MRC/UVRI Uganda Research Unit on AIDS

Cordaid

THE REPUBLIC OF UGANDA

STUDY ON GLOBAL AGEING AND ADULT HEALTH
sage

World Health Organization

UGANDA

Well-Being of Older People Study

A Study on global AGEing and adult health (SAGE) sub-study

WHO SAGE–WOPS WAVE 1

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The Study on global AGEing and adult health (SAGE) is part of a Longitudinal Survey Programme in WHO's Multi-Country Studies unit. The main SAGE surveys compile comparable longitudinal information on the health and well-being of adult populations and the ageing process from nationally representative samples in six countries (China, Ghana, India, Mexico, Russian Federation and South Africa). In addition, sub-studies and other research collaborations test methods and provide needed data to better understand the ageing process in different countries and contexts. One SAGE sub-study, the 2009/10 Well-Being in Older Persons Study, was conducted in Entebbe, Uganda and Hlabisa, South Africa. The study adapted survey instruments and materials from SAGE to examine the physical, emotional and social wellbeing of older people infected with and affected by HIV/AIDS. This report presents the descriptive results from Entebbe, Uganda.

http://www.who.int/healthinfo/systems/sage/en/index.html

Direct and indirect effects of HIV/AIDS and anti-retroviral treatment on the health and wellbeing of older people

Medical Research Council/
Uganda Virus Research Unit,
Research Unit on AIDS,
Entebbe, Uganda

Study Report May 2011

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Foreword

The Government of the Republic of Uganda has realized that the population of older persons is increasing and is committed to addressing their concerns. It recognizes that as people reach old age they should enjoy dignified life and actively participate in economic, social, cultural and political life in their communities.

The Ministry of Gender, Labour and Social Development emphasizes evidence-based policy development and planning. The Ministry therefore welcomes this report which provides evidence on health and well-being of older persons. There is no doubt that there is limited information on their health and well-being. Such information is required to plan the most effective ways of addressing their needs.

This study shows that most older persons suffer from very common health conditions which could easily be treated at low cost with generic medicines or prevented with simple interventions.

The study also highlights the role and task of older persons in families and the communities where they live. The study further highlights experiences of older persons especially on the care of their grand children and relatives and this burden affects their health. Some of the findings of the in-depth interviews show how older persons perceive their own situation.

Some of the findings of this study tell us about the importance of inclusion of older persons in the services delivered by Government and NGOs. It also reveals the importance of the community in the provision of care and support to older persons.

Older persons need to be seen as valuable members of the community. They need to participate in all activities in the spirit of active ageing to promote their longevity.

Many older persons live in abject poverty which is one of the causes of several ailments and other societal problems.

Service providers and community members need to act in unison to provide care and support to older persons.

The findings of the study indicate that many older persons are lonely and feel depressed. There is therefore need for service providers to add the component of psychosocial support as they deliver services to them.

This study is very useful and will help stakeholders in planning and implementing old-age friendly programmes for betterment of the lives of older persons.

Baryayebwa Herbert
Director, Social Protection

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We want also to express our gratitude to data analysis MRC data team, Susan Nakulbulwa and Sebastian Owilla and Jonathan Levin. We thank Joy Namutebi Matovu for coordinating the data entry.

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Rebecca Peters provided copyediting services and Rick Jones was responsible for the design and layout.

Last but not least, we wish to thank all participants who consented to participate in the study.

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Contents

1. Introduction

This report presents the general findings of a study which took place in Uganda in 2009/10, examining the effects of HIV/AIDS and antiretroviral therapy (ART) on the wellbeing of older people. The report includes the results of a pilot and the main study, a summary of the first local dissemination workshop and a discussion section on translating the study results into action. This study had both a quantitative and a qualitative component. Both addressed psychological and physical health, as well as the socioeconomic wellbeing of the study participants.

The quantitative component of the study included a systematic assessment of health, wellbeing and socioeconomic factors, as well as biological and clinical data collection. It adapted international measurement approaches, notably those used in the World Health Organization's multi-country Study on Global Ageing and Adult Health (SAGE), which has developed standardized modules for the assessment of both physical and mental health status. The data provide insights into the illnesses that affect people as they age (co-morbidities) and also the responsiveness of the health care system.

The qualitative component consisted of monthly visits for up to 12 months to collect an oral diary on each participant's life during the preceding week, and also to document their life story, in order to learn more about their wellbeing and the impact of HIV and AIDS on their lives. The qualitative study comprised twenty-three participants known to be HIV positive; furthermore, the study also incorporated monthly diary interviews and life history interviews for nineteen participant who had been tested negative. This has allowed some comparison during data analysis.

The integration of the quantitative and qualitative parts of this study has taken different forms. First, the themes developed for the qualitative work were guided by the pilot quantitative survey results. Second, the qualitative work was used to provide further insights into the reliability of the responses to the survey questionnaire. Third, the qualitative part helped to interpret the quantitative results from the survey; and vice versa, the quantitative results enabled us to put the qualitative findings into a broader public health perspective.

This report is descriptive. The tables are intended to describe the results of the survey and do not aim to analyze differences between the study groups or other subpopulations. Most results are also not age-adjusted, which is important as there are differences in the age composition of the study groups that need to be taken into account. The detailed analysis and examination of more causal associations will be presented in separate papers.

Some of the preliminary study findings have already been presented: in September 2010 at a rural district dissemination workshop in Masaka, Uganda; July 2010 as a poster presentation at the World AIDS Conference, Vienna; June 2010 at a WHO Health and Ageing meeting, Geneva; May 2010 in the Medical Research Council seminar, Entebbe; February 2010 at the Social Gerontology Course training, Malta; and October 2009 at a HelpAge International meeting in London.

1.1 Ageing issues, policies and programs in Uganda

The Government of the Republic of Uganda started to address ageing in 2009 when the Ministry of Gender, Labour and Social Development (MOGLSD)published its National Policy for Older Persons. This was developed with the input of other Ministries, local authorities, civil society organizations, faith-based groups, communities and older persons themselves. The policy provides a framework for legislation and programming, as well

as identifying opportunities to harness the potential of older persons. The priority areas of focus are food security and nutrition, health, HIV/AIDS, water and sanitation, shelter, gender inequalities, psychosocial support and care, economic empowerment, training and lifelong learning, conflicts and emergencies, access to physical facilities, services and information, research and documentation and financing the policy. The policy aims to guide decision makers, planners, development partners and program implementers.

This policy has encouraged us to collaborate with the Commissioner of Elderly and Disability in the Ministry of Gender, Labour and Social Development. We had several meetings with him during the study to share our progress. In September 2010, at our district-level dissemination workshop, the Commissioner's representative presented the Government's policy and programs on ageing.

Uganda has developed a National Minimum Health Care Package and promoted private-public partnerships to ensure that people receive appropriate health services; but these initiatives have paid little attention to the specific health needs of older people.

However, the National Programme Plan of Action for Older Persons 2010/2011-2014/2015 of the Ministry of Gender, Labour and Social Development provides all stakeholders with direction on delivery of services. It includes interventions to improve the quality of services for older persons at various levels. Among the proposed interventions for health are:

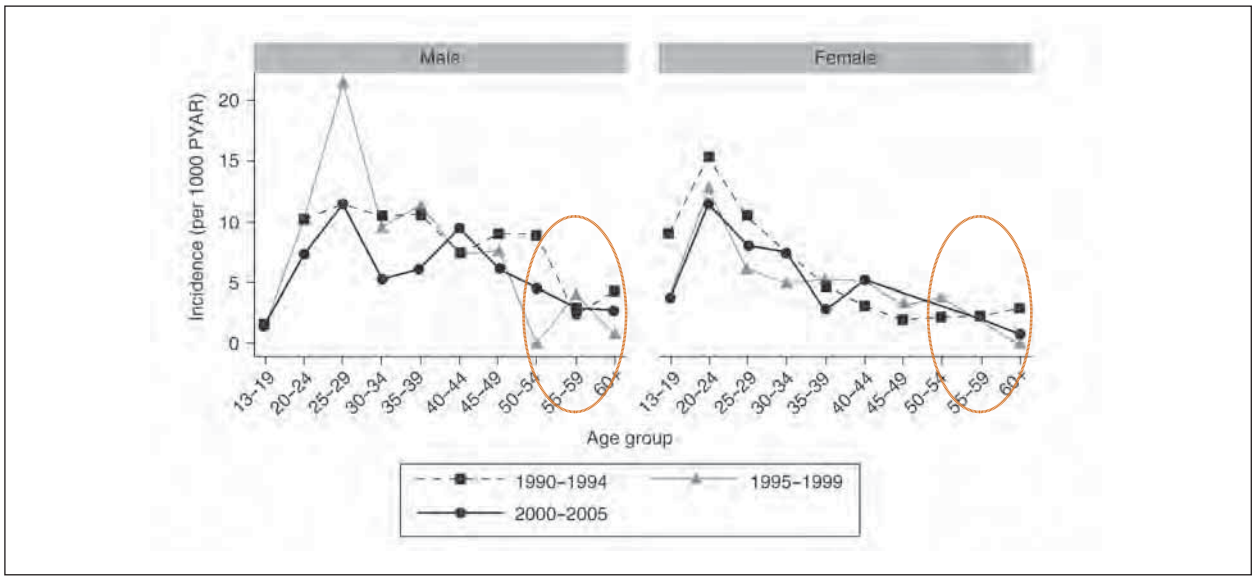
- mobilizing resources for service delivery
- promoting community participation in activities that benefit older persons
- including health issues of older persons in existing training curricula for health workers at all levels
- advocating for the rights and dignity of older persons
- including health issues of older persons in health surveillance programs
- reorienting health workers on older persons' issues
- promoting special health outreach programs for older persons
- including drugs for treatment of older persons on the essential drug list
- reviewing Health Management Information Systems to include issues of older persons.

1.2 Study background

This study included groups of older people who have experienced the direct effects of being HIV-positive themselves; and also older people who have experienced the indirect effects of the HIV / AIDS epidemic arising from living with a child infected with HIV/AIDS.

With regard to direct effects, we have limited understanding of the health-related impacts of living with HIV/AIDS in older adults and how these are modified by antiretroviral therapy. Older people are more likely

Figure 1 HIV incidence by age group and sex, Kyamulibwa community cohort study 1990–2005



Note: PYAR = person-years at risk.

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to have co-morbidities, more likely to experience a rapid progression to AIDS and, consequently, to have lower survival rates. There is also increased risk of side effects on ART and elevated risk of psychiatric disorders (Llorente and Malphurs 2006). The available data point to a substantial burden of HIV among persons aged 50 years and over. The HIV incidence among older people in Uganda has been shown to be lower than in people under 50, but only slightly so. HIV prevalence in the age group 50-59 is 5.8%, compared with 6.1% among people aged 15-49, according to the Ugandan AIDS Indicator Survey (AIS) 2004-05. Figure 1 shows that the HIV incidence rate for men over 50 was about 3 per 1000 person years. For women this was lower, especially after 1995, at about 1 per 1000 person years.

The indirect effects can be multiple as well. Caring for an adult child living with HIV/AIDS or losing an income-earning adult child to HIV/AIDS can have severe economic impacts. These include loss of receipts through transfers, increased expenditures (especially catastrophic health expenditures) and a forced continuation in, or return to, the labor force for the older person. An increased workload of older people has been shown to negatively affect physical and psychological wellbeing (see Ssengozi 2009; Dayton et al 2002; Knodel et al 2003; Nyambedha et al 2003; Oburu et al 2005; Ice et al 2010).

This study was conducted over the period June 2009–April 2010 in one urban and one rural area, following a pilot study conducted during April–May 2009 which was funded by Evidence for Action, an International Consortium conducting research on HIV treatment and care system . The aim of the pilot was to test the preliminary protocol and instruments for the quantitative study; and to prepare a final study protocol and instruments for submission to potential donors. The WHO supported the quantitative component of the study, as part of its work on ageing and health. The qualitative component was funded by CORDAID in The Netherlands.

1.3 Study setting

The two study areas were in southern Uganda. The rural site was in Masaka District, where in 1989 the Medical Research Council/ Uganda Virus Research Institute (MRC/UVRI) established a general population cohort to study the epidemiology of HIV. Annual demographic and serological surveys have been conducted with this population for the past 22 years, resulting in a wealth of data on approximately 20,000 people in 5000 households. People living in the study area are largely subsistence farmers who produce small amounts of cash crops such as beans, bananas and coffee. The majority (70%) of the population is ethnically Baganda, and there is a large representation of immigrants from Rwanda (15%). About 4% of the population is made up of 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 (60%) with 17% Protestant and 23% Muslim. Just over 50% of the population is under 15 years old. Most households have less than five acres of land. There are a few sizeable landowners and relatively few households are landless.

The urban site was in Wakiso, the district that includes Entebbe, where the MRC/UVRI headquarters is based. The MRC/UVRI has conducted a number of studies in Entebbe and the surrounding areas over the past 20 years. This study drew on people involved in some of the earlier research: the Entebbe HIV cohort, a study on strategies to reduce the burden of opportunistic infections and the International AIDS Vaccine Initiative Entebbe Project. In addition, some participants came from The AIDS Support Organisation (TASO) in Entebbe. In this report the 'urban' label refers to the site of service provision, not place of residence. Many participants lived in rural areas around Entebbe and were not, therefore, residents of the town. The population in Wakiso district is more mixed than at the rural research site in Masaka, because people from many different tribes have settled near Entebbe. While there is a strong Roman Catholic presence in the district, many other Christian denominations as well as Muslim groups are also represented. Many people in rural areas near the town still practice cultivation as their main form of livelihood, but there are also people engaged in fishing and various forms of trade, as well as formal employment in teaching, health care, etc.

The study objectives were:

1. Describe the roles, health problems (physical and mental) and social wellbeing of older people who are directly and indirectly affected by HIV/AIDS, with special attention to the effects of the introduction of ART.
2. Develop recommendations for policy and practice that can be expected to improve the wellbeing of older people affected by or infected with HIV/AIDS.

2. Methodology

The study had two parts: a quantitative survey and an in-depth qualitative study.

2.1 Study field teams

The quantitative survey team was made up of three men and five women. The team was led by a physician with four nurses and three interviewers who were not clinically trained. This team worked first in the rural and then in the urban site.

The qualitative study was conducted by two separate field teams: four people in the rural site and three in the urban site. To facilitate the rapport between interviewers and participants, all interviewers were local people from the study areas. The team leader (based in the rural site) was an experienced qualitative interviewer in her mid-fifties. The remaining team members, four women and two men, were aged over 60 (one of the men was over 70).

2.2 Quantitative sample design

The sample consisted of people aged 50 years and over, selected from existing databases. Five groups were selected, each with 100 participants of whom half were living in a rural area (Masaka district) and half in a peri-urban area (Entebbe). The groups were as follows:

1. Have an adult child who died of HIV/AIDS
2. Have an adult child who is living with HIV and on antiretroviral therapy (ART)
3. Have no child with HIV/AIDS and are not infected with HIV (comparison group)
4. Is HIV infected and on ART for at least one year
5. Is HIV infected and not on ART

The criteria for initiation of ART were determined by the Ministry of Health, based on WHO guidelines (WHO 2006). At the time, eligibility for ART was determined by a CD4+ cell count under 200 cells per mm^3 and by clinical criteria (stage 3 or 4 disease).

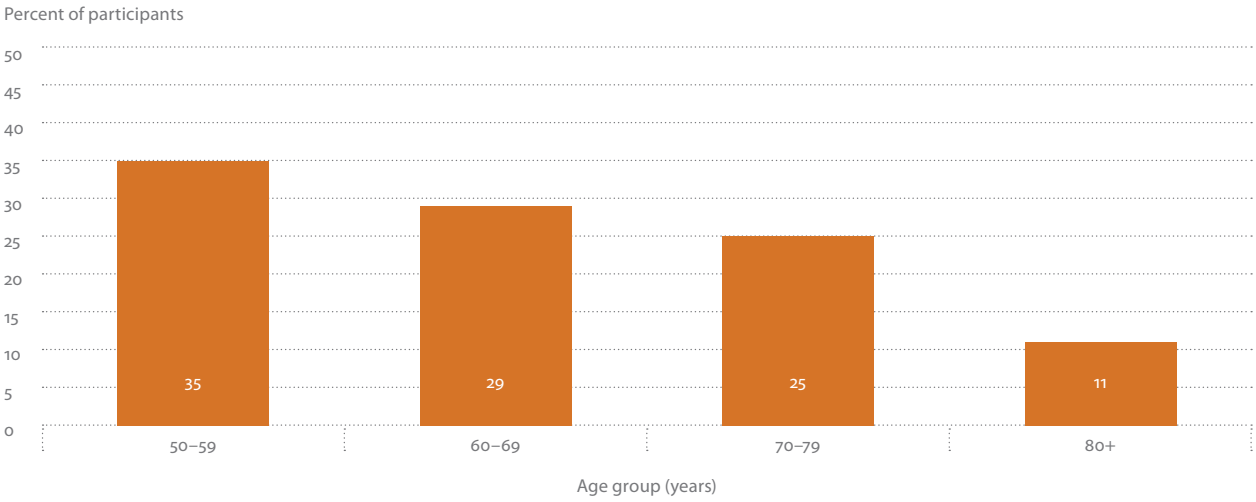
Rural respondents for the first three groups were randomly selected from the General Population Cohort database of MRC/UVRI. For groups 4 and 5, all available qualifying and consenting older people from the General Population Cohort were recruited; and an additional 67 rural respondents were randomly selected from the clinical databases of TASO and two other HIV care providers in the district.

The urban study respondents for groups 4 and 5 were randomly selected from the MRC/UVRI cohort and the HIV/AIDS clinic run by TASO in Entebbe. Respondents for group 1 and 2 were recruited from the families of the Entebbe HIV cohort participants. The respondents for group 3 were selected from self-support groups of older people unrelated to HIV/AIDS and from the outpatient clinic of Entebbe Hospital.

2.3 Final sample information and non-response

In total 510 people were interviewed in the quantitative component: 256 in the rural and 254 in the urban area, 61% women and 39% men. The mean age overall was 65 years, but for the HIV-positive groups (4 and 5) the mean age was 59. Figure 2.1 shows that 35% of participants were in the age group 50-59 years while 11% were 80 and older. The response rate was 99%, with very few refusals.

Figure 2.1 Age distribution of participants



2.4 Questionnaire design, anthropometrics, performance tests and biomarkers

The structured questionnaire and health examination were derived from existing instruments of the WHO multi-country Study on Global Ageing. This ensured alignment of the instruments with international standards.

The interviews were done in two visits. During the first visit, part 1 of the questionnaire was administered. This consisted of a household roster; questions on economic status; socio-demographic information such as age, sex, education, marital status and religion; work and living conditions; and also information on family support networks and financial transfers. It included a detailed assessment of health status, including self-ratings of health in a number of domains such as mobility and self-care; activities of daily living and instrumental activities of daily living (functional assessment); chronic diseases and their treatment; nutrition; and risk factors such as alcohol and tobacco use. Respondents were also asked about their quality of life, social networks and their experiences with the health care system.

The first visit also included a health examination conducted at home to measure blood pressure, height, weight, hip and waist circumference, vision test, grip strength, walking speed and cognition. If necessary, further investigations were performed in the clinic to clarify a participant's health condition.

Part 2 of the structured interviews was generally done the day after the first interview. Part 2 consisted of the caregivers' questionnaire, identifying not only the respondents' roles and responsibilities but also their experience of caregiving to adults and children. Respondents were asked about the nature of care and support they provided, including personal care as well as physical and financial assistance. They were also asked about the difficulty they had in providing this care and support and whether they were the main or the secondary provider. Those questions were asked to older people who:

a. were giving care /support to resident and non-resident adults at present;
b. had given care /support in the past to resident and non-resident adults who no longer needed it;
c. had given care and support in the past to adults who had since died.

When respondents had provided care and support to an HIV-positive person, questions were asked about their knowledge of ART and their involvement in the care.

The last module of this questionnaire focused on the care and support that the older person may have received. These included questions about the assistance and care the older person himself or herself may have needed and received, and also about their relationships with the care providers. These covered the same ground as the questions on the care and support which the respondents may have provided to others. Respondents were also asked about the difficulty of obtaining this care and support, and about their satisfaction with the care and support received.

The module included specific questions for HIV /AIDS-infected respondents. These included questions about their health now and before taking antiretroviral treatment, the experience of living with HIV (stigma-related

questions), ART side effects, and whether other members of the household support them in ART adherence and accompany them to the clinic for follow-up or resupply.

Whole blood samples were obtained through finger pricks and blotted onto filter paper known as dried blood spot (DBS) cards, not only to determine hemoglobin levels but also to look at additional biological markers related to cardiovascular, metabolic and physiological/stress function. The additional markers examined were glycosylated hemoglobin (HbA1c), C-reactive protein (CRP), and interleukin-6 (IL-6). In the future the same DBS cards will also be used to look for the Epstein-Barr virus (EBV) as a marker for chronic infectious disease. A lab technician from MRC received training in February 2010 to work with these assays in the MRC laboratory in Entebbe. The results of biological markers are not presented in the report because they were not yet available.

All the modules used in the questionnaires were translated into Luganda (the main local language) and tried out during the pilot study.

2.5 Training of the study interviewers and mobilizers

The eight field staff for the quantitative study were trained between February and May 2009. The interviewers and mobilizers came from diverse backgrounds: nurse, teacher, field worker, counselor, office messenger. Training included an overview of ageing issues and techniques for interviewing older people; an overview of the study and its objectives; detailed descriptions of all sections of the individual questionnaires; mock interviews between pairs of interviewers; and practicing the health assessment part of the questionnaire.

The seven qualitative study interviewers were also given an overview of ageing issues before an introduction to qualitative data collection. Their interviewing skills were assessed after a period of practising. We also used this period to refine the interview guide.

The general introduction to the topic and ensuing discussions about the relevance of particular questions turned out to be very instructive and motivating for the interviewers and mobilizers. Realizing that the health and social wellbeing of older people was a neglected topic, the team was motivated to address these issues in the study.

2.6 Implementation of the questionnaires

The WHO standardized modules for the assessment of health status and mental health were included in Part 1 (Household and Health) of the questionnaire.

The Part 1 questionnaire was quite long and some sections seemed repetitive, but with reassurance about the added value from the WHO SAGE team in Geneva, we included them all. During the field testing we made some adaptations in sequencing, e.g. between the health domains and functioning assessment we added blood pressure, weight and grip strength measurements. This change improved the respondents' concentration, not only because they did not have to answer questions for a moment but also because they felt satisfied that we were doing some physical assessments.

2.7 Translation of instruments

The tools were translated by a professional MRC translator and back-translated during the training; even so, during the training and field testing some questions had to be modified to ensure that the meaning was clear or because the question was not well understood. The latter was especially applicable to questions related to wellbeing, with much discussion during the training about abstract questions such as "how satisfied are you with yourself?" Participants in the pilot study often answered "you already asked that," because they felt that health and "satisfaction with yourself" were the same. Often a second or third explanation was required before the intention was clearly understood, and this was difficult for some interviewers.

The WHO SAGE team has developed a manual for the health modules which was very helpful, but still for some concepts it is doubtful whether the questions were well understood. A local translator from MRC Social Science Research Program adapted some of the translations after thorough explanation of the meaning, to ensure that the questions remained comparable between the rural and urban sites and also with the questions used in other countries.

2.8 Qualitative design and methods

For the qualitative study semi-structured, open-ended interviews and oral diaries were used in order to gain

Qualitative team, June 2010. © Celestine Ilakut

greater insights into older people's mental and physical wellbeing. Forty participants (20 from each site) were selected from the quantitative study sample. These participants were aged 60 years and over, in order to focus on people who may be more likely to face the challenges of failing health. In the rural sample all five different categories of participants were represented. However, in the urban site we decided to focus on older people living with HIV (groups 4 and 5). Some of these participants had also taken care of children with AIDS-related illnesses, some of whom had subsequently died.

Monthly visits were made to these 40 participants over a period of one year. The seven interviewers conducted semi-structured interviews, focusing on participants' life histories during the first interview.

These semi-structured interviews were followed by open-ended interviews (life course events investigations), designed to provide qualitative insights into changing family situations and relations, older people's tasks and responsibilities, and how these affect their health in the era of HIV/AIDS. The interviews also addressed participants' perceptions, expectations and experiences regarding ART.

The oral diaries were semi-structured interviews about events in the participant's home in the previous week and about their well-being and state of health. The recall period was restricted to allow probing for detail about a period that may still be relatively fresh in the participant's memory. Participants were asked to recall their hopes and concerns over that time, as well as information on their own and other household members' health status. These diaries can yield highly reliable data on the impact of early life experiences, gender differences and perceptions of support systems; as well as a valuable understanding of the relationship between perceived support and participants' physical and mental health. The interviewers made notes during the diary sessions and wrote up their notes into transcripts immediately so that information was not forgotten.

2.9 Research procedures: mobilization and field work

Before the field work began, we had several meetings with the MRC field staff in the rural study area to promote awareness of the study and encourage staff to communicate their knowledge of the study to community members. We also visited local officials before the commencement of the pilot and main study to discuss the purpose of the study, its design, implementation

and the need for community participation. We asked for their collaboration in encouraging older community members to participate, and we received full cooperation.

As noted above, we recruited participants for the rural site from the MRC/UVRI study area. This had the advantage that participants were accustomed to being asked questions about their household situation, and they were prepared to sit down and give us their time. (Some participants told our interviewers how much they appreciated the free health service offered to them by MRC/UVRI. In addition, they expressed gratitude that attention was being paid to the health of people over 50.)

2.10 Ethical considerations

All ethical procedures were strictly adhered to throughout the study, including the design, training and implementation stages. Participants were assured that the information collected would be kept confidential and would not be used for any reason apart from scientific purposes. It was stressed to the participants that they had the right to refuse participation and to withdraw from the study at any time.

We had undertaken to refer participants to a clinic when they were found to need further investigations and/or treatment. Several study participants in the urban area were referred to the UVRI clinic, which is also a category III Health Centre for the local population. We covered the cost of additional drugs for this health center. The rural site participants were referred to the MRC/UVRI clinic at the site.

Any study of the impact of HIV and AIDS on older people faces a number of challenges. The most obvious source of difficulty is the social and emotional sensitivity of the subject matter. Therefore, developing sensitive instruments and protecting confidentiality are of utmost importance. Careful explanation of all the information necessary to adequately inform the participants is required before asking for consent. In addition, participants need sufficient opportunity to consider whether to participate or not, and they can withdraw from the study at any point. We obtained ethical approval from the Uganda Virus Research Institute, Science and Ethics Committee (UVRI SEC) and overall clearance from the Uganda National Council for Science and Technology (UNCST). Progress reports were sent to them during the study.

A research team member taking blood pressure during an interview, June 2010. © Francien Scholten

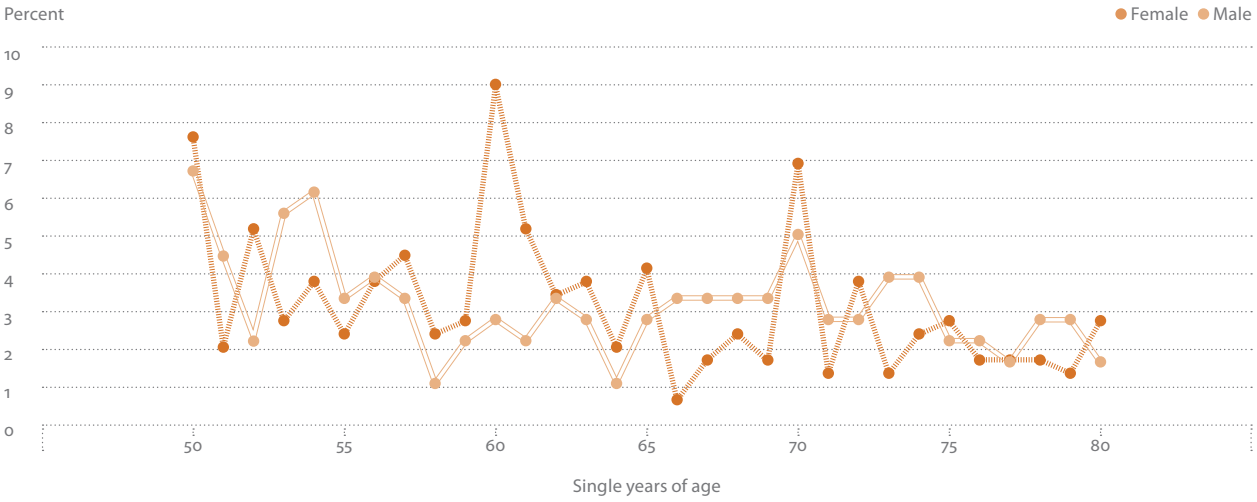
2.11 Blood sample collection

Whole blood samples were obtained through finger pricks in the field and blotted onto filter paper known as dried blood spot (DBS) cards. Before the DBS cards were obtained in the field the lab technician prepared the first spot with citrate buffer. All DBS cards were stored with desiccants and humidity indicators in plastic bags and air-dried before being turned over to the Project Leader. The Project Leader further checked the specimen details, filling in the lab forms and ensuring the accuracy of labeling and the quality of the sample. The details were entered in the register and the samples sent to the laboratory where the DBS were left to dry at room temperature (15-25C) before being logged and placed in -20C degrees freezer. The Project Leader kept one copy of the laboratory form in the office.

2.12 Age reporting

Age reporting was difficult and inconsistent, because many older Ugandans do not know their exact age. Our interviewers paid special attention to details which could help in ascertaining a respondent's age, including use of historical calendar, checking the ages of children, grandchildren or parents and relating the age of the respondent to others with known ages. The interviewers asked for age in completed years and birth date. The earlier studies in which respondents had participated provided an independent age report for comparison.

Figure 2.2 Age distribution in single years by age and sex



Source: WOPS 2009

If there were major inconsistencies, corrections were made based on further examination of records or further information from the field teams. The interviewers received additional training to help them estimate people's ages and minimize misreporting of age.

Figure 2.2 presents the age distribution in single years by age and sex for the 510 respondents. Age heaping was more severe for women, with marked peaks on multiple of 10, especially at 60 and 70 years. For men age heaping was relatively limited.

2.13 Data analysis, Quantitative study

The MRC ran the initial tables to detect missing values, outliers and inconsistencies and allow final editing of the data. It also conducted the analysis for the section on caregiving and care-receiving. The WHO SAGE team provided the standardized Stata code for the analysis of several sections of the questionnaire, including self-reported health, chronic conditions and risk factors; and also computed the wealth index score and composite measures of health and well-being such as WHODAS, WHOQoL and the health score based on item response theory-guided analysis. To assess socio-economic status we used a household asset score or wealth quintile. This score was developed using a principal component factor analysis and 34 variables derived from the 2005 South Africa census questionnaire, including information on type and size of dwelling, access to water and electricity, appliances and livestock owned and transport available.

This report presents the unadjusted results. Because there are differences in the age composition between the study groups, and age is strongly associated with several of the health outcomes, an age-adjusted analysis will be conducted in the next stage.

2.14 Data analysis, Qualitative study

Data were analyzed using thematic content analysis. In the initial stages of analysis, the study team read through the transcripts and discussed the emerging themes leading to the discussions in this report. Further analysis, both manual and electronic, is ongoing.

3. Socio-demographic information

3.1 Background characteristics of quantitative study respondents by study groups

Table 3.1 presents the background characteristics of quantitative study respondents by study group. Overall 39% were men. In groups 4 and 5 (the HIV-infected groups) participants were younger than in the other groups. About one-third of participants were married or cohabiting, and nearly half were widowed.

3.2 Background characteristics of respondent of the qualitative study

The qualitative study had 40 participants who were a subset of the quantitative study sample. In this study all 20 urban participants were HIV positive, compared with only three of 20 from the rural area. Nearly half the participants 48% (19), were aged 70-79 years. Only 10% (4) were aged 80 or above. 28% (11) of participants were married, of whom only one was female; 52% (21) were

Table 3.1 Background characteristics of respondents

Group		OP adult child died of AIDS	OP with adult child on ART	OP no child infected/died of HIV/AIDS	OP HIV + ve on ART	OP HIV + ve not on ART	Total
N of respondents		**106**	**101**	**104**	**101**	**98**	**510**
Sex	Male	30.2	30.7	48.1	45.5	39.8	38.8
	Female	69.8	69.3	51.9	54.5	60.2	61.2
Age	50–59	15.1	22.8	26.9	57.4	56.1	35.3
	60–69	28.3	33.7	26.9	34.7	25.5	29.8
	70–79	39.6	28.7	26.9	7.9	17.4	24.3
	80+	17.0	14.9	19.2	0.0	1.0	10.6
Residence	Rural	51.9	49.5	51.0	48.5	50.0	50.2
	Urban	48.1	50.5	49.0	51.5	50.0	49.8
Education	None	21.2	33.3	26.5	14.3	25.3	24.0
	Primary	56.7	40.6	46.9	51.0	47.4	48.7
	Secondary or higher	22.1	26.0	26.5	34.7	27.4	27.3
Marital status	Never married	1.9	1.0	1.9	1.0	1.0	1.4
	Married/cohabiting	31.1	28.7	41.4	27.7	32.7	32.4
	Divorced/separated	18.9	22.8	19.2	17.8	24.5	20.6
	Widowed	48.1	47.5	37.5	53.5	41.8	45.7
Wealth quintile	Lowest quintile	17.9	23.8	17.3	17.8	23.5	20.0
	Second	19.8	18.8	21.2	17.8	22.5	20.0
	Middle	17.0	21.8	16.4	22.8	22.5	20.0
	Fourth	19.8	14.9	25.0	21.8	18.4	20.0
	Highest quintile	25.5	20.8	20.2	19.8	13.3	20.0

Figure 3.1 Marital status among men and women

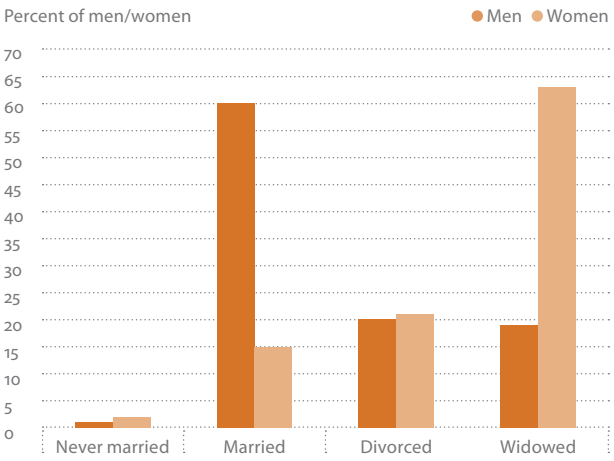
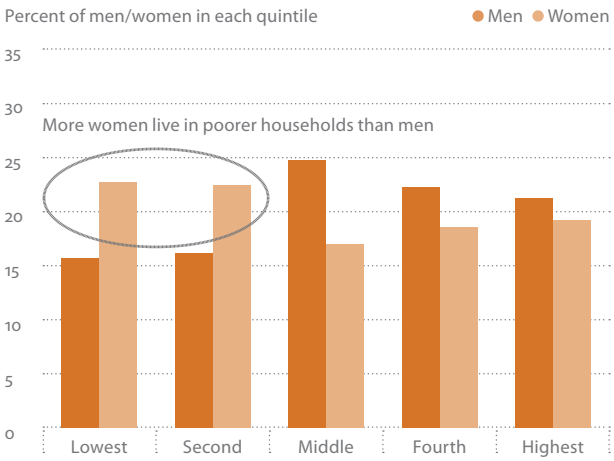


Figure 3.2 Wealth quintiles



widowed. Ten participants lived alone (6 men and 4 women) while others lived with their grandchildren or other relatives.

Since the study was conducted in the two districts of Wakiso and Masaka, the majority of the participants 63% (25) were ethnic Baganda. However, 26% (10) were of Rwandese or Burundian origin, having migrated in search of work and to escape civil wars in their countries. While 40 participants were originally recruited, one participant moved away during the study and was not replaced.

3.3 Background characteristics of quantitative study respondents by gender

The gender division by age, education, residence, marital status and wealth quintile (**Annex Table** 3.1) shows that women had lower levels of education than men: 16% of the men have less than primary education compared to 29% women.

A comparison on marital status (Figure 3.1) shows that 63% of the women were widowed, compared to 19% of the men. Only 15% of the women had a partner while 60% of the men were married or cohabiting. This is likely to be a result of age differences between spouses (men marrying younger women) as well as the greater tendency for men to remarry after divorce or the death of a spouse.

There are more women living in poor households than men (Figure 3.2).

Table 3.2 shows that better off households have the highest number of people in the household, with an average of 6.6 persons per household in the wealthiest quintile compared to 4.6 in the poorest. One-person households are most common among the poorest quintile (42%).

3.4 General characteristics of household of study respondents

The majority of older people interviewed in both rural and urban areas were Roman Catholic (**Annex Table** 3.2).

Table 3.2 Number of people in the household by wealth quintile

	Residence		Wealth quintile						
Household size	**Urban**	**Rural**	**Lowest**	**Second**	**Middle**	**Fourth**	**Highest**	**Total**	**Number**
1	50.0	50.0	42.4	19.7	18.2	13.6	6.1	100	66
2–5	44.5	55.5	19.7	22.3	20.5	21.4	16.2	100	229
6–10	50.6	49.4	11.2	18.0	21.3	21.9	27.5	100	178
11+	78.4	21.6	24.3	16.2	13.5	13.5	32.4	100	37
Total	49.8	50.2	20.0	20.0	20.0	20.0	20.0	100	510
Number	254	256	102	102	102	102	102	510	
Mean household size	5.8	4.8	4.6	4.8	5.1	5.3	6.6	5.3	

Table 3.3 Social network index by study groups, combined groups and residence (Mean score on 4 point scale)

	Group	OP adult child died of AIDS	OP with adult child on ART	OP no child infected/died of HIV/AIDS	OP HIV + ve on ART	OP HIV + ve not on ART	Total
Sex	Male	2.6	2.4	2.6	2.5	2.4	2.5
	Female	2.2	2.3	2.2	2.4	2.1	2.2
Age	50–59	2.6	2.6	2.7	2.5	2.4	2.5
	60–69	2.3	2.6	2.7	2.3	2.3	2.4
	70+	2.3	1.9	2.1	2.4	1.8	2.1
Residence	Rural	2.3	2.2	2.3	2.6	2.3	2.3
	Urban	2.4	2.4	2.5	2.3	2.2	2.3
Wealth quintile	Lowest quintile	1.9	1.9	1.9	1.9	1.8	1.9
	Highest quintile	2.6	2.6	2.8	2.8	2.4	2.6
All		2.3	2.3	2.4	2.4	2.2	2.3

In the rural area the main income was from farming and the sale of agricultural products; a very small proportion of older people had an income from other activities. In the rural area only 4% had wages from a job, compared with 13% in the urban area.

Among the age group 50-59, 42% (rural) and 38% (urban) had a regular source of income. By contrast, in the age group 80+ only 12% (rural) and 6% (urban) had a regular source of income.

In the rural area 63% of respondents had improved water supply, as did 85% in the urban area. Indoor cooking was done by 31% in the rural area and 17% in the urban area. Cooking inside the house can lead to older people, especially women, having higher risk of chronic respiratory disease and eye conditions. The small differences between the rural and urban areas in terms of access to water and cooking facilities illustrates the similarities between the two areas; many of the "urban" participants actually lived in rural settings outside Entebbe.

Women received more assistance – such as money, food, clothing or goods – than men. Most of this assistance came from relatives (63 %), then from friends (30%), community (20 %) and government (15 %).

At the time of the study 40% of respondents perceived their financial situation as bad or very bad. Compared to three years ago, 50% said their situation had got worse and 39% said somewhat worse. The majority said that drought and pests or climate change had caused their financial situation to worsen. Other reasons included no one being around to help now, more fees, less financial support, feeling too weak to work and going blind.

3.5 Social networks

To assess social integration we used Berkman's social network index (SNI), which has 4 components: marital status, closeness to friends and family, church and club memberships. The SNI was lowest for women, people over 70 and people not on ART (Table 3.3). However, the main factor affecting SNI was marital status. This index is being refined further by WHO, based on the findings of various studies (including this one) which have shown a close association between marriage and social networks.

4. Health and wellbeing

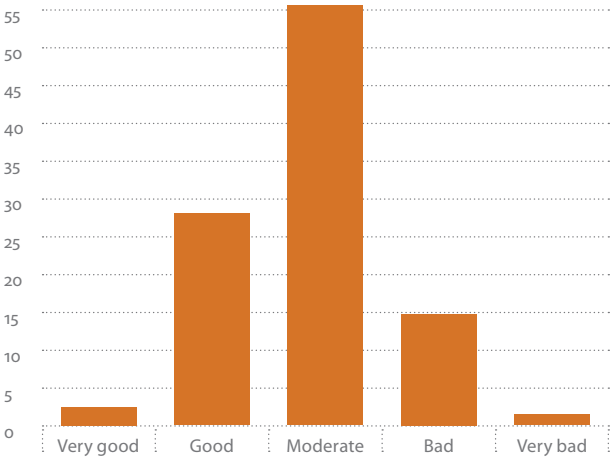
4.1 Approach

The quantitative survey followed the approach used in the SAGE study. The first question was about overall health: 'How do you rate your own health today?' The next question was: 'Overall in the last 30 days, how much difficulty did you have with work or household activities?'

Further disaggregation is helpful for understanding the determinants of health and possible differences between perceived and actual health. Therefore we asked the participants about mobility, self-care, pain and discomfort, cognition, interpersonal activities, vision, sleep and energy and affect. From those domains, a composite health score was computed.

The next section measured functioning in daily life, based on Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL). Functioning was assessed through the WHO Disability Assessment Scale (WHODAS), which contains the most commonly asked ADL and IADL questions, plus assessed severity of disability. A higher score indicates more disability: 100 is poorest functioning, 0 is best.

Figure 4.1 How do older people rate their own health today?



The last section measured quality of life, using the WHO Quality of Life (WHO QoL) scale. This is an 8-item index that includes questions about physical health, psychological health, social relationships and environment. WHO defines QoL as 'the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.'

4.2 General self-reported health

Figure 4.1 shows that 53% of participants perceived their own health as moderately good, 17% as good, 14% very good, 15% bad and 1% very bad.

HIV-positive participants on ART (group 4) were the least likely to perceive their health as bad or very bad (**Annex Table** 4.1). Among people aged over 70, 29% perceived their health as bad/very bad, compared with 9% in the age group 50-59 years. Among those who live in the poorest households, 22% said their health is bad/very bad, compared with 13% in the wealthiest households. A higher number of people with no education (25%) reported their health as bad/very bad, compared to 10% among those with higher education.

The qualitative study found inconsistencies in self-reported health. Firstly, there were fluctuations over time, as individuals' experiences changed from one month to the next – developments that were not discernable in the data recorded in the quantitative study. For example:

- In his first monthly interview, a 65-year-old male respondent reported that he gets backache (a psychometric indicator of depression used in the quantitative study), despite medicine from TASO (Septrin, not ART). However, backache was not

mentioned again in any subsequent interview. In the second month he reported that his condition was okay, he had gained weight and his leg pain had reduced. In the third month this respondent reported swollen legs, pain from his knees down to his feet, and general weakness preventing him from working as he wants. He said this was affecting his wellbeing.

- A 69-year-old male respondent experienced an "irritation below the belly" and slight backache, "paralysed" feet and legs which he "could not feel anymore", as well as chest pains and weight loss. Sometimes he does very little cultivation and rests because of feeling weakened by HIV/AIDS; other times he said he had a horse's strength.

Secondly, there were often significant differences between how a respondent perceived their health and how the same respondent would informally rate their health. Shifting perceptions and ratings of health were influenced by the general mood (not simply the physical health) of the respondent, which had in turn been influenced by a wide variety of factors: food availability and problems or successes with agricultural work; feeling particularly abandoned by a relative; instances of increased support from others; the number of recent funerals attended or death of a close relative. A low perception but high informal rating may be the result of optimism, or may be relative to prior health experiences; for example, bad health before being put on ART. For instance:

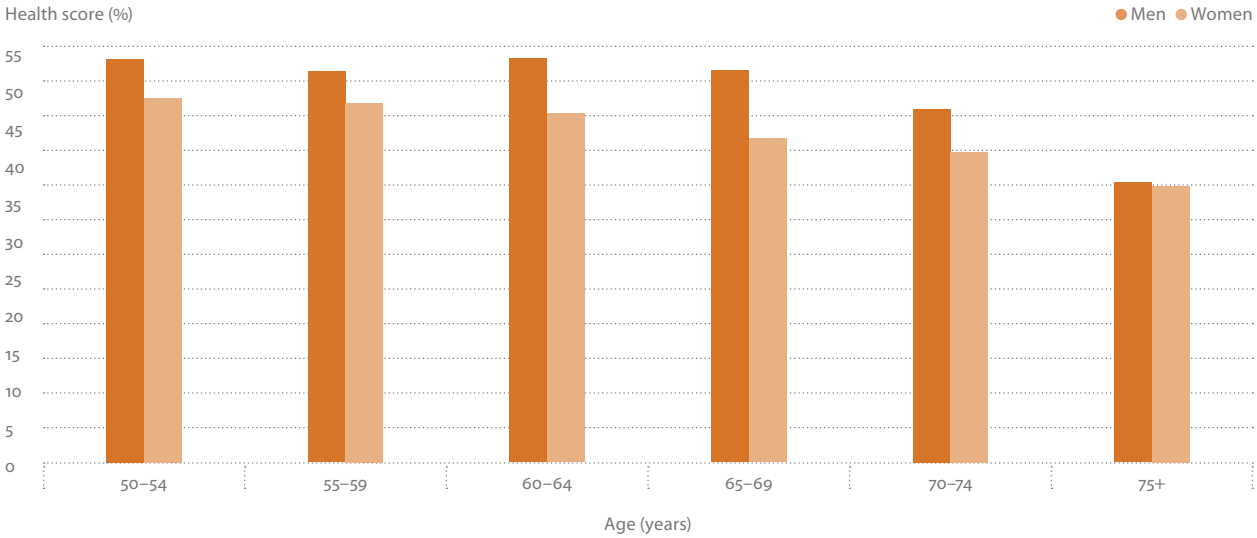
- A particularly remarkable case is that of a 63-year-old female respondent, who had been treated for TB years earlier, who is currently receiving cancer treatment as well as ART, and who also has eye problems. She walks with crutches and has experienced persistent thigh pain since falling down from the kitchen steps in January 2008 but had not reported this to the hospital due to fear that treatment would be expensive and that her property would be stolen by her co-wife's son (a drunkard who steals to pay for alcohol) in her absence.

  Despite all these health problems, when asked how she is feeling the respondent rated her health quite highly: she said she had not experienced any "serious illnesses" or had no "serious sickness" within the seven-day period before at least five of the monthly qualitative interviews. She said that ART and cancer treatment had caused a great change in her life and she no longer falls sick frequently, and that she was not affected by her age.
- In her first monthly interview, a 70-year-old female respondent complained of general weakness, fever, poor appetite and diarrhoea. During the subsequent four months she reported a pain in her right leg, "painful muscles without fever", a cough and flu, and yet she said there was "nothing disturbing" her, that she was doing well with her treatments and had "no serious health problems". She said that ART has greatly improved her health to the extent that health issues did not seem to affect her wellbeing.

4.3 Summary health scores

Annex Table 4.2 shows the health item scores by background characteristics and place of residence. The lowest health score was computed for respondents in study group 5 - HIV positive, but not yet on ART (40.5). The highest health scores were reported by those in study

Figure 4.2 Health scores by age and sex



group 1 – known HIV infection, child who died of HIV – (50.6) and those with at least secondary education (50.5).

Figure 4.2 shows that men have higher health scores than women, and there is a strong drop-off with age. For women this occurs from age 60, for men a little later.

4.4 Disability – WHODAS score

Annex Table 4.3 shows that women have poorer functioning than men according to the WHODAS scores of 30 and 23 respectively. People with poorer functioning were those aged 70 to 79 years (WHODAS score 32) and 80-plus years (52), those living in the poorest household (32) compared to the best off (24), those who lack formal education (35) compared to those with higher education (20), and those who are divorced (26) and widowed (32) compared to the married (21).

4.5 Quality of Life – WHOQoL score

In relation to the WHO quality of life score (WHO QoI), **Annex Table** 4.4 shows little gender difference; however those participants reporting a poorer quality of life were the same groups who had poorer functioning according to WHODAS scores. These were people over 70 years old, those living in the poorest households, those who are widowed or divorced, and those with no education.

HIV-positive older people on ART (group 4) reported a better quality of life than the other groups. This is more clear if the analysis is limited to people under 70 years as there are only few people over 70 with HIV and on ART. People who are HIV positive but not on ART (group 5) had the poorest WHO QoL score.

The qualitative study provided insights about HIV-positive older people's wellbeing, including reports of hope and happiness. Some respondents were happy to report that ART had restored their lives and now they are healthy, energetic and able to work without any difficulty. Speaking about HIV/AIDS and ART, one respondent reassured the interviewer:

> "That disease of mine, I am not worried about it since there are drugs [ARVs] which we take and which have restored our strength and we continue working for ourselves slowly by slowly. I am only worried about other diseases which can attack me!" (male respondent, aged 67).

For a 79-year-old man in the urban area, being on ART restored hope:

> "I went to TASO where I got counselors who created in me an attitude of hope; otherwise I had lost hope of living. Now I am living positively. I collect medicines on the appointed date and I am faithful in swallowing the pills at eight in the morning and eight in the evening. I use my small radio and wrist watch to tell the time."

In the urban area, 17 participants were on ART and three were taking Septrin because they were not yet in need of ART. The longed-for transition to ART was a subject of discussion for a number of respondents, who hoped that ARVs would transform their lives for the better:

- A male respondent in his late 60s is a fishmonger, also busy with private agricultural activities, and seems to be fairing better economically than many other HIV-positive respondents. He has money but says it "will never be enough", and has made many preparations in the hope that his family will survive economically in the event of his death. He expressed fear of dying and leaving his two wives, children and relatives. All his complaints are "pointing to poverty" and HIV/AIDS is "becoming a stumbling block". The respondent's health problems have included backache, swollen legs and pain from his knees down to his feet; he relies on a walking stick and feels bad when friends are moving at high speed but he cannot. General weakness prevents him from working as much as he would like, and this frustration affects his wellbeing. The respondent says he has "taken all kinds of drugs" for leg pain, but to no avail, and wishes the doctors could put him on ARVs because "maybe my legs would improve".

However, ART also brought challenges:

- A 73-year-old female respondent said that thanks to ARVs, her life has "become more vibrant, unlike before", she can now undertake simple work, and that most of her illnesses have subsided. She confessed to also taking "native medicine" (especially for toothache), but said she "cannot forget" to take ARVs and Septrin because she believes her life would be in danger without them. However, she saw this routine as a "drug burden": she said she was tired of taking drugs every day, but smiled when interviewer reassured her of the benefits of taking the drugs.

  On one occasion the interviewer noted that ARVs, Septrin and other drugs had "worsened her life",

and that her work is increasingly limited but feels better when resting. Although unconfirmed, it is possible that the respondent was experiencing side effects of ART treatment. Ultimately, the "drug burden" and potential side effects were seen as a trade-off against better health and expectation of a better quality of life.

Furthermore, the qualitative study found that for many respondents the main themes in their discussions on the quality of life were financial problems, support from others, and concerns about isolation. In other words, for these respondents, quality of life was not strongly associated with ART, but with factors comparable with poorer functioning in the WHODAS scores, i.e. the poorest households, and those who are widowed or divorced (as mentioned above). For example:

- The self-reported health of a 60-year-old male respondent (although estimated by interviewer to be above 70) deteriorated significantly through the period of monthly interviews despite being on ART. He explained that bad health affected his wellbeing, made him feel unhappy, prevented a "sound mind" and made him "lose peace". Although this respondent described himself with the metaphor of being eaten by "namuginga" – a pest that eats a sugar cane inside while appearing okay outside – he seemed conscious that both his poverty and HIV status were conspicuous, and this awareness seemed to affect his wellbeing.[1] He referred to those with HIV/AIDS and who had money: they appeared healthy and strong, rather than appearing to be infected with HIV/AIDS.

  The respondent lives alone and, despite bad health, has to force himself to do agricultural work each day to earn money and to eat, but sometimes he only has strength to work for an hour, or not at all. Financial problems and loneliness, specifically, the need to be financially better off in order to find a wife to look after him, were recurring topics of conversation and a cause of insomnia. For example, this respondent consistently fretted about how he lacked money to "get a woman who would make him happy". The respondent smiled when the interviewer assured him that through his daily work and continuing to take ARVs, he will gradually gain better health and become able to afford to resume communication with his relatives and find a wife.

- A 60-year-old woman who was not yet on ARVs (because her CD4 count was high) was prescribed Septrin to prevent sickness such as flu and malaria. She reported physical pains "constantly attacking" her, preventing enjoyment of life and causing insomnia. The respondent explained that she thinks a great deal about the "deadly disease, which is never going to cure" and she is worried that she may die at any time.

  However, HIV/AIDS is not the respondent's biggest burden and she hopes more for money than for ART. She is the head of her household with responsibility for numerous grandchildren, nephews and nieces. When a nephew began to support himself, she was brought another 3-year-old grandchild to look after. The support that the respondent received was invariably offset by obligations and the demands of the household; at times, her own wellbeing was directly compromised by her responsibilities to others. For example, one month she reported that she could not spare money for her own health treatment because she had to pay school fees for her nephew. The respondent explained that her most troubling problem is the daily struggle to "upgrade" her life. Financial worries and an unsatisfactory diet lead the respondent to think a lot about how she will get rich!

This question of material wealth – primarily as a means to provide enough to eat, to support others, or to reduce one's own isolation – profoundly affected the wellbeing of many HIV-positive respondents, and in turn affected their quality of life. The qualitative study found when considering quality of life and wellbeing, many respondents were often as concerned with issues of poverty and isolation than they were with health and ART.

Despite clear health benefits of ART treatment, not to mention the hope and optimism associated with it, there was also speculation and misinformation. Deteriorating health caused one respondent to doubt the long-term benefits of ARV drugs. He said:

> "I am now weak; I can no longer work seriously in other people's gardens as I used to do – maybe this drug [ARVs] also weakens the body as time goes by!" (male respondent, aged 57).

1 This case supports the above-mentioned WHO definition of quality of life as: "the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".

The interviewer explained that this was doubtful, pointing to all the reports of bed-ridden people whose lives were stabilised by ART. The respondent reportedly smiled and said that he just thought that but was not sure.

ART also brought challenges and worries for older people caring for others, but some of the concerns may have been caused by a lack of accurate information and counselling. One 70-year-old male who was looking after his 9-year-old granddaughter was concerned because "she had been on the drug for young children" but she would "now begin the dose for adults". He said:

> "That is the cross I have to bear now. [. . .] A person taking that drug needs to feed on a good diet [. . .]. They tell us that when you are taking that drug [ARVs] you have to feed on a rich diet! [. . .] Therefore I am worried of what to feed her on!"

The interviewer believed the man had heard hearsay from others about the necessary diet for those on ART. However, the following month, the grandfather repeated his concern:

> "Even that drug they gave her [ART] is almost finished. [. . .] But what to feed her on is our worry! We cannot manage eating well all the time!" (male respondent, aged 70).

One 74-year-old male discussed with the interviewer some of the challenges of being short of resources and related to limited access to food since he started ART in 2004. He said that it was a big blow to him when TASO stopped giving him food. TASO used to provide maize flour, cooking oil, salt, sugar and soap, but funding constraints led to the end of this practice.

He went on to comment:

> "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."

4.6 Stigma

Five stigma-related questions were put to HIV-positive respondents. There were 95 respondents in group 4 (on ART) and 88 in group 5 (no ART). For each statement the respondents were asked whether this problem happened never, seldom, sometimes, often or very often.

Respondents who were on ART were more often "worried that others will view me unfavorably because I am HIV-positive": 24% said often or very often, compared to 18% of those not on ART (Figure 4.3).

Almost half the respondents said they often or very often "Have been in situations where others say offensive things about people with HIV". This was again more common among those on ART than not on ART – 46% vs 41% respectively (Figure 4.4).

About one in six respondents said that often or very often they "have been treated as less competent by others when they learn that I am HIV-positive". This was equally common in both groups. However, more people who were not on ART responded "never" to this statement (76%), compared to those on ART (65%).

There were two statements about disclosure of HIV status. One quarter of respondents have often or very often "avoided telling others outside my immediate family that I am HIV-positive". This was more common

Figure 4.3 Stigma: worried that others will view me unfavourably because I am HIV+

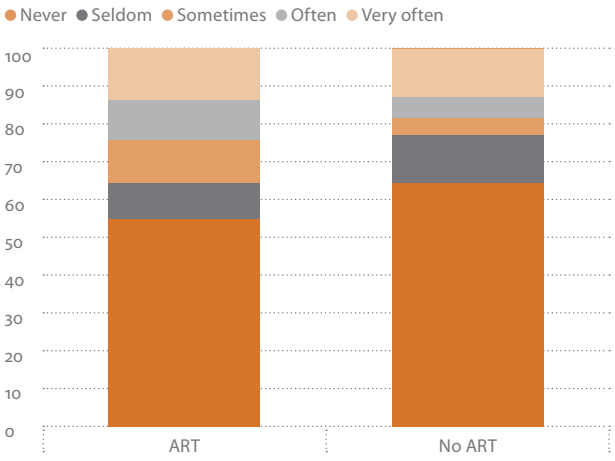


Figure 4.4 Stigma: have been in situations where others say offensive things about people with HIV

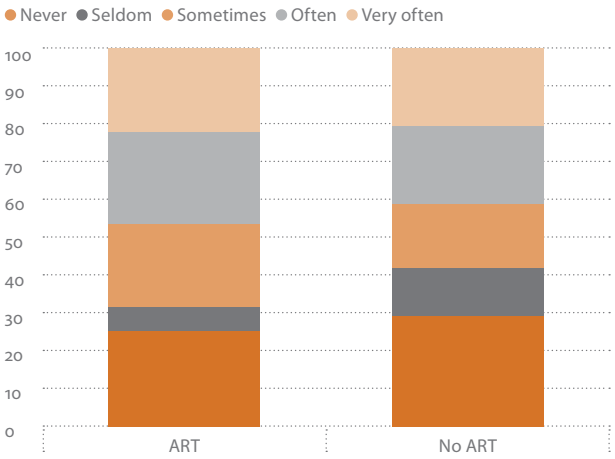


Figure 4.5 Stigma: have avoided telling others outside my immediate family that I am HIV+

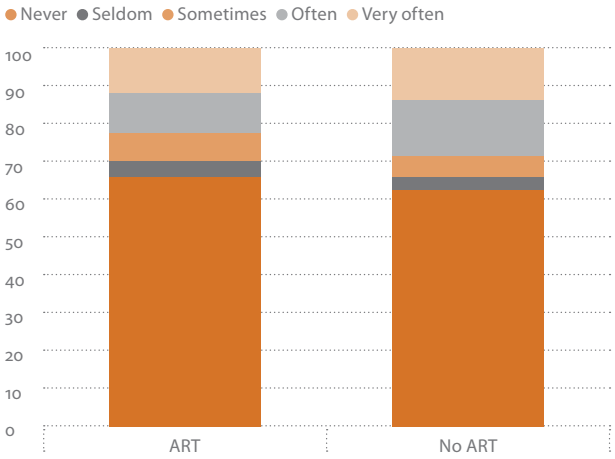
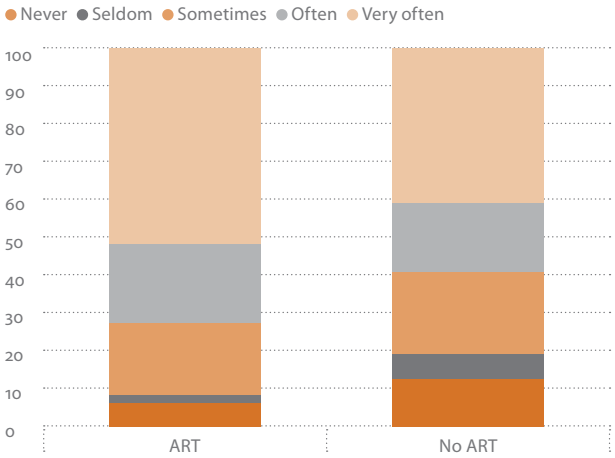


Figure 4.6 Stigma: have disclosed HIV status to other people



among people not on ART (28%) than among those on ART (22%) (Figure 4.5).

Disclosure to family members, which was 66% overall, was more common among those on ART: 73% said they often or very often disclosed, as opposed to 59% among those not on ART (Figure 4.6).

A summary stigma score was constructed from the five questions, in which a higher score meant a higher level of stigma. In a multivariate regression analysis the only significant effect was observed by age: people aged 60-69 reported a higher level of stigma than at age 50-59 (but respondents over 70 years old did not significantly differ from the others). There were no significant differences between those on ART and those who were not, between men and women, between urban and rural residents, or by education or marital status.

While some questions asked in the quantitative study may indicate the existence of stigma, they provide few insights into the respondents' own acceptance of HIV and strategies in confronting stigma. However, the qualitative study identified a distinction between stigma/discrimination and the effect of stigma on the wellbeing and quality of life of the respondents. This effect may ultimately be determined by the respondents' changing attitudes towards HIV/AIDS and an intolerance of stigma. Furthermore, the qualitative study found that when some respondents discussed HIV testing and how they confronted the prospect of HIV/AIDS, they used the overarching term "stigma" to describe what has been identified here as: (1) social stigma, and (2) health fears.

Firstly, social stigma may have included the potential fear of being tested, which may have encompassed fears of discrimination or public humiliation, and abandonment by relatives, friends and the community. This may stem from one's own HIV -related perceptions, or from direct experience of other people's stigma and sometimes internalised as self-stigma: that HIV is something to be ashamed of and something to be secretive about. For example:

- A 69-year-old male respondent had first experienced HIV/AIDS symptoms in the late 1990s and went for a test, not at the nearest centre where he apparently "feared the stigma" but at TASO Entebbe where he thought nobody would know him. In other words, he chose anonymity at TASO Entebbe rather than recognition in his local community where he anticipated social stigma. The prospect of the virus itself was not mentioned in this conversation about stigma and therefore does not seem to have been the respondent's primary fear.
- A 73-year-old female respondent encountered social stigma when she developed a skin disease and relatives and friends "feared to associate with her". This respondent said she "feared having gotten AIDS" but then "withstood all the fear and went to Kasanje health centre for an HIV test". Reportedly, "the fear intensified" when the results were positive.

Secondly, the respondents described a kind of health-related stigma such as the fear of deteriorating health and fear of dying. This may also be linked to worries about quality of life and survival, such as an anticipated inability to grow food or earn money due to deteriorating health. This fear is primarily concerned with oneself and one's dependents (i.e. worries about an inability to care for them), not necessarily with the opinions, criticisms or actions of others. A 70-year-old

female respondent who described coming to terms with social stigma as well as health fears:

- She had encountered stigma in the past: she had taken care of her nephew who had been neglected by relatives when diagnosed HIV positive. She reported having faced the prospect of her own positive status thanks to the support of her son who took her for the test. She says that otherwise, she would "probably be dead by now because she was dying of stigma and misery in the house". The support from her son helped her to sufficiently overcome any fear of either social stigma or abandonment by relatives, and allowed her to confront her own health fears and be tested.

The respondents frequently described how access to counselling and drugs made a difference to their lives and reduced self-stigma; ART in particular, as described earlier, provided renewed energy and hope that there was still a life to live. As the quantitative study showed, respondents on ART were more likely to disclose their status to family members.

One 73-year-old male respondent seemed to have been less affected by stigma than others:

- He reported that the counsellor at TASO was "so good" that he "did not feel bad when the sad news was given to him that he was HIV positive" and reportedly he "did not go through the episode people go through when they are told they are HIV positive".

A female respondent, aged 63, implied that she saw HIV/AIDS in health terms and spared little thought for social stigma:

- She had wanted herself and her husband to be tested, but the husband refused and later died; she went for a test at TASO Entebbe after developing rashes on her legs. This respondent now sees AIDS as "like suffering from malaria". However, she recognises that some of her friends are also sick, but they fear to interact with others and are dying without getting help. The respondent said that her life has been prolonged by ART. The interviewer noted that she does not look like a person with the virus – significantly, the interviewer did not attribute her appearance to ART, but to her attitude towards stigma – "because she has accepted herself and is now free in public".

The interview transcripts contained fragments of data that provide indications of how stigma is changing over time, and how some respondents felt free to disclose their status. For example, the 69-year-old male respondent (described above) who at first chose anonymity at TASO Entebbe rather than recognition in his local community described:how he is no longer ashamed of the virus because, he says, there is no stigma in his community. People know that he is sick and do not laugh at him because HIV/AIDS is now taken to be a "normal disease".

The 73-year-old female respondent (described above) whose relatives and friends had "feared to associate with her" when she developed a skin disease, stated that stigma is not as prevalent as it used to be. Sometimes she avoids public events due to gossip (not necessarily stigma) although she is open about her status and is volunteering as an HIV/AIDS 'consultant' in her village.

In the long term, the wellbeing and quality of life of at least some of the respondents did not appear to be adversely affected by stigma:

- A 65-year-old male respondent said that people used to laugh at him and he "had fear", but now he is very open about his status and advises others to be tested, having realised that HIV/AIDS is "a chronic disease and even fear will not help".

While stigma was reported to have changed over time, it still exists in different forms. For example, the experiences of a 60-year-old female respondent and her neighbour:

- The respondent said she is open about her HIV status and mostly has a good relationship with her family, neighbours and church, although she is still discrete about private matters. However, during two interviews she expressed being troubled by one neighbour who would block the way of visitors to her house and claim that the respondent is a witchdoctor with "charms", influencing the daily visitors who come to see only her.

This situation might be attributed to envy and resentment rather than HIV/AIDS stigma; however, this case is reminiscent of that of one respondent who reported that people told him he was "charmed" when he first became sick with HIV/AIDS, and initially he sought help from witchdoctors.

5. Chronic conditions and treatment

5.1 Introduction

In the survey we collected information about the prevalence and coverage of certain health conditions of older people. Chronic conditions included arthritis, stroke, hypertension, chronic lung disease, asthma, angina, depression, diabetes and cataract. We also included injuries, since these are the third broad grouping for burden of disease estimates and a growing burden for many countries. Questions about mouth and eyes were included to get a broad indication of selected sensory problems to determine levels of health coverage through indicator conditions like cataract. Sensory deficits are more likely to increase at older ages. We did not ask any questions related to communicable diseases except tuberculosis; however we did find poverty-related communicable disease such as jiggers. This was also reported from the qualitative study: due to isolation, neglect and lack of support, older people especially from the rural area suffered from lice, jiggers and bed bugs. This was more common among participants who lived alone.

We assessed the prevalence and coverage of the chronic conditions in three ways including:

1. Whether they had been diagnosed with a specific illness, e.g. "have you ever been told by a health professional that you have asthma?" If so, further questions were asked about their treatment and whether they were on current medication for the illness.
2. Asking a number of questions (algorithms) which are related, e.g. for asthma, "do you have attacks of wheezing or whistling?" and deriving a probable diagnosis based on the answers to those questions.
3. Based on physical assessment including blood pressure, height, weight, waist and hip circumference measurements, a usual pace 4-meter walk, rapid pace 4-meter walk, vision and a cognitive test. To gain a more comprehensive picture of the burden of chronic diseases among the older population we collected also whole blood samples obtained through finger prick and blotted onto DBS cards. It is planned to look at biological variables related to cardiovascular and metabolic function (glycosylated hemoglobin (HbA1c), HDL cholesterol and physiological factors or stress mediators such as C-reactive protein (CRP), interleukin-6 (IL-6) and Epstein-Barr virus (EBV). These additional tests will allow us to undertake a comprehensive comparison of our results with those from the other WHO SAGE study sites undertaking similar research. SAGE notes that biomarkers are intermediaries for chronic conditions and critical to assessing the true prevalence of morbidity and poor health conditions, particularly in rural, illiterate and poor populations with very high levels of undiagnosed diseases.

5.2 Prevalence and coverage of chronic conditions

Hypertension definitions are summarized in the table below. People on regular antihypertensive treatment were regarded as having hypertension regardless of their blood pressure readings.

Hypertension – A normal blood pressure was measured in 67% of the older people. **Annex Table** 5.1 shows that 18% had mild, 9% moderate and 6% had severe high blood pressure. The highest rate of severe high blood pressure was in those over 80 years old (22%). Women (11%) had a higher prevalence of moderate hypertension than men (6%) (Figure 5.1).

Definition of hypertension		
Category	Systolic (mmHg)	Diastolic (mmHg)
Optimal	<120	<80
Normal	<130	<85
High-Normal	130–139	85–89
Grade 1 (hypertension (mild)	140–159	90–99
Grade 2 (hypertension (moderate)	160–179	100–109
Grade 3 hypertension (severe)	>180	>110
Isolated Systolic Hypertension	>140	<90

Stroke – Participants were asked whether they had ever been told by a health professional that they have had a stroke during their lifetime. Of the 510 participants, 16 said they had had been told that they have suffered from a stroke.

Depression – Participants were asked whether they had ever been diagnosed with depression, and 22 people (4.3%) reported that this was the case. This figure clearly excludes those who have never had formal diagnosis.

Participants were asked a series of questions about how they had felt in the 12 months leading up to the survey, in order to assess the prevalence of depression that had not been formally diagnosed. The questions included 'have you had a period when you felt sad, empty or depressed?' and "have you felt that your energy levels have decreased?'. This information indicates that 23% of the participants had had an episode of depression during the previous year. **Annex Table** 5.2 and Figure 5.2 show a large gender difference, with depression being far more common among women (28%) than men (16%). It is also more common among those who are widowed (30%) and divorced (25%) compared to the married (13%). Depression was slightly higher in the urban area (25%) than the rural (22%).

From the qualitative study we learned that a number of older people reported being were very lonely and grieving the loss of their loved ones. Women tended to join social groups and a few men took to drinking in order to deal with their problems.

Just as the quantitative study revealed a significant difference between formal diagnosis and actual experiences of depression in the previous year (4.3% and 23% respectively), the qualitative study found that the wellbeing of many respondents (who had not been diagnosed with depression) was severely affected by their health and circumstances, possibly resulting in depression or prolonged feelings of despondency. For example, many respondents did regularly express sadness, isolation, and decreased energy levels:

A 70-year-old female respondent on ART experiences general weakness, backache, leg pain, poor appetite, and claims to have "ntondo" (irritability) brought by old age. She "feels bad" that she is old and unable to walk like before and lamented that when she was "young and energetic" she used to do her work without difficulty. But now, due to sickness and old age, she has difficulties walking long distances, difficulties washing clothes and cooking, difficulties when digging and

Figure 5.1 Prevalence of mild, moderate and severe hypertension among men and women

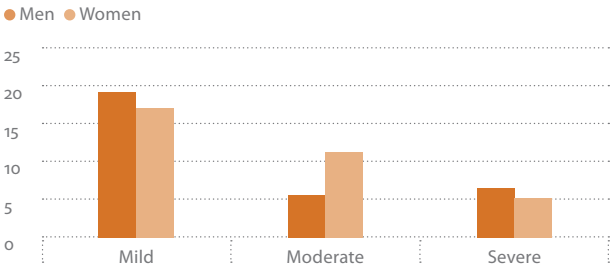
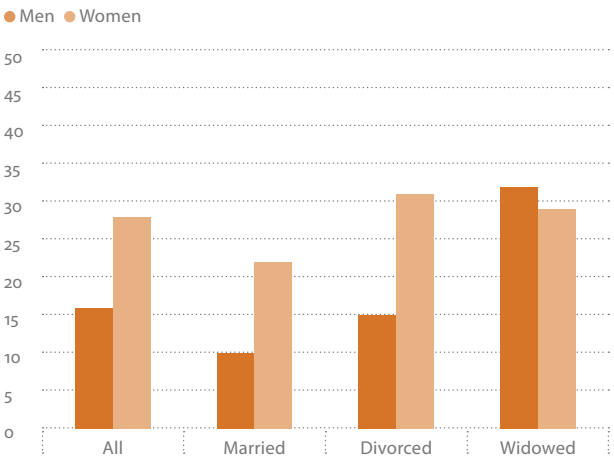


Figure 5.2 Prevalence of an episode of depression in last year, by marital status and sex



sweeping the house, difficulty in squatting on the pit latrine and washing thoroughly.

However, seemingly in contradiction of her health complaints, in one interview she reported that she is not sick. However, HIV as well as ageing and poverty make this respondent worry about dying and leaving her children. Some weeks she does not receive any assistance from anyone; she worries about support from others and feelings of isolation seem to affect her more than worries about her health. She said a lack of visitors makes her feel "more miserable". She was happy when her son promised to bring her sugar because when there is no sugar, she thinks of her dead children and other problems, and then she can't sleep so she starts talking and humming to herself. Sometimes she experiences loss of appetite due to worry. But it was also reported that she is generally happy about her life.

Although many respondents expressed a decrease in energy levels, this did not necessarily indicate depression; instead, as far as wellbeing is concerned, health issues are interrelated with problems and worries relating to finances, work, diet, dependant grandchildren, lack of assistance and loneliness. A number of older people reported being very lonely and grieving the loss of loved ones. A 73-year-old female respondent on ART seemed to belittle her physical health problems and had a particularly pragmatic outlook. However, her situation was very complex:

- Through the twelve-month study period, this 73-year-old woman experienced headaches, leg and feet pains, a cough, palpitations, ulcers, epsiterxis, toothache, severe neck pain, and an unspecified blood pressure concern. She said she was fluctuating between feeling fine one week and feeling sick the next. After listing her ailments, she would rate her health optimistically: she said she does not get sick often, that her life is fairly good, and she feels strong enough to care for herself.

  This respondent has difficulties with household activities due to old age, leg and foot pains, but other times she is able to walk as far as six kilometres and is able to work in her garden. She seemed to lament her changing health and increased difficulty with household activities but said: "I have to face the present situation and adjust my life". But the respondent explained that she experiences mood swings. Sometimes they could be triggered by interview questions and the interviewer had to stop to counsel her. She feels neglected by her son, and cries when she thinks about her late daughter who died in labour about 16 years previously. This sadness is also connected to worries about her granddaughter, and wishing her granddaughter could live with her. The respondent has financial problems and is worried that she will be left to live alone in future, with nobody to care for her. Currently, the only assistance she receives is from this grandson who lives with her, but he is often out working and may soon get married and leave.

In order to cope with feelings of loneliness and despondency, women tended to join social groups including church groups and a few men took to drinking in order to deal with their problems. One 60-year-old male respondent formed a support association, of which he was the chairman. Regular meetings gave this respondent the opportunity to socialise with others; the 39 members contributed money to the association and could request financial support but he, as the chairman could not request support. The interviewer noted that while this respondent's home environment "did not attract a happy living atmosphere" and he does not have a bed or a mattress all members of his association have health problems and therefore, he says, he cannot ask for a mattress.

Arthritis – The prevalence of arthritis based on symptom questions was 7%. Females (8%) were more likely than males (5%) to report arthritis. There was also quite a difference between rural (4%) compared to urban (9%).

Asthma – The prevalence of asthma based on symptom questions was 9%, with no gender difference. The rural rate was slightly higher (9%) than the urban (7%).

Diabetes – **Annex Table** 5.3 shows that 5% of participants have been diagnosed with diabetes (termed also as high blood sugar in the questionnaire): 6% of women compared with 4% of men. Diabetes was more common in the urban area (7%) compared to rural (3%); and more common among people with a higher education and those in the better off wealth quintiles. There was hardly any difference between age groups.

Angina – The rate of angina based on symptom questions was 1% in the urban area and 4% in rural. It is more common in people over 70 years old.

Cataract – This is diagnosed when the lens of an eye becomes cloudy and opaque, causing partial or total blindness. The lens can be removed and replaced with a plastic substitute, which normally results in vision being

fully restored. Overall, 33 respondents (6%) said they had been diagnosed with cataract in one or both eyes in the last five years, but only 9 of those had undergone surgery to remove the lens(es). Cataract is a very common condition. **Annex Table** 5.4 shows that 36% of respondents in the urban area and 34% in the rural area had cataract, based on symptom questions (cloudy or blurry vision and haloed vision problems). It was common in all age groups but especially in those over 70. People living in poorer households were most likely to report these symptoms – over 40%, compared with 33% in the wealthiest ones.

Visual acuity – Men and women both have more trouble seeing nearby than far away; this is more pronounced in women (39%) than in men (26%) (Figure 5.3)

Table 5.1 shows that the older age groups (over 60) have more difficulty than younger people in seeing nearby and far away.

Figure 5.3 Visual acuity test results

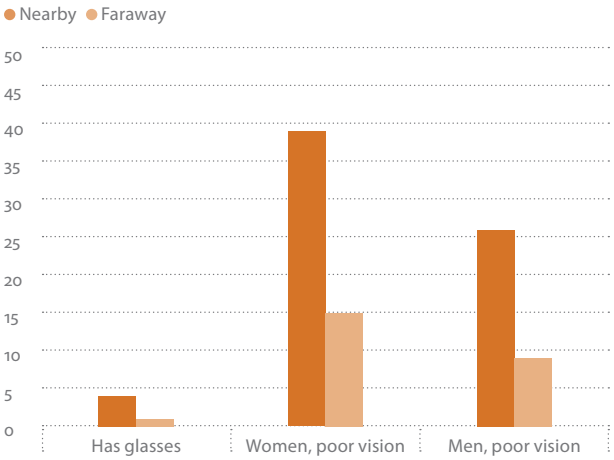


Table 5.1 Visual acuity (wearing glasses if available)

	Low distant vision	Number	Low near vision	Number
Sex				
Male	8.5	189	26.2	195
Female	14.6	294	39.1	304
Age				
50–59	5.2	173	33.5	176
60–69	10.3	146	36.2	149
70–79	18.3	120	30.1	123
80+	29.5	44	39.2	51
Residence				
Urban	10.7	243	39.2	250
Rural	13.8	240	28.9	249

Figure 5.4 Overall cognition score by age

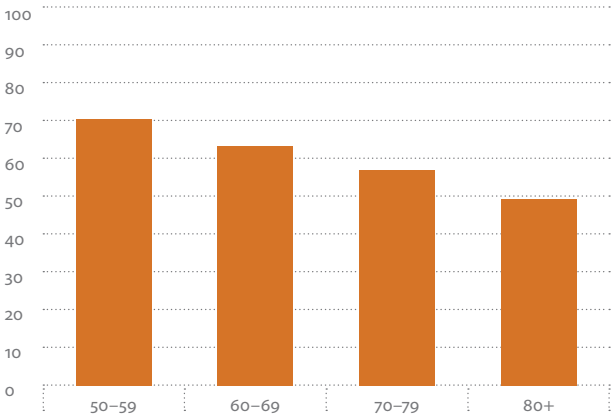
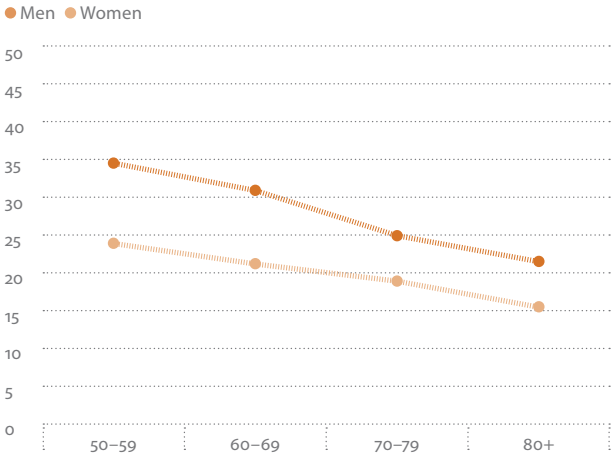


Figure 5.5 Mean grip strength by sex and age



The prevalence of poor vision varied markedly between the study groups among both men and women with no clear pattern emerging. Only a small proportion had glasses for distant vision or nearby vision (5% and 11% respectively), and often those with glasses still had poor vision scores on the test.

Loss of teeth was very common. Four percent of respondents had lost all their teeth and 24% almost all their teeth. Only 22% said they still had all their teeth.

The overall cognition score was determined by tests for verbal fluency, verbal recall, digit backward and digit forward span (**Annex Table** 5.5). These skills showed a gradual decline by age (Figure 5.4). There were no differences between men and women, but educational status did matter.

Mean grip strength for men and women (**Annex Table** 5.6) also declined gradually with age. The gap between the sexes decreases in those over 70 years of age (Figure 5.5).

Normal and rapid timed 4-meter walk averaged 7.3 and 4.2 seconds, respectively.

6. Risk factors – tobacco, alcohol and nutrition

6.1 Use of tobacco

The risks associated with tobacco use are well known. The survey asked about current and past use of any tobacco products, including inhaling, sniffing, chewing, as well as duration and quantity of daily use. The questions are based on the WHO definition ("guidelines for controlling and monitoring the tobacco epidemics"). **Annex Table** 6.1 shows that 13% of participants were daily smokers: 20% of men and 8% of women. 67% never smoked. Current daily tobacco use amongst those over 70 years old was more common among those with less than primary school education and among divorced/separated people.

6.2 Use of alcohol

Alcohol consumption, commercially available and home-brewed beverages need to be quantified in terms of alcohol content and quantity (that is, a standard drink). Participants were asked about their behavior in relation to consumption patterns and quantities of alcohol. Far more women (57%) than men (30%) were lifetime abstainers (**Annex Table** 6.2).

Frequent heavy drinking was higher among men (9%) than women (3%) and more common over 70 years old (11%). From the qualitative work we learned that some participants resorted to drinking alcohol as a way of associating with fellow elderly men. A 74-year-old man said it was difficult for him to abstain from alcohol because it helped him to keep up with friends and also helped him to sleep.

A 69 year old man commented:

> "The little alcohol I take is when I have gone to attend service/mass on Sunday. I pass by the drinking place with my friends; we sit and converse as we take our Kiganda brew".

- One 73-year-old male respondent on ART sells waragi (alcohol), so people are always coming and going. He says he has tried to avoid drinking, but in moderation it allows him to socialise with others, preventing loneliness, and helps him sleep. Sometimes he experiences insomnia; at other times, bad dreams trouble his mind, which the interviewer partly attributed to the respondent's experiences of the atrocities in Rwanda.

However, some older people gave up alcohol because they were concerned about maintaining their health.

> "I was a very good alcohol taker, but now I reduced because of that drug (antiretroviral), I now take it rarely". (Man, age 67)

- A 72 -year-old male respondent on Septrin works as a cobbler at Kakindu trading centre, but temporarily changed working places. However, some of the youths in the new location would regularly buy him beer so he moved back to Kakindu to avoid a drinking habit.

6.3. Nutrition

The nutrition questions asked about the quantity of fruit and vegetables consumed in a typical 24-hour period. According to WHO, an adequate intake of fruit and vegetables is five or more servings in a typical day; an intake of less than this is classified as insufficient. The focus is on food availability and access. "Availability" means sufficient quantities of necessary types of food and "access" means that incomes are adequate to purchase or barter for appropriate foods in sufficient amount.

Annex Table 6.3 shows that insufficient intake was highest over 80 years old (94%). There was almost

no gender difference, and also not much difference between rural (90%) and urban (88%) areas. The mean number of fruit and vegetable servings eaten on a typical day was one, well below the recommended amount.

28% of older people said they had been hungry but did not eat because they could not afford enough food in the last 12 months. Among these 24% said this happened every month, 24% said almost every month, 40% said some months of the year, and 13% only 1 or 2 months each year.

Overall, 14% of respondents said they were hungry every, or almost every month of the year. This was most common among the poorest: 22% of those said they were hungry most of the year. Hunger was also more commonly reported among urban residents (20%) and among those on ART (19%). In a logistic regression analysis a significantly higher level of self-reported hunger was observed among urban residents (Odds ratio=2.9, p<.001) and the poorest quintile (OR=1.8, p=.05), but not among those on ART (p=.106). There were no significant effects of sex and age.

From the qualitative study we learned that most of the older people depended on one meal a day; others survived on one meal for two or more days. Sometimes when respondents said they eat one meal a day, they also ate leftovers for supper or breakfast but they did not consider this to be a meal. Others described a daily meal as "one main meal a day", implying that they also ate leftovers. In other words, while the amount of leftovers available may often be totally insufficient, some of the respondents on "one meal a day" did eat something more often than once every 24 hours. There were also seasonal variations: poorer people usually experience exacerbated food shortages for one or two months each year during the dry season. However, during the study period, the dry spell lasted three to four months.

- During his first monthly interview, a 60-year-old male respondent on ART said he is confident that he will not be affected by the prevailing food shortage. He was very conscious to follow his counsellor's advice to eat well, but was limited to cooking one meal each day, accompanied by a cup of tea with sugar in it. Lunch leftovers were being saved for breakfast, consumed with a cup of tea at 10am after several hours of agricultural work. This respondent said he did not take supper that week; at other times, supper was lunch leftovers. In months 4 and 5, this respondent had tea for breakfast (perhaps with some leftovers), lunch in the middle of the day and supper (leftovers) in the evening. He said: "I don't eat what I would like to eat, and this makes me feel very weak because when I miss sugar, I don't feel very well and I don't sleep very well".
- A 73-year-old, HIV-positive female respondent who lives alone said that food was a problem. She was entirely dependent on the little that was available from her garden, and only managed to have one meal a day (supper) plus porridge for breakfast and lunch. She faced particular hardship in getting food during the dry season, and she said that digging cassava from the dry soil pained her very much.
- A 72-year-old male respondent on Septrin lives entirely at subsistence level, working as a cobbler to earn a living so he can buy food. He eats one meal each day. He said, "I always go to Kakindu Trading Centre to talk to friends who know my problems". These friends buy him food when he does not have sufficient money. In month 5, he reported epigastric pain and a slight headache. He had run out of medicine but had no money to take him to the TASO clinic in Entebbe. Sometimes he takes his drugs on an empty stomach but the interviewer told him he must eat first. Again, in month 9, he reported epigastric pain; the interviewer noted that this was possibly caused by taking drugs on an empty stomach.

The majority of respondents usually ate the same types of food, especially cassava and sweet potatoes, and posho (made from maize flour) and was commonly eaten in the poorest households. They commonly had green vegetables from their garden and silver fish (*mukene*) for sauce. A cup of silver fish (equivalent to ½ a kilogram) cost 200 Uganda shillings, which the majority could afford each week. Although very few older people could afford fish, meat or chicken, those who reared chickens slaughtered them once in a while to supplement their diet.

Height and weight were measured to calculate the Body Mass Index (BMI). This simple index of weight-for-height is commonly used to classify underweight, overweight and obesity in adults. It is defined as the weight in kilograms divided by the square of the height in metres (kg/m^2). For example, an adult who weighs 70kg and whose height is 1.75m will have a BMI of 22.9. BMI = 70 kg / (1.75 m^2) = 70 / 3.06 = 22.9

The International Classification of adult underweight, overweight and obesity according to BMI

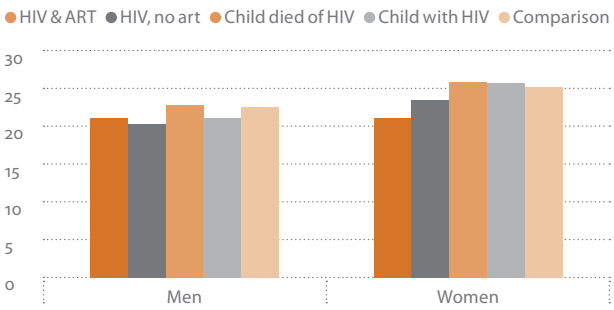
Classification	BMI(kg/m2)	
	Principal cut-off points	Additional cut-off points
Underweight	<18.50	<18.50
Severe thinness	<16.00	<16.00
Moderate thinness	16.00–16.99	16.00–16.99
Mild thinness	17.00–18.49	17.00–18.49
Normal range	18.50–24.99	18.50–22.99
		23.00–24.99
Overweight	≥25.00	≥25.00
Pre-obese	25.00–29.99	25.00–27.49
		27.50–29.99
Obese	≥30.00	≥30.00
Obese class I	30.00–34.99	30.00–32.49
		32.50–34.99
Obese class II	35.00–39.99	35.00–37.49
		37.50–39.99
Obese class III	≥40.00	≥40.00

Source: Adapted from WHO, 1995, WHO, 2000 and WHO 2004.

Annex Table 6.3 shows that underweight was more common in poorer households, and more common among men (19%) than women (11%). Pre-obesity was far more common among women (23%) than men (10%), as was obesity (13% of women vs 3% of men). Underweight was more prevalent above age 70 and among divorced / separated people. 16% of the obese participants were in the highest wealth quintile, compared to 10% in the lowest.

Figure 6.1 shows that men who are HIV-infected had a lower BMI than men in the other study groups. Among women this was only true for participants who were on ART, but not for those not yet on ART. The latter may have less advanced infection, and there are no consequences for the BMI at that stage. In a multi-variate analysis the BMI was significantly lower if the respondent was a man, HIV positive (irrespective of ART), rural, not in a marital union or older age.

Figure 6.1 Mean Body Mass Index by study group and sex



7. Health care utilization

7.1 General health service utilization

Figure 7.1 shows the percentage of people who were hospitalized in the last three years. Overall, 27% of respondents had been hospitalized. Among the 120 respondents who reported a reason for admission, 57% were considered acute infectious conditions. The highest proportion of respondents with admissions was observed in the HIV-positive study groups, especially those who are now on ART (39%). The proportions hospitalized were similar among women and men (28% and 24% respectively).

The majority (82%) of respondents had used outpatient services in the last year (Figure 7.1). This was most common among those who were HIV-positive (98% and 97%). 85% of women and 77% of men said they had used an outpatient clinic in the last year.

The type of outpatient services used is shown in Table 7.1. Overall, 18.4% did not use any outpatient services. The most common source of outpatient services was the MRC clinic: 22%.

Since the MRC clinic is only located in the rural area, only the rural participants reported frequent use: 43% of the rural respondents had used the MRC clinic in the last year (Figure 7.2). It is notable that the MRC clinic is equally frequently used by all study groups, indicating that it serves the whole population, and not just those who are HIV-positive.

In the urban areas the TASO clinic is the dominant source of care, but only for study groups 4 and 5, since the TASO clinic only serves those with HIV infection (except for HIV testing services). Public and private facilities provide almost one-fourth of outpatient services each in the urban area, but are much less common in the rural population. HIV -positive respondents obtain almost all their outpatient care from either the MRC or TASO clinic, and for about one-fifth of cases from public facilities.

Most respondents indicated that they had to wait quite long, long or very long in health facilities (58%). Only a minority said the health worker did not take time to explain their health problem: 10% said sometimes, not usually, or never did the health workers take enough

Figure 7.1 Percent of respondents by study group who had been hospitalized in the last three years and had used outpatient services in the last year

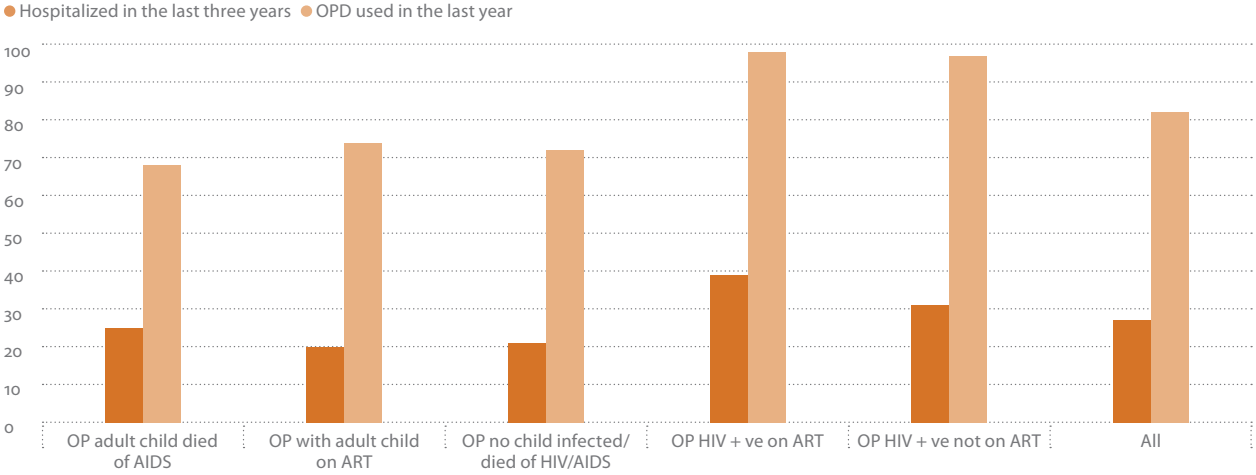


Table 7.1 Type of outpatient services use in the last year, by study group

	No use in last year	Private facility	Public facility	MRC clinic	TASO clinic	Other	Number
Study group							
OP adult child died of AIDS	32.1	19.8	17.0	27.4	0.0	3.8	106
OP with adult child on ART	25.7	20.8	24.8	20.8	0.0	7.9	101
OP no child infected/died of HIV/AIDS	27.9	21.2	25.0	21.2	1.0	3.9	104
OP HIV + ve on ART	2.0	1.0	19.8	19.8	46.5	10.9	101
OP HIV + ve not on ART	3.1	6.1	19.4	20.4	43.9	7.1	98
All	18.4	13.9	21.2	22.0	17.8	6.7	510

time (Figure 7.3). The percentage of people who said the health worker did not take enough time to explain the treatment was higher: 24% said sometimes, not usually, or never did the health workers take enough time. Overall, 83% of older people said they were satisfied or very satisfied with the health services.

TASO clinics scored highest, with 98% saying they were satisfied with the services. For the MRC clinic 86% were satisfied, and for private facilities 82%. The lowest score was for public facilities where 66% said they were satisfied. There were no differences between men and women.

7.2 Utilization of HIV testing and counseling

Access to HIV testing and counseling services for older people is important for both prevention and treatment.

Figure 7.2 Type of outpatient services used in the last year in urban and rural study populations

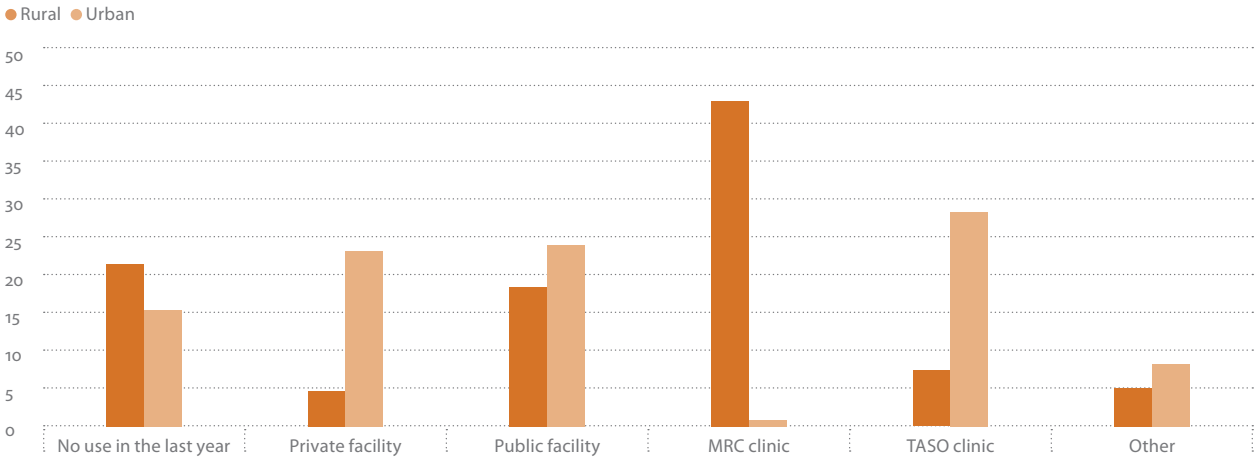


Figure 7.3 Percentage of respondents with their perceptions of the quality of the outpatient services

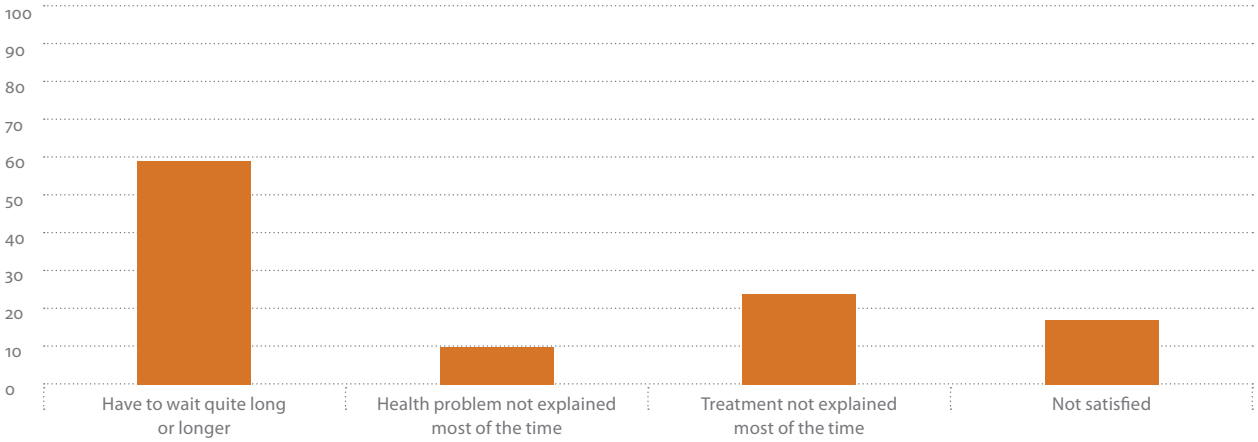


Table 7.2 shows that 76% of respondents had ever been tested; 30% said they had been tested in the last year, and 26% were tested in the last year and received the results of that test.

HIV testing rates were of course 100% among those who had been identified through the research studies of HIV-positive people (except one person who did not report ever being tested). But testing rates were also high among HIV-negative respondents. Testing rates were somewhat higher for men than for women, and less frequent among people over 70 years old. Interestingly, rural testing rates were twice as high as those in the urban population, because many of the participants had been tested during the annual sero-surveys performed by the MRC.

Table 7.2 Ever tested for HIV, tested in the last year, received the result

	Number	Ever tested	Last year tested	With results	Don't know
Study group					
OP adult child died of AIDS	104	52.9	28.9	21.7	1.0
OP with adult child on ART	98	56.1	29.9	22.5	2.0
OP no child infected/died of HIV/AIDS	99	73.7	50.3	40.9	2.0
OP HIV + ve on ART	100	100.0	5.0	5.0	0.0
OP HIV + ve not on ART	98	99.0	32.7	31.3	0.0
Sex					
Male	189	83.6	38.4	33.2	2.1
Female	310	71.6	24.6	21.9	0.3
Total	499	76.2	29.9	26.3	1.0
Age group in years					
50–59	175	96.0	38.4	35.7	0.0
60–69	146	78.8	28.3	25.1	0.0
70–79	125	64.0	27.8	21.9	1.6
80+	53	32.1	11.2	8.4	5.7
Education					
Less than primary	117	68.4	26.2	22.3	2.6
Completed primary	232	76.7	28.8	25.2	0.9
Completed secondary	54	75.9	35.2	27.5	0.0
Completed high school	37	83.8	29.7	29.7	0.0
Completed college/university	31	90.3	37.3	36.0	0.0
Completed post-grad	9	77.8	44.5	44.5	0.0
Marital status					
Never married	7	42.9	14.3	9.5	0.0
Married/cohabiting	158	82.3	39.0	33.2	0.6
Divorced/separated	104	76.0	34.3	30.4	0.0
Widowed	230	73.0	22.0	20.0	1.7
Residence					
Urban	253	70.8	20.6	20.1	0.0
Rural	246	81.7	39.1	31.1	2.0
Total	499	76.2	29.9	26.3	1.0

8. Older people as care providers

8.1 Introduction

This section includes the results of the structured interviews based on the caregivers' questionnaire. Questions were asked about care/support provided to adult residents and non-residents at present; to adults in the past who do not need care at present; and to adults in the past who have died. Participants were asked about the nature of care and support provided, including personal care, physical and financial assistance; and about their relationship with the person to whom they provided this support. They were asked about the difficulties of providing this care and support and whether they were the main or secondary provider. This was followed by questions about the experience of caregiving. We asked also if they knew the reason why this person needed care and support; and whether it was HIV/AIDS related, another health-related reason or some reason not related to health. If the participants knew that the adult they cared for was HIV-positive, then questions were asked about their ART knowledge and their involvement in this care. After completing the module on caring for adults, participants were asked about child members (<18 years old) in the household for whom they may provide care.

8.2 Older people providing care to adults

Table 8.1 shows that there were 56 households (11%) with one adult who needed care, and seven with more than one adult needing care. In 4.5% of households, older people provided care to an adult in the household. In addition, 11% of older people provided care to an adult outside the household. Most of the care was provided to a spouse, parent or sibling.

Of those who provide care/support, all gave some kind of physical assistance (100%), e.g. cooking, taking to the clinic etc; almost all gave financial assistance (85%), e.g. paying for food, clothing, medicines etc; and most gave personal care (67%), e.g. moving around in the house, dressing etc.

In the last five years 47% had given care to an adult. Most of this care was given to an adult household member who had died (38%) (Study group 1).

One striking case from the qualitative study is of a 71-year-old HIV-positive woman who is going blind, and who cares for her 90-year-old deaf, blind and incontinent husband. Their 14-year-old granddaughter

Table 8.1 Percent of households with adults who need care and receive care from the respondent

Number of adults	Adults in household		Receiving care from respondent			
	Needing care, now		In household, now		Outside household, now	
	Number	Percent	Number	Percent	Number	Percent
0	447	87.7	487	95.5	453	88.8
1	56	11.0	23	4.5	51	10.0
2	5	1.0			6	1.2
3	2	0.4				
Total	510	100.0	510	100.0	510	100.0

Table 8.2 Adult care by the respondents

Past care, in household, still alive		Past care, outside household, still alive		Past care, in household, adult died	
Number	Percent	Number	Percent	Number	Percent
491	96.3	452	88.6	318	62.4
18	3.5	53	10.4	145	28.4
1	0.2	5	1.0	47	9.2
510	100.0	510	100.0	510	100.0

was living with them but ran away during the course of the study, leaving the respondent to take care of all household and agricultural work. She was disappointed that her husband was tested and was HIV negative, as she was hoping that he would be able to access health care through TASO. Each month the respondent complained of terrible backache; she generally she feels weak but she tries her best to support herself and the husband.

8.3 Older people providing care to children

Overall 76% of the 510 households had children in the household from whom 42% of the households have at least one orphan. On average there were 2.7 children per household. One third of the children were orphans, including 13% double orphans (mother and father died).

Table 8.3 Care to children by the older respondent, as main or secondary caretaker

	Children in household	Main caretaker	Secondary caretaker	Main caretaker orphan	Secondary caretaker orphan	Care receiving children who are orphans
	Mean	Mean	Mean	Mean	Mean	Percent
All	2.70	1.74	0.85	0.70	0.17	34
Study group						
OP adult child died of AIDS	2.49	1.75	0.59	0.99	0.27	54
OP with adult child on ART	3.75	2.27	1.36	1.03	0.32	37
OP no child infected/died of HIV/AIDS	2.39	1.55	0.78	0.48	0.09	24
OP HIV + ve on ART	2.37	1.69	0.62	0.56	0.10	29
OP HIV + ve not on ART	2.52	1.44	0.93	0.44	0.07	22
Sex						
Female	2.96	1.87	1.00	0.91	0.21	39
Male	2.29	1.54	0.63	0.38	0.11	23
Residence						
Rural	2.68	1.86	0.66	0.56	0.11	27
Urban	2.72	1.61	1.04	0.85	0.23	40
Wealth quintile						
Lowest	2.44	1.26	1.08	0.60	0.21	34
Second	2.60	1.74	0.81	0.75	0.23	38
Middle	2.43	1.51	0.75	0.62	0.08	31
Fourth	2.73	1.90	0.71	0.70	0.20	34
Highest	3.31	2.28	0.92	0.85	0.15	31
Marital status						
Married	3.29	2.24	1.04	0.64	0.23	26
Divorced	1.98	1.13	0.77	0.50	0.16	35
Widowed	2.61	1.67	0.75	0.84	0.13	40

The wealthiest households had the most children: on average 3.3 children compared to the poorest with 2.4 (Table 8.3). Married respondents also had 3.3 children on average.

Each respondent was the main caretaker for 1.74 children on average, and the secondary caretaker for 0.85 If the older person is the main caretaker, it more commonly concerns orphans, 78% (0.70 out of (0.90) of orphans has an older caretaker as main caretaker.

The respondents who cared for the most children were those under 70 years old, those living in better-off households and those whose children had died of AIDS. Older women provide more care and assistance than men (2.9 versus 2.2 children).

8.4 The nature of care provided by older people to children

Table 8.4 shows that most of the care provided was physical assistance (68%), followed by financial support (65%) and personal care (29%).

Among the children cared for by respondents, 59% were said to be often sick. Respondents were asked whether a child had HIV infection, which is likely to be underreported; 7% said they provided care to one child who is HIV-positive and 3% to two children who are HIV-positive. Of the HIV-positive children, 5% were said to be having antiretroviral therapy. 3% accompany the children to the clinic.

The qualitative study included 40 participants, of whom all from the urban area were HIV positive, while three from the rural area were HIV positive. The majority of the participants (48%) were aged between 70-79 years old, 42% were between 60-69 years and 10% was 80 years older.

The majority (60%) cared for 1-5 children (below the age of 18 and 4 (10%) cared for 6-9 children. Those in the latter category had a heavier care-giving burden in terms of providing food, school fees and medical care. The majority (75%) of the participants in the rural area cared for grandchildren whose parents had died of AIDS, most of these children were below 18 years old.

Some of the grandchildren had a parent living in urban areas but who had left their children in the care of the grandparents; some of these parents returned periodically, bringing food and money, although not necessarily a sufficient amount to meet the needs of the household. Sometimes the grandparents complained about their difficulties in finding school fees and the struggle to provide enough food.

Table 8.4 Type of care provided by older respondents to children

	Children	
Provides:	**Number**	**Percent**
Personal or nursing care	149	29.2
Bathing	138	27.1
Eating	103	20.2
Dressing	129	25.3
Toileting	92	18.0
Other	2	0.4
Financial care	333	65.3
School and other fees	264	51.8
Clinic fees	251	49.2
Medicine costs	262	51.4
Food	291	57.1
Clothing	292	57.3
Transportation	236	46.3
Physical care	344	67.5
Buying food	277	54.3
Fetching water	121	23.7
Cooking	272	53.3
Taking for health care	297	58.2
Child often sick	300	58.8
Says at least 1 child has HIV	36	7.1
More than 1 child has HIV	15	2.9
Child(ren) on ARV therapy	26	5.1
Accompanies to clinic	14	2.7
Total	510	100

- A 63-year-old female respondent on ART has about thirteen people living in her home, which, the interviewer commented, looks like a school. Many of the children she has been given the responsibility for are actually the offspring of her deceased husband and co-wives. The respondent also looked after her

Table 8.5 Satisfaction of providing care among main and partial caretakers of children and adults by groups

	Yes	Somewhat	None	Percent
Does the role of caregiver, give you:				
chance to keep busy occupied	85.6	11.8	2.6	100.0
chance to do things that makes use of your abilities	89.7	8.5	1.9	100.0
chance to feel sense of accomplishment despite the difficulties	94.0	4.4	1.6	100.0
chance to do something useful for your child/grandchild	96.3	1.8	1.8	100.0
provide a reason to continue living	95.6	2.9	1.6	100.0

elderly mother-in-law until she passed away during the study period. The household receives many visitors and guests: most frequent is a stepdaughter who provides food and whose two children live in the house; a cousin-brother also helps with food and money; and neighbours pay frequent visits to check on them or bring some assistance. Although the respondent does receive a wide range of support from various sources, it is not necessarily proportionate to the number of responsibilities she has in terms of taking care of the children. She has "two major meals a day" but says she does not have a choice for her diet, and was happy when the number of people in the household reduced because that meant reduced food costs.

The qualitative study found that while female heads of households are often given the responsibility of adopting nieces, nephews and grandchildren, male respondents living alone are usually not. Unsurprisingly, the female respondents living in large households expressed less isolation and loneliness than the male respondents living alone.

- A 60-year-old male respondent said that living alone reduced his happiness, and loneliness affects his health. He feels less lonely when people visit and chat with him for a little while, but many villagers greet him and continue without stopping for a conversation. Geographical distance and lack of money meant that he was isolated from his sister and his children. He had a plan to reduce his loneliness by re-establishing contact with them and bringing a grandchild to live with him, and enrolling the child in a school. But he did not seem hopeful about this idea because he could not afford to make this a reality.

The majority of the 40 participants from the qualitative study provide financial (65%) and physical (67%) assistance; personal care (29%) was less common. Seven percent reported that they had at least one child who is HIV positive, 5% have children on ART, and 3% accompany the children to clinic. A 70 year old grandfather explained his fears for his grandchild living with HIV:

- He lived with his 78-year-old wife and three grandchildren. He worries about his 9-year-old granddaughter who is HIV positive. When asked if the schoolteachers were aware of the child's health status, the grandfather replied: "I did not disclose this directly to the headmistress" but he said that whenever the girl is sick, she is not able to attend school and this has to be reported to the school. He added that he told the headmistress that the child belongs to the MRC clinic. The interviewer asked what prevented him from direct disclosure and he quickly replied: "You cannot tell what one thinks about such a child, if they begin stigmatizing her at school, then I am the one who caused trouble! Let them [the teachers] find out by their own means so that I do not feel guilty!"

8.5 The experience of older people providing the care

As Table 8.5 shows, most of the participants had a positive feeling about caregiving. They felt a sense of accomplishment despite the difficulties (94%), or a chance to do something useful for their children or grandchildren (93%). However, there were also difficulties with caregiving, most commonly lack of energy to provide care (Table 8.6).

The case of a 60-year-old HIV-positive woman (described in Section 4.5 above, but elaborated upon here) further illustrates the difficulties experienced by older people caring for others:

Table 8.6 Caregiving experience among main and secondary caretakers of children and adults

	None	Some	Very much	Total
How much difficulty with:				
having enough energy to do the extra work	28.4	33.6	38.1	100
taking care of your own ailments/ (if any)	50.4	36.8	12.9	100
buying medications for your ailments	68.1	22.2	9.8	100
keeping in contact with people you like	70.5	21.3	8.2	100
visiting family, relatives and friends	60.9	28.6	10.5	100
sharing feelings about caregiving responsibilities	65.4	30.2	4.5	100
knowing the correct care to provide for health problems for (NAME)	80.6	13.7	5.8	100
knowing how to protect yourself, as the caregiver, from getting the illness/disease	88.7	8.7	2.6	100
experiencing stigma as a result of or associated with the illness or death	91.8	6.4	1.9	100

- The respondent is not yet on ART and experiences constant physical pain. She is the head of her household with responsibility for numerous grandchildren, nephews and nieces; she also supports one of her brothers. Sometimes she receives no visitors and no assistance. However, she did report receiving occasional support from her son and daughter: through the course of monthly interviews the interviewer listed the provision of salt, sugar, tea leaves, maize flour, rice, soap, matches, paraffin, and money. But the respondent said she cannot demand anything more than what they give voluntarily. The support this grandmother receives is invariably offset by obligations and the demands of the household, and at times, her own wellbeing is directly compromised by her responsibilities to others. For example, one month she reported that she could not spare money for her own health treatment because she had to pay school fees for her nephew.

  Significantly, this respondent spent a month in prison in 2008 for allegedly severely punishing one of the children. This incident might be an indication of the pressure she feels to maintain the household despite lack of financial support, and her inability to cope. She said, "I suffered in prison", and that the incident had left a scar on her heart.

8.6 Care received by older people

In total 30% of older people in our study needed care for more than a month in the last 5 years.

Half (52%) of the HIV-positive participants now on ART needed care for more than a month in the last five years, compared to 22% of the comparison group.

When asked about the difficulty of obtaining care and support, 46% of 313 participants who needed care said it was difficult to very difficult to get; in relation to physical assistance, 27% of 347 participants who needed it said it was difficult or very difficult to get.

The main providers of personal care (toileting, dressing, moving around, bathing and medication) were daughters, sons and siblings.

The main providers of financial assistance such as cash, paying for health care, medicine, schooling, food and clothing were daughters and sons.

Most of the physical assistance such as fetching water, agricultural work, cooking, and buying food was again provided by daughters and sons, followed by granddaughters and grandsons. 86% of those who got this physical assistance were satisfied or very satisfied with it.

9. Summary of the District dissemination workshop

A District-level dissemination workshop was held to share the findings of the study, with the aim of creating awareness of (1) older people's physical and mental health and wellbeing, and (2) the barriers preventing them from accessing services. Since the findings for the rural and urban areas were similar, we combined them in the presentations with a few exceptions. Workshop participants were given a handout of the study findings.

In addition to our own findings, the workshop also included the results of two other studies: (a) qualitative research by the Food and Agricultural Organization on older people's household needs and access to services; and (b) a study on education of children living in elderly people's homes which was part of a PhD by a doctoral student at MRC.

The sessions in the workshop covered: (a) General study results, (b) Self-reported health and chronic conditions, (c) Education of children living in elderly people's homes, (d) Older people's household needs and access to services in rural Southwestern Uganda, (e) the Ugandan Government's policies on older people, (f) Caregiving to adults and children and (h) Older people receiving care.

Psychiatrist Dr Eugene Kinyanda ran an interactive session on older people and their mental health. He discussed a range of mental health problems among older people, including dementia, delirium, depression and alcohol abuse.

In between presentations there were discussions, questions and clarifications. Some of the questions were about the items we had measured such as social networks and blood pressure. Others were about data collection, such as whether we collected data on deafness and blindness among older people (not included in the survey). Another question was about treatment-seeking behavior. (We had collected data on treatment-seeking behavior but we could not present them because they had not yet been analyzed.) We were asked about the age cut-off; for comparison with WHO SAGE studies in other countries we chose 50 years and above for the quantitative study, however for the qualitative study it was 60 years and above.

Most of the questions related to older people accessing services. For example, we were asked whether participants diagnosed with a chronic condition were referred to a clinic for further examination and treatment. As explained in this report, such cases were indeed referred and treated.

The participants wondered whether the government had specific services for older people. As we learned from the Commissioner's representative, there is a pilot project in Mukono district that serves to highlight the pros and cons of the program and a guide on how to make it better. Weekly they have free access to health services. The older people have an ID card with a picture and need not to wait in line. A participant asked that this program not be limited to Mukono District but eventually extended to the whole country.

The representative of the Commissioner said there is a pilot program in 5 districts to help older people with USH 20,000 [12 USD] a month. Questions were asked about the sustainability of this monthly payment to the vulnerable elderly. What criteria are used to choose the most vulnerable? How will it be accessed? What can be done to make this assistance more workable?

The Commissioner's representative replied that 20,000/= was seen as "half a loaf which is better than none"; and it would be given to the most vulnerable who would be identified by community leaders including the local council (LCs) leaders.

Another question was "Who in the government is in charge of caring for older people?" The Community Development Officer was reported as having this responsibility. However, one participant pointed out that the ability of that office to care for this group was questionable, given its underfunding and large workload. It was noted that unless the number of government extension workers was increased, the recommendation to visit the old people in their homes would not be implemented. It was also noted by participants that there were no social workers in the communities, so health workers often ended up doing the work that should be done by social workers. Since the health workers are not trained or equipped to do this work, it is not done well. How can a structure of social workers be set up? It was said that the government would offer training for the care of older people as per the government curriculum.

Important questions were also asked about the education of children living in elderly people's homes. For example, the data showed more girls enrolled in schools than boys, yet the norm in Uganda is to have more boys in school than girls. It was explained by the presenter that with the coming of Universal Primary Education, more girls have gone to school. One of the workshop participants was an inspector of schools and he confirmed that many schools have more girls than boys today.

Another question was whether disability was a reason why some children did not go to school. Data on disability have not been analyzed, however it was stated that all the children not in school were able bodied. It was noted that many older people did not send children to school because they mistakenly thought the children too young, since many children have stunted growth and ordinary people often judge the age of a child by its size.

In the presentation by the PhD student it appeared that children living with older people have lower aspirations, as reflected in the high rate of school dropout and teenage pregnancy. The presenter confirmed that the data showed that the older the care taker, the lower the aspirations.

It was noted that the data seems to have clear gender differences. The presenter explained that several educational outcomes showed girls doing better than boys. This could be attributed to the impact of UPE in positively changing attitudes towards the education of the girl child. Furthermore, many household were female-headed households and unlike male household heads, women rarely favored the boys over the girls but instead sent all the children to school.

In the afternoon after the presentation on caregivers we had group discussions about the services for older people in Uganda. The following questions were used:

- What are the strengths of the current services for the older people?
- What are the weaknesses of the current services for the older people?
- What are the opportunities (possible interventions) for the services of the older people?
- What challenges are there?

It is a positive development that attention is being given to older people at different levels. There is a national policy, the government has an action plan and programs are currently piloted.

More weaknesses were identified than strengths, because older people's issues are given sporadic attention and only a few civil society organizations provide services. The list of weaknesses included: little or no coordination among the services, lack of priority given to older people , they are not seen, they cannot count on the services, they are marginalized, the system of support for older people is not sustainable, there are no programs and no planning and there is age discrimination.

What are the opportunities to address these issues? (Possible interventions) Participants stated that the elderly are respected in the communities, and it is the responsibility of the government to address their needs and problems. It was reported that there is up-to-date data, the NGOs are in place, the government has the will to do something, policies are exist, community development is ready to give support – but greater awareness of policies and action plans is needed and the resources need to be in place. Last but not least, the elderly in our communities have great wisdom about how to address the needs and problems!

Unfortunately the time was too short to discuss on how we might work together in the future, but there will be several local dissemination meetings in the community and MRC will work closely with the district and local government officers to disseminate the study findings. We will contribute to the discussions on how the study findings can be translated into good practices and programs to improve the health and wellbeing of older people.

10. Discussion

10.1 Older people's health and wellbeing

The worst health was reported by people aged over 70, those living in the poorest households and those who do not have education.

Perception of their health was best among the HIV-positive participants who are on ART. They also had the best overall self-reported quality of life. This could be explained by the fact that before taking ART they may have been quite sick. Also, this group is regularly followed up by health service providers and thus receives treatment for a range of ailments.

HIV-positive older people do experience stigma, partly explainable by the difficulty older people have in talking about sexuality with their children and service providers (and vice versa). The fear of social rejection also plays a role. Another factor is a lack of awareness among health and social service providers that older people are exposed to HIV infection, leading to the exclusion of this group from preventive HIV programs.

Women were more likely than men to report difficulties in their daily activities. This could be because women are more active: in the urban area 61% of women and 39% of men were still working. The pattern was similar in the rural area: 60% of women and 40% of men. Women might be more aware of limitations on their functional abilities because their caring roles and responsibilities are so demanding; and yet they are in poorer health and living in the poorest households.

The prevalence of major chronic illnesses displayed some interesting patterns. Many older people had high blood pressure without being diagnosed or treated. Even those who were diagnosed did not always go for treatment because of obstacles such as the cost of transport and treatment (10% had difficulties buying their medications), not having time to go for treatment (13% had difficulties caring for their own ailments because of caregiving responsibilities) or not being satisfied with the health services. Women were more likely than men to report health problems for all conditions except angina, cataract and hypertension. The higher prevalence of health problems among women may be because women are more likely to report such problems to interviewers. However, it is possible that women do suffer from chronic diseases more than men and seek out health services more. It is clear that those in the wealthier quintile and those with higher education are better off health-wise except for the risk of cardiovascular diseases.

10.2 Older people providing care and support

The widening of access to antiretroviral therapy has created a shift in the dynamics of care. In the past most of the care older people provided was to their own adult children who fell ill. Older people still have care responsibilities for their adult children, but now the greater burden is related to the care they provide to young children.

Older people care for adults – mainly spouses, parents and siblings – mostly outside their own households. Most of the care they provide is to children within the household, many of them grandchildren. It is the financially better off families who provided most of the care to these children and the younger older people but still there are older people who are poor (more likely the divorced and widowed) who provide care to these children. Most of the divorced and widowed live in the poorest household and they perceive their health not good. For example, among widows and

divorced depression and high blood pressure is more common (when controlling for age) compared to the married ones.

10.3 Older people's caregiving experience

Despite poor health or difficulties in maintaining good health, older people do get satisfaction from providing care. 96% reported that this has given them the chance to do something useful for their children and grandchildren.

However, their mental and physical health is affected when they do not have sufficient means to provide this care. They may lack the time to deal with their own health problems and be unable to afford transport, medical fees and other costs associated with using the health services.

The burden of caregiving can be manageable if older people receive the support they need from family, community and service providers, if they have a chance to stay connected with their families and community members, and if they are able to look after their own health in order to prevent and postpone chronic conditions. When one or more of these conditions is not met, caregiving becomes a burden and their wellbeing is endangered.

It is not only caregivers who need care and support. Some older people who live alone and feel lonely, whether or not their health is poor, can have a poor quality of life because they are not connected to families and the communities they live in. These older people must also be taken into account when considering how to improve quality of life for vulnerable older people and enhance their functional ability to live an independent life.

10.4 Dissemination of study findings and what next

As a research institute we will continue to disseminate the study findings to the older people and their families, communities, local government, civil society organizations and district and national government. We hope that despite limited resources and other constraints reported by the participants in the dissemination workshop, further discussions on how to address older people's concerns, issues and problems will continue and be translated in action plans.

Perhaps families, communities, service providers and researchers need to think in terms of vulnerability to bring it to the next level of discussions on the study findings. What makes older people vulnerable in their families and communities? Is it, for example, that their children hardly stay in touch with them? Is it that they do not have enough eat and lack the strength to look after themselves? Is it the barriers to services – for example, health service providers not really listening to their health complains so the older people go back home undiagnosed and untreated? Is it a lack of awareness that older people can get infected with HIV? Are health services not adequately trained to address sexuality and HIV infection in older people? Are older people not informed about the services available from the government or civil society organizations? Perhaps combinations of these factors make older people vulnerable, or perhaps there are other reasons not mentioned here.

Our study participants were pleased to be asked about their own health and about the care they provide to others. It is a very positive action to visit older people in their communities and ask them the right questions about their health and wellbeing, knowing for example that failing bodies (poor health) and isolation will bring sadness, depression and worse health, regardless of their caregiving responsibilities. We appreciate what they tell us and we learn from them what needs to be done to improve their quality of life. We are making an effort to translate this information into a plan, partly created by older people themselves, and to implement this plan in collaboration with families, communities, local government, civil society, along with the district and national governments. Poverty and severe poverty among older people is common regardless of their caregiving burden, and it is obvious that it limits their use of social and health services. This all may contribute to poorer quality of life and isolation.

We shared the findings with the district officers, who mentioned repeatedly that they can improve their services if the national government gives them the authority and resources to implement those improvements. This important information needs to be conveyed to the right ministries. The study findings and the outcome of the rural dissemination workshop will be reported as a policy brief for the national and district government but there will be also a policy brief for the local government.

10.5 Recommendations

For direct service providers at the district and community level

Working in partnership with older people and other community members:

1. Identify older people who are in need of care and support. An important step is to engage older people in discussion, acknowledging that there are some who are vulnerable in the communities and need care and support. This is a two-way process that includes listening, mutual understanding, empathy and clarification.
2. Promote intergenerational programs to combat ageism, promoting the view that older people are as productive and valuable members of the community as the younger generation.
3. Plan, implement and evaluate initiatives and services to improve older people's health and socioeconomic wellbeing. (This includes encouraging older people to be tested for HIV—find testing results.)
4. Investigate the barriers stopping older people from accessing services and look for interventions to address the barriers.
5. Look for resources to provide care and support, access to health and social services and income.
6. Develop policies at community level to address a variety of issues/concerns/needs of older people; these policies should be accepted, adopted and monitored consistently.
7. Work with communities to identify the gender issues which are affecting women and men, such as wealth disparities, and design programs to address these issues.

For indirect service providers at the national level

8. Free up resources to replicate/scale up the economic programs (cash transfers) that not only support older people with responsibilities in HIV/ AIDS-affected families but also older people not affected by the HIV/AIDS who live in extreme poverty.
9. Address the education needs of health and social service providers to meet the health and socio-economic needs of older people. This will enhance older people's functional capability to live independently and contribute to their families and communities.
10. Train health professionals to recognize, diagnose and treat HIV and AIDS in older patients and to understand better the linkages between HIV and ageing.
11. Expand HIV prevention programs to target older people in an appropriate and age-sensitive manner.
12. Design and provide age-friendly primary health care services that include appropriate HIV services for older people.
13. Set up home-based care policies and programs, including standards of care guidelines to address the specific economic, health and psychosocial needs of older people. These should cater to older people who are vulnerable due to poverty and a heavy caregiving burden, as well as those who live alone, are ill or feel depressed/ lonely and have no one to care for them.

Annex tables

3. Socio-demographic information

Annex Table 3.1 Gender characteristics by age, education, residence, marital status, wealth quintile

	Men	Women
Number	198	312
Age group		
50–59	35	35
60–69	26	32
70+	39	34
Residence		
Rural	54	48
Urban	46	52
Marital status		
Not married	40	85
Married	60	15
Education		
Less than primary	16	29
Primary	44	51
Secondary or more	40	19
Wealth quintile		
Highest	16	23
Lowest	21	19

Annex Table 3.2 General characteristics of households and respondents

		Rural	Urban	Total
Number of respondents		256	254	510
Study group	OP adult child died of AIDS	16.4	23.6	20.0
	OP with adult child on ART	20.7	19.3	20.0
	OP no child infected/died of HIV/AIDS	21.5	18.5	20.0
	OP HIV + ve on ART	21.5	18.5	20.0
	OP HIV + ve not on ART	19.9	20.1	20.0
Religion	Roman Catholic	72.7	45.3	59.0
	Protestant	14.5	42.1	28.2
	Islam	10.9	7.1	9.0
	Other	2.0	5.5	3.7
Amenities	Uses improved water source	62.6	82.6	72.6
	Fetches water every day	62.1	53.1	57.7
	Improved sanitary facilities	0.4	3.4	1.8
	Electricity	1.6	28.4	14.9
Cooking	Uses firewood	97.3	67.7	82.6
	Uses open stove without chimney	91.4	80.1	86.3
	Cooking done indoors	31.4	16.5	24.0
Possessions	Mobile phone	28.1	49.6	38.8
	Radio	60.2	70.9	65.5
	TV	2.0	25.6	13.7
	Bicycle	32.0	20.9	26.5
Farming	Has plot nearby/walking distance	89.5	57.5	73.5
	Plot elsewhere	4.7	13.0	8.8
	No plot	5.9	29.5	17.7
	Keep farm animals	83.2	49.2	66.3
Main source income	Has regular household income	59.4	68.1	63.7
	Selling agricultural products	85.9	40.9	63.5
	Wages from a job	4.3	13.0	8.6
	Remittances from children	43.8	48.4	46.1
	Trading / hawking	5.5	13.4	9.4

4. Health state descriptions

Annex Table 4.1 Distribution of respondent rating of overall general health by selected demographic characteristics

		Own health bad/very bad	Activity problems severe/extreme
Study group	OP adult child died of AIDS	15.1	21.7
	OP with adult child on ART	22.8	23.8
	OP no child infected/died of HIV/AIDS	24.0	23.3
	OP HIV + ve on ART	6.9	17.8
	OP HIV + ve not on ART	11.2	19.4
Age groups	50–59	8.9	16.1
	60–69	9.9	15.1
	70+	28.7	31.6
Sex	Male	14.7	22.8
	Female	17.0	20.2
Residence	Rural	21.9	25.9
	Urban	10.2	16.5
Education	None	25.4	28.0
	Primary	14.6	21.0
	Secondary or higher	9.7	16.4
Wealth quintile	Lowest	21.6	27.5
	Second	17.7	22.8
	Middle	16.7	22.6
	Fourth	11.8	20.6
	Highest	12.8	12.8
Total		16.1	21.2

Annex Table 4.2 Summary health score by background characteristics and place of residence for men and women separately

		Health score
	N	Mean
Men – all	**198**	**48.2**
Study group		
OP adult child died of AIDS	32	50.6
OP with adult child on ART	31	50.4
OP no child infected/died of HIV/AIDS	50	49.4
OP HIV + ve on ART	46	47.8
OP HIV + ve not on ART	39	48.5
Residence		
Rural	106	48.7
Urban	92	49.8
Marital status		
Not married	79	48.9
Married	119	49.5
Education		
Less than primary	29	48.3
Primary	82	47.5
Secondary or more	75	50.5
Wealth quintile		
Lowest	31	47.2
Highest	42	49.3

		Health score
	N	Mean
Women – all	**312**	**43.8**
Study group		
OP adult child died of AIDS	74	43.6
OP with adult child on ART	70	44.6
OP no child infected/died of HIV/AIDS	54	42.8
OP HIV + ve on ART	55	45.1
OP HIV + ve not on ART	59	40.5
Residence		
Rural	150	44.8
Urban	162	42.8
Marital status		
Not married	266	43.5
Married	46	44.9
Education		
Less than primary	89	41.5
Primary	157	44.3
Secondary or more	59	45.1
Wealth quintile		
Lowest	71	42.6
Highest	60	45.5

Annex Table 4.3 WHODAS score by background characteristics (100 is worst, 0 is best)

		Mean	Number
Social Network Index	One	45.0	109
	Two	25.1	177
	Three	22.3	164
	Four	17.3	60
	Total	27.5	510
Study group	OP adult child died of AIDS	31.1	106
	OP with adult child on ART	30.2	101
	OP no child infected/died of HIV/AIDS	29.2	104
	OP HIV +ve on ART	21.5	101
	OP HIV +ve not on ART	25.4	98
	Total	27.5	510
Sex	Male	23.0	198
	Female	30.4	312
	Total	27.5	510
Age group in years	50–59	20.5	178
	60–69	23.4	150
	70–79	31.9	127
	80+	51.6	55
	Total	27.5	510
Education	Less than primary	35.4	118
	Completed primary	28.2	239
	Completed secondary	22.6	54
	Completed high school	19.5	38
	Completed college/university	17.2	33
	Completed post-grad	16.0	9
	Total	27.5	491
Marital status	Never married	42.4	7
	Married/cohabiting	20.9	165
	Divorced/separated	26.5	105
	Widowed	32.2	233
	Total	27.5	510
Wealth quintile	Lowest	32.4	102
	Second	29.8	102
	Middle	25.9	102
	Fourth	25.6	102
	Highest	24.0	102
	Total	27.5	510
Residence	Urban	26.5	254
	Rural	28.6	256
	Total	27.5	510

Annex Table 4.4 WHO-QoL score by background characteristics

		Mean	Number
Social Network Index	One	62.5	109
	Two	48.7	177
	Three	47.4	164
	Four	44.1	60
	Total	50.7	510
Study group	OP adult child died of AIDS	52.5	106
	OP with adult child on ART	52.6	101
	OP no child infected/died of HIV/AIDS	53.0	104
	OP HIV +ve on ART	44.4	101
	OP HIV +ve not on ART	50.9	98
	Total	50.7	510
Sex	Male	48.8	198
	Female	51.9	312
	Total	50.7	510
Age group in years	50–59	47.3	178
	60–69	48.0	150
	70–79	54.5	127
	80+	60.4	55
	Total	50.7	510
Education	Less than primary	57.3	118
	Completed primary	50.9	239
	Completed secondary	44.6	54
	Completed high school	44.0	38
	Completed college/university	47.5	33
	Completed post-grad	44.9	9
	Total	50.7	491
Marital status	Never married	62.3	7
	Married/cohabiting	46.9	165
	Divorced/separated	49.0	105
	Widowed	53.8	233
	Total	50.7	510
Wealth quintile	Lowest	54.8	102
	Second	54.2	102
	Middle	46.8	102
	Fourth	49.1	102
	Highest	48.5	102
	Total	50.7	510
Residence	Urban	50.3	254
	Rural	51.0	256
	Total	50.7	510

5 Chronic conditions

Annex Table 5.1 Prevalence of hypertension with selected characteristics

				Hypertension			
	Pulse rate mean	Diastole mean	Systole mean	Mild	Moderate	Severe	Number
Social Network Index							
One	76.5	76.5	131.3	16.8	9.3	5.6	107
Two	73.9	79.3	131.5	20.9	8.5	6.2	177
Three	72.4	79.2	131.9	15.9	9.1	6.7	164
Four	70.4	76.6	129.3	16.7	10.0	1.7	60
Total	73.6	78.4	131.3	17.9	9.1	5.7	508
Study group							
OP adult child died of AIDS	73.6	81.4	138.3	14.4	11.5	11.5	104
OP with adult child on ART	71.7	80.7	137.1	21.8	12.9	7.9	101
OP no child infected/died of HIV/AIDS	72.3	79.9	136.9	27.9	11.5	5.8	104
OP HIV +ve on ART	73.8	74.3	123	12.9	5.0	3	101
OP HIV +ve not on ART	76.5	75.2	120.5	12.2	4.1	0	98
Total	73.6	78.4	131.3	17.9	9.1	5.7	508
Sex							
Male	72.4	79.3	130.7	19.2	5.6	6.6	198
Female	74.3	77.8	131.7	17.1	11.3	5.2	310
Total	73.6	78.4	131.3	17.9	9.1	5.7	508
Age group in years							
50–59	73.7	77.4	124.1	12.4	7.3	1.1	178
60–69	74.0	77.8	129.1	18.8	6	5.4	149
70–79	72.5	79.0	137.7	27.8	13.5	5.6	126
80+	74.2	81.5	145.9	10.9	12.7	21.8	55
Total	73.6	78.4	131.3	17.9	9.1	5.7	508
Education							
Less than primary	74.5	77.5	131.6	18.6	10.2	5.1	118
Completed primary	73.4	77.7	131.1	17.6	8.0	6.3	238
Completed secondary	73.6	79.4	131.1	18.9	9.4	7.5	53
Completed high school	72.0	77.9	128.9	28.9	0.0	2.6	38
Completed college/university	74.3	83.9	132.5	15.2	9.1	6.1	33
Completed post-grad	76.5	74.0	121.4	0	11.1	0	9
Total	73.6	78.4	131.3	18.4	8.2	5.7	489
Marital status							
Never married	77.7	74.7	130.4	14.3	14.3	0.0	7
Married/cohabiting	70.8	79.8	132.2	18.2	6.7	7.3	165
Divorced/separated	75.5	78.4	129.1	19.2	8.7	4.8	104
Widowed	74.5	77.4	131.7	17.2	10.8	5.2	232
Total	73.6	78.4	131.3	17.9	9.1	5.7	508
Wealth quintile							
Lowest	76.0	80.6	134.7	19.6	10.8	9.8	102
Second	75.4	77	131	13.7	14.7	4.9	102
Middle	72.0	79	131.9	17.8	10.9	3	101
Fourth	73.2	77	128.4	21.8	2.0	5.9	101
Highest	71.2	78.2	130.6	16.7	6.9	4.9	102
Total	73.6	78.4	131.3	17.9	9.1	5.7	508
Residence							
Urban	74.1	79.5	133.8	21.4	10.3	7.9	252
Rural	73.0	77.2	128.9	14.5	7.8	3.5	256
Total	73.6	78.4	131.3	17.9	9.1	5.7	508

Annex Table 5.2 Prevalence of depression with selected characteristics by rural and urban comparison

	Urban	Rural	Total	Number
	Percent	Percent	Percent	
Social Network Index				
One	37.8	35.9	36.7	109
Two	24.0	24.7	24.3	177
Three	24.7	8.0	15.9	164
Four	11.1	21.9	16.9	60
Total	25.3	21.5	23.4	510
Study group				
OP adult child died of AIDS	29.4	29.1	29.2	106
OP with adult child on ART	19.6	24.0	21.8	101
OP no child infected/died of HIV/AIDS	20.0	22.6	21.4	104
OP HIV +ve on ART	34.6	12.2	23.8	101
OP HIV +ve not on ART	22.4	18.4	20.4	98
Total	25.3	21.5	23.4	510
Sex				
Male	14.3	17.0	15.7	198
Female	31.5	24.7	28.2	312
Total	25.3	21.5	23.4	510
Age group in years				
50–59	21.2	16.3	18.6	178
60–69	33.8	24.3	29.3	150
70–79	18.5	24.2	21.3	127
80+	30.4	25.0	27.3	55
Total	25.3	21.5	23.4	510
Education				
Less than primary	35.6	24.7	28.8	118
Completed primary	26.1	25.0	25.5	239
Completed secondary	29.0	17.4	24.1	54
Completed high school	10.0	0.0	5.4	38
Completed college/university	20.0	15.4	18.2	33
Completed post-grad	16.7	0.0	11.1	9
Total	25.3	21.5	23.9	491
Marital status				
Never married	25.0	33.3	28.6	7
Married/cohabiting	13.4	13.4	13.4	165
Divorced/separated	29.3	19.1	24.8	105
Widowed	32.1	27.4	29.6	233
Total	25.3	21.5	23.4	510
Wealth quintile				
Lowest	20.0	19.0	19.6	102
Second	34.7	18.9	26.5	102
Middle	23.4	23.6	23.5	102
Fourth	30.4	21.8	25.7	102
Highest	19.6	23.5	21.6	102
Total	25.3	21.5	23.4	510

Annex Table 5.3 Prevalence of diabetes with selected characteristics by rural and urban comparison

	Urban	Rural	Total	Number
	Percent	Percent	Percent	
Social Network Index				
One	8.9	7.8	8.3	109
Two	4.8	4.1	4.5	177
Three	7.8	0.0	3.7	164
Four	10.7	0.0	5.0	60
Total	7.1	3.1	5.1	510
Study group				
OP adult child died of AIDS	11.8	3.7	7.6	106
OP with adult child on ART	9.8	4.0	6.9	101
OP no child infected/died of HIV/AIDS	7.8	1.9	4.8	104
OP HIV +ve on ART	3.8	2.0	3.0	101
OP HIV +ve not on ART	2.0	4.1	3.1	98
Total	7.1	3.1	5.1	510
Sex				
Male	5.4	1.9	3.5	198
Female	8.0	4.0	6.1	312
Total	7.1	3.1	5.1	510
Age group in years				
50–59	7.0	4.3	5.6	178
60–69	8.8	2.9	6.0	150
70–79	7.7	1.6	4.8	127
80+	0.0	3.1	1.8	55
Total	7.1	3.1	5.1	510
Education				
Less than primary	2.2	1.4	1.7	118
Completed primary	5.0	4.2	4.6	239
Completed secondary	12.9	0.0	7.4	54
Completed high school	0.0	0.0	0.0	38
Completed college/university	0.0	15.4	6.1	33
Completed post-grad	33.3	0.0	22.2	9
Total	7.1	3.1	4.3	491
Marital status				
Never married	0.0	0.0	0.0	7
Married/cohabiting	8.4	0.0	4.2	165
Divorced/separated	5.2	2.1	3.8	105
Widowed	7.3	5.7	6.5	233
Total	7.1	3.1	5.1	510
Wealth quintile				
Lowest	1.7	0.0	1.0	102
Second	4.1	5.7	4.9	102
Middle	8.5	0.0	3.9	102
Fourth	14.9	3.6	8.8	102
Highest	7.8	5.9	6.9	102
Total	7.1	3.1	5.1	510

Annex Table 5.4 Prevalence of cataract with selected characteristics by rural and urban comparison

	Urban	Rural	Total	Number
	Percent	Percent	Percent	
Social Network Index				
One	51.1	42.2	45.9	109
Two	40.4	31.5	36.7	177
Three	29.9	25.9	27.8	164
Four	10.7	48.4	30.5	60
Total	35.8	34.4	35.1	510
Study group				
OP adult child died of AIDS	41.2	37.7	39.4	106
OP with adult child on ART	35.3	30.0	32.7	101
OP no child infected/died of HIV/AIDS	31.4	42.3	36.9	104
OP HIV +ve on ART	32.7	26.5	29.7	101
OP HIV +ve not on ART	38.8	34.7	36.7	98
Total	35.8	34.4	35.1	510
Sex				
Male	33.7	39.0	36.5	198
Female	37.0	31.1	34.2	312
Total	35.8	34.4	35.1	510
Age group in years				
50–59	30.2	20.9	25.4	178
60–69	35.0	35.7	35.3	150
70–79	40.0	50.0	44.8	127
80+	47.8	40.6	43.6	55
Total	35.8	34.4	35.1	510
Education				
Less than primary	42.2	34.7	37.6	118
Completed primary	36.1	38.1	37.1	239
Completed secondary	48.4	17.4	35.2	54
Completed high school	14.3	23.5	18.4	38
Completed college/university	25.0	23.1	24.2	33
Completed post-grad	33.3	66.7	44.4	9
Total	35.8	34.4	34.8	491
Marital status				
Never married	25.0	33.3	28.6	7
Married/cohabiting	27.7	34.6	31.1	165
Divorced/separated	36.2	29.8	33.3	105
Widowed	42.2	36.1	39.0	233
Total	35.8	34.4	35.1	510
Wealth quintile				
Lowest	40.0	41.5	40.6	102
Second	49.0	35.8	42.2	102
Middle	29.8	31.5	30.7	102
Fourth	25.5	32.7	29.4	102
Highest	33.3	32.0	32.7	102
Total	35.8	34.4	35.1	510

Annex Table 5.5 Cognition test results

	Verbal Recall	Verbal fluency	Forward digit span	Backward digit span	Overall cognition score	
	mean	mean	mean	mean	mean	Number
Study group						
OP adult child died of AIDS	5	13.2	4.2	2.6	58.6	106
OP with adult child on ART	5.3	14.9	4.3	2.6	62.1	101
OP no child infected/died of HIV/AIDS	5.4	14.8	4.4	2.7	62.9	104
OP HIV +ve on ART	5.9	15.0	4.7	2.8	67.8	101
OP HIV +ve not on ART	5.4	14.2	4.5	2.7	62.7	98
Sex						
Male	5.2	15.5	4.4	2.9	62.9	198
Female	5.5	13.7	4.4	2.5	62.7	312
Age group in years						
50–59	6.1	15.4	4.9	3.1	70.5	178
60–69	5.5	14.6	4.3	2.5	63.4	150
70–79	4.7	13.5	4.3	2.5	56.9	127
80+	4.1	12.9	3.8	2.1	49.3	55
Education						
Less than primary	4.8	13.5	3.9	2	55.9	118
Completed primary	5.3	14.0	4.4	2.6	61.9	239
Completed secondary	5.5	15.1	4.8	3.1	65.5	54
Completed high school	6.2	15.6	4.9	3.3	72.2	38
Completed college/university	5.7	16.1	5.1	3.3	68.7	33
Completed post-grad	5.9	18.1	5.3	3.7	72.2	9
Marital status						
Never married	4.3	11.0	3.5	2.5	49.4	7
Married/cohabiting	5.6	15.5	4.6	2.9	66.1	165
Divorced/separated	5.3	14.1	4.5	2.6	62.1	105
Widowed	5.3	13.9	4.3	2.5	61.0	233
Wealth quintile						
Lowest	5.1	12.6	4.1	2.2	58.1	102
Second	5.2	13.9	4.1	2.5	61.0	102
Middle	5.5	15.9	4.6	2.9	64.7	102
Fourth	5.2	13.7	4.5	2.7	60.9	102
Highest	5.9	16.0	4.8	3.1	69.2	102
Residence						
Urban	5.6	14.2	4.7	2.7	64.6	254
Rural	5.2	14.6	4.1	2.6	61.0	256
Total	5.4	14.4	4.4	2.7	62.8	510

Annex Table 5.6 Mean grip strength

	Grip Strength(kg)			
	Mean	Women	Men	Number
Study group				
OP adult child died of AIDS	22.5	19.7	28.8	106
OP with adult child on ART	23	21.0	27.3	101
OP no child infected/died of HIV/AIDS	23.8	18.9	29.1	104
OP HIV +ve on ART	27.9	24.2	32.3	101
OP HIV +ve not on ART	24.9	22.1	29.2	98
Total	24.4	21.1	29.5	510
Sex				
Male	29.5			198
Female	21.1			312
Total	24.4			510
Age group in years				
50–59	28.2	24.0	34.6	178
60–69	24.6	21.3	30.8	150
70–79	21.6	19.0	25.0	127
80+	18.1	15.6	21.6	55
Education				
Less than primary	20.7	19.7	23.9	118
Completed primary	23.6	20.9	28.9	239
Completed secondary	26.8	21.6	32.0	54
Completed high school	28.4	23.9	31.7	38
Completed college/university	29.6	27.0	31.1	33
Completed post-grad	31.8	21.0	37.2	9
Marital status				
Never married	19	19.8	17.5	7
Married/cohabiting	29.8	23.6	32.3	165
Divorced/separated	23.5	21.3	26.8	105
Widowed	21.1	20.5	24.3	233
Wealth quintile				
Lowest	22	20.2	25.8	102
Second	21.9	19.7	27.1	102
Middle	26.5	23.3	29.9	102
Fourth	24.9	21.0	29.9	102
Highest	26.7	22.0	33.3	102
Residence				
Urban	24.8	20.9	31.7	254
Rural	24	21.4	27.7	256
Total	24.4	21.1	29.5	510

6. Risk factors

Annex Table 6.1 Tobacco use

	Current daily smoker	Smoker, not daily	Not current smoker	Never smoker	Total	Number
	Percent	Percent	Percent	Percent	Percent	
Social Network Index						
One	14.7	8.3	13.8	63.3	100	109
Two	11.9	3.4	15.3	69.5	100	177
Three	11.7	4.3	14.1	69.9	100	163
Four	15	3.3	20	61.7	100	60
Total	12.8	4.7	15.1	67.4	100	509
Study group						
OP adult child died of AIDS	12.4	4.8	5.7	77.1	100	105
OP with adult child on ART	14.9	3	12.9	69.3	100	101
OP no child infected/died of HIV/AIDS	17.3	3.8	16.3	62.5	100	104
OP HIV +ve on ART	5.9	5	19.8	69.3	100	101
OP HIV +ve not on ART	13.3	7.1	21.4	58.2	100	98
Total	12.8	4.7	15.1	67.4	100	509
Sex						
Male	19.7	6.6	28.8	44.9	100	198
Female	8.4	3.5	6.4	81.7	100	311
Total	12.8	4.7	15.1	67.4	100	509
Agr group in years						
50–59	9	4.5	18.5	68	100	178
60–69	11.3	5.3	14	69.3	100	150
70–79	19.8	2.4	13.5	64.3	100	126
80+	12.7	9.1	10.9	67.3	100	55
Total	12.8	4.7	15.1	67.4	100	509
Education						
Less than primary	20.5	6	16.2	57.3	100	117
Completed primary	13.4	2.9	10.9	72.8	100	239
Completed secondary	3.7	1.9	18.5	75.9	100	54
Completed high school	5.3	10.5	26.3	57.9	100	38
Completed college/university	6.1	3	18.2	72.7	100	33
Completed post-grad	11.1	11.1	11.1	66.7	100	9
Total	12.9	4.3	14.7	68.2	100	490
Marital status						
Never married	14.3	0	14.3	71.4	100	7
Married/cohabiting	13.3	4.8	22.4	59.4	100	165
Divorced/separated	20	4.8	16.2	59	100	105
Widowed	9.1	4.7	9.5	76.7	100	232
Total	12.8	4.7	15.1	67.4	100	509

	Current daily smoker	Smoker, not daily	Not current smoker	Never smoker	Total	Number
	Percent	Percent	Percent	Percent	Percent	
Wealth quintile						
Lowest	11.9	5.9	13.9	68.3	100	101
Second	14.7	5.9	17.6	61.8	100	102
Middle	13.7	2	20.6	63.7	100	102
Fourth	16.7	2.9	14.7	65.7	100	102
Highest	6.9	6.9	8.8	77.5	100	102
Total	12.8	4.7	15.1	67.4	100	509
Residence						
Urban	6.7	3.5	17.3	72.4	100	254
Rural	18.8	5.9	12.9	62.4	100	255
Total	12.8	4.7	15.1	67.4	100	509

Annex Table 6.2 Alcohol use

	Life time abstainer	Non-heavy drinkers	Infrequent heavy drinkers	Frequent heavy drinkers	Total	Number
	Percent	Percent	Percent	Percent	Percent	
Social Network Index						
One	54.1	34.4	6.6	4.9	100	61
Two	42.7	37.5	11.5	8.3	100	96
Three	44.3	47.7	4.5	3.4	100	88
Four	35.1	54.1	5.4	5.4	100	37
Total	44.7	42.2	7.4	5.7	100	282
Study group						
OP adult child died of AIDS	43.1	49.2	4.6	3.1	100	65
OP with adult child on ART	48.5	39.7	5.9	5.9	100	68
OP no child infected/died of HIV/AIDS	50	42.4	1.5	6.1	100	66
OP HIV +ve on ART	54.3	37.1	2.9	5.7	100	35
OP HIV +ve not on ART	27.1	39.6	25	8.3	100	48
Total	44.7	42.2	7.4	5.7	100	282
Sex						
Male	29.6	55.2	6.4	8.8	100	125
Female	56.7	31.8	8.3	3.2	100	157
Total	44.7	42.2	7.4	5.7	100	282
Agr group in years						
50–59	35.2	52.3	10.2	2.3	100	88
60–69	47.1	39.1	9.2	4.6	100	87
70–79	48.8	37.5	3.8	10	100	80
80+	55.6	33.3	3.7	7.4	100	27
Total	44.7	42.2	7.4	5.7	100	282
Education						
Less than primary	57.9	35.1	3.5	3.5	100	57
Completed primary	41.4	44.3	7.9	6.4	100	140
Completed secondary	41.9	38.7	16.1	3.2	100	31
Completed high school	44.4	44.4	5.6	5.6	100	18
Completed college/university	35	55	5	5	100	20
Completed post-grad	0	66.7	33.3	0	100	3
Total	44.2	42.8	7.8	5.2	100	269
Marital status						
Never married	0	100	0	0	100	5
Married/cohabiting	34	49.1	10.4	6.6	100	106
Divorced/separated	40	50.9	5.5	3.6	100	55
Widowed	58.6	29.3	6	6	100	116
Total	44.7	42.2	7.4	5.7	100	282

	Life time abstainer	Non-heavy drinkers	Infrequent heavy drinkers	Frequent heavy drinkers	Total	Number
	Percent	Percent	Percent	Percent	Percent	
Wealth quintile						
Lowest	52.5	34.4	6.6	6.6	100	61
Second	47.9	43.8	4.2	4.2	100	48
Middle	39	45.8	10.2	5.1	100	59
Fourth	37.7	47.2	7.5	7.5	100	53
Highest	45.9	41	8.2	4.9	100	61
Total	44.7	42.2	7.4	5.7	100	282
Residence						
Urban	44.9	34.6	13.4	7.1	100	127
Rural	44.5	48.4	2.6	4.5	100	155
Total	44.7	42.2	7.4	5.7	100	282

Annex Table 6.3 BMI: underweight (<18.5), normal(18.5–24.9), overweight (25–29.9) and obese (≥30)

	Underweight	Normal	Overweight	Obese	N
	Percent	Percent	Percent	Percent	
Social Network Index					
One	23.7	54.6	13.4	8.2	97
Two	12.9	57.9	18.7	10.5	171
Three	9.2	64.1	20.9	5.9	153
Four	15.5	55.2	13.8	15.5	58
Study group					
OP adult child died of AIDS	11.5	52.1	19.8	16.7	96
OP with adult child on ART	16.3	50.0	19.4	14.3	98
OP no child infected/died of HIV/AIDS	18.9	49.5	20.0	11.6	95
OP HIV +ve on ART	11.5	75.0	12.5	1.0	96
OP HIV +ve not on ART	12.8	68.1	17.0	2.1	94
Sex					
Male	18.7	68.4	10.2	2.7	187
Female	11.3	52.7	22.6	13.4	292
Agr group in years					
50–59	8.2	61.8	20.0	10.0	170
60–69	14.6	58.3	18.1	9.0	144
70–79	20.2	52.1	17.6	10.1	119
80+	19.6	67.4	8.7	4.3	46
Education					
Less than primary	18.9	58.5	14.2	8.5	106
Completed primary	15.9	60.4	15.0	8.8	227
Completed secondary	12.0	46.0	32.0	10.0	50
Completed high school	5.4	62.2	21.6	10.8	37
Completed college/university	12.5	62.5	18.8	6.3	32
Completed post-grad	0.0	88.9	0.0	11.1	9
Marital status					
Never married	20.0	40.0	20.0	20.0	5
Married/cohabiting	15.1	57.2	17.6	10.1	159
Divorced/separated	16.5	57.7	17.5	8.2	97
Widowed	12.4	61.0	17.9	8.7	218
Wealth quintile					
Lowest	16.5	58.8	14.4	10.3	97
Second	16.5	61.5	17.6	4.4	91
Middle	17.5	59.8	15.5	7.2	97
Fourth	13.7	60.0	18.9	7.4	95
Highest	7.1	54.5	22.2	16.2	99
Residence					
Urban	9.3	56.0	21.4	13.3	248
Rural	19.5	61.9	13.9	4.8	231
Total	14.2	58.9	17.7	9.2	479

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