Poverty, ageing and HIV in Wakiso district Uganda

by

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Abstract

**Background:** HIV is becoming increasingly common among older people but very limited data exist on the impact of infection on their lives and general wellbeing, particularly in resource constrained settings. This paper is based on qualitative data from 10 men and 10 women aged 60 years and over who are HIV infected and taking antiretroviral therapy (ART). **Methods:** Participants were visited monthly for 12 months to collect an oral diary on the older person’s life during the week prior to the interview and to document their life story, in order to learn more about their well-being. Quantitative data were collected from these people, as part of a larger study, through a standardized WHO questionnaire on health and ageing. **Results:** All the participants faced problems accessing support. They had lost supportive children and grandchildren as a result of the epidemic and relied upon neighbours to help them get food and water. Such support could not be relied upon, and participants had to do as best they could to support themselves and, for those with a heavy care giving burden, their grandchildren. A number of people were also the receivers of care, sometimes from the grand children they looked after. In common with other older people in the communities in which they lived, they faced health-related problems of ageing but, ironically, because they were accessing ART they sometimes had better access to health service providers than their non-infected peers. That said, support for all older people living in poverty is lacking, and urgent attention needs to be paid to providing social protection in Uganda for these and other vulnerable groups.

**Keywords:** older people, Uganda, HIV/AIDS
Introduction

Limited information is available on the physical, mental and social well-being of older people in Africa and other resource-constrained settings, and Uganda is no exception. The HIV epidemic over the last three decades has added to the plight of many older people living in poverty in Uganda. Many studies have focused on the role of grandparents as caretakers of orphans (Foster et al. 1995, Foster 2000, Help Age International 2003, and Schatz 2007 for example). Limited research has been done on the impact of the HIV epidemic on older people’s own well-being and care when children who might have supported them in their old age have died as a result of AIDS-related illness (Knodel et al. 2007, Seeley et al. 2009) and on the impact of older people who are themselves infected with HIV (Whipple 1996, Linsk 2000, for example) and their support networks.

Information on the number of people who are living with HIV over 49 globally, are scarce. Knodel and VanLandingham (2002: 577) observe that estimates of adult HIV/AIDS prevalence often refer to people aged 15-49 years ‘thus giving the mistaken impression that older adults are somehow immune.’ The proportion of HIV-infected older people has increased in recent years in developed countries because of improved access to treatment (Zablotsky and Kennedy 1003, Grabar et al. 2006, Silverberg et al. 2007, Orchi 2008, Gebo 2009, among others). Nokes et al. (2000), for example, report that in 1998 11 percent of people diagnosed with AIDS in the United States were 50 years and older. The number of people over 50 years old living with HIV in developing countries is unknown, but likely to also be increasing. A national survey in Uganda in 2004-2005 reported a rate of 5.8 percent HIV infection among people 50-59 years, with little difference between men and women, while HIV prevalence among people aged 15-49 years was estimated at 5.4 percent (Government of Uganda 2006). In Kenya HIV prevalence for people aged 50-54 yrs was 8 percent compared with 4.1 percent among the 15-24 yrs in 2006 (National AIDS Control Council, Kenya, 2007). Less information is available for people over 60 years. However, there is evidence that these older people are not only growing older with HIV, but also acquire the infection in later life. Williams (2003: 164), for example, reports that the overall HIV incidence among males and females over 60 years in a cohort of 10,000 people in south west Uganda from 1990-1997 was three per 1000 person years.

Goodkin and colleagues (2003: s171) observe that older people living with HIV ‘confront many complex and demoralising factors related to ageing that greatly influence how they respond physiologically, psychologically, and socially to HIV-1 infection’. In their paper they review studies in North America that highlight the need to address the psychosocial needs of older people living with HIV and their care-givers. Older people with HIV have particular needs; as Llorente and Malphurs (2006) note, because they have less social and institutional

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support than younger people: they lack care-givers because they may have lost many friends and family to the infection, and they become dependent on the young children they care for, for their own care (Skovdal 2010). Importantly, they also may face ‘less acceptance of HIV status among family and friends’ fearing rejection by grown-up children and the loss of interaction with grandchildren (p.269). Llorente and Malphurs go on to observe that age related declines in immune function leave older persons more vulnerable to opportunistic infections, increased rates of HIV –related complications, more rapid progression to AIDS, and lower survival rates than younger adults with HIV disease.

Llorente and Malphurs’ research focused on older people in developed country settings. As noted above, there is a paucity of similar research on older people living with HIV in developing countries where studies, with a few notable exceptions (Kyobutungi et al. 2009), have largely focused on their care-giving role. Care-giving in itself can take a toll on health, negatively affecting the economic, health, physical and psychological wellbeing of older caregivers and leading to short term weight loss, physical pain, and depression (Ssengonzi 2007, Ssengonzi 2009; Dayton et al, 2002; Knodel et al, 2003; Nyambedha et al, 2003; Oburu et al, 2005). If those same care givers are also living with HIV, we could expect the impact on their health and wellbeing to be even greater. This situation is often further complicated by poverty. Lloyd-Sherlock (2000), Mark (2003), Najjumba-Mulindwa (2003) Aboderin (2004), Mudege and Ezeh (2009), and Seeley and Ekoru (2010) among others, have explored the relationship between poverty and ageing, bringing attention to the need for social protection initiatives to provide much needed support to the ageing population.

In this paper we describe the health and well-being of older people living in poverty and living with HIV in a resource-constrained setting in Uganda. Through both qualitative and quantitative data we describe the support older people receive, their care-giving burdens, the experience of other illness related to ageing, as well as HIV, and their access to care and support.

Methods

This paper draws on data from two studies in and around Entebbe town, Uganda. The first study consisted of a cross sectional, quantitative survey with 254 older people aged 50 years and above living in a radius of 20 km of Entebbe town (see map). The sample was stratified to ensure representation of different age groups of older people. The study population was made up of five groups, which were purposively selected. These groups were (1) older persons who have lost offspring due to HIV/AIDS; (2) older persons who have an HIV positive adult offspring who is ill (index case generally WHO stage 3 or 4) and are on Anti-Retroviral Therapy (ART) more than a year; or waiting to be on ART or on ART less than 3

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2 The two studies were also carried out in a rural population in Masaka District, but those data are not included in this paper because the design of the qualitative study in that District was slightly different from the Entebbe based study.
months; (3) older persons who do not have offspring infected or dead due to HIV/AIDS and who are not HIV positive themselves; (4) older persons who are HIV positive and who had been on ART for more than a year and finally (5) older persons who are HIV positive waiting to be on ART or on ART for less than three months. All these people were visited in their homes and interviewed using a structured questionnaire which explored care-giving and well-being as well as covering an objective health assessment of their; blood pressure, height, weight, vision, hand grip strength and hearing. The social support network of these people was also explored through a series of questions, adapted from a tool used by WHO, which asked about marital status, assistance received from family and friends who live outside the household as well as the Government, and assistance given by the older person’s own household. Participation in social meetings/religious events, visits to family and friends as well as visitors to the home were also explored. Participants were also asked if they would like to go out more and receive more visitors. The social network index (SNI) was calculated by combining these different factors to arrive at an SNI score.3

The other study, the data from which is the main focus of the findings in this paper, was qualitative. Twenty HIV-positive older people, aged 60 and above4, were purposively selected from groups four and five of the quantitative study population (see above), chosen to represent different age groups, as well as gender. Nine men and eleven women took part. All participants were receiving HIV care from The AIDS Support Organization (TASO). In 2009-2010 the participants were visited once a month for a year by three experienced interviewers (one man and two women) who were also aged above 60 years. In the first interviews they discussed the participant’s life-history and explored their changing family situations. During those visits and subsequent visits an oral diary was gathered for the week prior to the visit which covered the older people’s tasks, responsibilities, visitors and visits as well as their feelings about their health and well-being.

Ethical approval for both studies was given by the Science and Ethics Committee of the Uganda Virus Research Institute. Clearance for the research was provided by the Uganda National Council of Science and Technology.

While this paper focuses mainly on the qualitative data, we draw on the quantitative data to provide background information and explore some of the qualitative study findings.

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3 There is a considerable amount of literature on quantifying social networks see Seeman and Berman (1988) for background on its use in studies of older people, and Ertel et al. (2008) for the use of a social network index with an older population study.
4 It was decided to use 60 years rather than 50 years in this study because this allowed us, through the small sample size, to focus more on age groups more likely to have experienced the effects of ageing than the 50-59 year olds. The importance of taking account of the different age groups among older people has been explored elsewhere (Seeley et al. 2009).
Background

The study area has traditionally been the seat of the Baganda, the dominant tribe in that part of central Uganda, although many different ethnic groups have moved to the area over the last few decades, most notably Rwandese immigrants as well as people from other parts of Uganda who have been attracted by employment opportunities, which include fishing. While only 11 of the 20 people taking part in the qualitative study were Baganda, the available literature on residential patterns among that ethnic group broadly reflect the living arrangements found in the study area, so a description of those arrangements provides useful background information for our findings. Nahemow (1979: 172) describes the Baganda as having a 'loose patrilineal structure'. All children belong to their father’s clan (Roscoe [1911] 1965: 128). However, the system of descent does not mean that a father and his children, once grown, lived together. As Nahemow (1979: 172) observed, 'While they have a patrilineal kinship system, [the Baganda] are nuclear in their households and generations are often residentially segregated by considerable distances. This was the traditional pattern and is still true today.' The explanation she gives for this pattern is the
existence of plentiful fertile land over which settlements could spread. In addition, high rates of marital instability (Nabaitu et al. 1994), residential mobility for work/access to land and incidence of widows living with grown-up sons (Fallers 1960) all contributed to ‘considerable variability in the living arrangements and patterns of residential proximity among the Baganda’ (Nahemow 1979: 173). In the course of her research in 1971, prior to the HIV epidemic, Nahemow had found that among her sample of 115 elderly Baganda who were resident close to Kampala, 18 lived alone but most lived near a relative, most often adult offspring. She comments that ‘while dissatisfaction [with support and care] is prevalent among elderly Baganda, loneliness is not. […] their separation is a matter of personal preference and can be viewed as adaptive and consistent with societal norms’ (1979: 182). How much the HIV epidemic may have had an impact on this picture is one factor we explore in this paper, since the loss of children and access to care and support may have a profound impact upon intergenerational relations and the wellbeing of older people living with HIV.

Background to the study participants

The quantitative data were collected from 92 men and 162 women. Their ages are shown in Table 1 below. Seventy seven percent of these people had primary education or less (with 18 percent with no schooling at all). Four people had never married, 82 were currently married, 59 divorced or separated and 109 widowed.

<table>
<thead>
<tr>
<th>Age</th>
<th>Qualitative sample</th>
<th>Quantitative sample</th>
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<tbody>
<tr>
<td>50-59</td>
<td>-</td>
<td>95</td>
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<tr>
<td>60-69</td>
<td>9</td>
<td>80</td>
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<td>70-79</td>
<td>10</td>
<td>63</td>
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<tr>
<td>80+</td>
<td>1</td>
<td>16</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
<td>254</td>
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Among the qualitative study sample, five participants lived alone (two women, three men). Of the others, 14 lived in a household which included children or grandchildren under the age of 16. Seven of these people (six women and one man) were the only adult between 18 and 84 in their home.
Case studies

We begin with two case studies to provide an overview of the context in which the study participants lived, before discussing themes relating to social support and care arising from these two accounts, drawing on data from the rest of the qualitative study sample.

Grace

Grace is aged about 70 years old. She lives with her 90 year old husband and 14 year old granddaughter. Their house is made of mud walls and rusted iron sheets. Their property is located down a long and very bumpy dirt road, and they receive few visitors. During one interview Grace lamented ‘becoming old is really a big problem’ because they are so isolated. She said that it takes a long time for people to ‘branch’ off to visit their home and she worries: ‘well-wishers will find us dead in the house.’

Grace is the sole provider for the household, which receives little outside support. Grace says that they receive no material assistance from neighbours or the local authorities or charities. Grace works hard: she digs, fetches water and firewood, washes, and cooks; she also picks coffee and rears chickens, goats, and pigs- yet she still struggles to make ends meet. As she told the interviewer: ‘my husband is very old and I am also running out of energy. We cannot grow enough food for ourselves. We find trouble digging. We have no money to even hire labourers’.

Even when Grace does secure enough food for the household, she has difficulty cooking due to her lack of energy and a scarcity of firewood. The household members generally eat one meal per day, lunch, with tea and leftovers (if there are any) for supper. Meals consist largely of vegetables from the garden, supplemented occasionally by their own livestock or fish. There are food thieves in the area, and at one point during the study a pig was stolen from the household.

Grace is HIV-positive, but not yet on anti-retroviral therapy. She takes cotrimoxazole, panadol, and multivitamins, provided through TASO. She struggles to cope with household duties because of her physical ailments (such as severe back pain, swollen legs due to varicose veins, poor eyesight, and weakness). She told the interviewer: ‘I force myself to take the medicine as told by the doctor but the pain is severe and yet I have to force myself to dig and do all the household activities’.

Grace must walk on foot to receive medical care as she cannot afford transport; while this tires her, she expresses gratitude for the care and medicine offered to her. While Grace cites poverty, old age, and her daily drug regimen as burdensome, the biggest hardship Grace reports is looking after her husband, who is completely reliant on her care: he is deaf,

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5 Cotrimoxazole has been found to have a protective effect on people living with HIV who do not yet need ART. See Mermin et al. (2004).
incontinent, has no teeth, poor eyesight, and is largely immobile. Grace’s husband is HIV-negative, which she regrets in some ways because had he been positive she could have accessed care for him through TASO or the government health services that help people living with HIV.

Grace has two deceased children; the first-born died aged 40, leaving his daughter in Grace’s care, the second died soon after birth. While she is grateful to have her granddaughter to help with household chores, in nearly every interview she expresses distress at her granddaughter’s disruptive behaviour (such as staying out late, refusing to do chores, and stealing bits of Grace and her husband’s money). Despite acknowledging that this negatively affects her wellbeing, Grace intends to keep her promise to the child’s father to take care of her granddaughter and ensure she attends school.

When the interviewer visited in February 2010, Grace had completely lost sight in one eye and was struggling to see out of the other. During this visit she presented the interviewer with a photograph of her first-born son who died when he was 40, and said that her son will never get off her mind. Grace says they are very poor, and this makes her lament losing her two children, as they would have helped her now. She confided in the interviewer that her husband had engaged in extramarital affairs, which resulted in three children with another woman. Those children are grown now, with children of their own, and Grace blames them for not caring for their father/grandfather.

Grace worries who will support her in the future; who will look after her husband if she dies; who will take in her granddaughter; and if her granddaughter will be able to stay alone in such an old house, which is likely to collapse at any time.

Denis

Denis is 61 years old and lives in a rented room in a three-room house made of mud bricks and iron sheets. He has stayed alone in the same rented room for 27 years. He sleeps on a makeshift bed made of tree branches and grass, and cooks all his food in the corner of the room. He would like to buy a bed, but does not have the money.

When Denis first started to become sick- with what he would later find out was an AIDS-related illness- he and the people around him thought the sickness was a spell brought about by magic, and he went to traditional healers for a cure. He spent all of his money and sold everything he owned, including his bedding, cups and plates, to pay for treatment. Eventually he ran out of money, and was advised by a friend to go to TASO. He did, and is now grateful for the free services they provide.

Denis has trouble sleeping, and, in multiple interviews, he makes an analogy between his life and namuginga, a bug that eats and spoils beans and maize; as the interviewer explains: ‘the disease (HIV/AIDS) is what he compared to namuginga; that although he is living, there
is something eating him’. On a few occasions during the study Denis became sick (with fever, diarrhoea, and at one point a serious cough that left him bedridden for five days), however because of his good relationship with his landlord and neighbours they realised how ill he was and gave him food, water, medicine and care.

Denis works hard: he collects rainwater and firewood, and when it is sunny he rides his bicycle to collect water from a borehole two kilometres away. He has a very small area of land for his own cultivation, and would like to do more but cannot acquire more land; while he sometimes rents plots, this can be very costly. He cultivates each day, if not on his own plot then on someone else’s where he hires himself out as a labourer. His hard work affords him little more than basic food and necessities: he said, ‘Definitely poverty has hit me very much. Whenever I get a little money I find that it is all used in nothing else but eating.’

The interviewer reported that Denis goes out to work even though he does not feel very strong, he goes because he has no choice. Denis said, ‘Bwendi bwentyo, byennetaaga bingi naye nga sirina gwensuubira ku bimpa’ meaning ‘that is the situation, the necessities are many but there is no one I can approach to give a helping hand’. However, occasionally Denis’ friends visit, and he is grateful for visits and support from both the interviewer and members of TASO. Some weeks he is alone in the house, which makes him very sad. He would very much like to be involved with a woman, but laments the fact that his living conditions are poor, and he would not have enough money to feed or support her. He has no contact with his children, who were sent to live with his sister long ago, and while he frequently expresses that he would like to contact them, he has no way to do so and cannot afford transport to visit them. Denis would like to die on his ancestors land, but does not have the money to travel there; he worries that his strength is waning, and when he dies his friends may not be able to take his body back home.

Poverty is a frequent theme in Grace and Denis’ narratives. While they both complain of physical frailty they have to work hard to make a livelihood. Denis appears to have more support than Grace, from neighbours and friends and both have access to free medical care through TASO, for which they are very grateful. However, the picture that comes across from these stories is one of hardship and worry. The drugs they have to manage their HIV are keeping them alive, but they still lack many basic necessities. We now explore these themes through the case material from the remaining 18 study participants, to see understand more about HIV and ageing in this setting, but also the experience of ageing more generally.
Social support, access to care, poverty and ageing

All the other participants in the qualitative study appear to have more support than Grace. Family, friends and neighbours as well as civil society bodies are all mentioned in their oral diaries as helping them in some way. For example, one 60 year old woman, who had lost her husband and a son to AIDS praised an American donor organisation that was paying the school fees for the two grandchildren she cared for. Another son, living with HIV and like his mother on ART, who lived nearby brought her sugar, salt and soap when he could. Another woman, who was 74 years old, was also helped by her son, but she was also helping him. He shared a room with his mother so he could save money to send back to his family who were in a rural area. His mother had a very small pension from her former workplace in Entebbe but she also sold cooked bananas as snacks to make some money for them both so that his wages could be sent home.

A man, aged 79, lived with a young daughter, aged 12, who had been born to his third (and much younger) wife not long before that wife died in 2003. The child provided him with care and support, and did not go to school. She had helped him before he went on to treatment and it was clear that she had had a heavy care burden for a number of years. The interviewer, for example, noticed the man’s blanket was full of holes. The man said that his daughter had not managed to wash it properly when he had had severe diarrhoea so rats had come and eaten it. He had another daughter who lived some distance away and the 12 year old went to visit her from time to time to bring back money and food. Another woman, Agatha, was aged is 65 years, was supported by her sister. It had been her sister who had helped her when she was sick with AIDS-related illness. Agatha had been a fishmonger and had been living on one of the islands in an abusive relationship when she fell sick. She got herpes zoster and her partner had deliberately burnt her face with a charcoal stove in anger at her infection. Her sister had helped her then and brought her to the mainland where she still lived so that she can access care. Agatha said that she would not be alive if it were not for TASO, her sister and her grandchildren, who live with her and help in the house.

The wife of a 65 year old man provided all his support. She was twenty years his junior. He lamented his unfaithfulness to her which had resulted in him being HIV positive. His wife was HIV-negative. He constantly praised his ‘better half’ because she had stuck by him and supported him, ensuring that he and their family ate and were cared for. Most of the respondents, like Grace above, were care givers as well as recipients of care. Lydia, for example, was an important source of support to the people living nearby, not just her family. When her husband died he left her with some rooms which she let out for rent, and it was the money from the rent that she used to support her immediate and extended

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6 The organisation only provided support to ‘AIDS orphans’.
7 Herpes zoster is a common opportunistic infection in people infected with HIV.
family, although given the quality of the rooms that money was not much. She also helped her tenants, all low-paid workers, with food and care in medical emergencies. Lydia felt a duty to her deceased son and talked often of her obligation to care for her grandchildren who lived with her ‘they belong to me and no one will take them from my home’. The interviewer noted how well behaved the children were and observed, with approval, that the 15 year old girl shared a bedroom with her grandmother and was ‘under her control’.

Some of Lydia’s other grandchildren were not so well behaved or helpful. During another visit, when it was school holidays, the interviewer found that one of Lydia’s children had sent a grandson to stay with the grandmother to be disciplined. The boy was rude and unruly and there was obvious tension between himself and his grandmother but Lydia persisted in her attempts to discipline him.

Despite the help she gave her children and neighbours, her relationship with her children was not always cordial – during one visit the interviewer found her very distressed because one of her sons had been to visit her and told her to hurry up and die and leave them alone. She also told her interviewer that even after many years she still finds her HIV status difficult. She complained that people in the area ‘like gossiping and laughing at people who are HIV-positive’, so she did not want to be too open about her status, although her family knew.

Among other participants with a large care burden was Teddy. While she was not as well off as Lydia she provided help to many people. She stayed with seven children, who she looked after, as well as her mother in law who was about 90. That older woman had been refused care by her two remaining sons (Teddy’s husband was dead) and had come to stay with Teddy. Teddy and the children staying with her were, the interviewer observed, very caring towards the great grandmother who could not see or hear properly. When the old lady died in March 2010, Teddy was very distressed because she had lost her ‘friend and adviser’. The children Teddy cared for were the off-spring of her husband by other wives, who are either dead or had moved away. Teddy struggled to find school fees for some of her step children and she was grateful that her only child by her husband, a daughter, paid the school fees for one half-sibling even though she has two of her own children to care for.

Teddy’s husband had died in 2001. They had been quite well off before he died but they sold land and a house to pay for treatment. He had many children, all of whom wanted a share of his property. Teddy was afraid to leave the house for any length of time because she complained that the son of one of her co-wives stole her belongings. So, while Teddy was clearly a very caring and supportive person, she lived with a considerable amount of tension because of her close proximity to her co-wives children, some of whom she felt she could not trust, and like Lydia’s son above, wished her dead.

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8 During one visit a tenant rushed over to Lydia to borrow some money to give to another tenant whose wife was about to give birth.
There were a few cheering stories of caring relationships. One older lady, Imelda, did not have children living with her, but the interviewer noticed during her visits that two local children often came and played at her house. Imelda explained that they liked to come because she did not worry about the mess they make and she could sit and tell them stories about old times, which they enjoy (and she did too).

Not all the older people enjoyed having children around, or had accepted to take in children for care. One 61 year old woman stayed alone. She said it was too stressful to stay with grandchildren. She often remarked during visits how troublesome it would be to look after children! She was probably right to have concerns; another woman, aged 61, found the three children she took care of burdensome and difficult to control. However, she said that she dare not reprimand them. She had got into problems a few years before for deliberately burning one of the children with hot food to teach the child a lesson. The local authorities arrested and imprisoned her for a month because of that, so after that she was careful and bitterly regretted the harm she did to the child.

Both Grace and Denis, in the two case studies above, worked hard to make a living to support their households. All the other older people in the study also did something to try and get some income; none was wholly reliant on others however frail they were and only one person had a small pension. Michael, for example, was a 72 year old man. He had a bicycle accident many years ago which had stopped him from working. He had been given some land by a Catholic mission where he had worked before the accident, but over the years he has sold most of that land to cover his health and living expenses. At the time of the study he mended shoes in a trading centre about two kilometres from his home to get some money (he walked to and from the trading centre each day because he could not afford transport). He ate in the trading centre most days `if I collect 700/- [20 pence] then I can have posho [maize porridge] and beans but if I get 500/- [15 pence] then that is chapatti and beans. I take one meal a day’. Other times his neighbours helped him. However this was not frequently. One time when the interviewer visited him he found that he had not eaten the previous night or on the day of the visit because he had not earnt any money and had not been given anything by neighbours. He said he did not want to ask for help because it would sound as if he expected it.

Michael often complained of being alone in his house with no one to talk to – he said that he went to the trading centre every day so he had company. Finding company to stave off loneliness was important for the well-being of others in the study too. A 73 year old man and a 67 year old woman both sold alcohol to make their living and were grateful for the companionship it brought as customers came and drank at their homes. However, this was not always beneficial. The man shared a room with a friend where they both lived and complained that the friend caused him lots of problems because he often got drunk and abused the old man, but the this man had no one else to help him.
It should be remembered that all of these participants were HIV-positive and all were receiving ART or cotrimoxazole from TASO or a local health centre. All participants praised the non-governmental organisation, TASO, for the help and support they had received for their treatment; without that support most knew that they probably would no longer have been alive. The support provided by TASO and other organisations was more than the drugs they received. Teddy, for example, was provided with care by both TASO and a non-governmental organisation (NGO) that provided cancer care. She tested positive for HIV in 2002, after her husband died, and went to TASO. She was then found to have cancer in 2006 and has been under treatment at the cancer NGO — she was very happy that they paid for all her treatment and transport costs to and from the clinic.

Teddy broke her leg in a fall in 2008, but did not go for treatment because of worries about the cost and difficulties of transport, as well as concerns about the co-wife’s son stealing her possessions. When the interviewer first met her she could barely walk with a crutch (which she had got from a relative) and she could not bend or sit on the floor. A few months later she was very happy because the cancer NGO staff had provided her with physiotherapy and she was able to walk more easily. They had provided treatment even though the injury was nothing to do with her cancer.

The descriptions above provide a picture of lives linked by care and support by and for family, friends and neighbours. However, while all had benefited from the support and care they had received, everyday life for most participants was dogged by the struggle to make ends meet. It was apparent that poverty undermined the health and well-being of the majority of the participants. Several people, for example, mentioned severe stomach pains when they took their ART, which was caused by taking their drugs on an empty stomach, because they did not have enough food in the house. Their limited resources had to be shared with others, children in need of school fees, friends and family in need of medical care and the older people often seemed to sacrifice their own needs.

The notes from one interviewer after the visit to a 79 year old man provide a picture of the reality of some of these older people’s lives:

‘The old man said that he did not eat the previous night because he has no money to buy food and even his neighbours who normally assist at such times did not bring him food. He is just alone in his house with no one to talk to.’

We now turn briefly to findings from the quantitative study sample because they provide some useful context for the qualitative findings related to social networks and general wellbeing. When the social network index (SNI) was calculated we found significant associations between the strength of social networks and age, sex and access to ART for the 254 participants in that study. Older people (over 70) had a lower SNI than younger older people and women had lower SNI scores than men. People with more education had better
SNI scores than those with less education. People living with HIV, but not on ART, had lower SNI scores than other groups. However, for people on ART we found that their SNI scores were almost identical to those of the uninfected/unaffected group of older people in the study. This group scored equally as well as HIV negative people on almost all other health and wellbeing indicators measured in the study. Similar findings were found for the rural population (which, as noted above, are not reported here).

Discussion

The quantitative findings showed that HIV infection in older persons who were not yet on treatment is associated with an impaired social network, yet people on ART do better than HIV infected people not on ART, and score equally as well when the SNI is calculated as HIV negative people on almost all other indicators. It is not difficult to surmise why this may be so, when one looks at the qualitative data. All the people in the qualitative study were HIV-positive and all but one of the people in that sample was on ART. They were accessing care from TASO or health centres at regular intervals and had built up a relationship with those organisations. Their ailments were being attended to during their clinic visits. They had regular contact not only with clinical staff but also with counsellors. As we note above, it is not surprising that Grace, with a 90 year old HIV-negative infirm husband, openly expressed the desire that he would have been HIV-positive, because she could then have accessed health care for him. Access to care for older people not infected by HIV is scarce.

For people infected with HIV, but not yet on ART, clinic visits may not have been so frequent and also, perhaps, they were living with the continued fear that when their time came to take ART it would not work for them. In addition, despite the prevalence of HIV in Uganda, stigma is still a problem for many. Several participants confided in interviewers about their continued feelings of stigma, which affected who they disclosed their HIV status to. Those feelings are very likely to affect HIV-positive people not yet on ART, who may be more hesitant to disclose than those who have had their health restored by ART.

Our findings show the intergenerational dynamics in providing and also receiving care, mostly within the family. Nahemow (1979) had noted the importance of the having kin close by to provide support, and even with the losses due to AIDS several older people still relied on help from relatives. Large families had facilitated this in some cases. There was no doubt, however, that supportive off-spring had been lost to AIDS and other causes, as in Grace’s case, and where there were no others to step into the gap left by those lost children, the older person suffered.

The psychological distress among some older people in our study is apparent in the narratives. They are frustrated by growing older and worry that they will no longer be able to provide care for themselves and to their families due to their weaker bodies. Assets had often been depleted by efforts to find a cure for their HIV-related ailments, and they had to
cope with limited or very few resources to invest in their family, and their own wellbeing and health. In the absence of adequate social support there was a fear of losing strength and not being able to support themselves because of a decline in their health. They worried about becoming a burden for families. There was also a constant worry that because of poverty, when they died they would leave dependents behind unable to care for themselves. There was also the fear of rejection because of their HIV status.

Most of the participants faced problems accessing material and social support at some point over the year of the study. Some had lost supportive children and grandchildren as a result of the epidemic and relied upon neighbours to help them get food and water. Such support could not be relied upon, and participants had to do as best they could to support themselves and, for those with a heavy care giving burden, their grandchildren.

Conclusion

The relationship between poverty, ageing and HIV is complex. The main focus of this paper has been older people living with HIV and accessing ART/cotrimoxazole for their condition. However, it is apparent from the stories they tell of their day to day lives that like other older people in the communities in which they lived, they faced health-related problems of ageing compounded by poverty and the constant worry about getting food and support. It is ironic that because the men and women in our study were accessing ART/cotrimoxazole, they sometimes had better access to health service providers than their non-infected peers. Nevertheless, this support while life-saving in terms of staving off AIDS, was solely health-related. Apart from one person who had sponsorship for the school fees of her grandchildren, no one had had help in rebuilding their livelihoods or accessing food and other material support. Such support for all older people living in poverty in Uganda requires urgent attention. As our study data show, these older people are an invaluable resource to their families and communities and they need to be cherished and supported.

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