source of support.

> *Like you know that eats are few now days, I don't have them still. A person who would have had two meals a day, I may have it once a day because of lacking money to buy maize flour. When time for eating reaches, I eat with my family, I don't feel bad, I feel happy when am with my family. (Male aged 63 years; on ART)*

In most cases, participants were very forthcoming about the ways in which their family came to their aid.

> *My children usually send me money support through mobile money, I then send one child with the phone to go and collect it from the mobile money shop. The money sent to me is for treatment or for buying maize flour for home consumption or school fees for the grandchildren. (Female 54yrs old HIV negative)*

Like the except above, the value of family was evident in the vast majority of the interviews.

> *If they wanted to send me some support Children send it to my neighbor's phone. At least every three months they can send me around 30,000 or 50,000 shs and the phone owner withdraws the money and gives it to me. Besides giving me money if anyone is coming to check on me, he stock items for me such as soap, salt, sugar and paraffin. (Female 53 years old on ART)*

Labour as a Means of Surviving

Labour as a means of surviving was an additional subtheme that emerged. This subtheme encapsulates how participants used manual labour as a means of survival. For instance, sentiments such as "I struggle and get food from my kibanja, failure to get it I labour in the village. When I get paid, the money helps me to buy food" were quite common within the interviews. Likewise, one participant discussed how she worked in the village,

Once I don't have money I bear the condition (live without any coin) when I get it, say I have laboured in the village and I have been paid, I stock all the essential needs such as soap maize flour salt and paraffin and remain without anything in my pockets but when I have what to use at home. Female 55 years old on ART.

As with the participant above, labour took on various forms as a means of helping the participants.

I do casual labour. Someone may call me to dig for him and he pays me like 10000/=. Sometimes I go to the hospital and the health workers take use of me, they may tell me to help them do something and they pay me some money in return. (Female aged 61; on ART)

Subsistence Farming as a Source of Exchange

Subsistence farming was the third most common sub theme that emerged from the data. Commonly discussed crops used included coffee, cassava, maize posho, alcohol and pork. For example,

The good thing is that we have coffee which is our bank, before she (the daughter) sends anything; I sell coffee and buy things which may be missing at home. (Male aged 78 years; on ART)

An additional participant added,

I thank God because coffee harvest has helped us a lot and it is what we are relying on but it is like having a single match (he meant that one used to light fire) because anytime it gets finished, we don't know how we are going to cope. (Male aged 62; waiting to be on ART)

As well as growing and harvesting coffee, many participants grew multiple crops as a means of survival.

I operate a pork joint from which I earn a profit between 5000 – 10000 shillings when I slaughter a pig. Another source of income, I brew local alcohol called Kwete (a product of cassava flour mixed with millet and water). I sell some of this alcohol in my bar and also sell to other bar operators in nearby villages. (Male 61 yrs old HIV negative)

In addition to highlight how farming helped them, participants also discussed the difficulties they faced.

During the prevailing condition it's somehow difficult to get food but I can get hard food such as cassava and maize posho. Previously I used to grow cabbages, tomatoes and eggplants both for sell and home consumption. (Male 57 years old on ART)

Discussion

The purpose of the study was to gain an in-depth understanding of the poverty and food insecurity mechanisms for older persons affected by HIV/AIDS (OPLHA) in a rural setting in South Western Uganda. By focusing on the narratives of these community members, the findings

set the stage for more concerted efforts to observe, analyze, and address the ways in which food insecurity impacts this vulnerable population.

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