



# Working Paper Series



## The Impact of the AIDS Epidemic on the Lives of Older People in Rural Uganda

Janet Seeley, Elizabeth Kabunga,  
Grace Tumwekwase, Brent Wolff, and  
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The School of Development Studies, University of East Anglia  
Norwich, NR4 7TJ, United Kingdom

## DEV Working Paper 04

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## Abstract

The impact of HIV and AIDS on older people (over 60) is often portrayed as bound up in the care of children who are left when their parents die. There is, however, a growing awareness that the epidemic touches older people's lives in other ways; affecting their socio-economic situation, their own sexuality and choices about partnerships as well as affecting relationships with their remaining children and relatives. Growing old presents challenges beyond HIV and AIDS as health wanes and the ability to plan ahead and care for ones-self and any dependents decreases. It is these dimensions of older people's lives that we explore in this paper. Using a life-course approach we analyse longitudinal data from studies in 1991/1992 and 2006/2007 from rural Uganda to provide a picture of daily life of four older people, describing the challenges that they face in coming to terms with a world changed by the AIDS epidemic. By focusing on the lives of four people (three widows and a widower in their late 70s/80s) we show the great importance of their socio-economic status, as well as reciprocal relationships with family and friends, in sustaining them in the remaining years of their lives.

**Keywords:** Older people, Impact of HIV and AIDS, Uganda, Life-course.

## Introduction

*Here we have buried 15 of our children just two being grand children.<sup>2</sup> The children died from this prevailing disease. We managed to nurse most of them and witnessed the way they suffered. They deteriorated, vomited, some had diarrhoea, they lost appetite but personally I became firm reciting my Rosary having understood it was this killer disease finishing our children!*

(Sara,<sup>3</sup> aged 78)

This paper is about four people, Sara, Lydia, Madina and Kiwanuka who we first met in 1991/1992 when they took part in a year-long in-depth study exploring the socio-economic impact of HIV and AIDS on rural households. They live in a village in South Western Uganda. All four are now over 75 years old and have recently participated in 2006/2007 in a repeat of the earlier study. All have been affected by the AIDS epidemic. There have been many social, political and economic changes in Uganda over the last 50 years and the emergence of the AIDS epidemic 25 years ago has added further complexities to their lives, robbing many older people, like Sara quoted above, of their children and grandchildren and of the socio-economic security that those family members could provide.

Until recently the focus on older people and the AIDS epidemic has been on their role as grandparents caring for children left behind when their parents die (Foster *et al.* 1995, Foster 2000) with scant attention to the wider impact of the epidemic on their

lives, including the possibility of they themselves being or becoming infected. Indeed, as Knodel and VanLandingham (2002: 577) observe, estimates of adult HIV and AIDS prevalence often refer to people aged 15-49 years 'thus giving the mistaken impression that older adults are somehow immune.'<sup>4</sup>

In recent years Knodel and colleagues have documented the impact of HIV and AIDS on older people in Thailand and Cambodia (Knodel *et al.* 2001a, Knodel *et al.* 2001b, Knodel and VanLandingham 2002, Wachter *et al.* 2003, Knodel and Im-Em 2004, Knodel *et al.* 2007). Knodel, Watkins and VanLandingham (2003) describe the socio-demographic impact of AIDS on older people internationally, Hosegood and Timaeus (2006) and Merli and Palloni (2006) use quantitative data to do likewise for South Africa. Williams and Tumwekwase, through their ethnographic research in Uganda (Williams and Tumwekwase 1999a, 1999b, 2001, and Williams 2003), provide a vivid account of old age in one village, which includes information on the risk of HIV infection among the aged as well as the changes they have experienced as a result of the infection of their relatives. In this paper we seek to build on this small body of work.

The four older people who are the focus of this paper have lived over the last 16 years in a village close to the area in which Williams and Tumwekwase worked. We are able to provide the detail on these four people's lives over this period because they are all resident in a field-site of the MRC/UVRI Uganda Research Unit on AIDS (MRC/UVRI) and have been participants in annual demographic, medical and serological surveys since 1989 as well as taking part in the two studies of day to day life in 1991/1992 and 2006/2007.

We adopt a life-course approach to this study of ageing, analysing changes in these individuals' lives as they move through time in particular social contexts (Elder 1981, Espenshade and Braun 1982, Thomas 1995). Four themes, central to a life course approach (Elder 1994), shape our analysis and discussion in this paper. The first is about situating lives in historical time: when and where someone is born exposes that person to constraints and opportunities which may be different from someone born a decade earlier or later. The second theme concerns the exploration of the social timing of important life events: when a person takes up a role (such as wife, parent, or widow), how long the role lasts and the sequencing of roles in relation to each other will influence the course of a person's life. Elder (1994: 6) explains that timing may be crucial for someone's wellbeing. For example an ill-timed event in relation to age-norms, such as teenage child-bearing, may adversely affect a person's education, employment or marriage prospects or the untimely death of a young person may impact upon the lives of their parents, both emotionally and materially. The third theme is 'linked lives' which recognises that a person's life is embedded in social relationships with relatives, friends and neighbours across the life-span. Becoming a parent, for example, links a mother or father to a child who they often care for when

young and care about throughout their lives. The fourth theme is human agency, which examines how much people can or cannot influence the course of their life through the choices and plans they make. Gender, age, socio-economic status as well as social and geographical context can all influence the amount of agency a person can exercise in his or her own life.

Health and well-being are important in this paper because they are key factors in the ageing process as well as in the social and historical context in which this study is set. A focus on the life-cycle (growth and maturation followed by decline), implies a steady progression from youthful vigour to infirmity in old age. A life course approach allows a more nuanced view of bodily ageing as good health may wax and wane over a life time. As Gardner (2002: 213) reminds us, bodies not only move and change across space but also move and change across time, impacting on what someone can or cannot do at different points in their life. In addition, a focus on linked lives in the life course analysis of older people also allows us to look at the impact of sickness and untimely death of those in 'the prime of life' on whom an elder may have expected to depend. Moen, Robison and Dempster-McClain (1995: 259) suggest that care-giving for sick or dying relatives 'epitomizes this notion of linked lives', particularly for women who may give considerable amounts of time and attention to the care of others.

As noted above, the social context plays an important part in life-course analysis in influencing when and how different transitions take place and are experienced; the roles played and the stages through which life passes are both 'socially and culturally embedded' (Gardner 2002: 19). Therefore the emphasis in life-course analysis is on the study of an individual and his or her family within a specific socio-cultural context and from a historical perspective. That context includes, among other factors, the socio-economic status of an individual and his or her family. DeWilde (2003) refers to the importance of the socio-economic stratification of the life-course, she comments on 'the manner in which the state, the market and the family – as well as the interaction between these systems of resource distribution – influence the individual life-course and, in this process, create social differentiation and social inequality between groups and individuals'. This stratification is particularly important in the study of older people as the effects of wealth or poverty may increase over time resulting in 'socially structured trajectories of inequality' (DeWilde 2003: 123). Thus the rich may stay rich or become richer while the poor stay poor or become poorer because of their position in the social context in which they live (Dannefer 1987). For older people the socio-economic circumstances in which they grew up, as well as the historical time period through which they have lived, are likely to profoundly influence their wealth and well-being in old age. In the context of this study, that historical time period includes living through the AIDS epidemic.

To structure our findings we use the four aspects which Williams and Tumwekwase (2001: 234) identified as being where the impact of the AIDS epidemic was affecting older people's lives in rural Uganda. The four are: as parents attempting to protect their children from infection and, if unsuccessful, as the carers of those who fall sick (and who bury those who die); as grandparents fostering orphans or children of single parents who have to work away from the village in order to earn a living; as individuals who are themselves vulnerable to infection; and finally as dependent old people who are deprived of any support in their old age that their deceased adult children might have provided. We use our longitudinal data, 1989-2006, as well as retrospective data gathered on life histories prior to the study period to explore whether these four aspects summarise adequately the experience of living during the AIDS epidemic for our participants. In addition, we also aim to add to the literature illustrating the multi-faceted impact of HIV and AIDS on older people's lives.

## **The Setting**

MRC/UVRI has studied the progress of HIV and AIDS in a cohort of about 10,000 individuals living in 15 villages since 1989 and an additional 10,000, living in 10 villages, since 2000. In 1991/1992 an ethnographic study of household coping mechanisms was undertaken that looked at the experience of the members of 27 households selected from three of the MRC/UVRI cohort study villages. The findings of that study are presented in Seeley (1993). That study was repeated in 2006/2007. The focus of the study both in 1991/1992 and 2006/2007 was not only on HIV and AIDS but on wider aspects of daily life, because we were interested in understanding more about people's lives in general and all the challenges (as well as the opportunities) they face.

The study was conducted in a rural sub-county in Masaka District, Uganda. The people living in the area are largely subsistence farmers who produce small amounts of cash crops such as bananas and coffee. The majority of the population are ethnically Baganda (75 per cent), but there is a large representation of immigrants from Rwanda (15 per cent) who have tended to settle over the last 70 years on land at the outskirts of established villages. Four per cent of the population are immigrants from Tanzania. A mixture of other tribes makes up the remainder. The main local language is Luganda which is spoken and understood by all the tribes. The community is predominantly Roman Catholic (58 per cent), with 12 per cent Protestant and 28 per cent of the population is Muslim. Just over 50 per cent of the population is under 15, and the ratio of females to males for the total population is roughly 1.1:1. Most households have less than five acres of land. There are only a few sizeable land owners and relatively few households are landless.

Research in the MRC/UVRI cohort found HIV prevalence in the adult population (age 13+) of the original 15 villages to be 8.5 per cent in the annual survey round

1990/1991, 6.2 per cent in 1999/2000 and 7.7 per cent in 2004/2005. In the 10 new villages, which include the administrative and trading centre of the sub-county, prevalence rose steadily from 4.4 per cent in the 1999/2000 survey round to 8.2 per cent in the 2004/2005 survey round (Shafer *et al.* 2006). Williams (2003: 164) reports that overall incidence rates of HIV among males and females over 60 years in the MRC/UVRI cohort from 1990-1997 was three per 1000 person years, challenging the stereotype that older people are not infected or cannot be infected in later life.

Table 1, below, shows that three per cent of the population is over 70 years old, but as we aim to show in this paper, people in this small segment of the population have felt the impact of the AIDS epidemic on their lives.

**Table 1: Population distribution in the study area in 2005**

Age-group	Male		Female		Total	
	Number	Percentage	Number	Percentage	Number	Percentage
< 12	4621	22.31%	4566	22.04%	9187	44.35%
13-19	1997	9.64%	1908	9.21%	3905	18.85%
20-29	1180	5.70%	1423	6.87%	2603	12.57%
30-39	855	4.13%	901	4.35%	1756	8.48%
40-49	552	2.66%	677	3.27%	1229	5.93%
50-59	339	1.64%	427	2.06%	766	3.70%
60-69	294	1.42%	363	1.75%	657	3.17%
<b>70-79</b>	<b>200</b>	<b>0.97%</b>	<b>237</b>	<b>1.14%</b>	<b>437</b>	<b>2.11%</b>
<b>&gt; 80</b>	<b>92</b>	<b>0.44%</b>	<b>82</b>	<b>0.40%</b>	<b>174</b>	<b>0.84%</b>
Total	10130	48.90%	10584	51.10%	20714	100.00%

## Methods

Twenty seven households (defined as the people living together on a compound and sharing meals) participated in the study in 1991/1992. Members of 24 of those original households participated in the restudy in 2006/2007. During 1991/1992 researchers, all local people trained in ethnographic research, paid monthly visits of up to half a day to study households to chat to household members and take part in household activities so that they could learn about the changes in different aspects of the household's daily life such as composition, employment, health, food consumption and social networks. Detailed accounts of the visits were written up by team members and the visits (and the reports) were discussed with one of the social science team to ensure that important information had not been missed.<sup>5</sup> Monthly meetings were held so that the team could discuss emerging themes and agree if there was any particular issues that they should focus on in their next visits.



The 27 households had been selected from three villages in the MRC/UVRI study area, as noted above. The original 27 households were chosen purposively in 1990 to represent a cross-section of different household types (by sex and age of household head, as well as socio-economic status). However, there was a particular weighting towards female-headed households because we were at that time interested in understanding more about the factors that may put poorer women household heads at risk of HIV infection as well as factors that might make mitigating the impact of the epidemic difficult. The methodology used in the study is explained in detail in Seeley, Kajura and Mulder (1995). In 2006/2007 when the study was repeated the same approach was used. In addition to collecting detailed information on day to day life, as well as life stories from adults, and some older children. People were also asked to recall their memories of what has happened in the intervening 16 years. Information on two households which no longer exist because their household heads have died and their children have moved away was gathered from neighbours and relatives. One household refused to take part in the restudy.

The analysis of the data was done manually in both 1991/1992 and 2006/2007 by members of the whole team using content analysis. Themes, such as the one which is the focus of this paper, the older and the AIDS epidemic, were discussed in the team and where information was missing or unclear attempts were made in the follow-up visits to households to fill gaps. Kinship diagrams and social network diagrams were drawn for each household, which provided valuable background information with which to keep track of people mentioned during the monthly visits. Those visits, and the main visits, were always welcomed by the older participants who enjoyed the chance to chat and catch up on news.

Overall approval for the study was given by the Ugandan National Council of Science and Technology. Ethical approval was given by the review boards of the Uganda Virus Research Institute and the University of East Anglia. For both the 1991/1992 and the 2006/2007 studies consent was obtained from the participants. In the first study the household head gave verbal consent on behalf of all household members, in the second study written consent was obtained from the household head and then members over the age of 13 gave their verbal agreement to take part.

Twenty one female and six male headed households made up the original 27 households. Eleven household heads died in the intervening 15 years. In 2006 the distribution of participating household heads was 17 females and seven males.<sup>6</sup> Two of the female heads, one in her 70s and one in her 80s had moved out of the study area to be cared for by relatives. Four resident household heads, one man and three women, are over 80 years of age. We have chosen three of these for this paper, one for each wealth category as noted above. In 1991/1992 Lydia and Sara's household was relatively well-off, Kiwanuka was less well-off (less-poor) and Madina was poor.

The other household with a head over 80 was in the same wealth category as Lydia and Sara's in 1991.

## The participants

Lydia, Madina and Kiwanuka are in their eighties and Sara is in her late seventies. They were not very sure how old they were but they guessed birth dates of 1926, 1926, 1933 and 1929 respectively when the MRC/UVRI research programme census takers first asked them for their ages during the first General Population Cohort annual census in 1989/1990. While we think that Lydia, Madina and Sara's birthdates are likely to be close to their real dates because of events they remember from their childhoods, we now know that Kiwanuka was probably born nearly ten years before the date he gave, in 1924/1925, because he was about 15 years old when he joined the army at the beginning of the Second World War and was sent to Egypt to fight. Sara and Lydia are co-widows, their husband who participated in the 1991/1992 study died in 1992 and Lydia then became household head. Kiwanuka and Madina are single but they have both had more than one partner/spouse in the past, some of whom are known to now be dead.

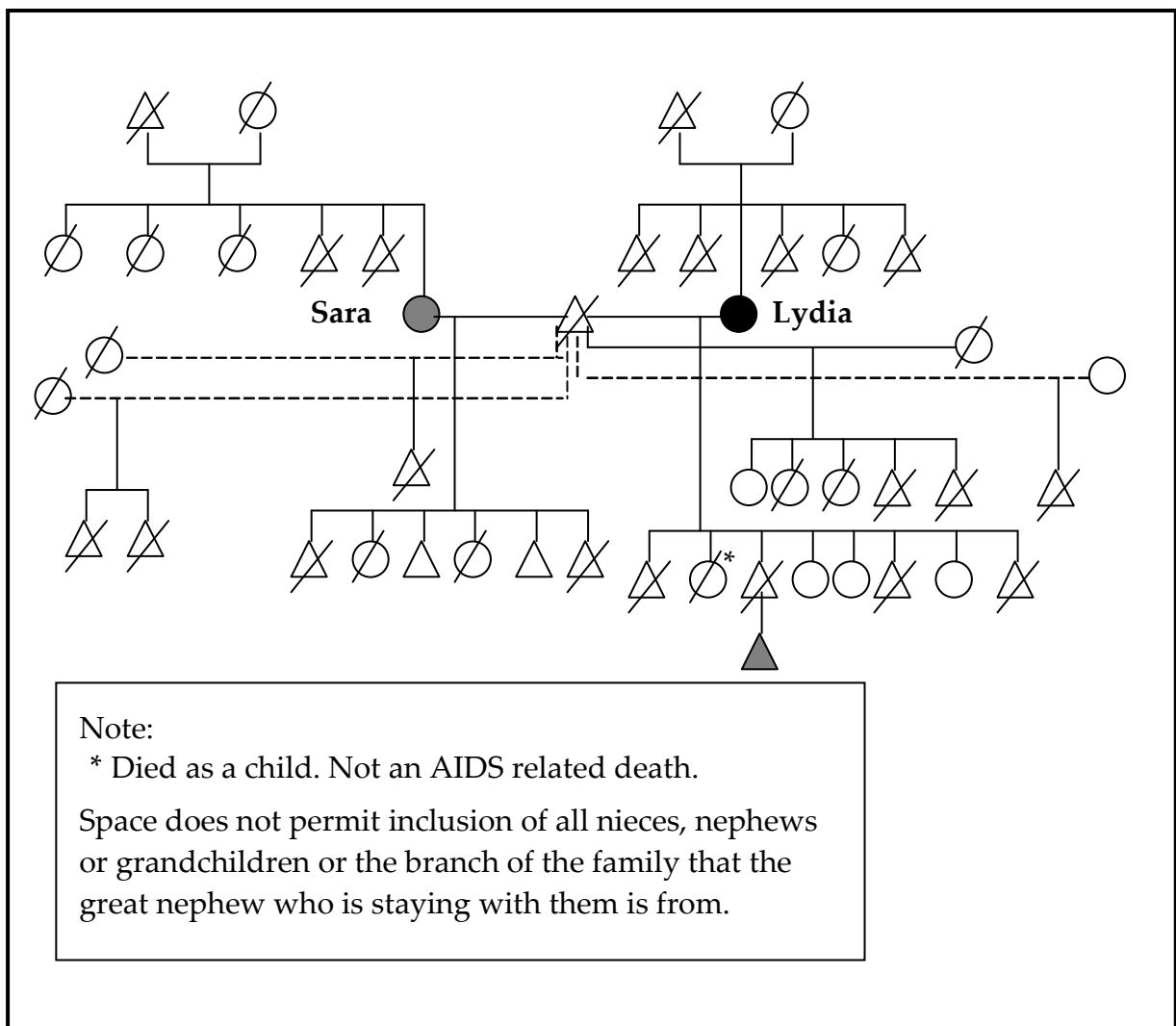
Lydia, Sara, Madina and Kiwanuka live in the same village some distance (about 10 kilometres) from the main trading centre where the MRC/UVRI office and clinic is based. There are no tarmac roads in the area and the mud roads connecting the villages, as well as the main road to Masaka, are often muddy and slippery when it rains or deeply rutted when it is dry, making travel, particularly for older people, difficult.

## The Households in 1991 and 2006

In 1991 Lydia and Sara lived with their husband Anatoli, then aged 71, who was household head. Anatoli had three other women he called wives: a woman in a nearby town who had five children, a woman on the Ssesse islands who had one child and another woman in a neighbouring sub-county who had had two children. Sara had had six children and Lydia eight. Anatoli, Sara and Lydia had seven grandchildren staying with them, five of whom had at least one parent still alive: grandsons aged 18, 14, 14, and nine and granddaughters: one aged 15 years, one aged six months and one aged one month (she joined the household on the death of her mother, the wife of one of Anatoli's son's who had died). Two great nieces of Lydia who were orphans were also taken in by the household during the year when their own grandmother who had been caring for them died. Their house was made of mud and wattle with an iron sheet roof. It had six rooms. The *kibanja* (cultivated land) was 19 acres (a large amount of land for people in the area), but Anatoli said that he had already given some of this land to his grandchildren who were living in Kampala. There was another *kibanja* that Anatoli owned in the village near the place that Sara used to stay before she was moved by Anatoli into the same house as Lydia.

In 2006 Lydia and Sara lived with two boys, who they called grandsons, aged 11 and six years. The old house was still standing, although was in need of repair. A new structure made of bricks and iron-sheets had been put up in the large compound. This was built by one of their sons who had intended to come and live there to care for them, but he died before the house was complete. The two women said that they were keeping that house ready for the children of the son if they should wish to come and live there. They still cultivated the same *kibanja* near the compound and a *kibanja* some distance from their home, in the same village. Lydia and Sara's kinship diagram (drawn in 2006) below shows the size of their extended family and, indicates the 'gaps' that now exist because of the number of children and grandchildren who have died.

**Figure 1: Sara and Lydia's kinship diagram**



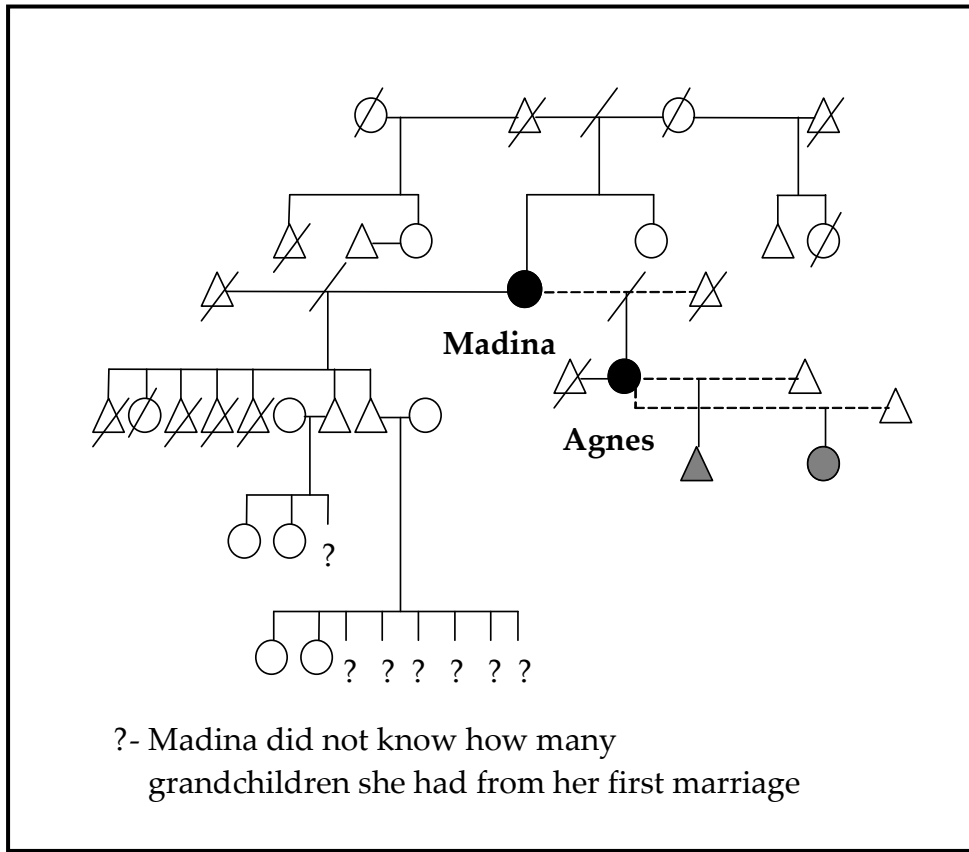
## Legend for kinship diagrams:

- △ Male
- Female
- ▲ Household head
- Resident household member
- Occasionally a resident household member
- Formal marriage
- Informal
- / Separation/divorce/death
- └ Denotes relationship of child or children to a couple

In 1991 Madina's household was made up of herself, then aged 62, her daughter Agnes (aged 25), and her daughter's son and daughter aged eight and five years old respectively. Agnes had had to leave school because of her first pregnancy. She then had a relationship with another man by whom she had her daughter. Madina was separated from her first husband with whom she had had six children. Agnes was the result of a relationship with a man who had since died who had brought Madina to the village as his second wife. The house they lived in was made of mud and wattle with a grass roof. It was in very poor condition. They had a *kibanja* of two acres which had been given to Madina by Agnes' father.

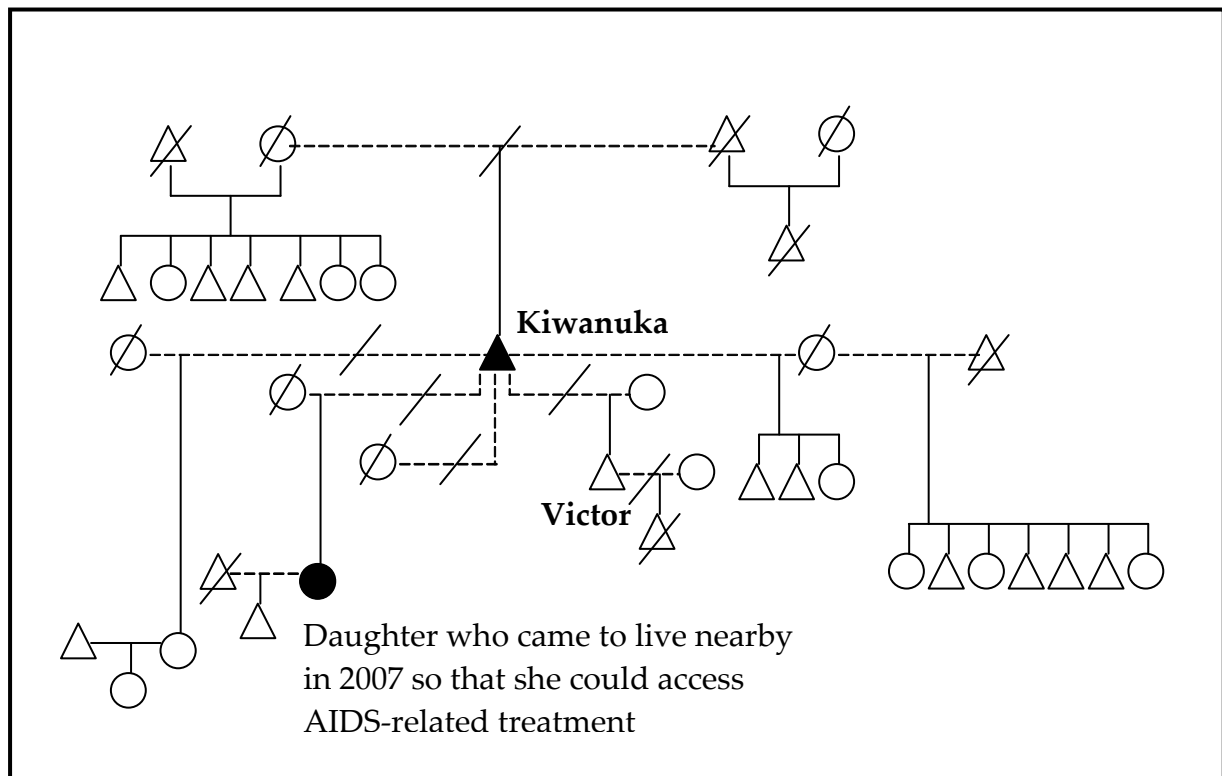
When the restudy began in 2006 Madina lived with the same grandson and granddaughter (both now in their 20s). The grandson ate with Madina and his sister but he slept in a room at the trading centre because he complained that Madina's house was too cramped. Agnes married a man in the village who had died in 2005. She did not have children with him and Madina was worried that his children by other wives would throw her off their land so Madina was building a simple mud and grass thatched structure on her compound for Agnes in case she needed a new home.<sup>7</sup> A two room mud brick house was built in 1996 to replace Madina's old house which fell down because it was attacked by termites. In addition to the two acres of land that they still had, they had another three acres of additional land at the place where Agnes stayed and the children had also borrowed one acre from a neighbour. The two children were using the land to grow crops for sale. Madina's grandson had a bicycle and a mobile 'phone that he had recently purchased. Madina's kinship diagram, drawn in 2006 before her daughter died, is shown below.

**Figure 2: Madina’s kinship diagram**



In 1991 Kiwanuka was aged about 60 and he was living with his son Victor aged 18. Next door to him lived his wife of that time and the three children she had had with him (and some of her children from an earlier marriage). Kiwanuka’s house was made of mud and wattle with a grass roof. It had four rooms. The kibanja was three acres.

By 2006 Kiwanuka was living alone in a house close to his own land. His own house had collapsed in 1994 and a neighbour had lent him the house he now lived in (which had been left empty when the occupant died). Like his old house it was made of mud and wattle with a grass roof. It was in bad condition. He did not have a kitchen, so he cooked outside. Maria, his wife next door, died in 1997 and her son from a previous marriage lived in her house with his family. The children she had with Kiwanuka came to live with him when she died but they were all teenagers so they soon left home leaving him alone. Victor, his son from a previous relationship, had been staying with his father until a few years ago but he was now living with his mother in another district because he was very sick. Kiwanuka’s kinship diagram shows the partners he considered ‘long-term’ and the children he had with them.

**Figure 3: Kiwanuka's Kinship Diagram**

### The impact of the AIDS epidemic on the lives of the participants

Using the four aspects suggested by Williams and Tumwekwase to structure our discussion, we now explore the impact of the AIDS epidemic on the four older people in the three different households.

#### Aspect 1. Older people as parents protecting, caring and burying their children

When we first asked Lydia for her consent to participate in the new study in January 2006 she said they would have little of interest to tell about the last 16 years because 'sickness and losing people are the only changes I know of in this household'. Sixteen of Anatoli's children and two grandchildren had died, at least 15 of AIDS-related illnesses. Their husband died of liver cancer. Kiwanuka had lost his last wife, Maria, to AIDS-related illnesses and his adult son Victor was very ill. Kiwanuka said that Victor had been bewitched by his ex-lover's husband, but the signs and symptoms he reported were suggestive of AIDS. Agnes, Madina's youngest daughter, had lost her husband because of AIDS-related illnesses and was, as noted above, terminally ill herself.

Lydia told us: *`Abazaala balina ennaku ekitabo ekitukuvu byekayogera byatuuka dda nti amabeere agazaala galyegomba amagumba!* (Those who bear children suffer great sorrow. What the holy book prophesied has already come to pass: “the breasts that bear children shall long for their bones”). Anatoli’s children had come to their father’s home when they were very sick. It was Lydia and Sara who nursed them, even the children of their co-wives. One of the first of these children had died during the 1991/1992 study period, the daughter of Sara. It was Lydia who had nursed that girl when she had returned home sick, because her own mother was undergoing treatment in Kampala for a hip fracture.

The quotation from Sara at the beginning of this paper describes in a straightforward way, Sara’s experience of seeing their children die. She was a staunch Catholic, the first wife of Anatoli and the only one married in church, she had held fast to her faith through all the trials and tribulations of her husband’s other relationships; that same faith comforted her as she had watched their children die.

Kiwanuka was rather different. He acknowledged that AIDS-related illnesses may have killed two of his former partners but he believed that witchcraft was the cause of his son Victor’s illness. Kiwanuka said that he moved his son away to stay with his former partner, Victor’s mother, when he fell sick, to get him away from the source of the witchcraft (the neighbour’s husband; Victor had had an affair with his wife), but we suspected that he wanted the mother to care for her ailing son rather than do it himself. Kiwanuka had tried to stop his son from carrying on the affair with the neighbour, who was more than 20 years Victor’s senior, but his son had not heeded his father’s advice.

Kiwanuka may not have given direct care to his son but he did what he could to send Victor support. In 2006 he sold a goat so he could get some money to send. He had got a goat from his friend and they had agreed to share the kids, so he had shared the proceeds of the sale of the kid and ended up with 12,000/- (about £4). He had sent a nephew who lived nearby to see Victor with 9000/- (£3) to give to him (he had kept 3000/- [£1] to use himself).

In 2000 Kiwanuka’s eldest daughter had lost her husband, Kiwanuka said he died of AIDS-related illnesses. The daughter went to stay with her mother (who was ill) and while there heard about the MRC/UVRI programme. She had started to fall sick and feared she was HIV-positive so she came to visit her father in 2002 to seek his help in accessing MRC/UVRI services. Kiwanuka recounts how he worked hard to persuade MRC workers to include his daughter as a member in his household. He was successful and she stayed for a month before she went back and since that time she had been getting treatment at the MRC/UVRI clinic. She visited her father when she came for check-ups.

Madina had a long list of cousins, nieces and nephews who had died over the last 16 years many, she says, of AIDS-related illnesses. In June 2006 another of a cousin's adult children died and Madina went to the burial, lamenting the efforts her cousin had made to educate her children, only to see them die in adulthood. As for Madina's children, she worried, justifiably, about her daughter Agnes, given that her husband died so recently of what she called 'this prevailing disease'.

Madina had lost contact with the children from her first marriage. She left those children when the eldest was only 12 years old. Of the six she had had, only three were still alive then (three had died when they were toddlers). Her marriage had broken down when she had had a series of miscarriages and her husband had decided to take another wife. So Madina left on bad terms. A few years ago the eldest remaining boy sought her out when he came to a nearby village for a funeral and she learnt that one of her other children had died as a young adult. Madina knew little about her grandchildren from her first marriage (as indicated by the question marks on the kinship diagram).

By 2007 Madina was nursing her daughter and she worried about her daughter's children.<sup>8</sup> She was concerned about these grandchildren's behaviour but felt powerless to influence what they did. During one of our visits, her granddaughter told Madina that she had something to do before collecting water. A few moments lapsed and we asked Madina where the girl had gone. She replied: 'My dear, youths, where shall I tell you she has gone?'

## **Aspect 2. Older people as foster parents of orphans and children of single parents**

For none of the families was fostering an unusual experience: Sara, Madina and Kiwanuka were brought up by relatives, not by their own parents. Fostering children, within the extended family, even when both biological parents are still alive, is an accepted practice among the Baganda (Roscoe 1965: 74). So the passage of children through the households, particularly of Lydia and Sara who are relatively well-off, is not unusual or surprising. In 1991 the two women were taking care of a number of grandchildren, only two of whom were orphans, and in 2006 we found them with two boys. One was the child of one of Lydia's sons who died and the other the son of a nephew who had died. Lydia commented that Universal Primary Education (UPE) has helped her a lot (in 1997 UPE was brought in doing away with fees for primary education, although some schools do still charge small amounts). She paid for the boys' books and uniforms. The money for those costs, as well as their living expenses, came from the sale of coffee and mbidde (bananas used in the brewing of local beer) which Lydia employed casual labourers to tend. Among those casual labourers were a granddaughter and her husband who Lydia and Sara helped out by paying them in return for work on their land.



Madina had lived with her two grandchildren since they were born. Madina's home was their residence; they did not go with their mother when she remarried, as is customary because they are not the children of her husband's lineage. The grandson had been in contact with his biological father from time to time in Kampala but Madina's household had not received any material help from that man. The granddaughter had had no contact with her father over the last 16 years. The situation of Madina's grandchildren might seem rather unusual given the customary practice among the Baganda where because of patrilineal kinship structures children would normally be fostered within the father's extended family. Children born into patrilineal families automatically took on the identity of their father's lineage and thus "belonged" to this line (Roscoe 1965: 82). Exceptions might be made for very young children where staying with maternal relatives may be seen as most appropriate but older children would be expected to be fostered by their father's kin. Yet, Madina's household's situation is not so unusual for children born to a woman while she was still in her parent's home. It may be that the fathers' of the children were not prepared to acknowledge their child or, at least, accept responsibility for the child's care.

Kiwanuka had little to do with the upbringing of his own children. He seemed unconcerned by the failure of any of them to continue in their education beyond primary school. His eldest son Victor had lived with him from time to time until 2004 when he became seriously ill. The three children he had by his wife next door stayed with him when their mother died, but by then they were teenagers and they soon left home. By 2006, the two boys were fishermen living at Lake Victoria and the daughter was also at the Lake, Kiwanuka said he was not sure what she was doing there.<sup>9</sup>

### **Aspect 3. Older people as individuals vulnerable to infection**

Only Kiwanuka had had a sexual partner in the last 16 years. Madina's partner died about five years ago and she said he had stopped coming to see her some time before that. Madina said that for the last several years she preferred to live a 'single life'. Kiwanuka's last wife, Maria, died in 1997. Maria had been sick for some time before that but in 1991/1992 they were still sexual partners. Maria was one of many women in Kiwanuka's life, although there are only some he refers to as wives. A look at his life history provides some background to his sexual history.

*After the Second World War he stayed with his mother for a while and started a business selling fresh fish. He bought himself some land, using the money he received on demobilisation, near the Lake (Victoria) to farm and started to work as a fisherman as well. He got his first wife while at the Lake but separated after three years because, he says, she was a drunkard. They did not have any children. Kiwanuka enjoyed fishing because in those days*

*earning money catching fish was not hard and he ate well but he decided to move to his present kibanja when he found out how much money could be made from growing coffee. He raised the money for the kibanja from his savings and from earnings he got ferrying people across the swamp that borders the village. At about this time he met the mother of Victor with whom he had stayed for one year and then the mother of his eldest daughter who was an alcohol seller in one of the towns on the highway. This woman had died in 2005. Then, he says, he had a casual relationship with the mother of his next daughter. That partner died 'many' years ago. Finally he had a relationship with Maria, his next door neighbour, when her husband died. There were other women as well, but these were his long-term partners.*

Kiwanuka was lonely in 2006. He told us that 'I am tired of living alone in the house what if a problem occurs when I am there alone! I don't have any one to share conversations with besides my radio.' While Kiwanuka did not live with his last wife, she did live next door and food was sent over to him from time to time. As far as he was concerned his sexual career was not yet over, he wanted more than someone to talk to, he wanted a new wife. He told us that he has a friend who has promised to get him a woman but he needed 30,000/- (£10) for transport to bring her to his home. His one concern about getting a new wife was, ironically, the risk of infection from HIV. Yet he told us he did not know his own HIV status and had no wish to know at his age. It would seem that Kiwanuka had already been exposed to HIV from the evidence available on the cause of death of two of his wives/partners. Perhaps he was one of those who is extremely fortunate in either remaining uninfected or asymptomatic (Serwadda *et al.* 1995, Bunnell *et al.* 2005). However, he was aware of his own vulnerability to infection, but seemed disinclined to do anything to protect himself or any prospective partner. Kiwanuka's situation brings to mind the words of one of the old women in Williams and Tumwekwase's study (2001: 225):

*We old people have it as well – in fact I suspect I am positive because one of my partners has died. I won't get a test because I know in my heart I am positive. Don't be surprised when you hear I have died!*

This fatalistic acceptance of what was seen to be inevitable is not surprising in a situation where many people have died. Yet, as Blaikie *et al.* (1994: 58) observe 'vulnerability is a hypothetical and predictive term, which can only be 'proved' by observing the impact of the event when, and if, it occurs'. Perhaps, for Kiwanuka, the 'event' of symptoms of AIDS-related illness will never come.

#### **Aspect 4. Older people as dependent old people deprived of support from their deceased adult children.**

Of the four older people we are discussing in this paper Lydia and Sara, and subsequently Madina, lost the support of children who had died as a result of the epidemic, although given the present state of health of Victor, Kiwanuka may also lose one of his sources of support in the near future. While the loss of 18 children, in the case of Lydia and Sara, is tragic, the fact that Anatoli had many children, and some of those children and grandchildren remained to provide support to the two elderly widows had been a great source of comfort to them. Even so, the loss of some particular children was still felt keenly, and the women were still grieving. For example, when Anatoli was dying in 1991/1992 we heard a lot about a son who was taking him to different hospitals trying his best to get his father treatment. It was that same son who constructed the new house on the compound that he planned to stay in to look after his old 'mothers'. He was the biological son of Lydia and she called him their 'right arm' because of all the help he gave them. She lamented his death 'Our son who was our right arm put up this house so that he could care for us when near us but he died and it was his dead body that entered here' she told us. Other children now helped with building and repairs. Lydia's daughter in Kampala had paid for bricks for the construction of a new kitchen by the old house and as 2006 drew to a close Sara said that that girl would pay for the construction work too.

It was for their health needs that Lydia and Sara were most dependent on their children, given they had enough income from their land to provide their daily necessities. Lydia had breast cancer in 2005 and had to have a mastectomy, which her children arranged and paid for. In 2006 she was suffering from complications from diabetes and had spent much of the last six months in Kampala under-going treatment. Sara had a badly healed broken thigh which impeded her movement (she broke her thigh in 1991/1992 during the first period of in-depth study). During 2006 Sara fell and hurt her thigh again and was bedridden for over a month. Their children in Kampala took control of that situation, indeed during one visit Sara told us that she was waiting for the children (she didn't say which children) to visit on Sunday to decide if she needed further treatment! A granddaughter who lived nearby came to stay with Sara to help with her care and to keep her company at night when she was immobile and when Lydia was away in Kampala. When thinking of the care she received Sara smiled and said:

*'They really help us a lot even now my fellow (meaning her co-wife Lydia) has not come back from Kampala. She is there at our children's and they care for her well. They even phoned us [a shop keeper has a phone and passes them messages] and informed us that she would have come back by now but she now got a fever. They really help us let it be sickness, essential*

*commodities, preparing for social functions like organising prayers for our dead people. They come in and help. They do not neglect us.'*

On another occasion we found Sara sitting with a physically and mentally disabled grandson who she was watching over, when she had been left in a shady spot by her granddaughter who had gone to dig in the *kibanja*. Sara commented:

*'That granddaughter of ours helps us a lot. She has now left her home and come to stay here to assist the other girl (a house girl the Kampala children employed to take care of the two women) in caring for us since I have been unable to support myself. She washes the clothes, she has been bathing me, she goes to the garden to dig and she has helped us very much to do the weeding in the banana plantation and right now she is down in the plantation with the girl. They are weeding there. They left me here after giving me my morning tea then they went to dig.' When we asked if the little boy had been left to keep her company she smiled and said; 'He keeps around here and moves slowly by slowly'.*

Lydia and Sara were fortunate to have the continued help of their large family. Kiwanuka and Madina were also fortunate because they too had children and grandchildren to support them. Kiwanuka complained that his children did not help him enough, but none of his family was that well-off and the children always seemed to bring him something when they came. One day when we were visiting him, one of his fisherman son's came unexpectedly. The first thing Kiwanuka said to him was 'where is the tilapia (fish) you have brought for me?' His son replied that there was a scarcity of fish so he had none to bring, to which Kiwanuka responded wistfully 'I have taken long without eating tilapia'. On that occasion the son was seeking his father's help because he had been imprisoned for damaging another fisherman's nets and he needed money, so he was not in a position to help his father. On other occasions Kiwanuka was more fortunate, the next time he visited that son left him with 5000/- and one kilogram of sugar (but no fish, which Kiwanuka complained about!). Kiwanuka's needs were quite modest, and his children knew that. He sold snuff, made from tobacco he grew or purchased from nearby farmers, which could earn him up to 10,000/- a month. He had a steady supply of customers (some of whom visited when we were visiting him). He used that income to cover his day to day expenses so he was not dependent on the food he grew on his land or on others to provide for him. While Kiwanuka complained of eye problems and aches and pains, he had not had any serious health problems and continued to work his land quite vigorously growing tobacco and a few food crops.

Madina's grandchildren were her main help. Her granddaughter cooked and cleaned for her, and collected the medication she required to control her asthma attacks from the MRC/UVRI clinic (she had been accessing treatment from the clinic for about 10 years). Her grandson had a job repairing bicycles and her granddaughter cleaned a house two mornings a week. They both worked hard

cultivating crops for sale. While they used their earnings on themselves (the granddaughter regularly had her hair permed and the grandson had bought himself a mobile 'phone in 2005) they shared their money with their grandmother. In June 2006 Madina received news that her cousin in a nearby town was ill. A local taxi driver brought her the message and offered to take her to her cousin. Her grandson gave her the money for the fare. That same month he gave her 10,000/- (£3) so she could put a door on the house she had constructed on her compound for their mother. Madina had paid for the construction out of the sale of crops but she still had a large debt (20,000/-, about £6) to pay to the man who did the construction. That man, she said, was sympathetic to her, so he was prepared to wait. Madina lamented the fact the both her grandchildren left school before completing their secondary education, this was particularly irksome to her because she had succeeded in securing a scholarship for her granddaughter to complete secondary school but the girl refused to go. Her grandson told his grandmother that his uncle, who financed his schooling, had not been to secondary school, and he was earning good money, so why should he continue to go to school! The uncle, the brother of the boy's father, accepted the boy's decision and took him to train in his shop as a bicycle repairer. In that, Madina says, he was very fortunate. Madina did not have the chance to go to school, her foster-father did not believe in educating girls. Perhaps that is why she was so annoyed that her grandchildren had failed to take up the opportunities they were offered.

All four older people received help from others outside their homes. Sara and Lydia, for example, received help from the shop keeper who had a telephone that they could receive messages from their children on and occasionally local men gave them a ride on their motorbikes to get to church or to the MRC/UVRI clinic. Kiwanuka had been having trouble collecting water during 2006 because the 20 litre jerry can was too heavy for him to lift. A local boy had said he would help him, and he helped a few times but most of the time Kiwanuka had to carry two small cans of five litres each to collect water himself. On a more positive note Kiwanuka had lent a piece of his *kibanja* to his neighbour, a young woman who was the daughter of his 'great friend', which helped her. She grew groundnuts on the plot and shared some of the crop with Kiwanuka as well as coming to chat. Madina received occasional help from her cousin in the nearby town and a richer man in the village who sometimes gave her beans or other items when he harvested.

The access to MRC/UVRI treatment was important to all four people. It is perhaps Madina who valued it most because she could not afford to pay for the treatment she got for her asthma. She could not always wait to get to the clinic and her grandson bought a few tablets from the shops to help her. This was particularly the case on weekends when the clinic is shut. Sara and Lydia complained that they had trouble getting to the clinic and then had to wait a long time to be seen, but when they needed help they could afford to find an alternative. Often their children took them

to Kampala for serious problems. Kiwanuka seldom went to the clinic because of the distance and the waiting time but once in 2006 when he had been suffering with an eye infection for more than a month his nephew gave him a lift to the clinic very early in the morning on the back of a bicycle so that he could be at the front of the queue!

## **Reflections on Ageing and the Impact of HIV and AIDS**

Our findings confirm the categorisation of impact provided by Williams and Tumwekwase, all the people described in this paper have been affected in more than one of the ways set out in the four aspects of the multi-faceted impact of HIV and AIDS that they describe in their paper (Williams and Tumwekwase 2001). We can, however, add to their analysis by including the dimension of socio-economic status as well as the detailed knowledge that we have of the lives of these people over the last 16 years, and the information they shared on their life histories.

The fact that Lydia and Sara are still alive, and still provide support to others in the community (mainly through providing employment and gifts and food at weddings and burials), is not a surprise given the wealth of their family in 1991 and now. It was their prosperity as well as, ironically, their large family (partly the result of the promiscuity of their husband) that had supported them through their losses. Ainsworth and Dayton (2003) in the study of the impact of the AIDS epidemic on older people in Tanzania, conclude that better-off households feel no significant long-term socio-economic impact of a 'prime-aged' adult death and even poorer households may not suffer a long-term decline if they are the recipient of outside assistance (from church or non-governmental organisation). They conclude that 'improving the incomes and assets of the poor are key' to improving the well-being of older people affected by the AIDS epidemic (203: 144). In the report of the 1991/1992 study Seeley had suggested that the better-off families would be more resilient in the face of the AIDS epidemic and there was a need for supportive interventions for poorer households (1993: 97).

However, suggestions around wealth and resilience can be called into question when one considers the two other households, particularly if socio-economic assessments are based on a single time period. Kiwanuka's situation, for example, was not as straightforward as that of Lydia and Sara. He lived in a very poor house, he cooked in the open air (sheltering under an old iron sheet when it rained) and to the casual observer looked to be a very poor man. He possessed a pot for keeping his water, a simple bed and a radio but no other significant assets. Indeed his asset base had not changed in 16 years. Yet, he had enough to satisfy his needs. He did not seem to care too much about investing in a better house when the one he had served his purposes. His income from selling snuff allowed him to buy food, alcohol (he complained he can not drink hard liquor as he used to, but he still enjoyed local beer)

and contributed small amounts to local functions (thereby ensuring he was a welcome guest). He could also afford to send support occasionally to his ailing son.

Kiwanuka had undoubtedly been affected by the loss of close family members because of the epidemic, particularly by the loss of his last partner, and the continuing sickness of his son. He often claimed that he did not know what killed his partner and blamed witchcraft for the sickness of his son. Perhaps Kiwanuka's reluctance to acknowledge the impact of HIV on his former lover and son (while accepting the fact that his daughter was infected and needed help) was because of his close relationship with both and therefore his concerns over his own status. His continued good health seemed, as we note above, to be due perhaps to good fortune.

Madina had been brought up by an uncle and aunt in a relatively well-off family. Her fall into poverty was directly a result of her relationship with the man who had made her pregnant and brought her to the village as a partner. He already had a wife and family who took most of his resources, so although he had given Madina access to land and had built a simple house with her, he had done little to help her on a day to day basis. In 1991 she earned for her family by brewing and selling beer and labouring on other people's land. They were poor in 1991 and during a time of food shortages she and her daughter struggled to get enough food for her grandchildren. She was better off in 2006, but her 'wealth' was likely to be transitory. In the demographic survey round in 2005/2006 Madina's household was listed as having a bicycle, a radio and a mobile 'phone. In 1991 in an earlier round of the same annual survey when asked about the items she owned on a 'household item index' she had told of only a dish rack and a bed. Those two items are still the only things she possessed on the index. The three new items, of which she was so proud and boasted to us (and the survey team) of owning, belonged to her grandson. In 2005 he had started to sleep at the trading centre away from his grandmother and sister. He complained that house was too cramped (he had to sleep in one of the two rooms with his sister) but Madina suspected that he wanted more freedom. By the end of 2006 we found Madina in despair because he had gone to Kampala. He had been talking about going to Kampala for some months and had often told us the only reason he stayed around was to care for his grandmother. In November 2006 he finally went and Madina feared he would not come back. Perhaps he had concluded that his sister was now earning so she could take care of Madina, The problem for Madina was that he not only helped her financially, but he had also done the heavy work on the land cultivating crops for sale. Without him she and her granddaughter could be little better off than they were in 1991. Her daughter Agnes was the one person who, because of her own personal circumstances, was likely to remain in the village and thereby be there for Madina in the future. Sadly, when she died in 2007, Madina was robbed of her companionship and support.

If we consider the other people who are over 70 among our 24 study households two have been taken out of the study area to be cared for by relatives, the other woman who is over 80 is, like Sara and Lydia,, a wealthy widow who has lost children and grandchildren to the AIDS epidemic but had other children who continued to care for her. The support of kin who have resources, as well as the personal wealth of the individual, had played a key part in these women's survival. Other, younger, household heads in our study who have lost children to AIDS-related illnesses, and in two cases were infected themselves, were struggling to make ends meet and despite being 20 years younger seemed more affected in terms of Williams and Tumwekwase's four aspects of AIDS impact than Sara, Lydia, Madina and Kiwanuka. Wealth had insulated Lydia and Sara from feeling any socio-economic impact of the epidemic and Kiwanuka and Madina had, so far, been able to maintain their resources because neither had had to invest too much in caring for people affected by the epidemic.

There is one other factor that we would suggest that has played a part in these four individuals passage to their eighties, and that is what might be called their personal sense of coherence (Lundberg and Nyström Peck 1994) and in the case of Madina and Lydia and Sara, their family as a whole. This strength is to some extent bound up in their feelings of security in their position and social status (Crosnoe and Elder 2002). This was perhaps most obvious in the case of Lydia and Sara. These two women were once rivals for their husband's affection. Anatoli had met and made Lydia pregnant soon after marrying Sara and Sara had, not surprisingly, seen Lydia as her rival. As time passed, and other women came into Anatoli's life, these two women found that he provided enough for their needs and the needs of their children and gradually they became close friends. Following Anatoli's death Lydia became household head partly because she was older than Sara but also because she had been active in local government and was well respected in the community. Sara was content with this situation although she would point out (with very little prompting) that she was Anatoli's first wife! Their close bond was reinforced by their continued occupancy of Anatoli's land, the place where he and their children are buried. Thomas (1995: 240), in his life-course analysis of older people among the Meru in Kenya, goes beyond old age and adds the post-burial existence of a deceased old person as a transition to a new state in the life-course because of the value of the act of remembering the deceased in drawing the family together. In Sara and Lydia's family, the continued memory of Anatoli, and the way he linked their lives, drew them together. Anatoli was very much the centre of the household when we first met him 16 years ago, and he continued to hold a key position in the home even in death, in keeping with Thomas' concept of 'honoured deceased clan stage' of life. Every year his children and grandchildren come home and hold a Mass to honour his memory. Williams (2003) recounts the way old people in his study area, close to the villages in which we are working, lamented the loss of their children who would have buried and mourned them, an important part of preserving their memory.



Without surviving off-spring an old person is 'no better' than a childless person. This is not a fate that Anatoli has suffered.

Madina's own sense of coherence has been shaken by her grandson's departure for Kampala, but the care he has shown for her and the affection he has shown his mother and sister would suggest that he would not forget them. William's (2003) catalogues the conflicts that arose between grandparents and grandchildren over the misuse of resources and, in the older people's eyes, unacceptable behaviour. Madina had not experienced such difficulties. Perhaps because the two children have always lived with her and regard her home as their home, they respected and cared for her.

## Conclusion

The narratives told about the lives of Lydia, Sara, Madina and Kiwanuka are punctuated by turning-points or transitions. Death, in particular, has often been an important turning point as has personal sickness and the ailments of family members. Gardner (2002: 177) observes that 'illness does not exist only within the individual, but is socially embedded. Like all human suffering, it is positioned in a field of social relations'. That is clearly illustrated for these four people as the impact on family and friends of AIDS-related illness and death has profoundly affected their life-course, altering expectations about their own futures and the futures of their children and grand children.

We have illustrated the importance of the past as well as the present social and cultural context in which these four older people live in mitigating or exacerbating the impact of the epidemic. We have also shown, particularly in the case of Kiwanuka, that older people do not necessarily just look for support but may desire to continue with an independent life (albeit in the company, he hoped, of a new wife). All four people illustrate through their stories how their lives are linked to those of their children who they may need to support as well as be supported by them, but also demonstrate very clearly their own agency through their independent thinking and their own hopes and aspirations.

Older people have undoubtedly shouldered much of the burden of care and grief that has resulted from the AIDS epidemic, burying children who they would have anticipated would have buried them. As we have tried to illustrate through the case studies in this paper, understanding the complex lives of older people calls for a more nuanced view of the experience of growing old during the AIDS epidemic that takes us beyond an image of an old person as a carer surrounded by dependent 'AIDS orphans'.

## Endnotes

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2. The family had actually lost 17 children and at least two grandchildren. Sara is referring to the children they had actually buried on their plot at the time. A few months after she said this another son died, and his body was brought back from Kampala for burial.
3. All the names of study participants have been changed and we do not use village names to help to protect the identities of our informants.
4. See for example the most recent UNAIDS Fact Sheet on HIV/AIDS and sexually transmitted infections for Uganda (UNAIDS 2006).
5. The Principal investigator worked with four post-graduate social scientists to support the field team in this study in 1991/1992. In 2006/2007 the field team was more experienced (it was led by the same woman that led the team in 1991/1992) and one social science graduate provided support.
6. For the restudy we included the surviving household heads from the original study and the successors of those who had died: sons and daughters of the original household head or a son-in-law.
7. Tragically, Agnes did need this home. In early 2007 she came to stay in it when she was very ill so that her mother and daughter could care for her. She subsequently died in that house in mid-2007
8. Agnes, Madina's daughter, was taking anti-retroviral therapy, but the drugs failed to work for her despite the efforts of the medical staff from MRC/UVRI caring for her.
9. Kiwanuka was reluctant to discuss this daughter and her employment at the Lake. That may be because he knows, as an ex-fishermen, that single women at the Lake may well be engaged in fish trading but they may also be providing sexual services to the many single men who stay at the fish landing sites.

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