UNIVERSITY OF SOUTHAMPTON

FACULTY OF SOCIAL AND HUMAN SCIENCES

Division of Social Statistics and Demography

Ageing with HIV: an investigation of the health and well-being of older people in a rural South African population with a severe HIV epidemic

by

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ABSTRACT

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AGEING WITH HIV: AN INVESTIGATION OF THE HEALTH AND WELL-BEING OF OLDER PEOPLE IN A RURAL SOUTH AFRICAN POPULATION WITH A SEVERE HIV EPIDEMIC

By Makandwe Nyirenda

This study aims to describe the living and informal care circumstances of older people in an area of rural South Africa severely affected by HIV, and examine how those circumstances may influence the physical health, emotional well-being and survival of older people. Using longitudinal surveillance and cross-sectional survey data this thesis is built around four separate but related papers. Specific study objectives were to: 1) investigate household living arrangements and informal care (financial, physical or emotional assistance) by or towards older people in rural South Africa; 2) describe the self-reported health and emotional well-being status of older people by HIV status; and 3) examine the association between self-reported health, emotional well-being and informal care and mortality in older people.

Surveillance data for 2005-2010 showed living arrangements remained stable, with over 85% of older people aged 60 years and above living in multi-generational households; over this period employment rates in both older and young people declined, but government grants receipt increased. Being co-resident with own children, household structure and size were important determinants of whether financial support flowed downward (from older to younger) or upward (from young to older person); while peer support (from one older person to another) was rare. Adjusting for age, marital status, education, place of residency and household socio-economic status, exchanges of financial resources in the study population are most likely to be downward or at best reciprocal (bidirectional with young people). Of the cross-sectional study participants (n=422) aged 50+, over 60% were care-givers (provided help with activities of daily living) to at least one adult (18-49 years) or child (below 18 years); around 84% (n=356) of older people were care-receivers; of whom over 92% (n=329) were receiving assistance with fetching water. Spouse, adult child, and grandchildren were the main sources of physical or emotional care for care-recipients. As expected health deteriorated with advancing age and women were less likely to be in good health. Further, care-giving was associated with improved functional ability but decreased emotional well-being. HIV-infected older participants reported better functional ability, quality of life and overall health state than HIV-affected (had an HIV-infected or HIV-related death of adult child) study participants. These differentials in health and well-being were also evident in mortality patterns over three years of follow-up. Mortality was higher among non-care-givers than in care-givers, in older people with poor self-rated health and in participants who had experienced a major depressive episode.

Findings suggest there is an intricate relationship between living arrangements, informal care and health, emotional well-being and survival of older people in severely HIV-affected settings. More crucially, with the considerable resources devoted to HIV Care and Treatment programmes, uninfected older persons may be highly vulnerable to poor health. A multifaceted intervention to improving older people's health and well-being is urgently required.

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Declaration of authorship

I, Makandwe Nyirenda, declare that this thesis titled

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and the work presented in it is my own and generated by me as the result of my own original research.

I confirm that:

- This work was done wholly or mainly while in candidature for a research degree at this University;
- Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- Where I have consulted the published work of others, this is always clearly attributed;
- Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- This is a PhD by publication thesis. Two of the papers included in this thesis have already been published in peer reviewed journals, while the other two have been submitted for publication consideration. I conducted all analyses and drafted the manuscripts. The contribution of other co-authors on the papers is duly acknowledged on the respective chapters.

Signed: .....

Date: 17th June 2014

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Thank you to all those who read and commented on particular chapters, and to my co-authors on various papers published or unpublished in this thesis; to Joanie Mitchell for proofreading parts of this thesis. I take responsibility for any remaining shorting comings. To my friend and colleague, Dr. James Ndirungu, with whom I began this PhD journey at about the same time as he did his, thank you for the encouragement and to your wife for bailing me out whenever I had child-care crises.

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"THE AGED NEED THE HELPFUL INFLUENCES OF THE FAMILY.....MAKE THEM FEEL THAT THEIR HELP IS VALUED, THAT THERE IS SOMETHING YET FOR THEM TO DO IN MINISTERING TO OTHERS, AND IT WILL CHEER THEIR HEARTS AND GIVE INTEREST TO THEIR LIVES....LET THEM BE CARED FOR BY LOVING AND TENDER HANDS."

E. G. White, The Ministry of Healing, p.131

"Many who are qualified to do excellent work accomplish little because the attempt little. Thousands pass through life as if they had no great object for which to live."

E.G. White, The Ministry of Healing, p.337

Research design and data collection role

The Africa Centre's surveillance has two components. 1) Household surveillance - through which routine information on births, deaths, population movement, and socio-economic status is collected. Data collection was initially (until 2012) in bi-annual surveillance rounds for the demographic information and annually for the socio-economic information; and 2) Individual surveillance – in which information on sexual behaviour, health bio-metrics and HIV is collected. From October 2006 to October 2009 I was the Project Leader of the Household Surveillance. My main responsibilities as Project Leader were to provide scientific oversight to the collection and processing of the data as per surveillance protocol and for routine monitoring of the quality of data. I was actively involved in the streamlining of data collection instruments and training of data collection and field quality control staff. I was also tasked with routine analysis and report writing from the household surveillance data and to establish my own research agenda using the household surveillance platform. This PhD thesis is a product of this research agenda I had personally established.

To supplement the surveillance data and answer other research questions I co-authored a research proposal to study the health and well-being of older people in the area which got funded by WHO. From October 2009 I was thus co-principal investigator on the Wellbeing of Older People Study (WOPS) and was responsible at the Africa Centre site for study design, questionnaire development and implementation of the study protocol. I was responsible for training of the field data collection nurses, quality control and with the assistance of a data base scientist was actively involved in design and maintenance of the Africa Centre-based WOPS database. WOPS essentially had two components: 1) self-reported health, mental well-being and care-giving measures, and 2) anthropometric and bio-makers measures which included a blood specimen for measuring chronic morbidity and cardiovascular disease risk in older persons. The first component was for my analyses as part of this PhD thesis, while my co-PI used the second component as part of her PhD. There was further expectation of comparative analyses at a later stage between these two components as well as with similar sub-study in Uganda.

My role in the operations and management of Africa Centre's household surveillance and WOPS formed an essential component of the PhD training, while the contribution of co-authors in resulting papers is acknowledged in Appendix 1, page 201.

Definitions and Abbreviations

ACDIS	Africa Centre Demographic Information System
DSA	Demographic Surveillance Area
DSS	Demographic Surveillance System
HIV	Human Immunodeficiency Virus
ART	Antiretroviral treatment
AIDS	Acquired Immune Deficiency Syndrome
HH	Household
HSE	Household socio-economic status
WHO	World Health Organization
aOR	Adjusted Odds Ratios
SAGE	Study on Adult Health and Global Ageing
SASSA	South Africa Social Security Agency
StatsSA	Statistics South Africa
SSA	sub-Saharan Africa
WOPS	Well-being of Older People Study

Chapter 1: **Introduction**

This thesis is built around four separate but related papers that aim to first describe the living arrangements and informal care (defined as material/financial, physical or emotional assistance) of older people aged 50 years and above in an area of rural South Africa severely affected by HIV, and second to examine how living arrangements and informal care are related to the physical health, emotional well-being and survival of older people. The analyses use data on older people from a longitudinal surveillance system in rural South Africa and a cross-sectional survey of 422 older people, a sample of the surveillance population. The situation of older people in severely HIV affected settings is poorly understood due to the lack of studies that have systematically measured their health and well-being, and the associations with living arrangements and informal care, which are central to the lives of older people in rural Africa. For which reason this study was undertaken to make a contribution to this limited body of knowledge.

1.1 Chapter outline

This chapter is organised as follows. In the next section a brief profile of older people globally and in South Africa will be discussed. Section 1.3 will then discuss living arrangements and financial, physical and financial aspect of care by and towards older people. An overview of the health and well-being of older people will be given in section 1.4. Then section 1.5 will sketch the interconnectedness of living arrangements and informal care with the health and well-being of older people. To be followed by justification of this study (section 1.6), study objectives (section 1.7), data sources and study design (section 1.8) and conceptual framework (section 1.9). The chapter will then close in section 1.10 with an outline of the structure for the rest of this thesis.

1.2 Profile of older people globally and in South Africa

Understanding the physical, mental, social, and economic well-being of older people has become of interest globally, largely motivated by the observed and projected trends of population ageing (Kinsella and He, 2009; United Nations, 2013). The world is at a watershed moment (Figure 1-1), by 2020 there will be more people aged 65 years

and above than children under 5 years of age (United Nations, 2011). Even in regions such as sub-Saharan Africa where during the 1990's and the early years of the 21st century the HIV epidemic resulted in sharp declines in life expectancy, the proportion of older people is projected to increase for some time to come (United Nations, 2013; Velkoff and Kowal, 2006). South Africa, an example of a sub-Saharan African (SSA) country with a rapidly ageing population (Smith and Mensah, 2003; Velkoff and Kowal, 2006), is projected to see an increase in the population aged 50 years and above from 5.9 million (13%) in 2000 to 16.9 million (27%) in 2050, with those aged 65 years and above increasing four-fold from 1.3 million to 5.6 million over the same period (United Nations, 2013). That is, nearly one in three of the total projected South African population in 2050 will be aged 50 years and above, up from one in eight in 2000. Globally, the population aged 50+ was estimated at 1.1 billion in 2000, and is projected under the medium fertility variant to increase nearly four-fold to 4.2 billion by 2050 (United Nations, 2013).

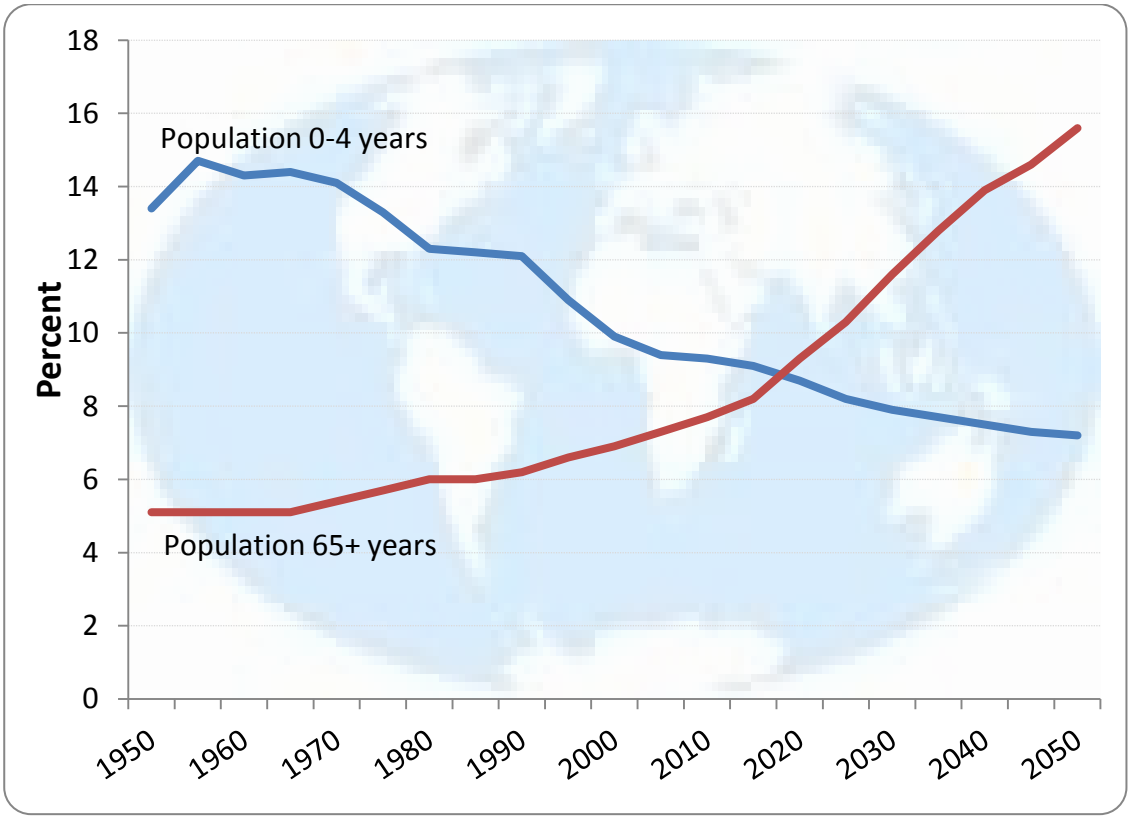


Figure 1-1: Global trends in population of older people and children, 1950-2050
Source: Prepared using data from World Population Prospects: The 2012 Revision. Available at: http://esa.un.org/wpp/Documentation/publications.htm

The transition to an increasingly ageing population is likely to result in new social, economic and health challenges globally and for developing countries in particular. Of special concern is the pace of population ageing, which is projected to be much more rapid in developing than in developed countries (Kalache and Keller, 2000; Kinsella and He, 2009). In Africa, this concern is not merely based on the close association between ageing, increasing chronic morbidity, physical and mental disability, but also on the recognition that because older people are not generally a policy issue priority, they are marginalised and increasingly vulnerable to greater poverty (Nabalamba and Chikoko, 2011). Ageing in Africa occurs in the context of high levels of poverty, high adult unemployment, high morbidity and mortality due to HIV, inadequate social protection programmes, as well as changing family and cultural norms related to the roles and responsibilities by and towards older people (Gorman and Zaidi, 2013; Haub, 2008; Kent and Haub, 2005; Nabalamba and Chikoko, 2011).

This rapid ageing phenomenon poses difficult questions for many governments, especially in developing countries still grappling with the inability to provide basic needs for the general population. Such as who will pay for social security for this growing older people population if there are not enough young people? How will the costs of an impending chronic health pandemic be met? What will become of filial piety and intergenerational exchanges in the face of high adult unemployment and labour migration and lack of a proper social security system for older people? Whose responsibility is it anyway to care for these older people, government or families? (Suzman and Beard, 2011; UNFPA, 2011). Policy and programme intervention informed by reliable empirical evidence are thus urgently needed to meet the challenges of rapidly ageing societies of the 21st century. In the next few sections, leading up to the justification of my study, I briefly discuss the situation of older people with a focus on South Africa in terms of health and well-being, informal care, living arrangements and survival.

1.3 Living arrangements, informal care and support for older people

Exchanges of care and support of both physical/emotional and financial nature within families between older and younger persons have always been an important part of

people's daily lives (Antonucci, Birdtt, Sherman *et al.*, 2011; Cantor and Hirshorn, 1989). With regard to parent-child dyads, in most societies there is an expectation and even obligation for parents to provide for needs of children initially, but as the parents get older or become frail for adult children to then care and support them (Diwan, Lee and Sen, 2011; Funk, 2012; Grundy, 2005; Sagner and Mtati, 1999; Van der Geest, 2002). According to the solidarity-conflict theory suggested by Bengtson (1975), customs, norms and socialisation play an important role in determining whether these filial relations that support intergenerational exchanges are positive, negative or ambivalent. That is, whether filial relations promote or hamper exchanges, or whether due to extenuating circumstances, such as distance or economic hardships, no exchanges occur despite strong filial piety. In South Africa, as in many other sub-Saharan African countries, a combination of high adult unemployment and the severe impact of HIV meant that when older people were expected to be receiving material support, physical or emotional care, many were instead increasingly supporting and caring for infected adults or children left behind orphaned (Hill, Hosegood and Newell, 2008; Hosegood and Timæus, 2006; Nyirenda and Newell, 2010; Ssengonzi, 2007; Zimmer and Dayton, 2003). Contemporary South Africa thus likely sees a reversal of the intergenerational flow of support from mainly upward (younger to older generation) to mostly downward (older to younger generation) (Ardington, Case, Islam *et al.*, 2010; Kimuna and Makiwane, 2007), but to date there has been little longitudinal evidence demonstrating such a reversal.

In rural South Africa, with or without the HIV epidemic, older people are important in the care and living arrangements of families (Hosegood, Benzler and Solarsh, 2006; Kimuna and Makiwane, 2007), as such their health and well-being has implications for the welfare of the entire population. An older person with a source of income, in the case of South Africa usually from government cash transfers, may facilitate mobility of adults with young children to other places in search of opportunities while their children are cared for by an older person in the family (Ardington, Case and Hosegood, 2009; Hosegood and Timæus, 2005a). The availability of pension grants, together with the severe HIV impact among the productive adult population (Dorrington, Johnson, Bradshaw *et al.*, 2006; Nyirenda, Hosegood, Bärnighausen *et al.*, 2007; Timæus and

Jasseh, 2004), and high adult unemployment levels (Muhwava, 2008; StatsSA, 2013) have contributed to older people increasingly becoming the primary source of care and support to adults and (grand)children (Connolly and Monasch, 2003; Hill, Hosegood and Newell, 2008; Schatz, 2007). Poor health and well-being and ultimately mortality among older people, therefore, have implications on potential life-years of care and support. More importantly for the older person themselves, care-giving is likely to impact on their health and well-being. However, there is a dearth of empirical studies from rural South Africa that provide a detailed investigation of the effect of care-giving and care-receipt on the health and well-being of older people. Studies from Kenya (Ice, Yogo, Heh *et al.*, 2010) and Uganda (Ssengonzi, 2009) suggest that care-giving negatively affects the health and well-being of older people. A recent study that compared the health of older people giving care to HIV-infected persons relative to care-givers to non-HIV infected persons and non-care-givers found care-givers to HIV-infected persons more likely to have poor health (Chepngeno-Langat and Evandrou, 2013), suggesting HIV status of the care-recipient is an important determinant of the health status of older people. However, the context and environment for care-giving in rural South Africa differs from the rest of sub-Saharan Africa, given widely accessible non-contributory old-age pensions and other cash transfer programmes in South Africa and lack thereof in other parts of SSA. While care tends to most frequently be described in terms of emotional or physical support (Van der Geest, 2002), there is a third dimension of care, exchanges of material resources, that is rarely considered in the literature. The first paper (Chapter Two) of this thesis is devoted to discussing living arrangements and exchanges of financial resources between young and older people using longitudinal surveillance data; whereas in the second paper (Chapter three) exchanges of physical and emotional aspects of care are considered in relation to the health and well-being of older people in rural South Africa using detailed cross-sectional survey data.

1.4 Overview of the health and well-being of older people

It is well-known that as individuals grow older, particularly beyond age 50, their physical functioning ability and their overall health declines (National Institute on Aging, 2007). However in sub-Saharan African countries, major differences in the

health and well-being of older people are likely to exist due to differences in socio-cultural, economic and health conditions. For example, a comparative study of older people in Uganda and South Africa (Nyirenda, Newell, Mugisha *et al.*, 2013c) showed that older people in Uganda than South Africa were more likely to be employed, most likely due to the lack of an established old-age social security system in Uganda. As a result, older people in Uganda reported better physical functioning ability but poorer emotional well-being, whereas in South Africa the reverse was the case. Furthermore, older people in rural South Africa compared to Uganda had statistically significantly higher odds of having a body mass index (BMI) greater than 30 (adjusted odds ratio (aOR) 5.3, 95% confidence interval (CI) 3.5-8.0) or reporting having a chronic condition of hypertension (aOR 2.8, 95% CI 2.1-3.7). This is consistent with observations that South Africa is currently burdened by four major causes of death: communicable, non-communicable, perinatal and maternal conditions, and injury-related deaths (Kahn, 2011; Mayosi, Flisher, Lalloo *et al.*, 2009; Tollman and Kahn, 2007). The non-communicable disease burden has emerged as a result of the rapid increase in the proportion and number of older people following rapid fertility declines and improved survival at older ages (Moultrie and Dorrington, 2004; Moultrie and Timæus, 2003).

Despite having an increasing older population and emergence of non-communicable diseases, little is known about the general health and wellbeing of older people in sub-Saharan Africa (SSA), particularly in the context of the wide-spread HIV epidemic (Ng, Kowal, Kahn *et al.*, 2010; Subramanian, Subramanyam, Selvaraj *et al.*, 2009). HIV in SSA remains a major public health challenge despite years of health behaviour change campaigns to reduce risk of acquisition and transmission, and the recent roll-out of antiretroviral treatment programmes. South Africa is among the worst HIV affected countries in the world with an estimated adult (15-49 years) HIV prevalence rate in 2012 of 17.9% (range 17.3-18.4%) (UNAIDS, 2013) and 10% in older people aged 50+ years (Wallrauch, Bärnighausen and Newell, 2010). According to the UNAIDS 2013 report, approximately 6.1 million (range 5.8-6.4 million) adults 15+ in South Africa were living with HIV as of end of 2012, of whom over 2.1 million were on antiretroviral treatment (ART). One glaring omission in the UNAIDS report, as is usually the case in reports based on demographic and health surveys (DHSs), is information on HIV in

older people aged 50+. Many HIV surveys only cover the population under 50 years or only up to 50-54 years particularly for men. This is in the face of clear evidence of differences in the effect of HIV on the health and well-being of older people relative to younger people from clinic/health facilities data or from small area specialised studies (Iwuji, Churchill, Gilleece *et al.*, 2013; Metallidis, Tsachouridou, Skoura *et al.*, 2013; Mutevedzi, Lessells, Rodger *et al.*, 2011). In one such study from Australia (Pitts, Grierson and Misson, 2005), HIV-infected older people aged 50+ were less likely to self-report their health as good or excellent, more likely to be co-morbid with cardiovascular diseases and less likely to be receiving HIV-related services than younger HIV-infected people.

With many studies even from across severely affected sub-Saharan Africa regions ignoring HIV (Debpuur, Welaga, Wak *et al.*, 2010; Gilbert and Soskolne, 2003; Kyobutungi, Egondi and Ezeh, 2010; Mwanyangala, Mayombana, Urassa *et al.*, 2010; Xavier Gomez-Olive, Thorogood, Clark *et al.*, 2010), the effect of HIV on the health and well-being of older people from rural Africa remains poorly understood. By describing and comparing the health and well-being of HIV-infected to that of HIV-affected older people (had an HIV-infected or HIV-related death of adult child) in the third paper of this thesis a contribution to this limited knowledge base will be made.

1.5 Linking health and survival among older people in HIV affected areas to living arrangements and informal care

Understanding causes and determinants of mortality in older people, especially in HIV affected areas, is important for policy and programme interventions where the focus tends to be on the health and well-being of adults (Negin, Mills and Albone, 2011). Studies show mortality is generally higher in older than younger HIV-infected people, as it is in HIV-infected than in HIV-uninfected people (Blacker, 2004; Herbst, Mafojane and Newell, 2011; Nyirenda, et al., 2007). The higher mortality in older adults has been shown to be largely driven by high non-AIDS-related deaths (Herbst, Cooke, Bärnighausen *et al.*, 2009; Herbst, Mafojane and Newell, 2011; Metallidis, et al., 2013). While globally causes and determinants of mortality in adults 15-59 years have been

well described (WHO, 2008), mortality in older people has only received scant attention. Likewise levels and patterns of mortality among the adult population in HIV affected developing countries have been well described (Blacker, 2004; Dorrington, et al., 2006; Nyirenda, et al., 2007; Timæus and Jasseh, 2004), but little is known about the causes and determinants of mortality in older people affected by HIV via an HIV-infected or HIV-related death of an adult child. A contributory factor to this is a lack of good quality vital registration systems in many developing countries. According to data obtained from the WHO health indicator database (Chandramohan, Shibuya, Setel *et al.*, 2008), only five countries in Africa had vital registration systems with more than 25% coverage. Studies from longitudinal surveillance sites then help to shed some light on mortality causes and determinants in older people within a severe HIV context (Garenne, Kahn, Tollman *et al.*, 2000).

In spite of the severe impact of HIV, many developing countries are starting to experience an epidemiological transition with non-communicable diseases beginning to replace communicable diseases as the leading causes of disability and mortality in older people (Ferri, Acosta, Guerra *et al.*, 2012). Data from a surveillance site in Hlabisa sub-district, northern KwaZulu-Natal, rural South Africa have shown that by 2000, before antiretroviral therapy (ART) became available, the probability of dying between ages 15 and 60 ($_{15}q_{45}$) was estimated at 58% and 75% for women and men respectively (Hosegood, Vanneste and Timæus, 2004). HIV, with or without tuberculosis, accounted for nearly half (48%) of those deaths; whereas in older people aged 60 years and above non-communicable diseases (mainly cerebrovascular diseases, heart disease and neoplasm) were responsible for 76% (women) and 71% (men) of all deaths by 2000 (Hosegood, Vanneste and Timæus, 2004). Although there are no clear trends between 2000 and 2009 in the contribution of non-communicable diseases to mortality in persons aged 65+, it has clearly been demonstrated that HIV-related mortality has been declining in the adult population in this rural South Africa surveillance area - by 2009 HIV accounted for only 16% of all deaths in the population 65+ (Herbst, Mafojane and Newell, 2011). However, non-communicable diseases (50%) remained the largest contributor to cause-specific mortality in older people in this setting. This is consistent with estimates from WHO which show that as of 2011 about 45% of disability–adjusted

life years lost (DALYs) in developing countries was due to non-communicable diseases whereas in developed countries over 90% of deaths were due to non-communicable diseases (WHO, 2013). Ferri and colleagues (2012) used data collected between 2003 and 2005 on 12,373 older people aged 65 years and above and followed-up for 3-5 years in China, India and five Latin American countries to show that 43% of deaths were due to chronic non-communicable conditions. When Ferri and colleagues excluded deaths with unknown cause, chronic conditions accounted for 57% of all causes. Stroke alone was found to account for one in five of all deaths in this group of older people.

Before the wide availability of ART for HIV infected people, the median survival time from HIV infection to death in developed countries was estimated at 12.5 years overall, but less at 7.9 years for those infected at ages 45-54 years (CASCADE, 2000). In sub-Saharan Africa, the time from infection to death has been estimated at 9.8 years (Morgan, Mahe, Mayanja *et al.*, 2002), with again a strong inverse relationship between age at infection and survival time. It is expected that the wide availability of ART will result in a growing proportion of people ageing with HIV (Hontelez, Lurie, Newell *et al.*, 2011; Pitts, Grierson and Misson, 2005). With ART resulting in increased survival among adults and older people alike, structural changes in care, support and living arrangements, within households are likely to take place. These changes will in turn influence mortality patterns among older people. Before ART became widely available, HIV was associated with household dissolutions (Hosegood, McGrath, Herbst *et al.*, 2004), older people caring for ailing adults (Zimmer and Dayton, 2003) and orphaned children (Hosegood, Floyd, Marston *et al.*, 2007; Nyirenda and Newell, 2010). However in the ART era, in addition to HIV infected people living longer, there is now evidence that there can be full recovery in employment after a few years of ART treatment for adults who were previously ill and unable to work (Bor, Tanser, Newell *et al.*, 2012). This may lead to HIV-infected adults in future needing less care from older people. On the other hand, older people, whether HIV-infected or not, will increasingly require care and support with advancing age.

The care-giving and care-receiving landscape is thus currently different from what it was prior to ART and is constantly evolving. However, it is unclear from the available evidence what the relationship is between informal care provision and the physical, mental, emotional state as well as mortality levels and patterns in older people (O'Reilly, Connolly, Rosato *et al.*, 2008; Vlachantoni, Evandrou, Falkingham *et al.*, 2013a). While the association between age, sex, lifestyles and socio-economic factors like education, occupation, employment status and income is well known (Menvielle, Leclerc, Chastang *et al.*, 2010; WHO, 2013), the association of mortality with informal care by and towards older people which is an important part of this rural South African society is a neglected topic. This will be the subject matter examined in the fourth paper in this thesis.

1.6 Justification for the study

While the course and implications of ageing in developed countries has been well described (Velkoff and Kowal, 2006), ageing in developing countries, particularly sub-Saharan African countries is an emergent area of research. The above discourse highlights that little is known about the lives and situations of older people in developing countries (Gorman and Zaidi, 2013). As a consequence, any policies and programmes regarding the wellbeing of older people have been made on a basis of lack of evidence. In Africa, including South Africa, understanding of the physical, mental, social well-being and mortality patterns associated with population ageing in the context of a mature HIV epidemic is limited due to a lack of reliable studies on the subject. Although the broad impact of population ageing on health in South Africa has been previously reviewed (Joubert and Bradshaw, 2006), only a limited collection of studies have included older people's health as a central topic or measured their health and well-being in a systematic manner (He, Muenchrath and Kowal, 2012; Ice, Zidron and Juma, 2008; Ng, et al., 2010). Neither is it fully understood how self-reported health and care-giving dynamics relate to mortality in older people in rural South Africa.

Hence there is scope and justification for the present study, the overarching aim of which is to examine the physical, social, mental well-being and mortality patterns of

older people, defined as aged 50 years and above, in rural South Africa. There are three main objectives in this study as detailed below.

1.7 Main study objectives

- To analyse household-living arrangements and informal care and support by and towards older people in rural South Africa (Chapters 2 and 3);
- To describe the health and well-being of older people in rural South Africa by HIV status (Chapter 4); and
- To examine the association of self-reported physical health status and emotional well-being as well as informal care with levels and patterns of mortality among older people adjusting for HIV status (Chapter 5).

A peer-reviewed journal article has been prepared based on each of the main objectives, except for objective two for which two separate articles were prepared. Versions of the analyses presented in Chapters three (Nyirenda, Evandrou, Mutevedzi *et al.*, 2013b) and four (Nyirenda, Chatterji, Falkingham *et al.*, 2012) have since been published in peer-reviewed journals, while the analyses presented in Chapters two and five are yet to be published (see Appendix 1, pp. 201 for details). In a rural study community with high HIV prevalence and incidence, findings from this project will contribute to improved understanding of factors influencing the health, wellbeing, informal care and survival among older people. Although these findings may not be fully generalizable to South Africa or sub-Saharan Africa as a whole, they inform a better understanding of the situation of older people in rural African communities severally impacted by HIV. This study has implications for the design of health and social policy interventions as the dynamics of population ageing in rural African societies have hitherto not been fully studied.

1.8 Data sources, study design and analysis

Analyses for this project were largely based on two data sources.

1.8.1 Africa Centre's longitudinal surveillance system

The first data source was the Africa Centre's longitudinal demographic and health surveillance system; whose surveillance area is located in KwaZulu-Natal, one of the

nine provinces of South Africa on the eastern coast (Figure 1-2). In the north-east of KwaZulu-Natal (shaded green in top half of map) is the Hlabisa district (shaded black) within which the demographic surveillance area (DSA) covering an area of 435 square kilometres is located (shaded grey and enlarged in bottom half of map). The DSA is well defined by features such as the Hluhluwe/Umfolozi game reserve to the west, the Umfolozi river to the south, the National road (N2) to the east, and lastly a smaller tributary river (Nyalazi river) and forest plantation make up the northern boundary.

Since 2000, demographic, social, economic and health data have been collected in over 11,500 households with about 90,000 resident and non-resident household members (Tanser, Hosegood, Bärnighausen *et al.*, 2008). On 1st January 2010, there were 61 431 household members resident within the surveillance area, of whom 13% were aged 50 and above. There are large variations in population density across the DSA from 2,660 people/km^2 in the township in the south-east to 5 people/km^2 in the more rural and hilly northwest of the surveillance area (Tanser, 2002). The DSA is predominantly rural with only about 10% of the surveyed population residing in areas recognised as urban. The population in the study area is almost exclusively from the Zulu ethnic tribe (www.africacentre.com). Although largely rural, there is very little subsistence farming in the area and most people rely for daily living on income from state cash transfer schemes or formal employment (Burns, Keswell and Leibbrandt, 2005; Curtis, Bradshaw and Nojilana, 2002; Duflo, 2003; Muhwava, 2008).

Demographic, social and health data on all members of the household are collected bi-annually from a household key informant. Data collected include births, deaths, population movements and household membership (Tanser, et al., 2008). For each death recorded during the routine household visits, detailed cause of death information is collected by trained nurses within six months of the death being reported using a validated verbal autopsy (VA) data collection instrument (Kahn, Tollman, Garenne *et al.*, 2000). Before 2010 these verbal autopsy forms were then passed on to two independent physicians who assigned using the International Classification of Diseases version 10 (ICD-10) a cause of death (WHO, 2004). From 2010 causes of death have been assigned using a computer algorithm based on Bayesian

theorem called InterVA (Byass, Fottrell, Dao *et al.*, 2006). An evaluation of the differences between physician coding and InterVA coding was recently done, demonstrating high reliability of the InterVA (Herbst, Mafojane and Newell, 2011). In addition once a year (except for 2008), data are collected on socio-economic variables, such as household assets, access to electricity, sanitation facilities, government cash transfers, employment status, energy sources and educational attainment. Also separately collected annually are data on sexual behaviour and HIV status based on sero-testing of dry blood spots (DBS) specimen collected from all eligible and consenting adult household members (15 years and above) (Tanser, et al., 2008).

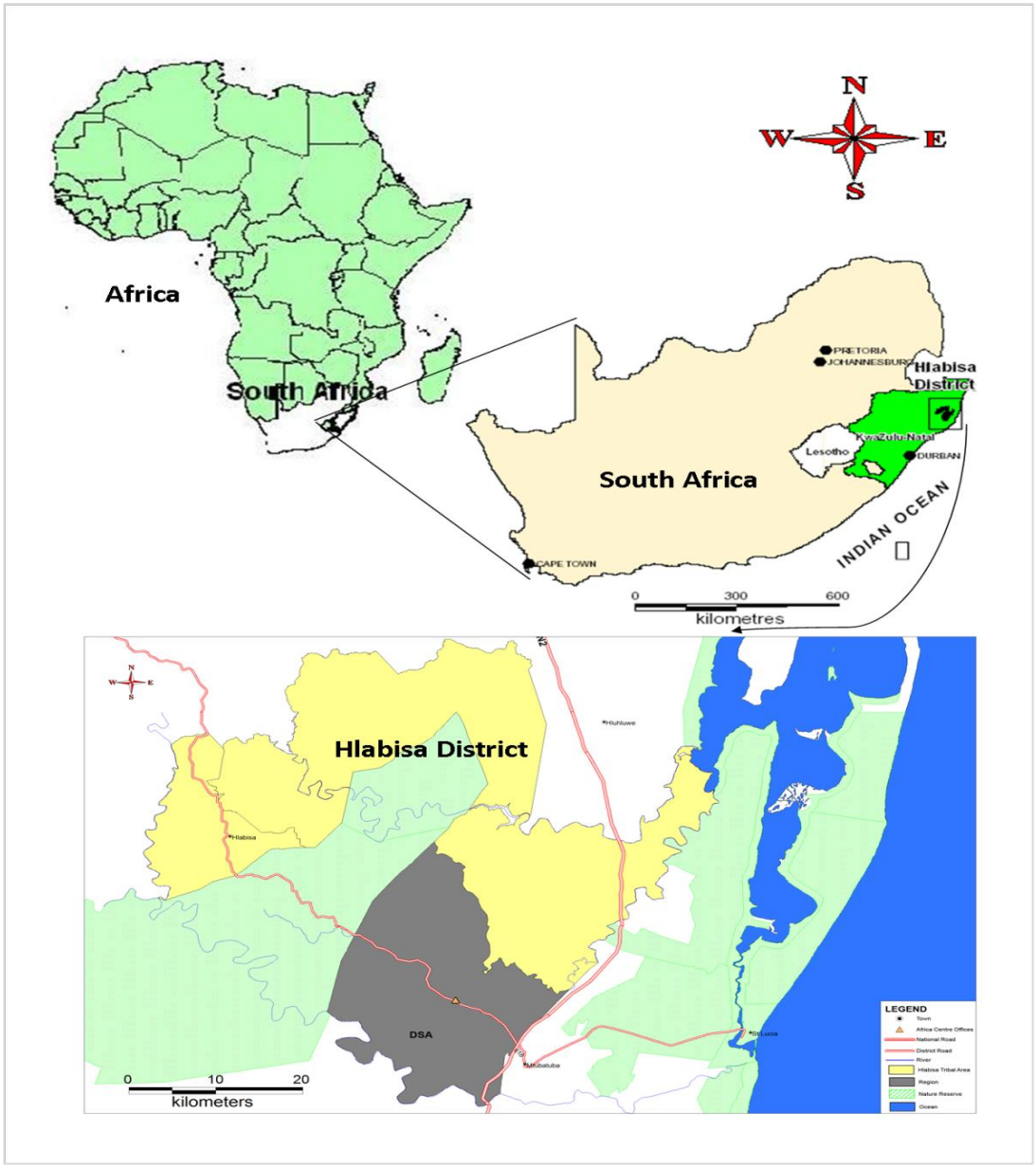


Figure 1-2: Maps of study site in the context of Africa, South Africa and the Hlabisa district

Fertility in the surveillance area is low, with fewer than 2.5 children per woman by age 50 years (Moultrie, Hosegood, McGrath *et al.*, 2008). Current estimates indicate that fertility is slowly approaching replacement levels of 2.1 children per woman (www.africacentre.com), which is uncharacteristic of rural African populations. Furthermore, there is a high level of internal and external migration in the surveillance area (Muhwava, Hosegood, Nyirenda *et al.*, 2010). Lastly, although adult life expectancy has increased following widespread roll out of ART (Bor, Herbst, Newell *et al.*, 2013; Herbst, et al., 2009), as of 2011 the area remained characterised by generally low life expectancy at birth of 60.5 years (95% CI, 59-62 years), (65 years women and 56 years men) (Bor, et al., 2013) typical of developing country populations. Ethical approval for the Africa Centre's surveillance was first granted in 2000 (Appendix 3, pp 218 and is annually recertified there after (see Appendix 4, pp. 219 for latest recertification). Details about the Africa Centre's longitudinal surveillance have been published elsewhere (Hosegood, Benzler and Solarsh, 2006; Hosegood and Timæus, 2005a; Houlihan, Bland, Mutevedzi *et al.*, 2011; Tanser, et al., 2008) and are available from www.africacentre.com.

1.8.2 Wellbeing of Older People Study (WOPS)

The second source of data for this project was the health and well-being of older people study (WOPS) conducted between March and August 2010 on a sample of 422 older persons aged 50 years and above within the Africa Centre's surveillance area. Instruments used to collect the data in WOPS were based on the World Health Organisation's (WHO) Study on Global Ageing and Adult Health (SAGE) (WHO, 2011). These instruments were adapted to the local context as well as shortened to capture essential elements of the health and well-being of participants. Also WOPS was partially harmonized with a similar sub-study in Uganda (Scholten, Mugisha, Seeley *et al.*, 2011), to facilitate proposed cross-country comparisons. The overall aim of WOPS was to investigate the direct and indirect effects of HIV on the health and well-being of people aged 50-plus years. Before data collection, the study questionnaire was translated from English to Zulu and then back-translated by local staff and then tested in a pilot study and revised. The size of the pilot sample was 10% of the target main

sample; individuals included in the pilot were not included in the main study. All data were collected by two trained professional nurses. The ethics approval (Appendix 5, pp. 220), informed consent sheet (Appendix 6, pp. 222) and questionnaires (Appendix 7, pp. 223) used in WOPS are attached as appendices to this thesis.

The target sample was 400 individuals comprised of four groups of older people differently affected by HIV (see below). The sample size was purposively set and determined to be adequate for a description of the health and well-being of older people in the study area. Having at least 100 people in each group made it possible to test for statistically significant differences between the groups at 5% level of significance. It was also determined to be appropriate for proposed cross-site analyses with a similar study conducted in Uganda within the Medical Research Council/Uganda Virus Research Institute's general population and Entebbe cohorts (Nyirenda, et al., 2013c; Scholten, et al., 2011). The study instrument had three main components: 1) detailed questionnaire on basic demographic information, description of health state including functional ability assessment, subjective well-being, chronic health conditions and symptoms, health care utilisation, care-giving and -receiving, and the experience of living with HIV; 2) collection of anthropometric measurements; and, 3) blood draw for laboratory measured health risk biomarkers for cardiovascular diseases, diabetes and hypertension. Data collected in the anthropometric measurements and the blood specimen were not used here in describing the health and well-being of older people as that was outside the scope of this thesis.

A stratified random sampling approach was used to select participants into the four defined groups into this study from eligible sub-populations within the surveillance population as shown in Figure 1-3. The eligibility criteria, in addition to being aged 50+ and under surveillance, specific for each group were: Group 1 – being HIV-infected and on antiretroviral treatment (ART) for a year or longer; Group 2 – being HIV-infected and on ART for three months or less including those waiting to initiate ART; Group 3 – having an HIV-infected adult child aged 18-49 years on ART for a year or longer, or on ART for three months or less; and Group 4 – having experienced an HIV-related death of an adult child (18-49 years) between 2008-2010. The starting point for selection of

participants into groups 1 and 2 was the Hlabisa HIV Treatment and Care Programme (Houlihan, et al., 2011). This is a South African Department of Health programme run in partnership with the Africa Centre, from which persons in the Antiretroviral Therapy Evaluation and Monitoring Information System (ARTemis) database were selected to be invited to participate based on inclusion criteria. ARTemis captures information relating to all HIV-infected people accessing HIV care at any one of the 17 primary health care clinics and the district hospital within the Hlabisa sub-district and served as the sampling frame for groups 1 and 2. Around 40% of individuals in the Hlabisa HIV Treatment and Care Programme reside in the Africa Centre surveillance area (Houlihan, et al., 2011). With appropriate ethical approval, information collected from the Africa Centre surveillance activities were linked to information collected in the Treatment and Care Programme and those that met the criteria for groups 1 and 2 were randomly selected and approached for informed consent. Group 3 participants were selected by first identifying all adults (18-49 years) in ARTemis who were also under demographic surveillance. Their households were then identified and any person aged 50+ in those households was approached for inclusion in the study. Group 4 participants were selected by identifying all deaths of adult household members (18-49 years) resident in the surveillance area classified as HIV-related from the VA data. A random sample of households in which older persons who were identified to have been co-resident with the adult at the time of death was then drawn, and these older persons approached for inclusion.

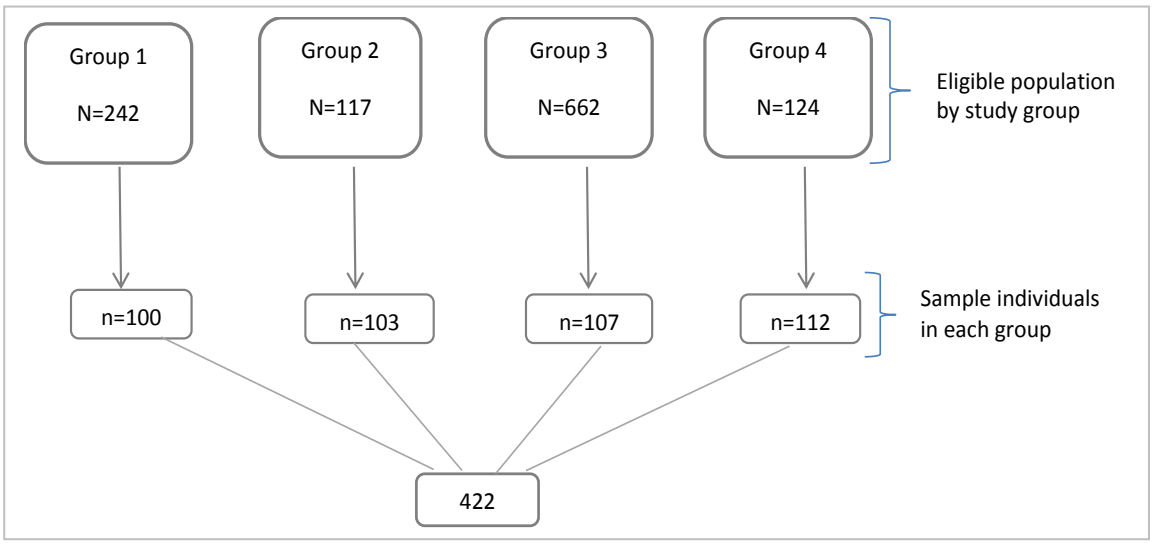


Figure 1-3: Flow chart of sample selection

WOPS thus contained detailed information on older people who are infected with HIV as well as those HIV-affected through their care-giving role to HIV-infected offspring or death of an adult household member due to HIV-related causes. This sub-study within the surveillance provided data for a detailed analysis of older people's self-reported health state and informal care patterns associated with HIV. With linkage to the surveillance data, household-living arrangements could be interrogated and their link with the health and well-being of older people in this rural community explored. Further details on these data sources are presented and discussed in the respective papers included in this thesis. Standard demographic and statistical methods for analysing longitudinal data including regression models and proportional hazards models of event histories were used. This thesis overall focuses on differences in health and well-being in older people by HIV status, and how physical health, emotional well-being, and living circumstances influence mortality levels and patterns in this age group.

1.9 Conceptual framework

Cantor's model (Cantor, 1979; Cantor, 1991; Cantor and Hirshorn, 1989) presents an individual as at the centre of concentric rings that influence their support system. An individual will usually turn to those in the inner rings before ultimately turning to the outer most ring of the state. The model was developed and presented within the context of a care or support system.

In this study I extended this model to explore factors in these concentric rings and how they relate to the health, well-being and mortality patterns of people aged 50 years and above in rural South Africa (Figure 1-4). The health of an older person is determined by individual socio-economic factors (inner-most ring), all the way through to state structures or policies (outer-most ring) that promote the health and well-being of older people such as social security schemes and free medical care for senior citizens. A similar conceptual framework has been suggested by Dahlgren and Whitehead (1991) in recommendations on policies and strategies to promote social equity in health. In this policy framework the health of an individual is mapped in relation to individual lifestyle factors, social and community network factors, and

finally to general socio-economic, cultural and environmental conditions (Dahlgren and Whitehead, 1991; Whitehead, Dahlgren and Gilson, 2001). Such a policy framework in promoting equity in health has been adopted by the World Health Organization in the report by the Commission on Social Determinants of Health (CSDH, 2008).

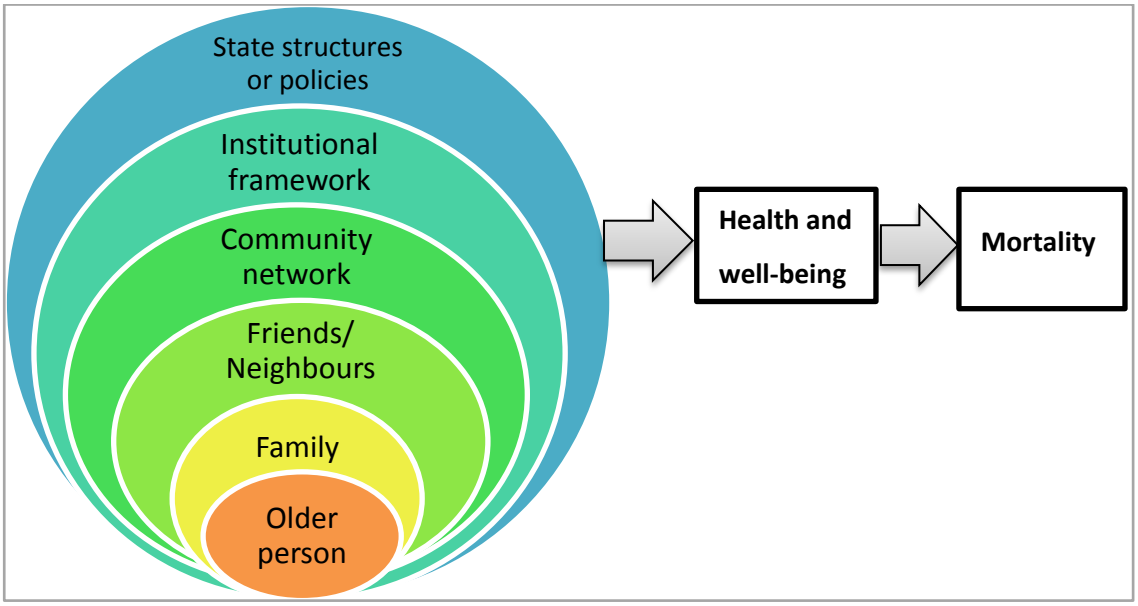


Figure 1-4: Contextual framework

Source: Adapted from Cantor (1979, 1991).

In the first two papers, the focus will be on family, friends, neighbours and community structures on the one hand (household-living arrangements) and institutional or state structures (having an income source) on the other hand, to investigate potential support flows between older and younger people. An examination of this informal care system and the household living arrangements which are likely to affect who the older person is likely to turn to for care and support will be the subject of discussion in Chapter Two and Three. With emphasis on the inner-most-ring, Chapter Four will explore factors associated with the health and well-being of older people. The health and well-being of older people is additionally affected by the care and support system around the older person. Ultimately factors in the inner-most and outer rings will impact on the survival probabilities of an older person via their influence on the health and well-being status. This will be explored and discussed in Chapter Five.

Table 1-1 shows factors explored in each of the concentric rings and their likely effect on older people's mortality. Details on each of these factors are given in respective chapters.

Table 1-1: Contextual factors examined and their likely effect on older person's mortality

Concentric ring	Factors	Expected effect on mortality
Older person	Age, sex	Direct
	Employment status	Indirect via its effect on health and well-being
	Education	Indirect via its effect on health and well-being
	Health status	Direct
	HIV status	Direct but also indirectly by influencing care dynamics and living arrangements which in turn affect health and well-being
	Marital status	Indirect via its effect on health and well-being
Family	Care-giving or -receiving	Indirect via its effect on health and well-being
	HH structure/typology; HH living arrangements	Indirect via its effect on health and well-being
	HH headship	Indirectly via care and living arrangements which in turn affect health and well-being
	Number earning income in	Indirectly via care and living arrangements which in turn affect health and well-being
	Resident versus non-resident members	Indirectly by influencing care dynamics which in turn affect health and well-being
	HH socio-economic status	Indirect via its effect on health and well-being
Neighbours/ community	Help from friends, church or neighbours; Place of residency	Indirect via its effect on health and well-being
Institutional/ State structures	Access to grants	Indirectly via care and living arrangements which in turn affect health and well-being

1.10 Outline of thesis structure

Chapter Two provides a broad overview of older people in the surveillance area over the period 2005-2010. The paper then describes household-living arrangements, having an income from employment or government cash transfer programmes, and discusses the potential implications of these factors on exchanges of financial support between older and younger people. The paper in Chapter Three examines the associated effect of informal care-giving or -receiving on the physical health and emotional well-being of older people. The paper in Chapter Four then describes in detail the physical health and emotional well-being of HIV-infected relative to HIV-affected older people. The paper on the relationships between informal care and health status with survival patterns of older people is presented in Chapter Five. Finally, overall conclusions, policy implications and a highlight of potential future works are discussed in Chapter Six.

Chapter 2: **Household living arrangements and having an income in old age: Implications for intergenerational support in rural South Africa**[1]

2.1 Abstract

The purpose of this paper is to examine household living arrangements of older people and the availability of an income from older and other younger household members; and to postulate on the likely intergeneration directional flow of financial resources.

Data come from the Africa Centre Socio-Demographic Surveillance located in uMkhanyakude district in northern KwaZulu-Natal province, South Africa. Living arrangements, having an income and support flows are examined over the period 2005-2010. Support flows are categorised into: peer/self (to one-self or to another older person); downward (from older to younger persons); upward (from younger to older person); and reciprocal (bidirectional flows). The analysis included 6806 older people aged 60 years and above under observation in the surveillance over the study period; of whom 45% (n=2745) were observed throughout the study period. Multinomial logistic regressions are run to explore changes in directional flow of support between 2005 and 2010, given changes in living arrangements.

There was a decline over time in employment rates in older and younger people alike, but an increase in the proportion with access to government grants. Over 85% of older people lived in multi-generational households; over the study period living arrangements remained largely unchanged. Peer support was rare; most of older people were instead involved in reciprocal support. Adjusting for age, education, marital status, place of residency and household socio-economic status, changes in living arrangements into skip-generation or multi-generation households were significantly associated with transition into downward and reciprocal support.

Findings here strongly suggest, when all else is considered, that exchanges of financial resources in the study population are most likely downward or at best (in the context of older people) reciprocal. Ensuring all eligible older persons get their old-age pension is therefore essential, but some support to unemployed adults in the form of say an unemployment grant may also be necessary to enable them make a contribution to household income and intergenerational exchanges.

Key Words: Intergenerational support, living arrangements, older people, income, South Africa.

[1] **Note:** In this chapter older people are defined as aged 60 years and above in contrast to age 50 years and above used in the chapters to follow. Justification for adopting this age cut-off is provided in section 2.5.1, pp 30.

2.2 Chapter outline

The analysis presented in this chapter employs descriptive and regression analyses to examine household living arrangements and access to income by older people and other members of their household over the period 2005-2010, and on the basis of the patterns and trends to postulate on the probable directional flow of support from, to and between older and younger persons. Longitudinal surveillance data collected in rural South Africa for the period 2005-2010 was used. The chapter begins with a short introduction of the purpose and rationale of the paper. Then section 2.4 provides an overview of household living arrangements, sources and sharing of incomes within households and a review of the limited studies examining living arrangements and support exchanges as a background. This will then be followed by section 2.5 on the study objectives and section 2.6 on the methods and data sources. Thereafter section 2.7 will present this study's findings and a discussion of the findings will follow in section 2.8. The chapter ends in section 2.9 with some conclusions.

2.3 Introduction

The purpose of this article is to examine living arrangements and having a regular source of income (from government grants or employment) among older and younger people in rural Africa; and then to postulate on the likely directional flow of financial resources between the older and the younger generation. Whether driven by altruism or obligation, exchanges of care and support within families between older and younger people is normative in most societies (Lee, 2012; Silverstein, Conroy and Gans, 2012; Zimmer and Dayton, 2003). For programmatic and policy response it is imperative to understand the flows of support between the older and younger generations in order to target appropriate interventions in resource limited settings. However, one needs to be cognizant of the fact that there are essentially three dimensions to intergenerational support exchanges: emotional, physical and material. Studies examining intergenerational support exchanges and living arrangements in older people have tended to focus on the emotional and physical dimensions of care (Chen and Chen, 2012; Gierveld, Dykstra and Schenk, 2012; Silverstein, Cong and Li, 2006; Van der Geest, 2002). In this paper, whether older people have an income

themselves or from other co-resident household members is considered for the implications on support exchanges given whether the older person is in a single or older-only household, in skip-generation households (with adults or children only), or in multi-generation households (with adults and children). Given that individuals who make up households tend to usually be kin-related (Hosegood and Timæus, 2005a), and have a socially-binding obligation towards each other (Sagner and Mtati, 1999), the theoretical framework of solidarity theories (Bengtson, 1975; Giarrusso, Silverstein, Gans *et al.*, 2005; Lowenstein, 2005) is used to examine intergenerational exchanges of financial resources. As the name implies, solidarity models posit that given shared norms, values and expectations, individuals are governed by strong family bonds to transfer resources between the older and the younger generations.

2.4 Background

2.4.1 Ageing trends and household living arrangements

Data from the United Nations shows there were approximately 737 million people aged 60 years and above in 2009 globally; this figure was projected to increase to over 2 billion by 2050 (United Nations, 2009). Understandably, there is public policy concern about such a rapid increase in the older population especially with regard to impact on social security programmes and health care (Edmonds, Mammen and Miller, 2005; Falkingham and Grundy, 2007; National Institute on Aging, 2007). In addition, concern has also been expressed regarding implications of an aging population for living arrangements and support networks (Aboderin, 2007). In both developed and developing countries income poverty in old-age may be high due to limited contribution to a pension during productive years and/or lack of a comprehensive non-contributory social pension (Barrientos, 2006 ; Berthoud, Blekesaune and Hancock, 2006; Dominy and Kempson, 2006; Help Age International, 2006; Mordaunt, Rake, Wanless *et al.*, 2003; National Institute on Aging, 2007; Vlachantoni, 2009).

For sub-Saharan Africa, severely affected by HIV, there is a further concern of the impact of HIV on household living arrangements and concomitantly on support structures. Kautz et. al. (2010), using Demographic and Health Survey (DHS) data from

1991 to 2006 for 22 African countries, showed that the proportion of older people aged 60+ in single-person households had increased as had that of older persons living only with children aged under 10 years (refered to as skip-generation households); there was also an increase of adults aged 18-59 years living with older people, indicative of increased dependency or need of care by adults in ill-health. Using data from a longitudinal surveillance system in rural South Africa, Hosegood and Timæus (2005b) found that the great majority (87%) of older people lived in multi-generational households (older person with children and grandchildren), which is in line with findings from a study that compared changes in household structure between 1996 and 2003 from nationally-representative surveys and longitudinal surveillance data in rural South Africa (Wittenberg and Collinson, 2007). Wittenberg and Collinson (2007) found in the longitudinal surveillance that over the period there was an increase in multi-generational linear (household head with children and grandchildren) and multi-generational skip households (head with grandchildren but no children), but that in the national survey data there was a sharp increase in single-person households. They explained these different findings by differences in the definition of households, with surveys restricting definition to individuals spending most of their time in a week in the household whereas in the surveillance persons absent from the household even for a long time may be included as household members; the latter group of individuals are likely to appear in surveys as single-person households. However, overall, data for South Africa consistently show the majority (over 70%) of older adults to be living in households with adult children and grandchildren (multi-generational households) (United Nations, 2005; United Nations, 2009). Also relative to households without older individuals, households with older people tend to be poorer and older people, especially those in single-person or in skip-generation households, tend to be the poorest (Hosegood and Timæus, 2005b).

Even though the study area considered in this analysis is largely rural, there is little subsistence farming (Curtis, Bradshaw and Nojilana, 2002; Muhwava and Nyirenda, 2008). Daily living is predominantly built around a cash economy. Government grants and formal employment are the major sources of income on which this rural

population is heavily reliant (Ardington, Case and Hosegood, 2009; Leibbrandt, Finn and Woolard, 2012; Neves, Samson, Ingrid van Niekerk *et al.*, 2009; Tanser, et al., 2008). Unemployment levels in South Africa among the adult population 15-64 years were 21.8% in the last quarter of 2008 since when unemployment rates steadily increased to 25.6% by the second quarter of 2013 (StatsSA, 2013). In the study area, only 37% of the resident adult population (15-64 years) were in paid employment (including self-employment) in 2010 (www.africacentre.com), considerably less than the national employment levels.

2.4.2 Theoretical basis for intergenerational support exchanges

Having a regular income (from employment or grants), especially in the study population which relies heavily on a cash economy, is vital for living arrangements and support structures. As noted by Lee (2012), humans as social beings live and share resources within families, and intergenerational transfers are an expression of the interconnectedness among individuals who are usually kin. Using anthropological data to examine care-giving to older people and by whom or why it was provided, van der Geest (2002) showed that care is basically either emotional or physical, with exchange of material support a third dimension of care often neglected. Emotional and physical aspects of care including helping with activities of daily living such as washing clothes, taking a bath, and going to the toilet was discussed in detail in a separate analysis published earlier (Nyirenda, et al., 2013b) and presented in Chapter Three. In the present analysis the focus will be on material support in the form of intergenerational exchanges of financial resources. Among previous studies to have examined intergenerational exchanges of support and living arrangements of older people, the focus has tended to be on the effect of receiving physical or emotional care from adult children (Gierveld, Dykstra and Schenk, 2012; Silverstein, Cong and Li, 2006). The focus has especially tended to be on the well-being of older people living alone or with a spouse only.

There are several theoretical bases for why intergenerational exchanges in households would occur. According to the solidarity theory of intergenerational support

exchanges, the transfer of care and support between younger and older generations is governed by family bonds, which include emotional connectedness, geographical proximity, shared norms, values and expectations (Bengtson, 1975; Giarrusso, et al., 2005; Lowenstein, 2005). Implicitly, solidarity theories entail reciprocity in support exchanges, such that if parents provided the expected care to their children they can be assured of being cared for in return during their old age (Van der Geest, 2002). In this regard there are two factors of relevance in the context of sub-Saharan Africa, which have contributed to growing ambiguity around solidarity within households and the expected reciprocity in support exchanges. The first relates to constraints imposed by economic circumstances: high adult unemployment may limit the ability of adult children to support their older parents irrespective of the strength of intra-familial relations (Aboderin, 2005). The second is the HIV epidemic, which severely affected the health and economic well-being of prime-aged adults and contributed to older people having to take on a major role in the care for HIV-related ailing adults and orphaned children (Ardington, et al., 2010; Hosegood and Timæus, 2006; Nyirenda and Newell, 2010; Schatz, 2007). Consequently at a time when older people are most in need of care and support they may not be able to access this as either the adults are economically unable or they are no longer available due to the high HIV-related adult mortality (Hosegood and Timæus, 2005b; Muhwava, 2008; Schatz and Ogunmefun, 2007). In spite of this, whether out of an altruistic impulse or sense of obligation (Lee, 2012; Silverstein, Conroy and Gans, 2012), intra-household intergenerational exchanges remain the norm rather than the exception in Africa and households as socially determined institutions are vital to support exchanges between older and younger people (Zimmer and Dayton, 2003).

2.4.3 Household income sources and pooling of resources

Older people in rural South Africa do not always solely rely on income from adult children for support; South Africa has a system of social assistance[2] in the form of cash

[2] See Appendix 8, pp. 240 for a table of the various grants, their amounts and eligibility criteria adapted from Nyirenda, M. and Newell, M.-L. 2010. Orphanhood and HIV risk in rural KwaZulu-Natal In Nzimande, N.B. (ed), *State of the population of KwaZulu-Natal: demographic profile and development indicators* Dept of Social Development/UNFPA, Durban, 159-186.

transfers (known as grants) to older people[3], persons with disabilities and children (Case and Deaton, 1998; Devereux, 2007; Devereux, 2011; Gomersall, 2013; Knight, Hosegood and Timæus, 2013; Moller and Radloff, 2013; Woolard, Harttgen and Klasen, 2011). By the end of 2010 about 14.6 million of the 49 million people in South Africa were government cash transfer recipients (Woolard, Harttgen and Klasen, 2011); by November 2013 an estimated 15.7 million people received social assistance, of which the majority (10.9 million) received child-support grants or old-age pension grants (2.9 million) (SASSA, 2014). A number of empirical studies have evaluated the impact of government cash transfers on health, education and nutrition (Case, 2004; Case and Ardington, 2006; Case and Menendez, 2007; Coetzee, 2013; Duflo, 2000; Duflo, 2003), labour force participation of prime-aged adults (Ardington, Case and Hosegood, 2009; Bengtsson, 2012; Edmonds, Mammen and Miller, 2005; Jensen, 2004; Ranchhod, 2006), crowding out of private transfers (Jensen, 2004; Surender, Noble, Wright *et al.*, 2010) and on poverty levels (Barrientos, Møller, Saboia *et al.*, 2013; Booysen, 2004; Lloyd-Sherlock, Barrientos, Moller *et al.*, 2012a; Raniga and Simpson, 2011; Woolard and Klasen, 2005). Others have also looked at older people as recipients of remittances from migrant adult offspring (Collinson, 2010; Neves and du Toit, 2013; Posel, 2001a; Posel, 2001b). Findings from all these studies show clearly that there is a great deal of income sharing within households, particularly in rural South Africa. As Sagner and Mtati (1999) so poignantly put it:

> "Kinship as a moral order implies the recognition of social obligations towards kin, that is, the acknowledgement of mutual responsibility to each other, even if it is a burden. This social morality is incompatible with an unfettered individualism which claims the moral right of individuals of absolute control over their possessions." (Sagner and Mtati, 1999, pg 400).

[3] The old-age pension in South Africa was introduced as early as 1928, although it was only as recently as 1993 that racial disparities in accessibility were abolished. Devereux, S. 2007. Social pensions in Southern Africa in the twentieth century. *Journal of Southern African Studies*, **33**(3), 539-560, Woolard, I., Harttgen, K. and Klasen, S. 2011. The history and impact of social security in South Africa: experiences and lessons. *Canadian Journal of Development Studies*, **32**(4), 357-380.

Thus whether it is the older person with an income or other household members with an income, transfer of resources between the older and the younger generation are likely when needed. There is a lack of studies that have considered having an income not just by the older person but including income from all other household members and the likely implication of this on the directional flow of financial resources between older and younger people, taking into account household structures.

2.4.4 Review of living arrangements and flows of resources studies

Among the few studies investigating the impact of the old-age pension income on living arrangements in South Africa, Edmonds, Mammen and Miller (2005) found that in a household where at least one person received an old-age pension, prime-aged adults were more likely to leave the household in search of employment opportunities elsewhere, and there was likely to be an increase of young children aged under 5 years and young women in early child-bearing ages (18-23 years) in the household; this was confirmed later in a study using data from a population under demographic surveillance in rural South Africa (Ardington, Case and Hosegood, 2009). However, these studies did not consider access to income by any other household members and did not examine income sources in the household in the long term beyond the point of old-age pension age-eligibility. An earlier study by Knodel and Saengtienchai (1999) focused on the methodological challenges of research on this topic with regard to definition of households, treatment of co-residence as a dichotomous variable, and not being cognizant of the fact that this may be an emotionally sensitive subject for respondents as it touches on expectations of care and support between older people and their adult offspring. For example, Knodel and Saengtienchai (1999) noted that surveys tend to define a household narrowly, which may then inadequately capture reality, especially when considering living arrangements such as co-residence with adult children. The challenges they identified are most easily addressed by the use of longitudinal surveillance data as is the case for this paper. Empirical knowledge about living arrangements, having an income from household members and the likely directional flow of support between the younger and the older generation would

inform policy response and programmatic intervention within a context of limited resources.

2.5 Study aim and objectives

The main aim of this analysis is to contribute to the discourse on intergenerational exchanges of support between younger and older people aged 60 years or above by examining their household living arrangements and access to regular income over the period 2005-2010[4] in rural South Africa. Specifically the objectives of this study are:

1. To describe household living arrangements of older people aged 60+ in rural South Africa over the period 2005-2010;
2. To examine access to income (from government cash transfers or employment) by the older person and other household members over the same period; and
3. To postulate on the probable directional flow of support exchanges between younger and older people given income sources and living arrangements within the household.

Excluded from the analysis is any potential income from remittances or donations that older people or any other household members may be receiving from non-resident household members or extended family as those data were unavailable; there are also considerable measurement challenges for these alternative sources of income (Lund, 1999: 58). Leaving out remittances should not significantly bias this study's findings as it has previously been noted (2004) that receipt of government cash transfers results in significant reductions in remittances to older people of around 30 cents per rand of cash transfer received. That is to say, the likelihood that households in receipt of government cash transfers receive additional remittances decreases with the amount of cash transfers received. Maitra and Ray (2006) further showed substantial declines in the province of KwaZulu-Natal in remittances over the period 1993-1998, which is within the first five years after racial disparities in access to old-age pensions were removed (Devereux, 2007; Woolard, Harttgen and Klasen, 2011).

[4] This period was chosen because it relates to a period for which full data collected in a consistent way are available; 2010 is also when the cross-sectional survey on the health, well-being and care-giving characteristics was conducted that forms part of this body of work, allowing us to examine physical, emotional and material aspects of care for 2010.

2.5.1 Definition of terms

In this analysis, older people were defined as those aged 60 years or older, while adults denote those aged 18-59 years and children those aged less than 18 years. Age 60 was used as a cut-off for old-age as that is presently the age-eligibility for old-age pensions in South Africa and to be consistent with other studies (Kakwani and Subbarao, 2007; Knodel and Saengtienchai, 1999). It is further widely used by international agencies to define ageing populations (United Nations, 2009). The definition of children was partly based on the education system and labour laws of South Africa; age 18 is the time around completing secondary education, and many seek their first job.

2.6 Methods

2.6.1 Sources of data and study design

Data for this analysis come from the longitudinal Africa Centre Demographic and Health Surveillance located in uMkhanyakude district in northern KwaZulu-Natal, South Africa. Since 2000, data on demographic, social, health and household characteristics are collected from a key household respondent on all household members (Tanser, et al., 2008), in bi-annual rounds until end of 2011 and tri-annual thereafter. A distinctive feature of the Africa Centre's surveillance is the definition of a household not as a group of related individuals dwelling together or eating from the same pot, but as a social unit of related or unrelated individuals who identify themselves as one either through a shared household head or owner of dwelling unit (Hosegood and Timæus, 2005a). As a result, even individuals not physically resident in the surveillance area can be included as non-resident members provided the key household informant considers such individuals to be household members. Individuals belonging to one household but spanning different spatial locations form an important feature of the South African population particularly with regard to support exchanges, which can be traced back to the legacy of the apartheid era policies as well as to the government cash transfer programme in contemporary South Africa (Posel, 1991; Posel, Fairburn and Lund, 2006). In addition, individuals can be reported as belonging to more than one household in the surveillance area, with their record updated at each of the households of which they are a member, although they can only be

resident in one household at a particular time (Hosegood, Benzler and Solarsh, 2006; Hosegood and Timæus, 2005a).

In addition to the demographic information collected, household and individual socio-economic (HSE) status data such as asset ownership, access to water, electricity, sanitation facilities, education, employment and receipt of government grants has been collected annually from 2001 except for 2008. This paper is restricted to the analysis of data collected over the period 2005-2010. Details about the Africa Centre surveillance have been previously presented elsewhere (Hosegood, Benzler and Solarsh, 2006; Tanser, et al., 2008) and are regularly updated on www.africacentre.ac.za.

2.6.2 Analytical sample

This analysis considers the population of older people aged 60 years and above included in the Africa Centre longitudinal surveillance over the period 2005 to 2010. The surveillance population as at mid-year of each year are divided into three broad age groups of children, adults and older people. Of interest in this analysis are older people and all households to which they belong and/or are resident. Household composition, living circumstances and having a regular income source (from government cash transfers or employment) of all registered household members is explored. In Table 2-1 descriptive statistics of the population of older people in the surveillance over the period 2005-2010 stratified by whether they were non-resident or resident household members are presented[5].

[5] Information for 2008 is not included in the table as the socio-economic characteristics key to this analysis - employment, grant access, education - for this year were not available.

Table 2-1**:** Description of the surveillance population aged 60 years and above as at mid-year by residency status, 2005-2010

	Non-Resident					Resident					
Characteristics	**2005**	**2006**	**2007**	**2009**	**2010**	**2005**	**2006**	**2007**	**2009**	**2010**	**p-value***
Number of older persons	662	652	655	628	666	4231	4232	4209	4322	4420	
Median age	66	67	67	67	67	69	69	69	69	70	
Sex											<0.001
Male	53.2	51.5	52.7	51.6	54.5	30.0	30.0	29.8	29.6	28.8	
Female	46.8	48.5	47.3	48.4	45.5	70.0	70.0	70.2	70.4	71.2	
Place of residency											<0.001
Urban	3.2	3.2	3.8	5.6	4.7	2.6	3.0	3.1	3.4	3.6	
Peri-Urban	27.0	27.8	27.5	26.8	26.6	24.6	24.2	24.5	25.8	26.0	
Rural	69.8	69.0	68.7	67.7	68.8	72.8	72.8	72.4	70.8	70.4	
Education completed											<0.001
No formal education	45.2	41.3	39.5	34.9	30.0	52.0	49.3	48.5	45.6	40.2	
Primary	17.7	16.0	14.5	14.0	13.7	23.8	22.3	21.1	20.1	19.1	
Secondary+	9.5	9.2	10.4	7.3	8.6	8.0	7.3	8.3	8.7	8.2	
Missing	27.6	33.6	35.6	43.8	47.7	16.3	21.1	22.1	25.6	32.5	
Grant receipt											<0.001
Recipient	55.4	64.1	71.5	67.4	67.1	80.9	86.7	90.6	88.2	88.5	
Non-recipient	32.3	27.5	20.6	20.9	21.2	11.2	8.0	6.2	6.8	6.3	
Don’t know	12.2	8.4	7.9	11.8	11.7	7.9	5.3	3.2	5.0	5.2	
Marital status											<0.001
Never been married	23.1	23.6	25.6	28.0	27.8	15.6	15.9	16.6	18.0	18.6	
Married	42.1	40.2	40.8	38.5	39.6	36.2	37.2	36.5	35.6	34.1	
Previously Married	33.8	34.8	31.9	28.3	26.7	47.8	46.2	45.9	43.5	43.5	
Don’t know	0.9	1.4	1.7	5.1	5.9	0.4	0.6	1.0	2.8	3.8	
HH size - Overall											<0.001
1	3.0	3.7	3.4	2.7	2.4	2.3	2.4	2.6	2.5	2.5	
2-6	27.2	25.6	26.9	27.1	28.7	23.5	22.9	22.6	22.2	22.3	
7-10	31.1	32.7	32.4	31.1	29.4	30.3	30.7	29.8	28.9	28.8	
11+	38.7	38.0	37.4	39.2	39.5	43.9	44.0	45.0	46.4	46.4	

* p-value for chi square comparisons of resident to non-resident older persons by selected characteristics of surveillance population.

Close to three-quarters of resident older people were female compared to less than 50% of non-resident older people. For each year, a slightly higher proportion of non-resident than resident older people lived in urban areas. On the other hand, a higher percentage of resident than non-resident older people reported not to have completed any formal education, to be unemployed, to be receiving government grants and to belong to large households of 11 or more members (Table 2-1). That is, there were statistically significant differences between the resident and non-resident populations. This analysis as a result is restricted to only individuals who were resident in the surveillance area as at mid-year for each of the years from 2005-2010. In addition, no data is collected on the composition, living arrangements or potential support exchanges by and from household members outside of the surveillance area. However, the differences by residency status in socio-economic variables highlight the importance to allow in subsequent analyses for whether a household had non-resident members or not.

In addition to restricting the analysis to only resident older people, the analytical sample was further restricted to only older persons with complete yearly status observations (n=2749) in the surveillance over the period 2005-2010. This was specifically done for analyses on changes in support flow status over the study period. A detailed explanation of this sub-analysis and the analytical sample is provided in sub-section 2.6.4 below.

2.6.3 Measures

The unit of analysis in this paper is the individual older person, but in addition to individual characteristics of the older person characteristics of the households in which older people reside are also considered. At individual level the following variables potentially associated with intergenerational flow of support are explored: age (in five and ten-year age groups), sex (male or female), place of residency (urban, peri-urban or rural), employment status (yes/no), receipt of government grants (yes/no), being a primary care giver to children under 18 years (yes/no), co-residency with one's own children for matched parent-child dyads and marital status (never been married,

married, previously married). At household level the variables are: household size, number of members in employment, number receiving grants, household headship, and household composition defined as sole older person household, older persons' only households, skip generation household (older plus adult child or grandchild only), or multi-generation household (children, adults and older persons). These factors were selected based on prior findings in the literature as potential confounders of the relationship between income and intergenerational support exchanges.

The main outcome variables in this analysis were directional flow of intergenerational support, which was estimated from information on employment and access to government grants within the household – the major sources of income in rural South Africa (Booysen, 2004; Kimuna and Makiwane, 2007), and changes in support flows given change in living arrangements. An indicator variable was generated for exchanges of support between older and younger people (intergenerational exchanges), with four categories:

1) in the case of a single older person or an older-persons-only household, with an older person employed or receiving a grant, the directional flow of support was assumed to be self or peer-support;
2) where the older person in a household with adults and/or children was the only person listed as employed or receiving a grant (sole income earner in household) the directional flow of support was assumed to be downward;
3) where the older person was not employed or receiving a grant but an adult or child in the household was recorded to be in employment or receiving a government grant, the directional flow of support was assumed to be upward; and
4) where an older person had an income (from employment or grants) and there was at least one other adult or child in the household also having an income the directional flow of support was assumed to be bi-directional or reciprocal.

A diagrammatic representation of these support flows is presented in Figure 2-1.

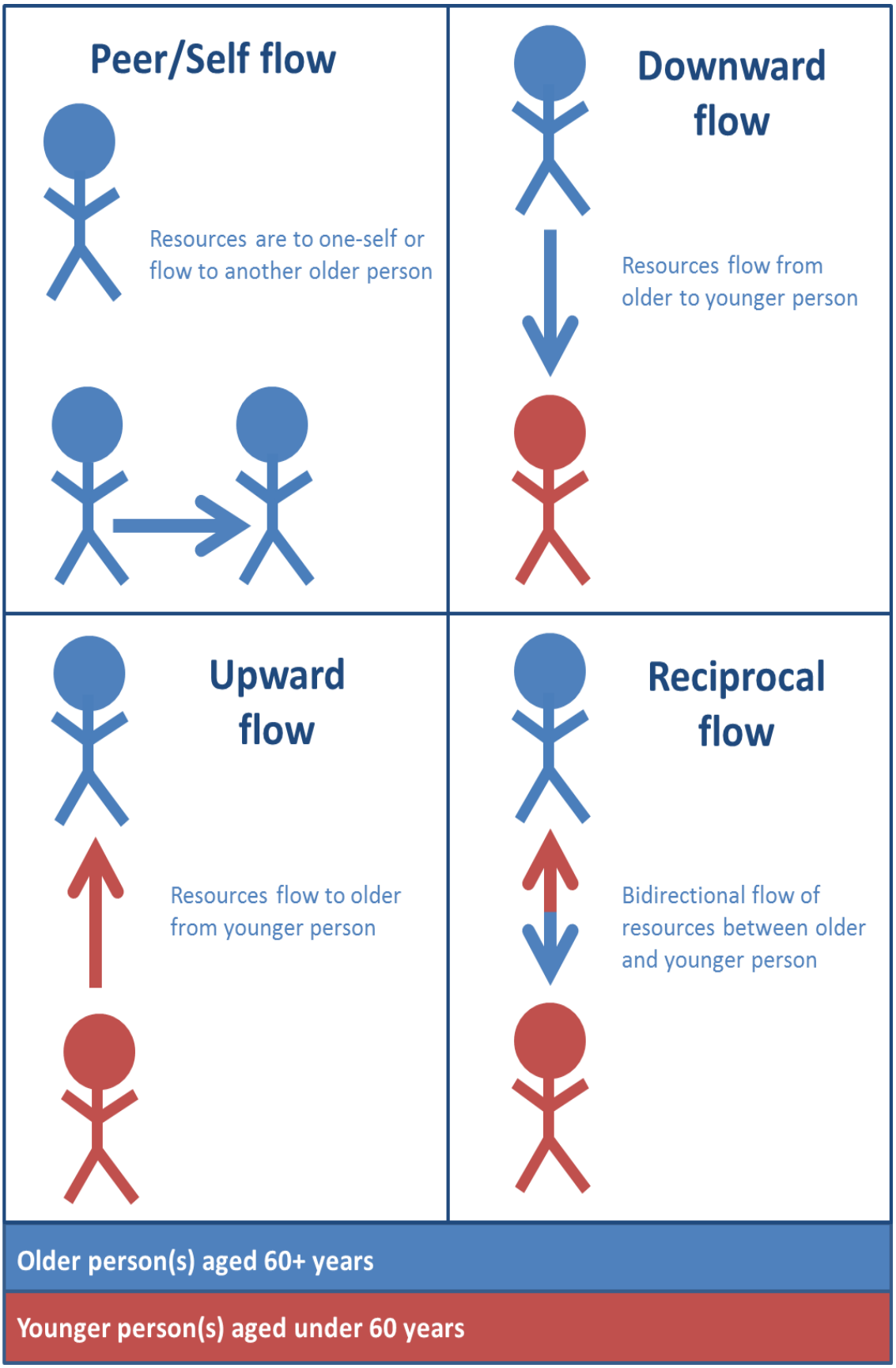


Figure 2-1: Diagrammatic representation of support flows between older and younger generations

2.6.4 Statistical analysis

Bivariate and multivariate descriptive statistics were assessed using chi-squared, t-tests and log-rank tests. Changes over time in household size, structure (sole older person household, proportion of adults, children and older people, and household headship), composition (in employment, in receipt of government grants), and household socio-economic status were also examined. Information on employment, government cash transfers and household living arrangements at individual level was taken as at mid-year for 2005-2010. The year 2008 was excluded from the analysis because the household social economic module (HSE) in which information on employment and grants is collected was not conducted. There were therefore up to five repeat observations for the n=6806 persons aged 60+ during the period 2005-2010. About 15% (n=906) of the study participants had only a single observation; close to half (45%, n=2749) were observed in each of the years over the study period (2005, 2006, 2007, 2009 and 2010). For those older persons observed throughout the study period (n=2749) multinomial logistic regressions were conducted to explore transition into various categories of intergenerational support flows between t_0 and t_1, where t_0 refers to characteristics of older persons at baseline observation in 2005 and t_1 are their characteristics as at last observation in 2010. Multinomial logistic regressions were run for change between t_0 and $t_1$into peer, downward, upward and reciprocal support using no change in intergenerational transfer flows as the base outcome, given changes in living arrangements. All models were adjusted for age, education, marital status, place of residency and household wealth status (or socio-economic status (SES)) as at t_1. An alpha level of 0.05 was set to test statistical significance. All analyses were conducted using Stata 11.2 (StataCorp, 2009).

2.6.5 Missing data

To accommodate missing data for some of the covariates included in the models, informed imputations were used on the basis of information collected in earlier or later years if available. For instance, if an individual had missing data on grant receipt in later years but was known to be receiving a grant in earlier years that information was carried forward provided the individual was age eligible for that particular grant.

To further address remaining missing data, an extra 'missing/don't know' category was created for affected variables. Although this could potentially introduce some bias in this study's estimates, any such bias is likely to be small if the correlation between the outcome and explanatory variable is weak (Steele, Kallis and Joshi, 2006), as was the case here.

2.6.6 Ethics approval

Ethics approval for all data used in this analysis was obtained from the University of KwaZulu-Natal Biomedical Research Ethics Committee (Ref: E009/00) (see Appendix 3, pp. 218), which is annually re-certified (see Appendix 4, pp. 219). Participation in the Africa Centre's household surveillance is by verbal informed consent.

2.7 Study findings

2.7.1 A description of older people in rural South Africa

There has been a modest increase in the total population under surveillance by the Africa Centre in northern KwaZulu-Natal, South Africa. The total mid-year population increased from around 88,900 in 2005 to about 92,401 in 2010; with more women (52%) than men (48%) overall. The surveillance population as a whole is relatively young, with a median age of 20 years (IQR = 10-33). Of the total mid-year population, around 6% were older people aged 60 years or older. The overall median age among older people was 69 years (IQR = 65-76); 68 (IQR = 62-75) for men and 70 (IQR = 65-76) for women.

Socio-demographic details and some living arrangement characteristics for resident older people stratified by sex are shown in Table 2-2. The population of older people comprised about 70% women; over 40% of both men and women were in the age range 60-69 years. There was little difference between men and women with regard to co-residency with own children, place of residency and household size, although a slightly higher percentage of older women than older men were co-resident in the same homestead with their own children. Overall, close to 29% (n=1464) of older people, most of whom women, were listed as primary care givers to one or more young children (<18 years) (Table 2-2); women were also more likely to look after more

than one child than men were. In over half of the cases where an older person was said to be a primary care-giver it was to an orphaned child.

Table 2-2: Description of surveillance resident population aged 60 years and above, 2005-2010

Residents	**Males**						**Females**					
Characteristics	2005	2006	2007	2009	2010	p-value	2005	2006	2007	2009	2010	p-value
Number of individuals	1271	1270	1254	1281	1274		2960	2962	2955	3041	3146	
Age group						<0.001						<0.001
60-64	31.1	29.2	29.0	29.8	31.6		24.6	22.5	21.9	24.0	26.7	
65-69	25.0	27.6	28.2	28.1	24.4		25.1	26.4	27.0	24.0	20.3	
70-74	16.1	15.0	15.2	15.3	18.0		21.8	19.9	18.9	18.6	20.3	
75-79	17.0	16.8	14.8	12.3	10.9		16.7	18.1	17.9	17.6	15.7	
80+	10.8	11.5	12.7	14.5	15.1		11.8	13.1	14.3	15.9	17.0	
Marital status						<0.001						<0.001
Never been married	21.5	21.7	21.4	21.2	21.4		13.1	13.4	14.6	16.7	17.4	
Married	66.9	67.7	66.9	66.6	64.6		23.1	24.2	23.6	22.6	21.7	
Previously married	11.3	9.9	10.4	9.4	10.6		63.4	61.8	60.9	57.9	56.8	
Don't know	0.3	0.7	1.4	2.9	3.5		0.4	0.6	0.9	2.8	4.0	
Education completed						<0.001						<0.001
No formal education	48.0	44.9	42.8	39.1	32.4		53.7	51.2	50.9	48.3	43.4	
Primary	21.1	19.1	17.9	17.7	17.0		24.9	23.6	22.5	21.1	19.9	
Secondary+	11.7	9.1	11.3	11.7	10.0		6.4	6.5	7.0	7.4	7.4	
Missing	19.2	26.9	28.0	31.5	40.5		15.0	18.6	19.6	23.2	29.3	
Place of residency						0.358						0.364
Urban	2.0	2.3	2.5	2.8	3.1		2.8	3.2	3.3	3.6	3.8	
Peri-Urban	23.4	22.4	23.4	24.9	25.3		25.1	24.9	25.0	26.2	26.3	
Rural	74.6	75.3	74.2	72.3	71.6		72.0	71.8	71.7	70.2	69.9	
Is a primary care-giver*						<0.001						<0.001
No	92.8	93.0	96.4	97.8	96.5		48.8	47.5	49.7	56.1	57.3	
Yes	7.2	7.0	3.6	2.2	3.5		51.2	52.5	50.3	43.9	42.7	
Co-resident with own children						0.917						0.631
No	20.1	20.1	20.4	20.8	21.4		17.5	17.7	17.9	18.5	18.8	
Yes	79.9	79.9	79.6	79.2	78.6		82.5	82.3	82.1	81.5	81.2	
Household Headship						0.750						<0.001
Self	91.0	90.6	91.2	90.2	91.8		44.9	46.6	48.9	51.2	53.3	
Spouse	0.9	1.3	1.1	1.0	1.3		23.2	22.9	22.5	22.3	21.7	
Other	8.1	8.1	7.7	8.8	6.9		31.9	30.5	28.6	26.5	25.0	

* Older person is listed in the household surveillance as a primary care-giver for a household member child aged less than 18 years.

p-value = difference in the categories for each variable over time for males and females

2.7.2 Household typology, employment and grant receipt patterns in rural South Africa

Table 2-3 shows older men and women by selected characteristics and trends over time of households in which they reside. The percentage of older people in older-only households was very small, but there were relatively more men than women in older-only households. A higher proportion of women than men were in multi-generational households. Proportion of older people in skip-generation households was very low for both men and women. Consistent with an average household size of eight persons, the majority of older people belonged to households with seven or more persons; household sizes varied widely from 1 to 61 household members (median seven).

Table 2-3: Older people by characteristics of households in which they reside, 2005-2010

			Male			
	2005	**2006**	**2007**	**2009**	**2010**	**p-value**
Number of individuals	1,271	1,270	1,254	1,281	1,274	
Household typology						0.364
Older only HH	5.4	5.1	5.4	4.8	4.6	
Older + children HH	1.2	0.9	0.9	0.9	0.7	
Older + adults HH	9.2	9.9	10.0	12.1	12.3	
Multi-generational HH	84.2	84.1	83.7	82.3	82.3	
Household size						0.292
1	3.5	3.5	3.7	3.3	3.5	
2-6	23.1	23.0	23.1	21.6	21.8	
7-10	37.3	37.9	37.0	34.5	34.2	
11+	36.1	35.6	36.2	40.6	40.5	
			Female			
Number of individuals	2,960	2,962	2,955	3,041	3,146	
Household typology						0.906
Older only HH	2.7	2.5	3.1	3.0	2.7	
Older + children HH	1.0	1.0	0.9	0.7	0.8	
Older + adults HH	8.8	8.8	8.8	9.4	9.3	
Multi-generational HH	87.6	87.7	87.2	86.9	87.2	
Household size						0.927
1	1.8	1.9	2.2	2.1	2.1	
2-6	23.7	22.9	22.4	22.4	22.5	
7-10	37.5	37.1	37.2	36.7	36.4	
11+	37.0	38.2	38.3	38.8	39.0	

Note: HH = Household

* p-value from chi square tests of trends over time by characteristics of households in which older men and women reside respectively.

Employment rates have generally declined in the area over the study period. As shown in Figure 2-2 panel A, there was a downward trend in the proportion of older males and females in households with at least one employed person (adult or older person). For example, older men living in households with at least one employed household member declined from 72.9% in 2005 to 62.5% in 2010. The proportion of older women who lived in a household with at least one person in employment was a few percentage points higher than for men, but similarly declined from 75.1% in 2005 to 66.3% in 2010. Employment levels among older people (Figure 2-2 panel B) themselves have similarly declined over time; employment rates among older men were higher than among older women. In addition, the proportion of older people who were the only employed person in the household has also fallen, especially among older women for whom this is now very rare.

In contrast, the proportion of older people accessing a government grant has steadily increased for both men and women, substantially so among older men (Figure 2-2 panel C). In spite of the upward trend in grant receipt, the proportion of older persons who were the only grant recipient in the household has fallen over time.

Combining information on employment status and access to grants for older people and other household members shows upward trends in older persons residing with at least one person with an income in the household, such that by 2010 about 87% and 92% older men and women respectively belonged to a household with at least one person earning a regular income (Figure 2-2 panel D). However, the proportion of older persons who were the sole income earners in their household declined over time; by close to 50% for example among women from 13.2% in 2005 to 6.7% in 2010.

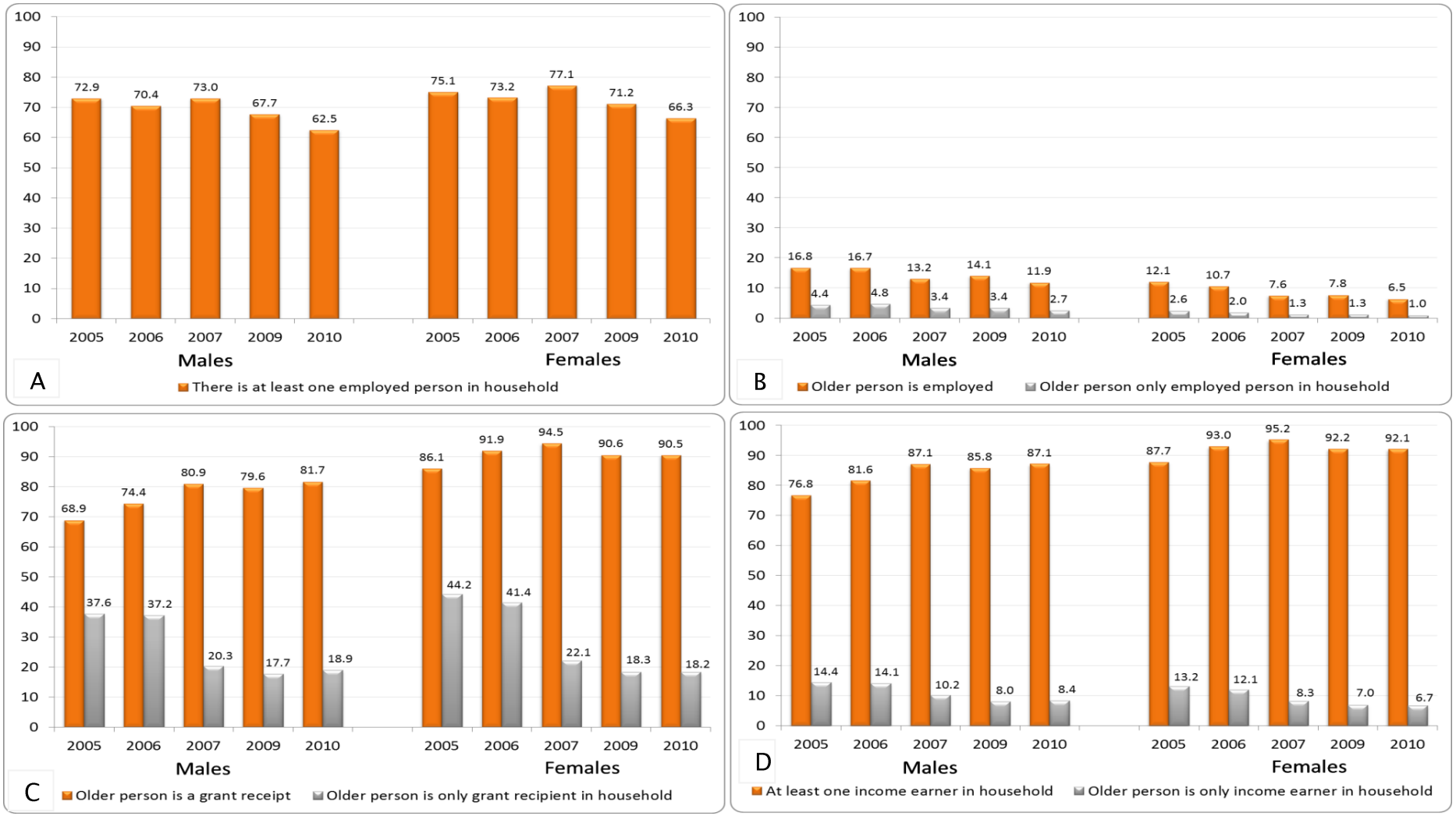


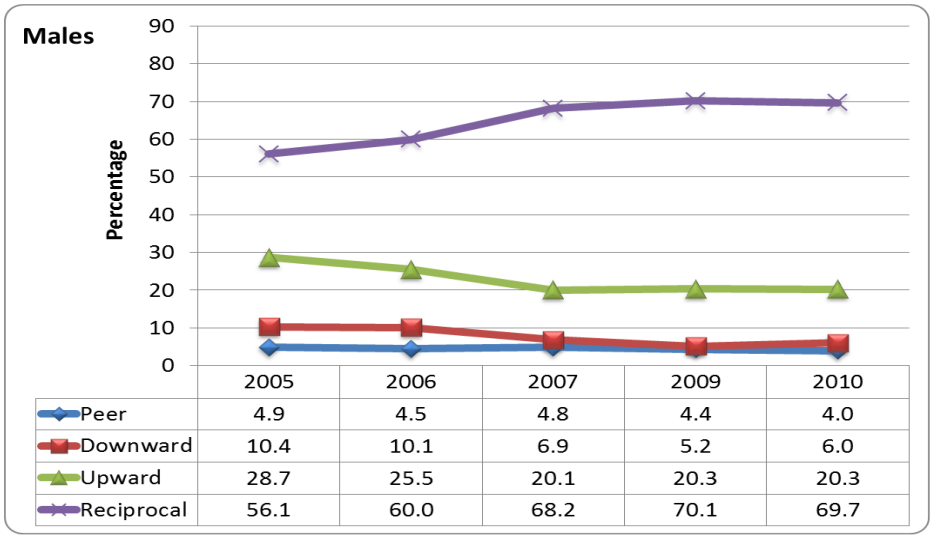
Figure 2-2: Employment, receipt of government grants and having an income among older people over time by sex, 2005-2010

2.7.3 Patterns and trends of intergenerational flows of support, 2005-2010

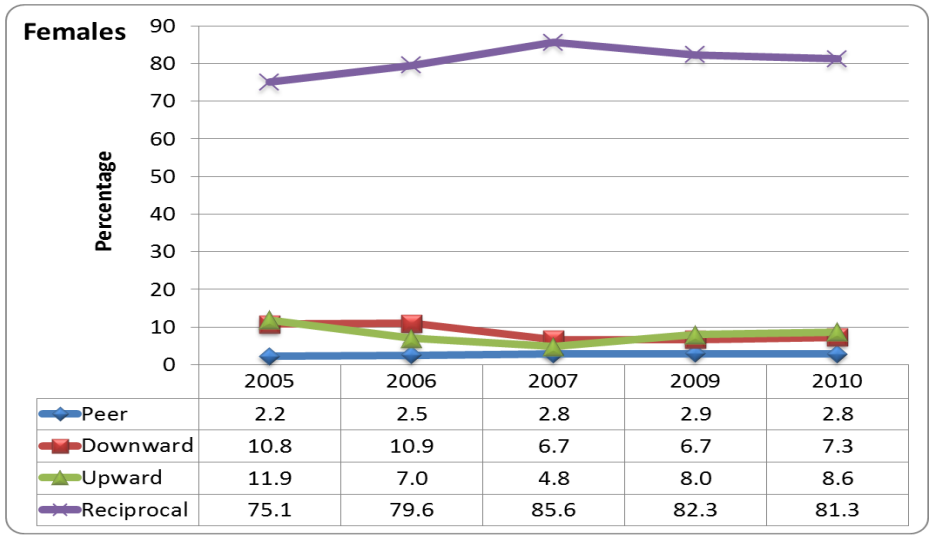
Using data on grants and employment status of older persons and other household members, Figure 2-3 shows the likely directional flow of support exchanges on the assumption that whatever income is earned (from employment or grants) by household members will be shared in some way.

If adults or children are the only source of income then support will predominantly flow upward (from younger to older person); if the older person is the only one with an income then support will most likely flow downwards, and where both younger and older people have an income then there is likely to be some sharing of material resources (reciprocal) within the household. For older-only households financial resources will either flow towards self or to another older person (peer-support).

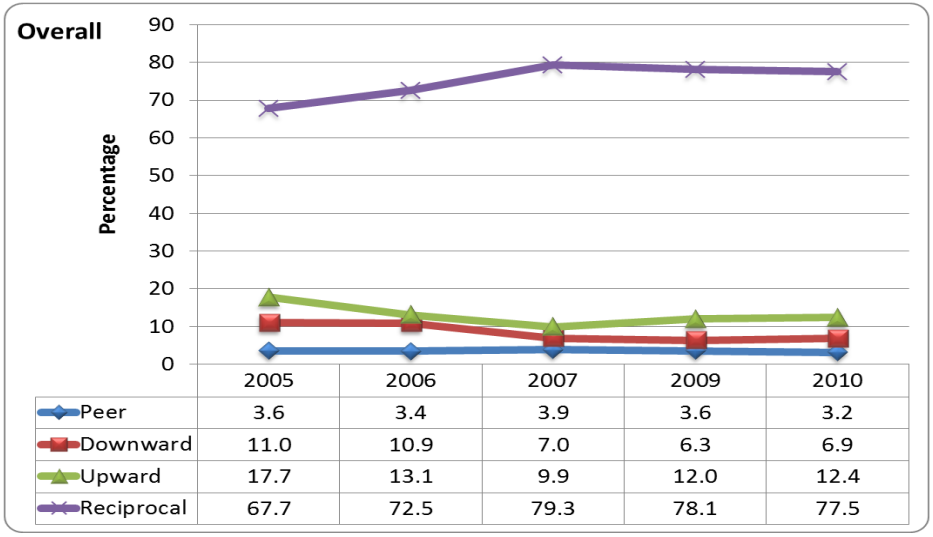
Figure 2-3 shows that the proportion of households where the likely directional flows of support is peer-support has remained relatively constant at around 5% for men and 3% women. The proportion of households with downward flow of support was always low and has declined for men and women separately and overall declined from around 11% in 2005 to 7% in 2010. The percentage of older people likely to be receiving material support from younger persons (upward support) was much higher than for downward or peer support flows ranging from 8% to 30%, but upward material support also declined over time. The number of households where older and younger people are supposedly financially supporting each other (reciprocal support) has further increased overall from a high of 68% in 2005 to 78% in 2010.



	2005	2006	2007	2009	2010
Peer	4.9	4.5	4.8	4.4	4.0
Downward	10.4	10.1	6.9	5.2	6.0
Upward	28.7	25.5	20.1	20.3	20.3
Reciprocal	56.1	60.0	68.2	70.1	69.7



	2005	2006	2007	2009	2010
Peer	2.2	2.5	2.8	2.9	2.8
Downward	10.8	10.9	6.7	6.7	7.3
Upward	11.9	7.0	4.8	8.0	8.6
Reciprocal	75.1	79.6	85.6	82.3	81.3



	2005	2006	2007	2009	2010
Peer	3.6	3.4	3.9	3.6	3.2
Downward	11.0	10.9	7.0	6.3	6.9
Upward	17.7	13.1	9.9	12.0	12.4
Reciprocal	67.7	72.5	79.3	78.1	77.5

Figure 2-3: Intergenerational flows of support among older people by year and Sex, 2005-2010

Table 2-4 presents differentials in directional flows of support by characteristics of older people for 2010. Neither the percentage of men nor of women receiving peer-support varied much with age. The percentage of men supporting younger people and those in reciprocal support significantly increased with age, while the percentage receiving support from younger people declined with increasing age. For women, support flows did not change significantly with age.

In 2010, for both men and women differentials by place of residency were significant: upward support was highest for urban dwellers, while reciprocal support was more common in peri-urban and rural areas. In terms of marital status, reciprocal support was more common for married men and women who were previously married. A relatively higher proportion of older men resident with their own children (45%) were likely to receive upward support than seen among older women in this category (37%). Among older people co-resident with their own children the highest proportion were in reciprocal support flow households among both men and women.

Table 2-4 further shows that most older people listed as main care-givers were likely to be in reciprocal support flows, consistent with findings regarding co-residency with own children. Other differentials worth mentioning relate to household structure. In particular, whereas about 44% of older people living with children only were likely to be receiving financial support from the children (upward support), less than 40% of older persons resident with adults only were likely to be receiving support from the adults. Over 50% of older persons belonging to households with 7 or more members were in reciprocal financial support flows among both men and women.

Table 2-4: Differentials in support flows by characteristics of older people, 2010

	MALES					FEMALES				
	Peer	Down	Up	Reciprocal		Peer	Down	Up	Reciprocal	
	%	%	%	%	p-value	%	%	%	%	p-value
Age Group					0.011					0.08
60-69	4.5	2.7	44.7	48.1		2.1	2.8	37.8	57.3	
70-79	4.9	5.7	38.6	50.8		3.1	4.0	33.7	59.2	
80+	4.7	6.2	32.6	56.5		3.4	4.5	36.6	55.6	
Place of residency					0.047					<0.01
Urban	7.5	2.5	60.0	30.0		2.5	6.7	53.3	37.5	
Peri-Urban	5.6	5.9	38.5	50.0		3.5	3.7	32.6	60.1	
Rural	4.2	3.5	41.2	51.1		2.4	3.3	36.5	57.9	
Marital status					<0.01					<0.01
Never married	9.3	4.9	40.7	45.1		5.2	3.7	34.8	56.4	
Married	2.2	2.6	41.8	53.5		1.6	2.8	40.1	55.5	
Previously married	7.1	8.6	36.4	47.9		2.0	3.5	34.3	60.2	
NA/DKN	14.0	14.0	46.5	25.6		7.4	7.4	47.1	38.0	
Co-resident with own children					<0.01					<0.01
No	21.6	9.9	27.5	41.0		14.2	9.0	30.9	45.9	
Yes	0.0	2.5	44.9	52.6		0.0	2.3	37.3	60.4	
Main Care Giver					0.441					<0.01
No	4.8	4.1	41.1	50.0		4.7	5.2	37.5	52.7	
Yes	0.0	2.3	43.2	54.5		0.0	1.3	34.2	64.5	
HH Headship					0.332					<0.01
Self	4.9	4.2	40.7	50.2		4.0	4.5	33.7	57.8	
Spouse	0.0	5.9	64.7	29.4		2.2	2.9	39.9	55.0	
Other	2.3	2.3	42.0	53.4		0.3	1.9	37.9	59.9	
HH SES					<0.01					<0.01
Poor	8.4	6.6	23.2	61.7		4.7	5.6	21.7	68.0	
Moderate	1.5	3.7	32.5	62.3		1.0	2.7	24.3	72.0	
Richer	1.4	4.1	29.4	65.1		1.2	3.1	24.1	71.6	
HH structure					<0.01					<0.01
Older only HH	100.0	0.0	0.0	0.0		100.0	0.0	0.0	0.0	
Older + children	0.0	33.3	44.4	22.2		0.0	24.0	44.0	32.0	
Older + adults	0.0	23.6	39.5	36.9		0.0	20.8	36.2	43.0	
Multi-gen HH	0.0	1.1	43.7	55.2		0.0	1.6	37.1	61.3	
HH size					<0.01					<0.01
1	100.0	0.0	0.0	0.0		100.0	0.0	0.0	0.0	
2-6	5.4	17.3	38.5	38.8		2.5	14.1	36.2	47.2	
7-10	0.0	0.9	42.9	56.3		0.0	1.1	34.8	64.1	
11+	0.0	0.2	44.3	55.5		0.0	0.1	38.6	61.4	
Number of observations	59	52	524	639		84	111	1136	1815	

Note: HH = household; p-value = difference in intergenerational support flows by categories for each variable for males and females; NA/DKNn= Not applicable or don't know

2.7.4 Changes in living arrangements and intergenerational support flows over time

In the sub-sample of participants with complete information throughout the period 2005-2010 (n=723 men and 2026 women), changes in living arrangements between t_0 (baseline) and t_1 (last observation) are presented in Table 2-5 and Table 2-6 by 10-year age groups for men and women respectively, which revealed considerable stability by age group and overall for many of the characteristics considered.

For example among older men (Table 2-5), 80% of men co-resident with their own child at t_0 were still in that category at t_1; 16% were not co-resident at both t_0 and t_1. Household structure had also remained unchanged over the period for around 90% of these older men. Similarly, the majority of older men reported at both times to be either poor (close to 60%) or rich (one in five). With regard to employment status and access to grants, just a little over one half of older people belonged to households with at least one employed person or were grant recipients in the household at both t_0 and t_1. There were significant changes in household size over time; overall, close to 50% of older men belonged to households that increased in size between t_0 and t_1; household size declined for almost 30% of male participants.

Changes in living arrangements observed for older men were generally similar to those for older women (Table 2-6). Some notable differences pertained to change in being a main care-giver; with for instance over 10% of older women who were not a main care-giver at t_0 becoming a main care-giver at t_1 compared to less than 3% for men. However, living arrangements characteristics among older women were generally as stable as among older men. This was the case even when the analysis was extended to all participants observed at least twice over the period 2005-2010 (n=1587 men and 3620 women) (results not shown); living arrangements with respect to co-residency with own children, household SES, household size, household structure, employment and grant receipt status remained largely unchanged even among this extended sub-sample.

Table 2-5: Changes by age in living arrangements of older men in rural South Africa*

	60-69	70-79	80-89	90+	Total	p-value
Number of observations	234	319	142	28	723	
Change in co-residency status						0.768
Not Co-resident at t_0 and t_1	13.2	18.2	14.8	10.7	15.6	
Co-resident at t_0 but not at t_1	2.1	3.4	4.2	3.6	3.2	
Not Co-resident at t_0 but co-resident at t_1	1.3	0.9	1.4	0.0	1.1	
Co-resident at t_0 and at t_1	83.3	77.4	79.6	85.7	80.1	
Change in HH socio-economic status						0.377
No change, rich at t_0 and t_1	22.2	22.2	17.4	21.7	21.2	
Has become richer, was poor at t_0 but rich at t_1	6.8	11.7	6.4	13.0	9.1	
Has become poorer, was rich at t_0 but poor at t_1	13.1	14.6	10.1	17.4	13.3	
No change, poor at t_0 and at t_1	58.0	51.5	66.1	47.8	56.3	
Change in HH size						0.300
HH size has remained same between t_0 and t_1	21.8	25.1	23.2	28.6	23.8	
HH size has increased between t_0 and t_1	48.3	47.3	47.9	25.0	46.9	
HH size has declined between t_0 and t_1	29.9	27.6	28.9	46.4	29.3	
Change in being Main Caregiver						0.322
No change, Not a Main Caregiver at t_0 and t_1	90.6	90.0	91.5	85.7	90.3	
Main caregiver at t_0 but not at t_1	8.1	6.9	4.2	7.1	6.8	
Not Main Caregiver at t_0 but has become at t_1	1.3	3.1	4.2	7.1	2.9	
No change, Main Caregiver at t_0 and t_1	0.0	0.0	0.0	0.0	0.0	
Change in HH structure						0.591
No change in HH typology between t_0 and t_1	92.3	89.0	88.7	85.7	89.9	
Became Older-only HH between t_0 and t_1	1.7	1.3	0.7	0.0	1.2	
Became Older with children only HH between t_0 and t_1	0.4	0.0	0.0	0.0	0.1	
Became Older with adults only HH between t_0 and t_1	4.3	6.0	6.3	7.1	5.5	
Became multigenerational HH between t_0 and t_1	1.3	3.8	4.2	7.1	3.2	
Change in having an employed person in HH						0.149
No change, No Employed person in HH at t_0 and t_1	10.7	14.4	11.3	14.3	12.6	
Employed person in HH at t_0 but not at t_1	18.4	26.0	25.4	28.6	23.5	
No employed person in HH at t_0 but has at least one at t_1	15.8	10.0	12.0	21.4	12.7	
No change, Has at least one employed person at t_0 and t_1	55.1	49.5	51.4	35.7	51.2	
Change in older person receiving a grant HH						<0.001
No change, no grant receipt older person in HH at t_0 and t_1	15.6	3.0	0.0	0.0	6.3	
Older grant Receipt person in HH at t_0 but not at t_1	8.7	18.5	11.7	25.0	14.2	
No older grant receipt person in HH at t_0 but has at t_1	52.0	11.2	0.9	0.0	21.6	
No change, has older grant receipt person at t_0 and t_1	23.7	67.4	87.4	75.0	57.9	

* For participants observed throughout 2005 to 2010; baseline (t_0) is observation in 2005, while t_1 is status at last observation in 2010; Age as at last observation.

Table 2-6: Changes by age in living arrangements of older women in rural South Africa*

	60-69	70-79	80-89	90+	Total	p-value
Number of observations	561	997	399	69	2026	
Change in co-residency status						<0.001
Not Co-resident at t_0 and t_1	11.1	11.6	18.3	23.2	13.2	
Co-resident at t_0 but not at t_1	2.9	5.7	7.0	2.9	5.1	
Not Co-resident at t_0 but co-resident at t_1	1.2	1.0	1.0	1.4	1.1	
Co-resident at t_0 and at t_1	84.8	81.6	73.7	72.5	80.7	
Change in HH socio-economic status						0.133
No change, rich at t_0 and t_1	19.7	20.8	18.6	11.3	19.7	
Has become richer, was poor at t_0 but rich at t_1	13.3	10.3	7.5	7.5	10.4	
Has become poorer, was rich at t_0 but poor at t_1	10.6	13.1	12.4	11.3	12.2	
No change, poor at t_0 and at t_1	56.4	55.9	61.5	69.8	57.7	
Change in HH size						0.746
HH size has remained same between t_0 and t_1	19.4	21.9	21.8	20.3	21.1	
HH size has increased between t_0 and t_1	45.5	46.4	44.1	42.0	45.6	
HH size has declined between t_0 and t_1	35.1	31.7	34.1	37.7	33.3	
Change in being Main Caregiver						<0.001
No change, Not a Main Caregiver at t_0 and t_1	21.7	31.7	44.1	56.5	32.2	
Main caregiver at t_0 but not at t_1	24.8	25.5	30.3	29.0	26.4	
Not Main Caregiver at t_0 but has become at t_1	10.0	10.7	9.5	7.2	10.2	
No change, Main Caregiver at t_0 and t_1	43.5	32.1	16.0	7.2	31.2	
Change in HH structure						0.05
No change in HH typology between t_0 and t_1	90.2	90.1	92.7	85.5	90.5	
Became Older-only HH between t_0 and t_1	0.7	1.5	0.0	1.4	1.0	
Became Older with children only HH between t_0 and t_1	0.4	0.3	0.3	1.4	0.3	
Became Older with adults only HH between t_0 and t_1	6.2	4.1	4.3	8.7	4.9	
Became multigenerational HH between t_0 and t_1	2.5	4.0	2.8	2.9	3.3	
Change in having an employed person in HH						0.019
No change, No Employed person in HH at t_0 and t_1	8.9	10.7	11.8	15.9	10.6	
Employed person in HH at t_0 but not at t_1	20.3	23.6	19.8	21.7	21.9	
No employed person in HH at t_0 but has at least one at t_1	13.9	11.4	11.0	1.4	11.7	
No change, Has at least one employed person at t_0 and t_1	56.9	54.3	57.4	60.9	55.8	
Change in older person receiving a grant HH						<0.001
No change, no grant receipt older person in HH at t_0 and t_1	4.3	0.5	0.9	0.0	1.7	
Older grant Receipt person in HH at t_0 but not at t_1	17.4	17.8	20.0	20.8	18.2	
No older grant receipt person in HH at t_0 but has at t_1	10.5	2.7	1.3	0.0	4.5	
No change, has older grant receipt person at t_0 and t_1	67.8	79.0	77.8	79.2	75.6	

* For participants observed throughout 2005 to 2010; baseline (t_0) is observation in 2005, while t_1 is status at last observation in 2010; Age as at last observation.

Despite the relative stability in living arrangement patterns, Figure 2-4 shows there were significant changes in probable directional flows of support among participants observed throughout the period 2005-2010 between baseline and last observation status. However, around 51% (n=371/723) of older men and 46% (n=934/2026)

women experienced changes in the directional flows of support between t_0 and t_1 with the biggest changes being those into upward and reciprocal support.

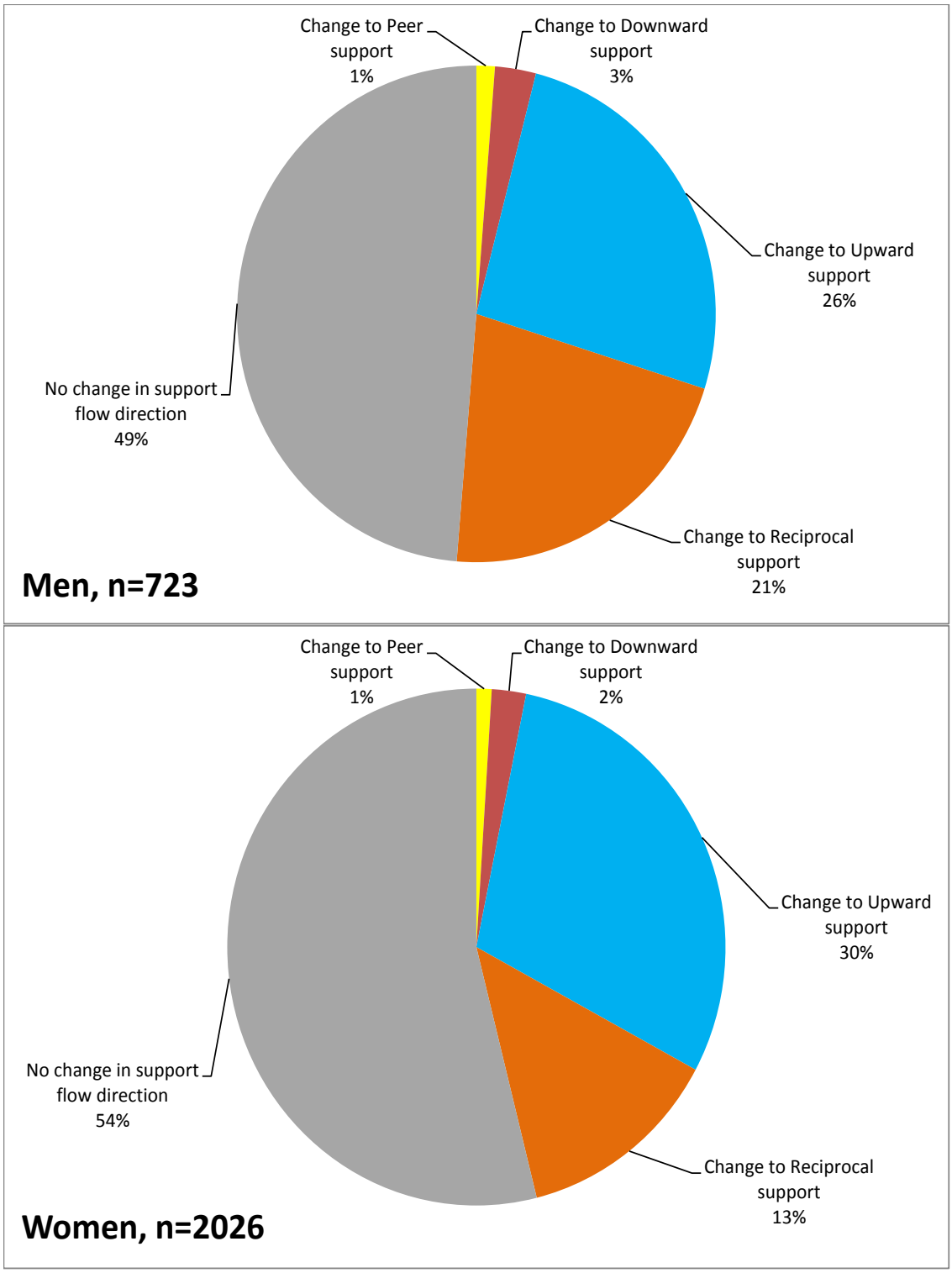
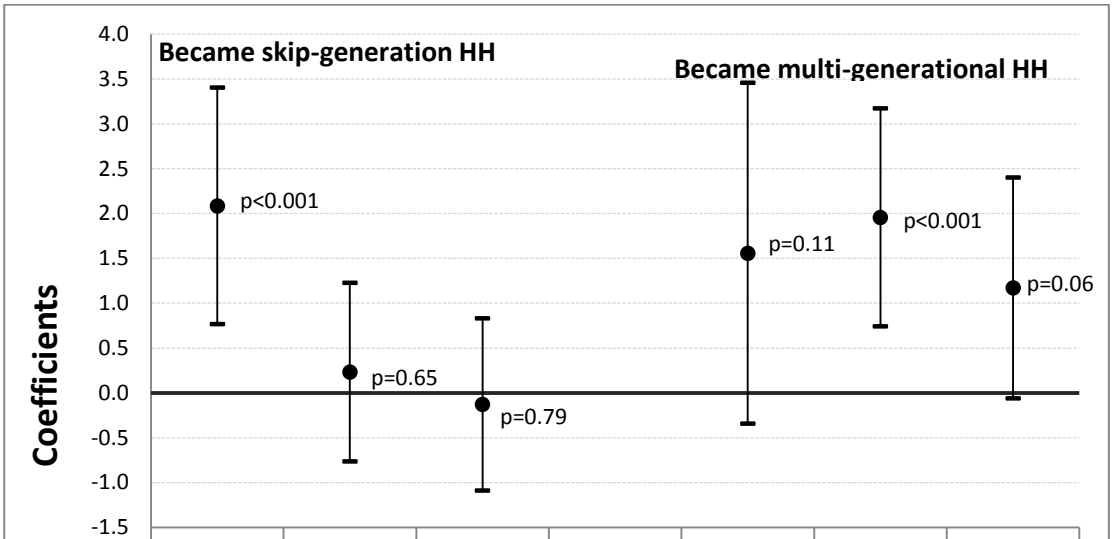


Figure 2-4: Changes in intergenerational support flows over time for men and women

2.7.5 Relationship between living arrangement and intergenerational flows

This section explores in multinomial regression analyses of the sub-sample with full observations over the period 2005-2010 (n=2479), the relative risk of changes in intergenerational support flows contingent on changes in household living arrangements. Figure 2-5 shows for older men results from the regressions of transitions between baseline and last observation into various categories of intergenerational support flows, given changes in living arrangements, using no change in support flows as base category and adjusted for age, education, marital status, place of residency and household wealth status as at t_1 (2010). For older men whose household had changed to a skip-generation household, there was a statistically significant increased likelihood of change in intergenerational support flows to downward support. Whereas for older men in households which had become multigenerational, there was a statistically significantly increased likelihood of change into upward support flows. Multigenerational household structure was further associated with marginally increased relative risks of transition into reciprocal support.

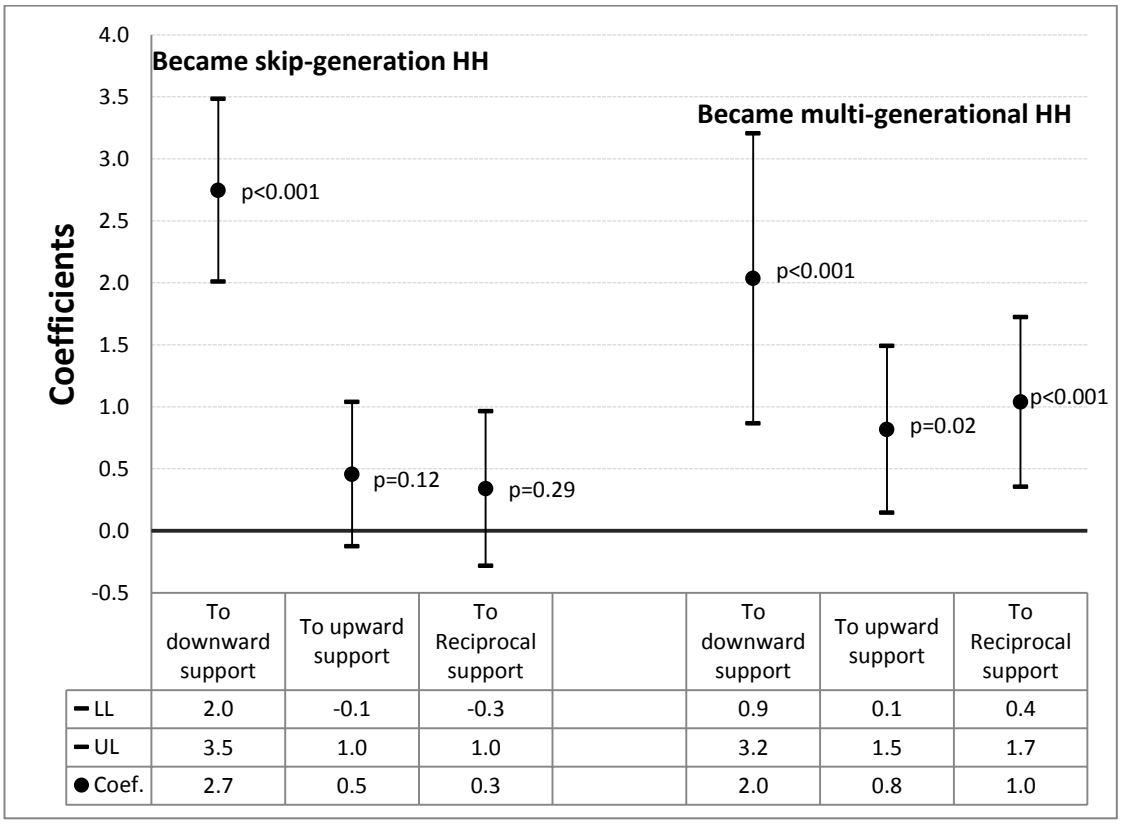


	To downward support	To upward support	To Reciprocal support		To downward support	To upward support	To Reciprocal support
━ LL	0.8	-0.8	-1.1		-0.3	0.7	-0.1
━ UL	3.4	1.2	0.8		3.5	3.2	2.4
● Coef.	2.1	0.2	-0.1		1.6	2.0	1.2

Figure 2-5: Relative risk of change in support flows given change in living arrangements between t_0 and t_1, Males

Note: Models adjusted for age, marital status, education, place of residency and household wealth status at t_1. HH=Household

As was the case for older men, Figure 2-6 shows that when households with older women became skip-generation or multi-generational, this was statistically significantly associated with transition into downward and upward support flows, respectively. It is also worth pointing out that for both men (Figure 2-5) and women (Figure 2-6), where the change in living arrangements was to become a skip-generation households, the relative risks of transition into upward support and reciprocal support were not statistically significant relative to no change in support flows between t_0 and t_1. For older women, change into multigenerational households was associated with significantly increased relative risk of transition into downward support relative to no change in support flows between t_0 and t_1. There was in addition a statistically significant increased likelihood of reciprocal support when households with older women became multigenerational households.



	To downward support	To upward support	To Reciprocal support		To downward support	To upward support	To Reciprocal support
LL	2.0	-0.1	-0.3		0.9	0.1	0.4
UL	3.5	1.0	1.0		3.2	1.5	1.7
Coef.	2.7	0.5	0.3		2.0	0.8	1.0

Figure 2-6: Relative risk of change in support flows given change in living arrangements between t_0 and t_1, Females

Note: Models adjusted for age, marital status, education, place of residency and household wealth status at t_1. HH=Household

2.8 Discussion

In this analysis, household living arrangements, having an income from employment or government grants, and the potential implication of these on support exchanges between older and younger generations were investigated. Although the general population under surveillance in the Africa Centre surveillance study area is relatively young, at 6% the proportion of older people aged 60 years and above is nearly twice as high as seen in many sub-Saharan African countries like Uganda, Niger, Guinea and Tanzania (United Nations, 2002). With projections indicating further rapid increases in this ageing trend, older people have become of growing social and public health concern (He, Muenchrath and Kowal, 2012; Kalache and Keller, 2000), and this analysis makes an important contribution to the discourse.

Despite the rural location of the population considered in this analysis, for survival most people rely on income from formal employment and/or from government social grants, in particular the old-age pension and child support grants (Ardington, Case and Hosegood, 2009; Leibbrandt, Finn and Woolard, 2012; Neves, et al., 2009; SASSA, 2014). Consistent with declining employment trends in South Africa (StatsSA, 2013), findings here revealed a steady decline in the proportion of older people in households with at least one employed person. Levels of employment in the households were relatively constant from 2005 to about 2007, since when there were noticeable declines in employment levels of adults and older people up to 2010, during the time of the global financial crisis. Trends in the proportion receiving government grants, especially among older men, were in the opposite direction over the study period, and overall there was an increase over time in the proportion of older people with an income. By 2010 around 90% of older people in the study had an income, mostly from grants. The increasing accessibility to government grants has followed legislative changes as well as pressure from civil society on government to rapidly roll-out cash-transfers to people country-wide, not only those of old-age but younger people as well, women and children in particular (Devereux, 2011; Woolard, Harttgen and Klasen, 2011). The effect of this wide accessibility to grants can be seen in this analysis particularly for men - as older people were increasingly accessing grants, the

proportion of households where the older person was the only person receiving a government grant was declining.

Although the study area is characterised by very low adult paid employment rates of about 37% in 2010 (www.africacentre.ac.za), by combining access to grants and employment, over 90% of older persons belonged to households with at least one person with a recognised regular income source. This suggests households are most likely built around an employed person and/or persons with a government grant. This lends credence to assertions of income pooling in rural South African settings (Ardington and Lund, 1995; Case, 2004; Case and Deaton, 1998; Edmonds, Mammen and Miller, 2005; Lund, 2002; Maitra and Ray, 2006; Neves and du Toit, 2013; Woolard, Harttgen and Klasen, 2011). Income from government grants and/or employment is highly likely to be shared within the household (Booysen, 2004; Hosegood and Timæus, 2005a; Kimuna and Makiwane, 2007; Moller and Radloff, 2013; Sagner and Mtati, 1999), and influences mobility and living arrangements of household members (Ardington, Case and Hosegood, 2009; Booysen and Van Der Berg, 2005; Møller and Ferreira, 2003; Neves, et al., 2009). The nuances of how this income may or may not be shared in the household was beyond the scope of this analysis, with the focus here merely on the potential for exchanges of support given who in the household has an income. It was previously shown that over four-in-five older people receiving a grant said they used it on household expenses rather than to meet their own needs (Nyirenda, et al., 2013b). Therefore, if older people with an old-age pension living with others in the household share their income, then it is highly likely that adults or children with an income will equally be expected to share some of their income with other household members. Hosegood and Timæus (2005a) argue that although not all members of a household would be related to each other, may not eat from one pot or care physically for one another, it is highly likely that household members will be related to each other somehow, will share their incomes and care for each other. While Sagner and Mtati (1999), believe an individual not transferring some of their financial resources, if they have the means, to a kin-related person in need would be against the morally expected standard.

No significant differences were observed between older men and women regarding marital status, education level, place of residency and household size, but there were significant differences between men and women in being a primary care-giver, and co-residency with own children – with more women than men for each of these factors. Co-residency with one's own children is not only important for potential exchanges of support but for psychological well-being as well. A Chinese study demonstrated how older people co-resident with adults had a better life satisfaction compared to those living alone or even those living with a spouse only (Wang, Chen and Han, 2013). It appears this association of co-residence with adult children with psychological well-being may be due to the potential for mutual exchanges of instrumental support (financial resources) between older people and their adult children. A Korean study examining intergenerational exchanges of financial resources between co-resident adult children and older people showed that older people giving and receiving (reciprocal flows) instrumental support were more likely to be in good psychological well-being (Lee, Lyu, Lee *et al.*, 2014).

Overall, only around 4% of older persons in the study were in older-only or older with children-only households (around 6% for older men, 3% for women); the overwhelming majority of older people, 85%, were in multigenerational households, that is, there were older persons, adults and young children in the household, which is consistent with what others have shown (Hosegood and Timæus, 2005b; United Nations, 2005; Wittenberg and Collinson, 2007). The proportion of households where one older person was likely to be supporting self or another older person (peer-support) remained stable over the study period at 3-5%. However, both the proportion of households where an older person may be supporting younger people (downward support) and where younger people are supporting an older person (upward support) declined over the study period. What has evidently increased, and remains the predominant likely directional flow of support (78% overall), is younger and older people helping to support each other i.e reciprocal support. There also appeared to be some shifting from upward and downward into reciprocal support over the period 2005-2010.

Findings from this analysis show stable living arrangements for both older men and women over the study period; around 80% of older people observed throughout the period remained co-resident with their own children, about 60% remained poor and close to 90% had no change in their household structure. Changes in access to income by older persons and other household members have implied major changes in the probable directional flows of support between older and younger people. This was particularly the case with regard to access to grants. Nearly 80% of older people not receiving a grant at baseline were probably receiving support from younger persons (upward support), but if they then had acquired a grant subsequently, about 87% changed to reciprocal support exchanges. Conversely, if they had been receiving a grant at baseline but were not at a later time point, 80% would initially have been in reciprocal support households, while 94% were in upward support at the latter time point. That is, when older persons have an income they are less likely to be a financial burden on younger persons and usually make a contribution to household income (Edmonds, Mammen and Miller, 2005; Lloyd-Sherlock, et al., 2012a; Neves, et al., 2009).

Findings here suggest an older person living with adults only or with children only (skip-generation households) is more likely to be supporting the children or adults rather than the other way round, which given strong family relations is to be expected. Another study from rural South Africa showed how older people felt strongly obligated to provide care and support to their children or grandchildren with sentiments such as: “taking care of my own blood”, “I am bound to look after them” or “it is my responsibility” (Schatz, 2007). Older people are prepared to provide care and share their incomes even at great cost to their own physical and emotional well-being (Aboderin, 2007; Kreager and Schroder-Butterfill, 2008; Nyirenda, et al., 2013b; Sagner and Mtati, 1999). Findings here further suggest that for older people in multi-generational households it was highly likely that they were supporting the younger generation or at best both younger and older persons were contributing to household income. Findings here are thus consistent with observations from developed country settings (Gierveld, Dykstra and Schenk, 2012; Grundy, 2005), suggesting that despite a strong reciprocity in intergenerational exchanges, on the balance of probability

intergenerational exchanges are more downward than upward. Similar findings from developing country context have also been shown (Aboderin, 2004; Kreager and Schroder-Butterfill, 2008; Maitra and Ray, 2006).

2.8.1 Limitations

In this analysis other sources of income such as informal employment, remittances, substance farming, and trading were not included. Aside from the measurement challenges associated with such alternative sources of income (Lund, 1999: 58), there is evidence from others to suggest remittances as a share of income inflows into households have declined over time. Using data on households observed in 1993 and 1998, Maitra & Ray (2006) showed that remittances as a share of total household income significantly declined from about 9% in 1993 to 3% in 1998 in KwaZulu-Natal. Other studies also show considerable declines in remittances per unit increase in social grant receipt especially old-age pension grants (Jensen, 2004). It is unlikely therefore that restricting the analysis to regular incomes from employment and grants, which are the major sources of income in the study area, could have severely biased the study findings with regard to potential intergenerational transfer of resources.

Neither nuanced information on income sharing within the household nor a monetary value of the different sources of income were available for this analysis. Even though potentially income from employment may be larger than from government grants, given the type of employment individuals in the study setting tend to be involved in evidence suggests that income from grants particularly the old-age pension is roughly the same and in some cases more than income from employment (Case and Deaton, 1998; Leibbrandt, Finn and Woolard, 2012).

The sub-analysis on changes in directional flow of support over time considered only the sub-sample of individuals who had been observed throughout the study period 2005-2010 (n=2749). This could potentially have introduced selection effects as these individuals could have been ‘selected’ for their stability in living arrangements, whereas older persons in less stable households could be more likely to drop out or to be unobserved in repeat follow-ups in the surveillance. However, a check on patterns

of household dissolution among individuals not observed throughout the period relative to those included in this sub-analysis did not reveal significant statistical differences. The main reasons for not being observed throughout the period pertained to migration and death, thus the potential effect of this selection bias was assumed to have been minimal to significantly have affected findings of this analysis.

Lastly, the definition of directional flow of support exchanges used here only considered age and having an income among resident household members. Non-resident members may be important for social and economic exchanges or support system of older persons regarding remittances. Information on remittances is, however, not routinely collected in the surveillance although in the very first household social economic module in 2001 some limited information on remittances was collected. Changes to surveillance data collection instruments may be necessary for a robust examination of income flows from non-resident members and its impact on support flow exchanges.

2.9 Conclusions

Over the five year study period, household living arrangements changed very little, which would indicate the robustness of living arrangements to shocks such as high HIV prevalence and wide spread access to HIV treatment that have led to major changes in adult mortality rates (Herbst, et al., 2009; Hosegood, Vanneste and Timæus, 2004). Highly likely due to widespread poverty in the study area as well as cultural expectations, households either stay together or some members move away to other places to increase their employment opportunities. As a result, income earned by any household members is highly likely to be shared within the household (Booysen, 2004; Hosegood and Timæus, 2005a; Kimuna and Makiwane, 2007; Moller and Radloff, 2013; Sagner and Mtati, 1999). Findings in this analysis are in line with assumptions of strong family relations between older and younger people, as suggested by intergenerational solidarity theories (Bengtson, Elder and Putney, 2005; Lowenstein, 1999). However, despite strong desires to do so, socio-political circumstances (Phillipson, 2005), economic deprivation (Aboderin, 2005) and individual relations or characteristics

within families (Antonucci, et al., 2011; Johnson, 2005) may hamper potential material exchanges between younger and older people.

When all else is considered, the financial support flows for older people living with adult offspring were most likely to be downward or at best reciprocal. For policy response to these findings, the coming together of adults or children to live with older persons should not be presented in a negative light. Rather in the absence of creation of employment opportunities within the study community, access to government grants should extend to all who are eligible. For unemployed adults, who do not qualify for any of the current grants, a form of unemployment benefit may be helpful in enabling them to make some contribution to household income and in so doing lessen the strain on the income from the older person. Evidence from South Africa's exemplary social assistance programme shows several benefits of grants not just for the recipient but for their whole household (Devereux, 2011; Moller and Radloff, 2013; Woolard, Harttgen and Klasen, 2011). Hence additional benefits would be expected from introduction of a grant targeting unemployed adults.

Finally, given rapid ageing trends and further increasing unemployment levels in South Africa, concerns about the sustainability of the expanding cash transfers social protection system in South Africa are valid. Should the government fail in its attempt to create more jobs and broaden the tax base to fund the social welfare system, older people may in future find themselves having to rely heavily on their families, which are in poverty themselves, for financial support.

Chapter 3: **Care-giving and -receiving and older people's physical health and mental well-being in rural South Africa**[6]

3.1 Abstract

This paper examines how care-giving to adults and/or children and care-receiving is associated with the health and well-being of older people aged 50+ in rural South Africa. Data used are from a cross-sectional survey adapted from WHO's Study on Global Ageing and Adult Health (SAGE) conducted in 2009/10 in rural South Africa. Bivariate statistics and multivariate logistical regressions are used to assess the relationship between care-giving and/or care-receiving with functional disability, quality of life or emotional well-being and self-rated health status, adjusted for socio-demographic factors. 63% of 422 older people were care-givers to at least one young adult or child; 27% of older people were care-givers due to HIV-related reasons in young adults. 84% of participants were care-recipients mainly from adult children, grandchildren and spouse. In logistic regressions adjusting for sex, age, marital status, education, receipt of grants, household headship, household wealth and HIV status, care-giving was statistically significantly associated with good functional ability as measured by ability to perform activities of daily living. This relationship was stronger for older people providing care-giving to adults than to children. In contrast, care-givers were less likely to report good emotional well-being; again the relationship was stronger for care-givers to adults than children. Simultaneous care-giving and -receiving was likewise associated with good functional ability, but about a 47% lower chance of good emotional well-being. Participants who were HIV-infected were more likely to be in better health and less likely to be receiving care than those who were HIV-affected. Findings suggest a strong relationship between care-giving and poor emotional well-being via an economic or psychological stressor pathway. Interventions that improve older people's socio-economic circumstances and reduce financial hardship as well as those that provide social support would go some way towards mitigating this relationship.

Key Words: South Africa, older people, care-giving, HIV-infected, self-reported health, functional disability, emotional wellbeing.

[6] This chapter is an extended version of a paper that was published earlier, Nyirenda, M., et al., 2013. *Who cares? Implications of care-giving and -receiving by HIV-infected or -affected older people on functional disability and emotional wellbeing*. Ageing & Society, p. 1-34. See Appendix 1, pp. 201 for citation details and co-author contributions.

3.2 Chapter outline

Chapter Two was devoted to assessing potential exchanges of financial resources between older and younger people using longitudinal surveillance data. Chapter Three is dedicated to examining physical and emotional aspects of care, albeit also touching very briefly on financial reports, using data collected in a cross-sectional study of a sample of the older population under surveillance. The two chapters thus provide a complete examination of the three dimensions of informal care (material, physical, and emotional).

The outline of this chapter is as follows. An overview of the health and well-being of older people as well as studies done by others is provided in the background section in 3.3. The study design, data sources, statistical analysis, outcome and explanatory variables are then presented in the methods section in 3.4. Study findings of this analysis follow in section 3.5. These results are then discussed in section 3.6 and the chapter ends with some policy implications and recommendations in section 3.7.

3.3 Background

Older people in rural South African communities are a vital source of financial, physical and emotional support to (grand)children and adults alike (Ardington, et al., 2010; Hosegood and Timæus, 2006; Nyirenda and Newell, 2010; Schatz, 2007). In severely HIV affected areas such as the study population, older people are at the forefront of providing long-term personal and health care to their adult offspring infected with HIV and to the children they leave behind orphaned (Connolly and Monasch, 2003; Hill, Hosegood and Newell, 2008; Ssengonzi, 2007; Zimmer and Dayton, 2003). It is, however, well-known that as individuals grow older, particularly beyond age 50, their physical functioning ability as well as their overall health declines (National Institute on Aging, 2007). Furthermore, older people are not immune to HIV acquisition (Cooperman, Arnsten and Klein, 2007; Dougan, Payne, Brown *et al.*, 2004; Wallrauch, Bärnighausen and Newell, 2010), with additional cases of infection emanating from adults on HIV treatment surviving longer into older age (Nguyen and Holodniy, 2008). As such older people are simultaneously sources of care and support as well as in need of care and support themselves.

Independent of the HIV pandemic, co-residence with older people in rural South Africa has been found to be important for care and living arrangements (Hosegood, Benzler and Solarsh, 2006). Having an older person in the household with an income source, such as the old age grant, facilitates the migration of adults to other cities in search of employment leaving behind their young children in a safe and secure environment (Ardington, Case and Hosegood, 2009; Hosegood and Timæus, 2005a). The dominant household living arrangement in the study area in rural South Africa is of multi-generational households, which are defined as households made up of grandparents, their adult children and grandchildren living in the same dwelling unit (Hosegood, Benzler and Solarsh, 2006; Hosegood and Timæus, 2005a). As discussed in Chapter Two, due to the high unemployment levels among the adult population (Curtis, Bradshaw and Nojilana, 2002; Muhwava, 2008), government cash transfers to older people 60 years and over are the main source of household income in rural South Africa (Booysen, 2004; Burns, Keswell and Leibbrandt, 2005; Duflo, 2003; Kimuna and Makiwane, 2007). The burden of care and support of the household is particularly heavy on older women (Burns, Keswell and Leibbrandt, 2005; Duflo, 2003; Schatz and Ogunmefun, 2007).

The psychosocial ability of older people to provide care particularly due to the impact of HIV on their children and grandchildren in South Africa has been previously explored (Boon, James, Ruiter *et al.*, 2010; Schatz and Ogunmefun, 2007). Others have also explored the secondary stigma such as isolation and separation from family that older people experience as a result of caring for HIV-infected adults and children (Ogunmefun, Gilbert and Schatz, 2011). Also explored and demonstrated is that the government cash transfers system in South Africa has helped mitigate the financial implications of care-giving by older people (Ardington, et al., 2010). For instance no expenditure differences were found between households with older people providing care to AIDS-orphaned children and households with older people not providing care when the former were in receipt of government cash transfers (Ardington, et al., 2010). While the psychosocial and financial challenges of care-giving by older people has previously been studied, very little has been said about how this care-giving role

and need for care is related to the physical health and mental well-being of older people in rural South Africa.

According to Ssengonzi (2009), one of the few who has examined in a qualitative study the impact of care-giving by older people on their health and well-being in rural Uganda, this care-giving role is likely to result in emotional, physical health and psychological stress. Another study from east Africa that used three waves of panel data collected between 2005 and 2007 to examine the impact of care-giving to orphaned children on the health and well-being of older people aged 60 years and above, suggested care-giving did not result in ill-health using objective measures of hypertension, body mass index (BMI), blood pressure, haemoglobin and blood glucose assessment (Ice, et al., 2010). However, Ice et. al. (2010) did find that over time older people who were primary care-givers to orphaned children had poorer self-perceived health status and mental health. Although the health and well-being of older people caring for their grandchildren has been discussed previously (Minkler and Fuller-Thomson, 1999; Zhang, 2008), little is known about the health effect on older people of caring for their adult offspring.

To support older people in rural South Africa who are increasingly taking on the responsibilities of caring for their adult offspring and grandchildren, an understanding of how care-giving influences their health and well-being is needed. The aim of this analysis is to examine whether care-giving to adults and/or to children by older people in rural South Africa is associated with poor self-assessed health and emotional well-being among older people. The study further seeks to assess whether older people in receipt of care are associated with better health and emotional well-being. Older people here are defined as persons aged 50 years and above in line with previous work on ageing in Africa (Hosegood and Timæus, 2006; Kowal, Kahn, Ng *et al.*, 2010; Ssengonzi, 2007); whereas adults are persons aged 18-49 years and children in this analysis are all those aged less than 18 years.

3.4 Methods

3.4.1 Sources of data and study design

Data for this analysis come from a cross-sectional study of the health and well-being of older people (WOPS). In this WHO-supported study conducted between March and August 2010 the main criteria for inclusion was being aged 50 years and above, under demographic surveillance in the Africa Centre surveillance and resident in the surveillance area during the study period. Detailed information about the Africa Centre's surveillance can be found in earlier analyses (Hosegood, Benzler and Solarsh, 2006; Tanser, et al., 2008) or by visiting www.africacentre.com.

A shortened version of the World Health Organisation (WHO) Study on Global Ageing (SAGE) instrument (WHO, 2011) was used to collect the data. Information that is routinely collected in the surveillance system such as basic demographic description and HIV status of participants was left out from the WOPS forms to avoid duplication and an unnecessarily burdening the participants with a long instrument. The adaption process of the SAGE form was also to ensure the questions were appropriate for the local setting (see section 1.8.2 pp. 14 for detailed description of WOPS and Appendix 7, pp. 223 for copy of study questionnaires).

Stratified random sampling was used to select participants. The first stage of the sampling was identification of eligible participants in the four specified strata, and the second stage was the random sampling of 100 participants in each stratum from the eligibility list. Other criteria for inclusion specific to each stratum were that for stratum one participants had to be HIV-infected and on HIV-treatment for a year or longer; for stratum two participants had to be HIV-infected and on HIV-treatment for three months or less or waiting to initiate treatment. The third and fourth strata consisted of participants defined as HIV-affected for purposes of this study. Stratum three consisted of participants who had an adult offspring (18-49 years) who was HIV-infected and on treatment for a year or longer, or on treatment for three months or less; while stratum four was composed of participants who had experienced a death of an adult household member between 2008 and 2010 (two years prior to the study), which death was classified as HIV-related from the verbal autopsy (VA) data. The first

three groups were selected by first linking information in the Hlabisa HIV Treatment and Care programme to the Africa Centre surveillance. About 40% of the people in the treatment programme are part of the surveillance (Houlihan, et al., 2011). For the present study, participants in strata 1 and 2 were combined into HIV state category of 'HIV-infected', while those in strata 3 and 4 were categorised as 'HIV-affected'. Further details about the health and well-being of older people study (WOPS) were presented in (Nyirenda, et al., 2012).

3.4.2 Outcome and control variables

3.4.2.1 Dependent variables

The two principal dependent variables were physical health status and quality of life, a measure of mental well-being, both derived using validated World Health Organization (WHO) instruments (WHO, 2010; WHOQoL Group, 1993). Self-rated overall health status, reported health status in the last 2 weeks and self-reported quality of life as other measures of health and well-being were also explored.

3.4.2.2 Physical health status

This was measured using the World Health Organisation's Disability Assessment Scale II (WHODAS-II) (WHO, 2010). Participants in WOPS were asked about difficulties experienced in the last 30 days with performing activities of daily living such as walking, standing, stooping, kneeling or crouching, getting up from sitting position, getting up from lying down position, picking up things from the table, doing household chores as well as instrumental activities of daily living like getting dressed, bathing, eating, getting to the toilet, using public transport and participation in community activities. Responses to these items were based on a five-point Likert-type scale of 'none', 'mild', 'moderate', 'severe', and 'extreme/cannot do'. Responses to these items were used to compute a WHODAS disability score with a scale of 0-100, with a high score indicating great difficulty in performing physical activities (functional disability). To ensure comparability with similar earlier work (Ng, et al., 2010), the score was then inverted (WHODASi) on the same scale of 0-100 but now a low score indicated low physical functioning ability (high disability) and a high score a high functioning ability (low disability).

The score was further divided into quintiles, which were in turn categorised into a dichotomous physical health status variable for use in the logistic regressions. This categorisation into poor and good health, for use in ordinary logistic regression models, based on quintile distributions, follows the precedence set by Gomez-Olive, et al. (2010) who similarly defined best health as that reported by participants in the top two quintiles, while reported from participants in the lower three quintiles were defined as worst health. This derivation of a binary variable from quintiles (here as well as for the other health measures listed below) was adopted to facilitate comparability of this study's findings to those from Gomez-Olive, et al. (2010) as well as others who have adopted a similar approach (Debpuur, Welaga, Wak *et al.*, 2010; Hirve, et al., 2010; Kowal, Kahn, Ng *et al.*, 2010; Kyobutungi, Egondi and Ezeh, 2010; Mwanyangala, Mayombana, Urassa *et al.*, 2010; Ng, Kowal, Kahn *et al.*, 2010; Razzaque, Nahar, Akter Khanam *et al.*, 2010; Van Minh, Byass, Chuc *et al.*, 2010).

However, reducing the five quintiles to such a binary outcome in ordinary logistic regressions does not adequately reflect the ordinal scale of the data (Armstrong and Sloan, 1989). The decision rule as to which quintiles constitute poor or good health is largely arbitrary, with potentially different model outcomes if different cut-points are adopted (McCullagh, 1980; StataCorp., 2009; UCLA Academic Technology Services, 2011). As an alternative and to avoid any potential biases due to this limitation, ordered logistic regression models were instead used in Chapter Four (section 4.4.4, p. 117). Ordered logistic models do not require any arbitrary decision rules as to which quintiles constitute poor or good health, but rather model proportional odds of a lower category to a higher category of an ordered variable (Armstrong and Sloan, 1989; McCullagh, 1980); in this case health status in quintiles ordered from poorest health in first quintile to best health in fifth quintile."

3.4.2.3 Quality of life

This was measured using the WHO Quality of Life (WHOQoL) score (WHOQoL Group, 1993) derived from responses to questions on a participant's satisfaction with among other things, their self, health, living conditions, personal relationships, ability to

perform daily living activities, and their life as a whole. Also included were questions on how often they felt unable to control important things in their life and their inability to cope with situations. Eight questions were used to compute the WHOQoL score, which ranged from 8-40. This was then transformed into a scale of 0-100, where 100 corresponded to best quality of life (best emotional well-being). For the logistic regressions, as for physical health status, quintiles and then a dichotomous variable of quality of life (poor vs good) was created from the WHOQoL score.

3.4.2.4 Self-rated health status

Participants in WOPS were asked "In general, how would you rate your health today?" In spite of some comparability and inconsistency concerns (Bowling, 2005; Fayers and Sprangers, 2002; Salomon, Nordhagen, Oza *et al.*, 2009), this global question of self-reported health status has been shown extensively even across different cultures to be a good indicator of public health and mortality in a population (Fayers and Sprangers, 2002; Idler and Benyamini, 1997; Wang, Wu, Zhao *et al.*, 2008). In WOPS the question had five response categories (Very good, good, moderate, bad and very bad). For this analysis the response categories were collapsed into two: "Good" composed of 'very good and good'; whereas "Bad" was composed of 'moderate, bad and very bad'.

3.4.2.5 Health status in the last two weeks

Respondents in WOPS were asked how their health had been in the two weeks prior to the interview date. From the 5-point Likert-type scale of the question, a dichotomous variable was created: "Good" (very good and good) and "Bad" (moderate, bad, very bad). This question may be a better indicator of health status than the global self-rated health status question which only asks for health status on the day of contact, whereas this question allows the respondent to reflect on their health over a two-week window hence is likely to capture long term and chronic illnesses common among older people.

3.4.2.6 Self-reported quality of life

In this question participants in WOPS were asked "How would you rate your overall quality of life?" This question similarly had five response categories. These were as

above dichotomised into “Good” and “Bad” quality of life. This question was included as an outcome variable to compare with outcomes from the WHOQoL measure.

3.4.2.7 Independent variables

In this analysis care-giving was defined as an older person assisting an adult (18-49) or child (<18 years) with activities of daily living such as eating, dressing, bathing, toileting, moving around the house as well as assistance with such as going to the clinic or traditional healer, dressing of wounds, administering medicines, cooking, fetching water and shopping. When an older person was unable to perform any of these tasks and was getting assistance from someone else they were defined as ‘care-receiving’. Care-giving and care-receipt were used as the main independent variable in this analysis, and will be more generally referred to as informal care. In the logistic regressions, this variable had two categories: ‘Yes, providing (or receiving) care’ or ‘No, not providing (or receiving) care’. Other care variables defined were physical care and nursing care. The former referred to assistance with activities such as cooking, fetching water, taking to the clinic or traditional healer, shopping and moving around, while the latter referred to assistance with eating, bathing, dressing, toileting, administering medicines, and dressing of wounds. In the survey, information about financial support with regard to paying for food, clothing, doctor or traditional healer fees, paying for transportation and school fees for children (<18 years) was collected, but this was considered separately from care as providing physical or nursing care is likely to have very different effects on health and well-being from financial assistance.

Given that the health and well-being of older people is affected by different socio-demographic, economic and household living arrangement factors, several of these factors were controlled for in order to arrive at the independent effect of informal care on the health and mental well-being of older people. The factors controlled for were: age (50-59, 60-69, 70-79 and 80+), sex (male or female), marital status (never married, married, previously married), education attainment (no formal education, primary, secondary), receipt of grants, and living arrangements (household wealth quintiles, household headship, household typology (older person-only, living with children only or with both adults and children), and self-perceived household financial status).

3.4.2.8 Data analysis

This analysis is based on a sample of 422 persons aged 50 years and above who participated in the well-being of older people study (WOPS) between March and August 2010, which yielded detailed information on the health status and social care patterns among these older people. Initially, the data were analysed using descriptive and bivariate analyses to describe the socio-demographic and living arrangements of older people in the study area. Then, multivariable logistic regressions were used to examine the association of care-giving to adults (18-49) and to children (<18) on the physical health, mental well-being, health in the last 2 weeks, overall self-rated health status and self-rated quality of life, controlling for socio-demographic and living arrangements variables. Additionally, the relationship between receipt of care by older people and their health and well-being was assessed. All data were analysed using Stata 11.2 (StataCorp, 2009).

3.4.3 Ethical clearance

Approval for the study was in the first instance obtained from the local community via the community advisory board (CAB) and then the University of KwaZulu-Natal Biomedical Research Ethics Committee (Ref No. BF136/09). In the well-being of older people study (WOPS), written informed consent was obtained from all participants; they had to sign or thumb-print the consent form.

3.5 Results

3.5.1 Socio-demographic and economic characteristics of the study population

Overall, the WOPS sample was predominantly female (75%); the majority (45%) were aged 50-59 years; around 49% were currently married; predominantly not working (91%) and nearly half (48%) had no formal education (Table 3-1). Most of the study participants were household heads (58%) or belonged to households headed by their spouse (21%). When asked about their financial situation at interview date compared to an arbitrary chosen three years ago, most study participants rated their situation as worse off (52%, n=219). Only 16% (n=67) said they were more comfortable now than three years ago, while the rest said their financial situation had not changed (32%, n=136) (Table 3-1).

Table 3-1: Socio-demographic characteristics by care-giving status, rural South Africa 2010

	Overall		Non-caregiver		Care-giver		
Characteristics	n	%	n	%	n	%	**P-value**
n	422	100	156	37.0	266	63.0	
Sex							<0.001
Male	106	25.1	61	57.5	45	42.5	
Female	316	74.9	95	30.1	221	69.9	
Age group in years							0.188
50-59	188	44.5	64	34.0	124	66.0	
60-69	128	30.3	45	35.2	83	64.8	
70+	106	25.1	47	44.3	59	55.7	
Marital status							<0.001
Never married	117	27.7	48	41.0	69	59.0	
Married	206	48.8	95	46.1	111	53.9	
Previously married	99	23.5	13	13.1	86	86.9	
Education							0.959
No formal education	201	47.6	73	36.3	128	63.7	
6 years or less	140	33.2	53	37.9	87	62.1	
More than 6 years	81	19.2	30	37.0	51	63.0	
Employment							0.489
Unemployed	382	90.5	142	37.2	240	62.8	
Employed	38	9.0	13	34.2	25	65.8	
Missing	2	0.5	1	50.0	1	50.0	
Grant receipt							0.081
None	82	19.4	22	26.8	60	73.2	
Disability	114	27.0	48	42.1	66	57.9	
Old-age pension	226	53.6	86	38.1	140	61.9	
Perceived financial status							0.001
Better	67	15.9	38	56.7	29	43.3	
No change	136	32.2	46	33.8	90	66.2	
Worse	219	51.9	72	32.9	147	67.1	
Household Headship							0.201
Self	244	57.8	96	39.3	148	60.7	
Spouse	87	20.6	25	28.7	62	71.3	
Other	91	21.6	35	38.5	56	61.5	
Wealth quintile							0.515
First (Poorest)	74	17.5	31	41.9	43	58.1	
Second	92	21.8	36	39.1	56	60.9	
Third	82	19.4	23	28.0	59	72.0	
Fourth	69	16.4	25	36.2	44	63.8	
Fifth (Best-off or least poor)	53	12.6	22	41.5	31	58.5	
Missing	52	12.3	19	36.5	33	63.5	
Household typology							0.006
Solo HH	9	2.1	7	77.8	2	22.2	
Older-only	7	1.7	4	57.1	3	42.9	
Skip-generation	4	0.9	2	50.0	2	50.0	
Second-generation	20	4.7	13	65.0	7	35.0	
Multi-generation	366	86.7	124	33.9	242	66.1	
Missing	16	3.8	6	37.5	10	62.5	

Note: 'Overall' column presents column percentages while the 'Non-Caregiver' and 'Care-giver' columns present row percentages. Skip-generation = Older person plus children (<18years) only household; Second-generation = older person plus adults (18-49 years) only household; Multi-generation= older person plus adults and children household.

Government cash transfers are widely accessed in this rural study population. As shown in Figure 3-1, over four in five (81%, n=340) of older people studied were in receipt of government cash transfers (old-age pension 54%, n=226 and disability grant 27%, n=114). This is consistent with findings presented in Chapter Two on the general surveillance population showing that around 82% men and 91% women aged 60+ were in receipt of a government grant (see Figure 2-2, pp. 41).

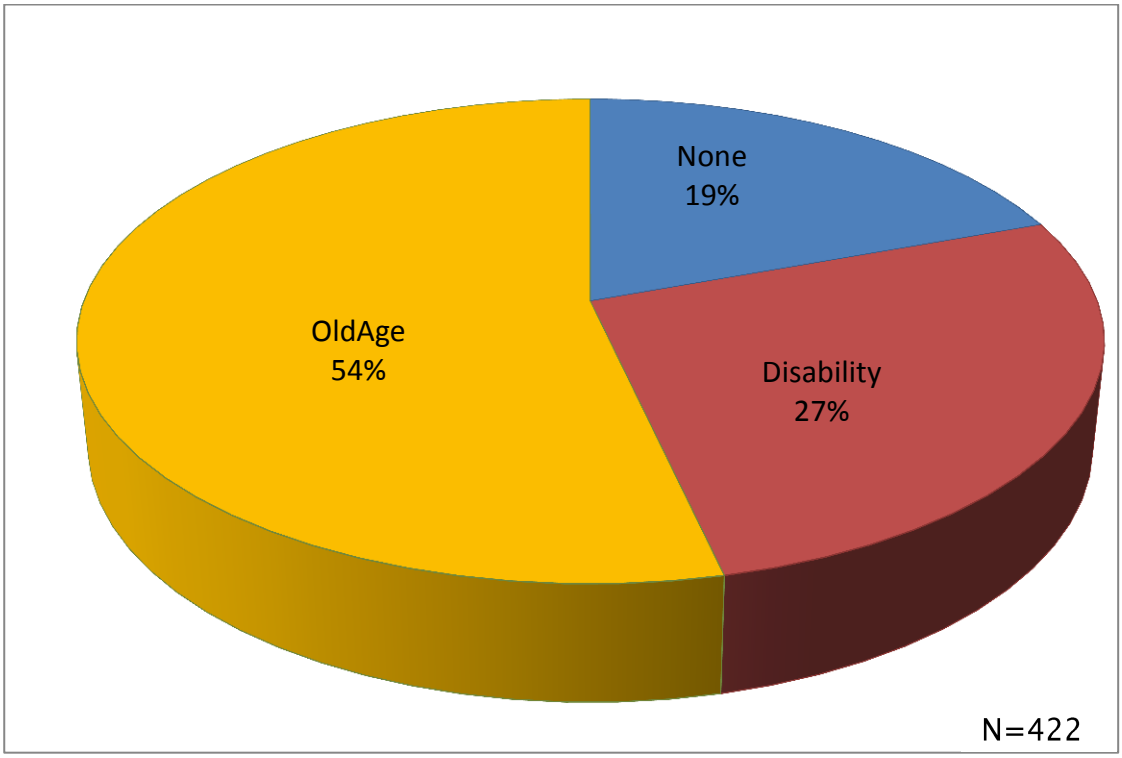


Figure 3-1: Receipt of government grants by type, rural South Africa 2010

3.5.2 Care-giving characteristics and patterns of rural South Africa older people

Overall, 63% (n=266) of study participants were providing care to either an adult or child (Table 3-1). Significant gender differences were observed with regard to care-giving; close to 70% of older women were care-givers compared to only 43% among older men (Table 3-1). The proportion of older people who were care-givers was also substantially higher among previously married participants (separated, divorced, or widowed). Other significant differences with regard to care-giving status and socio-demographic characteristics were observed for self-reported financial situation and household typology (Table 3-1).

Table 3-2: Care-giving to adults or children characteristics in percent, rural South Africa 2010

		Care-giving to Adults			Care-giving to Children		
Characteristics	N	No	Yes	p-value	No	Yes	p-value
Overall	422	58.5	41.5		43.4	56.6	
Sex				0.656			<0.001
Male	106	60.4	39.6		65.1	34.9	
Female	316	57.9	42.1		36.1	63.9	
Age group				0.363			0.190
50-59	188	62.2	37.8		42.6	57.4	
60-69	128	57.0	43.0		39.8	60.2	
70-79	75	50.7	49.3		44.0	56.0	
80+	31	61.3	38.7		61.3	38.7	
Marital status				0.000			0.001
Never married	116	66.4	33.6		47.4	52.6	
Married	206	73.8	26.2		50.5	49.5	
Separated	5	20.0	80.0		40.0	60.0	
Divorced	3	66.7	33.3		33.3	66.7	
Widowed	91	16.5	83.5		23.1	76.9	
Education				0.177			0.896
NFE/AEO	201	54.2	45.8		42.8	57.2	
6 years or less	140	64.3	35.7		42.9	57.1	
More than 6 years	81	59.3	40.7		45.7	54.3	
Employment				0.402	0.0	0.0	0.322
Employed	38	63.2	36.8		45.8	54.2	
Unemployed	382	57.9	42.1		43.3	56.7	
Grant receipt				0.270			0.031
None	82	56.1	43.9		32.9	67.1	
Disability	114	64.9	35.1		51.8	48.2	
Old-age pension	226	56.2	43.8		42.9	57.1	
Perceived financial status				0.000			0.006
Better	67	83.6	16.4		61.2	38.8	
No change	136	55.1	44.9		39.0	61.0	
Worse	219	53.0	47.0		40.6	59.4	
HH Headship				0.214			0.290
Self	244	55.3	44.7		46.3	53.7	
Spouse	87	60.9	39.1		35.6	64.4	
Other	90	65.6	34.4		43.3	56.7	
Wealth quintile				0.861			0.458
First (Poorest)	74	64.9	35.1		51.4	48.6	
Second	92	55.4	44.6		44.6	55.4	
Third	82	59.8	40.2		35.4	64.6	
Fourth	69	56.5	43.5		40.6	59.4	
Fifth (Best-off or least poor)	53	58.5	41.5		47.2	52.8	
Missing	52	55.8	44.2		42.3	57.7	
Household typology				0.560			<0.001
Solo HH	9	77.8	22.2		88.9	11.1	
Older-only	7	71.4	28.6		71.4	28.6	
Skip-generation	4	75.0	25.0		50.0	50.0	
Second-generation	20	70.0	30.0		85.0	15.0	
Multi-generation	366	56.8	43.2		39.3	60.7	
Missing	16	62.5	37.5		43.8	56.3	

Note: Skip-generation = Older person plus children (<18years) only household; Second-generation = older person plus adults (18-49 years) only household; Multi-generation= older person plus adults and children household.

Stratified analyses of care-giving to adults (18-49 years) and care-giving to children (<18 years), revealed that just under 42% (n=175) of study participants were providing care to adult household members (Table 3-2). Around 57% (n=239) of WOPS participants reported that they were providing care to at least one child. Similar percentages of older men and women were care-providers to adults (around 40%), but a substantially higher percentage of older women (64%) than men (35%) were care-givers to children.

A very high proportion (over 60%) of participants who were separated, divorced or widowed said they were care-givers to children, but over 80% of separated and widowed participants were care-givers to adults (Table 3-2). Although most of the participants perceived their financial situation to be worse off than three years earlier, a higher proportion felt this way among older people providing care to children compared to care-givers to adults (59% vs 47%).

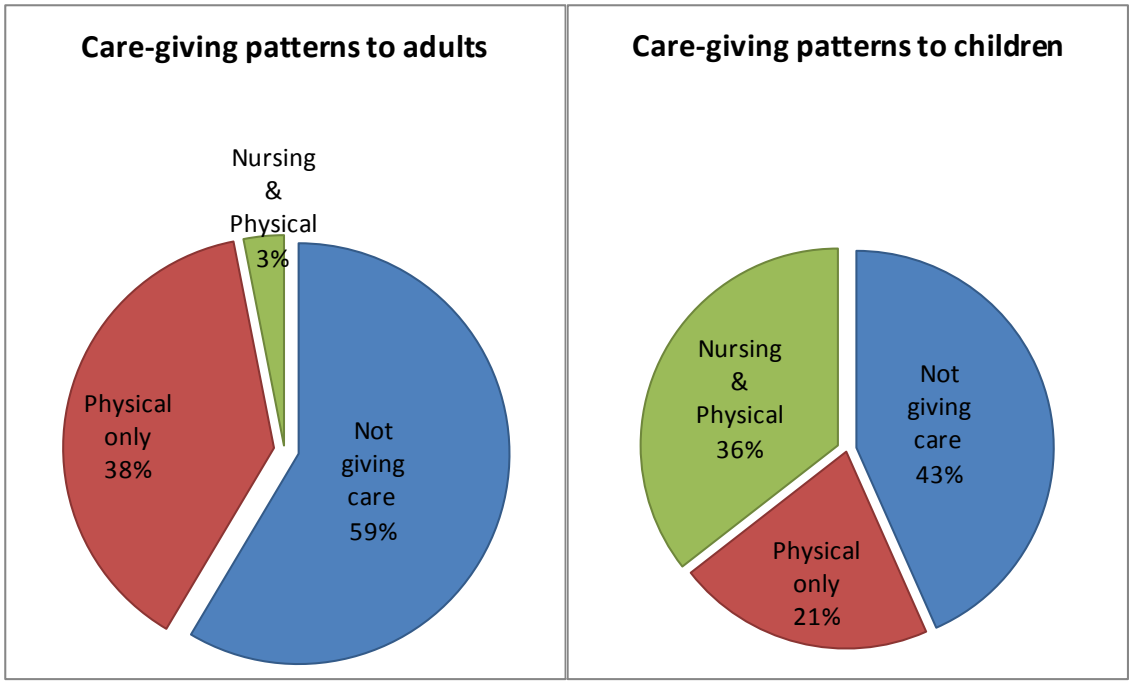


Figure 3-2: Care-giving patterns to adults and children, rural South Africa 2010

Figure 3-2 shows that most of the care to adults was physical care only, that is assistance with regard to cooking, fetching water, and taking to clinic. Among older people providing care to adults, physical care only represented 93% (n=162) of care-

giving. Only a minority of older people were providing adults with nursing care, defined to include assistance with eating, bathing, toileting, giving medicines and dressing of wounds. In contrast, majority of older people were providing children with both nursing and physical care (Figure 3-2). Among care-providers to children, 63% (n=150) were providing children with both physical and nursing care; 37% (n=89) were providing physical care only.

Over 27% of adults needing care were said to be doing so for HIV-related reasons. Of the 175 older people providing care to adult household members, 42% reported that the adults cared for had been contributing to the household income prior to their illness. It should not be surprising then that when asked whether they had difficulties in providing care to adults, 65% (n=114) said they found it very difficult and a further 23% said they had some difficulty. Only about 10% said they had no difficulties. Just around 4% of children were reported to be needing care for HIV-related reasons. In older people providing care to children (n=239), only 23% of the children being cared for were contributing to household income before; and 48% of the older people reported experiencing great difficulties in providing care to children.

Although in the analysis care-giving was stratified into care-giving to adults and to children, care-giving to children and adults are not mutually exclusive. Table 3-3 shows that over 35% (n=148) of study participants were caring for both adults and children. That is, over 56% of the n=266 care-givers were caring for at least a child under 18 years. Gender, age, receipt of grants and household typology were other factors significantly related with care-giving patterns to adults and/or children (Table 3-3).

Table 3-3: Care-giving to adults and/or children, rural South Africa 2010

Characteristics	Non-caregiver n	%	Care-giver - Adults only n	%	Care-giver - Children only n	%	Care-giver - Both n	%	P-value
Overall	156	37.0	27	6.4	91	21.6	148	35.1	
HIV status									0.001
HIV-affected	75	48.1	8	29.6	41	45.1	95	64.2	
HIV-infected	81	51.9	19	70.4	50	54.9	53	35.8	
Sex									<0.001
Male	61	57.5	8	7.5	3	2.8	34	32.1	
Female	95	30.1	19	6.0	88	27.8	114	36.1	
Age group									0.004
50-59	64	34.0	16	8.5	53	28.2	55	29.3	
60-69	45	35.2	6	4.7	28	21.9	49	38.3	
70+	47	44.3	5	4.7	10	9.4	44	41.5	
Marital status									0.000
Never married	48	41.0	7	6.0	29	24.8	33	28.2	
Married	95	46.1	9	4.4	57	27.7	45	21.8	
Previously married	13	13.1	11	11.1	5	5.1	70	70.7	
Education									0.434
NFE/AEO	73	36.3	13	6.5	36	17.9	79	39.3	
6 years or less	53	37.9	7	5.0	37	26.4	43	30.7	
More than 6 years	30	37.0	7	8.6	18	22.2	26	32.1	
Employment									0.414
Employed	142	37.2	27	7.1	79	20.7	134	35.1	
Unemployed	13	34.2	0	0.0	11	28.9	14	36.8	
Missing	1	50.0	0	0.0	1	50.0	0	0.0	
Grant receipt									0.034
None	22	26.8	5	6.1	24	29.3	31	37.8	
Disability	48	42.1	11	9.6	26	22.8	29	25.4	
Old-age pension	86	38.1	11	4.9	41	18.1	88	38.9	
Perceived financial status									<0.001
Better	38	56.7	3	4.5	18	26.9	8	11.9	
No change	46	33.8	7	5.1	29	21.3	54	39.7	
Worse	72	32.9	17	7.8	44	20.1	86	39.3	
HH Headship									0.044
Self	96	39.3	17	7.0	39	16.0	92	37.7	
Spouse	25	28.7	6	6.9	28	32.2	28	32.2	
Other	35	38.5	4	4.4	24	26.4	28	30.8	
Wealth quintile									0.579
First (Poorest)	31	41.9	7	9.5	17	23.0	19	25.7	
Second	36	39.1	5	5.4	15	16.3	36	39.1	
Third	23	28.0	6	7.3	26	31.7	27	32.9	
Fourth	25	36.2	3	4.3	14	20.3	27	39.1	
Fifth (Best-off)	22	41.5	3	5.7	9	17.0	19	35.8	
Missing	19	36.5	3	5.8	10	19.2	20	38.5	
Household typology									0.013
Solo HH	7	77.8	1	11.1	0	0.0	1	11.1	
Older-only	4	57.1	1	14.3	1	14.3	1	14.3	
Skip-gen	2	50.0	0	0.0	1	25.0	1	25.0	
Second-gen	13	65.0	4	20.0	1	5.0	2	10.0	
Multi-gen	124	33.9	20	5.5	84	23.0	138	37.7	
Missing	6	37.5	1	6.3	4	25.0	5	31.3	

3.5.3 Factors associated with care-giving to adults or children by older people in rural South Africa

In adjusted logistic regressions, older people who were HIV-infected were significantly less likely to be care-giving to adults or children or to both adults and children (Table 3-4). Women were significantly more likely to be care-providers to children. Participants who were currently married compared to those never married had about a 50% lower chance of being a care-giver to adults or children. Whereas on the other hand being previously married (separated, widowed or divorced) relative to never married was associated with higher odds of being a care-giver to adults and/or children.

Table 3-4 further shows that older people who said their financial position had not changed or had worsened relative to three years ago had four-fold higher odds of being a care-giver to adults as well as to both adults and children. Self-rating of financial situation as no change or worse was associated with two-fold higher odds of being a care-giver to children.

In the variable care-giving to any, which considered any care-giving either to adults or children, women relative to men, those previously married compared to never married and self-perceived financial status of 'no change' or 'worse' were statistically significantly more likely to be a care-giver; those aged 70+ were statistically significant less likely to be care-givers to adults or children than those in the 50-59 year age group (Table 3-4).

Table 3-4: Factors associated with care-giving, rural South Africa 2010

	Care-giver to Adults	Care-giver to Child	Care-giver to Both	Care-giver to Any
	aOR [95% CI]	aOR [95% CI]	aOR [95% CI]	aOR [95% CI]
HIV status				
HIV-affected	1.00	1.00	1.00	1.00
HIV-infected	0.51 [0.30 - 0.89]	0.52 [0.31 - 0.88]	0.39 [0.22 - 0.68]	0.63 [0.37 - 1.08]
Sex				
Male	1.00	1.00	1.00	1.00
Female	0.63 [0.35 - 1.11]	2.98 [1.75 - 5.07]	0.71 [0.40 - 1.28]	2.74 [1.59 - 4.71]
Age group				
50-59	1.00	1.00	1.00	1.00
60-69	1.20 [0.49 - 2.96]	0.90 [0.37 - 2.21]	1.61 [0.63 - 4.10]	0.70 [0.28 - 1.77]
70+	0.85 [0.30 - 2.47]	0.38 [0.13 - 1.06]	1.06 [0.36 - 3.16]	0.29 [0.10 - 0.85]
Marital status				
Never married	1.00	1.00	1.00	1.00
Married	0.49 [0.28 - 0.88]	0.90 [0.52 -1.53]	0.52 [0.28 - 0.95]	0.82 [0.48 - 1.42]
Previously married	9.63 [4.73 - 19.60]	3.46 [1.78 - 6.74]	6.33 [3.23 - 12.42]	6.47 [3.00 - 13.95]
Education				
NFE/AEO	1.00	1.00	1.00	1.00
6 years or less	0.86 [0.50 - 1.46]	1.11 [0.67 - 1.82]	0.98 [0.57 - 1.70]	1.00 [0.59 - 1.67]
More than 6 years	1.13 [0.58 - 2.20]	1.12 [0.61 - 2.09]	0.99 [0.50 - 1.97]	1.26 [0.66 - 2.39]
Grant receipt				
None	1.00	1.00	1.00	1.00
Disability	0.99 [0.50 - 1.98]	0.43 [0.22 - 0.85]	0.71 [0.35 - 1.47]	0.53 [0.26 - 1.07]
Old-age pension	0.77 [0.28 - 2.12]	0.66 [0.24 - 1.83]	0.57 [0.20 - 1.66]	0.82 [0.28 - 2.36]
HH headship				
Self	1.00	1.00	1.00	1.00
Spouse	2.28 [1.18 - 4.39]	1.47 [0.80 - 2.72]	1.97 [1.00 - 3.89]	1.79 [0.94 -3.41]
Other	0.70 [0.37 - 1.30]	1.10 [0.63 - 1.93]	0.79 [0.42 - 1.48]	0.96 [0.54 - 1.72]
Financial status self				
Better	1.00	1.00	1.00	1.00
No change	4.04 [1.77 -9.23]	2.15 [1.12 - 4.15]	3.98 [1.64 - 9.65]	2.44 [1.25 - 4.77]
Worse	4.28 [1.91 - 9.60]	1.86 [0.99 - 3.51]	3.88 [1.62 - 9.30]	2.30 [1.21 - 4.40]
Wealth quintile				
First (Poorest)	1.00	1.00	1.00	1.00
Second	1.11 [0.53 - 2.33]	1.22 [0.62 - 2.42]	1.44 [0.67 - 3.12]	0.98 [0.48 - 2.00]
Third	1.15 [0.54 - 2.48]	2.02 [0.99 - 4.12]	1.41 [0.63 - 3.14]	1.89 [0.89 - 4.00]
Fourth	1.09 [0.48 - 2.47]	1.54 [0.73 - 3.22]	1.56 [0.67 - 3.61]	1.20 [0.56 - 2.61]
Fifth (Best-off)	1.09 [0.45 - 2.61]	1.09 [0.49 - 2.44]	1.45 [0.58 - 3.59]	0.88 [0.39 - 2.02]
Missing	1.21 [0.52 - 2.82]	1.51 [0.69 - 3.34]	1.83 [0.77 - 4.39]	1.15 [0.51 - 2.62]

Note: HH = Household; NFE/AEO = No formal education or adult education only

3.5.4 Care-receipt characteristics and patterns of rural South Africa older people

A very high proportion of WOPS participants (84%, n=356) said they were receiving physical assistance. Fetching water was the main activity (n=329) in which older people were receiving assistance. A grandchild (65%), son or daughter (63%) or spouse (18%)

were the main sources of physical assistance or care (Figure 3-3). Outside of the family, a small fraction of the older people had hired assistants (primarily domestic workers) to help with activities of daily living. Since these were community dwelling older people there was no one getting assistance from an old-age care facility.

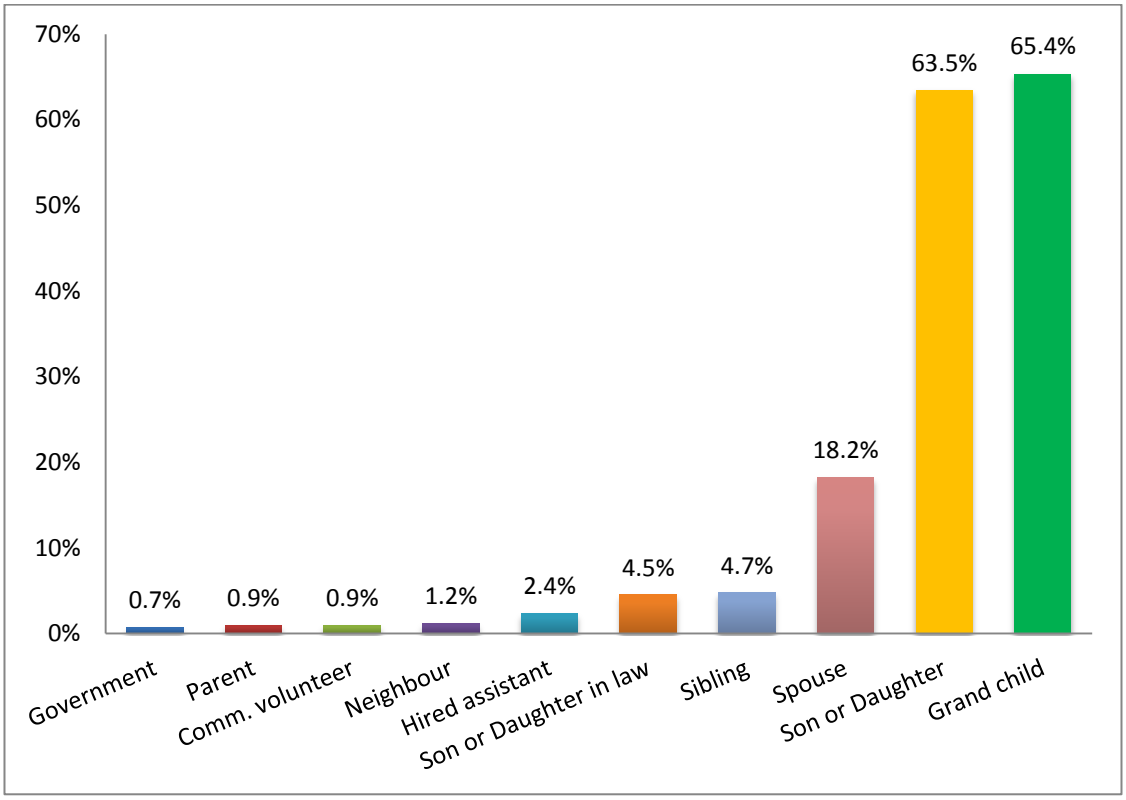


Figure 3-3: Who are the sources of care for older people in rural South Africa, 2010?

With regard to nursing care which comprises assistance with bathing, eating, toileting, incontinence, taking medicines, only 6% (n=25) of the older people said they were receiving such assistance. This is a very small fraction of the n=265 (63%) who said they were in need of care, support or treatment. HIV and TB related (n=162), and health related but not HIV (n=69) were the main reasons older people gave for being in need of care, support or treatment. Around 60% (n=208) of older people receiving physical or nursing care said they were satisfied with the care they received, but a not insignificant proportion, 35% (n=125), reported to be dissatisfied with care received.

Financial assistance was another area of need for older people in rural South Africa. Items for which older people in the study reported being most in need of financial assistance for were, buying food (89%), buying clothing (88%) and transportation (83%). Study participants reported the government as being the main source of financial assistance, reflecting the importance of government cash transfers, which around 81% of participants were in receipt thereof. In a distant second and third respectively were son or daughter (8%) and spouse (7%) as sources of financial assistance. Government cash transfers in South Africa are a very important source of income especially in rural households. Over 91% (n=304) of the older people said they used the grant for household expenses, only 8% (n=28) used the grant they received for their own upkeep. The analysis in Chapter Two was based on the assumption that whatever income is earned by household members will be somewhat shared within the household. This finding here of over 90% of older people sampled saying grants received are spent on household expenses lends further credence to that assumption. As testament of how widely and easily accessible the grants are, among those receiving the grants (n=333), the majority (66%) said it had not been difficult for them to start receiving this financial assistance; 15% said it had been a little difficult and only 17% said it was very difficult. Around n=329 older people said they had been contributing to household income in the past before being in poor health, of these 64% (n=211) said they had been the main income provider.

3.5.5 Factors associated with care-receiving among study participants

Table 3-5 shows socio-demographic factors associated with care-receiving among older people in rural South Africa, results of adjusted logistic regressions. Older people who were HIV-infected were associated with statistically significant lower odds of being care-receivers (Table 3-5). Other factors associated with lower odds of being in receipt of care were having some education level compared to no formal education. Self-reported financial situation having not changed or worsened compared to three years ago was statistically significant associated with higher likelihood of receiving care.

Table 3-5: Factors associated with care-receiving, rural South Africa 2010

	aOR	[95%	CI]
HIV status			
HIV-affected	1.00		
HIV-infected	0.32	0.16	0.66
Sex			
Male	1.00		
Female	0.66	0.32	1.37
Age group			
50-59	1.00		
60-69	0.89	0.29	2.78
70+	1.91	0.38	9.64
Marital status			
Never married	1.00		
Married	1.65	0.81	3.32
Previously married	2.00	0.83	4.83
Education			
No formal education	1.00		
6 years or less	0.45	0.23	0.90
More than 6 years	0.39	0.17	0.89
Grant receipt			
None	1.00		
Disability	1.19	0.56	2.56
Old-age pension	2.26	0.60	8.47
HH headship			
Self	1.00		
Spouse	1.52	0.65	3.58
Other	1.19	0.55	2.58
Financial status self			
Better	1.00		
No change	3.40	1.40	8.25
Worse	2.92	1.32	6.43
Wealth quintile			
First (Poorest)	1.00		
Second	0.56	0.22	1.42
Third	1.34	0.49	3.64
Fourth	0.96	0.34	2.70
Fifth (Best-off or least poor)	0.62	0.21	1.83
Missing	1.38	0.46	4.15

3.5.6 Factors associated with simultaneously care-giving and care-receiving

Further analyses considered whether study participants were exclusive care-givers or care-recipients. As stated earlier, the severe impact of HIV and economic circumstances among adults on one hand and increasing frailty and HIV infection among older people on the other hand may lead to older people simultaneously providing and needing care. Results (Table 3-6) show that 56% (n=238) of all study participants were simultaneously care-givers and care-receivers. Statistically significant differences in proportions providing and/or receiving care were observed by gender, age, marital status, education level attained, receipt of grants, self-perceived financial status and household typology. For instance within each variable the highest percentage of participants who were both care-givers and care-receivers were observed for women, those previously married (separated, divorced or widowed), those with no formal education and those not in receipt of government grants (Table 3-6).

Table 3-6: Proportion giving and/or receiving care, rural South Africa 2010

	Neither		Care-giver Only		Care-receiver Only		Both		P-value
Characteristics	n	%	n	%	n	%	n	%	
n	37	8.8	28	6.6	119	28.2	238	56.4	
Sex									<0.001
Male	14	13.2	3	2.8	47	44.3	42	39.6	
Female	23	7.3	25	7.9	72	22.8	196	62.0	
Age group									<0.001
50-59	22	11.7	22	11.7	42	22.3	102	54.3	
60-69	11	8.6	6	4.7	34	26.6	77	60.2	
70+	4	3.8	0	0.0	43	40.6	59	55.7	
Marital status									<0.001
Never married	19	16.2	9	7.7	29	24.8	60	51.3	
Married	13	6.3	14	6.8	82	39.8	97	47.1	
Previously married	5	5.1	5	5.1	8	8.1	81	81.8	
Education									0.027
NFE/AEO	12	6.0	6	3.0	61	30.3	122	60.7	
6 years or less	16	11.4	12	8.6	37	26.4	75	53.6	
More than 6 years	9	11.1	10	12.3	21	25.9	41	50.6	
Employment									0.622
Employed	31	8.1	25	6.5	111	29.1	215	56.3	
Unemployed	6	15.8	3	7.9	7	18.4	22	57.9	
Grant receipt									<0.001
None	9	11.0	9	11.0	13	15.9	51	62.2	
Disability	16	14.0	13	11.4	32	28.1	53	46.5	
Old-age pension	12	5.3	6	2.7	74	32.7	134	59.3	
Financial status self									0.001
Better	11	16.4	7	10.4	27	40.3	22	32.8	
No change	8	5.9	5	3.7	38	27.9	85	62.5	
Worse	18	8.2	16	7.3	54	24.7	131	59.8	
HH Headship									0.310
Self	24	9.8	15	6.1	72	29.5	133	54.5	
Spouse	3	3.4	9	10.3	22	25.3	53	60.9	
Other	10	11.0	4	4.4	25	27.5	52	57.1	
Wealth quintile									0.782
First (Poorest)	5	6.8	6	8.1	26	35.1	37	50.0	
Second	9	9.8	7	7.6	27	29.3	49	53.3	
Third	7	8.5	3	3.7	16	19.5	56	68.3	
Fourth	6	8.7	4	5.8	19	27.5	40	58.0	
Fifth (Best-off)	7	13.2	4	7.5	15	28.3	27	50.9	
Missing	3	5.8	4	7.7	16	30.8	29	55.8	
Household typology									<0.001
Solo HH	5	55.6	1	11.1	2	22.2	1	11.1	
Older-only	0	0.0	1	14.3	4	57.1	2	28.6	
Skip-gen	1	25.0	0	0.0	1	25.0	2	50.0	
Second-gen	4	20.0	2	10.0	9	45.0	5	25.0	
Multi-gen	25	6.8	24	6.6	99	27.0	218	59.6	
Missing	2	12.5	0	0.0	4	25.0	10	62.5	

Women compared to men, participants who were previously married relative to those never married, older people who reported their financial situation not to have changed or worsened, as well as those in the third (medium) household wealth quintile relative to first (poorest) wealth quintile were highly likely to be both care-givers and care-receivers, while participants who were HIV-infected were less likely than those who were HIV-affected to be simultaneously giving and receiving care (Table 3-7).

Table 3-7: Factors associated with simultaneously care-giving and care-receiving

	aOR	[95%	CI]
HIV status			
HIV-affected	1.00		
HIV-infected	0.45	0.26	0.75
Sex			
Male	1.00		
Female	1.95	1.14	3.32
Age group			
50-59	1.00		
60-69	0.91	0.37	2.20
70+	0.41	0.14	1.16
Marital status			
Never married	1.00		
Married	0.79	0.46	1.35
Previously married	5.01	2.48	10.12
Education			
No formal education	1.00		
6 years or less	0.83	0.50	1.37
More than 6 years	0.86	0.46	1.60
Grant receipt			
None	1.00		
Disability	0.58	0.30	1.13
Old-age pension	0.89	0.33	2.42
Financial status self			
Better	1.00		
No change	3.03	1.54	5.98
Worse	2.78	1.44	5.37
Wealth quintile			
First (Poorest)	1.00		
Second	0.94	0.47	1.88
Third	2.42	1.16	5.03
Fourth	1.36	0.64	2.90
Fifth (Best-off or least poor)	0.95	0.42	2.15
Missing	1.28	0.58	2.84

3.5.7 Care-giving, health and well-being of older people in rural South Africa

Five different health measures were used as outcomes in this analysis. Physical health status using the WHO disability index (WHODAS), self-reported health status in the last fortnight; self-rated overall health status; emotional well-being measured using the WHO quality of life index (WHOQoL) and self-reported quality of life were examined in this analysis. Quintile distributions for each of the outcome health measures by care-giving status are presented in Table 3-8.

Table 3-8: Health measures (in quintiles) by care-giving status, rural South Africa 2010

	Overall		**Non-caregiver**		**Care-giver**		P-value
Characteristics	n	%	n	%	n	%	
n	422	100	156	37.0	266	63.0	
Physical functioning (WHODAS)							0.002
First quintile (Poorest health)	98	23.2	52	33.3	46	17.3	
Second quintile	71	16.8	28	17.9	43	16.2	
Third quintile	87	20.6	27	17.3	60	22.6	
Fourth quintile	91	21.6	26	16.7	65	24.4	
Fifth quintile (Best health)	75	17.8	23	14.7	52	19.5	
Quality of Life (WHOQoL)							0.003
First quintile (Poorest health)	101	23.9	23	14.7	78	29.3	
Second quintile	80	19.0	30	19.2	50	18.8	
Third quintile	84	19.9	29	18.6	55	20.7	
Fourth quintile	81	19.2	38	24.4	43	16.2	
Fifth quintile (Best health)	76	18.0	36	23.1	40	15.0	
Self-rated overall health status							<0.001
Very good	11	2.6	10	6.4	1	0.4	
Good	182	43.1	63	40.4	119	44.7	
Moderate	167	39.6	52	33.3	115	43.2	
Bad	57	13.5	26	16.7	31	11.7	
Very bad	5	1.2	5	3.2	0	0.0	
Health last 2 weeks							0.002
Very good	6	1.4	5	3.2	1	0.4	
Good	90	21.3	24	15.4	66	24.8	
Moderate	232	55.0	80	51.3	152	57.1	
Bad	88	20.9	44	28.2	44	16.5	
Very bad	5	1.2	3	1.9	2	0.8	
Self-rated quality of life							0.581
Very good	3	0.7	1	0.6	2	0.8	
Good	61	14.5	28	17.9	33	12.4	
Moderate	227	53.8	78	50.0	149	56.0	
Bad	108	25.6	41	26.3	67	25.2	
Very bad	23	5.5	8	5.1	15	5.6	

For self-rated overall health status, health in the last two weeks and self-rated quality of life, participants were concentrated in the second to fourth health quintiles. There were substantially lower proportions in the first (poorest) and fifth (best) health quintiles. The percentage distributions were much more evenly spread for physical functioning ability (WHODAS) and quality of life (WHOQoL). Findings still indicate a non-caregivers were concentrated in quintiles 1-3 (poorer health quintiles), while care-givers were mainly in quintiles 3-5 (better health quintiles) (Table 3-8).

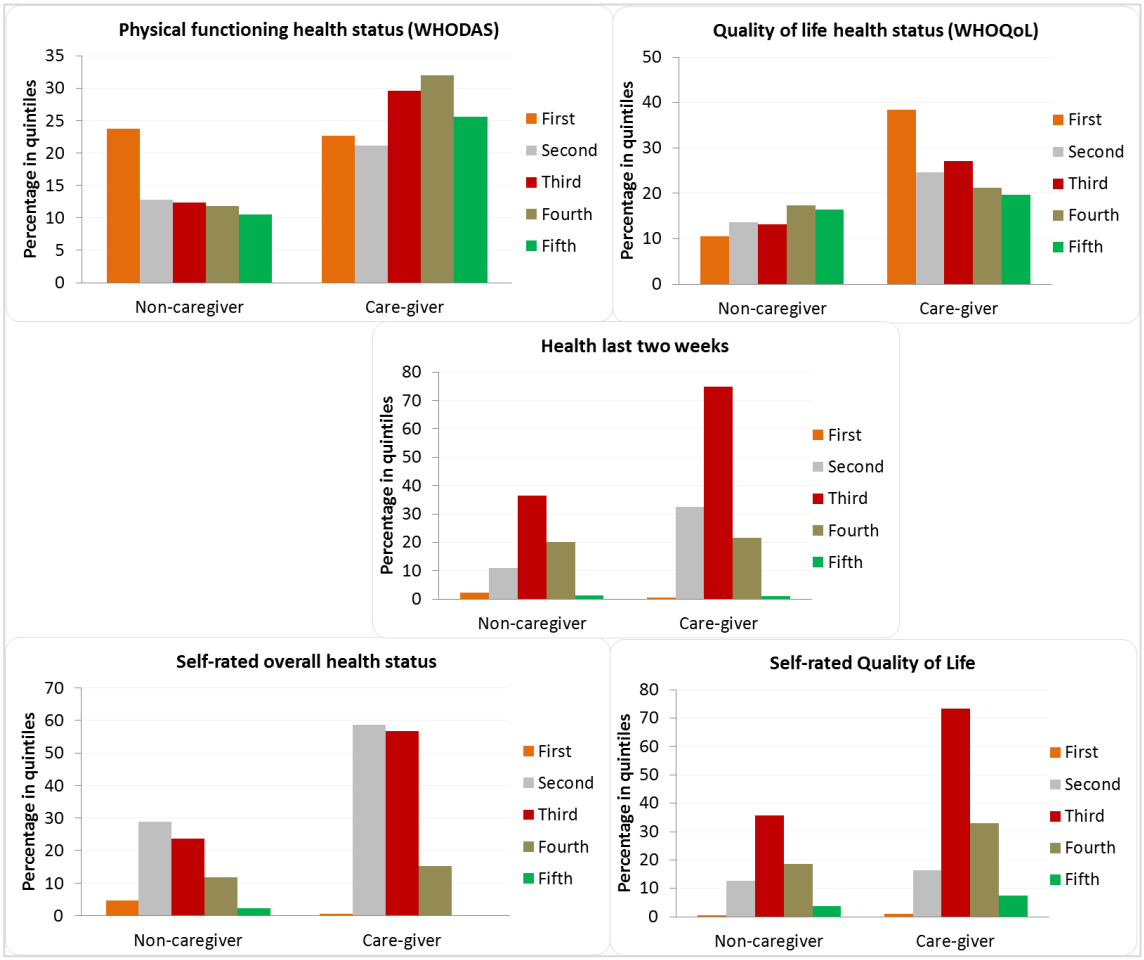


Figure 3-4: Health status in quintiles by care-giving status, rural South Africa 2010

For quality of life a higher proportion of participants were in the fourth and fifth quintiles among non-caregivers and in the first to the third quintiles among care-givers. The quintile distributions of the health measures can be clearly seen in Figure 3-4. These differences were statistically significant for all health measures except self-rated quality of life. For dichotomised health measures, statistically significant

differences were only observed for physical functioning and quality of life (Table 3-9). For all health measures nonetheless, a higher proportion of participants were in poor health status in both non-caregivers and care-givers as well as for the overall sample.

Table 3-9: Health measures (dichotomised) by care-giving status, rural South Africa 2010

	Overall		**Non-caregiver**		**Care-giver**		P-value
Characteristics	n	%	n	%	n	%	
n	422	100	156	37.0	266	63.0	
Physical functioning (WHODAS)							0.011
Good	166	39.3	49	31.4	117	44.0	
Poor	256	60.7	107	68.6	149	56.0	
Quality of Life (WHOQoL)							0.001
Good	157	37.2	74	47.4	83	31.2	
Poor	265	62.8	82	52.6	183	68.8	
Self-rated overall health status							0.738
Good	193	45.7	73	46.8	120	45.1	
Poor	229	54.3	83	53.2	146	54.9	
Health last 2 weeks							0.119
Good	96	22.7	29	18.6	67	25.2	
Poor	326	77.3	127	81.4	199	74.8	
Self-rated quality of life							0.133
Good	64	15.2	29	18.6	35	13.2	
Poor	358	84.8	127	81.4	231	86.8	

Logistic regressions were used to assess the association of care-giving to adults and/or to children with the health and well-being of study participants in this rural South African community. Results of the regression analyses of the association between care-giving to adults and health are presented in Table 3-10 and shown graphically in Figure 3-5. Study participants who were providing care to adults had statistically significant lower odds of being in poor physical health adjusting for HIV state (HIV-infected vs HIV-affected), age, gender, marital status, education level completed, receipt of government grants, and household wealth quintiles (Figure 3-5). That is, older people who were providing care to adults were more likely to be in good physical health relative to older people not providing care. Older people who were providing care to adults were also less likely to report themselves as being in poor physical health in the last two weeks or in the overall self-rated health status question, but the latter association was not statistically significant.

Table 3-10: Care-giving to adults or children and older people's physical health and mental well-being by HIV category

	Care-giving = reference category					
	Care-giving to adults			Care-giving to children		
Dependant variables	aOR	[95%	CI]	aOR	[95%	CI]
Physical Health (WHODAS)						
Good	1.00			1.00		
Poor	0.20	0.12	0.33	0.43	0.26	0.70
Constant (-2 LL)	221.62**			238.17**		
Model χ^2	122.44			89.33		
Degrees of freedom	15			15		
Number	422			422		
Mental well-being (WHOQoL)						
Good	1.00			1.00		
Poor	2.64	1.68	4.14	1.63	1.05	2.55
Constant (-2 LL)	248.65**			255.61**		
Model χ^2	59.77			45.85		
Degrees of freedom	15			15		
Number	422			422		
Health Status Last 2 Weeks						
Good	1.00			1.00		
Poor	0.35	0.21	0.57	0.51	0.30	0.87
Constant (-2 LL)	205.43**			211.36*		
Model χ^2	41.71			29.84		
Degrees of freedom	15			15		
Number	422			422		
Self-Rated Overall Health Status						
Good	1.00			1.00		
Poor	0.88	0.58	1.32	0.93	0.60	1.42
Constant (-2 LL)	273.98*			274.12*		
Model χ^2	33.97			33.71		
Degrees of freedom	15			15		
Number	422			422		
Self-reported Quality of Life						
Good	1.00			1.00		
Poor	1.45	0.78	2.67	1.47	0.80	2.72
Constant (-2 LL)	152.96**			152.91**		
Model χ2	122.44			53.37		
Degrees of freedom	15			15		
Number	422			422		

Note: Logistic regressions were run separately for each outcome variable. In each model the following were controlled for: age, sex, education, receipt of government grants, household wealth quintiles, and HIV category (HIV-infected relative to HIV-affected).

* p<0.05 ** p<0.001

LL = log likelihood

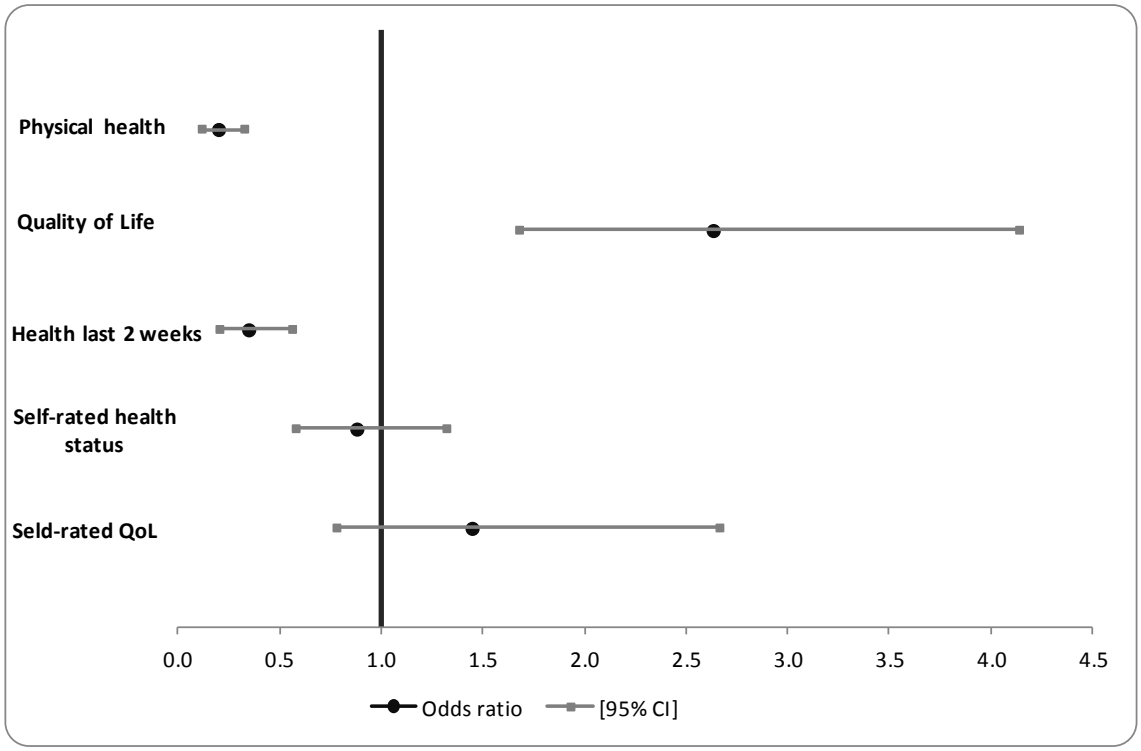


Figure 3-5: Odds of being in poor health by health measure for care-givers to adults

NB: Figure 3-5 shows the adjusted odds of being in poor relative to good health, as measured using five different measures of health status. Odds ratios adjusted for age, gender, marital status, education, receipt of government grants, household wealth quintiles, and HIV status (HIV-infected vs HIV-affected).

The association between care-giving to adults and emotional well-being was different from that of care-giving and physical health. Older people who were care-givers to adults were close to three times more likely to report poor quality of life (emotional well-being) adjusting for the same factors as in the physical health models (Figure 3-5). Study participants who were care-givers to adults were likewise more likely to self-rate their quality of life as poor, although this association did not reach statistical significance.

The associations of care-giving to children with respective health measures (presented in Table 3-5 and shown in Figure 3-6) were identical to those for care-giving to adults. Care-giving to children was significantly associated with lower odds of being in poor physical health and in poor health status in the last two weeks on one hand, and on the other hand was statistically significant associated with higher likelihood of being in poor quality of life, adjusting for HIV status, age, gender, marital status, education level

completed, receipt of government grants, and household wealth quintiles (Figure 3-6). Self-rated overall health status and self-rated quality of life were both not statistically significant associated with care-giving to children among study participants in multivariable adjusted models.

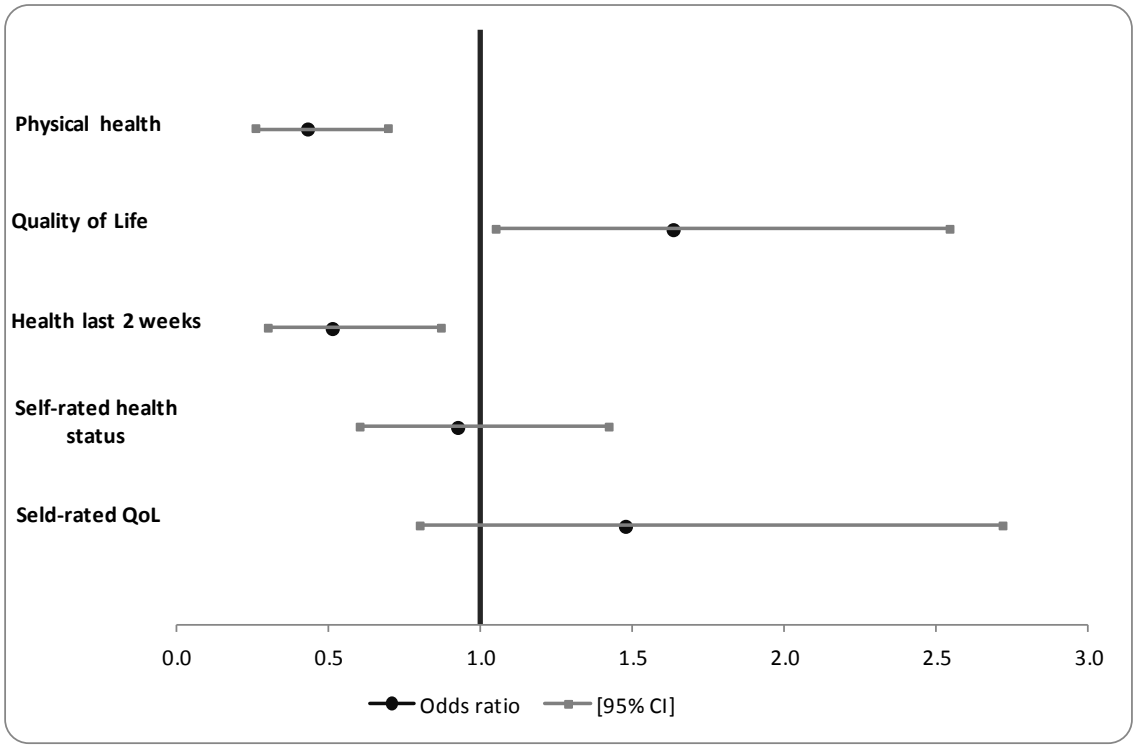


Figure 3-6: Odds of being in poor health by health measure for care-givers to children

NB: Figure 3-6 shows the adjusted odds of being in poor relative to good health, as measured using five different measures of health status. Odds ratios adjusted for age, gender, marital status, education, receipt of government grants, household wealth quintiles, and HIV status (HIV-infected vs HIV-affected).

In stratified analyses by HIV status (HIV-infected relative to HIV-affected), similar patterns in the effect of care-giving to adults on older people's health and well-being as presented here were observed (Table 3-11); whereas Table 3-12 shows that care-giving to children was only significantly associated with lower odds of being in poor physical health among HIV-affected participants.

Table 3-11: Care-giving to adults and older people's physical health and mental well-being by HIV category

	Care-giving to adults = reference category					
	HIV-infected			HIV-affected		
Dependant variables	aOR	[95%	CI]	aOR	[95%	CI]
Physical Health (WHODAS)						
Good	1.00			1.00		
Poor	0.32	0.16	0.64	0.12	0.06	0.26
Constant (-2 LL)	111.21*			101.12**		
Model χ^2	58.76			69.11		
Degrees of freedom	13			13		
Number	203			219		
Mental well-being (WHOQoL)						
Good	1.00			1.00		
Poor	2.65	1.38	5.10	2.43	1.25	4.72
Constant (-2 LL)	124.50*			117.19**		
Model χ^2	27.67			41.56		
Degrees of freedom	13			13		
Number	203			219		
Health Status Last 2 Weeks						
Good	1.00			1.00		
Poor	0.46	0.22	0.95	0.23	0.11	0.50
Constant (-2 LL)	102.03*			98.06*		
Model χ^2	22.58			28.95		
Degrees of freedom	13			13		
Number	203			219		
Self-Rated Overall Health Status						
Good	1.00			1.00		
Poor	0.72	0.39	1.33	1.03	0.58	1.86
Constant (-2 LL)	131.85			138.52*		
Model χ^2	17.32			23.21		
Degrees of freedom	13			13		
Number	203			219		
Self-reported Quality of Life						
Good	1.00			1.00		
Poor	1.42	0.64	3.15	1.43	0.51	4.00
Constant (-2 LL)	92.74*			55.60*		
Model χ2	24.16			24.05		
Degrees of freedom	13			12		
Number	203			204		

Note: Logistic regressions were run separately for each outcome variable. In each model the following were controlled for: age, sex, education, receipt of government grants, and household wealth quintiles.

* p<0.05 ** p<0.001

LL = log likelihood

Table 3-12: Effect of care-giving to children on older people's physical health and mental well-being by HIV category

	Care-giving to children = reference category					
	HIV-infected			HIV-affected		
Dependant variables	aOR	[95%	CI]	aOR	[95%	CI]
Physical Health (WHODAS)						
Good	1.00			1.00		
Poor	0.50	0.24	1.03	0.31	0.14	0.65
Constant (-2 LL)	114.92**			113.80**		
Model χ2	51.35			43.75		
Degrees of freedom	13			13		
Number	203			219		
Mental well-being (WHOQoL)						
Good	1.00			1.00		
Poor	1.21	0.63	2.34	1.76	0.91	3.41
Constant (-2 LL)	128.79			119.32**		
Model χ2	19.08			37.30		
Degrees of freedom	13			13		
Number	203			219		
Health Status Last 2 Weeks						
Good	1.00			1.00		
Poor	0.41	0.18	0.93	0.56	0.26	1.21
Constant (-2 LL)	101.87*			104.65		
Model χ2	22.90			15.84		
Degrees of freedom	13			13		
Number	203			219		
Self-Rated Overall Health Status						
Good	1.00			1.00		
Poor	0.78	0.40	1.50	1.04	0.57	1.91
Constant (-2 LL)	132.12			138.52*		
Model χ2	16.78			23.22		
Degrees of freedom	13			13		
Number	203			219		
Self-reported Quality of Life						
Good	1.00			1.00		
Poor	1.73	0.76	3.94	0.82	0.28	2.36
Constant (-2 LL)	92.27*			55.76**		
Model χ2	25.10			23.73		
Degrees of freedom	13			12		
Number	203			204		

Note: Logistic regressions were run separately for each outcome variable. In each model the following were controlled for: age, sex, education, receipt of government grants, and household wealth quintiles.

* p<0.05 ** p<0.001

LL = log likelihood

In the sub-sample of older people providing care to both adults and children (n=148), care-giving was significantly associated with lower odds of being in poor physical health, poor health status in the last two weeks and poor self-rated overall health status, in contrast it was associated with higher odds of being in poor quality of life and poor self-rated quality of life in adjusted logistics regression models (Figure 3-7). Detailed results on which Figure 3-7 is based with a summary of some model parameters are presented in Table 3-13.

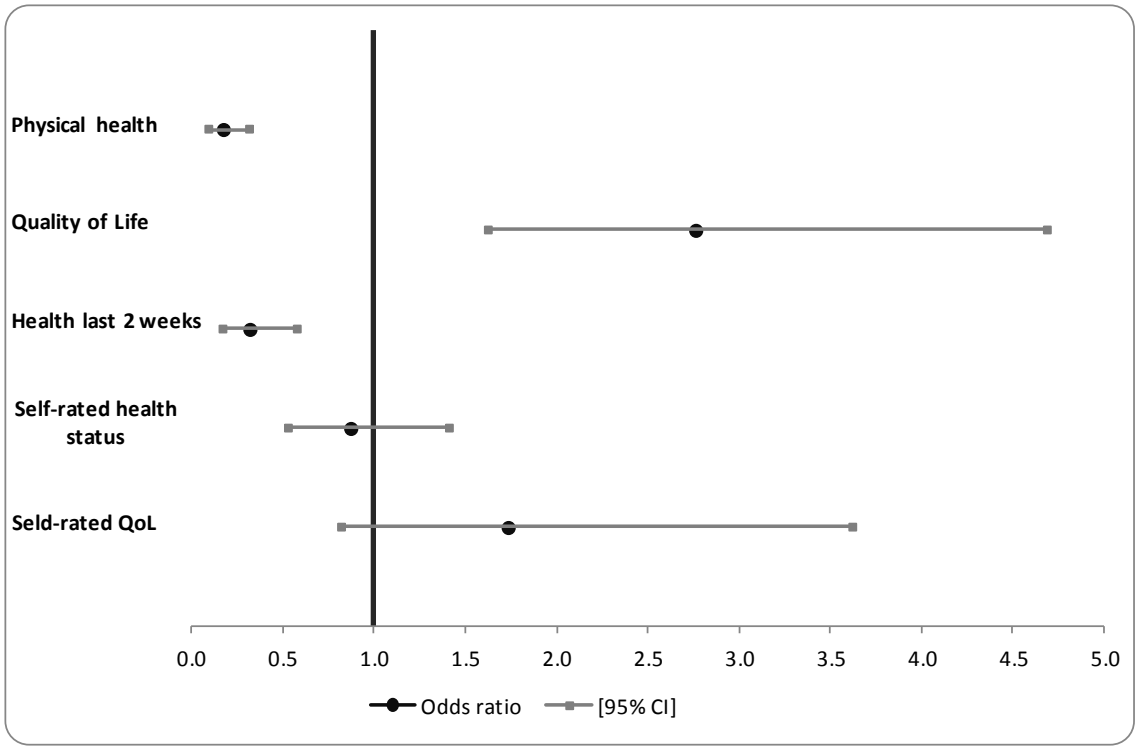


Figure 3-7: Odds of being in poor health for care-givers to both adults and children

NB: Figure 3-7 shows the adjusted odds of being in poor relative to good health, as measured using five different measures of health status. Odds ratios adjusted for age, gender, marital status, education, receipt of government grants, household wealth quintiles, and HIV status (HIV-infected vs HIV-affected).

Table 3-13: Effect of care-giving on older people's physical health and mental well-being

	Non-Caregiver = reference category[ψ]					
	Care-giving to adults and children (both)			Care-giving to either adults or children only		
Dependant variables	aOR	[95%	CI]	aOR	[95%	CI]
Physical Health (WHODAS)						
Good	1.00			1.00		
Poor	0.17	0.09	0.32	0.64	0.34	1.20
Constant (-2 LL)	224.36**			224.36**		
Model χ^2	116.96			116.96		
Degrees of freedom	16			16		
Number	422			422		
Mental well-being (WHOQoL)						
Good	1.00			1.00		
Poor	2.76	1.63	4.69	1.18	0.69	2.04
Constant (-2 LL)	249.89**			249.89**		
Model χ^2	57.28			57.28		
Degrees of freedom	16			16		
Number	422			422		
Health Status Last 2 Weeks						
Good	1.00			1.00		
Poor	0.32	0.18	0.58	0.88	0.44	1.78
Constant (-2 LL)	205.58**			205.58**		
Model χ^2	41.41			41.41		
Degrees of freedom	16			16		
Number	422			422		
Self-Rated Overall Health Status						
Good	1.00			1.00		
Poor	0.87	0.53	1.41	0.98	0.57	1.67
Constant (-2 LL)	273.99*			273.99*		
Model χ^2	33.95			33.95		
Degrees of freedom	16			16		
Number	422			422		
Self-reported Quality of Life						
Good	1.00			1.00		
Poor	1.73	0.82	3.62	0.99	0.48	2.07
Constant (-2 LL)	152.32**			152.32**		
Model χ2	54.54			54.54		
Degrees of freedom	16			16		
Number	422			422		

Note: Logistic regressions were run separately for each outcome variable. In each model the following were controlled for: age, sex, education, receipt of government grants, household wealth quintiles, and HIV category (HIV-infected relative to HIV-affected).

ψ Run single model with care-giving variable having 3 categories of 'Non-caregiver', 'care-giver to adults and children', and 'care-giver to either adults or children only'

* p<0.05 ** p<0.001. LL = log likelihood

3.5.8 Care-receiving association with health status and mental well-being

The odds of being in poor health for older people receiving care are shown in Figure 3-8 with detailed data presented in Table 3-14. Older people who were receiving care were more likely to be in poor health on all health measures considered except for self-reported health status in the last two weeks in adjusted multivariable models (Figure 3-8). Factors adjusted for were HIV state, age, gender, marital status, education level completed, receipt of government grants, and household wealth quintiles. However, only quality of life and self-rated quality of life were significantly associated with higher likelihood of being in poor health for participants in receipt of care.

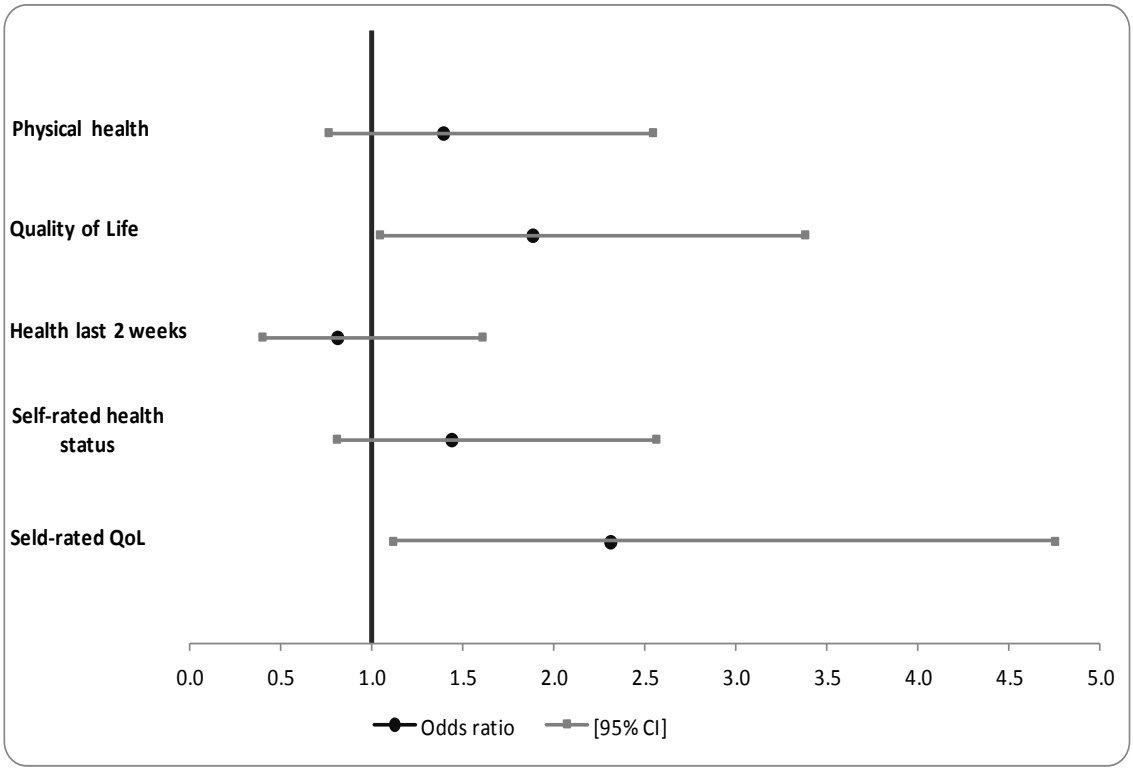


Figure 3-8: Odds of being in poor health by health measure for older people receiving care

NB: Figure 3-8 shows the adjusted odds of being in poor relative to good health, as measured using five different measures of health status. Odds ratios adjusted for age, gender, marital status, education, receipt of government grants, household wealth quintiles, and HIV status (HIV-infected vs HIV-affected).

Table 3-14: Effect of care-receiving on older people's physical health and mental well-being

	Care-receiving = reference category		
Dependant variables	aOR	[95% CI]	
Physical Health (WHODAS)			
Good	1.00		
Poor	1.39	0.76	2.55
Constant (-2 LL)	243.63**		
Model χ^2	78.40		
Degrees of freedom	15		
Number	422		
Mental well-being (WHOQoL)			
Good	1.00		
Poor	1.88	1.04	3.38
Constant (-2 LL)	255.76**		
Model χ^2	45.54		
Degrees of freedom	15		
Number	422		
Health Status Last 2 Weeks			
Good	1.00		
Poor	0.80	0.40	1.61
Constant (-2 LL)	214.35		
Model χ^2	23.87		
Degrees of freedom	15		
Number	422		
Self-Rated Overall Health Status			
Good	1.00		
Poor	1.44	0.80	2.56
Constant (-2 LL)	273.43*		
Model χ^2	35.09		
Degrees of freedom	15		
Number	422		
Self-reported Quality of Life			
Good	1.00		
Poor	2.31	1.12	4.76
Constant (-2 LL)	151.19**		
Model χ2	56.80		
Degrees of freedom	15		
Number	422		

Note: Logistic regressions were run separately for each outcome variable. In each model the following were controlled for: age, sex, education, receipt of government grants, household wealth quintiles, and HIV category (HIV-infected relative to HIV-affected).

* p<0.05 ** p<0.001. LL = log likelihood

In separate analyses for HIV-infected and HIV-affected participants, only physical health and self-rated quality of life were statistically significant associated with higher likelihood of older people in receipt of care being in poor health (Table 3-15).

Table 3-15: Care-receipt and older people's physical and mental well-being by HIV category

	Care-receiving (Yes) = reference category					
	HIV-infected			HIV-affected		
Dependant variables	aOR	[95%	CI]	aOR	[95%	CI]
Physical Health (WHODAS)						
Good	1.00			1.00		
Poor	2.64	1.17	5.94	0.96	0.25	3.67
Constant (-2 LL)	111.66**			106.99**		
Model χ^2	57.86			57.36		
Degrees of freedom	17			17		
Number	203			219		
Mental well-being (WHOQoL)						
Good	1.00			1.00		
Poor	1.64	0.76	3.52	2.32	0.66	8.11
Constant (-2 LL)	114.98**			117.34**		
Model χ^2	46.70			41.27		
Degrees of freedom	17			17		
Number	203			219		
Health Status Last 2 Weeks						
Good	1.00			1.00		
Poor	1.02	0.45	2.31	0.42	0.05	3.60
Constant (-2 LL)	102.56			97.17*		
Model χ^2	21.52			30.79		
Degrees of freedom	17			17		
Number	203			219		
Self-Rated Overall Health Status						
Good	1.00			1.00		
Poor	1.32	0.65	2.70	2.33	0.71	7.68
Constant (-2 LL)	130.76			136.82		
Model χ^2	19.67			26.62		
Degrees of freedom	17			17		
Number	203			219		
Self-reported Quality of Life						
Good	1.00			1.00		
Poor	2.52	1.08	5.88	0.76	0.06	9.25
Constant (-2 LL)	86.19*			48.70*		
Model χ^2	37.27			37.86		
Degrees of freedom	17			16		
Number	203			219		

Note: Logistic regressions were run separately for each outcome variable. In each model the following were controlled for: age, sex, marital status, education, receipt of government grants, household wealth quintiles, self-perceived financial status, and HIV category (HIV-infected relative to HIV-affected).

* p<0.05 ** p<0.001. LL = log likelihood

Older people who were care-givers and care-receivers at the same time had about a 60% lower likelihood of being in poor physical health and were nearly twice as likely as the rest of the older people to be in poor quality of life (Figure 3-9). The association of health in the last two weeks with being a care-giver and care-receiver simultaneously was borderline statistically significant, but self-rated health status and self-rated quality of life were not statistically significant (Figure 3-9). Detailed results on which Figure 3-9 is based are presented in Table 3-16.

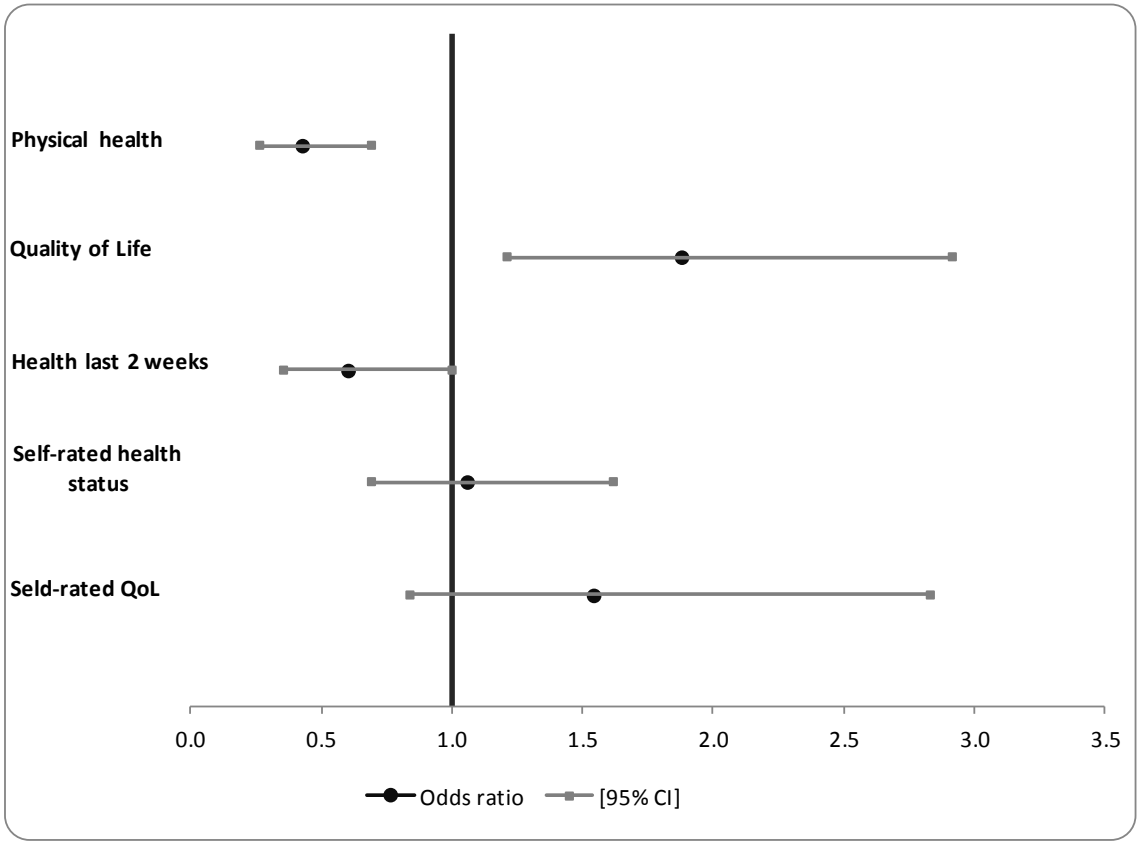


Figure 3-9: Odds of being in poor health for older people giving and receiving care

NB: Figure 3-9 shows the adjusted odds of being in poor relative to good health, as measured using five different measures of health status. Odds ratios adjusted for age, gender, marital status, education, receipt of government grants, household wealth quintiles, and HIV status (HIV-infected vs HIV-affected).

Table 3-16: Care-giving and care-receiving and older people's physical health and mental well-being

	Other = reference category$^{\psi}$		
	Care-giver and care-receiver		
Dependant variables	aOR	[95%	CI]
Physical Health (WHODAS)			
Good	1.00		
Poor	0.43	0.26	0.69
Constant (-2 LL)	237.97**		
Model χ^2	89.73		
Degrees of freedom	15		
Number	422		
Mental well-being (WHOQoL)			
Good	1.00		
Poor	1.88	1.21	2.92
Constant (-2 LL)	253.96**		
Model χ^2	49.15		
Degrees of freedom	15		
Number	422		
Health Status Last 2 Weeks			
Good	1.00		
Poor	0.60	0.36	1.00
Constant (-2 LL)	212.59*		
Model χ^2	27.39		
Degrees of freedom	15		
Number	422		
Self-Rated Overall Health Status			
Good	1.00		
Poor	1.06	0.69	1.62
Constant (-2 LL)	274.14*		
Model χ^2	33.66		
Degrees of freedom	15		
Number	422		
Self-reported Quality of Life			
Good	1.00		
Poor	1.54	0.84	2.83
Constant (-2 LL)	152.69**		
Model χ2	53.82		
Degrees of freedom	15		
Number	422		

Note: Logistic regressions were run separately for each outcome variable. In each model the following were controlled for: age, sex, education, receipt of government grants, household wealth quintiles, and HIV category (HIV-infected relative to HIV-affected).

ψ Run single model with dichotomous care variable having categories of 'care-giver and care-receiver' and 'Other - not care-giver and care-receiver '

* p<0.05 ** p<0.001.

LL = log likelihood

3.6 Discussion

Of the 422 older people in the study sample, around 42% were care-givers to adult household members and 57% care-givers to children. Overall, over 60% of the study participants were caring for at least an adult or child; of these over one-half were care-givers to both adults and children in their household. Results of this analysis show that the proportion of older people giving care to either adults or children declines with age. This may be a function of increasing frailty and need of care with increasing age by older people. These findings further suggest that the burden of care-giving among older people is heavier for women than men; overall 83% of care-givers were women (76% among care-givers to adults, 84% among care-givers to children). This may be a contributory factor to something that has been considered by others as a paradox in that women tend to have longer life expectancies but seem to report more ill-health, disability and mental health problems than men (Arber and Cooper, 1999; Case and Paxson, 2005; Christensen, 2008; Rieker and Bird, 2005; Yount and Agree, 2005).

The high proportion of children being provided both nursing and physical care (63%) compared to only 7% among adults is indicative of the dependent nature of children which gets exacerbated with ill health. A very high proportion of the study participants (65% of care-givers to adults, 48% of care-givers to children) said they faced great difficulties in providing care. However, findings showing that a very high proportion of the study participants were both giving and receiving care suggests that while older people may be primary care-givers to adults and children, they may also be receiving some assistance from other household members in fulfilling the role of care-giver. This is likely to militate against some of the negative effects of care-giving on health and well-being.

In this cross-sectional study, care-providers both among HIV-infected and HIV-affected older people were more likely to be in good physical health. This may be so as most of the care to adults was physical only. Even among children though, assistance with physical activities was a large component of care-giving. On the other hand care-giving

to adults was associated with higher likelihood to be in poor mental well-being. Similar patterns are seen for care-giving to children as well as for care-giving to both adults and children. Participants who were simultaneously care-givers and care-receivers, were more likely to report good physical health but were two-times more likely to be in poor quality of life than the rest of study participants.

These findings thus suggest that older people need to be in good physical health to provide care, however they may be suffering emotionally as they provide this care. A longitudinal study would be helpful in establishing whether over time care-giving would lead to poorer physical health among the study participants. This appears to be the case as suggested by findings from a Kenyan longitudinal grandparent study (Ice, et al., 2010). The Kenyan longitudinal grandparent study demonstrated that while cross-sectionally care-giving older people had better health than non-care-giving older people ($\beta = 0.78$, $p = 0.03$), over time, and adjusting for perceived stress, care-givers experienced declining health ($\beta = -0.53$, $p = 0.03$). Even though non-care-givers did similarly experience a decline in their health status, the decline was not statistically significant ($\beta = -0.05$, $p = 0.76$). However, there are some conflicting results from America which found care-giving older people had poorer physical health than non-care-givers. For instance a study by Minkler and Fuller-Thomson (1999) found that older care-givers had limitations in four of five activities of daily living (ADLs), with care-givers having about 50% higher odds of having at least one ADL limitation. A major difference of studies from America and other developed countries with those from Africa and other developing nations is that custodial care of grandchildren is not as normative as in developing countries (Ice, et al., 2010). Other factors contributing to the difference in results is that in Western populations most of the care-giving is to a spouse rather than a child or grandchild, and care-givers tend to be relatively older than from Africa. Care-giving is thus likely to be more of a physiological strain in developed countries leading to poorer physical health than in developing countries where grandparents may actually derive some satisfaction from care-giving (Ice, Zidron and Juma, 2008).

Part of the reasons that being a care-giver may be associated with higher odds of poor quality of life may be related to caring for orphaned children, and an emotional impact of the death of their adult children. The financial strain of care-giving may be an additional source of emotional ill-health, as is the expectation that care and support should be flowing the other way, i.e from adults and grandchildren to the older person. The analysis in Chapter Two demonstrated that flow of material resources in this study population is more likely to be downwards from older to younger persons or at best for there to be bidirectional exchanges of material support between older and younger people, adjusting for age, education, marital status, place of residency and socio-economic status. As reported previously by others, care-giving does have a financial implication on older people (Ardington, et al., 2010). Around 42% of adults being cared for in this study had been contributing to household income before they became ill compared to 23% of children being cared for. As such care-giving is not only likely to impact the physical functioning ability but the financial situation of older people. Findings in this chapter and the previous one thus demonstrate how older people are key to providing material, physical and emotional care to others, sometimes even at great financial, physical and emotional cost to themselves (Kreager and Schroder-Butterfill, 2008; Sagner and Mtati, 1999; Van der Geest, 2002).

An overwhelming majority of the study participants belonged to households headed by themselves or another older person. Household headship comes with certain expectations and responsibilities of care and support for the households. This expectation of care and support for the household comes into sharp focus when considering that the majority (91%) of study participants were not working. It therefore was no surprise that most of the older people in the WOPS study cited government cash transfers as the main source of income. Care-givers were more likely to say their financial situation had deteriorated compared to three years ago, indicative of the financial strain associated with care-giving. This may to a large extent explain why those who were giving care to adults significantly more likely report poor emotional well-being (adjusting for age, sex, grant receipt, education, marital status, and household living arrangements). The apparent reversal of the wealth and support flow may be cause for distress among older people. Older people without a steady

source of income or with limited resources are likely to suffer mental ill-health. In the study "Does money matter for mental health" (Plagerson, Patel, Harpham *et al.*, 2010), it was found that cash-transfer recipients had a lower risk of common mental disorders (CMD).

The potential pathways through which care-giving leads to ill-health and wellbeing among older people may therefore be summed into two alternatives. One pathway through which care-giving could lead to poor health and well-being of the care provider is through a shortage of resources to meet the needs of the household. When older people take on the primary care responsibilities in severely HIV affected communities it is usually due to HIV-related illness and death and thus there is a decline in household income per capita as well as the ability of the household to produce food (Donovan and Massingue, 2007). In South Africa where older people are reliant on old-age pension grants to meet the needs of the household, taking on care responsibilities means overstretching the limited pension grant to cater for the needs of adults and children for whom the grant is not intended. The major challenges that care-giving older people face centres around limited financial support, in the face of needing to provide for orphaned children, medical expenses for ailing adults or children and day-to-day survival (Agyarko, Kalache and Kowal, 2000; Nyambedha, Wandibba and Aagaard-Hansen, 2003). These challenges lead to increased physical, financial and emotional stress (Agyarko, Madzingira, Mupedziswa *et al.*, 2002; Schatz, 2007), and are ultimately likely to lead to ill-health among older people (Schatz and Gilbert, 2012). The second pathway through which care-giving could lead to poor health and well-being among older people could be when care-giving acts as a psychological stressor. According to the stress process models (Pearlin, Mullan, Semple *et al.*, 1990), day-to-day care-giving with its associated challenges may lead to psychological strains for care-givers. If this strain is prolonged it may for example lead to high levels in the body of toxic chemicals cortisol and catecholamine which are risk factors for cardiovascular diseases in older people (McEwen, 2001; Sapolsky, 1996; Sapolsky, 1999). Older people are said to be highly susceptible to these effects of chronic stress (Sapolsky, Armanini, Packan *et al.*, 1987). The results for the analysis presented here show that care-giving is associated with higher odds of poor quality of

life, as indicated both by the computed quality of life index and participants self-perceived quality of life. Should this care-giving stress among older people be sustained for a long period, they are likely to suffer serious health problems such as hypertension, cardiovascular disease, stroke and even death according to the stress process models.

Alternatively, one could turn to role-enhancement and role-strain theories to explain findings of this analysis. According to the role-strain theory, the challenge of meeting multiple demands of an individual's obligation is likely to lead to poor health in the care-giver (Goode, 1960). Care-giving to adults is generally more taxing. In addition, being a care-giver to adults and children at the same time is likely to be associated with higher risks of poorer health than care giving to children or adults only. However, care-giving is not the only role of these older people; in many cases they contribute vital income to the household- and as heads of households are expected to provide guidance to their household members and to participate in community activities. Facing challenges in meeting these multiple roles is thus normative and may result in ill-health according to the role-strain theory. Alternatively, role-enhancement theories suggest that combining multiple care-giving roles or responsibilities is associated with better health and functional ability (Marks, 1977; Sieber, 1974). However, Reid and Hardy (1999) show that whereas those with multiple roles were more likely to report depressive symptoms, after adjusting for demand and satisfaction derived from those roles, having multiple roles was not statistically significantly associated with well-being of the carer. In this study, caring for adults and children has similar effects on older people's health and well-being as caring for either adults or children only. Overall, these findings would not support the postulates of the role-enhancement theory but are suggestive of role-strain.

These alternate pathways that could be used to explain the effect of care-giving on the health and wellbeing of the care-giver point to the complexity of the impact of care-giving on the care-giver, as recently highlighted in a review article by Vlachantoni and colleagues (2013). Associations between care-giving and health have been observed for both self-perceived health and objectively measured health status including

antibodies, stress hormones, blood pressure, blood glucose levels and medication use (Ice, et al., 2010; Pinquart and Sörensen, 2003; Vitaliano, Zhang and Scanlan, 2003). While care-giving is generally associated with subsequently being in poor health (Ice, et al., 2010; Schatz and Gilbert, 2012; Ssengonzi, 2009), the impact of care-giving may be positive or negative depending on a host of factors such as the relatedness of the person being cared for (Schatz and Gilbert, 2012; Schatz, 2007; Vlachantoni, 2010), the health (including duration of illness) of the person being cared for (Chepngeno-Langat, Madise, Evandrou *et al.*, 2011; Schulz and Beach, 1999; Vitaliano, Young and Zhang, 2004), and characteristics of the care-giver such as their health status, age, and socio-economic status (Pinquart and Sörensen, 2007). Whether the effect of care-giving on the health of the care-giver is positive, negative or neutral also depends on the timing of effect measuring. Some report that, when measured cross-sectionally, care-giving by older people is associated with good health, but when observed longitudinally the health of care-givers has been shown to significantly decline with duration of care-giving (Ice, et al., 2010). In contrast, a recent report showed that while care-givers, especially new care-givers, were generally in poorer health than non-caregivers, over time, care-givers, particularly men, showed an improvement in health, which was suggested to be due to adaptation to their care-giving role (Chepngeno-Langat and Evandrou, 2013). One plausible explanation for care-giving to be associated with good health, especially in cross-sectional studies, could be due to the 'healthy carer' selection effect in that people in good health are self-selected into the caring role. Thus where informal care-giving is widely practiced, care-giving is likely to affect the physical health of the care-giver negatively with increased intensity of care-giving, duration of care-giving, lack of support for the care-giver, low socio-economic status, advancing age or psychological distress about the care-giving role (Pinquart and Sörensen, 2007; Schulz and Beach, 1999; Vlachantoni, Shaw, Evandrou *et al.*, 2013). With time, therefore, care-givers in the study reported in this thesis would be expected to suffer poor physical health because they currently already report poor emotional wellbeing despite reporting to currently be in good physical health.

Care-receipt by older people in this study was dominated by assistance with fetching water. This assistance was mostly from grandchildren, own children and spouses. A

large number of households in the surveillance area do not have piped water in the homestead and rely on a communal tap, borehole or river water (Muhwava, 2008; Muhwava and Nyirenda, 2008). HIV and other health related reasons were the main causes for need of care by study participants. Results here show that older people who were in receipt of care were more likely to be in poor health on all health measures considered, except on self-reported health status in the last two weeks, although the findings were only statistically significant for the quality of life measures. This is not unexpected as the reason for needing care in the first place would be poor health. It remains to be seen, however, whether with time care-recipients would be associated with better health, if according to the stress process models (Pearlin, et al., 1990) being cared for leads to reduced stress which in turn is linked to better health. It will be interesting to see how this turns out as already from this analysis findings show that over 60% of care-recipients were happy with the care being received.

3.6.1 Limitation of the study

This was a cross-sectional study, and causality between care-giving or care-receiving with health and well-being cannot be inferred. For instance there could have been a healthy selection effect in that participants in the study would be survivors of their respective cohorts and older people who were hospitalised or at home but too sick to participate were excluded. Only longitudinal follow-up would allow an assessment of whether the health and well-being of care-givers declines over time. Furthermore, these results may not be generalizable to the general population of older people in South Africa, since study participants were purposefully selected into four strata, which were categorised into HIV-infected and HIV-affected groups. The study population in addition to the small numbers in the sample was nested in a population that has been under demographic and health surveillance for a long time with good access to a well-functioning HIV care and treatment programme delivered at primary care level, which limits over interpretation and generalizability of these findings to other dissimilar settings.

All the health measures reported on in this study are based on self-reporting. There may therefore have been some desirability bias in the reporting. Older people who are

giving care to orphans and HIV-affected adults may over-estimate their ill-health and well-being status owing to the widespread presentation of caring for orphaned children and HIV-affected adults as a burden. Another limitation of this study was that care-giving from one older person to another was not included. These data were not collected in the survey. Studies from the USA suggest older people care-givers tend to have multiple limitations in activities of daily living (Ice, et al., 2010; Minkler and Fuller-Thomson, 1999). Thus what is presented here may only be a small reflection of the effect of caring on the health and well-being of older people.

Other household-living arrangements such as household composition, other persons contributing to household income, number of children in the household, relationship and orphanhood status of children being cared for were not included as variables in this analysis. This was the subject matter covered in Chapter Two, which explored these household living arrangements and their implications on intergenerational flows of material support using longitudinal surveillance data. In spite of these limitations the study still makes an important contribution to the limited knowledge of the effect of care-giving and care-receipt on the health and well-being of older people in rural South Africa. These findings strongly suggest care-givers are in better physical health, but poorer mental well-being than non-care-givers, adjusting for among others things age, gender, HIV state, and household wealth status.

3.7 Policy implication and recommendations

There is need for increased support to care-giving older people, who, although currently reporting good health, over time are likely to suffer ill-health (Ice, et al., 2010) and who once beyond a certain critical stage of frailty may suffer rapid decline and death (Wilson, Adamchak, Nyanguru *et al.*, 1991).

The government should consider extending the old-age pension programme to all older people aged 50 years and above to not only alleviate them from poverty but to also contribute to improving their metal well-being, as previous work has shown cash transfer recipients tend to have a lower risk of mental ill-health (Plagerson, et al., 2010). Such a policy measure would also be in cognizance of the fact that care-giving in

many instances starts way before the present age eligibility for the old-age grant. While extending the old-age cash transfer programme to all persons aged 50+ particularly care-givers (to adults or children) may help to reduce their likelihood of being in poor quality of life implementation of this policy recommendation has undoubtedly fiscal challenges given the limited resources at government disposal. A more sustainable policy response could be to provide employment opportunities to adults and young people to lessen dependence on the older person.

Family, especially an older person's children and grandchildren, are an important source of care and support for the older person. Thus older people who are childless are likely to be vulnerable when in need of care and support. There is therefore need to establish and strengthen institutional care facilities in the area to especially cater for those without a circle of immediate family members from whom to tap care and support. The two pathways of economic stressor or psychological stressor through which care-giving could lead to ill-health and well-being are by no means mutually exclusive (Ice, et al., 2010; Pearlin, et al., 1990). When designing interventions for care-giving older people it is therefore important to intervene both at the socio-economic circumstances and the emotional well-being level.

Chapter 4: **Correlates of health and well-being in HIV-infected or -affected older people in rural South Africa**[7]

4.1 Abstract

South Africa is in a health transition characterised by communicable and non-communicable diseases. The latter a result of increasing proportions of older people, and in spite of severe HIV impact on adult mortality. The country's health care system is not prepared or well-equipped to deal with needs of older people. Further, the health and well-being of older people is not well understood, especially in rural South Africa, owing to limited studies that explore direct and indirect effects of HIV on health status of older people. The aim of this analysis is to identify and evaluate correlates of health and well-being of HIV-infected people aged 50 year and above, relative to their HIV-affected peers in rural South Africa.

Data were collected in a nested sub-study of the Africa Centre surveillance, using instruments adapted from the World Health Organization (WHO) Study on global AGEing and adult health (SAGE). A stratified random sample of 422 people aged 50+ participated. Health correlates of HIV-infected and HIV-affected (had HIV-infected relative or death of adult child due to HIV-related cause) are compared using ordered logistic regressions. Health status has been measured using three instruments: disability index, quality of life and a composite health score.

Median age was 60 years (range 50-94). Overall, HIV-infected participants had better physical functional ability ($p<0.001$), quality of life ($p=0.011$) and overall health state ($p<0.001$) than HIV-affected participants. Demographic factors like age and sex are strongly correlated with functional ability and overall health state, but income and household wealth status were stronger correlates of quality of life in older people. Women had 70-85% lower odds of good functional ability and health state than men in both HIV-infected (aOR 0.15, 95% CI 0.08-0.29) and HIV-affected participants (aOR 0.20, 95% CI 0.08-0.50).

Differences in the health state and well-being of HIV-infected relative to HIV-affected participants could partly be explained by the enhanced healthcare received as part of anti-retroviral (ART) treatment. The enormous resources devoted to HIV care clearly benefit the overall well-being of HIV-infected older people. This is not the case for general health needs of older persons not HIV-infected, contributing to their risk of poorer health relative to HIV-infected older people. Given the increasing numbers of older people, policy and programme interventions are urgently needed to treat health conditions in older persons outside the HIV-related care system.

Key Words: South Africa, older people, health status, functional ability, quality of life

[7] This chapter is an extended version of a paper that was published earlier, Nyirenda, M., et al., 2012. *An investigation of factors associated with the health and well-being of HIV-infected or HIV-affected older people in rural South Africa.* BMC Public Health. **12**(1): p. 259. See Appendix 1, pp. 201 for citation details and co-author contributions.

4.2 Chapter outline

Chapters Two and Three were devoted to analysing informal care by and towards older people in the study area. Chapter Four on the other hand aims to describe the physical health and emotional well-being of the older people, with the aim of then discussing the relationship between informal care and the health and well-being of older people in Chapter Five.

This chapter is structured as follows. Section 4.3 provides a background to this analysis through an overview of aspects of the health and well-being of older people that have been studied by others, highlighting the need for a better understanding of the socio-economic and demographic correlates of the health and well-being of older people within a high HIV prevalence context. The study design, data sources, analytical methods, analytical measures are then presented in the methods section in 4.4. Results of this analysis then follow in section 4.5. These study findings are then discussed in section 4.6 and finally, conclusions are drawn in section 4.7.

4.3 Background

There is limited reliable information on the health and well-being of older people in Africa including their physical, mental and social well-being (Ice, Zidron and Juma, 2008; Joubert and Bradshaw, 2006; Ng, et al., 2010). This is because many studies on older people in Africa have tended to focus on their role as caregivers of orphaned children and ailing adults (Ardington, et al., 2010; Hosegood and Timæus, 2006; Nyirenda and Newell, 2010; Schatz, 2007; Ssengonzi, 2007; Ssengonzi, 2009; Zimmer and Dayton, 2003). Only a limited collection of studies in sub-Sahara Africa have comprehensively investigated or measured the health of older people in a systematic manner (Ice, Zidron and Juma, 2008; Ng, et al., 2010). This paper uses a multi-dimensional approach to measuring the health status of older people in rural South Africa in an attempt to contribute to this limited knowledge base by examining correlates of the health and well-being of HIV-infected and HIV-affected older people using the World Health Organization's disability assessment score (WHODAS) (WHO, 2010), quality of life (WHOQoL) (WHOQoL Group, 1993) and a composite health state score which utilises item response theory modelling (Reeve, Hays, Chang *et al.*, 2007).

South Africa is in the midst of a health transition characterised by four disease burdens: communicable, perinatal and maternal mortality, injury-related and non-communicable diseases (Kahn, 2011; Mayosi, et al., 2009; Tollman and Kahn, 2007). The latter burden is a result of a demographic transition largely characterised by declines in fertility (Moultrie and Dorrington, 2004; Moultrie and Timæus, 2003) and improved survival at older ages, which has led to an increasing proportion of older people in South Africa (Kinsella and Ferreira, 1997; Mayosi, et al., 2009). A projected 15% of the total South African population in 2050 will be aged 60 years or over, up from around 8% of the total 2011 population (United Nations, 2011). This rapidly increasing proportion of older people in South Africa is occurring in spite of the severe impact of HIV on adult mortality, and poses social, economic and health challenges; not least of which is the need to simultaneously deal with communicable and chronic non-communicable conditions. The South African health care system is as yet not adequately prepared for and well-equipped to deal with the needs of older people and chronic conditions, nor is the health and well-being of older people in Africa well understood owing to the paucity of studies on the health status of older people (Ice, Zidron and Juma, 2008; Joubert and Bradshaw, 2006; Ng, et al., 2010), especially those from rural South Africa.

Some studies have looked at the impact of specific chronic diseases on the health and well-being of older South Africans (Thorogood, Connor, Hundt *et al.*, 2007; Westaway, 2010b). Westaway and others (2010b; 2004) showed that older people in South Africa, urban South Africa in particular, with chronic conditions (for example diabetes mellitus, hypertension) had poorer functioning, health and well-being than those without, but with medical care the former could achieve comparatively high physical and social functioning. Whereas, a study from rural South Africa that applied World Health Organization's (WHO) functional disability and quality of life instruments found age, gender, education and occupational status to be significantly associated with poor functioning health status and quality of life (Xavier Gomez-Olive, et al., 2010). In studies conducted in South Africa, the HIV status of older people has either not been explicitly studied (Benitha and Tikly, 2007; Gilbert and Soskolne, 2003; Westaway,

2010b; Xavier Gomez-Olive, et al., 2010), or the focus has solely been on HIV-infected people (Louwagie, Bachmann, Meyer *et al.*, 2007; Peltzer and Phaswana-Mafuya, 2008; Wouters, Heunis, van Rensburg *et al.*, 2009). Thus, in South Africa where HIV is a major public health issue, there is limited information on the physical, mental and social well-being of HIV-infected compared to HIV uninfected older people. This research presented here should therefore be highly useful for policy makers and programme implementers to make informed policies and interventions, and spur further research.

The population in the study area in rural South Africa, as shown in Chapter Two (see Table 2-3, pp. 39), is characterised by people living in predominantly multi-generational households consisting of grandparents, adults and children (Hosegood, Benzler and Solarsh, 2006; Hosegood and Timæus, 2005a). In most of these living arrangements, people over 60 years of age in receipt of government old-age grants are often the main source of income (Burns, Keswell and Leibbrandt, 2005; Duflo, 2003), given the high unemployment rate among adults (Curtis, Bradshaw and Nojilana, 2002; Muhwava, 2008). In addition to the challenge of providing financial support to their households, given the high HIV burden in South Africa, older persons are also providing long-term personal and health care to their adult offspring infected with HIV and to younger children after the death of their parents (Ardington, et al., 2010; Hosegood and Timæus, 2006; Nyirenda and Newell, 2010; Schatz, 2007; Ssengonzi, 2007; Ssengonzi, 2009; Zimmer and Dayton, 2003). Furthermore, older people are at risk of becoming HIV-infected themselves (Cooperman, Arnsten and Klein, 2007; Dougan, et al., 2004; Wallrauch, Bärnighausen and Newell, 2010), and increasing numbers of HIV-infected adults on treatment live into older age (Hontelez, et al., 2011; Nguyen and Holodniy, 2008). These socio-economic and demographic factors are likely to influence the health and well-being of older people, and a clear understanding of this mechanism is thus an important research need.

The main aim in this paper is to analyse correlates of health and well-being of HIV-infected older people aged 50 years and above, relative to their HIV-affected peers in rural South Africa. HIV-affected older people are defined as those with an adult HIV-

infected household member (18-49 years) or with an HIV-related death of an adult household member between 2008 and 2010, approximately two years prior to the interview.

4.4 Methods

4.4.1 Study setting

Data used in this study were collected within the Africa Centre surveillance area located in rural northern KwaZulu-Natal, South Africa, using instruments adapted from the World Health Organization (WHO) Study on global AGEing and adult health (SAGE) (WHO, 2011). The Africa Centre's surveillance has followed around 90,000 members in 11,500 households annually since 2000 (Tanser, et al., 2008). Data on demographic, social and general health are routinely collected in the surveillance from a key household informant. In addition, individual level data on sexual behaviour and HIV status have also been collected since 2003 initially on adults 15 years to 50 years for women and to 54 years for men, but since 2007 on all adults 15 years and above. Details about the Africa Centre surveillance can be found elsewhere (Hosegood, Benzler and Solarsh, 2006; Tanser, et al., 2008) or by visiting www.africacentre.com.

Within this surveillance population a cross-sectional study on the health and well-being of older people was conducted in 2010 and is the basis of the present analysis. A detailed description of both the surveillance population and the sample survey was presented in Chapter One (section 1.8, pp. 11). Here only a brief description of the cross-sectional study is rehashed below.

4.4.2 The SAGE Well-Being of Older People study (WOPS)

The Well-Being of Older People Study (WOPS) was carried out from March-August 2010, using a shortened version of the SAGE instrument (for details see section 1.8.2, pp. 14). The criteria for inclusion in WOPS were being aged 50 years or above, under demographic observation and resident within the Africa Centre surveillance area. Other specific requirements according to criteria for inclusion in the four defined groups of participants in this study were:

- group 1, HIV-infected participants and on treatment for one year or longer;

- group 2, an individual had to be HIV-infected and on treatment for 3 months or less or waiting to initiate antiretroviral treatment (ART);
- group 3 consisted of older people who had an adult child 18-49 years who was HIV-infected and either on treatment for one year or more, or for three months or less;
- group 4 consisted of older people who had experienced death of an adult member between 2008 and 2010, and that death was identified to be HIV-related using the verbal autopsy (VA) data.

The target sample size in WOPS was 400 individuals, but a total of 422 individuals participated in the study as a result of having more than one older person in some households, particularly in groups 3 and 4. All persons meeting the inclusion criteria in a visited household were offered the opportunity to participate. This sample size although purposively set, was determined to be adequate in describing the health and wellbeing of older people in the study setting. Having at least 100 participants in each study group was adequate for tests of statistical significance at 5% level of significance within and between groups.

It was hypothesized that HIV-infected people (groups 1 and 2) would have poorer health status than HIV-affected people (groups 3 and 4), since the former would be highly susceptible to HIV-related conditions which potentially impact on their physical, social and emotional well-being. Within the HIV-infected group, considering the pharmacodynamics of ART medications, it was expected that those on ART for three months or less could have poorer health than those on treatment for a year or longer (Mutevedzi, et al., 2011). For analyses in this paper, participants in group 1 and 2 are combined into one HIV-infected group because exploration of their health status scores showed the two groups of participants were not statistically significantly different.

4.4.3 Measures of health and well-being

There are generally two approaches one could use to measure the health and well-being of older people. The first could be to use objective measures such as blood

pressure measurements, hypertension readings, blood glucose levels, or hand grip tests for physical health (Ice, Yogo, Heh *et al.*, 2010), and cognitive tests or validated psychological evaluation tools for mental health (Blay, Andreoli, Fillenbaum *et al.*, 2007; Chan, Chiu, Chien *et al.*, 2009; Saito, Iwata, Kawakami *et al.*, 2010). The second approach widely used to measure health is self-reported (by the respondent) health status. The widely used form of this Self-Rated Health (SRH) status in main stream demographic and epidemiological literature is use of a global question "*How do you rate your current health (*or your health today)*?*" with response options usually on a 5-point Likert-type scale from 'very good' to 'very poor'. This global question has been validated in several studies and proved to be a good indicator of morbidity and mortality (Fayers and Sprangers, 2002; Idler and Benyamini, 1997; Olgiati, Bärnighausen and Newell, 2012; Wang, Wu, Zhao *et al.*, 2008); individuals who rate their health to be bad or poor face higher mortality risks than those who rate their health favourably (Lee, 2000; Singh-Manoux, Dugravot, Shipley *et al.*, 2007). While this single question has been shown to be a good predictor of morbidity and mortality, it has comparability and inconsistency concerns (Bowling, 2005; Fayers and Sprangers, 2002; Salomon, Nordhagen, Oza *et al.*, 2009). These concerns arise from the measure being subjective (Fayers and Sprangers, 2002), and influenced by cultural and contextual factors (Jylhä, 2009; Sen, 2002; Zimmer, Natividad, Lin *et al.*, 2000).

To overcome some of the shortcomings of this global question such as which health indicators are used as point of reference or which aspects of health (physical or emotional) to emphasize (Bowling, 2005; Fayers and Sprangers, 2002; Salomon, et al., 2009), a multi-dimensional approach to assess self-reported health and well-being, adapted from the World Health Organization's (WHO) Study on global AGEing and adult health (SAGE) (WHO, 2011) and the short form-36 (SF-36) (http://www.sf-36.org/home.aspx) was utilised in this analysis (see Appendix 7, pp. 223 for study instruments used). In this approach, participants were asked to rate their health using a set of questions encompassing physical functioning and emotional wellbeing. Using such an approach is useful in that it provides all respondents with the same health indicators as a point of reference (Hirve, Juvekar, Lele *et al.*, 2010), and guides them to which aspects of health to emphasize (Jylhä, 2009). The use of multiple constructs

rather than a single question to assess health provides a more robust assessment of health and helps reduce measurement bias (Bowling, 2005), and facilitates comparability across countries (Sen, 2002). Specifically, Mishra and colleagues (2011) were able to demonstrate the uni-dimensionality and reliability of all six SF-36 sub-scales with Cronbach's alphas ranging from 0.70 to 0.92, except for sub-scales on general health and mental health.

In the analysis presented here, three measures further explained below were used as outcome variables to describe the health and wellbeing of older people: 1) functional ability, which focuses on the physical health status of participants, 2) quality of life/subjective well-being, which is an indicator of participants' emotional wellbeing; and, 3) a composite health state score (HSS), which combines physical health and emotional wellbeing constructs. As results presented later, and discussed in this chapter, will show, use of a single construct of self-reported health may over- or under-estimate the health status of participants given the different aspects of health that the particular measure emphasises. This is further discussed in Chapter Five, p. 143, with regard to the effect of these different constructs of self-reported health on subsequent mortality.

4.4.3.1 Physical functional ability (WHODAS)

The first measure of physical health status used is based on the World Health Organization's Disability Assessment Score , version 2 (WHODAS-II) (WHO, 2010), which is designed to measure functional disability from responses to questions on physical functioning in a range of activities of daily life as well as instrumental activities of daily life. Using questions derived from WHODAS instruments, and modified to suit the local environment (see Appendix 7, pp. 223 for details), participants were asked about difficulties in the last 30 days with performing activities of daily living such as walking, standing, kneeling or bending, raising from sitting position, raising from lying down position, ability to perform household tasks as well as instrumental activities of daily living, inter alia, dressing oneself, bathing, eating, accessing the toilet, use of public transport and participation in community events. Responses to these questions were scored using a five-point likert-type response scale, 'none', 'mild', 'moderate',

'severe', and 'extreme/cannot do'. Twelve questions in this health domain were used to compute the WHODAS score, which ranged from 0-36 and later transformed to make interpretations easier into 0-100 with 100 being severe/extreme disability. To make the WHODAS measure consistent with the other two measures of health to be employed in this paper, it was inverted (WHODASi) so that a low score indicated low physical functioning ability (high disability) and a high score, high physical functioning ability (low disability).

4.4.3.2 Emotional well-being or Quality of life (WHOQoL)

The second measure of health status used in this analysis was designed to get an indication of the subjective emotional well-being of study participants, and is based on the World Health Organization's Quality of Life Index (WHOQoL) (WHOQoL Group, 1993). The WHO defines quality of life as an "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." (WHOQoL Group, 1993). The WHOQoL was derived from responses to questions about a participant's satisfaction with among other things, their self, health, living conditions, personal relationships, ability to perform daily living activities, and their life as a whole. Eight questions in this health domain were used to compute the WHOQoL score, which ranged from 8-40. The WHOQoL was similarly transformed to a scale of 0-100, with 0 indicating best quality of life and 100 indicating worst quality of life possible. To make this measure intuitively sensible it was inverted, as was done for the WHODAS, such that 100 now corresponded to best quality of life.

4.4.3.3 Health state score (HSS)

The final measure of health status used in this analysis was the composite health state score (HSS). The HSS was derived parsimoniously by combining physical functional ability and quality of life health domains, using Rasch models in Winsteps statistical package (http://www.winsteps.com). The underlying theorem in these models is Item Response Theory (IRT). Item response theory uses Joint Maximum Likelihood Estimation (JMLE) as the estimation method to model the relationship between the probability of a respondent responding to an item, and the inherent difficulty in an

item (Reeve and Fayers, 2005; Reeve, et al., 2007; Wilson, Allen and Li, 2006). The statistical package Winsteps (Adjuik, Kanyomse, Kondayire *et al.*, 2010) uses the Rasch models or analysis to obtain objective measures from stochastic distributions of ordered categorical responses (Crampin, Glynn, Ngwira *et al.*, 2003). In WOPS respondents were asked about difficulties in performing various activities of daily living (ADLs) and instrumental activities of daily living (IADLs), as well as about their emotional well-being by saying how satisfied they were with their life, living arrangements, personal interactions, and community participation. Response options to these questions were on a 5-point likert-type ordered scale starting from 'none' to extreme/cannot do'. Hence Rasch models could then easily be applied to combine responses to these items into a composite health state score for the respondents.

The Rasch models in Winsteps has several families of the logit linear models (Adjuik, et al., 2010), but in this analysis only the polytomous "Rating scale" and "partial Credit" models within the logit linear family were applied. These models can be described as follows:

Polytomous Rating Scale model: $\log(P_{nij}/ P_{ni(j-1)}) = B_n - D_i - F_j$

and

Polytomous Partial Credit model: $\log(P_{nij}/ P_{ni(j-1)}) = B_n - D_i - F_{ij} = B_n - D_{ij}$

where,

P_{nij} is the probability of person n responding to item i being observed in category j,

B_n is the "ability" of individual n to respond to the items,

D_i is the "difficulty" associated with responding to item i,

F_j is the "calibration" measure for where categories j-1 and j are equally likely.

The health state score was scaled from 0-100 with 100 representing best health and 0 poorest health. The WHODAS, WHOQoL and HSS were all transformed on the same scale (0-100) to eased description and comparisons of the measures, which were then divided into quintiles for further analyses.

This analysis used only sections of the questionnaire that collected information on health status in eight domains (mobility, self-care, affect, vision, pain/discomfort, sleep

/energy, interpersonal activities, and cognition), disability and functioning as measured by the 12-item WHO Disability Assessment Schedule, version 2 (WHODAS-II) (WHO, 2010), and subjective well-being as measured by the 8-item WHO Quality of Life (WHOQoL) (WHOQoL Group, 1993) instrument. Study instruments are attached in the appendices (Appendix 7, p.223) and are available at www.who.int/healthinfo/systems/sage.

4.4.4 Analytical methods

Ordered logistic regression (Hamilton, 2009) was used to assess the relationship between factors potentially associated with health and well-being. Ordered logistic analysis is an alternative to binary logistic models which avoid arbitrary dichotomisation of an outcome variable that has more than two levels (McCullagh, 1980; StataCorp., 2009). Ordered logistic regression findings are interpreted as the proportional odds to move from one level of the response variable relative to all other levels of the response variable for a one unit change in the predictor variable (McCullagh, 1980; UCLA Academic Technology Services, 2011). In this analysis, the ordering of the outcome variable was based on quintiles, where the first quintile represented poorest and fifth quintile best health state status. All analyses were conducted in Stata 11.2 (StataCorp, 2009).

4.4.5 Control variables

The independent factors considered in this analysis, informed by the literature (Ng, et al., 2010), were sex, age group, marital status, household headship, education attainment, income source, household wealth quintiles and rural/urban place of residency. Advancing age is strongly linked to health status. For this analysis, three age groups, 50-59, 60-69 and 70+, were used. Marital status was categorised into never married, currently married and previously married (which included participants reporting to be widowed, divorced or separated). Household headship was used as a proxy for independence and responsibility for care and support of the household. It was categorised into self, spouse or any other person. Education attainment was categorised into: no formal education (including those who only attended adult education classes), completed 6 years or less, or completed more than 6 years of

education. The latter two categories are consistent with UNESCO's standard classification of primary and secondary education (http://www.uis.unesco.org/Library). Income source was based on whether a participant had no income, had a government grant (mostly old-age pension grant) or had another income source. Household wealth was measured from possession of assets such as television, radio, and fridge as well as access to amenities like electricity, water, and toilet facilities. Principal component analysis was used to derive household wealth scores which were later categorised into quintiles. Place of residency was divided into rural or urban.

4.4.6 Ethical clearance

For the household demographic surveillance oral informed consent was obtained from a proxy household respondent, usually the household head but in his/her absence any competent adult household member. For the individual sexual behaviour and HIV surveillance, written informed consent was obtained from each individual participant. In the well-being of older people study (WOPS) written informed consent was obtained from all participants; they had to sign or thumb-print the consent form. The Africa Centre Surveillance was approved in 2000 by the ethics committee of the University of KwaZulu-Natal (Appendix 3, pp. 218), with annual re-certification since then (Appendix 4, pp. 219). For the WOPS, approval for the study was in the first instance obtained from the local community via the community advisory board (CAB) and then the University of KwaZulu-Natal Biomedical Research Ethics Committee (Ref No. BF136/09).

4.5 Results

The median age of the 422 participants included was 60 years (range 50-94). Overall there were about three times more women than men (Table 4-1). Significant differences (using chi-square p-values <0.05) between the study groups were observed in the proportions for age and source of income among men, while among women significant differences were observed for age, marital status and highest education level attained. The other socio-demographic factors shown in Table 4-1 were not statistically significantly different by study group for either men or women.

Table 4-1: Background characteristics by gender and study group of WOPS participants, rural South Africa 2010

	Males					Females				
	Group 1	**Group 2**	**Group 3**	**Group 4**		**Group 1**	**Group 2**	**Group 3**	**Group 4**	
Characteristics	n(%)	n(%)	n(%)	n(%)	p-value	n(%)	n(%)	n(%)	n(%)	p-value
n	35(33.3)	28(26.7)	20(19.0)	22(21.0)		64(20.3)	75(23.7)	87(27.5)	90(28.5)	
Age group					<0.001					<0.001
50-59	19(54.3)	25(89.3)	1(5.0)	4(18.2)		40(62.5)	51(68.0)	27(31.0)	22(24.4)	
60-69	10(28.6)	2(7.1)	9(45.0)	10(45.5)		24(37.5)	19(25.3)	27(31.0)	27(30.0)	
70-79	6(17.1)	1(3.6)	10(50.0)	8(36.4)		0(0.0)	5(6.7)	33(37.9)	41(45.6)	
Marital status					0.226					0.004
Never married	8(22.9)	10(35.7)	3(15.0)	6(27.3)		22(34.4)	32(42.7)	17(19.5)	18(20.0)	
Married	17(48.6)	16(57.1)	13(65.0)	14(63.6)		27(42.2)	29(38.7)	49(56.3)	40(44.4)	
Previously married	10(28.6)	2(7.1)	4(20.0)	2(9.1)		15(23.4)	14(18.7)	21(24.1)	32(35.6)	
HH Headship					0.635					0.773
Self	30(85.7)	19(67.9)	16(80.0)	18(81.8)		38(59.4)	37(49.3)	40(46.0)	45(50.0)	
Spouse	0(0.0)	2(7.1)	1(5.0)	1(4.5)		14(21.9)	21(28.0)	26(29.9)	22(24.4)	
Other	5(14.3)	7(25.0)	3(15.0)	3(13.6)		12(18.8)	17(22.7)	21(24.1)	23(25.6)	
Education					0.280					0.007
No formal education	12(34.3)	10(35.7)	12(60.0)	10(45.5)		20(31.3)	33(44.0)	51(58.6)	53(58.9)	
6 years or less	15(42.9)	7(25.0)	5(25.0)	6(27.3)		28(43.8)	29(38.7)	28(32.3)	23(25.6)	
More than 6 years	8(22.9)	11(39.3)	3(15.0)	6(27.3)		16(25.0)	13(17.3)	8(9.2)	14(15.6)	
Source of income					0.024					0.080
None	5(14.3)	7(25.0)	0(0.0)	1(4.5)		3(4.7)	11(14.7)	7(8.0)	6(6.7)	
Other	4(11.4)	7(25.0)	1(5.0)	3(13.6)		10(15.6)	11(14.7)	8(9.2)	5(5.6)	
Grants	26(74.3)	14(50.0)	19(95.0)	18(81.8)		51(79.7)	53(70.7)	72(82.8)	79(87.8)	
Wealth quintile					0.855					0.728
First	8(22.9)	7(25.0)	4(20.0)	5(22.7)		9(14.1)	20(26.7)	17(19.5)	23(25.6)	
Second	5(14.3)	5(17.9)	2(10.0)	6(27.3)		12(18.8)	15(20.0)	18(20.7)	13(14.4)	
Third	7(20.0)	3(10.7)	5(25.0)	5(22.7)		16(25.0)	17(22.7)	17(19.5)	16(17.8)	
Fourth	8(22.9)	7(25.0)	7(35.0)	3(13.6)		12(18.8)	14(18.7)	17(19.5)	18(20.0)	
Fifth	7(20.0)	6(21.4)	2(10.0)	3(13.6)		15(23.4)	9(12.0)	18(20.7)	20(22.2)	
Place of residency					0.834					0.334
Urban	4(11.4)	2(7.1)	3(15.0)	3(13.6)		10(15.6)	12(16.0)	8(9.2)	8(8.9)	
Rural	31(88.6)	26(92.9)	17(85.0)	19(86.4)		54(84.4)	63(84.0)	79(90.8)	82(91.1)	

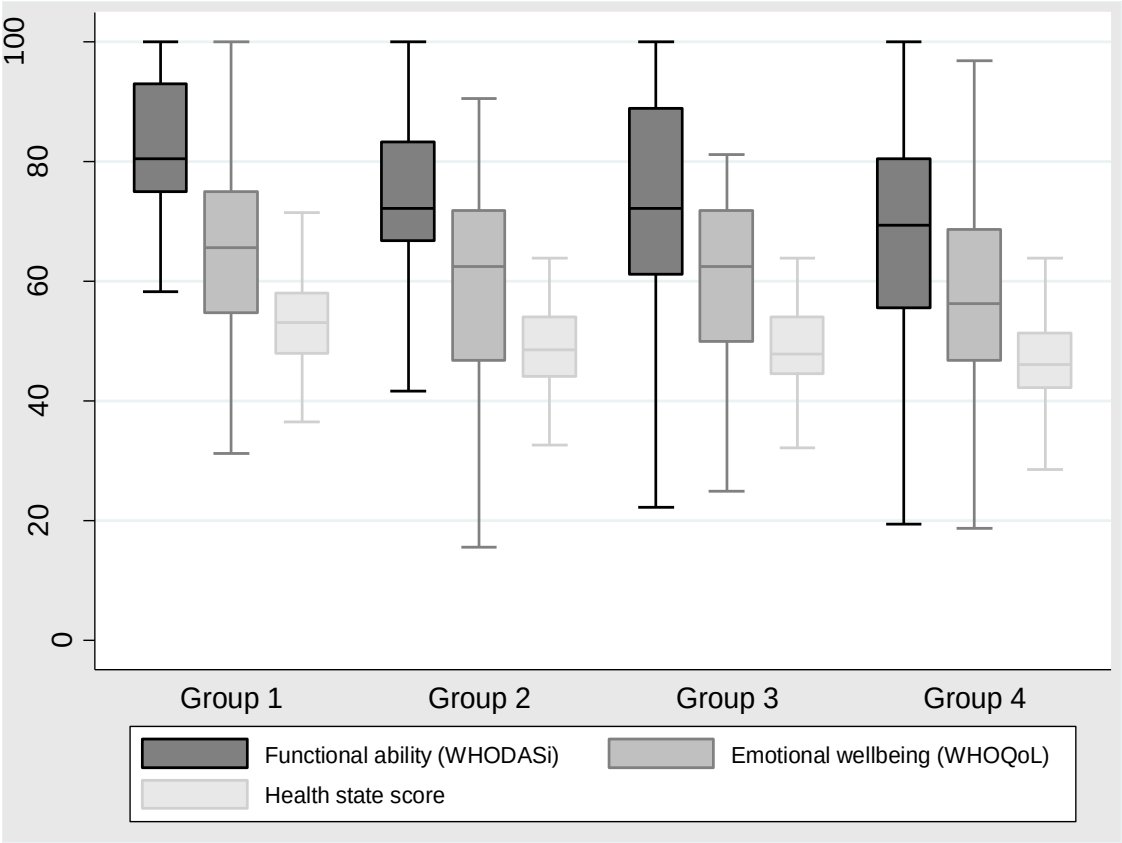


Figure 4-1: Health status by health measure and study group among study participants

- Note: All health measures are on a scale 0-100, where 100 represents best health status.
- Group 1 is participants on HIV treatment for 1 year or more; Group 1 is older people on HIV treatment for 3 months or less; Group 3 is participants with an adult offspring who is HIV-infected in the household; Group 4 is participants who had experienced an HIV-related death of adult household member.

The scores of the three health measures (WHODAS, WHOQoL and HSS), on a scale of 0-100, where 100 is best health status are presented by study groups in Figure 4-1. For all four groups, the median scores on the functioning ability (WHODAS) measure were higher than for the other two measures of health status. The lowest median scores, with comparatively lower variability, were observed for the HSS (Figure 4-1).

Overall comparisons of the HIV-infected (groups 1 and 2) and HIV-affected participants (groups 3 and 4) showed differences with regard to all socio-demographic characteristics except for household headship and household wealth quintiles (Table 4-2), confirming the need for separate analyses by HIV status.

Table 4-2: Background characteristics of older people by HIV status, rural South Africa 2010

Characteristics	HIV-infected n(%)	HIV-affected n(%)	P-value
N	203(48.1)	219(51.9)	
Sex			0.003
Female	139(68.5)	177(80.8)	
Age group			<0.001
50-59	136(67.0)	54(24.7)	
60-69	55(27.1)	73(33.3)	
70-79	12(5.9)	92(42.0)	
Marital status			0.002
Never married	72(35.5)	44(20.1)	
Married	90(44.3)	116(53.0)	
Previously Married	41(20.2)	59(26.9)	
Household Headship			0.305
Self	125(61.6)	119(54.3)	
Spouse	37(18.2)	50(22.8)	
Other	41(20.2)	50(22.8)	
Education			<0.001
No formal education	75(36.9)	126(57.5)	
6 years or less	79(38.9)	62(28.3)	
More than 6 years	49(24.1)	31(14.2)	
Source of income			0.001
None	26(12.8)	14(6.4)	
Other	33(16.3)	17(7.8)	
Grants	144(70.9)	188(85.8)	
Household wealth quintiles			0.995
First (Poorest)	44(21.7)	49(22.4)	
Second	37(18.2)	39(17.8)	
Third	43(21.2)	43(19.6)	
Fourth	41(20.2)	45(20.5)	
Fifth (Rich)	38(18.7)	43(19.6)	

p-values compares HIV-infected to HIV-affected participants by background characteristics; p-value<0.05 indicates statistically significant differences

Table 4-3 presents the median health scores of HIV-infected and HIV-affected older people for men and women separately. For men, the health scores did not differ significantly between the HIV-infected and the HIV-affected groups. Among women on the other hand, those who were HIV-infected had better WHODAS and HSS scores than those HIV-affected. For both sexes combined, median health scores were substantially higher for HIV-infected than HIV-affected older people for all three health measures (Table 4-3). Comparing the health scores presented in Table 4-3 for men who are HIV-

infected to women who are HIV-infected, and likewise among the HIV-affected participants, revealed that men reported better health than women in both HIV-infected and HIV-affected participants. These differences were statistically significant for functional ability (p-value<0.001) and health score (p-value=0.002) among HIV-infected, and only for functional ability (p-value <0.001) among HIV-affected participants.

Table 4-3: Median health scores for HIV-infected and HIV-affected older people, rural South Africa 2010

Measure	HIV-infected	HIV-affected	p-value
		Males	
Functional ability	87.5	81.9	0.551
Quality of life	68.8	64.1	0.550
Health score	54.1	50.7	0.551
		Females	
Functional ability	75.0	69.4	0.002
Quality of life	62.5	59.4	0.276
Health score	49.2	47.3	0.041
		Both sexes	
Functional ability	77.8	69.4	<0.001
Quality of life	62.5	59.4	0.011
Health score	50.7	47.3	0.001

p-values show test of equality of medians comparing HIV-infected to HIV-affected for males and females separately. A p-value<0.05 indicates statistically significantly different medians.

4.5.1 Correlates of health and well-being among study participants

The association of HIV status with the health and well-being of older people was further examined in three separate multivariable models for functional ability, quality of life and composite health state respectively. Results are presented in Table 4-4. Being HIV-affected due to having an adult household member who was HIV positive (group 3) was associated with higher odds of being in good functional ability, quality of life and overall health state, compared to being HIV-affected through a recent HIV-related death of an adult household member (group 4). Being HIV-infected (groups 1 and 2) was similarly significantly associated with higher odds of being in good physical functioning ability, emotional well-being and health state relative to being HIV affected due to a recent HIV-related death of an adult household member.

Table 4-4: Factors associated with good health and well-being adjusted for HIV category

	Functional ability aOR(95%CI)	**Quality of life** aOR(95%CI)	**Health state** aOR(95%CI)
HIV category			
HIV-affected (via HIV-related adult death)	1.00	1.00	1.00
HIV-affected (with infected adult)	2.54(1.02-6.35)	2.52(1.13-5.61)	2.64(1.19-5.88)
HIV-infected	1.91(1.05-3.48)	1.81(1.02-3.19)	1.90(1.09-3.33)
Sex			
Male	1.00	1.00	1.00
Female	0.21(0.11-0.39)	0.76(0.41-1.41)	0.30(0.16-0.57)
Age group			
50-59	1.00	1.00	1.00
60-69	0.79(0.38-1.65)	1.76(0.85-3.64)	1.01(0.49-2.10)
70+	0.19(0.10-0.37)	0.49(0.26-0.93)	0.24(0.13-0.47)
Marital Status			
Never Married	1.00	1.00	1.00
Married	0.83(0.46-1.49)	2.17(1.20-3.94)	1.26(0.74-2.17)
Previously Married	3.33(1.57-7.05)	0.67(0.34-1.35)	1.82(0.94-3.51)
HH Heads			
Self	1.00	1.00	1.00
Spouse	1.21(0.60-2.44)	0.74(0.39-1.39)	1.05(0.53-2.08)
Other	0.95(0.54-1.70)	1.13(0.60-2.11)	1.05(0.61-1.78)
Education level			
No formal education	1.00	1.00	1.00
6 years or less	1.47(0.88-2.45)	1.40(0.85-2.33)	1.46(0.86-2.45)
More than 6 years	3.38(1.72-6.65)	1.37(0.75-2.51)	2.49(1.37-4.55)
Source of income			
None	1.00	1.00	1.00
Other	1.33(0.44-3.99)	3.70(1.22-11.19)	2.34(1.01-5.43)
Grants	1.17(0.42-3.23)	2.33(0.93-5.79)	1.75(0.80-3.80)
Wealth quintiles			
First	1.00	1.00	1.00
Second	0.61(0.28-1.36)	1.65(0.84-3.23)	0.94(0.45-1.99)
Third	0.71(0.35-1.44)	1.65(0.79-3.42)	0.84(0.42-1.69)
Fourth	1.22(0.56-2.66)	2.56(1.24-5.31)	1.55(0.74-3.25)
Fifth	0.55(0.25-1.22)	2.28(1.08-4.78)	0.88(0.44-1.77)
Rural/urban			
Urban	1.00	1.00	1.00
Rural	3.00(1.06-8.47)	1.88(0.59-5.94)	2.51(0.74-8.50)

In each of the models presented in Table 4-4, interactions between age and gender, and between age and HIV were tested; none were statistically significant. Overall, adjusting for gender and an interaction term of age and HIV status, compared to HIV-infected participants HIV-affected people were statistically significantly less likely to

have high functional ability (aOR 0.27, 95% CI 0.14-0.50) and health state (aOR 0.32, 95% CI 0.18-0.58). HIV-affected participants were further more likely to have low quality of life compared to HIV-infected participants (aOR 0.58, 95% CI 0.33-1.03), but this did not reach statistical significance.

Table 4-5: Factors associated with physical functioning (WHODAS) by HIV category

	HIV-Infected		HIV-Affected	
	Unadjusted OR [95% CI]	Adjusted aOR [95% CI]	Unadjusted OR [95% CI]	Adjusted aOR [95% CI]
Sex				
Male	1.00	1.00	1.00	1.00
Female	0.25 [0.13-0.48]	0.15 [0.08-0.29]	0.30 [0.12-0.75]	0.20 [0.08-0.50]
Age group				
50-59	1.00	1.00	1.00	1.00
60-69	0.81 [0.45-1.47]	0.84 [0.46-1.54]	0.75 [0.37-1.50]	0.46 [0.19-1.13]
70+	0.43 [0.11-1.60]	0.19 [0.05-0.75]	0.34 [0.17-0.67]	0.17 [0.06-0.46]
Marital Status				
Never married	1.00	1.00	1.00	1.00
Married	0.92 [0.51-1.66]	0.67 [0.33-1.36]	0.91 [0.50-1.67]	1.08 [0.42-2.74]
Previously married	1.74 [0.80-3.81]	1.80 [0.70-4.63]	2.04 [0.95-4.40]	4.80 [1.61-14.32]
Household Head				
Self	1.00	1.00	1.00	1.00
Spouse	0.89 [0.46-1.73]	1.98 [0.87-4.48]	0.82 [0.42-1.60]	1.19 [0.42-3.38]
Other	1.01 [0.50-2.04]	1.21 [0.57-2.53]	0.78 [0.40-1.52]	0.92 [0.44-1.95]
Education level				
No formal education	1.00	1.00	1.00	1.00
6 years or less	1.89 [1.02-3.50]	1.90 [1.00-3.61]	1.06 [0.58-1.93]	1.26 [0.63-2.54]
More than 6 years	1.67 [0.85-3.31]	1.70 [0.81-3.54]	3.38 [1.35-8.50]	5.54 [2.00-15.33]
Source of income				
None	1.00	1.00	1.00	1.00
Other	1.26 [0.42-3.78]	1.39 [0.43-4.54]	2.27 [0.66-7.86]	1.55 [0.21-11.56]
Grants	1.15 [0.41-3.21]	1.80 [0.68-4.76]	0.87 [0.30-2.55]	1.08 [0.17-7.02]
Wealth quintiles				
First	1.00	1.00	1.00	1.00
Second	1.08 [0.42-2.82]	1.73 [0.66-4.52]	0.38 [0.15-0.94]	0.44 [0.14-1.39]
Third	1.46 [0.65-3.27]	1.81 [0.72-4.57]	0.55 [0.23-1.33]	0.52 [0.19-1.42]
Fourth	1.33 [0.59-2.98]	1.48 [0.64-3.45]	1.39 [0.52-3.69]	1.24 [0.40-3.78]
Fifth	1.02 [0.43-2.42]	1.40 [0.49-4.03]	0.49 [0.21-1.11]	0.38 [0.12-1.15]
Rural/urban				
Urban	1.00	1.00	1.00	1.00
Rural	0.82 [0.42-1.60]	1.03 [0.46-2.30]	0.79 [0.28-2.27]	1.30 [0.48-3.56]

Stratified analyses of HIV-infected and HIV-affected older people, presented in Table 4-5 and Table 4-6, show similar factors to be associated with WHODAS and HSS. Sex was strongly linked to the WHODAS and HSS measures among these older people, yet

was also clearly measuring different constructs. Adjusting for age, marital status, household headship, education level, household socio-economic status, source of income and place of residency, older women had 70-85% lower odds of better WHODAS and HSS scores than older men.

Table 4-6: Factors associated with health state by HIV category, rural South Africa 2010

	HIV-Infected		HIV-Affected	
	Unadjusted OR [95% CI]	Adjusted aOR [95% CI]	Unadjusted OR [95% CI]	Adjusted aOR [95% CI]
Sex				
Male	1.00	1.00	1.00	1.00
Female	0.30 [0.17-0.54]	0.20 [0.11-0.37]	0.37 [0.15-0.95]	0.31 [0.12-0.81]
Age group				
50-59	1.00	1.00	1.00	1.00
60-69	0.93 [0.51-1.68]	0.94 [0.45-1.95]	0.92 [0.46-1.86]	0.70 [0.30-1.64]
70+	0.51 [0.15-1.76]	0.20 [0.05-0.73]	0.35 [0.18-0.67]	0.25 [0.10-0.58]
Marital Status				
Never married	1.00	1.00	1.00	1.00
Married	1.22 [0.67-2.21]	0.96 [0.44-2.09]	1.41 [0.77-2.57]	1.53 [0.69-3.39]
Previously married	0.95 [0.42-2.15]	0.86 [0.36-2.06]	1.49 [0.68-3.24]	2.79 [1.11-7.02]
Household Head				
Self	1.00	1.00	1.00	1.00
Spouse	0.70 [0.37-1.32]	0.95 [0.44-2.06]	1.16 [0.56-2.39]	1.30 [0.48-3.54]
Other	0.79 [0.41-1.52]	0.91[0.43-1.94]	0.89 [0.48-1.64]	1.31 [0.63-2.75]
Education level				
No formal education	1.00	1.00	1.00	1.00
6 years or less	1.65 [0.89-3.05]	1.72 [0.87-3.39]	1.38 [0.73-2.64]	1.36 [0.68-2.74]
More than 6 years	1.71 [0.88-3.33]	1.29 [0.63-2.64]	3.76 [1.64-8.63]	4.50 [1.76-11.51]
Source of income				
None	1.00	1.00	1.00	1.00
Other	2.67 [1.04-6.85]	3.67 [1.15-11.66]	2.59 [0.94-7.12]	1.72 [0.36-8.13]
Grants	1.72 [0.85-3.48]	3.13 [1.34-7.28]	1.14 [0.46-2.83]	1.31 [0.32-5.34]
Wealth quintiles				
First	1.00	1.00	1.00	1.00
Second	1.68 [0.69-4.09]	2.17 [0.85-5.52]	0.73 [0.31-1.71]	0.78 [0.28-2.18]
Third	1.69 [0.78-3.66]	1.86 [0.77-4.52]	0.87 [0.36-2.09]	0.70 [0.26-1.90]
Fourth	2.23 [1.04-4.76]	2.52 [1.09-5.84]	1.77 [0.65-4.84]	1.49 [0.52-4.23]
Fifth	2.27 [1.00-5.17]	2.65 [0.85-8.19]	0.86 [0.38-1.95]	0.59 [0.22-1.56]
Rural/urban				
Urban	1.00	1.00	1.00	1.00
Rural	1.26 [0.66-2.39]	1.41 [0.66-2.99]	1.28 [0.51-3.23]	2.05 [0.78-5.36]

The oldest age category in both HIV-infected and HIV-affected older people was statistically significantly associated with lower odds of better WHODAS and HSS in the adjusted models. Among HIV-affected older people, being previously married and having more than six years of education were significantly associated with higher odds of better WHODAS and HSS. Adjusting for other factors in the model, HIV-infected older people who had some source of income compared to none were significantly more likely to report a high health state score (Table 4-6).

Table 4-7: Factors associated with emotional wellbeing (WHOQoL) by HIV category

	HIV-Infected		HIV-Affected	
	Unadjusted OR [95% CI]	Adjusted aOR [95% CI]	Unadjusted OR [95% CI]	Adjusted aOR [95% CI]
Sex				
Male	1.00	1.00	1.00	1.00
Female	0.53 [0.29-0.96]	0.40 [0.21-0.79]	0.75 [0.35-1.60]	0.88 [0.34-2.28]
Age group				
50-59	1.00	1.00	1.00	1.00
60-69	1.20 [0.64-2.26]	1.47 [0.67-3.25]	1.06 [0.53-2.09]	0.96 [0.45-2.04]
70+	0.76 [0.24-2.43]	0.26 [0.07-1.01]	0.63 [0.31-1.25]	0.62 [0.26-1.50]
Marital Status				
Never married	1.00	1.00	1.00	1.00
Married	1.66 [0.91-3.03]	1.73 [0.80-3.73]	2.54 [1.22-5.28]	2.39 [1.02-5.61]
Previously married	0.39 [0.17-0.92]	0.32 [0.13-0.80]	0.85 [0.34-2.16]	0.97 [0.37-2.57]
Household Head				
Self	1.00	1.00	1.00	1.00
Spouse	0.89 [0.46-1.70]	0.70 [0.33-1.49]	1.21 [0.64-2.29]	0.86 [0.34-2.16]
Other	0.94 [0.45-1.99]	0.98 [0.40-2.45]	0.78 [0.38-1.62]	1.28 [0.53-3.11]
Education level				
No formal education	1.00	1.00	1.00	1.00
6 years or less	1.20 [0.64-2.25]	1.15 [0.59-2.25]	2.29 [1.23-4.25]	1.59 [0.81-3.12]
More than 6 years	1.31 [0.67-2.56]	0.69 [0.33-1.46]	2.71 [1.17-6.27]	2.24 [0.91-5.52]
Source of income				
None	1.00	1.00	1.00	1.00
Other	4.92 [1.84-3.15]	6.81 [2.04-2.73]	3.07 [0.60-15.61]	2.25 [0.33-15.13]
Grants	2.77 [1.41-5.46]	3.89 [1.56-9.70]	1.78 [0.53-6.00]	1.68 [0.31-9.03]
Wealth quintiles				
First	1.00	1.00	1.00	1.00
Second	2.11 [0.93-4.75]	2.42 [1.02-5.76]	1.97 [0.83-4.68]	1.71 [0.68-4.33]
Third	1.83 [0.77-4.39]	2.40 [0.91-6.30]	2.39 [0.89-6.42]	1.91 [0.69-5.28]
Fourth	2.84 [1.33-6.09]	3.70 [1.45-9.45]	3.20 [1.21-8.42]	3.07 [1.04-9.11]
Fifth	3.38 [1.62-7.08]	3.85 [1.36-10.92]	3.13 [1.22-8.07]	2.20 [0.83-5.80]
Rural/urban				
Urban	1.00	1.00	1.00	1.00
Rural	1.72 [0.76-3.91]	1.25 [0.50-3.10]	2.17 [1.31-3.60]	2.93 [1.44-5.98]

Table 4-7 presents the quality of life results. For quality of life or subjective well-being, having some source of income and being in the upper two wealth quintiles were highly associated with the likelihood of having a good WHOQoL score among HIV-infected older people even after adjusting for other factors in the model. Being female and having been previously married were associated with lower odds of good WHOQoL in HIV-infected older people. Amongst HIV-affected participants, being currently married was associated with better quality of life. Furthermore, having some level of education compared to none was associated with higher likelihood of good quality of life in HIV-affected older people, although statistical significance was not reached after adjusting for other variables. Being in the fourth household wealth quintile (richer but not richest) and residing in the rural segment of the surveillance area were other factors among HIV-affected older people strongly associated with better WHOQoL scores even after adjustment.

4.6 Discussion

Results of this analysis indicate that the majority of older people aged 50-plus years rated their functional ability favourably (median by gender and HIV status from 69 to 88). The lowest scores were observed for the multi-dimensional health state, suggesting a much lower health status than reported using the functional ability or quality of life measures separately. These differences could partly be explained by the underlying methodology in computing the scores for these health measures. The WHO tools used for functional ability and quality of life assessment are simple arithmetic additive scores, while the health state score was generated using Item Response Theory and Rasch models. However, in spite of these differences in methodologies, correlates of the WHODAS and HSS scores were very similar for both HIV-infected and -affected people. This may be reflective of the stronger contributions from the health domains describing physical functioning than those that are more subjective to the composite health state score. Findings here highlight and support previous findings that although use of a single health outcome measure may be useful to describe the overall health status of older people, use of a single measure may have some

important limitations (Van Minh, Huong, Wall *et al.*, 2010b). For instance, using only the composite health score would have underestimated the health status of study participants. Use of a multi-dimensional approach, as was the case in this analysis, can also enable an investigation of the contributions of the specific domains to overall health to be undertaken for more precise description of health and to design interventions (Debpuur, et al., 2010).

Findings here suggest that the effect of being HIV-affected differs between those who are affected via having an adult HIV-infected adult household member and those affected via an HIV-related death of a household member. Older people who had lost an adult due to HIV were more likely to be in poor physical and emotional health than those with a living HIV-infected adult (Table 4-4). Death of an adult child is likely to take its toll on the physical health of older people who had to care for the adult during the time of sickness (Boon, et al., 2010; Kimuna and Makiwane, 2007) and may additionally be emotionally affected upon death (Schatz, 2007). Death of an adult child may furthermore place greater household responsibilities on the older person as there may be loss of household income from the deceased adult (Ardington, et al., 2010; Kimuna and Makiwane, 2007; Ssengonzi, 2009). Thus death of an adult child is likely to strain the older person physically, emotionally and financially, which in turn is likely to contribute to their poorer physical and emotional health relative to older people just living with an infected adult.

Overall combining the two HIV-affected groups into one, it was shown in this paper that HIV-infected participants had better functional ability, quality of life and overall health than HIV-affected participants. This may seem counterintuitive in that ill-health may be expected to be more common among HIV-infected people (Debpuur, et al., 2010; Mutevedzi, et al., 2011), but may partly be explained by the enhanced health care that this group receives as part of their regular clinic visits for antiretroviral (ART) treatment. These findings are consistent with a study by Louwagie et. al. (2007) who compared health related quality of life (QoL) of patients on ART to those awaiting ART initiation, and showed that patients on ART had on average higher health-related QoL and were more likely to have a higher QoL score. Other studies in South Africa have

also demonstrated the beneficial effects of HIV treatment on health and well-being. In a study in the Free-State province of South Africa, where changes over a 12-month period in the physical and emotional quality of life of people on ART were examined (Wouters, et al., 2009), it was shown that at follow-up people on treatment had fewer adverse events than at baseline; adverse events were negatively associated with physical and emotional quality of life. Evidence of ART leading to improved health can also be inferred from previous work in the same study community that showed that ART has contributed to a substantial decline in mortality among adults (Bor, et al., 2013; Herbst, Mafojane and Newell, 2011). The considerable evidence that HIV treatment is effective in achieving sustained improvement in the health and well-being of HIV-infected people (Fairall, Bachmann, Louwagie *et al.*, 2008; Wouters, et al., 2009), partly contributes to the superior health status of HIV-infected people that is observed in this analysis.

Further, findings from this analysis suggest that as age advances irrespective of HIV group, study participants were increasingly faced with poorer functional ability and overall health, with major gender differences. Women reported poorer health status than men among both HIV-infected and HIV-affected participants. These results showing a male advantage in self-reported health in later life are consistent with other studies (Kowal, et al., 2010; Kyobutungi, Egondi and Ezeh, 2010; Wang, Zheng, Kurosawa *et al.*, 2009; WHO, 2001; Xavier Gomez-Olive, et al., 2010; Zimmer, Chayovan, Lin *et al.*, 2004). A pooled analysis of data collected in four African and four Asian sites, whose study instruments as in the present study were adapted from WHO's Study on global AGEing and adult health (SAGE), reported that older women had significantly lower health scores than older men at all age groups (Ng, et al., 2010). According to findings from a nationally representative study from Thailand (2003), a larger part of women's remaining life expectancy in old-age is spent in a disabled state. These gender differentials in health are said to be more complicated and nuanced than can be explained by biological or medical factors alone (Moen and Chermack, 2005). Hirve and colleagues (2010) argue that this female disadvantage in health may be accounted for by advancing age, societal norms concerning women, occupation, lower education attainment and lower empowerment. The societal norms and

institutionalisation that tend to fuel this sex disparity in health mostly occur around life's central foci of 'paid work or unpaid family work' (Moen and Chermack, 2005). In South Africa, people in the age range considered for this study come from a generation renowned for migration of men to the mines and cities for paid work while the women remained in their rural homes with the care burden for children and those with disabilities (Posel, 1991). This exposed men and women to different health-related resources as well as risks, and may have contributed to the sex disparities in health observed here. This is in addition to the generally observed differential mortality by sex at younger ages where male mortality tends to be higher, implying these older men in the study are selective survivors of their cohorts. Independent of HIV status and selection bias, however, older women are clearly more vulnerable than men to poorer health and functional ability limitations, which are a function of circumstances over the life course.

Being in the richer and richest household wealth quintiles was strongly associated with quality of life, even after adjusting for other factors in HIV-infected participants. This is consistent with a study among older people aged 50+ in Pune district, India, which found that older people in higher household wealth quintiles were more likely to report better quality of life than those in lower wealth quintiles (Hirve, et al., 2010). However, results here and study setting context differ from the Pune district study in that in their case there was no ready access to government cash transfers and they did not find a significant association between gender and quality of life. As mentioned in Chapter Two, in the study area of this analysis government cash transfers in the form of old-age pensions are widely available; around 80% of older people sampled in 2010 were receiving a grant. In addition, there was a significant association between gender and quality of life, as well as between having some income source and quality of life. Most of this income which is linked to the quality of life of older people in rural South Africa is from non-contributory government cash transfers or grants, therefore rapid increases in the proportion of older people poses serious challenges to their well-being by threatening the sustainability of the cash transfers programme.

Gender, advancing age, education and income were independently strongly associated with the health and well-being of older people in this study. The factors reported here associated with health status were similarly reported on by others using similar study instruments (Debpuur, et al., 2010; Hirve, et al., 2010; Kowal, et al., 2010; Kyobutungi, Egondi and Ezeh, 2010; Mwanyangala, et al., 2010; Ng, et al., 2010; Razzaque, et al., 2010; Van Minh, et al., 2010a; Xavier Gomez-Olive, et al., 2010). In six of these studies all individuals aged 50+ were eligible for inclusion and in two studies a random sample of households containing at least one older person aged 50+ was targeted. For this study, individuals among HIV-infected and HIV-affected clusters of older people within the community were selected. Another main methodological difference to these other studies is that they applied binary logistic regressions to the quintile health scores, where they defined those in the highest two quintiles as healthy and the rest as unhealthy. The decision as to at which quintile the cut-off into healthy and unhealthy should be is highly arbitrary (McCullagh, 1980; StataCorp., 2009; UCLA Academic Technology Services, 2011) and different results may be obtained if different cut-points are used. Ordered logistic regression analyses, which make use of the quintile distributions without an arbitrary cut-point, were used in this study. Despite these methodological differences, findings here confirm that health and wellbeing of older people varies by socio-demographic characteristics such as age group, gender, education attainment and income. These results contribute to a better understanding of the association of these factors with the health status and well-being of older people, and are further strongly linked to whether the older person is HIV-infected or HIV-affected.

4.6.1 Limitations

Participants categorised into HIV-infected or HIV-affected groups, were purposefully sought, with limited sample sizes. Some of the potential sampling bias was corrected by applying sampling weights and making use of survey tools in the statistical software package used in the analyses. Another limitation of the analysis is the possibility that some of the participants categorised as HIV-affected were actually HIV-infected. This could have occurred if participants were tested and/or accessing HIV treatment outside of the Hlabisa sub-district or from private practitioners and hence not captured

in the Hlabisa HIV Treatment and Care Programme. The likelihood of accessing treatment and care outside the sub-district happening is, however, remote given the logistical and financial implications particularly for older people: hence this potential bias was assumed to be negligible. Although a blood specimen was collected from all participants as per study protocol these specimen were not tested for HIV antibodies. All participants were informed that no HIV testing would be done on the specimen. However, an earlier study from the same study population showed that HIV prevalence in the population 50+ in 2008 was 9.5% (95% CI 8.4-10.7), with an incidence rate of 0.5% (95% CI 0.3-1.0) (Wallrauch, Bärnighausen and Newell, 2010). Therefore, not many infected older people could have been unknowingly included as HIV-affected, and the findings reported here are unlikely to be significantly biased.

Caution is nonetheless urged in the interpretation of these results, particularly the association of age with poorer functional ability and health state because of small-numbers and limited statistical power, especially in the oldest age group. There may have been a healthy selection effect into the WOPS - those that participated in the study may be survivors from their cohorts. As mentioned earlier, despite self-reported health (SRH) measures being a good predictor of morbidity and mortality (Fayers and Sprangers, 2002; Idler and Benyamini, 1997; Olgiati, Bärnighausen and Newell, 2012; Wang, et al., 2008) there are comparability and inconsistency concerns (Bowling, 2005; Fayers and Sprangers, 2002; Salomon, et al., 2009) given that such measures may be highly subjective, influenced by cultural and contextual factors (Fayers and Sprangers, 2002; Jylhä, 2009; Sen, 2002; Zimmer, et al., 2000). Thus reporting bias from the SRH measures used in this analysis may be another limitation of this study.

The study was cross-sectional, and it is not possible to make causal inferences between the socio-demographic factors considered and health status. Further, generalisation of these findings to the general older population of South Africa is limited since study participants came from a population under constant surveillance with ready access to a comprehensive HIV care and treatment programme (Houlihan, et al., 2011). In addition other household factors such as number of HIV-infected persons in the household, living arrangements (living alone, in skip-generation household or

multigenerational household) and cash transfers to other household members were not allowed for in this analysis, as that was beyond the scope of the present analysis. These results here nonetheless make an important contribution to understanding the correlates of health and well-being of older people in rural South Africa.

4.7 Conclusion

For both HIV-infected and HIV-affected participants, women had poorer health status than men. To address the poorer health status among older women relative to men will require a life-course perspective, targeting the varied contributory factors to this female disadvantage in health in later life. There is need for policy interventions and a change of societal norms regarding paid work and unpaid family work to ensure women are not overburdened with informal care responsibilities and which address issues related to limited access to education, the labour market and means of production such as land, all of which contribute to this poorer health status in later life.

There is urgent need for the healthcare system in South Africa to start responding to the needs of the increasingly ageing population. A lot of resources have been dedicated to HIV care and management in terms of manpower, infrastructure, and interventions, which has greatly contributed to improving the overall health and well-being of HIV-infected older people. Not the same amount of resources have been devoted to the general health and well-being of all older people such as the care and management of chronic health conditions associated with advancing age like hypertension, diabetes, cancer and cardiovascular diseases. As such older people who are not HIV-infected may be at increased vulnerability of poorer health than those who are HIV-infected. Policy and programme interventions are urgently needed given increasing numbers of older people.

This, however, is the first time it is being shown that HIV-infected compared to HIV-affected older people are associated with better functional ability and health state. Future research extending the spatial and temporal scope of this analysis using representative population-based data would therefore be a useful addition to the findings reported here.

Chapter 5: **Informal care, self-reported health, depression and older people's mortality levels and patterns in rural South Africa**[8]

5.1 Abstract

With the twin challenges of widespread poverty and a severe HIV pandemic in South Africa, older people are central to informal care provision; caring is dependent on older people's physical health and mental well-being, and is linked to survival. However, causes and correlates of mortality in older adults aged 50 years or over in this setting are incompletely understood. The objective of this analysis is to quantify levels and patterns of mortality in older people (aged 50 years or over) in rural South Africa between 2010 and 2013; and associations with informal care, self-reported health and depression within a context of a severe HIV pandemic.

This analysis uses data from a prospective cohort of older people first observed between March-August 2010 and followed until July 2013, nested within a longitudinal surveillance in predominantly rural northern KwaZulu-Natal, South Africa. Cox survival analysis with person-years under observation measured as the interval between date of interview and of last observation, right censored on 1st July 2013, is used to examine mortality in older people by informal care dynamics, self-reported health and depression adjusting for age, sex, marital status, highest education level attained, receipt of government grants, household socio-economic status (SES), household headship and HIV status.

There were 58 deaths over 1028.3 person-years of follow-up in 422 older adults, for an overall mortality rate of 5.6 per 100 person-years (95% CI 4.4-7.4). Median age at death was 66 years. Mortality rates increased monotonically with increasing age, and differed significantly by sex, education level, receipt of government grants and household headship. Care-giving was associated with reduced mortality (aHR 0.38, 95% CI 0.21-0.70), and receipt of care with increased mortality (aHR 1.33, 95% CI 0.52-3.38). Older people with poor relative to good self-reported health were about 2 times more likely to have died (aHR 1.96, 95% CI 1.09-3.52). Although the observed mortality rate was highest in older people with a major depressive episode (7.1/100py, 95% CI 4.5-12.1) reported at baseline relative to those with a brief depressive episode (5.4/100py, 95% CI 3.1-10.4) or with none (5.2/100py, 95% CI 3.7-7.5), findings in this study suggest a complex relationship between depression and mortality in the study area.

Despite the complex nature of the relationships between informal care, health, depression and survival, findings here suggest that the living circumstances of older people can predict their relative mortality risk over a three-year follow-up period. A multi-faceted approach to improving the health and well-being of older people, especially those needing care or with depressive symptoms that are at increased mortality risk, is an urgent and important need.

Key Words: Informal care, self-reported health, depression, mortality, HIV, South Africa.

[8] A version of this paper has been submitted to Plos One Journal for publication consideration. See Appendix 1, pp. 201 for citation details and co-author contributions for the submitted manuscript.

5.2 Chapter outline

This chapter examines how the three aspects of older people studied as part of this research, relates to survival among study participants. The three aspects being, 1) informal care - presented in Chapter Two and the paper published in Ageing and Society Journal (Nyirenda, et al., 2013b) presented in Chapter Three; 2) health and well-being status - presented in Chapter Four and published in BMC Public Health Journal (Nyirenda, et al., 2012); and 3) depression status also published already in Journal of Affective Disorders (Nyirenda, Chatterji, Rochat *et al.*, 2013a), but only included here in the appendices (see Appendix 2, pp. 202) since there were already more than the required number of papers included in this thesis for the 'three-paper' dissertation.

This chapter is structured as follows. Section 5.3 provides background to this analysis, highlighting a gap in the knowledge with regard to the association with mortality levels and patterns of care-giving or -receiving (informal care), self-perceived health status and depression symptomatology in a high HIV prevalence area. The study design, data sources, analytical methods, analytical measures then follow in the methods section in 5.4. Results of this analysis are then presented in section 5.5 and then discussed in section 5.6. Finally, conclusions are drawn in section 5.7.

5.3 Background

Mortality levels and patterns, and the contribution of HIV infection, in adults of reproductive ages (15-49 years) in HIV affected areas have been extensively described (Blacker, 2004; Dorrington, et al., 2006; Dorrington, Moultrie and Timæus, 2004; Nyirenda, et al., 2007; Timæus and Jasseh, 2004). Recent evidence shows substantial improvements in HIV-related mortality at population level following the roll-out of antiretroviral therapy (ART) programmes (Bor, et al., 2013; Herbst, et al., 2009; Herbst, Mafojane and Newell, 2011; Jahn, Floyd, Crampin *et al.*, 2008). Longer survival of HIV infected people on treatment, together with the number of new HIV cases diagnosed in older ages (Simone and Appelbaum, 2008; Wallrauch, Bärnighausen and Newell, 2010), is likely to lead to growing numbers of people ageing with HIV (Atun, Gurol-Urganci and McKee, 2009; Grabar, Weiss and Costagliola, 2006; Schmid,

Williams, Garcia-Calleja *et al.*, 2009; Simone and Appelbaum, 2008). This in turn is further likely to lead to changes in the causes and patterns of mortality amongst older people. However, mortality in adults aged 50 years or over in severely HIV-affected populations is under-researched partly because of the difficulties in ascertaining cause of death in this age group. In this analysis the aim is to contribute to this limited body of literature by investigating mortality levels by care-giving or –receiving (informal care), self-perceived health status and depression, in a high HIV prevalence rural area of South Africa.

In later life, provision and/or receipt of informal care is common (Hill, Hosegood and Newell, 2008; Nyirenda and Newell, 2010; Pickard, Wittenberg, Comas-Herrera *et al.*, 2000). It was previously shown (see Chapter Three), in a study of 422 older people aged 50 years or older from rural South Africa (Nyirenda, et al., 2013b), that 62% were providing care to one or more adult children or grandchildren; and care-giving was associated with lower functional disability but higher likelihood of self-reported poor emotional well-being. Findings in Chapter Two further suggest material resources more likely flow downwards from older to younger people. However, it is unclear from the available evidence what the relationship is between informal care and mortality of older care-givers (O'Reilly, et al., 2008; Vlachantoni, et al., 2013a).

Although there are concerns relating to comparability, consistency and subjectivity (Bowling, 2005; Fayers and Sprangers, 2002; Jylhä, 2009; Salomon, et al., 2009; Sen, 2002; Zimmer, et al., 2000), it is generally accepted that Self-Rated Health (SRH) based on the question “How do you rate your current health?” is a valid and good indicator of morbidity and mortality (Fayers and Sprangers, 2002; Idler and Benyamini, 1997; Wang, et al., 2008). However, most of the evidence establishing this relationship between SRH and future mortality comes from developed countries (Jylhä, 2009). In a meta-analysis from a systematic search of MEDLINE and EMBASE databases of studies reporting on all-cause mortality prediction from a single question of general self-reported health, which had 22 studies included in the final analysis, none were from a developing country (DeSalvo, Nicole, Kristi *et al.*, 2006). DeSalvo and colleagues (2006) were nonetheless able to find from their analysis that relative to persons self-reporting

their health as “excellent”, persons self-reporting “poor” health status were at a two-fold increased risk for mortality. A recent study from rural South Africa investigated whether self-assessments of health predicted future mortality (Olgiati, Bärnighausen and Newell, 2012), showing that adults aged 15-54 years in this high HIV prevalence area who rated their health status as poor had a more than four-fold higher mortality risk in the short-term (within 3 years of follow-up) than adults who self-assessed their health as excellent, adjusted for age, sex, marital status, socio-economic status, education, HIV status and ART uptake. However, in the longer-term (4-8 years of follow-up), once HIV status was adjusted for, self-reported health (SRH) was no longer significantly associated with future mortality. In the present analysis the association of SRH with mortality within three years of follow-up will be further explored, but this time with respect to older people aged 50+ who are either HIV-infected or -affected.

Self-reported health measures can be useful indicators with strong predictive power of future mortality even in older people (Dowd and Zajacova, 2007; Lima-Costa, Steptoe, Cesar *et al.*, 2012; Pu, Tang, Huang *et al.*, 2011; Tsuji, Minami, Keyl *et al.*, 1994). In resource-limited settings, the costs and difficulties in terms of time, expenditures, human resource, training and logistics relating to the objective measures of health such as collection of biomarkers, physical health testing, and clinical cognitive evaluation are prohibitive with regard to use of such measures (Kuhn, Rahman and Menken, 2006). Self-rated health measures then offer a valuable tool in low-resource settings not only in predicting future mortality, but in examining morbidity burden and evaluating health interventions.

As with SRH, evidence abounds of increased mortality in persons who have had a depressive episode, but again most of these studies have been conducted in the developed world or in populations not severely affected by HIV (Cuijpers and Smit, 2002; Schulz, Drayer and Rollman, 2002; Sun, Xu, Chan *et al.*, 2013). The study population is not only burdened by HIV, but is also faced with a high level of depression in adults, including older people (Nyirenda, et al., 2013a; Rochat, Tomlinson, Bärnighausen *et al.*, 2011). Nyirenda and others (2013a) previously reported that among 422 older people aged ≥50 years about 42% self-reported having

experienced a depressive episode, with women and care-givers more likely to have had a depressive episode (see Appendix 2, pp. 202 for a copy of the manuscript). Interestingly, older people with a depressive episode were two to three times more likely to self-report their health as poor.

Understanding the relationships between informal care, self-perceived health, emotional well-being and mortality in older people aged ≥50 years faced with a double burden of HIV and non-communicable diseases (Mayosi, et al., 2009) is important for policy and planning. Older people are increasingly taking on the care-giving role in response to the severe impact of the HIV pandemic (Hill, Hosegood and Newell, 2008; Schatz, 2007; Zimmer and Dayton, 2003) and/or socio-economic deprivation (Ardington, Case and Hosegood, 2009; Leibbrandt, Finn and Woolard, 2012; Neves and du Toit, 2013). Given that care-giving in older adults has been shown to be negatively associated with physical health and mental well-being, research to investigate mortality patterns in this group would be useful to gain an indication of potential life-years of care that may be lost due to mortality in older people. The aim of this analysis is to quantify the levels and patterns of mortality in older people infected or affected by HIV in rural South Africa between 2010 and 2013 nested in an ongoing longitudinal surveillance; and the association with informal care, self-reported health, and depression status at baseline.

5.4 Methods

5.4.1 Sources of data and study design

This analysis uses data from a prospective cohort of older people (aged 50 years or over) resident in the area covered by the Africa Centre's demographic and health surveillance in rural northern KwaZulu-Natal, South Africa. As detailed in Chapter One (see section 1.8.1, pp. 11), information on births, deaths and migration on about 90,000 household members belonging to approximately 11, 500 household units has been collected since 2000 in bi-annual (tri-annual since 2012) surveillance rounds (Tanser, et al., 2008). In addition, information on general health, sexual partnerships and HIV status has been collected annually on consenting adults aged 15-49 years (women) and 15-54 years (men) between 2003 and 2006 and on all adults aged 15

years and above since 2007. HIV status is unknown for non-consenting adults. The surveillance population is characterised by high levels of adult (15-49 years) HIV incidence (3.4 per 100 person-years between 2003 and 2007) (Bärnighausen, Tanser and Newell, 2009) and prevalence rates of around 29% in 2011 (Zaidi, Grapsa, Tanser *et al.*, 2013). HIV prevalence and incidence in older people aged 50+ in 2008 was estimated to be 9.5 and 0.5 per 100 person years, respectively (Wallrauch, Bärnighausen and Newell, 2010).

Between March-August 2010 a study was carried out on the health and well-being of older people (WOPS) aged 50 years or over nested within the Africa Centre surveillance. WOPS studied 422 older people from the surveillance population of older people using a shortened version, adapted to the local population, of the SAGE (WHO, 2011). The basic criteria for inclusion in WOPS was being aged 50+ years, resident in the area and under demographic and health surveillance by the Africa Centre. Written informed consent was obtained from all participants. Study participants were categorised into four defined groups:

- older people who were HIV-infected and on ART for one year or longer;
- older people who were HIV-infected but on ART for less than three months or not yet on ART (that is, were ART-naïve);
- older people who had an HIV-infected adult child (18-49 years) who was HIV-infected and had been on ART for at least a year or was ART-naïve; and
- older people who had experienced the death of an adult child (18-49 years) within two years prior to the study (between 2008 and 2010), and whose death was diagnosed as HIV-related using verbal autopsy (VA) data.

The four categories were then broadly combined as HIV-infected (groups 1 and 2) or HIV-affected (groups 3 and 4). The population of older people in the area eligible in each group was 241 (group 1), 117 (group 2), 662 (group 3) and 142 (group 4) from which 103, 100, 107 and 112 participated in groups 1 to 4 respectively. The initial target sample size was 400 participants, deemed adequate by power calculations to detect statistically significant differences between the groups at 5% level of significance. The final study sample was slightly higher than targeted largely because

all older people found at target homestead were offered the opportunity to participate in the study provided they met the inclusion criteria. As a result there was in the end more than one older person per homestead in a few cases particularly for the HIV-affected groups leading to a final sample size of 422. Overall consent rates were very high mainly because the targeted population was of older people already participating in the surveillance or the HIV treatment programme. Only nine older people were excluded for being too sick to participate (n=3), non-contact (n=2) and refusals (n=4). Details about the WOPS have been published earlier (Nyirenda, et al., 2012; Nyirenda, et al., 2013b) or see Chapter One (section 1.8.2, pp. 14) for a detailed description in this dissertation).

5.4.2 Observation time and verification of death outcomes

Observation time for each participant in the study was measured from date of interview to the latest of date of death, date of last visit (or date of last ART follow-up for individuals on HIV treatment), or at the censoring date (1st July 2013). To assess accuracy of the mortality data, death reports in the surveillance were compared to reports in the treatment programme. Of the 28 deaths in HIV-infected participants, 24 (86%) were recorded in both data sources and of the remaining four deaths, two were recorded as lost to follow-up in the treatment programme, while one was reported as still under observation and the other as out-migrated from the surveillance area. For the two captured as lost to follow-up the death reports were verified via repeat observation in the surveillance, whereas for the other two inconsistencies the death report was maintained in the analysis given that the numbers were too small to significantly bias the study outcomes. Cause of death information was taken from verbal autopsy (VA) diagnoses based on the standardized Indepth/WHO verbal autopsy questionnaires (Kahn, et al., 2000). Completion of VA questionnaires in the Africa Centre surveillance is done by trained nurses who visit the homestead to interview a competent respondent about the death at least 6 months after death notification. The assigning of cause of death was based on application of Bayesian theorem called InterVA on likely cause of death from VA data (Byass, et al., 2006). Prior to 2010, assigning of cause of death was based on physician review of VA data (Soleman, Chandramohan and Shibuya, 2006). There is substantial agreement in cause of death

diagnosis between physician coding and InterVA (Herbst, Mafojane and Newell, 2011). For this analysis, given the time-lag in completing verbal autopsies which can be as long as one year after the death occurred, 28% (n=16) of the deaths in this analysis did not have a cause of death recorded.

5.4.3 Measures

5.4.3.1 Informal care measures

Informal care was defined as assistance with activities of daily living such as cooking, fetching water from a public tap or river, eating, bathing, dressing up, getting to or from the toilet, going to the clinic or traditional healer, dressing of wounds, and administering of medicines. If an older person was being helped in any of these activities they were categorised as care-receiving and if they were assisting an adult (18-49 years) or a child (<18 years) they were defined as care-givers and as non-care-givers otherwise. In the analysis a distinction was made between care-giving to adults only, to children only or to both adults and children. A distinction was also made between nursing care (help with toileting, taking and preparing medicines, dressing of wounds, bathing) and physical care (help with activities such as cooking, fetching water, and mobility). In addition, participants were asked if they were receiving financial support from family, friends, neighbours or government for their daily living expenses or health care.

5.4.3.2 Health status measures

Self-reported health was determined initially from the question “How do you rate your overall health today?” A similar global question was used for quality of life. In addition, participants were asked to rate their health in the two weeks prior to interview. All questions used a five-point Likert-type scale from very bad to very good, later dichotomised into bad (very bad, bad, moderate) and good (very good, good) health status. For objectively measured health status from self-reports the WHO functional disability index (WHODAS) was used, which was obtained from a set of 12 questions asking about difficulties a participant may have experienced with regard to activities of daily living (like getting up from sitting or lying down position, walking, standing, stooping, crouching, picking small things from the table, and doing household chores),

and instrumental activities of daily living (such as bathing, getting dressed, eating, getting to or from the toilet, and using public transport). For subjective or emotional well-being, the WHO quality of life score (WHOQoL) was computed from a set of eight questions asked on satisfaction with such as living conditions, own self, personal relationships, and ability to perform activities of daily living. For both WHODAS and WHOQoL scores, quintiles were created and then dichotomised into bad (lowest 3 quintiles) and good (top- two quintiles) heath status. For details about derivation of WHODAS and WHOQoL scores see (Nyirenda, et al., 2012) or Chapter Four in this thesis.

In the regression analyses, a multi-dimensional approach of five different health measures was used to assess the relationship between self-reported health and mortality outcomes in older people. The five measures used were: 1) self-rated health from the question 'How do you rate your health today?' 2) Self-rated quality of life from the question 'How do you rate your quality of life today?' 3) Health in the last 2 weeks from the question 'How do you rate your health in last 2 weeks?' 4) Functional ability measured using WHODAS, and 5) subjective wellbeing measured using WHOQoL. Both the WHODAS and WHOQoL measures have been validated in similar populations to the one studied here (WHO, 2010; WHOQoL Group, 1993). The aim of using these differing constructs of health status was to establish firstly, whether the well-established relationship in the adult population between SRH and mortality from the global question in the first health measure (Fayers and Sprangers, 2002; Idler and Benyamini, 1997; Wang, et al., 2008), holds for older people, given the comparability and consistency concerns raised against this measure (Bowling, 2005; Fayers and Sprangers, 2002; Salomon, et al., 2009). Secondly, to establish whether the relationship also holds when different constructs of self-reported health status (SRH) are used. The first three measures of health are directly self-rated by the participants, whereas the fourth and fifth are more objectively measured using statistical tools based on self-reports of participants on several aspects of their physical and emotional wellbeing respectively. Use of more than one construct of health status covering both physical and emotional aspects of health in the modelling enables a robust assessment of health, minimises measurement bias (Bowling, 2005) and facilitates comparability

across sites (Sen, 2002). Results of the analyses presented in Chapters Three and Four suggest it is important to distinguish between physical and emotional wellbeing aspects of SRH; for example older care-givers reported good physical health, but poor emotional wellbeing. After three years of follow-up, these associations were evident in mortality patterns: participants initially reporting good physical health had lower mortality hazards than participants reporting poor emotional wellbeing. Using multiple measures of SRH therefore allowed the telling of a comprehensive story and to highlight the contribution of different constructs of SRF to mortality patterns.

5.4.3.3 Depression measures

Depression status was determined using a set of depressive symptomatology questions adapted from the Composite International Diagnostic Interview 3rd edition (CIDI 3.0) depression module (Kessler and Ustun, 2004). These questions were administered to WOPS participants in face-to-face interviews by native isiZulu-speaking trained nurses. The depression module itself had questions which could be categorised into two criteria (see Appendix 7, pp. 223) using the diagnostic criteria for research of depressive episodes of the International Classification of Diseases 10th edition (ICD 10-DCR) (WHO, 1993). Under the first criteria participants were asked about symptoms of feeling sad or empty (depressed mood); feeling like not wanting to do things a person usually enjoys doing (loss of interest); and feeling reduced energy or perpetually tired without any physical activity (fatigue). Under the second criteria, participants were asked whether at any time that they experienced any of the symptoms of the first criteria they also experienced loss of appetite, thought of or attempted suicide, had concentration difficulties, felt hopelessness, lost interest in sex, had worry or anxiety, were sleep deprived, or experienced psychomotor restless. According to the ICD 10-DCR diagnostic criteria, a person experiencing at least two of either depressed mood, loss of interest or fatigue plus one or more of the symptoms under the second criteria, in the last 12 months, is diagnosed as having had a depressive episode. Depressive episodes were further classified into major depressive episode (MDE) when the individual meeting the criteria had experienced the symptoms 'most of the day or nearly every day' for two weeks or more. Otherwise, it was categorised as a brief depressive episode (BDE) if the symptoms were experienced

for less than a two week period. Details about the derivation of the depression measure and a further discussion of depression in older people in rural south Africa were published earlier (Nyirenda, et al., 2013a) and included in Appendix 2, pp. 202.

Other factors controlled for in this analysis were: age – categorised into ten-year age groups (50-59, 60-69, 70-79 and 80+ years); sex (male or female); marital status – as never married, currently married, and previously married (separated, divorced or widowed); education level - as no formal education, primary, secondary or higher; having an income source from government grants or other; employment status; household headship in three categories of self, spouse or other; household socio-economic status (household wealth quintiles and self-perceived household financial status) and HIV status in three categories of negative, positive or unknown. Although a blood specimen was obtained from almost all participants in this study, these specimen were not tested for HIV as per study protocol guidelines and the consent obtained from the participants. The HIV status of participants was based on information from either the voluntary participation Africa Centre surveillance or the HIV treatment database (Houlihan, et al., 2011; Tanser, et al., 2008), thus HIV status was unknown for 23% (n=98) of study participants (Table 5-1). However, given an HIV incidence rate of only 1% in this age group (Wallrauch, Bärnighausen and Newell, 2010), it is highly likely that majority of participants whose HIV status was unknown were actually HIV-uninfected. All the above variables were obtained from data collected between March-August 2010 in WOPS, whereas the survival status of study participants was obtained from the routine Africa Centre longitudinal surveillance data over a three-year follow-up period.

5.4.4 Analytical models

Cox survival analysis methods are used in this analysis, with time measured in days between the date of interview and last date of observation for interval censored observations and right-censored on 1st July 2013 for persons who had not yet experienced the event of death. This was later converted into person-years at risk using the scale one year = 365.25 days. Mortality hazard ratios (HR) with 95% confidence intervals (CI) adjusted for socio-demographic characteristics of age, sex,

marital status, highest education level attained, receipt of government grants, household socio-economic status (SES), household headship and HIV status were calculated. Proportional hazard assumptions were tested using Log-log plot of survival, Kaplan-Meier and predicted survival plots as well as scaled Schoenfeld residuals, which all indicated the models met the Cox proportionality assumptions. All analyses here were conducted using Stata, version 11.2, (StataCorp, 2009).

5.4.5 Ethical approval

Ethical approval for data sources used here - the Africa Centre surveillance system (ref. BE066/07), ARTemis (ref. E009/00), and WOPS (ref. BF136/09) - was obtained from the University of KwaZulu-Natal Biomedical Research Ethics Committee. Approval has further been obtained to link information from the ART programme database (ARTemis) to the surveillance information (ref. HRKM012/07). Informed consent was obtained from all participants in the Africa Centre surveillance verbally, and written for ARTemis and WOPS.

5.5 Results

5.5.1 Mortality rates by socio-demographic characteristics

Table 5-1 provides a description of survival status by socio-demographic characteristics at baseline in 2010 of this prospective cohort of adults aged 50 years or over. There were 58 deaths (n=38, 66%, women) over 1028.3 person-years of follow-up of 422 individuals, for an overall mortality rate of 5.6 per 100 person-years (95% confidence interval (CI) 4.4-7.4). The median age at death in years was 65.7 (95% CI 60.8-70.0) among women, 64.0 (95% CI 57.2-73.4) in men and 65.5 (95% CI 61.2-68.2) overall. Among all deaths, 17% (n=10) were in HIV-negative, 52% (n=30) in HIV-positive and 31% (n=18) in HIV unknown older people. The mortality rate per 100 person-years was significantly higher among older people with unknown HIV status than among HIV-infected participants followed by in HIV-uninfected people. Mortality rates increased monotonically with increasing age at baseline: from 3.4 per 100 person-years among people aged 50-59 years to 8.7 per 100 person-years in people aged 80+. Other significant patterns were for mortality rates by education level, receipt of government grants and household headship (Table 5-1).

Table 5-1: Mortality rates per 100 person-years by baseline socio-demographic characteristics

Characteristic	Alive n (%)	Dead n (%)	Mortality rates/00 pyo	p-value
Sex				0.10
Male	84 (80.8)	20 (19.2)	8.14[5.25-12.62]	
Female	280 (88.1)	38 (11.9)	4.85[3.53-6.67]	
Age Group				0.01
50-59	172 (91.5)	16 (8.5)	3.41[2.09-5.57]	
60-69	106 (82.8)	22 (17.2)	7.08[4.66-10.75]	
70-79	61 (81.3)	14 (18.7)	7.82[4.63-13.2]	
80+	25 (80.6)	6 (19.4)	8.67[3.9-19.3]	
Marital status				0.49
Never Married	98 (83.8)	19 (16.2)	6.74[4.3-10.57]	
Married	180 (87.4)	26 (12.6)	5.13[3.49-7.53]	
Prev. Married	86 (86.9)	13 (13.1)	5.43[3.15-9.35]	
Education level				p<0.01
No formal education	165 (82.1)	36 (17.9)	7.76[5.6-10.76]	
Primary	125 (89.3)	15 (10.7)	4.21[2.54-6.98]	
Secondary+	74 (91.4)	7 (8.6)	3.36[1.6-7.05]	
Source of Income				0.06
None	37 (92.5)	3 (7.5)	3.01[0.97-9.32]	
Other	47 (94.0)	3 (6.0)	2.34[0.76-7.27]	
Grants	280 (84.3)	52 (15.7)	6.49[4.95-8.52]	
Grant receipt				p<0.01
None	78 (95.1)	4 (4.9)	1.91[0.72-5.08]	
Disability grant	100 (87.7)	14 (12.3)	4.97[2.94-8.39]	
Old-Age pension	186 (82.3)	40 (17.7)	7.45[5.46-10.16]	
Employment status				0.10
Employed	35 (92.1)	3 (7.9)	2.94[0.95-9.13]	
Unemployed	328 (85.9)	54 (14.1)	5.85[4.48-7.64]	
Financial status				0.83
Comfortable	56 (83.6)	11 (16.4)	6.89[3.82-12.45]	
Moderate	120 (88.2)	16 (11.8)	4.83[2.96-7.89]	
Poor	188 (85.8)	31 (14.2)	5.76[4.05-8.2]	
Household wealth quintiles				0.72
First	65 (87.8)	9 (12.2)	4.99[2.60-9.59]	
Second	78 (84.8)	14 (15.2)	6.32[3.74-10.67]	
Third	68 (82.9)	14 (17.1)	7.10[4.21-12.00]	
Fourth	62 (89.9)	7 (10.1)	4.05[1.93-8.49]	
Fifth	47 (88.7)	6 (11.3)	4.49[2.02-9.99]	
Missing	44 (84.6)	8 (15.4)	6.51[3.26-13.02]	
Household Head				0.05
Self	202 (82.8)	42 (17.2)	7.06[5.22-9.55]	
Spouse	79 (90.8)	8 (9.2)	3.74[1.87-7.48]	
Other	83 (91.2)	8 (8.8)	3.65[1.82-7.3]	
HIV status				0.03
Negative	100 (27.5)	10 (17.2)	3.67[1.98-6.82]	
Positive	184(50.5)	30(51.7)	5.63[3.94-8.06]	
Unknown	80 (22.0)	18 (31.0)	8.05[5.07-12.78]	

* Number alive or dead (Percentage in brackets). 95% confidence interval in parenthesis. Mortality rates per 100 person years of observation (pyo).

* p-values denote significance tests for trend of rates across categories using Mantel-Cox methods.

5.5.2 Cause of death and health care utilisation

Verbal autopsy records were not available for 28% (n=16) of the deaths, which included 11 for whom VA was not yet done and 5 who refused to participate in the VA. Of the 42 deaths with VA records, six had an undefined cause of death. Excluding persons with undefined cause of death, the leading causes of death in this cohort of older people were TB (30%) and HIV (14%), followed by non-communicable diseases of stroke (11%), heart disease (8%), diabetes (8%), kidney disorders (8%), malignancy (8%) and other (14%). When grouped into broad global burden of disease categories, 51% of the deaths were due to non-communicable diseases and 49% due to communicable diseases. But excluding TB and HIV, only 5% of deaths would be classed as due to communicable diseases.

Among older persons who had died, information on health care utilisation was not available for 16% (n=9). Among those with known information, 14% (n=7) were treated as an outpatient at a primary health care clinic just prior to death and 33% (n=16) had been hospitalised then died. However, the majority of people who died (53%, n=26) had not accessed a clinic or hospital for health care for the poor health condition they were experiencing, despite half of them (n=13) having been reportedly taken to the hospital at the point of dying.

5.5.3 Mortality rates by care-giving and –receiving status

Table 5-2 presents the findings regarding the mortality patterns of older people by informal care patterns. Both the observed and age-sex adjusted mortality rates were lower in care-givers than in people not providing any care. This was the case even after disaggregating into who was being cared for. Adjusting for age and sex, the mortality rate in non-care-givers to adults (9.2/100 pyo) was nearly double that of care-givers to adults (4.7/100 pyo). Similarly after adjustment for age and sex, the mortality rate was more than doubled in non-care-givers compared to care-givers to children. As a partial indicator of the care-giving load, while mortality remained highest in non-care-givers, the level of mortality was about three-times as high in people simultaneously care-giving to adults and children compared to those who were care-givers to either adults or children only.

Table 5-2: Percentage alive or dead, and mortality rates per 100 person-years by baseline care-giving or receiving status

	Alive n (%)	**Dead** n (%)	**Observed mortality**	**Age-sex Adjusted**
Care-giver				
No	122(78.2)	34(21.8)	9.72	8.06
Yes	242(91.0)	24(9.0)	3.54	5.69
Care-giver to adults				
No	208(84.2)	39(15.8)	6.66	9.24
Yes	156(89.1)	19(10.9)	4.3	4.74
Care-giver to children				
No	143(78.1)	40(21.9)	9.64	9.48
Yes	221(92.5)	18(7.5)	2.93	4.27
Care-giver status				
Non-caregiver	122(78.2)	34(21.8)	9.72	8.06
To adults only	21(77.8)	6(22.2)	9.22	1.42
To children only	86(94.5)	5(5.5)	2.12	1.18
Both adults & children	135(91.2)	13(8.8)	3.45	3.32
Receiving care				
No	56(86.2)	9(13.8)	5.53	2.13
Yes	308(86.3)	49(13.7)	5.66	11.61
Receive nursing care				
No	352(88.7)	45(11.3)	4.57	10.66
Yes	12(48.0)	13(52.0)	29.28	3.08
Receive physical care				
No	57(86.4)	9(13.6)	5.44	2.13
Yes	307(86.2)	49(13.8)	5.68	11.61
Receive financial support				
No	44(95.7)	2(4.3)	1.73	0.47
Yes	320(85.1)	56(14.9)	6.14	13.35
Giving and receiving care				
No	148(80.4)	36(19.6)	8.51	8.53
Yes	216(90.8)	22(9.2)	3.63	5.21
Care-give and receive				
Neither	30(81.1)	7(18.9)	7.82	1.66
Care-giver only	26(92.9)	2(7.1)	2.73	0.47
Care-receive only	92(77.3)	27(22.7)	10.37	6.40
Both care-giver & -receiver	216(90.8)	22(9.2)	3.63	5.21

With regard to receiving care, while the observed mortality rates were very similar between care-recipients (5.7/100 pyo) and those not receiving any help with activities of daily living (5.5/100 pyo), after age-sex adjustment mortality rates were higher in

care-recipients (11.6/100 pyo) than in non-care-recipients (2.1/100 pyo). This pattern remained when care-receiving was disaggregated into physical care and financial support, but for receiving nursing care lower mortality was observed, perhaps due to small numbers. Combining giving- and receiving- care, both observed and adjusted mortality rates were highest in the exclusively care-recipients group and lowest in the exclusively care-giving group. Although the adjusted mortality rate in participants not giving or receiving care was higher than in exclusive care-givers, it was substantially lower than in exclusive care-recipients or in those giving and receiving care (Table 5-2).

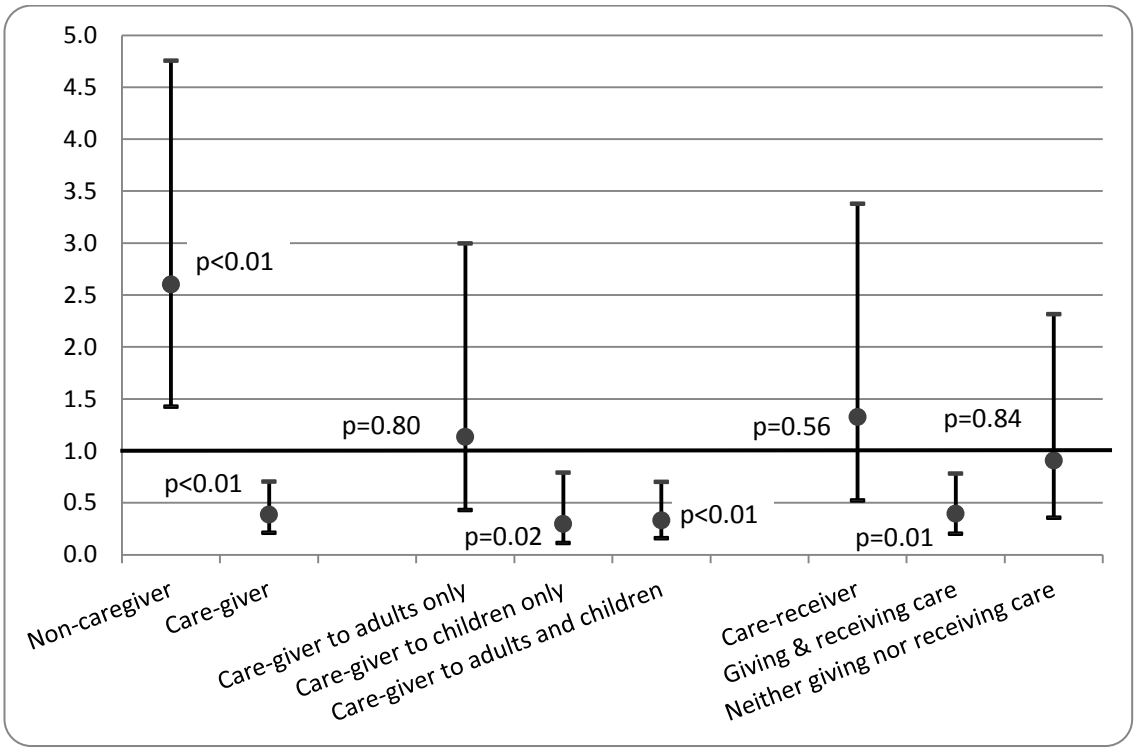


Figure 5-1: Adjusted mortality hazard ratios by care-giving or receiving status

Note: Figure 5-1 shows the adjusted mortality hazards by care-giving or -receiving status. Each measure is a binary (Yes/No) variable with 'No' as the referent category. All models are adjusted for age, gender, marital status, household headship, education level, government grant receipt and HIV status

Figure 5-1 presents the hazards of dying over three years of follow up by baseline care-giving or care-receiving status adjusted for socio-demographic factors – age, sex, marital status, household headship, education level, government grant receipt and HIV status. Relative to care-givers, older people who were not giving care to adults or children had an over two-fold increased risk of mortality (aHR 2.6, 95% CI 1.4-4.8). Whereas care-giving was associated with lower mortality risks (aHR 0.4, 95% CI 0.2-0.7)

in this group of older people, care-givers to adults only had non-statistically significant elevated hazards of dying (aHR 1.1, 95% CI 0.4 – 3.0). Relative to non-care-givers, care-givers to children only (aHR 0.3, 95% CI 0.1-0.8) or to both adults and children (aHR 0.3, 95% CI 0.2-0.7) had significantly reduced adjusted hazards of dying. There was no conclusive evidence found of care-receivers having higher mortality hazards than non-care-receivers (aHR 0.8, 95% CI 0.4-1.9), allowing for socio-demographic factors. But compared to care-receivers only, older people simultaneously giving and receiving care had statistically significantly lower mortality risk (aHR 0.2, 95% CI 0.2-0.8).

5.5.4 Mortality levels by self-reported health and depression status

Table 5-3 shows observed and age-sex adjusted mortality after three-years follow-up by self-reported health and depression status observed at baseline in 2010.

Table 5-3: Mortality rates per 100 person-years by reported health status at baseline

	Alive n (%)	**Dead** n (%)	**Observed**	**Age-sex Adjusted**
Dichotomous SRH				
Good	175(90.7)	18(9.3)	3.75	4.27
Poor	189(82.5)	40(17.5)	7.29	9.48
Health last 2 weeks				
Good	86(89.6)	10(10.4)	4.14	2.37
Poor	278(85.3)	48(14.7)	6.1	11.37
Self-rated QoL				
Good	60(93.7)	4(6.3)	2.4	0.95
Poor	304(84.9)	54(15.1)	6.27	12.80
WHOQoL				
Good	143(91.1)	14(8.9)	3.6	3.32
Poor	221(83.4)	44(16.6)	6.88	10.51
WHODAS				
Good	151(91.0)	15(9.0)	3.58	3.55
Poor	213(83.2)	43(16.8)	7.05	10.27
Depression				
None	212(87.2)	31(12.8)	5.16	7.35
BDE	72(86.7)	11(13.3)	5.40	2.84
MDE	80(83.3)	16(16.7)	7.14	3.79
Any episode	152(84.9)	27(15.1)	6.31	6.64

* WHOQoL = World health organization Quality of Life index; WHODAS = World Health Organization Disability Assessment Score; SRH = Self-rated health; BDE = brief depressive episode, MDE = major depressive episode

In dichotomised SRH, the mortality rate was higher among participants who at baseline rated their health as poor, for both crude and age-sex adjusted rates. Similar patterns

were found for SRH in the last two weeks, self-rated quality of life, as well as the objectively measured WHO quality of life (WHOQoL) and functional disability (WHODAS). That is, mortality rates, particularly after age-sex adjustment, were substantially higher in older people with poor than with good health.

Crude mortality was lowest among participants who had not experienced any depressive episode in the preceding year and highest among those who had experienced a major depressive episode (Table 5-3). Among those who had experienced a depressive episode, mortality was higher in participants with a MDE than among those with a BDE. However, adjusting for age and sex, mortality was highest in older people who had not experienced any depressive episode, but stayed significantly higher in participants with a MDE compared to with a BDE (Table 5-3).

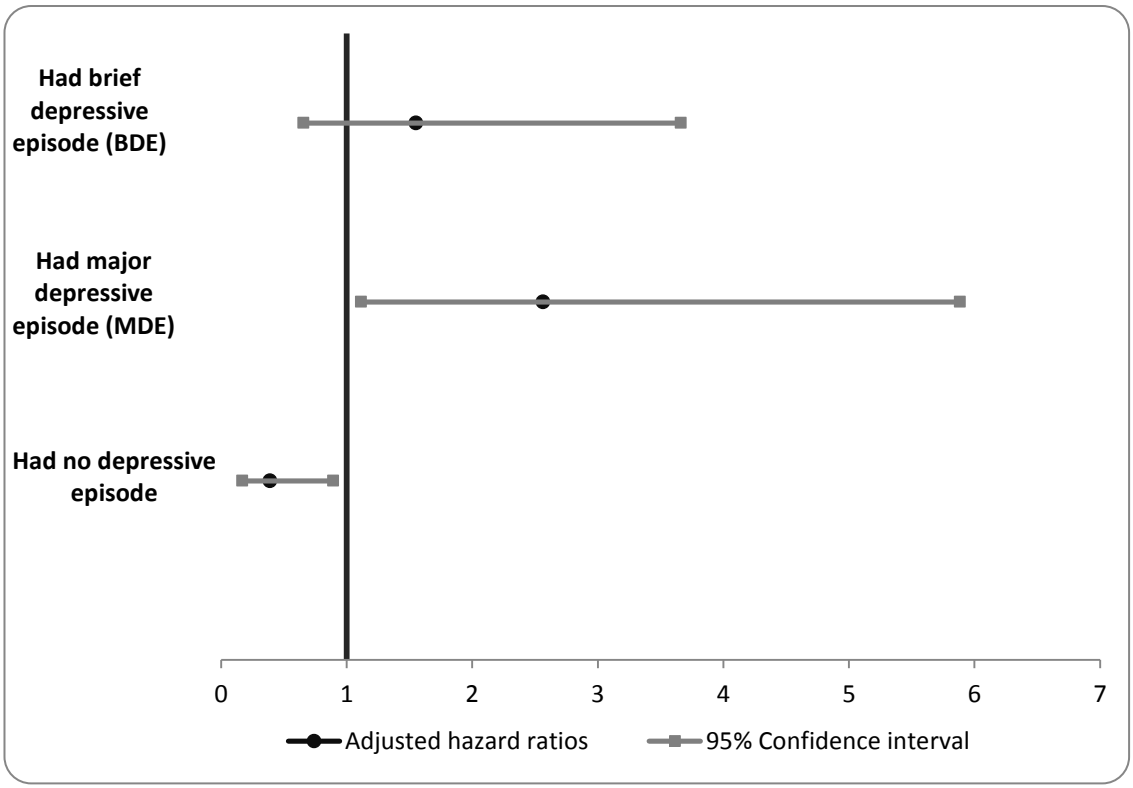


Figure 5-2: Adjusted mortality hazard ratios by depressive episode status

Note: Figure 5-2 shows the adjusted mortality hazards by depression status. The referent category for had BDE and MDE is 'Had no depressive episode', while for 'Had no depressive episode' it is 'had any depressive episode'. All models are adjusted for age, gender, marital status, household headship, education level, government grant receipt and HIV status

Findings from proportional hazards models shown in Figure 5-2 revealed that older people who had a MDE had over two-fold significantly increased mortality risks (aHR 2.6, 95% CI 1.1-5.9) relative to older people who did not experience any depressive episodes. Likewise, older people who had a BDE had a higher hazard of dying within the three years of follow-up (aHR 1.6, 95% CI 0.7-3.7), but this did not reach statistical significance.

5.5.5 Association of self-reported health status with mortality rates adjusted for socio-demographic factors

Table 5-4 shows the mortality hazards for being in poor (moderate, bad, very bad) health relative to good (very good, good) health at interview, in further multivariable analyses adjusted for HIV status, age, sex, marital status, education level, receipt of government grants and household headship. Model 1 presents findings for self-rated health and shows that older people who rated their health poor had nearly double the risk of mortality compared to those who rated their health as good. Likewise, older people rating their quality of life as poor were over three-fold more likely to die over the subsequent three year period.

Using validated WHO measures of functional disability and subjective well-being, older people with poorer functional ability and subjective well-being had a more than double the risk of mortality. The only measure of health status which did not show statistically significantly higher mortality hazard ratios was participants' self-rated health status in the two weeks prior to interview.

Table 5-4: Mortality hazard ratios by reported poor health status adjusted for socio-demographic factors

	Model 1: Self-rated health			**Model 2: S**elf-rated QoL			**Model 3:** Health last 2 weeks			**Model 4:** Functional ability			**Model 5:** Subjective wellbeing		
	aHR	**[95%**	**CI]**	**aHR**	**[95%**	**CI]**	**aHR**	**[95%**	**CI]**	**aHR**	**[95%**	**CI]**	**aHR**	**[95%**	**CI]**
Poor health[g]	1.96**	[1.09	3.52]	3.46**	[1.05	11.38]	1.95	[0.91	4.17]	2.10**	[1.08	4.08]	2.35**	[1.21	4.57]
HIV Status															
Positive on ART	2.66**	[1.04	6.83]	2.93**	[1.16	7.37]	2.53	[0.99	6.46]	2.59	[1.02	6.58]	3.04**	[1.19	7.74]
Positive ART naïve	1.81	[0.73	4.48]	1.91	[0.78	4.69]	1.79	[0.73	4.42]	1.83	[0.74	4.51]	2.01	[0.80	5.01]
Unknown	2.53**	[1.14	5.62]	2.42**	[1.09	5.36]	2.51**	[1.13	5.58]	2.46**	[1.11	5.45]	2.69**	[1.20	6.02]
Age Group															
60-69	1.52	[0.65	3.55]	1.74	[0.73	4.14]	1.56	[0.67	3.61]	1.41	[0.60	3.29]	1.57	[0.67	3.69]
70-79	1.77	[0.63	4.94]	2.23	[0.80	6.22]	1.92	[0.70	5.27]	1.71	[0.62	4.73]	2.17	[0.77	6.08]
80+	1.71	[0.51	5.75]	1.90	[0.57	6.30]	1.61	[0.48	5.36]	1.31	[0.39	4.44]	1.71	[0.52	5.65]
Gender (Female)	0.68	[0.36	1.27]	0.71	[0.38	1.34]	0.69	[0.37	1.30]	0.62	[0.33	1.19]	0.71	[0.38	1.33]
Grant receipt	1.33	[0.97	1.83]	1.29	[0.93	1.78]	1.31	[0.96	1.80]	1.32	[0.97	1.80]	1.33	[0.97	1.82]
Marital status															
Married	0.55	[0.28	1.07]	0.54	[0.28	1.08]	0.53	[0.27	1.04]	0.54	[0.28	1.06]	0.59	[0.30	1.18]
Previously married	0.49	[0.23	1.06]	0.47	[0.22	1.03]	0.49	[0.23	1.07]	0.53	[0.24	1.17]	0.43**	[0.20	0.94]
Educational level															
Primary	0.57	[0.31	1.06]	0.60	[0.32	1.12]	0.55	[0.29	1.02]	0.62	[0.33	1.15]	0.66	[0.35	1.24]
Secondary+	0.45	[0.18	1.11]	0.49	[0.20	1.20]	0.42	[0.17	1.03]	0.43	[0.18	1.07]	0.48	[0.20	1.20]
Household Head															
Spouse	0.66	[0.29	1.53]	0.68	[0.29	1.59]	0.68	[0.29	1.58]	0.68	[0.30	1.58]	0.63	[0.27	1.47]
Other	0.43**	[0.19	0.95]	0.42**	[0.19	0.95]	0.42**	[0.19	0.93]	0.44**	[0.20	0.99]	0.39**	[0.18	0.88]

[g] Hazards of being in bad/poor health relative to good health. QoL = Quality of life. ** p<0.05

aHR = adjusted hazard ratios, adjusted for HIV status, age, gender, marital status, education level, receipt of government grants and household headship.

5.6 Discussion

5.6.1 Comment on levels and patterns of mortality among older people

In a study area with widespread poverty, high unemployment and high HIV prevalence, older people play an important role in informal care giving, but as they grow older may also be in need of care. Given the severe impact of HIV on adult (15-49 years) mortality (Nyirenda, et al., 2007), this much needed care by older people may not be readily available. An investigation of informal care, the physical and mental health of older people, and how these characteristics relate to older people's survival is therefore important for the well-being of the entire population as it is likely to impact on person-years of care by and towards older people.

Over a three year follow-up period, there were 58 deaths in 1028 person years of observation. Nearly two-thirds of the total deaths were in women, consistent with the male:female ratio in the study and in the HIV treatment programme (Houlihan, et al., 2011). The median age at death was around 66 years in women (64 in men), and mortality rates increased with age. HIV/TB contributed about one half of mortality causes while the other half was due to a host of non-communicable diseases prevalent in older populations. As such, older people in the study area are clearly as in the rest of South Africa faced with a double burden of communicable and non-communicable mortality causes (Coovadia, Jewkes, Barron *et al.*, 2009; Mayosi, et al., 2009). This large contribution of HIV/TB to older people's mortality is disconcerting as it may delay the much needed response to non-communicable diseases associated with old-age as policy response and health spending is likely to remain focused towards infectious diseases (Lloyd-Sherlock, McKee, Ebrahim *et al.*, 2012b). Care-giving was associated with reduced mortality, whereas those receiving care had generally higher mortality levels than older people not receiving any care. This finding is supported by what was reported in Chapter Three (see Table 3-10, pp. 86) that care-givers to adults (aOR 0.20, 95% CI 0.12-0.33) or to children (aOR 0.43, 95% CI 0.26-0.70) compared to non-caregivers were statistically significantly less likely to be in poor health; whereas care-receivers had higher odds of poor physical health (aOR 1.39, 95% CI 0.76-2.55).

Similarly, results showing participants with poor compared to good self-reported health being associated with about three times higher likelihood of mortality are consistent with findings presented in Chapters Three and Four as they were more likely to be associated with poor physical functional health and to be receiving physical or nursing care. Although the number of deaths was highest in HIV-infected older people, mortality rates were highest in HIV unknown status participants followed by HIV-infected and HIV-negative participants. This again is supported by findings from Chapter Four, which showed HIV-infected older people to be associated with better physical functional ability ($p<0.001$), emotional well-being ($p=0.011$) and overall health state ($p<0.001$) than HIV-affected older people (see Table 4-3, pp. 122). HIV unknown participants were all under the category of HIV-affected in Chapter Four.

The high proportion of older people not utilising health facilities immediately prior to death (53%) is disconcerting, especially in light of the fact that about half of those who died did so at a health facility. Studies in HIV-infected people have shown that those aged 50+ tend to present late for HIV treatment, have a faster progression to AIDS and have a higher mortality risk than those aged under 50 years (Iwuji, et al., 2013; Metallidis, et al., 2013; Mutevedzi, et al., 2011). A combination of late presentation for treatment and assuming any signs or symptoms to be old-age related (Bodner, Bergman and Cohen-Fridel, 2012; Lapid and Rummans, 2003; Thornton, 2002; van den Heuvel, 2012) may have contributed to the high proportion not utilising health facilities prior to death. With close to half of all deaths in this cohort of older people due to TB or HIV and the other half due to a number of non-communicable conditions, older people in this population are faced with a double burden of communicable and non-communicable diseases, consistent with reports from elsewhere (Mayosi, et al., 2009; Smith and Mensah, 2003; Westaway, 2010a). In this severely HIV-affected population this is of great concern as HIV prevalence in older people is expected to keep rising for some time to come due to the successes of antiretroviral treatment (Bor, et al., 2013; Herbst, Mafojane and Newell, 2011). It remains to be seen whether over time the major causes of death will shift from TB/HIV to non-communicable diseases associated with old-age such as stroke, heart disease or diabetes.

5.6.2 Care-giving and mortality among older people

Findings of this analysis suggest a strong association between informal care and mortality, supported by earlier findings in Chapter Three of associations between care-giving or -receiving with the health and well-being of older people. The age-sex adjusted mortality level was higher in non-care-givers than care-givers irrespective of whether they were care-givers to adults or children, as care-givers to adults (aOR 0.20, 95% CI 0.12-0.33) or children (aOR 0.43, 95% CI 0.26-0.70) were less likely to be in poor health (see Table 3-10, pp. 86). A few other studies have also shown that care-givers have a lower mortality risk than non-caregivers (Fredman, Cauley, Hochberg *et al.*, 2010; O'Reilly, et al., 2008). However, with increasing intensity of care provision in terms of hours spent care-giving the mortality risk of care-givers also increases (O'Reilly, et al., 2008). In addition to intensity, a higher care-giving load is likely to increase the mortality risks of care-givers as was found in this analysis that older people caring for adults and children at the same time were three-times more likely to die than care-givers to adults or children only. Thus, for care-givers, findings here support the evidence of mortality differentials by increased load of care-giving. The high mortality among non-care-givers can be attributed to the well-established relationship between poor health and higher mortality risk (DeSalvo, et al., 2006; Idler and Benyamini, 1997; Jylhä, 2009). Non-care-giving was associated with poor self-reported health (Chapter Three). This poor health status in turn can be linked to most of them not being HIV-infected. It was established in previous findings (Chapter Four) that HIV-infected older people in the study area were in better physical health and well-being than their HIV-affected counterparts (Nyirenda, et al., 2012), and was argued that this differential in health status was highly likely related to the fact that those who are HIV-infected benefit from the amount of resources devoted to the HIV treatment and care programme, and utilise health facilities as part of their HIV care to the benefit of their overall health (Mutevedzi, Rodger, Kowal *et al.*, 2013; Negin, Nyirenda, Seeley *et al.*, 2013).

While the observed mortality rate was very similar between care-recipients (5.7/100 pyo) and those not receiving any help with activities of daily living (5.5/100 pyo), after age-sex adjustment it was substantially higher in care-recipients (11.6/100 pyo) than in

non-care-recipients (2.1/100 pyo). This was true for both physical care and receiving financial support, but not for receiving nursing care, possibly due to small numbers and limited statistical power. Of concern is the association between receiving financial support and high mortality rates in older people. Much of the financial support reported by participants in this study was from government cash transfers, which would mostly have been pensions as reported in Chapters Two and Three (see Figure 2-2, pp. 41 and Figure 3-1, pp. 70). Given the low employment levels in the study population, older people receiving cash transfers have become an important resource for care and support of young children and adults alike (Ardington, Case and Hosegood, 2009; Schatz, 2007). A high mortality rate in older people receiving an income is not good news for the general population in this highly deprived study area.

Although mortality risk was higher in care-receiving than non-care-receiving older people, the difference did not reach statistical significance, which could have been due to the fact that many care-receiving older people were also care-givers to someone else. This study shows that older people giving and receiving care at the same time had a lower mortality risk than those only receiving care. This is consistent with an earlier published finding (Nyirenda, et al., 2012) that showed care-givers to be in better physical health than non-caregivers and reported here in Chapter Three (see Table 3-10, pp. 86). Similar findings have also been shown in the UK (Fredman, et al., 2010). It is worth noting that the higher mortality rates in older people receiving physical care reported in the present analysis, may be indicative of increasing frailty (Finkelstein, 2003).

5.6.3 Self-reported health and mortality among older people

Older people rating their health status as poor rather than good had a statistically significantly higher mortality risk (2-3 times higher) over the subsequent three years, although this association did not hold for self-reported health in the two weeks before baseline report. An earlier study among adults 15-54 years from the same study area showed adults self-rating their health as poor at increased likelihood of mortality within three years of follow-up (Olgiati, Bärnighausen and Newell, 2012). These findings are largely in line with those from elsewhere showing a relationship between

poor self-reported health and subsequent increased mortality risk both in developed and developing countries (DeSalvo, et al., 2006; Frankenberg and Jones, 2004; Idler and Benyamini, 1997; Jylhä, 2009). Findings in this analysis make an important contribution to this discourse by showing the relationship holds even in older adults from a largely rural African population severely affected by HIV.

5.6.4 Depression and mortality among older people

Another area of older people's health covered in this analysis related to depression. The association between depression and higher mortality risk among older people has been well documented (Cuijpers and Smit, 2002; Schulz, Drayer and Rollman, 2002; Sun, et al., 2013). Data from an American cluster randomized clinical trial of older adults seeking care in primary health care settings (Gallo, Morales, Bogner *et al.*, 2013) found that older adults aged 60+ who had major depression were nearly two-times more likely to die than their counterparts with no depression (HR 1.90, 95% CI 1.57-2.31) in the standard of care arm of the study. A number of factors such as disability (Lopez, Mathers, Ezzati *et al.*, 2006; Murray and Lopez, 1997), health behaviours like smoking and physical inactivity (Freedland, Carney and Skala, 2005), and declines in cognitive function (Alexopoulos, Meyers, Young *et al.*, 2000; Cui, Lyness, Tu *et al.*, 2007) which may in turn affect adherence to medical treatment and self-care (Ciechanowski, Katon and Russo, 2000; Villes, Spire, Lewden *et al.*, 2007), have been suggested to explain this strong association between depression and higher mortality risk in older people.

The study reported here offered a unique opportunity to validate depression as a predictor of future mortality rates of older people in rural impoverished areas severely affected by HIV. Results showed a statistically significant higher mortality rate among older people who experienced a major depressive episode relative to those who only experienced a brief depressive episode, irrespective of HIV status. It was interesting, however, to find that adjusting for age and sex, mortality was significantly higher among participants reporting no depressive episode relative to those reporting a depressive episode (major or brief). Older people not reporting any depressive episode were less likely to be HIV-infected, this could partly explain their observed higher

mortality as findings reported in Chapter Four showed that participants who were only HIV-affected were more likely than participants who are HIV-infected to be in poor health. Suggesting the pathway from depression to mortality could be via poor health status rather than direct. As such, no clear pattern emerged from this study in the effect of depression on mortality among study participants adjusting for HIV status. This could have been as well confounded by the informal care circumstances, which appear to suggest for instance care-giving to be associated with good physical health but poor emotional well-being. Factors that could have contributed to the lack of a clear association between depression and mortality could also include the period of observation (3 years) being too short to observe the full effect of having a depressive episode on mortality, the sample size available to this study being small, use of a brief depression module (Akena, Joska, Obuku *et al.*, 2012), and underreporting of depressive episodes due to the stigma associated with depression (Barney, Griffiths, Jorm *et al.*, 2006; Collins, Patel, Joestl *et al.*, 2011) or recall bias. It should also be pointed out that most of the studies establishing a link between depression and mortality in older people have been conducted in health facility settings and/or in developed countries. Further research extending the temporal and spatial scope of this analysis with more specially designed depression modules than were available to this study may be required to fully understand the nuances of depression and its predictive power of future mortality in later life in such study settings.

In this study area severely affected by HIV (Zaidi, et al., 2013) and faced with a high burden of depression in adults (Rochat, et al., 2011) and older people (Nyirenda, et al., 2013a), interventions may be needed to mediate the potential effect of depression on future mortality in older people. As demonstrated in the randomized clinical trial from America, an intervention involving enhanced care for depression that includes psychotherapy, increasing anti-depressant dosages, and monitoring of symptoms, side-effects and treatment adherence, was effective in reducing the impact of major depression on mortality by 24% (HR 0.76, 95% CI 0.57-1.00) in intervention relative to standard of care participants (Gallo, et al., 2013).

5.6.5 Some limitations of the study

A limitation of this study lies in the cross-sectional nature of the data, which hinders causal inferences. In addition, the sample size of the study was relatively small, which limited statistical power in some areas. The unavailability of health care utilisation and cause of death data for some deaths was another limitation. However, even if these data had been available, this would unlikely to have significantly changed what is reported here given the dominance of HIV and TB as major cause of mortality in this population.

Given that care-giving exerts physical demands on older people experiencing increasing frailty with age and has been associated with poor emotional well-being (Ice, Sadruddin, Vagedes *et al.*, 2012; Nyirenda, et al., 2013b), it was somewhat paradoxical that mortality in this study was lower in older people who were care-givers than in non-caregivers. This could partly be explained by a selection bias in that to be a care-giver one would have to be in reasonably good health. Only with longitudinal data would it be possible to disentangle this selection effect as demonstrated by Ice and others (2010) who showed that while care-giving was associated with good health cross-sectionally, over time adjusting for age, the health of care-givers declined significantly compared to non-care-givers.

All measures used here to describe the health and well-being of older people were based on self-reports at baseline visit and a three-year observation period in the wider surveillance. Likewise, depressive episodes were based on self-reporting of symptoms and not on a clinical diagnosis. Furthermore, a shortened version of the depression module was used and not the long comprehensive schedule for depression screening. Nonetheless, other than the probable bias that could have been introduced by recall or stigma (Barney, et al., 2006; Collins, et al., 2011), the results presented here are likely to be reliable as it has been established that both the brief and the longer depression screening instruments produce accurate depression diagnostics even in high HIV developing country settings (Akena, et al., 2012). As for self-reported health status, that too has been well documented to be a strong predictor of mortality in later life (DeSalvo, et al., 2006; Fayers and Sprangers, 2002; Idler and Benyamini, 1997; Jylhä,

2009; Wang, et al., 2008). Finally, the aim of this analysis was to establish a relationship between informal care, self-reported health and depression with mortality levels and patterns in older people within three years of baseline observation. The median period of observation was 2.7 (interquartile range 0.35) years. The period of observation may have been too short to fully observe the effect of the variables of interest on survival patterns. A longer duration of follow-up with potentially more events is likely to provide the necessary statistical power to further strengthen findings of this study.

This analysis shows that circumstances for older people around informal care, self-perceived health and mental well-being are associated with risk of subsequent mortality. The three factors considered here are interlinked – care-giving as reported in Chapter Three is related to poor emotional well-being (Ice, et al., 2012; Nyirenda, et al., 2013b; Pearlin, et al., 1990) and probable declines in physical health over time (Ice, et al., 2010); poor health in older people as reported in Chapter Four, in particular physical functional disability, in turn has been found to be positively related to depression (Greenglass, Fiksenbaum and Eaton, 2006); while prolonged stress which could be occasioned by older people providing or receiving care (Ice, Zidron and Juma, 2008), is associated with increased risk for poor physical health including cardiovascular diseases (Sapolsky, 1996; Sapolsky, 1999), depression and ultimately mortality (Antelman, Kaaya, Wei *et al.*, 2007; Snowden, Steinman and Frederick, 2008). A multi-faceted approach to improving the health and well-being of older people is therefore an important and urgent need.

5.7 Conclusions

This analysis has highlighted mortality patterns in older people who were HIV-infected or –affected. Adjusting for socio-demographic factors, the risk of dying was higher amongst older people who rated their health poor, were non-care-givers, were care-receivers or had experienced a major depressive episode in the 12 months preceding the interview. These findings highlight the complex nature of the relationship between care-giving, self-reported health status, mental well-being and mortality in this

population, compounded by a severe HIV epidemic. There is scope for further research to elucidate the complex relationship between care-giving, health status, and mortality. Policy and programme intervention are needed to improve the health and well-being of older care-givers, especially those in need or indeed already receiving care as well as those with depressive symptoms as they are particularly at greater mortality risk.

Chapter 6: **Concluding remarks**

6.1 Chapter outline

This chapter begins with a brief introduction in section 6.2. Then Table 6.1 presents the main objectives of this research, analyses carried out towards each objective, the chapters in which results of each analysis are presented, and a key message from each analysis. Section 6.3 is a synopsis of the main findings in each chapter, and a synthesis regarding informal care, health and survival of older people is given in section 6.4. Policy implications of the findings in this study are in section 6.5. Finally, section 6.6 gives potential future research that could result from this work.

6.2 Introduction

The HIV epidemic has had a severe impact on the population of sub-Saharan Africa, which accounted for around 69% of the global population aged 15+ living with HIV in 2012 (UNAIDS, 2013). Older people, in particular, are vulnerable as their physical and mental health may be affected directly if they are HIV infected or indirectly if they have to take on the responsibility of caring for ailing HIV infected adult offspring and their orphaned grandchildren.

However, the challenges facing older people directly and indirectly affected by HIV are not well understood owing to the lack of studies that have systematically measured their health and well-being and the association with informal care dynamics, which are central to the lives of older people in rural Africa. In recognition of this knowledge gap, the aim of this PhD has been to describe and examine living arrangements, informal care provision or receipt, physical health, emotional well-being and survival of older people in HIV severely affected rural South Africa.

This thesis is built around four separate but related papers with an introductory chapter at the beginning; whereas, this final chapter of the thesis is a synthesis of the key findings, policy implications and recommendations for potential future research emanating from the four papers.

Table 6-1: Overall study objectives, design, and key message from each chapter

Objectives	Analyses carried out	Data sources	Where results are given	Key message from each chapter
1) Analyse household living arrangements and informal care among older people in rural South Africa	Descriptive statistics, ordinary and multinomial logistic regressions	Africa Centre Longitudinal surveillance and cross sectional survey data	Chapter Two (for financial/materiel support) and Chapter Three (focusing on physical and emotional care)	➢ Older people mostly live in multi-generational households and informal care (material, physical or emotional care) predominantly flows from older to younger people. ➢ Care-givers are associated with good physical health but poorer emotional well-being
2) Describe the health and well-being of older people in rural South Africa by HIV status	Descriptive statistics and ordinal logistic regressions	Cross-sectional survey data (WOPS)	Chapter Four	➢ Older people who are HIV-infected are statistically significantly associated with better physical functional health, quality of life and overall health state than HIV-affected older people
3) Examine association of self-reported physical health, emotional well-being and informal care with older people's mortality	Descriptive statistics, logistic regressions and survival analysis	Longitudinal surveillance and cross sectional survey data	Chapter Five	➢ Being a non-caregiver, having a depressive episode and poor self-rated health at baseline are associated with increased subsequent mortality after three years of follow-up ➢ Thus care-giving, depression symptoms and SRH are good predictors of mortality risk in older people.

6.3 Summary of key findings from each chapter

6.3.1 Living arrangements, income and transfers by and towards older people

Chapter two provided a broad overview of the characteristics of older people in the surveillance area in rural South Africa over the period 2005-2010, noting that at 6% the proportion of older people aged 60+[9] in this area is nearly twice as high as in many sub-Saharan African countries. Also explored was having an income from employment or government cash transfers and household living arrangements in old age and the implications of these for intergenerational support[10]. Although the study area is overwhelmingly rural, daily living is largely built around a cash economy with almost all households reliant on wages from formal employment and/or government cash transfers. As argued by others, this income is highly likely shared in some way within the household (Booysen, 2004; Hosegood and Timæus, 2005a; Kimuna and Makiwane, 2007; Sagner and Mtati, 1999; Van der Geest, 2002), and has an impact on mobility and household living arrangements (Ardington, Case and Hosegood, 2009; Møller and Ferreira, 2003; Neves, et al., 2009). About 90% of older people aged 60+ years resident in the study area had an income source - the bulk from government grants.

The results from the analyses presented in Chapter Two suggest interesting trends in employment and access to grants between younger and older people. Over the years 2005-2010 the proportion of employed persons in the household (both young and old) declined, but the proportion of persons with an income increased. This could be explained by a steady increase in the proportion of older people, especially older men, receiving a government grant, mostly pensions. Interestingly, there was nearly a 50% drop in the proportion of older people aged 60+ who reported to be the sole income earner in their household; explained by an increase in other, younger, household members equally increasingly accessing grants in particular child support grants. Together, these findings suggest the possibility of transfers between older and younger people in rural South Africa more likely to be reciprocal rather than upward (from

[9] Older people throughout this study are defined as aged 50 years and above, except in Chapter two where age 60 was used.

[10] The caveat made in chapter two is repeated here: the nuances of how this income may or may not be shared in the household was beyond the scope of this analysis, the focus here was merely on the potential for exchanges of support given who in the household has an income.

younger to older persons), given the predominantly multigenerational household living arrangements in the study area. As Figure 2-3 (page 43) shows, while both downward and upward support have declined, the proportion of older people living in households with potential reciprocal transfers between younger and older people increased to about 78% in 2010 from 68% in 2005. Results in Chapter Two further showed that over the period 2005-2010 household living arrangements were largely stable, but where changes into skip-generation or multi-generation households did occur, intergenerational exchanges of support were significantly more like to change into downward or reciprocal support adjusting for age, education, marital status, place of residency and household socio-economic status of older people. Findings in Chapter Two are consistent with results from other studies showing older people are more likely to provide financial support to younger people than receive from the younger generation (Aboderin, 2004; Gierveld, Dykstra and Schenk, 2012; Grundy, 2005; Kreager and Schroder-Butterfill, 2008; Maitra and Ray, 2006). Within the context of solidarity theories (Bengtson, 1975; Bengtson, Elder and Putney, 2005; Lowenstein, 1999), which suggest older people do provide for their adult children or grandchildren even at great cost to themselves (Kreager and Schroder-Butterfill, 2008; Sagner and Mtati, 1999; Van der Geest, 2002), findings here would suggest that rather than disparaging unemployed younger people living with these older people with an income, some assistance in the form of an unemployment grant may be necessary to help them make a contribution to household income.

6.3.2 Informal care and the health and well-being of older people

In Chapter Three overall informal care and support by or for older people was examined, and the association of informal care circumstances with the physical health and emotional well-being of older people assessed. A version of the paper in Chapter Three was published earlier (Nyirenda, et al., 2013b). Care-giving and -receipt are both commonplace in later life in rural South Africa. As shown in the published paper (Nyirenda, et al., 2013b) of Chapter Three over 60% of a sample of 442 older people representative of the study setting, were shown to be care-givers to at least one adult

or child, and over 80% reported to be receiving some care and support from someone else (own children, grandchildren and spouses were the overwhelming sources of this care). Reasons given by older people for caring for adults and children included, but were not limited to, ill-health, high adult unemployment levels, care for children left behind by labour migrants, and children left orphaned due to death of adult offspring, findings that are consistent with previous research (Ardington, Case and Hosegood, 2009; Hosegood, Benzler and Solarsh, 2006; Nyirenda and Newell, 2010; Ssengonzi, 2007). Women in particular were found to be not only more likely to be care-givers, but also to be caring for a greater number of people than older men, suggestive of a heavier load on older women of any potential care-giving burden.

Care-giving in later life was associated with good self-reported physical health but poor(er) emotional well-being, whereas care-receiving was generally associated with both poor physical and emotional health. However, care-giving appeared to provide some benefit for older people providing and receiving care. Kim et. al (2000) also found that older people simultaneously giving and receiving care had a very high self-reported quality of life and urged policy makers to explore this potential benefit of giving and receiving care. Given that care-giving has financial implication for older people (Ardington, et al., 2010), financial strain was assumed to be a contributory factor to the emotional ill-health linked with care-giving. This was corroborated by many older care-givers reporting that their financial situation had deteriorated, and that nearly half of the adults being cared for had been contributing to the household income prior to becoming ill. As presented in Chapters Two and Three, for the majority of older people the old-age government grant was the major source of household income. Other researchers have also shown the benefits of this grant for both the physical well-being as well as mental health of recipients (Case and Menendez, 2007; Plagerson, et al., 2010). Despite the finding that around 90% of the sampled older persons aged 60+ were in receipt of some government grant in 2010 (Figure 2-2), it was noted in Chapter Three that the care-giving role which older people increasingly take up and its concomitant challenges could lead to increased physical, financial and emotional stress (Agyarko, et al., 2002; Schatz, 2007) and ultimately ill-health and mortality of older people (Schatz and Gilbert, 2012).

6.3.3 Health, emotional well-being and survival of older people

Chapters Four and Five then focused on the health, well-being and survival of older people. In Chapter Four results were presented of a detailed investigation of the physical health and emotional well-being of older people, stratified by whether they were HIV-infected or HIV-affected (through an HIV-infected or HIV-related death of adult child). Although older people are usually assumed to have physical or mental deterioration and ill-health (Bodner, Bergman and Cohen-Fridel, 2012; Sijuwade, 2009; van den Heuvel, 2012), participants of the studies presented in this thesis reported unexpectedly good health. For example, on a scale of 0-100, with 100 being best health, the median physical functional ability score was 78 for HIV-infected and 69 for HIV-affected older persons (Table 4-3). Another unexpected finding from Chapter Four was that HIV-infected participants were more likely to report better physical functional ability, quality of life and overall health than HIV-affected participants. The potential positive effect of the HIV treatment and care programme on these findings has been suggested to be the likely reason for this finding (Negin, et al., 2013). This is further supported by earlier findings by among others Louwagie et. al. (2007), who found people on antiretroviral treatment (ART) on average had a higher health-related quality of life than those waiting for ART. Also worth recapping from Chapter Four is that among both HIV-infected and HIV-affected older people, women reported poorer health than men, again consistent with findings from elsewhere (Jitapunkul, et al., 2003; Kowal, et al., 2010; Wang, et al., 2009; WHO, 2001; Xavier Gomez-Olive, et al., 2010; Zimmer, et al., 2004). This sex disparity in old-age health is attributable to several biological, medical, social and individual factors (Hirve, et al., 2010). The societal norms and institutionalisation fuelling this disparity are said to occur over a life course around ‘paid work or unpaid family work’ (Moen and Chermack, 2005).

Taking this forward then, Chapter Five investigated the association of informal care, self-reported health and depression with mortality levels and patterns of older people over three years of follow-up. Nearly half of the deaths in the older people in the study were due to HIV or TB and the other half to a number of non-communicable diseases, indicating the double burden of communicable and non-communicable diseases

among older people in South Africa, in line with findings from other studies (Mayosi, et al., 2009; Westaway, 2010a). Further consistent with others (McFadden, Luben, Bingham *et al.*, 2009; Olgiati, Bärnighausen and Newell, 2012; Singh-Manoux, et al., 2007), mortality was observed to be two to three times higher among older people who had self-reported their health status as poor at baseline. The observed differentials in health status by age, sex, HIV status, and care-giving were maintained in survival patterns: mortality levels increased with age, were higher among older men than women and in HIV-affected than HIV-infected older people. Chapter Five further revealed a strong relationship between informal care reported at baseline and mortality after three years of follow-up. Care-givers were less likely to die than non-care-givers in the three years after the baseline interview. This is supported by findings from other studies showing care-givers to have lower mortality risks than non-caregivers (Fredman, et al., 2010; O'Reilly, et al., 2008), although an increased intensity of care-giving may actually result in increased mortality hazards among care-givers (O'Reilly, et al., 2008). On the other hand, older people in this rural setting of South Africa who were receiving care were at increased mortality risk. Although findings in this chapter suggested a rather complex relationship between depression and mortality, it was evident that participants who had experienced a major depressive episode were at increased relative mortality risk compared to those with a brief depressive episode or none. Findings from analyses in Chapters Four and Five showed that living arrangements of older people which are likely to influence informal care giving or receiving, their physical and emotional well-being including having a depressive episode, can predict older people's relative risk for mortality in at least the subsequent three years. Thus a multi-faceted approach would be needed to improve the health and well-being of older people.

6.4 Synthesis of the situation for older people regarding informal care, health and survival in rural South Africa

This thesis makes an important contribution to the limited knowledge of the situation faced by older people regarding informal care, health status and mortality in a rural South African area severely affected by HIV, by documenting how income received or

earned by older persons is crucial for maintaining household living arrangements, and the high level of informal care by and for older persons. These factors were then shown to be associated with self-reported health, well-being and survival of both HIV-infected or -affected older persons.

The research findings presented in this PhD thesis add to an emerging body of evidence suggesting rather surprising benefits of HIV treatment for the health and well-being of HIV-infected older people relative to their uninfected counterparts (Louwagie, et al., 2007; Mutevedzi, et al., 2013; Negin, et al., 2013; Nyirenda, et al., 2012). However, there remains an urgent need for public health policy response to support older people and scope for further research to elucidate in greater detail the complex relationships between informal care, health status, depression and mortality in older people compounded by a severe HIV epidemic and widespread ART coverage.

6.5 Policy implications

6.5.1 Support to multi-generational households

Regarding household living arrangements, Chapter Two showed that neither living only with 'children-only' nor 'adults-only' were ideal for older people as such arrangements only increase the probability for older persons to be the main source of support for the younger generation. Transition into a multigenerational household increases the likelihood for older people to be supported by the younger generation or for reciprocal transfers. This was attributed to the potential increase in the number of contributors to household income that multigenerational households offer. For unemployed adults perhaps some form of unemployment benefit to them to enable them make some contribution to household income and well-being should be considered. In addition, given that institutional care facilities are non-existent and not normative in this society, there is a need to encourage community leaders, religious organisations and neighbours to play a greater role in the care and support for older persons, particularly those highly vulnerable due to lack of adult children or grandchildren to support them.

6.5.2 Changes to age-eligibility for pension grants or a care-givers grant

Data presented in Chapter Two showed how the proportion of older people aged 60+ with an income in the household substantially increased over the period 2005-2010. Noted in particular was the increase among older men attributed to legislative changes regarding age eligibility for old-age grants (SASSA, 2013). Whereas it may be easier to prescribe a policy recommendation for considering further legislative changes to age-eligibility for the old-age grant from currently 60 to perhaps 50 years as a large proportion of older people reported to be care-givers would have assumed care-giving responsibilities well before age 60 years, this is highly unsustainable. Such a policy change plus the rapid population ageing trend would no doubt pose serious balancing act challenges for policy makers already increasingly needing to put more people on the cash transfer programme and keeping the system sustainable; in addition to meeting other demands on government's fiscal programme. Alternatively government could consider introducing a care-givers grant to cater for care-recipients who may be ineligible for child-support, foster or disability grants.

For impoverished rural areas, this would not only improve the health and well-being of older people, but also that of the general population. This is so given the wealth-health nexus (Bloom and Canning, 2008; Deaton, 2003; Michaud and van Soest, 2008; Smith, 2004), in which low economic status is associated with poor health and high economic status with good health. Using the case of pension income in South Africa, Case, (2004) showed that pension income for older people was protective for the health of all household members, enhanced living conditions and reduced stress for day-to-day life among all adult household members. Thus, for a national government faced with limited resources, if the introduction of a care-givers grant or lowering the age-eligibility for the old-age pension from 60 to 50 years is not feasible, then increases in the old-age grant at current eligibility criteria even by relatively small margins such as R50 per month should be considered to enhance the health and wellbeing of the population in rural South Africa. While the state may consider such increases in pension grants too high in the immediate term, there are considerable potential long term benefits to such a policy change. Available evidence supports this recommendation in that even relatively small cash transfer payments to older people,

who usually share their pensions with other household members, are effective in reducing the prevalence and depth of household poverty (Lloyd-Sherlock, Barrientos, Moller *et al.*, 2012a; Lloyd-Sherlock, Minicuci, Beard *et al.*, 2012b).

6.5.3 A cross-cutting socio-psycho-economic response to support care-giving older people

Policy makers should take note of the need to improve older people's socio-economic circumstances, reduce financial hardships and provide some social support to redress the strong association observed in this PhD research between poor emotional well-being and care-giving among older people. A pilot study in the Eastern Cape province of South Africa has already demonstrated the benefits of a community-based health education intervention in helping care-givers cope with their HIV-related care-giving responsibilities (Boon, Ruiter, James *et al.*, 2009). At national level, the Department of Health (DOH) is currently piloting the National Health Insurance (NHI) plan in 11 of the 52 districts in the country (DOH, 2012; DOH, 2013). The primary objective of the NHI, to be implemented over a 14-year period, is to provide appropriate, efficient and quality health care to all South Africans, which is intended to be free at the point of care (DOH, 2011). One strategy under the NHI for providing access to health services for all will involve a re-engineering of the primary health care system. Under this strategy an outreach team comprised of six community health workers (CHWs) led by a nurse will be assigned a ward covering about 7660 individuals or 1620 households (Africa Health Placements, 2014). The task of this team will include health promotion and prevention, screening and referrals for further health care, social mobilisation and helping to bridge the gap between the community and health services. While the NHI sets out plans that are great in principle, it faces enormous implementation challenges (Matsotso and Fryatt, 2013; Pillay and Barron, 2012). The initiative is further focused on maternal and child health and reducing the burden of HIV and TB, with little mention of geriatric health care. An additional potential intervention worth exploring could involve routine community-based psychosocial support and mental health screening targeted at older people especially care-givers. Such an intervention has added benefits of most likely increasing uptake within the primary health care system of currently available mental health services (Petersen, Baillie and Bhana, 2012; Petersen, Bhana, Campbell-Hall *et al.*, 2009). Researchers and policy makers should

explore interventions that cut across socio-economic and emotional well-being levels as there is both an economic and psychological stressor pathway through which care-giving could lead to ill-health (Ice, et al., 2010; Pearlin, et al., 1990).

6.5.4 Health care system changes to address older people's health challenges

The health care system in South Africa needs to urgently start responding to the increasingly ageing population as presently older people are already faced with a double burden of communicable and non-communicable diseases. Although this double burden has been acknowledged (Mayosi, et al., 2009), there is currently little policy and programme intervention as exemplified by the limited coverage of geriatrics and gerontological health care in the proposed National Health Insurance plan (DOH, 2011). The past few decades have seen considerable resources with regard to human capital, infrastructure and interventions devoted to managing communicable diseases in particular HIV and TB. In contrast, relatively very little has as yet been devoted to the management of chronic non-communicable conditions like hypertension, stroke, diabetes, cancers and cardiovascular diseases despite these conditions being highly prevalent (Bradshaw, Norman, Pieterse *et al.*, 2007; Coovadia, et al., 2009; Westaway, 2010b). As a consequence, older people who are not HIV-infected may be at increased risk of ill-health in that their chronic condition would be less likely to be diagnosed in time and managed well.

Responding to the challenge of women's generally poorer health in old-age requires a multifaceted life-course perspective solution as factors such as limited education, marginalisation in the labour market and greater household chores responsibilities that fuel ill-health in older women occur over a life course (Hirve, et al., 2010). This solution should revolve around changing societal norms and practices regarding paid and unpaid family work so that women are not overburdened with care-giving responsibilities and limited income earning capability at the same time.

Fast-tracking implementation of the re-engineering of the primary health care system which includes having a nurse-led team of community health workers under the NHI

(Africa Health Placements, 2014; DOH, 2011; Matsotso and Fryatt, 2013; Pillay and Barron, 2012) is highly recommended here given that a high proportion of older people who had died had not utilised a health facility immediately prior to death despite many eventually dying at a health facility. This may be explained by late presentation for treatment associated with older persons (Iwuji, et al., 2013; Metallidis, et al., 2013; Mutevedzi, et al., 2011), as well as stereotypical attitudes of consigning their ailments as 'normal' conditions of ageing (Bodner, Bergman and Cohen-Fridel, 2012; Thornton, 2002; van den Heuvel, 2012).

For a country faced with the triple burden of wide-spread poverty, high adult unemployment and a severe HIV pandemic, investing in the health of older people, who are vital to the informal care system, could have economic benefits. This was noted more than 50 years ago in a seminal paper by Mushkin, (1962) on health as an investment: "health services…are partly investment and partly consumption" and that 'when an individual is in good health they can more effectively fulfil their role as a producer'. In the context of older people in rural South Africa, who are not very active in the labour market but are vital for informal care, good health enables them to be more effective in care-giving. For example, Bor et. al. (2012) showed that HIV-infected adults experienced a considerable decline in employment before ART initiation, but after a few years on HIV treatment and improvement in their health their employment levels rebounded. At the time when these adults were in ill-health and dropped out of employment, they would likely have relied on older people for physical, material and emotional care. This informal care is usually not quantified in economic terms nor its value appreciated in the economic wellbeing of society. In developed countries where such informal care is not normative, persons in need of care rely on expensive state-funded institutional care facilities. Thus policy makers need to appreciate the wider economic benefits of investments in the health care system as recommended in this section; people in poor health are an economic burden to society.

6.6 Potential directions for future research

6.6.1 Expanding on current themes

A number of research themes in this thesis could be developed further in future research. A synopsis of some of these themes is presented in this sub-section. The primary focus of this study was on older people providing care to adults (18-49 years) or children (under 18 years) or receiving care from the same adults or children. Other than a brief mention of potential peer-to-peer transfers in Chapter Two, peer-to-peer informal care-giving or -receiving were not examined in detail. Studies from developed countries suggest older people, mostly spouses, providing care to their peers are more likely to have multiple limitations in activities of daily living or suffer mental ill-mental (Braun, Mikulincer, Rydall *et al.*, 2007; Byrne, Orange and Ward-Griffin, 2011; Ice, et al., 2010). As populations continue to age, peer-to-peer care and support is likely to become an important part of older people. Therefore a thorough understanding of the financial situation, care dynamics and the health and well-being of older care-givers to their peers in rural Africa would benefit from work extending findings of this thesis.

A number of the major findings of this thesis would benefit from analysis of the data from a second wave of the Well-being of Older People Study (WOPS) that contacted again in 2013 the same group of older people seen in 2010, with matched replacements for attrition. Data collection of WOPS wave two finished in late September 2013 and these data will soon be available for analysis. It will be interesting to use these data to confirm whether the relationships between informal care dynamics and the health and well-being of older people described in Chapter Three have remained fairly robust to change or whether the associations over time have changed. Some questions to be answered using these data include: i) are participants reported to be care-givers in 2010 relative to non-care-givers still likely to be in better physical health in 2013 or has their physical health deteriorated over time?; ii) are care-givers in 2010 associated with poor emotional well-being relative to non-care-givers still associated with poor emotional well-being in 2013 or has their emotional well-being improved over time?; and iii) does the health and well-being of older people in receipt of care improve over time? These data will be useful for follow-up

investigations of the observed relationship between informal care and older people's health and well-being described in Chapter Three, as well as to examine time-varying co-variants such as socio-economic conditions and living arrangements as determinants of the health and well-being of older people. It will be interesting to investigate whether findings reported in this thesis are period or cohort effects. Further work will seek to corroborate studies by others such as the study by Chepngeno-Langat and Evandrou (2013), which used panel data of a cohort of older people aged 50+ in Nairobi slums, Kenya, and found that while there was support of the adaptation model in that there was an improvement in health after three years of follow-up, care-givers were nonetheless still more likely to report ill-health than non-care-givers.

The published paper in Chapter Four (Nyirenda, et al., 2012) is among the first to report that HIV-infected older persons, most of whom were on ART, are in better health than their HIV uninfected peers, suggestive of potential benefits of their engagement with the HIV treatment and care programme (Louwagie, et al., 2007; Mutevedzi, et al., 2013; Negin, et al., 2013). This finding not only necessitates further research especially using population-based data, but will also benefit from data from the recently completed second wave of WOPS. Data from this second wave will be used for a trends-over-time comparative analysis to corroborate whether with longer time since infection and/or on ART, HIV-infected older people continue to be more likely to report better health and well-being than their HIV-affected peers. There is further a need to monitor and evaluate the impact of the primary health care re-engineering plan with its community-based health teams on the health and well-being of older people more generally but especially older people not in regular contact with the health care services.

Another finding of this study which deserves further monitoring and research, including extension of its spatial and temporal scope, includes mortality patterns and trends in older people in light of the increasing numbers of older people ageing with HIV and increased ART access. Future work will seek to quantify the extent to which major causes of death will shift from communicable (mostly TB and HIV) to old-age

related non-communicable diseases such as stroke, heart disease or diabetes. Documenting how the current double burden of disease in older people pans out with time deserves to be pursued in future research.

6.6.2 An in-depth look at the themes using qualitative (or mixed) methods

This thesis is based largely on cross-sectional and longitudinal population-based data using quantitative methods. Data on remittances, income and details about sharing of financial resources are not available in the Africa Centre's surveillance system. Hence, a detailed investigation about how much income is earned and how it is shared among household members was beyond the scope of this analysis. Such a type of investigation is well suited to a qualitative type of analysis. There is need for example for qualitative data to tease out in more details the nuances of how incomes from government grants and other sources are shared in the household. Research capable of probing in more detail what it is about care-giving that is likely to account for poor emotional well-being, given that care and support between older and younger persons is a well-established tradition in rural Africa, would be highly valuable. Further qualitative or mixed methods analyses would undoubtedly add to a better understanding of the situation of older people regarding informal care, health status and survival.

6.6.3 Exploring new frontiers of research

Given that exchanges of care and support between older and younger persons is expected and even obligated in many societies (Aboderin, 2005; Antonucci, et al., 2011; Diwan, Lee and Sen, 2011; Funk, 2012; Sagner and Mtati, 1999; Van der Geest, 2002), and given results from this thesis that a high proportion of older people are care-givers and that financial resources on balance of probabilities flow more downwards than upwards, ill-health or death of older persons is likely to result in some loss of potential sources of care and support. I would like to explore in future new frontiers of research what poor health or death of an older person implies in terms of potential life-years of care lost akin to disability-adjusted life years (DALYs) in general morbidity and mortality studies (Fox-Rushby and Hanson, 2001; Larson, 2013). Other concepts to be potentially explored in future are care-adjusted life years (CALY) to be

modelled on quality-adjusted life years (QALYs) as a measure of the quality and quantity of life lived with care-giving burden. Such analyses are presently lacking in established demographic literature.

This thesis makes no claim of generalizability of its findings to all rural Africa, nor suggests that these are invariant 'models' of causality between living arrangements, informal care, health status and survival among older people. Instead this thesis provides some critical body of evidence towards a fuller understanding of the health and well-being of older people in a specific type of setting, that is, a rural African population severely impacted by HIV and widespread ART availability; to such settings findings reported in this thesis would be applicable.

List of References

Aboderin, I. 2004. Decline in material family support for older people in Urban Ghana, Africa: Understanding processes and causes of change. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, **59**(3), S128-S137.

Aboderin, I. 2005. Changing family relationships in developing countries. In Johnson, M.L., Bengston, V.L., Coleman, P.G. and Kirkwood, T.B.L. (eds), *Age and Ageing*. Cambridge University Press, Cambridge, 469-475.

Aboderin, I. 2007. Development and Ageing Policy in Sub-Saharan Africa: Approaches for Research and Advocacy. *Global Ageing*, **4**(3), 7-23.

Adjuik, M., Kanyomse, E., Kondayire, F., Wak, G. and Hodgson, A. 2010. Clustering of under-five mortality in the Navrongo HDSS in the Kassena-Nankana District of northern Ghana. *Global Health Action*, **3**(Supplt 1), 15-25.

Africa Health Placements. 2014. The reengineering of the primary healthcare in South Africa.http://www.ahp.org.za/news-detail/229/the-reengineering-of-primary-healthcare-in-south-africa [Accessed 05 March 2014]

Agyarko, R.d., Kalache, A. and Kowal, P. 2000. Older people, children and the HIV/AIDS Nexus. In *XIII International AIDS conference 9-14 July 2000*. Durban.

Agyarko, R.d., Madzingira, N., Mupedziswa, R., Mujuru, N., Kanyowa, L. and Matorofa, J. 2002. Impact of AIDS on older people in Africa: Zimbabwe case study. World Health Organization (WHO): Geneva.

Akena, D., Joska, J., Obuku, E.A., Amos, T., Musisi, S. and Stein, D.J. 2012. Comparing the accuracy of brief versus long depression screening instruments which have been validated in low and middle income countries: a systematic review. *BMC psychiatry*, **12**(1), 187.

Alexopoulos, G.S., Meyers, B.S., Young, R.C. and et al. 2000. EXecutive dysfunction and long-term outcomes of geriatric depression. *Archives of General Psychiatry*, **57**(3), 285-290.

Antelman, G., Kaaya, S., Wei, R., Mbwambo, J., Msamanga, G.I., Fawzi, W.W. and Fawzi, M.C. 2007. Depressive symptoms increase risk of HIV disease progression and mortality among women in Tanzania. *Journal of Acquired Immune Deficiency Syndrome*, **44**(4), 470-477.

Antonucci, T.C., Birdtt, K.S., Sherman, C.W. and Trinh, S. 2011. Stability and change in the intergenerational family: a convoy approach. *Ageing & Society*, **31**(07), 1084-1106.

Arber, S. and Cooper, H. 1999. Gender differences in health in later life: the new paradox? *Social Science & Medicine*, **48**(1), 61-76.

Ardington, C., Case, A. and Hosegood, V. 2009. Labor supply responses to large social transfers: Longitudinal evidence from South Africa. *American economic journal. Applied economics*, **1**(1), 22-48.

Ardington, C., Case, A., Islam, M., Lam, D., Leibbrandt, M., Menendez, A. and Olgiati, A. 2010. The impact of AIDS on intergenerational support in South Africa: Evidence from the Cape Area Panel Study. *Research on Aging*, **32**(1), 97-121.

Ardington, E. and Lund, F. 1995. Pensions and development: Social security as complementary to programmes of reconstruction and development 1. *Development Southern Africa*, **12**(4), 557-577.

Armstrong, B.G. and Sloan, M. 1989. Ordinal regression models for epidemiologic data. *American Journal of Epidemiology*, **129**(1), 191-204.

Atun, R.A., Gurol-Urganci, I. and McKee, M. 2009. Health systems and increased longevity in people with HIV and AIDS. *BMJ*, **338**, b2165.

Barney, L.J., Griffiths, K.M., Jorm, A.F. and Christensen, H. 2006. Stigma about depression and its impact on help-seeking intentions. *Australian and New Zealand Journal of Psychiatry*, **40**(1), 51-54.

Bärnighausen, T., Tanser, F. and Newell, M.L. 2009. Lack of a decline in HIV incidence in a rural community with high HIV prevalence in South Africa, 2003-2007. *AIDS Research and Human Retroviruses*, **25**(4), 405-9.

Barrientos, A. 2006 Ageing, poverty, and public policy in developing countries: new survey evidence In *FISS 13th International Research Seminar on Issues in Social Security 'Social Protection in an Ageing World'*. Sigtuna, Sweden.

Barrientos, A., Møller, V., Saboia, J., Lloyd-Sherlock, P. and Mase, J. 2013. 'Growing' social protection in developing countries: Lessons from Brazil and South Africa. *Development Southern Africa*, **30**(1), 54-68.

Bengtson, V.L. 1975. Generation and Family Effects in Value Socialization. *American Sociological Review*, **40**(3), 358-371.

Bengtson, V.L., Elder, G.H. and Putney, N.M. 2005. The lifecourse perspective on ageing: linked lives, timing and history. In Johnson, M.L., Bengston, V.L., Coleman, P.G. and Kirkwood, T.B.L. (eds), *Age and Ageing*. Cambridge University Press, Cambridge, 493-501.

Bengtsson, N. 2012. The Marginal Propensity to Earn and Consume out of Unearned Income: Evidence Using an Unusually Large Cash Grant Reform. *Scandinavian Journal of Economics*, **114**(4), 1393-1413.

Benitha, R. and Tikly, M. 2007. Functional disability and health-related quality of life in South Africans with rheumatoid arthritis and systemic lupus erythematosus. *Clinical Rheumatology*, **26**(1), 24-29.

Berthoud, R., Blekesaune, M. and Hancock, R. 2006. Are 'poor' pensioners 'deprived'? Department for Work and Pensions. http://sticerd.lse.ac.uk/seminarpapers/wpa01112006.pdf

Blacker, J. 2004. The impact of AIDS on adult mortality: evidence from national and regional statistics. *AIDS*, **18**(Suppl 2), S19-26.

Blay, S.L., Andreoli, S.B., Fillenbaum, G.G. and Gastal, F.L. 2007. Depression morbidity in later life: prevalence and correlates in a developing country. *American Journal of Geriatric Psychiatry*, **15**(9), 790-9.

Bloom, D.E. and Canning, D. 2008. Population health and economic growth. The International Bank forReconstruction and Development / The World Bank

On behalf of the Commission on Growth and Development Bank, T.W., Washington, DC. http://siteresources.worldbank.org/EXTPREMNET/Resources/489960-1338997241035/Growth_Commission_Working_Paper_24_Population_Health_Economic_Growth.pdf

Bodner, E., Bergman, Y.S. and Cohen-Fridel, S. 2012. Different dimensions of ageist attitudes among men and women: a multigenerational perspective. *International Psychogeriatrics*, **24**(06), 895-901.

Boon, H., James, S., Ruiter, R.A.C., van den Borne, B., Williams, E. and Reddy, P. 2010. Explaining perceived ability among older people to provide care as a result of

HIV and AIDS in South Africa. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, **22**(4), 399-408.

Boon, H., Ruiter, R.A., James, S., Van Den Borne, B., Williams, E. and Reddy, P. 2009. The impact of a community-based pilot health education intervention for older people as caregivers of orphaned and sick children as a result of HIV and AIDS in South Africa. *Journal of Cross-Cultural Gerontology*, **24**(4), 373-89.

Booysen, F. 2004. Social grants as safety net for HIV/AIDS-affected households in South Africa. *SAHARA Journal: Journal of Social Aspects of HIV/AIDS Research Alliance* **1**(1), 45-56.

Booysen, F. and Van Der Berg, S. 2005. The role of social grants in mitigating the socio-economic impact of HIV/AIDS in two Free State communities. *South African Journal of Economics*, **73**(Supplt S1), 545-563.

Bor, J., Herbst, A.J., Newell, M.L. and Bärnighausen, T. 2013. Increases in adult life expectancy in rural South Africa: valuing the scale-up of HIV treatment. *Science*, **339**(6122), 961-5.

Bor, J., Tanser, F., Newell, M.L. and Bärnighausen, T. 2012. In a study of a population cohort in South Africa, HIV patients on antiretrovirals had nearly full recovery of employment. *Health Affairs (Millwood)*, **31**(7), 1459-69.

Bowling, A. 2005. Just one question: If one question works, why ask several? *Journal of Epidemiology and Community Health*, **59**(5), 342-5.

Bradshaw, D., Norman, R., Pieterse, D. and Levitt, N.S. 2007. Estimating the burden of disease attributable to diabetes in South Africa in 2000. *South African Medical Journal*, **97**(8 Pt 2), 700-6.

Braun, M., Mikulincer, M., Rydall, A., Walsh, A. and Rodin, G. 2007. Hidden Morbidity in Cancer: Spouse Caregivers. *Journal of Clinical Oncology*, **25**(30), 4829-4834.

Burns, J., Keswell, M. and Leibbrandt, M. 2005. Social assistance, gender and the aged in South Africa. *Feminist Economics*, **11**(2), 103-115.

Byass, P., Fottrell, E., Dao, L.H., Berhane, Y., Corrah, T., Kahn, K., Muhe, L. and Do, D.V. 2006. Refining a probabilistic model for interpreting verbal autopsy data. *Scandinavian Journal of Public Health*, **34**(1), 26-31.

Byrne, K., Orange, J.B. and Ward-Griffin, C. 2011. Care Transition Experiences of Spousal Caregivers: From a Geriatric Rehabilitation Unit to Home. *Qualitative Health Research*, **21**(10), 1371-1387.

Cantor, M.H. 1979. Neighbors and Friends: An Overlooked Resource in the Informal Support System. *Research on Aging*, **1**(4), 434-463.

Cantor, M.H. 1991. Family and Community: Changing Roles in an Aging Society. *The Gerontologist*, **31**(3), 337-346.

Cantor, M.H. and Hirshorn, B. 1989. Intergenerational transfers within the family context - motivating factors and their implicationas for caregiving. *Women & Health*, **14**(3-4), 39-51.

CASCADE. 2000. Time from HIV-1 seroconversion to AIDS and death before widespread use of highly-active antiretroviral therapy: a collaborative re-analysis. Collaborative Group on AIDS Incubation and HIV Survival including the CASCADE EU Concerted Action. Concerted Action on SeroConversion to AIDS and Death in Europe. *Lancet*, **355**(9210), 1131-7.

Case, A. (ed) 2004. *Does money protect health status? Evidence from South African pensions*. University of Chicago Press.

Case, A. and Ardington, C. 2006. The impact of parental death on school outcomes: longitudinal evidence from South Africa. *Demography*, **43**(3), 401-20.

Case, A. and Deaton, A. 1998. Large cash transfers to the elderly in South Africa. *Economic Journal*, **108**(450), 1330-1361.

Case, A. and Menendez, A. 2007. Does money empower the elderly? Evidence from the Agincourt demographic surveillance site, South Africa. *Scandinavian Journal of Public Health*, **35**(Supplt 69), 157-164.

Case, A. and Paxson, C. 2005. Sex differences in morbidity and mortality. *Demography*, **42**(2), 189-214.

Chan, S.W.C., Chiu, H.F.K., Chien, W.T., Goggins, W., Thompson, D. and Hong, B. 2009. Predictors of change in health-related quality of life among older people with depression: a longitudinal study. *International Psychogeriatrics*, **21**(6), 1171-1179.

Chandramohan, D., Shibuya, K., Setel, P., Cairncross, S., Lopez, A.D., Murray, C.J., Zaba, B., Snow, R.W. and Binka, F. 2008. Should data from demographic surveillance systems be made more widely available to researchers? *PLoS Medicine*, **5**(2), e57.

Chen, Y.J. and Chen, C.Y. 2012. Living Arrangement Preferences of Elderly People in Taiwan as Affected by Family Resources and Social Participation. *Journal of Family History*, **37**(4), 381-394.

Chepngeno-Langat, G. and Evandrou, M. 2013. Transitions in Caregiving and Health Dynamics of Caregivers for People With AIDS:: A Prospective Study of Caregivers in Nairobi Slums, Kenya. *Journal of Aging and Health*, **25**(4), 678-700.

Chepngeno-Langat, G., Madise, N., Evandrou, M. and Falkingham, J. 2011. Gender differentials on the health consequences of care-giving to people with AIDS-related illness among older informal carers in two slums in Nairobi, Kenya. *AIDS Care*, **23**(12), 1586-1594.

Christensen, K. 2008. Human biodemography: some challenges and possibilities for aging research. *Demographic Research*, **19**(43), 1575-1586.

Ciechanowski, P.S., Katon, W.J. and Russo, J.E. 2000. Depression and diabetes: impact of depressive symptoms on adherence, function, and costs. *Arch Intern Med*, **160**(21), 3278-85.

Coetzee, M. 2013. Finding the benefits: estimating the impact of the South African child support grant. *South African Journal of Economics*, **81**(3), 427-450.

Collins, P.Y., Patel, V., Joestl, S.S., March, D., Insel, T.R., Daar, A.S., Bordin, I.A., Costello, E.J., Durkin, M. and Fairburn, C. 2011. Grand challenges in global mental health. *Nature*, **475**(7354), 27-30.

Collinson, M.A. 2010. Striving against adversity: the dynamics of migration, health and poverty in rural South Africa. *Global Health Action*, **3**(5080), 1-14.

Connolly, M. and Monasch, R. 2003. *Africa's orphaned generation*. UNICEF, New York.

Cooperman, N.A., Arnsten, J.H. and Klein, R.S. 2007. Current sexual activity and risky sexual behavior in older men with or at risk for HIV infection. *AIDS Educ Prev*, **19**(4), 321-33.

Coovadia, H., Jewkes, R., Barron, P., Sanders, D. and McIntyre, D. 2009. The health and health system of South Africa: historical roots of current public health challenges. *The Lancet*, **374**(9692), 817-834.

Crampin, A.C., Glynn, J.R., Ngwira, B.M., Mwaungulu, F.D., Ponnighaus, J.M., Warndorff, D.K. and Fine, P.E. 2003. Trends and measurement of HIV prevalence in northern Malawi. *AIDS*, **17**(12), 1817-25.

CSDH. 2008. Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health. Commission on Social Determinants of Health, World Health Organization: Geneva. http://whqlibdoc.who.int/publications/2008/9789241563703_eng.pdf

Cui, X., Lyness, J.M., Tu, X., King, D.A. and Caine, E.D. 2007. Does depression precede or follow executive dysfunction? Outcomes in older primary care patients. *American Journal of Psychiatry*, **164**(8), 1221-8.

Cuijpers, P. and Smit, F. 2002. Excess mortality in depression: a meta-analysis of community studies. *Journal of Affective Disorders*, **72**(3), 227-236.

Curtis, B., Bradshaw, D. and Nojilana, B. 2002. Socio-Demographic Profile of the Magisterial District of Hlabisa- 1996 Census. South African Medical Research Council: Durban, 1-22. http://www.mrc.ac.za/bod/hlabisafinal.pdf

Dahlgren, G. and Whitehead, M. 1991. Policies and strategies to promote social equity in health. Background document to WHO - strategy paper for Europe. Institute for Futures Studies: Stockholm. http://EconPapers.repec.org/RePEc:hhs:ifswps:2007_014

Deaton, A. 2003. Health, Inequality, and Economic Development. *Journal of Economic Literature*, **41**(1), 113-158.

Debpuur, C., Welaga, P., Wak, G. and Hodgson, A. 2010. Self-reported health and functional limitations among older people in the Kassena-Nankana District, Ghana. *Global Health Action*, **3**(Supplt 2), 54-63.

DeSalvo, K.B., Nicole, B., Kristi, R., Jiang, H. and Paul, M. 2006. Mortality prediction with a single general self-rated health question. A meta-analysis. *Journal of General Internal Medicine*, **21**(3), 267 - 75.

Devereux, S. 2007. Social pensions in Southern Africa in the twentieth century. *Journal of Southern African Studies*, **33**(3), 539-560.

Devereux, S. 2011. Social protection in South Africa: exceptional or exceptionalism? *Canadian Journal of Development Studies*, **32**(4), 414-425.

Diwan, S., Lee, S. and Sen, S. 2011. Expectations of Filial Obligation and Their Impact on Preferences for Future Living Arrangements of Middle-Aged and Older Asian Indian Immigrants. *Journal of Cross-Cultural Gerontology*, **26**(1), 55-69.

DOH. 2011. Government gazette: National Health Insurance in South Africa. National Department of Health: Pretoria.

DOH. 2012. The NHI pilot sites in South Africa. National Department of Health: Pretoria, 1-18.

DOH. 2013. Status of NHI pilot districts: 12-month progress report. National Department of Health: Pretoria, 1-110.

Dominy, N. and Kempson, E. 2006. Understanding older people's experiences of poverty and material deprivation. Department for Work and Pensions: London.

Donovan, C. and Massingue, J. 2007. Illness, death, and macronutrients: adequacy of rural Mozambican household production of macronutrients in the face of HIV/AIDS. *Food and Nutrition Bulletin*, **28**(2 Suppl), S331-8.

Dorrington, R., Johnson, L., Bradshaw, D. and Daniel, T. 2006. *The Demographic Impact of HIV/AIDS in South Africa*. Centre for Actuarial Research, South African Medical Research Council and Actuarial Society of South Africa, Cape Town.

Dorrington, R., Moultrie, T.A. and Timæus, I.M. 2004. Estimation of mortality using the South African census 2001 data. Centre for Actuarial Research: Cape Town.

Dougan, S., Payne, L.J., Brown, A.E., Evans, B.G. and Gill, O.N. 2004. Past it? HIV and older people in England, Wales and Northern Ireland. *Epidemiology & Infection*, **132**(6), 1151-60.

Dowd, J.B. and Zajacova, A. 2007. Does the predictive power of self-rated health for subsequent mortality risk vary by socioeconomic status in the US? *International Journal of Epidemiology*, **36**(6), 1214-21.

Duflo, E. 2000. Child health and household resources in South Africa: Evidence from the Old Age Pension program. *American Economic Review*, **90**(2), 393-398.

Duflo, E. 2003. Grandmothers and granddaughters: Old-age pensions and intrahousehold allocation in South Africa. *World Bank Economic Review*, **17**(1), 1-25.

Edmonds, E.V., Mammen, K. and Miller, D.L. 2005. Rearranging the Family?: Income Support and Elderly Living Arrangements in a Low-Income Country. *Journal of Human Resources*, **40**(1), 186-207.

Fairall, L.R., Bachmann, M.O., Louwagie, G.M.C., van Vuuren, C., Chikobvu, P., Steyn, D., Staniland, G.H., Timmerman, V., Msimanga, M., Seebregts, C.J., Boulle, A., Nhiwatiwa, R., Bateman, E.D., Zwarenstein, M.F. and Chapman, R.D. 2008. Effectiveness of Antiretroviral Treatment in a South African Program: A Cohort Study. *Archives of Internal Medicine*, **168**(1), 86-93.

Falkingham, J. and Grundy, E. 2007. Demographic aspects of population ageing. Economic and Social Research Council: Swindon.

Fayers, P.M. and Sprangers, M.A.G. 2002. Understanding self-rated health. *The Lancet*, **359**(9302), 187-188.

Ferri, C.P., Acosta, D., Guerra, M., Huang, Y., Llibre-Rodriguez, J.J., Salas, A., Sosa, A.L., Williams, J.D., Gaona, C., Liu, Z., Noriega-Fernandez, L., Jotheeswaran, A.T. and Prince, M.J. 2012. Socioeconomic factors and all cause and cause-specific mortality among older people in Latin America, India, and China: a population-based cohort study. *PLoS Medicine*, **9**(2), e1001179.

Finkelstein, M.S. 2003. A model of aging and a shape of the observed force of mortality. *Lifetime Data Analysis*, **9**(1), 93-109.

Fox-Rushby, J.A. and Hanson, K. 2001. Calculating and presenting disability adjusted life years (DALYs) in cost-effectiveness analysis. *Health Policy Plan*, **16**(3), 326-31.

Frankenberg, E. and Jones, N.R. 2004. Self-rated health and mortality: does the relationship extend to a low income setting? *Journal of Health and Social Behavior*, **45**(4), 441-52.

Fredman, L., Cauley, J.A., Hochberg, M., Ensrud, K.E. and Doros, G. 2010. Mortality associated with caregiving, general stress, and caregiving-related stress in elderly women: results of caregiver-study of osteoporotic fractures. *Journal of the American Geriatrics Society*, **58**(5), 937-43.

Freedland, K.E., Carney, R.M. and Skala, J.A. 2005. Depression and smoking in coronary heart disease. *Psychosomatic Medicine*, **67 Suppl 1**, S42-6.

Funk, L.M. 2012. 'Returning the love', not 'balancing the books': talk about delayed reciprocity in supporting ageing parents. *Ageing & Society*, **32**(04), 634-654.

Gallo, J.J., Morales, K.H., Bogner, H.R., Raue, P.J., Zee, J., Bruce, M.L. and Reynolds, C.F., 3rd. 2013. Long term effect of depression care management on mortality in older adults: follow-up of cluster randomized clinical trial in primary care. *BMJ*, **346**, f2570.

Garenne, M., Kahn, K., Tollman, S. and Gear, J. 2000. Causes of death in a rural area of South Africa: an international perspective. *Journal of Tropical Pediatrics*, **46**(3), 183-90.

Giarrusso, R., Silverstein, M., Gans, D. and Bengston, V.L. 2005. Ageing parents and adult children: new perspectives on intergenerational relationships. In Johnson, M.L., Bengston, V.L., Coleman, P.G. and Kirkwood, T.B.L. (eds), *Age and Ageing*. Cambridge University Press, Cambridge, 413-421.

Gierveld, J.d.J., Dykstra, P.A. and Schenk, N. 2012. Living arrangements, intergenerational support types and older adult loneliness in Eastern and Western Europe. *Demographic Research*, **27**(7), 167-199.

Gilbert, L. and Soskolne, V. 2003. Health, ageing and social differentials: a case study of Soweto, South Africa. *Journal of Cross-Cultural Gerontology*, **18**(2), 105-25.

Gomersall, J. 2013. The performance of the Child Support Grant: Review and research priorities. *Development Southern Africa*, **30**(4-5), 525-544.

Goode, W.J. 1960. A theory of role strain *American Sociological Review*, **25**(4), 483-496.

Gorman, M. and Zaidi, A. 2013. Global AgeWatch index 2013: insight report. HelpAge International. http://www.helpage.org/resources/publications/

Grabar, S., Weiss, L. and Costagliola, D. 2006. HIV infection in older patients in the HAART era. *Journal of Antimicrobial Chemotherapy*, **57**(1), 4-7.

Greenglass, E., Fiksenbaum, L. and Eaton, J. 2006. The relationship between coping, social support, functional disability and depression in the elderly. *Anxiety Stress and Coping*, **19**(1), 15-31.

Grundy, E. 2005. Reciprocity in relationships: socio-economic and health influences on intergenerational exchanges between Third Age parents and their adult children in Great Britain. *The British Journal of Sociology*, **56**(2), 233-255.

Hamilton, L.C. 2009. *Statistics with STATA*. Brooks/Cole CENGAGE Learning, Belmont, CA, 491.

Haub, C. 2008. Global aging and the demographic divide. Population Reference Bureau: Washington, DC.

He, W., Muenchrath, M. and Kowal, P. 2012. Shades of gray: a cross-country study of health and well-being of the older populations in SAGE countries, 2007–2010. US Census Bureau: U.S. Government Printing Office, Washington DC.

Help Age International. 2006. Pensions for all: a question of cost. In *Ageing and Development*.

Herbst, A.J., Cooke, G.S., Bärnighausen, T., KanyKany, A., Tanser, F. and Newell, M.L. 2009. Adult mortality and antiretroviral treatment roll-out in rural KwaZulu-Natal, South Africa. *Bulletin of the World Health Organisation*, **87**(10), 754-62.

Herbst, A.J., Mafojane, T. and Newell, M.L. 2011. Verbal autopsy-based cause-specific mortality trends in rural KwaZulu-Natal, South Africa, 2000-2009. *Population Health Metrics*, **9**(1), 47.

Hill, C., Hosegood, V. and Newell, M.-L. 2008. Children's care and living arrangements in a high HIV prevalence area in rural South Africa. *Vulnerable Children and Youth Studies*, **3**(1), 65-77.

Hirve, S., Juvekar, S., Lele, P. and Agarwal, D. 2010. Social gradients in self-reported health and well-being among adults aged 50 and over in Pune District, India. *Global Health Action*, **3**(Supplt 2), 88-95.

Hontelez, J.A., Lurie, M.N., Newell, M.L., Bakker, R., Tanser, F., Bärnighausen, T., Baltussen, R. and de Vlas, S.J. 2011. Ageing with HIV in South Africa. *AIDS*, **25**(13), 1665-7.

Hosegood, V., Benzler, J. and Solarsh, G.C. 2006. Population mobility and household dynamics in rural South Africa: implications for demographic and health research. *Southern African Journal of Demography*, **10**(1&2), 43-67.

Hosegood, V., Floyd, S., Marston, M., Hill, C., McGrath, N., Isingo, R., Crampin, A. and Zaba, B. 2007. The effects of high HIV prevalence on orphanhood and living arrangements of children in Malawi, Tanzania, and South Africa. *Population Studies: A Journal of Demography*, **61**(3), 327-36.

Hosegood, V., McGrath, N., Herbst, K. and Timæus, I.M. 2004. The impact of adult mortality on household dissolution and migration in rural South Africa. *AIDS*, **18**(11), 1585-90.

Hosegood, V. and Timæus, I.M. 2005a. Household Composition and Dynamics in KwaZulu Natal, South Africa: Mirroring Social Reality in Longitudinal Data Collection. In Etienne van der Walle (ed), *African Households. Census data*. M.E. Sharpe Inc., New York, 58-77.

Hosegood, V. and Timæus, I.M. 2005b. The impact of adult mortality on the living arrangements of older people in rural South Africa. *Ageing & Society*, **25**(06), 431-444.

Hosegood, V. and Timæus, I.M. 2006. HIV/AIDS and older people in South Africa. In Cohen, B. and Menken, J. (eds), *Aging in sub-Saharan Africa: recommendations for furthering research*. The National Academic Press, Washinton, D.C., 250-275.

Hosegood, V., Vanneste, A.M. and Timæus, I.M. 2004. Levels and causes of adult mortality in rural South Africa: the impact of AIDS. *AIDS*, **18**(4), 663-71.

Houlihan, C.F., Bland, R.M., Mutevedzi, P.C., Lessells, R.J., Ndirangu, J., Thulare, H. and Newell, M.L. 2011. Cohort profile: Hlabisa HIV treatment and care programme. *International Journal of Epidemiology*, **40**(2), 318-26.

Ice, G.H., Sadruddin, A.F., Vagedes, A., Yogo, J. and Juma, E. 2012. Stress associated with caregiving: an examination of the stress process model among Kenyan Luo elders. *Social Science & Medicine*, **74**(12), 2020-7.

Ice, G.H., Yogo, J., Heh, V. and Juma, E. 2010. The Impact of Caregiving on the Health and Well-being of Kenyan Luo Grandparents. *Research on Aging*, **32**(1), 40-66.

Ice, G.H., Zidron, A. and Juma, E. 2008. Health and health perceptions among Kenyan grandparents. *Journal of Cross-Cultural Gerontology*, **23**(2), 111-29.

Idler, E.l. and Benyamini, Y. 1997. Self-Rated Health and Mortality: A Review of Twenty-Seven Community Studies. *Journal of Health and Social Behavior*, **38**(1), 21-37.

Iwuji, C.C., Churchill, D., Gilleece, Y., Weiss, H.A. and Fisher, M. 2013. Older HIV-infected individuals present late and have a higher mortality: Brighton, UK cohort study. *BMC Public Health*, **13**(397), 1-9.

Jahn, A., Floyd, S., Crampin, A.C., Mwaungulu, F., Mvula, H., Munthali, F., McGrath, N., Mwafilaso, J., Mwinuka, V., Mangongo, B., Fine, P.E., Zaba, B. and Glynn, J.R. 2008. Population-level effect of HIV on adult mortality and early evidence of reversal after introduction of antiretroviral therapy in Malawi. *Lancet*, **371**(9624), 1603-11.

Jensen, R.T. 2004. Do private transfers 'displace' the benefits of public transfers? Evidence from South Africa. *Journal of Public Economics*, **88**(1–2), 89-112.

Jitapunkul, S., Kunanusont, C., Phoolcharoen, W., Suriyawongpaisal, P. and Ebrahim, S. 2003. Disability-free life expectancy of elderly people in a population undergoing demographic and epidemiologic transition. *Age & Ageing*, **32**(4), 401-405.

Johnson, M.L. 2005. The social construction of old age as a problem. In Johnson, M.L., Bengston, V.L., Coleman, P.G. and Kirkwood, T.B.L. (eds), *Age and ageing*. Cambridge University Press, Cambridge, 563-571.

Joubert, J. and Bradshaw, D. 2006. Population ageing and health challenges in South Africa. In Steyn, K., Fourie, J. and Temple, N. (eds), *Chronic Diseases of Lifestyle in South Africa: 1995 - 2005*. South African Medical Research Council, Cape Town.

Jylhä, M. 2009. What is self-rated health and why does it predict mortality? Towards a unified conceptual model. *Social Science & Medicine*, **69**(3), 307-316.

Kahn, K. 2011. Population health in South Africa: dynamics over the past two decades. *Journal of Public Health Policy*, **32**(S1), S30-S36.

Kahn, K., Tollman, S.M., Garenne, M. and Gear, J.S. 2000. Validation and application of verbal autopsies in a rural area of South Africa. *Tropical Medicine & International Health*, **5**(11), 824-31.

Kakwani, N. and Subbarao, K. 2007. Poverty among the elderly in sub-Saharan Africa and the role of social pensions. *Journal of Development Studies*, **43**(6), 987-1008.

Kalache, A. and Keller, I. 2000. The greying world: a challenge for the twenty-first century. *Science Progress*, **83 (Pt 1)**, 33-54.

Kautz, T., Bendavid, E., Bhattacharya, J. and Miller, G. 2010. AIDS and declining support for dependent elderly people in Africa: retrospective analysis using demographic and health surveys. *BMJ*, **340**(c2841), 1-6.

Kent, M.M. and Haub, C. 2005. Global demographic divide. *Population Bulletin*, **60**(4), 3-24.

Kessler, R.C. and Ustun, T.B. 2004. The World Mental Health (WMH) Survey Initiative Version of the World Health Organization (WHO) Composite International Diagnostic Interview (CIDI). *International Journal of Methods in Psychiatric Research*, **13**(2), 93-121.

Kim, H.-K., Hisata, M., Kai, I. and Lee, S.-K. 2000. Social support exchange and quality of life among the Korean elderly. *Journal of Cross-Cultural Gerontology*, **15**(4), 331-347.

Kimuna, S.R. and Makiwane, M. 2007. Older people as resources in South Africa: Mpumalanga households. *Journal of Aging & Social Policy*, **19**(1), 97-114.

Kinsella, K. and Ferreira, M. 1997. Ageing Trends: South Africa. U.S. Department of Commerce, Bureau of the Census: Washington. http://www.census.gov/ipc/prod/ib-9702.pdf

Kinsella, K. and He, W. 2009. An aging world 2008. U.S. Department of Commerce, Census Bureau Office, U.S.G.P., Washington, DC. http://www.census.gov/ipc/prod/ib-9702.pdf

Knight, L., Hosegood, V. and Timæus, I.M. 2013. The South African disability grant: Influence on HIV treatment outcomes and household well-being in KwaZulu-Natal. *Development Southern Africa*, **30**(1), 135-147.

Knodel, J. and Saengtienchai, C. 1999. Studying living arrangements of the elderly: Lessons from a quasi-qualitative case study approach in Thailand. *Journal of Cross-Cultural Gerontology*, **14**(3), 197-220.

Kowal, P., Kahn, K., Ng, N., Naidoo, N., Abdullah, S., Bawah, A., Binka, F., Chuc, N.T., Debpuur, C., Ezeh, A., Xavier Gomez-Olive, F., Hakimi, M., Hirve, S., Hodgson, A., Juvekar, S., Kyobutungi, C., Menken, J., Van Minh, H., Mwanyangala, M.A., Razzaque, A., Sankoh, O., Kim Streatfield, P., Wall, S., Wilopo, S., Byass, P., Chatterji, S. and Tollman, S.M. 2010. Ageing and adult health status in eight lower-income countries: the INDEPTH WHO-SAGE collaboration. *Global Health Action*, **3**(Supplt 2), 11-22.

Kreager, P. and Schroder-Butterfill, E. 2008. Indonesia against the trend? Ageing and inter-generational wealth flows in two Indonesian communities. *Demographic Research*, **19**(52), 1781-1810.

Kuhn, R., Rahman, O. and Menken, J. 2006. Survey measures of health: how well do self-reported and observed indicators measure health and predict mortality? In Cohen, B. and Menken, J. (eds), *Aging in sub-Saharan Africa: recommendations for furthering research* The National Academies Press, Washington, D.C., 314-341.

Kyobutungi, C., Egondi, T. and Ezeh, A. 2010. The health and well-being of older people in Nairobi's slums. *Global Health Action*, **3**(Supplt 2), 45-53.

Lapid, M.I. and Rummans, T.A. 2003. Evaluation and management of geriatric depression in primary care. *Mayo Clin Proc*, **78**(11), 1423-9.

Larson, B.A. 2013. Calculating disability-adjusted-life-years lost (DALYs) in discrete-time. *Cost Effectiveness and Resource Allocation*, **11**(1), 1478-7547.

Lee, H.J., Lyu, J., Lee, C.M. and Burr, J.A. 2014. Intergenerational financial exchange and the psychological well-being of older adults in the Republic of Korea. *Aging & Mental Health*, **18**(1), 30-39.

Lee, R. 2012. Intergenerational Transfers, the Biological Life Cycle, and Human Society. *Population and Development Review*, **38**(Suppl 1), 23-35.

Lee, Y. 2000. The predictive value of self assessed general, physical, and mental health on functional decline and mortality in older adults. *Journal of Epidemiology and Community Health*, **54**, 123-129.

Leibbrandt, M., Finn, A. and Woolard, I. 2012. Describing and decomposing post-apartheid income inequality in South Africa. *Development Southern Africa*, **29**(1), 19-34.

Lima-Costa, M.F., Steptoe, A., Cesar, C.C., De Oliveira, C., Proietti, F.A. and Marmot, M. 2012. The influence of socioeconomic status on the predictive power of self-

rated health for 6-year mortality in English and Brazilian older adults: the ELSA and Bambui cohort studies. *Annals of Epidemiology*, **22**(9), 644-8.

Lloyd-Sherlock, P., Barrientos, A., Moller, V. and Saboia, J. 2012a. Pensions, poverty and wellbeing in later life: Comparative research from South Africa and Brazil. *Journal of Aging Studies*, **26**(3), 243-252.

Lloyd-Sherlock, P., McKee, M., Ebrahim, S., Gorman, M., Greengross, S., Prince, M., Pruchno, R., Gutman, G., Kirkwood, T., O'Neill, D., Ferrucci, L., Kritchevsky, S.B. and Vellas, B. 2012b. Population ageing and health. *Lancet*, **379**(9823), 1295-6.

Lloyd-Sherlock, P., Minicuci, N., Beard, J. and Chatterji, S. 2012c. Social protection and preventing illness in developing countries: Establishing the health effects of pensions and health insurance. *International Social Security Review*, **65**(4), 51-68.

Lopez, A.D., Mathers, C.D., Ezzati, M., Jamison, D.T. and Murray, C.J. (eds). 2006. *Global Burden of Disease and Risk Factors*. World Bank, Washington (DC).

Louwagie, G., Bachmann, M., Meyer, K., Booysen, F., Fairall, L. and Heunis, C. 2007. Highly active antiretroviral treatment and health related quality of life in South African adults with human immunodeficiency virus infection: A cross-sectional analytical study. *BMC Public Health*, **7**(1), 244.

Lowenstein, A. 1999. Intergenerational family relations and social support. *Zeitschrift Fur Gerontologie Und Geriatrie*, **32**(6), 398-406.

Lowenstein, A. 2005. Global ageing and challenges to families. In Johnson, M.L., Bengston, V.L., Coleman, P.G. and Kirkwood, T.B.L. (eds), *Age and ageing*. Cambridge University Press, Cambridge, 403-412.

Lund, F. 1999. Understanding South African social security through recent household surveys: New opportunities and continuing gaps. *Development Southern Africa*, **16**(1), 55-67.

Lund, F. 2002. 'Crowding in' care, security and micro-enterprise formation: revisiting the role of the state in poverty reduction and in development. *Journal of International Development*, **14**(6), 681-694.

Maitra, P. and Ray, R. 2006. Household expenditure patterns and resource pooling: evidence of changes in post-apartheid South Africa. *Review of Economics of the Household*, **4**(4), 325-347.

Marks, S.R. 1977. Multiple roles and role strain: some notes on human energy, time and commitment. *American Sociological Review* **42** (6), 921–936.

Matsotso, M.P. and Fryatt, R. 2013. National Health Insurance: the first 18 months. In Padarath, A. and English, R. (eds), *South African Health Review*. Health Systems Trust, Durban.

Mayosi, B.M., Flisher, A.J., Lalloo, U.G., Sitas, F., Tollman, S.M. and Bradshaw, D. 2009. The burden of non-communicable diseases in South Africa. *The Lancet*, **374**(9693), 934-947.

McCullagh, P. 1980. Regression Models for Ordinal Data. *Journal of the Royal Statistical Society. Series B (Methodological)*, **42**(2), 109-142.

McEwen, B.S. 2001. From molecules to mind. Stress, individual differences, and the social environment. *Annals of the New York Academy of Sciences*, **935**, 42-9.

McFadden, E., Luben, R., Bingham, S., Wareham, N., Kinmonth, A.-L. and Khaw, K.-T. 2009. Does the association between self-rated health and mortality vary by social class? *Social Science & Medicine*, **68**(2), 275 - 80.

Menvielle, G., Leclerc, A., Chastang, J.F. and Luce, D. 2010. Socioeconomic inequalities in cause specific mortality among older people in France. *BMC Public Health*, **10**(260), 1-9.

Metallidis, S., Tsachouridou, O., Skoura, L., Zebekakis, P., Chrysanthidis, T., Pilalas, D., Bakaimi, I., Kollaras, P., Germanidis, G., Tsiara, A., Galanos, A., Malisiovas, N. and Nikolaidis, P. 2013. Older HIV-infected patients-an underestimated population in northern Greece: epidemiology, risk of disease progression and death. *International Journal of Infectious Diseases*, **17**(10), e883-e891.

Michaud, P.-C. and van Soest, A. 2008. Health and wealth of elderly couples: Causality tests using dynamic panel data models. *Journal of Health Economics*, **27**(5), 1312-1325.

Minkler, M. and Fuller-Thomson, E. 1999. The health of grandparents raising grandchildren: results of a national study. *American Journal of Public Health*, **89**(9), 1384-1389.

Mishra, G., Gale, C., Sayer, A., Cooper, C., Dennison, E., Whalley, L., Craig, L., Kuh, D. and Deary, I. 2011. How useful are the SF-36 sub-scales in older people? Mokken scaling of data from the HALCyon programme. *Quality of Life Research*, **20**(7), 1005-1010.

Moen, P. and Chermack, K. 2005. Gender disparities in health: strategic selection, careers, and cycles of control. *Journals of Gerontology: SERIES B*, **60**(Special issue II), 99-108.

Møller, V. and Ferreira, M. 2003. Benefits of non-contributory pension income for older South African households. Institute of Ageing in Africa, University of Cape Town: Cape Town.

Moller, V. and Radloff, S. 2013. Perceptions of Fortune and Misfortune in Older South African Households: Social Assistance and the 'Good Life'. *Social Indicators Research*, **111**(3), 633-664.

Mordaunt, S., Rake, K., Wanless, H. and Mitchell, R. 2003. One in four. Age Concern and Fawcett Society: London.

Morgan, D., Mahe, C., Mayanja, B., Okongo, J.M., Lubega, R. and Whitworth, J.A. 2002. HIV-1 infection in rural Africa: is there a difference in median time to AIDS and survival compared with that in industrialized countries? *AIDS*, **16**(4), 597-603.

Moultrie, T.A. and Dorrington, R. 2004. Estimation of fertility from the 2001 South African census data. Centre for Actuarial Research: Cape Town.

Moultrie, T.A., Hosegood, V., McGrath, N., Hill, C., Herbst, K. and Newell, M.L. 2008. Refining the criteria for stalled fertility declines: an application to rural KwaZulu-Natal, South Africa, 1990-2005. *Stud Fam Plann*, **39**(1), 39-48.

Moultrie, T.A. and Timæus, I.M. 2003. The South African fertility decline: evidence from two censuses and a Demographic and Health Survey. *Population Studies*, **57**(3), 265-83.

Muhwava, W. 2008. Trends in economic status of households in the ACDIS. In *Monograph Series No. 3*. Africa Centre for Health and Population Studies, Somkhele.

Muhwava, W., Hosegood, V., Nyirenda, M., Herbst, K. and Newell, M.-L. 2010. Levels and determinants of Population Movements and Migration in rural KwaZulu Natal, South Africa. *African Population Studies*, **24**(3), 260-280.

Muhwava, W. and Nyirenda, M. 2008. Demographic and socio-economic trends in the ACDIS. Africa Centre for Health and Population Studies, Somkhele.http://www.africacentre.ac.za/Portals/0/Monograph2.pdf [Accessed 10-10-2008]

Murray, C.J. and Lopez, A.D. 1997. Global mortality, disability, and the contribution of risk factors: Global Burden of Disease Study. *Lancet*, **349**(9063), 1436-42.

Mushkin, S.J. 1962. Health as an Investment. *Journal of Political Economy*, **70**(5), 129-157.

Mutevedzi, P.C., Lessells, R.J., Rodger, A.J. and Newell, M.L. 2011. Association of age with mortality and virological and immunological response to antiretroviral therapy in rural South African adults. *PLoS One*, **6**(7), e21795.

Mutevedzi, P.C., Rodger, A.J., Kowal, P., Nyirenda, M. and Newell, M.-L. 2013. Decreased Chronic Morbidity but Elevated HIV Associated Cytokine Levels in HIV-Infected Older Adults Receiving HIV Treatment: Benefit of Enhanced Access to Care? *PLoS One*, **8**(10), e77379.

Mwanyangala, M.A., Mayombana, C., Urassa, H., Charles, J., Mahutanga, C., Abdullah, S. and Nathan, R. 2010. Health status and quality of life among older adults in rural Tanzania. *Global Health Action*, **3**(Supplt 2), 36-44.

Nabalamba, A. and Chikoko, M. 2011. Aging challenges in Africa. *African Development Bank (AfDB)*, **1**(1), 1-19.

National Institute on Aging. 2007. Why population aging matters: a global perspective. National Institute on Aging, National Institute of Health: Washington, DC.

Negin, J., Mills, E.J. and Albone, R. 2011. Continued neglect of ageing of HIV epidemic at UN meeting. *Lancet*, **378**(9793), 768.

Negin, J., Nyirenda, M., Seeley, J. and Mutevedzi, P. 2013. Inequality in Health Status Among Older Adults in Africa: The Surprising Impact of Anti-Retroviral Treatment. *Journal of Cross-Cultural Gerontology*, **28**(4), 491-493.

Neves, D. and du Toit, A. 2013. Rural Livelihoods in South Africa: Complexity, Vulnerability and Differentiation. *Journal of Agrarian Change*, **13**(1), 93-115.

Neves, D., Samson, M., Ingrid van Niekerk, Hlatshwayo, S. and du Toit, A. 2009. The use and effectiveness of social grants in South Africa. Institute for Poverty, Land and Agrarian Studies (PLAAS): Trust, F., Cape Town.

Ng, N., Kowal, P., Kahn, K., Naidoo, N., Abdullah, S., Bawah, A., Binka, F., Chuc, N.T., Debpuur, C., Egondi, T., Xavier Gomez-Olive, F., Hakimi, M., Hirve, S., Hodgson, A., Juvekar, S., Kyobutungi, C., Van Minh, H., Mwanyangala, M.A., Nathan, R., Razzaque, A., Sankoh, O., Kim Streatfield, P., Thorogood, M., Wall, S., Wilopo, S., Byass, P., Tollman, S.M. and Chatterji, S. 2010. Health inequalities among older men and women in Africa and Asia: evidence from eight Health and Demographic Surveillance System sites in the INDEPTH WHO-SAGE Study. *Global Health Action*, **3**(Supplt 2), 96-107.

Nguyen, N. and Holodniy, M. 2008. HIV infection in the elderly. *Clinical Interventions in Aging*, **3**(3), 453-72.

Nyambedha, E.O., Wandibba, S. and Aagaard-Hansen, J. 2003. "Retirement lost"-the new role of the elderly as caretakers for orphans in Western Kenya. *Journal of Cross-Cultural Gerontology*, **18**(1), 33-52.

Nyirenda, M., Chatterji, S., Falkingham, J., Mutevedzi, P., Hosegood, V., Evandrou, M., Kowal, P. and Newell, M.-L. 2012. An investigation of factors associated with

the health and well-being of HIV-infected or HIV-affected older people in rural South Africa. *BMC Public Health*, **12**(1), 259.

Nyirenda, M., Chatterji, S., Rochat, T., Mutevedzi, P. and Newell, M.L. 2013a. Prevalence and correlates of depression among HIV-infected and -affected older people in rural South Africa. *Journal of Affective Disorders*, **151**(1), 31-38.

Nyirenda, M., Evandrou, M., Mutevedzi, P., Hosegood, V., Falkingham, J. and Newell, M.-L. 2013b. Who cares? Implications of care-giving and -receiving by HIV-infected or -affected older people on functional disability and emotional wellbeing. *Ageing & Society*, **FirstView**, 1-34.

Nyirenda, M., Hosegood, V., Bärnighausen, T. and Newell, M.L. 2007. Mortality levels and trends by HIV serostatus in rural South Africa. *AIDS*, **21**(Suppl 6), S73-9.

Nyirenda, M. and Newell, M.-L. 2010. Orphanhood and HIV risk in rural KwaZulu-Natal In Nzimande, N.B. (ed), *State of the population of KwaZulu-Natal: demographic profile and development indicators* Dept of Social Development/UNFPA, Durban, 159-186.

Nyirenda, M., Newell, M.L., Mugisha, J., Mutevedzi, P.C., Seeley, J., Scholten, F. and Kowal, P. 2013c. Health, wellbeing, and disability among older people infected or affected by HIV in Uganda and South Africa. *Global Health Action*, **6**, 1-11.

O'Reilly, D., Connolly, S., Rosato, M. and Patterson, C. 2008. Is caring associated with an increased risk of mortality? A longitudinal study. *Social Science & Medicine*, **67**(8), 1282-1290.

Ogunmefun, C., Gilbert, L. and Schatz, E. 2011. Older Female Caregivers and HIV/AIDS-Related Secondary Stigma in Rural South Africa. *Journal of Cross-Cultural Gerontology*, **26**(1), 85-102.

Olgiati, A., Bärnighausen, T. and Newell, M.L. 2012. Do self-assessments of health predict future mortality in rural South Africa? The case of KwaZulu-Natal in the era of antiretroviral treatment. *Tropical Medicine and International Health*, **17**(7), 844-53.

Pearlin, L.I., Mullan, J.T., Semple, S.J. and Skaff, M.M. 1990. Caregiving and the stress process: an overview of concepts and their measures. *The Gerontologist*, **30**(5), 583-94.

Peltzer, K. and Phaswana-Mafuya, N. 2008. Levels of ability and functioning of persons living with HIV and AIDS using the WHO DAS II in a South African context. *Journal of Social Development in Africa*, **23**(2), 33-53.

Petersen, I., Baillie, K. and Bhana, A. 2012. Understanding the benefits and challenges of community engagement in the development of community mental health services for common mental disorders: lessons from a case study in a rural South African subdistrict site. *Transcult Psychiatry*, **49**(3-4), 418-37.

Petersen, I., Bhana, A., Campbell-Hall, V., Mjadu, S., Lund, C., Kleintjies, S., Hosegood, V. and Flisher, A.J. 2009. Planning for district mental health services in South Africa: a situational analysis of a rural district site. *Health Policy and Planning*, **24**(2), 140-50.

Phillipson, C. 2005. The political economy of old age. In Johnson, M.L., Bengston, V.L., Coleman, P.G. and Kirkwood, T.B.L. (eds), *Age and ageing*. Cambridge University Press, Cambridge, 502-509.

Pickard, L., Wittenberg, R., Comas-Herrera, A., Davies, B. and Darton, R. 2000. Relying on informal care in the new century? Informal care for elderly people in England to 2031. *Ageing & Society*, **20**(06), 745-772.

Pillay, Y. and Barron, P. 2012. The implementation of PHC re-engineering in South Africa. http://www.phasa.org.za/wp-content/uploads/2011/11/Pillay-The-implementation-of-PHC.pdf

Pinquart, M. and Sörensen, S. 2003. Associations of Stressors and Uplifts of Caregiving With Caregiver Burden and Depressive Mood: A Meta-Analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, **58**(2), P112-P128.

Pinquart, M. and Sörensen, S. 2007. Correlates of Physical Health of Informal Caregivers: A Meta-Analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, **62**(2), P126-P137.

Pitts, M., Grierson, J. and Misson, S. 2005. Growing older with HIV: a study of health, social and economic circumstances for people Living with HIV in Australia over the age of 50 years. *AIDS Patient Care STDS*, **19**(7), 460-5.

Plagerson, S., Patel, V., Harpham, T., Kielmann, K. and Mathee, A. 2010. Does money matter for mental health? Evidence from the Child Support Grants in Johannesburg, South Africa. *Global Public Health*, **6**(7), 760-776.

Posel, D. 1991. *The Making of Aparthied 1948-1961: Conflict and Compromise*. Clarendon Press, Oxford.

Posel, D. 2001a. How do households work? Migration, the household and remittance behaviour in South Africa. *Social Dynamics-a Journal of the Centre for African Studies University of Cape Town*, **27**(1), 165-189.

Posel, D., Fairburn, J.A. and Lund, F. 2006. Labour migration and households: A reconsideration of the effects of the social pension on labour supply in South Africa. *Economic Modelling*, **23**(5), 836-853.

Posel, D.R. 2001b. Intra-family transfers and income-pooling: A study of remittances in Kwazulu-Natal. *South African Journal of Economics*, **69**(3), 501-528.

Pu, C., Tang, G.J., Huang, N. and Chou, Y.J. 2011. Predictive power of self-rated health for subsequent mortality risk during old age: analysis of data from a nationally representative survey of elderly adults in Taiwan. *Journal of Epidemiology*, **21**(4), 278-84.

Ranchhod, V. 2006. The effect of the South African old age pension on labour supply of the elderly. *South African Journal of Economics*, **74**(4), 725-744.

Raniga, T. and Simpson, B. 2011. Poverty, HIV/AIDS and the old age pension in Bhambayi, Kwazulu-Natal, South Africa. *Development Southern Africa*, **28**(1), 75-85.

Razzaque, A., Nahar, L., Akter Khanam, M. and Kim Streatfield, P. 2010. Socio-demographic differentials of adult health indicators in Matlab, Bangladesh: self-rated health, health state, quality of life and disability level. *Global Health Action*, **3**(Supplt 2), 70-77.

Reeve, B.B. and Fayers, P. 2005. Applying item response theory modeling for evaluating questionnaire item and scale properties. In Fayers, P. and Hays, R. (eds), *Assessing Quality of Life in Clinical Trials: Methods of Practice*. Oxford University Press, Oxford, NY, 55-73.

Reeve, B.B., Hays, R.D., Chang, C.-H. and Perfetto, E.M. 2007. Applying item response theory to enhance health outcomes assessment. *Quality of Life Research*, **16** (Suppl 1), 1-3.

Reid, J. and Hardy, M. 1999. Multiple roles and well-being among midlife women: testing role strain and role enhancement theories. *The journals of gerontology. Series B, Psychological sciences and social sciences*, **54**(6), S329-38.

Rieker, P.P. and Bird, C.E. 2005. Rethinking gender differences in health: why we need to integrate social and biological perspectives. *The Journals of Gerontology. Series B, Psychological sciences and social sciences*, **60**(Spec No 2), 40-7.

Rochat, T.J., Tomlinson, M., Bärnighausen, T., Newell, M.L. and Stein, A. 2011. The prevalence and clinical presentation of antenatal depression in rural South Africa. *Journal of Affective Disorders*, **135**(1-3), 362-73.

Sagner, A. and Mtati, R.Z. 1999. Politics of pension sharing in urban South Africa. *Ageing and Society*, **19**(4), 393-416.

Saito, M., Iwata, N., Kawakami, N., Matsuyama, Y., Ono, Y., Nakane, Y., Nakamura, Y., Tachimori, H., Uda, H., Nakane, H., Watanabe, M., Naganuma, Y., Furukawa, T.A., Hata, Y., Kobayashi, M., Miyake, Y., Takeshima, T. and Kikkawa, T. 2010. Evaluation of the DSM-IV and ICD-10 criteria for depressive disorders in a community population in Japan using item response theory. *International Journal of Methods in Psychiatric Research*, **19**(4), 211-22.

Salomon, J.A., Nordhagen, S., Oza, S. and Murray, C.J. 2009. Are Americans feeling less healthy? The puzzle of trends in self-rated health. *American Journal of Epidemiology*, **170**(3), 343-51.

Sapolsky, R., Armanini, M., Packan, D. and Tombaugh, G. 1987. Stress and glucocorticoids in aging. *Endocrinology and metabolism clinics of North America*, **16**(4), 965-80.

Sapolsky, R.M. 1996. Why stress is bad for your brain. *Science*, **273**(5276), 749-50.

Sapolsky, R.M. 1999. Glucocorticoids, stress, and their adverse neurological effects: relevance to aging. *Experimental Gerontology*, **34**(6), 721-32.

SASSA. 2013. Grant for older persons. South African Social Security Agency.http://www.sassa.gov.za/Grant-for-older-persons-668.aspx [Accessed 6th October 2013]

SASSA. 2014. A statistical summary of social grants in South Africa. South African Social Security Agency. http://www.sassa.gov.za/index.php/statistical-reports

Schatz, E. and Gilbert, L. 2012. “My heart is very painful”: Physical, mental and social wellbeing of older women at the times of HIV/AIDS in rural South Africa. *Journal of Aging Studies*, **26**(1), 16-25.

Schatz, E. and Ogunmefun, C. 2007. Caring and contributing: The role of older women in rural South African multi-generational households in the HIV/AIDS era. *World Development*, **35**(8), 1390-1403.

Schatz, E.J. 2007. "Taking care of my own blood": older women's relationships to their households in rural South Africa. *Scandinavian Journal of Public Health*, **69**(Suppl), 147-54.

Schmid, G.P., Williams, B.G., Garcia-Calleja, J.M., Miller, C., Segar, E., Southworth, M., Tonyan, D., Wacloff, J. and Scott, J. 2009. The unexplored story of HIV and ageing. *Bulletin of the World Health organization*, **87**(3), 162.

Scholten, F., Mugisha, J., Seeley, J., Kinyanda, E., Nakubulwa, S., Kowal, P., Naidoo, N., Boerma, T., Chatterji, S. and Grosskurth, H. 2011. Health and functional status among older people with HIV/AIDS in Uganda. *BMC Public Health*, **11**(1), 886.

Schulz, R. and Beach, S.R. 1999. Caregiving as a risk factor for mortality: The caregiver health effects study. *JAMA*, **282**(23), 2215-2219.

Schulz, R., Drayer, R.A. and Rollman, B.L. 2002. Depression as a risk factor for non-suicide mortality in the elderly. *Biological Psychiatry*, **52**(3), 205-225.

Sen, A. 2002. Health: perception versus observation. *BMJ*, **324**(7342), 860-1.

Sieber, S.D. 1974. Towards a theory of role accomulation. *American Sociological Review* **39**(4), 567-578.

Sijuwade, P.O. 2009. Attitudes towards old age: a study of the self-image of aged. *Studies on Home and Community Science*, **3**(1), 1-5.

Silverstein, M., Cong, Z. and Li, S. 2006. Intergenerational transfers and living arrangements of older people in rural China: Consequences for psychological well-being. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, **61**(5), S256-S266.

Silverstein, M., Conroy, S.J. and Gans, D. 2012. Beyond solidarity, reciprocity and altruism: moral capital as a unifying concept in intergenerational support for older people. *Ageing & Society*, **32**(7), 1246-1262.

Simone, M.J. and Appelbaum, J. 2008. HIV in older adults. *Geriatrics*, **63**(12), 6-12.

Singh-Manoux, A., Dugravot, A., Shipley, M.J., Ferrie, J.E., Martikainen, P., Goldberg, M. and Zins, M. 2007. The association between self-rated health and mortality in different socioeconomic groups in the GAZEL cohort study. *International Journal of Epidemiology*, **36**(6), 1222-8.

Smith, J.P. 2004. Unraveling the SES health connection. IFS Working Papers, Institute for Fiscal Studies (IFS): (IFS), I.f.F.S., London. http://hdl.handle.net/10419/71512

Smith, S.M. and Mensah, G.A. 2003. Population aging and implications for epidemic cardiovascular disease in Sub-Saharan Africa. *Ethnicity & Disease*, **13**(2 Suppl 2), S77-80.

Snowden, M., Steinman, L. and Frederick, J. 2008. Treating depression in older adults: challenges to implementing the recommendations of an expert panel. *Preventing Chronic Disease*, **5**(1), A26.

Soleman, N., Chandramohan, D. and Shibuya, K. 2006. Verbal autopsy: current practices and challenges. *Bulletin of the World Health Organization*, **84**(3), 239-45.

Ssengonzi, R. 2007. The plight of older persons as caregivers to people infected/affected by HIV/AIDS: evidence from Uganda. *Journal of Cross-Cultural Gerontology*, **22**(4), 339-53.

Ssengonzi, R. 2009. The impact of HIV/AIDS on the living arrangements and well-being of elderly caregivers in rural Uganda. *AIDS Care*, **21**(3), 309-14.

StataCorp. 2009. Stata: Release 11. Statistical Software. In StataCorp LP, College Station, TX.

StataCorp. 2009. STATA base reference manual: release 11. Stata Press, College Station, Texas 77845.

StatsSA. 2013. Quarterly labour force survey: quarter 2, 2013. In Statistics South Africa, Pretoria.

Steele, F., Kallis, C. and Joshi, H. 2006. The formation and outcomes of cohabiting and marital partnerships in early adulthood: the role of previous partnership experience. *Journal of the Royal Statistical Society: Series A (Statistics in Society)*, **169**(4), 757-779.

Subramanian, S.V., Subramanyam, M.A., Selvaraj, S. and Kawachi, I. 2009. Are self-reports of health and morbidities in developing countries misleading? Evidence from India. *Social Science & Medicine*, **68**(2), 260-5.

Sun, W.J., Xu, L., Chan, W.M., Lam, T.H. and Schooling, C.M. 2013. Are depressive symptoms associated with cardiovascular mortality among older chinese: a cohort study of 64,000 people in Hong Kong? *American Journal of Geriatric Psychiatry*, **21**(11), 1107-1115.

Surender, R., Noble, M., Wright, G. and Ntshongwana, P. 2010. Social Assistance and Dependency in South Africa: An Analysis of Attitudes to Paid Work and Social Grants. *Journal of Social Policy*, **39**, 203-221.

Suzman, R. and Beard, J. 2011. Global health and aging. National Institutes of Health; World Health Organization. http://www.nia.nih.gov/sites/default/files/global_health_and_aging.pdf

Tanser, F., Hosegood, V., Bärnighausen, T., Herbst, K., Nyirenda, M., Muhwava, W., Newell, C., Viljoen, J., Mutevedzi, T. and Newell, M.-L. 2008. Cohort Profile: Africa Centre Demographic Information System (ACDIS) and population-based HIV survey. *International Journal of Epidemiology*, **37**(5), 956-62.

Tanser, F.C. 2002. The application of GIS technology to equitably distribute fieldworker workload in a large, rural South African health survey. *Tropical Medicine & International Health*, **7**(1), 80-90.

Thornton, J.E. 2002. Myths of aging or ageist stereotypes. *Educational Gerontology*, **28**(4), 301-312.

Thorogood, M., Connor, M.D., Hundt, G.L. and Tollman, S.M. 2007. Understanding and managing hypertension in an African sub-district: a multidisciplinary approach. *Scandinavian Journal of Public Health*, **35**(Suppl. 69), 52-9.

Timæus, I.M. and Jasseh, M. 2004. Adult mortality in sub-Saharan Africa: evidence from Demographic and Health Surveys. *Demography*, **41**(4), 757-72.

Tollman, S.M. and Kahn, K. 2007. Health, population and social transitions in rural South Africa. *Scandinavian Journal of Public Health*, **35**(Suppl. 69), 4-7.

Tsuji, I., Minami, Y., Keyl, P.M., Hisamichi, S., Asano, H., Sato, M. and Shinoda, K. 1994. The predictive power of self-rated health, activities of daily living, and ambulatory activity for cause-specific mortality among the elderly: a three-year follow-up in urban Japan. *Journal of the American Geriatrics Society*, **42**(2), 153-6.

UCLA Academic Technology Services. 2011. Stata annotated output: ordered logistic regression. UCLA Academic Technology Services http://www.ats.ucla.edu/stat/stata/output/stata_ologit_output.htm [Accessed 07 July 2011]

UNAIDS. 2013. Global report: UNAIDS report on the global AIDS epidemic 2013. Joint United Nations Programme on HIV/AIDS (UNAIDS): Geneva. http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/UNAIDS_Global_Report_2013_en.pdf

UNFPA. 2011. Facing the new challenges of an ageing world. United Nations Population Fund.http://www.unfpa.org/public/home/news/pid/7258 [Accessed 15 October 2013]

United Nations. 2002. World population ageing: 1950-2050. In Department of Economic and Social Affairs, United Nations, New York.

United Nations. 2005. Living arrangements of older persons around the world. Department of Economic and Social Affairs, Population Division, United Nations: New York.

United Nations. 2009. World population ageing 2009. Department of Economic and Social Affairs, Population Division, United Nations: New York. http://www.un.org/esa/population/publications/WPA2009/WPA2009_WorkingPaper.pdf

United Nations. 2011. World population prospects: the 2010 revision. United Nations, Department of Economic and Social Affairs, Population Division: New York, NY.

United Nations. 2013. World population prospects: The 2012 Revision, Volume I: Comprehensive Tables. United Nations, Department of Economic and Social Affairs, Population Division: New York, NY. http://esa.un.org/wpp/Documentation/publications.htm

van den Heuvel, W.J. 2012. Discrimination against older people. *Reviews in Clinical Gerontology*, **22**(04), 293-300.

Van der Geest, S. 2002. Respect and reciprocity: Care of elderly people in rural Ghana. *Journal of Cross-Cultural Gerontology*, **17**(1), 3-31.

Van Minh, H., Byass, P., Chuc, N.T. and Wall, S. 2010a. Patterns of health status and quality of life among older people in rural Viet Nam. *Global Health Action*, **3**(Supplt 2), 64-69.

Van Minh, H., Huong, D., Wall, S., Chuc, N. and Byass, P. 2010b. Multilevel analysis of covariation in socioeconomic predictors of physical functioning and psychological well-being among older people in rural Vietnam. *BMC Geriatrics*, **10**(1), 7.

Velkoff, V.A. and Kowal, P.R. 2006. Aging in sub-Saharan Africa: the changing demography of the region. In Cohen, B. and Menken, J. (eds), *Aging in sub-Saharan Africa: recommendations for furthering research*. The National Academic Press, Washinton, D.C., 55-91.

Villes, V., Spire, B., Lewden, C., Perronne, C., Besnier, J.M., Garre, M., Chene, G., Leport, C., Carrieri, M.P. and Le Moings, V. 2007. The effect of depressive symptoms at ART initiation on HIV clinical progression and mortality: implications in clinical practice. *Antiviral Therapy*, **12**(7), 1067-74.

Vitaliano, P.P., Young, H.M. and Zhang, J. 2004. Is Caregiving a Risk Factor for Illness? *Current Directions in Psychological Science*, **13**(1), 13-16.

Vitaliano, P.P., Zhang, J. and Scanlan, J.M. 2003. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull*, **129**(6), 946-72.

Vlachantoni, A. 2009. Individualised pensions and women in Greece: caveats and opportunities. Centre for Research on Ageing, School of Social Science, University of Southampton, UK.

Vlachantoni, A. 2010. The demographic characteristics and economic activity patterns of carers over 50: evidence from the English Longitudinal Study of Ageing. *Population Trends*, **141**(1), 54-76.

Vlachantoni, A., Evandrou, M., Falkingham, J. and Robards, J. 2013a. Informal care, health and mortality. *Maturitas*, **74**(2), 114-8.

Vlachantoni, A., Shaw, R.J., Evandrou, M. and Falkingham, J. 2013b. The determinants of receiving social care in later life in England. *Ageing & Society*, **FirstView**, 1-25.

Wallrauch, C., Bärnighausen, T. and Newell, M.-L. 2010. HIV prevalence and incidence in people 50 years and older in rural South Africa. *South African Medical Journal*, **100**(12), 812-814.

Wang, D.W., Zheng, J.M., Kurosawa, M. and Inaba, Y. 2009. Relationships between age and gender differentials in health among older people in China. *Ageing & Society*, **29**, 1141-1154.

Wang, J., Chen, T. and Han, B. 2013. Does co-residence with adult children associate with better psychological well-being among the oldest old in China? *Aging & Mental Health*, **18**(2), 232-239.

Wang, R., Wu, C., Zhao, Y., Yan, X., Ma, X., Wu, M., Liu, W., Gu, Z., Zhao, J. and He, J. 2008. Health related quality of life measured by SF-36: a population-based study in Shanghai, China. *BMC Public Health*, **8**(1), 292.

Westaway, M.S. 2010a. Effects of ageing, chronic disease and co-morbidity on the health and well-being of older residents of Greater Tshwane. *South African Medical Journal*, **100**(1), 35-36.

Westaway, M.S. 2010b. The impact of chronic diseases on the health and well-being of South Africans in early and later old age. *Archives of Gerontology and Geriatrics*, **50**(2), 213-221.

Westaway, M.S. and Maluka, C.S. 2004. Impact of chronic diseases on the health-related quality of life of South Africans. *South African Medical Journal* **94**(12), 937.

Whitehead, M., Dahlgren, G. and Gilson, L. 2001. Developing the policy response to inequities in Health: a global perspective. In *Challengieg inequities in health care: from ethics to action*. Oxford University Press, New York, 309-322.

WHO. 1993. *The ICD-10 classification of mental and behavioural disorders: diagnostic criteria for research (DCR-10)*. World Health Organization, Geneva.

WHO. 2001. Men ageing and health: achieving health across the life span. World Health Organization: Geneva. http://whqlibdoc.who.int/hq/2001/WHO_NMH_NPH_01.2.pdf

WHO. 2004. *ICD-10: International statistical classification of diseases and related health problems*. World Health Organization, Geneva.

WHO. 2008. The global burden of disease: 2004 update. World Health Organization (WHO): Geneva. http://www.who.int/healthinfo/global_burden_disease/2004_report_update/en/index.html

WHO. 2010. Measuring health and disability: manual for WHO Disability Assessment Schedule (WHODAS 2.0) In Üstün, T.B., Kostanjsek, N., Chatterji, S. and Rehm, J. (eds), World Health Organization, Geneva.

WHO. 2011. WHO Study on global AGEing and adult health (SAGE) http://www.who.int/healthinfo/sage/en/index.html [Accessed 01 March 2011]

WHO. 2013. Global causes of death 2000-2011. World Health Organization, Geneva:.http://www.who.int/gho/mortality_burden_disease/causes_death/2000_2011/en/index.html [Accessed 24 October 2013]

WHOQoL Group. 1993. Study protocol for the World Health Organization project to develop a Quality of life assessment instrument (WHOQoL). *Quality of Life Research*, **2**(2), 153-159.

Wilson, A.O., Adamchak, D.J., Nyanguru, A.C. and Hampson, J. 1991. A Study of Well-being of Elderly People in Three Communities in Zimbabwe. *Age and Ageing*, **20**(4), 275-279.

Wilson, M., Allen, D.D. and Li, J.C. 2006. Improving measurement in health education and health behavior research using item response modeling: introducing item response modeling. *Health Education Rresearch*, **21**(Suppl. 1), i4–i18.

Wittenberg, M. and Collinson, M.A. 2007. Household transitions in rural South Africa, 1996-2003. *Scandinavian Journal of Public Health*, **35**, 130-137.

Woolard, I., Harttgen, K. and Klasen, S. 2011. The history and impact of social security in South Africa: experiences and lessons. *Canadian Journal of Development Studies*, **32**(4), 357-380.

Woolard, I. and Klasen, S. 2005. Determinants of income mobility and household poverty dynamics in South Africa. *Journal of Development Studies*, **41**(5), 865-897.

Wouters, E., Heunis, C., van Rensburg, D. and Meulemans, H. 2009. Physical and emotional health outcomes after 12 months of public-sector antiretroviral treatment in the Free State Province of South Africa: a longitudinal study using structural equation modelling. *BMC Public Health*, **9**, 103.

Xavier Gomez-Olive, F., Thorogood, M., Clark, B.D., Kahn, K. and Tollman, S.M. 2010. Assessing health and well-being among older people in rural South Africa. *Global Health Action*, **3**(Supplt 2), 23-35.

Yount, K.M. and Agree, E.M. 2005. Differences in Disability among Older Women and Men in Egypt and Tunisia. *Demography*, **42**(1), 169-187.

Zaidi, J., Grapsa, E., Tanser, F., Newell, M.L. and Bärnighausen, T. 2013. Dramatic increases in HIV prevalence after scale-up of antiretroviral treatment: a longitudinal population-based HIV surveillance study in rural Kwazulu-Natal. *AIDS*, **27**(14), 2301-2305.

Zhang, Z. 2008. The effects of adult children's caregiving on the health status of their elderly parents: protection or selection? In Yi, Z., Poston, D.L., Vlosky, D.A. and Gu, D. (eds), *Healthy Longevity in China*. Springer Netherlands, 251-268.

Zimmer, Z., Chayovan, N., Lin, H.-S. and Natividad, J. 2004. How indicators of socioeconomic status relate to physical functioning of older adults in three Asian societies. *Research on Aging*, **26**(2), 224-258.

Zimmer, Z. and Dayton, J. 2003. The Living Arrangements of Older Adults in Sub-Saharan Africa in a Time of HIV/AIDS. No 169. Population Council: New York.

Zimmer, Z., Natividad, J., Lin, H.-S. and Chayovan, N. 2000. A Cross-national Examination of the Determinants of Self-assessed Health. *Journal of Health and Social Behavior*, **41**(4), 465-481.

Appendices

Appendix 1: List of publications and co-author contributions

Manuscripts already published

1. Nyirenda, M.; Evandrou, M.; Mutevedzi, P.; Hosegood, V.; Falkingham, J.C.; Newell, M-L.. *Who cares? Implications of care-giving and -receiving by HIV-infected or -affected older people on functional disability and emotional wellbeing.* Ageing & Society. 2013;FirstView:1-34. doi:10.1017/S0144686X13000615. URL: http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9000197.

Author contribution: MN performed the statistical analyses and drafted the manuscript. MN and PCM were co-principal investigators and actively participated in conception, study design, participant sampling, data collection and supervision of WOPS. ME, VH, JF and MLN gave constructive comments on the draft manuscript.

Presented in: Chapter Three

2. Nyirenda, M.; Chatterji, S.; Falkingham, J.C.; Mutevedzi, P.; Hosegood, V.; Evandrou, M.; Kowal, P. ; Newell, M-L.. *An investigation of factors associated with the health and well-being of HIV-infected or HIV-affected older people in rural South Africa.* BMC public health. 2012; 12(1):259. doi:10.1186/1471-2458-12-259. URL: http://www.biomedcentral.com/1471-2458/12/259.

Author contribution: MN conceptualized the analysis; participated in data collection, co-ordination; performed the statistical analysis and drafted the manuscript. SC, PK, MN, PM and MLN conceived and participated in the design of the WOPS study. JF, ME, PK, VH and MLN gave constructive comments on the draft manuscript.

Presented in: Chapter Four

Manuscripts not yet published

1. *Household living arrangements and having an income in old age: Implications for intergenerational support in rural South Africa*

Presented in: Chapter Two

2. M. Nyirenda, M-L. Newell, M. Evandrou, and J.C. Falkingham. *The influence of informal care, self-reported health status and HIV on older people's mortality levels and patterns* (submitted to PLoS One Journal)

Author contribution: MN conceptualized the study, performed the statistical analysis and drafted the manuscript; also actively participated in data collection and study co-ordination. MLN, ME and JCF gave constructive comments on the draft manuscript.

Presented in: Chapter Five

Appendix 2: Depression and older people in rural South Africa

Prevalence and correlates of depression among HIV-infected and -affected older people in rural South Africa

M. Nyirenda, S. Chatterji, T. Rochat, P. Mutevedzi, M-L. Newell[11]

Abstract

Background: Little is known about depression in older people in sub-Saharan Africa, the associated impact of HIV, and the influence on health perceptions.

Objectives: Examine the prevalence and correlates of depression; explore the relationship between depression and health perceptions in HIV-infected and -affected older people.
Methods: In 2010, 422 HIV-infected and -affected participants aged 50+ were recruited into a cross-sectional study. Nurse professionals interviewed participants and a diagnosis of depressive episode was derived from the Composite International Diagnostic Interview (Depression module) using the International Classification of Diseases diagnostic criteria and categorised as major (MDE) or brief (BDE).

Results: Overall, 42.4% (n=179) had a depressive episode (MDE: 22.7%, n=96; BDE: 19.7%, n=83). Prevalence of MDE was significantly higher in HIV-affected (30.1%, 95% CI 24.0-36.2%) than HIV-infected (14.8%, 95% CI 9.9-19.7%) participants; BDE was higher in HIV-infected (24.6%, 95% CI 18.7-30.6%) than in HIV-affected (15.1%, 95% CI 10.3-19.8%) participants. Being female (aOR 3.04, 95% CI 1.73-5.36), receiving a government grant (aOR 0.34, 95% CI 0.15-0.75), urban residency (aOR 1.86, 95% CI 1.16-2.96) and adult care-giving (aOR 2.37, 95% CI 1.37-4.12) were significantly associated with any depressive episode. Participants with a depressive episode were 2-3 times more likely to report poor health perceptions.

Limitations: Study limitations include the cross-sectional design, limited sample size and possible selection biases.

Conclusions: Prevalence of depressive episodes was high. Major depressive episodes were higher in HIV-affected than HIV-infected participants. Psycho-social support similar to that of HIV treatment programmes around HIV-affected older people may be useful in reducing their vulnerability to depression.

Key words: Depression; major depressive episode; brief depressive episode; older people; HIV-infected; South Africa.

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Background

Depression is a leading cause of disease burden globally (Collins, et al., 2011; Mathers and Loncar, 2006; Patel, Boyce, Collins *et al.*, 2011), and with the growing proportions of older people, the overall numbers of people with depressive symptoms are expected to rise. Projections suggest that by 2030 unipolar depressive disorders will contribute 6.2% to the global burden of disease in terms of disability-adjusted life years, roughly equal to the contribution of heart disease (WHO, 2008). Estimates of depression in older people vary widely across regions and populations. Early estimates from a systematic review of community-based studies of older people put the weighted average of major depression at about 2% (Beekman, Copeland and Prince, 1999). More recently, substantially higher estimates have been reported from various settings: between 8% and 20% (Barry, Allore, Guo *et al.*, 2008; Beekman, Deeg, Geerlings *et al.*, 2001; Blazer, 2003); in a European study, estimated prevalence ranged from 18% in Denmark to 37% in Spain (Castro-Costa, Dewey, Stewart *et al.*, 2007) and a review of studies in Africa, South America and Asia reported estimates from 11% to 53% (Akena, et al., 2012). However, a recent study from South Africa reported a low prevalence of depression in older people of 4% (Peltzer and Phaswana-Mafuya, 2013). Overall, the prevalence of depression in older people in sub-Saharan Africa remains poorly quantified, partly because it is rarely diagnosed in the public health care systems, partly because older people are seldom research subjects, and lastly because differences in diagnostic methodology hinder the interpretation of differences in prevalence estimates (Robins and Cottler, 2004).

While frequently under-diagnosed, depression in older people is fairly commonplace and debilitating (Lapid and Rummans, 2003; Reynolds, Haley and Kozlenko, 2008); is associated with increased disability (Arnow, Hunkeler, Blasey *et al.*, 2006; Castro-Costa, et al., 2007); increased burden on public health service utilization (García-Peña, Wagner, Sánchez-Garcia *et al.*, 2008; Lapid and Rummans, 2003; Rowan, Davidson, Campbell *et al.*, 2002) and increased risk of mortality (Antelman, et al., 2007; Snowden, Steinman and Frederick, 2008). Older people are also at risk of other chronic morbidities such as hypertension, arthritis, heart disease and diabetes (Christensen, Doblhammer, Rau *et al.*, 2009; He, Muenchrath and Kowal, 2012; Mayosi, et al., 2009a); the management and outcomes of which may be impacted by undiagnosed depression (Demyttenaere, Bruffaerts, Posada-Villa *et al.*, 2004). When depression occurs in the context of these chronic diseases it is known to complicate help-seeking, diagnosis (Cuijpers, de Graaf and van Dorsselaer, 2004; Pilling, Anderson, Goldberg *et al.*, 2009) and can adversely impact health status (Moussavi, Chatterji, Verdes *et al.*, 2007) and adherence to medical treatments (Andrews, 2001; Kagee, 2010).

Sub-Saharan Africa faces a triple burden of HIV, TB and chronic disease epidemics. In South Africa, communicable and non-communicable disease burden is high (Coovadia, et al., 2009; Karim, Churchyard, Karim *et al.*, 2009; Mayosi, Flisher, Lalloo *et al.*, 2009b) as is the burden of depression (Tomlinson, Grimsrud, Stein *et al.*, 2009). Psychological distress has been associated with HIV as well as hypertension and diabetes (Kagee, 2010). However, the relationship between depression and HIV is complex (Gupta, Dandu, Packel *et al.*, 2010). Some studies report a HIV diagnosis to be associated with becoming depressed (Boarts, Buckley-Fischer, Armelie *et al.*, 2009; Hand, Phillips and Dudgeon, 2006), while others report that depression is associated with rapid HIV disease progression (Ickovics, Hamburger, Vlahov *et al.*, 2001) either directly, or through inconsistent use or poor adherence to antiretroviral treatment (Carrico, Riley, Johnson *et al.*, 2011; Gonzalez, Batchelder, Psaros *et al.*, 2011). There is even evidence of an increased risk of onset of HIV-related dementia among depression patients (Farinpour, Miller, Satz *et al.*, 2003), but less information on the impact of antiretroviral treatment (ART) on this relationship.

In Southern Africa older people have been shown to have a higher burden of HIV than previously expected (Mutevedzi and Newell, 2011; Negin and Cumming, 2010; Wallrauch, Bärnighausen and Newell, 2010), and are frequently caregivers of children and young adults (Richter and Desmond, 2008). Little is however known of the prevalence and correlates of depression in older people by HIV status or how this may impact on their health perceptions. The aim of this analysis was to examine the prevalence and correlates of depression in HIV-infected and HIV-affected older people living in a rural area of South Africa heavily affected by HIV. We also explored the relationship between depression and self-reported health.

Methods

Research context

The Wellcome Trust-funded Africa Centre for Health and Population Studies (www.africacentre.com) is based in rural northern KwaZulu-Natal, South Africa and is heavily affected by HIV (Tanser, et al., 2008). The Africa Centre carries out socio-demographic and HIV surveillance in a geographically defined area in the south of the Hlabisa sub-district. The population in the Demographic Surveillance Area (DSA) covers about 40% of that of the sub-district. Approximately 11,500 households, with approximately 90,000 resident and non-residents members, are visited twice a year since 2000. Nested within the household surveillance cohort is the population-based HIV cohort which started in 2003. Between 2003 and 2006, all women aged 15-49 years and men aged 15-54 years resident in the surveillance area were eligible for HIV testing. From 2007, eligibility was extended to all residents aged ≥ 50 years of age. In addition, there is extensive Geographic Information System (GIS) location information of all structures in the Surveillance, including homes, clinics, and roads (Tanser, et al., 2008; Tanser, Hosegood, Benzler *et al.*, 2001).

The Health and Well-being of Older People Study (WOPS)

Data used for this analysis was collected as part of a cross-sectional study called the 'Health and Well-being of Older People Study (WOPS)'. In this World Health Organisation (WHO) supported study inclusion criteria required participants to be: aged 50 years or above; members of the Africa Centre for Health and Population Studies Demographic Surveillance System (ACDIS) (Tanser, et al., 2008); and resident in the surveillance area during the study period (March - August 2010). WOPS and some of the main findings regarding the health status of older people are described in detail elsewhere (Nyirenda, et al., 2012). The WOPS study was endorsed by the Africa Centre community advisory board (CAB) on behalf of the study community. All participants in the study provided written informed consent. The University of KwaZulu-Natal Biomedical Research Ethics Committee provided ethical approval of the study (Ref No. BF136/09).

Sampling strategy

Given that HIV infection, HIV treatment and/ or HIV burden in the household may affect depression status, the sample was selected using stratified random sampling of older people aged 50 years and above in four groups of:

1. Older persons who were HIV-infected and on ART for a year or longer;
2. Older persons who were HIV-infected but not yet on ART or on ART for up to 3 months;
3. Older persons living with an adult HIV infected offspring (18-49 years) who is on ART; and
4. Older persons with an adult child who died of HIV-related causes.

Participants could belong to only one of the four groups. For the few individuals who were HIV-infected but also had an HIV-infected adult or HIV-related death of an adult offspring, their

own HIV-status was prioritised and assigned to either group 1 or 2, as applicable. The sampling frame identified 241, 117, 662 and 142 participants eligible for groups 1 to 4 respectively, from which 100 participants were randomly selected for each group. Participants in groups 1 and 2 were later categorised as 'HIV-infected', while those in groups 3 and 4 were categorised as 'HIV-affected'. All sampled individuals were visited at their homesteads and if other older people 50+ who met the eligibility criteria were found at the homesteads they were similarly invited to participate in the study; the final sample consisted of 422 older people aged 50+.

Depression assessment

A shortened version of the WHO Study on Global Ageing (SAGE) instrument (WHO, 2011) was used, including a set of questions on depressive symptoms adapted from the Composite International Diagnostic Interview (CIDI 3.0) depression module (Kessler and Ustun, 2004) translated into the local language, IsiZulu, using a standard WHO translation protocol involving translation, back-translation and review by bilingual experts. The study questionnaires were administered in face-to-face interviews by two IsiZulu-speaking professional nurses.

In determining depression status, two sources of information were used. Initially all study participants were asked to report whether they had ever been diagnosed or told by a health professional that they had depression; we expected only a very small number of study participants to ever have been formally diagnosed with depression (Lapid and Rummans, 2003). Second, participants were asked a set of questions based on CIDI 3.0 to assess the likelihood of them having had a depressive episode within the 12 months prior to the interview. These symptomatology questions can be categorised into two criteria sets based on the International Classification of Diseases 10th edition, Diagnostic Criteria for Research for depressive episode (ICD 10-DCR) (WHO, 1993). Criteria A symptoms ask about feeling sad or empty (depressed mood), loss of interest in things one usually enjoys doing (loss of interest) and feeling decreased energy or tired all the time (fatigue). Participants experiencing one or more of the Criteria A symptoms in the previous 12 months were then asked to respond to questions on the Criteria B symptoms, which include loss of appetite, worry and anxiety, sleep deprivation, suicide ideation, psychomotor restlessness, loss of confidence, concentration difficulties, hopelessness and loss of interest in sex.

Presence of a depressive episode in the past year was determined based on the ICD 10-DCR. Persistence of symptoms and duration, required by the ICD 10 DCR, were determined by questions about whether the period of depressed mood, loss of interest or fatigue lasted for 'most of the day, nearly every day' for 2 weeks or more. We categorised episodes as major depressive episode (MDE) if the symptom criteria were met, were persistent (most of the day, nearly every day) and had lasted for 2 weeks or more. Symptoms of less than two weeks duration were categorized as a brief depressive episode (BDE).

Literature suggests that recent bereavement is associated with increased presentation of depressive symptoms (Fiske, Gatz and Pedersen, 2003; Yunming, Changsheng, Haibo *et al.*, 2012) and thus may lead to over-estimation of depression. Although the prevalence of a MDE or any depressive episode (MDE and BDE combined) was highest in participants who had experienced a recent HIV-related death of an adult offspring, excluding this group did not significantly change our findings or their interpretations. We thus did not exclude this group from the final results presented here.

Data analysis

During data analysis, because previous research has shown that the health and well-being of older people is affected by socio-demographic, economic and household living-arrangement

factors (Nyirenda, et al., 2012; Scholten, et al., 2011), we controlled for these factors when examining correlates of depression in HIV-infected and HIV-affected older people. Specifically, these factors included: age (50-59, 60-69, 70-79 and 80+ years); sex (male or female); marital status (never married, currently married, previously married); source of income (none, government grants, other); educational attainment (no formal education, primary, secondary); place of residence (rural or urban); household socio-economic status using an index based on asset ownership (McKenzie, 2005) and care-giving.

Chi square statistics were used to explore socio-demographic characteristics of participants by depression status; multivariable logistic regressions were used to determine the associations between the socio-demographic factors and depression. We further examined in logistic regressions the relationship of depression with a composite health status score that combines multiple items covering functioning in a range of domains broken down by tertiles that we labelled good, moderate or poor, as detailed previously (Nyirenda, et al., 2012; Nyirenda, et al., 2013c). All statistics were 2-tailed and a p-value <0.05 was used to determine statistical significance. All data were analysed using Stata 11.

Results

Of the 422 older people included in the study, only a very small proportion, 3% (n=12), reported that they had ever been diagnosed or told by a health professional that they had depression; 3 of the 12 reported taking medication for depression in the two weeks prior to the interview. About one third of participants (36%, n=152) did not report any criteria A symptoms; 15% (n=63) had one; 24% (n=100) two and 25% (n=107) three Criterion A symptoms. With regard to Criterion B symptoms, 64% (n=269) reported at least one of these symptoms. Excluding the 36% (n=153) without Criterion B symptoms, the median number of Criterion B symptoms reported was 4 (IQR 2); the four most commonly reported symptoms were sleep deprivation, psychomotor restlessness, worry and anxiety, and loss of confidence.

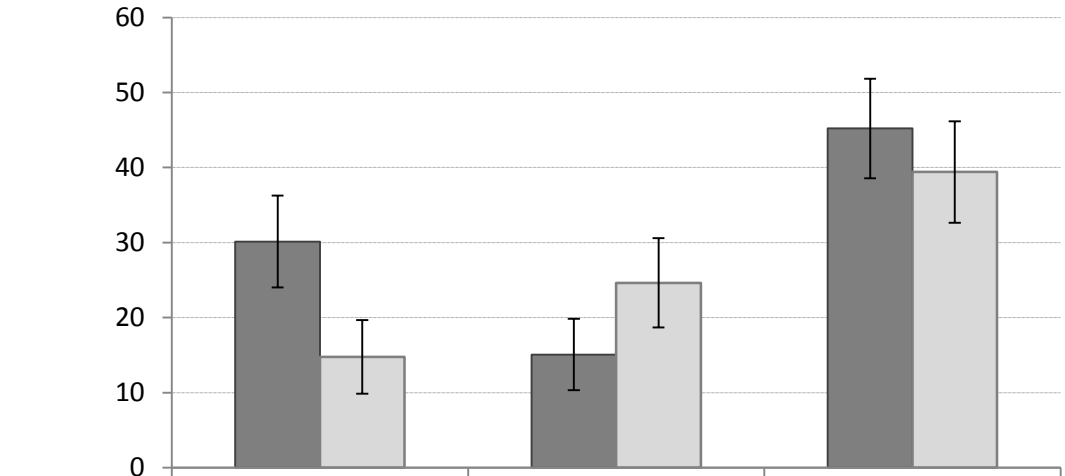
Table 1: Prevalence levels of depressive episodes in HIV-infected or HIV-affected older people, rural South Africa

	Major depressive episode	Brief depressive episode	Any depressive episode
	% (95% CI)	% (95% CI)	% (95% CI)
Older people on HIV treatment for 1 year or longer	14.0 (7.1 - 20.9)	25.0 (16.4 - 33.6)	39.0 (29.4 - 48.6)
Older people not yet on ART or on ART for 3 months or less	15.5 (8.5 - 22.6)	24.3 (15.9 - 32.6)	39.8 (30.3 - 49.3)
Older people with an HIV-infected adult offspring	21.5 (13.7 - 29.3)	15.0 (8.1 - 21.8)	36.4 (27.3 - 45.6)
Older people who had experienced an HIV-related adult death	38.4 (29.3 - 47.5)	15.2 (8.5 - 21.9)	53.6 (44.3 - 62.9)
Overall	22.7 (18.7 - 26.8)	19.7 (15.9 - 23.5)	42.4 (37.7 - 47.2)
n	96	83	179

Table 1 presents the prevalence of depressive episodes, based on reported symptoms, disaggregated into the four groups, and for the overall sample. Overall, 42.4% (n=179) had a depressive episode in the preceding 12 months; 22.7% (n=96) had MDE and 19.7% (n=83) had

BDE. The prevalence of any depressive episode was highest in older people who had experienced an HIV-related death of an adult offspring in the two years prior to interview, followed by older people who were HIV-infected but not yet on ART or on ART for less than 3 months; and the prevalence was lowest in older people with an HIV-infected adult offspring on treatment (Table 1). Our findings further show that the prevalence of MDE was higher in older people with adult offspring who had died of HIV-related cause and in older people with an HIV-infected adult offspring; whereas BDE was highest among HIV-infected older people on ART for a year or longer. This became clearer when the four groups were combined into two groups of HIV-infected and HIV-affected older people. The prevalence of MDE was significantly higher in HIV-affected (30.1%, 95% CI 24.0-36.2%) than HIV-infected (14.8%, 95% CI 9.9-19.7%) participants; while the prevalence of BDE was higher in HIV-infected (24.6%, 95% CI 18.7-30.6%) than in HIV-affected (15.1%, 95% CI 10.3-19.8%) older people (Figure 1).

Figure 1: Prevalence of depression in HIV-infected and HIV-affected older people, rural South Africa



	Major depressive episode	Brief depressive episode	Any depressive episode
HIV-affected	30.1	15.1	45.2
HIV-infected	14.8	24.6	39.4

In multivariable analyses including sex, age, marital status, education, source of income, place of residence, household wealth quintile and caregiving, women were 3 times more likely than men to have had a depressive episode (aOR 3.0, 95% CI 1.7-5.4); and primary or higher level of education was associated with decreased likelihood of a depressive episode, but this was only statistically significant in unadjusted analyses (Table 2). Participants receiving a government grant had a 64% adjusted reduced odds of having had a depressive episode compared to those without any source of income (aOR 0.34, 95% CI 0.15-0.75). Lastly, care-giving to adults (18-49 years) or children (under 18 years) was associated with an increased risk of having experienced a depressive episode, although after adjustment only care-giving to adult offspring remained significantly associated (aOR 2.37, 95% CI 1.37-4.12).

Table 2: Factors associated with having a depressive episode in older people, rural South Africa

Factors	OR [95% CI]	aOR [95% CI]
Sex		
Male	1.00	1.00
Female	2.89 [1.76-4.74]	3.04 [1.73-5.36]
Age group		
50-59	1.00	1.00
60-69	0.82 [0.52-1.31]	0.78 [0.44-1.37]
70-79	1.64 [0.95-2.81]	1.60 [0.80-3.19]
80+	1.92 [0.88-4.18]	1.90 [0.74-4.87]
Marital status		
Never married	1.00	1.00
Married	0.48 [0.30-0.77]	0.58 [0.34-0.99]
Previously married	2.04 [1.18-3.53]	1.24 [0.64-2.41]
Education level		
None	1.00	1.00
Primary	0.52 [0.34-0.80]	0.77 [0.47-1.26]
Secondary or higher	0.52 [0.28-0.97]	0.96 [0.45-2.07]
Source of income		
None	1.00	1.00
Government grants	0.44 [0.22-0.86]	0.34 [0.15-0.75]
Other	0.23 [0.10-0.57]	0.20 [0.07-0.54]
Place of residency		
Rural	1.00	1.00
Urban	1.73 [1.17-2.56]	1.86 [1.16-2.96]
Household socio-economic status in quintiles		
First	1.00	1.00
Second	0.78 [0.43-1.44]	0.98 [0.49-1.98]
Third	0.85 [0.47-1.53]	0.88 [0.44-1.73]
Fourth	0.64 [0.35-1.15]	0.69 [0.35-1.39]
Fifth	0.54 [0.29-1.00]	0.71 [0.33-1.51]
Care-giving to adults (18-49 years)		
No	1.00	1.00
Yes	2.96 [1.98-4.42]	2.37 [1.37-4.12]
Care-giving to children (under 18 years		
No	1.00	1.00
Yes	1.95 [1.31-2.91]	0.96 [0.57-1.63]

Note: OR = Odds ratio; AOR = Adjusted Odds ratio, adjusted for age, sex, marital status, education, source of income, place of residency, household socio-economic status and care-giving

Table 3 presents the relationship between a depressive episode and self-reported health status. Relative to self-reporting good health, older people who reported symptoms of a depressive episode in the past 12 months were more likely to self-report their health status as poor after adjustment for age and sex, which are independently associated with poor self-reported health. Among participants who had experienced a MDE in the past one year, the odds of reporting poor or moderate health status compared to good health status were

statistically significantly higher for older people who were HIV-infected and not yet on ART or on ART for 3 months or less as well as for older people with an HIV-infected adult offspring. There were no significant associations between having had a MDE and self-reported health in older people who were HIV-infected and on ART for a year or longer, or in older people who had experienced an HIV-related death of an adult offspring. Similarly, no significant associations were found for any of the study groups between having had a BDE and self-reported health. Overall, older people with a major depressive episode had about three-fold increased adjusted odds of poor self-reported (aOR 2.68, 95% CI 1.34-5.38); and approximately double the adjusted odds of moderate or poor self-reported health status if they had any depressive episode.

Table 3: Age-sex adjusted odds of the association of depressive episodes with self-reported health status in HIV-infected or HIV-affected older people, rural South Africa

	Major depressive episode	**Brief depressive episode**	**Any Depressive episode**
Self-reported health status as	aOR [95% CI]	aOR [95% CI]	aOR [95% CI]
	Older people on HIV treatment for 1 year or longer		
Good	1.00	1.00	1.00
Moderate	1.42 [0.38-5.26]	1.69 [0.59-4.86]	1.86 [0.71-4.90]
Poor	1.74 [0.28-10.93]	0.76 [0.13-4.43]	1.13 [0.26-4.99]
	Older people not yet on ART or on ART for 3 months or less		
Good	1.00	1.00	1.00
Moderate	9.58 [1.11-82.63]	0.65 [0.22-1.94]	1.65 [0.61-4.46]
Poor	12.81 [1.38-118.58]	1.41 [0.39-5.13]	3.95 [1.18-13.23]
	Older people with an HIV-infected adult offspring		
Good	1.00	1.00	1.00
Moderate	4.96 [1.45-16.95]	1.31 [0.42-4.07]	3.38 [1.35-8.47]
Poor	11.96 [2.30-62.21]	-	2.97 [0.71-12.49]
	Older people who had experienced an HIV-related adult death		
Good	1.00	1.00	1.00
Moderate	1.66 [0.65-4.20]	1.53 [0.43-5.49]	1.93 [0.80-4.62]
Poor	0.86 [0.26-2.82]	3.71 [0.84-16.41]	1.76 [0.57-5.43]
	Overall		
Good	1.00	1.00	1.00
Moderate	2.43 [1.40-4.23]	1.14 [0.66-1.96]	1.98 [1.27-3.09]
Poor	2.68 [1.34-5.38]	1.28 [0.61-2.67]	2.36 [1.28-4.33]

Discussion

Prevalence of depression in older people

This study is one of the first assessments of depression among older people in a rural population in Southern Africa, a setting heavily affected by HIV, TB and chronic illness (Houlihan, Mutevedzi, Lessells *et al.*, 2010; Wallrauch, Heller, Lessells *et al.*, 2010). Based on the ICD10-DCR, we found that nearly half of all study participants had experienced a depressive episode in the 12 months prior to the survey, and just over one in five had experienced a major depressive episode in the same time period. The prevalence of depression in this study was similarly high to that reported in other studies (Akena, et al., 2012; Castro-Costa, et al., 2007), but higher than reported by Peltzer and Phaswana-Mafuya

(2013). The elevated levels of depression in our sample, when major and minor depressive episodes are combined, could be due to the nature of the population: our study participants live in a setting severely affected by HIV and all participants were either HIV-infected themselves or HIV-affected. As Bor and others (2012) showed, in 2010 around 40% of people in the study area lived in a household with at least one person who had accessed the HIV treatment programme. Research with another high risk population of pregnant women in this community also reported high depression prevalence (47%) using interviewers trained in the structured clinical interview for DSM-IV (Rochat, et al., 2011). Although the estimated prevalence of depression, on the basis of reported symptoms, in our study was high, only a very small proportion of the study participants reported ever having been diagnosed with depression by a health worker and a few of those were on treatment. This is not surprising since depression screening in primary health care system in South Africa, as in many low and middle income countries (LMIC), is not routine, even among older people at high risk of depression (Gupta, et al., 2010; Luijendijk, van den Berg, Dekker *et al.*, 2008).

Given that depression is rarely diagnosed but can have serious debilitating effects on older people (Reynolds, Haley and Kozlenko, 2008), it is vital to combine major and brief depressive episodes to get a fuller picture of the scale of the problem. As noted by Lee and others (2012) emphasising only major depression would leave many, in our case one in five, undiagnosed, untreated and at increased risk of multiple morbidities (Castro-Costa, et al., 2007; Lapid and Rummans, 2003) and mortality (Antelman, et al., 2007; Snowden, Steinman and Frederick, 2008). Some evidence suggests that mild to moderate depression can have as significant an impact on health functioning as severe depression, in particular in low income groups (Ayuso-Mateos, Nuevo, Verdes *et al.*, 2010; Lee, et al., 2012; Meeks, Vahia, Lavretsky *et al.*, 2011).

Predictors of depression in older people

Variables significantly associated with increased chances of having a depressive episode included being female, having no source of regular income, living in an urban area and being a care-giver, in particular to an adult offspring. We also show that older people who had experienced a depressive episode in the preceding 12 months were 2 to 3 times more likely to report their health status as moderate or poor. However, the results for specific groups of older people such as the group of participants who were not yet on ART, or on ART for less than 3 months, and older people with an HIV-infected adult offspring should be interpreted with caution given the wide confidence intervals and small sample sizes.

Our results suggests that the well-documented poor health status of older women relative to men (Arber and Cooper, 1999; Yount and Agree, 2005) is not restricted to reporting of disability but is pervasive to mental health as well (Rieker and Bird, 2005). It is equally plausible that depression may influence the health reporting of these women, since depression is known to influence thoughts and perceptions negatively and to reduce problem solving (Patel, Simon, Chowdhary *et al.*, 2009). It has long been known that women are particularly vulnerable to both depression and HIV, and it seems likely, given that women carry a disproportioned burden of caregiving in most low and middle income settings, that the effects of depression extend to impact on the family and the quality of care, rather than being limited to the individual. In earlier analyses (Nyirenda, et al., 2013c) we found that 2 in 3 of the older people were care-givers to at least one adult offspring or child; and as seen in other studies, a higher proportion of older people are main care-givers to HIV-infected adults and to children they leave behind orphaned (Hill, Hosegood and Newell, 2008; Schatz, 2007; Ssengonzi, 2007). Here we show a strong association between care-giving, especially to adults, and having a depressive episode. This may partly contribute to our other major finding that the prevalence of having had a major depressive episode was significantly higher in HIV-affected (30.1%, 95% CI 24.0-36.2%) than HIV-infected (14.8%, 95% CI 9.9-19.7%) older people. The Hlabisa HIV

treatment and care programme, as in the rest of South Africa, is mostly nurse and counsellor led and follows the South African Department of Health (DoH) guidelines (Houlihan, et al., 2011). Older people who are HIV-infected usually receive psychosocial counselling before, during and after HIV testing. HIV-infected people are further encouraged to have a 'support-buddy' to help them with managing their HIV status. A qualitative study of 30 HIV-infected older women aged 60 years and older demonstrated how a psycho-socio-environmental support model was useful in helping older people come to terms with their physical, mental and social well-being in the context of HIV (Schatz and Gilbert, 2012). Such a support structure around an older person who is HIV-uninfected but giving care to an HIV-infected adult or who has to deal with an HIV-related death in the household may not be readily available, which may explain the higher levels of depressive episodes we find among HIV-affected older people.

Our findings adjusting for age and other socio-demographic factors show that older adults accessing government grants were nearly two-thirds less likely to have had a depressive episode in the preceding 12 months than those without a source of income. These findings are consistent with previous findings from South Africa which show that older adults who were in receipt of government old-age pension grants had decreased risk of having common mental disorders (CMD) (Plagerson, et al., 2010) and presents a supportive case for the government to consider a universal old-age grant for all older persons, unlike the present case were it is means-tested. The government should also consider some welfare support to older persons aged 50-59 years without an income but not yet age-eligible for the old-age pension grant. In rural areas such as in our study area there is wide spread deprivation with around 82% of households living in poverty (Fiorenza, Candy and Peter, 2009) as such nearly all older people in the area are vulnerable and in need to welfare support. Even though the relationship between income support and mental health is complex and poorly understood in LMIC settings (Lund, Breen, Flisher *et al.*, 2010; Lund, De Silva, Plagerson *et al.*, 2011), the known benefits of a pension grant for the entire household (Booysen, 2004; Case and Menendez, 2007b) and our finding of grant recipients being associated with lower odds of having a depressive episode may well justify this policy recommendation of a universal old-age grant. Furthermore, the important role played by older caregivers in Africa should not be underestimated, for example in South Africa, the presence of an older aged adult in receipt of a pension grant can significantly increase the odds of improved growth and education outcomes for children (Case and Menendez, 2007b; Richter and Desmond, 2008). As such depression amongst older caregivers may significantly impact on the wellbeing of households more generally.

Depression and health perceptions

Depression may adversely influence the health status of older adults, and adversely impact health seeking behaviour (Barney, et al., 2006). We found that persons with a depressive episode were more likely to self-report their health as poor. This appears to support previous findings which show co-morbidities between chronic conditions (e.g angina, diabetes, arthritis and asthma) and depression are common (Moussavi, et al., 2007). Our results are thus in line with other studies showing depressed people are highly likely to consume more health care services than non-depressed people (Rowan, Davidson, Campbell et al., 2002; Lapid and Rummans, 2003; García-Peña, Wagner, Sánchez-Garcia et al., 2008). The increased likelihood that self-reported health was moderate or poor in older people with a depressive episode may partially explain this increased health service utilization. If depression screening is not routinely carried out but these symptoms are assumed to be normal symptoms of ageing instead (Lapid and Rummans, 2003), depression is likely to go undiagnosed and untreated (Reynolds, Haley and Kozlenko, 2008). Depressed older people are then also highly likely to return repeatedly to health facilities (Luber, Meyers, Williams-Russo *et al.*, 2001) becoming a serious burden on already resource-constrained health facilities.

Conclusions

Our findings suggest very high levels of either inadequate recognition or inadequate treatment of depression among older people in rural South Africa, with higher prevalence of major depressive episode in HIV-affected than in HIV-infected older people. Women, those with no source of income and care-givers were particularly vulnerable to reporting symptoms suggestive of depression. These vulnerable groups should be targeted for any intervention in the form of psycho-social and financial support. In populations with a severe HIV burden, psycho-social support should also be available to HIV-uninfected older people to reduce their risk of having a depressive episode, especially as they often face the burden of caring for HIV-infected adults and orphans. This study sheds some light on the prevalence and correlates of depression in HIV-infected or HIV-affected older people in rural Africa, but further research is needed to inform understanding of the nuanced nature in which depression relates to HIV status of older people particularly using longitudinal population-based data sources.

Limitations

Data for this analysis came from a cross-sectional study, and causality cannot be inferred. Further, the levels of depression reported are based on self-reports of depression symptoms rather than a formal clinical diagnosis, and participants could have over-or under- reported their symptoms. We are unable to test the extent to which this misreporting could have influenced our results, but our findings are likely to be valid since they are consistent with results by others in similar study settings (Akena, et al., 2012; Olley, Seedat, Nei *et al.*, 2004; Rochat, et al., 2011). Recall bias in the reporting of depressive symptoms or diagnosis due to social stigma associated with depression could also have played a role, as could memory lapse due to cognitive functioning decline with age, but again the similarity of our estimated prevalence of depression compared to that in other studies is re-assuring.

References

Akena, D., Joska, J., Obuku, E. A., Amos, T., Musisi, S., Stein, D. J. 2012. Comparing the accuracy of brief versus long depression screening instruments which have been validated in low and middle income countries: a systematic review. *BMC psychiatry,* 12**,** 187.

Andrews, G. 2001. Should depression be managed as a chronic disease? *BMJ (Clinical research ed,* 322**,** 419-421.

Antelman, G., Kaaya, S., Wei, R., Mbwambo, J., Msamanga, G. I., Fawzi, W. W., Fawzi, M. C. 2007. Depressive symptoms increase risk of HIV disease progression and mortality among women in Tanzania. *Journal of Acquired Immune Deficiency Syndrome,* 44**,** 470-477.

Arber, S., Cooper, H. 1999. Gender differences in health in later life: the new paradox? *Social Science & Medicine,* 48**,** 61-76.

Arnow, B. A., Hunkeler, E. M., Blasey, C. M., Lee, J., Constantino, M. J., Fireman, B., Kraemer, H. C., Dea, R., Robinson, R., Hayward, C. 2006. Comorbid depression, chronic pain, and disability in primary care. *Psychosomatic medicine,* 68**,** 262-268.

Ayuso-Mateos, J. L., Nuevo, R., Verdes, E., Naidoo, N., Chatterji, S. 2010. From depressive symptoms to depressive disorders: the relevance of thresholds. *Br J Psychiatry,* 196**,** 365-71.

Barney, L. J., Griffiths, K. M., Jorm, A. F., Christensen, H. 2006. Stigma about depression and its impact on help-seeking intentions. *Australian and New Zealand Journal of Psychiatry,* 40**,** 51-54.

Barry, L. C., Allore, H. G., Guo, Z., Bruce, M. L., Gill, T. M. 2008. Higher burden of depression among older women: the effect of onset, persistence, and mortality over time. *Archives of general psychiatry,* 65**,** 172-8.

Beekman, A. T., Copeland, J. R., Prince, M. J. 1999. Review of community prevalence of depression in later life. *Br J Psychiatry,* 174**,** 307-11.

Beekman, A. T., Deeg, D. J., Geerlings, S. W., Schoevers, R. A., Smit, J. H., Van Tilburg, W. 2001. Emergence and persistence of late life depression: a 3-year follow-up of the Longitudinal Aging Study Amsterdam. *J Affect Disord,* 65**,** 131-8.

Blazer, D. G. 2003. Depression in late life: review and commentary. *J Gerontol A Biol Sci Med Sci,* 58**,** 249-65.

Boarts, J. M., Buckley-Fischer, B. A., Armelie, A. P., Bogart, L. M., Delahanty, D. L. 2009. The impact of HIV diagnosis-related vs. non-diagnosis related trauma on PTSD, depression, medication adherence, and HIV disease markers. *Journal of evidence-based social work,* 6**,** 4-16.

Booysen, F. 2004. Social grants as safety net for HIV/AIDS-affected households in South Africa. *SAHARA J : journal of Social Aspects of HIV/AIDS Research Alliance / SAHARA , Human Sciences Research Council,* 1**,** 45-56.

Bor, J., Tanser, F., Newell, M. L., Barnighausen, T. 2012. In a study of a population cohort in South Africa, HIV patients on antiretrovirals had nearly full recovery of employment. *Health Aff (Millwood),* 31**,** 1459-69.

Carrico, A. W., Riley, E. D., Johnson, M. O., Charlebois, E. D., Neilands, T. B., Remien, R. H., Lightfoot, M. A., Steward, W. T., Weinhardt, L. S., Kelly, J. A., Rotheram-Borus, M. J., Morin, S. F., Chesney, M. A. 2011. Psychiatric Risk Factors for HIV Disease Progression: The Role of Inconsistent Patterns of Antiretroviral Therapy Utilization. *JAIDS Journal of Acquired Immune Deficiency Syndromes,* 56**,** 146-150 10.1097/QAI.0b013e318201df63.

Case, A., Menendez, A. 2007. Does money empower the elderly? Evidence from the Agincourt demographic surveillance site, South Africa. *Scandinavian journal of public health,* 35**,** 157-64.

Castro-Costa, E., Dewey, M., Stewart, R., Banerjee, S., Huppert, F., Mendonca-Lima, C., Bula, C., Reisches, F., Wancata, J., Ritchie, K., Tsolaki, M., Mateos, R., Prince, M. 2007. Prevalence of depressive symptoms and syndromes in later life in ten European countries: the SHARE study. *Br J Psychiatry,* 191**,** 393-401.

Christensen, K., Doblhammer, G., Rau, R., Vaupel, J. W. 2009. Ageing populations: the challenges ahead. *Lancet,* 374**,** 1196-208.

Collins, P. Y., Patel, V., Joestl, S. S., March, D., Insel, T. R., Daar, A. S., Bordin, I. A., Costello, E. J., Durkin, M., Fairburn, C. 2011. Grand challenges in global mental health. *Nature,* 475**,** 27-30.

Coovadia, H., Jewkes, R., Barron, P., Sanders, D., Mcintyre, D. 2009. The health and health system of South Africa: historical roots of current public health challenges. *The Lancet,* 374**,** 817-834.

Cuijpers, P., De Graaf, R., Van Dorsselaer, S. 2004. Minor depression: risk profiles, functional disability, health care use and risk of developing major depression. *Journal of affective disorders,* 79**,** 71-79.

Demyttenaere, K., Bruffaerts, R., Posada-Villa, J., Gasquet, I., Kovess, V., Lepine, J. P., Angermeyer, M. C., Bernert, S., De Girolamo, G., Morosini, P., Polidori, G., Kikkawa, T., Kawakami, N., Ono, Y., Takeshima, T., Uda, H., Karam, E. G., Fayyad, J. A., Karam, A. N., Mneimneh, Z. N., Medina-Mora, M. E., Borges, G., Lara, C., De Graaf, R., Ormel, J., Gureje, O., Shen, Y., Huang, Y., Zhang, M., Alonso, J., Haro, J. M., Vilagut, G., Bromet, E. J., Gluzman, S., Webb, C., Kessler, R. C., Merikangas, K. R., Anthony, J. C., Von Korff, M. R., Wang, P. S., Brugha, T. S., Aguilar-Gaxiola, S., Lee, S., Heeringa, S., Pennell, B. E., Zaslavsky, A. M., Ustun, T. B., Chatterji, S. 2004. Prevalence, severity, and unmet need for treatment of mental disorders in the World Health Organization World Mental Health Surveys. *JAMA,* 291**,** 2581-90.

Farinpour, R., Miller, E. N., Satz, P., Selnes, O. A., Cohen, B. A., Becker, J. T., Skolasky, R. L., Jr., Visscher, B. R. 2003. Psychosocial risk factors of HIV morbidity and mortality: findings from the Multicenter AIDS Cohort Study (MACS). *J Clin Exp Neuropsychol,* 25**,** 654-70.

Fiorenza, M., Candy, D., Peter, B. 2009. Indicator comparisons by district. *In:* Candy, D., Peter, B., Fiorenza, M., Elliot, S. (eds.) *The District Health Barometer 2007/08.* Durban: Health Systems Trust.

Fiske, A., Gatz, M., Pedersen, N. L. 2003. Depressive symptoms and aging: the effects of illness and non-health-related events. *J Gerontol B Psychol Sci Soc Sci,* 58**,** P320-8.

García-Peña, C., Wagner, F. A., Sánchez-Garcia, S., Juárez-Cedillo, T., Espinel-Bermúdez, C., García-Gonzalez, J. J., Gallegos-Carrillo, K., Franco-Marina, F., Gallo, J. J. 2008. Depressive Symptoms Among Older Adults in Mexico City. *Journal of General Internal Medicine,* 23**,** 1973-1980.

Gonzalez, J. S., Batchelder, A. W., Psaros, C., Safren, S. A. 2011. Depression and HIV/AIDS Treatment Nonadherence: A Review and Meta-analysis. *JAIDS Journal of Acquired Immune Deficiency Syndromes,* 58**,** 181-187 10.1097/QAI.0B013E31822D490A.

Gupta, R., Dandu, M., Packel, L., Rutherford, G., Leiter, K., Phaladze, N., Korte, F. P., Iacopino, V., Weiser, S. D. 2010. Depression and HIV in Botswana: a population-based study on gender-specific socioeconomic and behavioral correlates. *PLoS One,* 5**,** e14252.

Hand, G. A., Phillips, K. D., Dudgeon, W. D. 2006. Perceived stress in HIV-infected individuals: physiological and psychological correlates. *AIDS Care,* 18**,** 1011-7.

He, W., Muenchrath, M., Kowal, P. 2012. Shades of gray: a cross-country study of health and well-being of the older populations in SAGE countries, 2007–2010. Washington DC: US Census Bureau.

Hill, C., Hosegood, V., Newell, M.-L. 2008. Children's care and living arrangements in a high HIV prevalence area in rural South Africa. *Vulnerable Children and Youth Studies,* 3**,** 65-77.

Houlihan, C. F., Bland, R. M., Mutevedzi, P. C., Lessells, R. J., Ndirangu, J., Thulare, H., Newell, M. L. 2011. Cohort profile: Hlabisa HIV treatment and care programme. *International Journal of Epidemiology,* 40**,** 318-26.

Houlihan, C. F., Mutevedzi, P. C., Lessells, R. J., Cooke, G. S., Tanser, F. C., Newell, M. L. 2010. The tuberculosis challenge in a rural South African HIV programme. *BMC Infect Dis,* 10**,** 23.

Ickovics, J., Hamburger, M., Vlahov, D., Schoenbaum, E., Schuman, P., Boland, R., Moore, J., Hiv Epidemiology Research Study Group 2001. Mortality, CD4 cell count decline, and depressive symptoms among HIV-seropositive women: longitudinal analysis from the HIV Epidemiology Research Study. *JAMA,* 285**,** 1466-1474.

Kagee, A. 2010. Psychological distress among persons living with HIV, hypertension, and diabetes. *AIDS Care,* 22**,** 1517-1521.

Karim, S. S. A., Churchyard, G. J., Karim, Q. A., Lawn, S. D. 2009. HIV infection and tuberculosis in South Africa: an urgent need to escalate the public health response. *The Lancet,* 374**,** 921-933.

Kessler, R. C., Ustun, T. B. 2004. The World Mental Health (WMH) Survey Initiative Version of the World Health Organization (WHO) Composite International Diagnostic Interview (CIDI). *International journal of methods in psychiatric research,* 13**,** 93-121.

Lapid, M. I., Rummans, T. A. 2003. Evaluation and management of geriatric depression in primary care. *Mayo Clin Proc,* 78**,** 1423-9.

Lee, M. J., Hasche, L. K., Choi, S., Proctor, E. K., Morrow-Howell, N. 2012. Comparison of major depressive disorder and subthreshold depression among older adults in community long-term care. *Aging & Mental Health***,** 1-9.

Luber, M. P., Meyers, B. S., Williams-Russo, P. G., Hollenberg, J. P., Didomenico, T. N., Charlson, M. E., Alexopoulos, G. S. 2001. Depression and service utilization in elderly primary care patients. *Am J Geriatr Psychiatry,* 9**,** 169-76.

Luijendijk, H. J., Van Den Berg, J. F., Dekker, M. J., Van Tuijl, H. R., Otte, W., Smit, F., Hofman, A., Stricker, B. H., Tiemeier, H. 2008. Incidence and recurrence of late-life depression. *Archives of general psychiatry,* 65**,** 1394-401.

Lund, C., Breen, A., Flisher, A. J., Kakuma, R., Corrigall, J., Joska, J. A., Swartz, L., Patel, V. 2010. Poverty and common mental disorders in low and middle income countries: A systematic review. *Social Science & Medicine,* 71**,** 517-528.

Lund, C., De Silva, M., Plagerson, S., Cooper, S., Chisholm, D., Das, J., Knapp, M., Patel, V. 2011. Poverty and mental disorders: breaking the cycle in low-income and middle-income countries. *The Lancet,* 378**,** 1502-1514.

Mathers, C. D., Loncar, D. 2006. Projections of global mortality and burden of disease from 2002 to 2030. *PLoS Medicine,* 3**,** e442.

Mayosi, B. M., Flisher, A. J., Lalloo, U. G., Sitas, F., Tollman, S. M., Bradshaw, D. 2009a. The burden of non-communicable diseases in South Africa. *The Lancet,* 374**,** 934-947.

Mayosi, B. M., Flisher, A. J., Lalloo, U. G., Sitas, F., Tollman, S. M., Bradshaw, D. 2009b. The burden of non-communicable diseases in South Africa. *Lancet,* 374**,** 934-47.

Mckenzie, D. J. 2005. Measuring inequality with asset indicators. *Journal of Population Economics,* 18**,** 229-260.

Meeks, T. W., Vahia, I. V., Lavretsky, H., Kulkarni, G., Jeste, D. V. 2011. A tune in "a minor" can "b major": A review of epidemiology, illness course, and public health implications of subthreshold depression in older adults. *J of Affect Disord,* 129**,** 126-142.

Moussavi, S., Chatterji, S., Verdes, E., Tandon, A., Patel, V., Ustun, B. 2007. Depression, chronic diseases, and decrements in health: results from the World Health Surveys. *Lancet,* 370**,** 851-8.

Mutevedzi, P. C., Newell, M. L. 2011. A missing piece in the puzzle: HIV in mature adults in sub-Saharan Africa. *Future virology,* 6**,** 755-767.

Negin, J., Cumming, R. G. 2010. HIV infection in older adults in sub-Saharan Africa: extrapolating prevalence from existing data. *Bull World Health Organ,* 88**,** 847-53.

Nyirenda, M., Chatterji, S., Falkingham, J., Mutevedzi, P., Hosegood, V., Evandrou, M., Kowal, P., Newell, M.-L. 2012. An investigation of factors associated with the health and well-being of HIV-infected or HIV-affected older people in rural South Africa. *BMC public health,* 12**,** 259.

Nyirenda, M., Newell, M. L., Mugisha, J., Mutevedzi, P. C., Seeley, J., Scholten, F., Kowal, P. 2013. Health, wellbeing, and disability among older people infected or affected by HIV in Uganda and South Africa. *Glob Health Action,* 6**,** 1-11.

Olley, B. O., Seedat, S., Nei, D. G., Stein, D. J. 2004. Predictors of major depression in recently diagnosed patients with HIV/AIDS in South Africa. *AIDS Patient Care STDS,* 18**,** 481-7.

Patel, V., Boyce, N., Collins, P. Y., Saxena, S., Horton, R. 2011. A renewed agenda for global mental health. *The Lancet,* 378**,** 1441-1442.

Patel, V., Simon, G., Chowdhary, N., Kaaya, S., Araya, R. 2009. Packages of Care for Depression in Low- and Middle-Income Countries. *PLoS Med,* 6**,** e1000159.

Peltzer, K., Phaswana-Mafuya, N. 2013. *Depression and associated factors in older adults in South Africa*.

Pilling, S., Anderson, I., Goldberg, D., Meader, N., Taylor, C. 2009. Depression in adults, including those with a chronic physical health problem: summary of NICE guidance. *BMJ (Clinical research ed,* 339.

Plagerson, S., Patel, V., Harpham, T., Kielmann, K., Mathee, A. 2010. Does money matter for mental health? Evidence from the Child Support Grants in Johannesburg, South Africa. *Glob Public Health***,** 1-17.

Reynolds, S. L., Haley, W. E., Kozlenko, N. 2008. The impact of depressive symptoms and chronic diseases on active life expectancy in older Americans. *Am J Geriatr Psychiatry,* 16**,** 425-32.

Richter, L. M., Desmond, C. 2008. Targeting AIDS orphans and child-headed households? A perspective from national surveys in South Africa, 1995–2005. *AIDS Care,* 20**,** 1019-1028.

Rieker, P. P., Bird, C. E. 2005. Rethinking gender differences in health: why we need to integrate social and biological perspectives. *The journals of gerontology. Series B, Psychological sciences and social sciences,* 60 Spec No 2**,** 40-7.

Robins, L. N., Cottler, L. B. 2004. Making a structured psychiatric diagnostic interview faithful to the nomenclature. *American journal of epidemiology,* 160**,** 808-13.

Rochat, T. J., Tomlinson, M., Barnighausen, T., Newell, M. L., Stein, A. 2011. The prevalence and clinical presentation of antenatal depression in rural South Africa. *J Affect Disord,* 135**,** 362-73.

Rowan, P. J., Davidson, K., Campbell, J. A., Dobrez, D. G., Maclean, D. R. 2002. Depressive symptoms predict medical care utilization in a population-based sample. *Psychological Medicine,* 32**,** 903-908.

Schatz, E., Gilbert, L. 2012. “My heart is very painful”: Physical, mental and social wellbeing of older women at the times of HIV/AIDS in rural South Africa. *Journal of Aging Studies,* 26**,** 16-25.

Schatz, E. J. 2007. "Taking care of my own blood": older women's relationships to their households in rural South Africa. *Scandinavian journal of public health,* 69**,** 147-54.

Scholten, F., Mugisha, J., Seeley, J., Kinyanda, E., Nakubulwa, S., Kowal, P., Naidoo, N., Boerma, T., Chatterji, S., Grosskurth, H. 2011. Health and functional status among older people with HIV/AIDS in Uganda. *BMC public health,* 11**,** 886.

Snowden, M., Steinman, L., Frederick, J. 2008. Treating depression in older adults: challenges to implementing the recommendations of an expert panel. *Prev Chronic Dis,* 5**,** A26.

Ssengonzi, R. 2007. The plight of older persons as caregivers to people infected/affected by HIV/AIDS: evidence from Uganda. *Journal of Cross Cultural Gerontology,* 22**,** 339-53.

Tanser, F., Hosegood, V., Bärnighausen, T., Herbst, K., Nyirenda, M., Muhwava, W., Newell, C., Viljoen, J., Mutevedzi, T., Newell, M.-L. 2008. Cohort Profile: Africa Centre Demographic Information System (ACDIS) and population-based HIV survey. *International Journal of Epidemiology,* 37**,** 956-62.

Tanser, F., Hosegood, V., Benzler, J., Solarsh, G. 2001. New approaches to spatially analyse primary health care usage patterns in rural South Africa. *Trop Med Int Health,* 6**,** 826-38.

Tomlinson, M., Grimsrud, A. T., Stein, D. J., Williams, D. R., Myer, L. 2009. The epidemiology of major depression in South Africa: results from the South African stress and health study. *SAMJ: South African Medical Journal,* 99**,** 368-373.

Wallrauch, C., Bärnighausen, T., Newell, M.-L. 2010a. HIV prevalence and incidence in people 50 years and older in rural South Africa. *S Afr Med J,* 100**,** 812-814.

Wallrauch, C., Heller, T., Lessells, R., Kekana, M., Barnighausen, T., Newell, M. L. 2010b. High uptake of HIV testing for tuberculosis patients in an integrated primary health care HIV/TB programme in rural KwaZulu-Natal. *S Afr Med J,* 100**,** 146-7.

Who 1993. *The ICD-10 classification of mental and behavioural disorders: diagnostic criteria for research (DCR-10),* Geneva, World Health Organization.

Who 2008. The global burden of disease: 2004 update. Geneva: World Health Organization.

Who. 2011. *Health statistics and health information systems* [Online]. Available: http://www.who.int/healthinfo/systems/sage/en/index1.html [Accessed 01 March 2011.

Yount, K. M., Agree, E. M. 2005. Differences in Disability among Older Women and Men in Egypt and Tunisia. *Demography,* 42**,** 169-187.

Yunming, L., Changsheng, C., Haibo, T., Wenjun, C., Shanhong, F., Yan, M., Yongyong, X., Qianzhen, H. 2012. Prevalence and risk factors for depression in older people in Xi'an China: a community-based study. *Int J Geriatr Psychiatry,* 27**,** 31-9.

Appendix 3: Africa Centre demographic surveillance ethical approval

UNIVERSITY OF NATAL

FACULTY OF MEDICINE

MEMORANDUM

TO:	FROM:
Professor GC Solarsh Paediatrics & Child Health Faculty of Medicine	Mrs Anita Walker Postgraduate Administration Faculty of Medicine

6 September 2000

PROTOCOL: A socio-demographic platform for population-based reproductive health research in a rural health district of KwaZulu-Natal. GC Solarsh. Paediatrics. Ref E009/00

Thank you for submitting the Zulu translation of section E9 – information given to subjects. Full ethical approval is granted as of this day.

Anita Walker
Postgraduate Administration
Aw/ethics/solarsh.15

Appendix 4: Africa Centre surveillance ethical approval recertification

UNIVERSITY OF
KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI
RESEARCH OFFICE
BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za
Website: http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx

21 October 2013

Dr K Herbst
Africa Centre for Health & Population Studies
Nelson R Mandela School of Medicine
University of KwaZulu-Natal
kherbst@africacentre.ac.za

Dear Dr Herbst

PROTOCOL: A socio-demographic platform for population-based reproductive health research in a rural health district of KwaZulu-Natal. Dr A J Herbst. Ref: E009/00

RECERTIFICATION APPLICATION APPROVAL NOTICE

Approved: 20 November 2013
Expiration of Ethical Approval: 19 November 2014

I wish to advise you that your application for Recertification dated 21 August 2013 for the above protocol has been noted and approved by a sub-committee of the Biomedical Research Ethics Committee (BREC) for another approval period. The start and end dates of this period are indicated above.

If any modifications or adverse events occur in the project before your next scheduled review, you must submit them to BREC for review. Except in emergency situations, no change to the protocol may be implemented until you have received written BREC approval for the change.

This approval will be ratified by a full Committee at its next meeting taking place on 12 November 2013.

Yours sincerely

Mrs A Marimuthu
Senior Administrator: Biomedical Research Ethics

Appendix 5: Wellbeing of Older People Study (WOPS) ethical approval

UNIVERSITY OF
KWAZULU-NATAL

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za
Website: http://research.ukzn.ac.za/ResearchEthics11415.aspx

26 November 2009

Prof. Marie- Louise Newell
Africa Centre for Health and Population Studies
PO Box 198
Mtubatuba, KwaZulu- Natal
3935
South Africa

Dear Prof Newell

PROTOCOL: Wellbeing of Older Poeples Study (WOPS). Prof. Marie- Louise Newell Africa Centre for Health and Population Studies. REF: BF136/09.

The Biomedical Research Ethics Committee (BREC) has considered the abovementioned application.

The study was approved by a quorate meeting of BREC on **11 August 2009** pending appropriate responses to queries raised. Your responses dated 09 October 2009 to queries raised on 03 September 2009 have been noted by a sub-committee of the Biomedical Research Ethics Committee. The conditions have now been met and the study is given **full ethics approval** and may begin as from **today; 26 November 2009.**

The protocol and related study documents have been reviewed and approved:

This approval is valid for one year from **26 November 2009.** To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2004), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at http://research.ukzn.ac.za/ResearchEthics11415.aspx.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

The following Committee members were present at the meeting held on 11 August 2009:

Professor D Wassenaar	Chair
Professor S Collings	Psychology
Professor D J Pudifin	Medicine
Mrs P Naidoo	External
Dr M A Sathar	Medicine
Dr Z Khumalo	KZN Health (External)
Ms T Esterhuizen	Faculty of Medicine
Dr S Paruk	Psychiatry
Dr U Govind	Private Pract. - Gen. Practitioner
Professor T E Madiba	General Surgery
Professor V Rambiritch	Pharmacology

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely

PROFESSOR D R WASSENAAR
Chair: Biomedical Research Ethics Committee

Appendix 6: Wellbeing of Older People Study (WOPS) informed consent form

I..... agree to be part of the Wellbeing of Older People Study (WOPS). The study has been orally explained to me and I fully understand the information written in the study information sheet. I understand the implications of joining the study and that I will be asked for a venous blood sample in addition to being interviewed. I also understand that my weight, height and blood pressure will be measured.

Yes ☐ **No** ☐

In addition I do understand that if I am found to be ill at the time of the home visit, I may be referred for further health management.

Yes ☐ **No** ☐

It has been explained to me and I fully understand that information relating to me previously collected in the Africa Centre Surveillance or in the Hlabisa HIV Treatment and Care programme may be used together with the information collected in this study.

Yes ☐ **No** ☐

I also understand that all the information collected will be kept confidential and that all information will be anonymised and my name or any other personal identifier will not be used in any of the analyses.

Yes ☐ **No** ☐

I understand that joining the study is completely voluntary and also understand that even if I join the study, I am free to withdraw from the study at any time and I will not be discriminated or penalized in any way for doing so.

Yes ☐ **No** ☐

I consent to have my blood specimen stored for use by Africa Centre researchers for additional tests in the future provided that such tests are approved by the Ethics Committee.

Yes ☐ **No** ☐

I consent to be contacted for future WOPS studies.

Yes ☐ **No** ☐

_____	_____
Signature of Participant	**Signature of Witness**
_____	_____
Signature of Research nurse	**Date of consent**

Appendix 7: Wellbeing of Older People Study (WOPS) questionnaires

Wellbeing of Older People Study (WOPS), Somkhele, South Africa
in collaboration with the WHO Study on Global Ageing and Health (SAGE)

WOPS ID	Respondent's DSID	Respondent's BSID
Interviewer code	Respondent's Name Surname, First name(s)	BS Owner
Date of Interview Y Y Y Y / M M / D D	Household Head	Location/Isigodi:
Start time of interview H H : M I N S	Date of Birth Y Y Y Y / M M / D D	Age Sex: Male ○ Female ○

Section 1: Respondent and household characteristics

101	What is your relationship to the head of this household?	
102	What is your current marital status?	☐☐☐
103	What is your highest level of education attained? *(Tick only one)*	Grade ☐☐☐ or No formal education / Less than 1 year / Adult education only / Certificate Diploma / Bachelors degree / Honours/Masters+ / Don't know
104	Are you currently in employment?	Yes No
105	What is the main source of drinking water for members of this household? *(Tick only one)*	Piped - inside house / Piped - public tap/kiosk / Borehole / Well (non-borehole) Rainwater / Protected spring / Flowing river/stream / Dam/Stagnant water Other, specify _____
106	What type of toilet facilities do members of your household mainly use? *(Tick only one)*	Flush toilet ○ VIP ○ Ordinary Latrine ○ Bucket/Chemical toilet ○ No facilities (bush) ○ Neighbour's latrine ○ Other, specify _____
107	What type of fuel does your household mainly use for cooking? *(Tick all mentioned)*	Electricity from generator ☐ Gas (LPG) ☐ Electricity from solar energy ☐ Wood ☐ Electricity from grid ☐ Coal / charcoal ☐ Kerosene/paraffin ☐ Other, specify _____
108	Is your house connected to an electricity grid?	Yes No
109	Does anyone in your household have any of the following in good working condition….? *(Tick all mentioned)*	Bicycle ☐ Gas cooker ☐ Radio ☐ Fridge/freezer ☐ Mobile/cellular telephone ☐ TV ☐ Video recorder/DVD player ☐ Sofa/sofa set ☐
110	Does your household have any of the following domestic animals/fowl? *(Tick all mentioned)*	Cows ☐ Goats ☐ Pigs ☐ Chickens/ducks ☐ Rabbits ☐ Other, specify_____
111	[Please tell me] which of these sources is your main source of household income, by that I mean from which source does most of the money used in this household come from? *(Tick only one)*	Earnings from selling or trading / Income from rental property Wages, salary from job / Government grants No source of income / Other, specify _____
112	Compared to 3 years ago would you say your financial situation is better or worse?	Better / About the same / Much worse

Section 2: Health State Description

Interviewer to read: Now we will ask questions specifically about your health. The first questions are about your overall health, including both your physical and your mental health.

201	In general, how would you rate your health today?	Very Good ○ Good ○ Moderate ○ Bad ○ Very Bad ○
202	Overall, in the last 30 days/month, how much difficulty did you have with work or household activities?	None ○ Mild ○ Moderate ○ Severe ○ Extreme/cannot do ○
203	How was your health during the last two weeks? *If 'Very Good' or 'Good' skip to Q205*	Very Good ○ Good ○ Moderate ○ Bad ○ Very Bad ○
204	What signs of illness did you experience in the last two weeks? *Tick all that respondent mentions then read the others and tick all that apply*	Diarrhoea ☐ Itchy skin ☐ Herpes zoster ☐ Night sweats ☐ Vomiting ☐ Incontinence ☐ Feeling very weak ☐ Not able to sleep ☐ Confused ☐ Painful wounds ☐ Pain in the body ☐ Cough, chest pain ☐ Fever ☐ Could not eat because of nausea ☐ Could not eat because of pain when swallowing ☐ Others Specify _____

Interviewer to read: I would like to review the different functions of your body. When answering these questions, I would like you to think about the **last 30 days/ month**, taking both good and bad days into account.
When I ask about difficulty, I would like you to consider **how much difficulty** you have had, on an average, in the past one month, while doing the activity in the way that you usually do it. By **difficulty, I mean** requiring increased effort, discomfort or pain, slowness or changes in the way you do the activity. Please answer this question taking into account any assistance you have available (answer this question the difficulty you might have when you do it without assistance).

Mobility

	Overall in the last 30 days/month … *Read and show scale to respondent*	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/cannot do	6. N/A
205	….. how much difficulty did you have with moving around?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
206	… how much difficulty did you have in vigorous activities (digging in the garden, lifting heavy objects such as a bag of potatoes)? (Vigorous activities require hard physical effort and cause large increases in breathing or heart rate)	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○

Self Care

207	….. how much difficulty did you have with self-care, such as bathing/washing or dressing yourself?	1. ○	2. ○	3. ○	4. ○	5. ○
208	….. how much difficulty did you have in taking care of and maintaining your general appearance (for example grooming, looking neat and tidy)	1. ○	2. ○	3. ○	4. ○	5. ○
209	…..how much difficulty did you have in staying by yourself for a few days (3 to 7 days)?	1. ○	2. ○	3. ○	4. ○	5. ○

Pain and discomfort

210	….. how much of bodily aches or pains did you have?	1. ○	2. ○	3. ○	4. ○	5. ○
211	….. how much bodily discomfort did you have?	1. ○	2. ○	3. ○	4. ○	5. ○
	If Q210 AND Q211 are 'NONE' skip to Q213					
212	…..how much difficulty did you have in your daily life because of your aches pain or discomfort?	1. ○	2. ○	3. ○	4. ○	5. ○

Cognition

	Read responses	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/cannot do
213	….. how much difficulty did you have with concentrating or remembering things?(e.g. cooking, bathing).	1. ○	2. ○	3. ○	4. ○	5. ○
214	…..how much difficulty did you have in learning a new task (for example, learning how to get to a new place)?	1. ○	2. ○	3. ○	4. ○	5. ○

Interpersonal activities

215	….. how much difficulty did you have with personal relationships or participation in the community?(eg attending ceremonies, meetings)	1. ○	2. ○	3. ○	4. ○	5. ○
216	…..how much difficulty did you have in dealing with conflicts and tensions with others (e.g. family/community matters)?	1. ○	2. ○	3. ○	4. ○	5. ○
217	….. how much difficulty did you have with making new friendships or maintaining current friendships?	1. ○	2. ○	3. ○	4. ○	5. ○
218	…..how much difficulty did you have with dealing with strangers?	1. ○	2. ○	3. ○	4. ○	5. ○

Sleep and energy

219	….. how much of a problem did you have with sleeping, such as falling asleep, waking up frequently during the night or waking up too early in the morning or sleeping too much?	1. ○	2. ○	3. ○	4. ○	5. ○
220	…..how much of a problem did you have due to not feeling rested and refreshed during the day?	1. ○	2. ○	3. ○	4. ○	5. ○

Affect

221	… how much of a problem did you have with feeling sad, low or unhappy?	1. ○	2. ○	3. ○	4. ○	5. ○
222	…..how much of a problem did you have with worry or anxiety (having the experience receiving bad news and having fast heart beating)	1. ○	2. ○	3. ○	4. ○	5. ○

Vision

(If respondent normally wears glasses or contact lenses, should ask the following Qs as "Since starting to wear glasses/contact lenses….".)

223	Have you ever had your eyes examined by a medical professional? If yes, when was the last time? ***Interviewer: Enter years or months ago. Enter "00" if less than 1 year or 1 month ago.***	YES ○ NEVER ○ DON'T KNOW ○ If Yes when, years ☐☐ months ☐☐
224	Do you use eyeglasses or contact lenses to see far away (for example across the street)?	YES ○ No ○
225	Do you use eyeglasses or contact lenses to see up close (for example at arms length, like when you are reading)?	YES ○ No ○

226	…. how much difficulty did you have in seeing and recognizing an object or a person you know across the road (from a distance of about 20 metres)? ***INTERVIEWER: Indicate a spot that is similar distance for each respondent.***	1. ○	2. ○	3. ○	4. ○	5. ○
227	…..how much difficulty did you have in seeing and recognizing an object at arm's length (for example, sorting beans, groundnuts or rice)? ***If Q226 & Q227are 'None' skip to Q229***	1. ○	2. ○	3. ○	4. ○	5. ○
228	…..how much difficulty do you have fulfilling daily tasks because of not seeing properly? (e.g. cooking, washing)	1. ○	2. ○	3. ○	4. ○	5. ○

Subjective wellbeing

Interviewer to read: Now, we would like to ask for your thoughts about your life and life situation. We want to know how you feel about your health and quality of life.

229	Do you have enough energy for everyday life? *Read and show scale to respondent*	Completely ○	Mostly ○	Moderate ○	A little ○	None at all ○
		1. Very Satisfied	2. Satisfied	3. Neither satisfied nor dissatisfied	4. Dissatisfied	5. Very dissatisfied
230	How satisfied you are with your health?	1. ○	2. ○	3. ○	4. ○	5. ○
231	How satisfied you are with your self?	1. ○	2. ○	3. ○	4. ○	5. ○
232	How satisfied you are with your ability to perform your daily living activities?	1. ○	2. ○	3. ○	4. ○	5. ○
233	How satisfied you are with your personal relationships?	1. ○	2. ○	3. ○	4. ○	5. ○
234	How satisfied you are with the conditions of your living place?	1. ○	2. ○	3. ○	4. ○	5. ○
235	Taking all things together, how satisfied are you with your life as a whole these days?	1. ○	2. ○	3. ○	4. ○	5. ○
236	How often have you felt that you were unable to control the important things in your life? **Read responses**	Never ○	Almost never ○	Sometimes ○	Fairly often ○	Very often ○
237	How often have you found that you could not cope with all the things that you had to do? **Read responses**	Never ○	Almost never ○	Sometimes ○	Fairly often ○	Very often ○
238	How would you rate your overall quality of life? **Read responses**	Very Good ○	Good ○	Moderate ○	Bad ○	Very Bad ○

Functioning assessment

These next questions ask about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs. Think back over the last 30 days and answer these questions thinking about how much difficulty you had doing the following activities.

INTERVIEWER: *For each question, please tick only one response.*

	In the last 30 days/month, how much difficulty did you have … *Read responses*	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/cannot do	6. NAD
239	… in sitting for long periods?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
240	… in walking 100 metres?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
241	… in standing up from sitting down?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
242	… in standing for long periods?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
243	… with climbing one flight of stairs without resting?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
244	… with stooping, kneeling or crouching?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
245	…picking up things with your fingers (such as a coin from a table)?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
246	… in taking care of your household responsibilities?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
247	… in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
248	… concentrating on doing something for 10 minutes?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
249	… in walking a long distance such as a kilometre?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
250	… in bathing/washing your whole body?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
251	… in getting dressed?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
252	… in your day to day work?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
253	… with carrying things?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
254	… with moving around inside your home (such as walking across a room)?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○

		1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/cannot do	6. NAD
255	… with eating (including cutting up your food)?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
256	… with getting up from lying down?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
257	… with getting to and using the toilet?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
258	… with getting where you want to go, using private or public transport if needed?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
259	… getting out of your home?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
260	In the last 30 days/month, how much have you been emotionally affected by your health condition(s)?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
261	Overall, how much did these difficulties interfere with your life?	1. ○	2. ○	3. ○	4. ○	5. ○	6. ○
262	Besides any vision (eyeglasses, contact lenses) or hearing aids, do you use any other devices (such as a cane, walker, or other) for any difficulties you experience?						Yes ○ No ○

Depression

Interviewer to read: Now I would like to ask you questions about your feelings of sadness or depression

263	Have you ever been diagnosed with depression? *If 'NO' SKIP to Q266*	Yes ○ No ○
264	During the last 2 weeks have you been taking any medications or other treatment for it? (Other treatment can include attending therapy or counselling sessions.)	Yes ○ No ○
265	During the last 12 months have you been taking any medications or other treatment for it?	Yes ○ No ○
266	During the last 12 months, have you had a period lasting several days when you felt sad, empty or depressed?	Yes ○ No ○
267	During the last 12 months, have you had a period lasting several days when you lost interest in most things you usually enjoy such as personal relationships, work or hobbies/recreation?	Yes ○ No ○
268	During the last 12 months, have you had a period lasting several days when you have been feeling your energy decreased or that you are tired all the time?	Yes ○ No ○
	INTERVIEWER: IF ANY ONE OF Q266, Q267 OR Q268 IS "YES", CONTINUE TO Q269. IF ALL 3 ARE "NO", GO TO Q301	
269	Was this period [of sadness/loss of interest/low energy] for more than 2 weeks?	Yes ○ No ○
270	Was this period [of sadness/loss of interest/low energy] most of the day, nearly every day?	Yes ○ No ○
271	During this period, did you lose your appetite?	Yes ○ No ○
272	Did you notice any slowing down in your thinking?	Yes ○ No ○
273	Did you notice any problems falling asleep?	Yes ○ No ○
274	Did you notice any problems waking up too early?	Yes ○ No ○
275	During this period, did you have any difficulties concentrating; for example, listening to others, working, watching TV, listening to the radio?	Yes ○ No ○
276	Did you notice any slowing down in your moving around?	Yes ○ No ○
277	During this period, did you feel anxious and worried most days?	Yes ○ No ○
278	During this period, were you so restless or jittery nearly every day that you paced up and down and couldn't sit still?	Yes ○ No ○
279	During this period, did you feel negative about yourself or like you had lost confidence?	Yes ○ No ○
280	Did you frequently feel hopeless - that there was no way to improve things?	Yes ○ No ○
281	During this period, did your interest in sex decrease?	Yes ○ No ○
282	Did you think of death, or wish you were dead?	Yes ○ No ○
283	During this period, did you ever try to end your life?	Yes ○ No ○

Section 3: Chronic conditions and health service coverage

Interviewer: Now I would like to read you questions about some health problems or health care needs that you may have experienced, and the treatment or medical care received

		HEART DISEASE Angina/angina pectoris	ARTHRITIS	STROKE	HYPER-TENSION	CHRONIC LUNG DISEASE	ASTHMA	DIABETES	CANCER
301	Have you ever been diagnosed with/told you have?	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○
302	How long ago was the diagnosis?	0-6 months ○ 7-12 months ○ >12 months ○	0-6 months ○ 7-12 months ○ >12 months ○	0-6 months ○ 7-12 months ○ >12 months ○	0-6 months ○ 7-12 months ○ >12 months ○	0-6 months ○ 7-12 months ○ >12 months ○	0-6 months ○ 7-12 months ○ >12 months ○	0-6 months ○ 7-12 months ○ >12 months ○	0-6 months ○ 7-12 months ○ >12 months ○
303	Have you been taking medications or other treatment for……. during the last 2 weeks?	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○
304	……. during the last 12 months?	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○

Interviewer: Now I would like to ask you about some health symptoms you may have experienced, and the treatment or medical care received

Heart Disease/Angina

305	During the last 12 months have you experienced discomfort, pain, or heaviness in chest, arm, or breastbone when walk uphill or in a hurry?	Yes ○ No ○
306	During the last 12 months/year have you experienced any pain or discomfort in your chest when you walk at ordinary pace on level ground?	Yes ○ No ○ *If Q305 & 306 are 'NO' Q313*
307	What do you do if you get the pain or discomfort when walking? *(Tick only one)*	Stop/slow down ○ Carry on walking ○ Take pain relief medicine then carry on ○
308	If you stand still, what happens to the pain or discomfort?	Relieved ○ Not relieved ○
309	Have you experienced these symptoms in the last 2 weeks?	Yes ○ No ○
310	Have you been seeing a doctor or other health worker for these symptoms?	Yes ○ No ○
311	During the last 12 months/year have you seen a traditional healer for these symptoms?	Yes ○ No ○
312	Are you currently taking any herbal or traditional remedy for your symptoms?	Yes ○ No ○

Arthritis

313	During the last 12 months/year have you experienced pain, aching, stiffness or swelling in or around joints (arms, hands, feet) not related to injury & lasted for more than a month?	Yes ○ No ○
314	During the last 12 months/year have you experienced any stiffness in the joint in the morning after getting up from bed or after a long rest?	Yes ○ No ○ *If Q313 & 314 are 'NO' Q322*
315	How long does this stiffness last?	30 mins or less ○ More than 30 mins ○
316	Does this stiffness go away after exercise or movement in the joint?	Yes ○ No ○
317	Have you experienced these symptoms in the last 2 weeks?	Yes ○ No ○
318	Have you experienced back pain during the last month? On how many days if yes?	Yes ○ Days_____ No ○
319	Have you been seeing a doctor or other health worker for these symptoms?	Yes ○ No ○
320	During the last 12 months/year have you seen a traditional healer for these symptoms?	Yes ○ No ○
321	Are you currently taking any herbal or traditional remedy for your symptoms?	Yes ○ No ○

Stroke

322	Have you ever suffered from sudden onset of paralysis or weakness in your arms or legs on one side of your body for more than 24 hours?	Yes ○ No ○
323	Have you ever had, for more than 24 hours, sudden onset of loss of feeling in one side of your body, without anything having happened to you immediately before?	Yes ○ No ○

Hypertension

324	During the last 12 months have you seen a traditional healer for raised blood pressure (hypertension)?	Yes ○ No ○ *If 'NO' Q327*
325	Are you currently taking any herbal or traditional remedy for your raised blood pressure (hypertension)?	Yes ○ No ○
326	Do you currently eat any special food for your raised blood pressure (hypertension)? Name the food, if yes	Yes ○ Food _____ No ○

Chronic Lung Disease

327	During the last 12 months/year have you experienced any shortness of breath while at rest or while awake?	Yes ○ No ○
328	During the last 12 months/year have you experienced any coughing or wheezing for 10 minutes or more at a time?	Yes ○ No ○
329	During the last 12 months/year have you experienced any coughing up sputum or phlegm for most days of the month for at least 3 months?	Yes ○ No ○ *If 327 to 329 are 'NO'* *333*
330	These symptoms that you say you experienced, have you experienced them in the last 2 weeks?	Yes ○ No ○
331	Have you been taking any medications or other treatment for your symptoms during the last 2 weeks?	Yes ○ No ○
332	Have you been taking any medications or other treatment for your symptoms during the last 12 months?	Yes ○ No ○
333	In the last 12 months/year have you had a tuberculosis (TB) test?	Yes ○ No ○
334	Have you had blood in your phlegm or have you coughed blood?	Yes ○ No ○

Asthma

335	During the last 12 months/year have you experienced any attacks of wheezing or whistling breathing?	Yes ○ No ○
336	During the last 12 months/year have you experienced any attacks of wheezing that came on after you stopped exercising or some physical activity?	Yes ○ No ○
337	During the last 12 months/year have you experienced any feeling of tightness in your chest?	Yes ○ No ○
338	Have you woken up with a feeling of tightness in your chest in the morning or any other time?	Yes ○ No ○
339	Have you experienced shortness of breath that came on without obvious cause when you were not exercising or doing some physical activity?	Yes ○ No ○
340	*Go to Q344 if Q335, 336, 337, 338 & 339 are all 'NO'* Have you experienced any of these symptoms you describe in the last 2 weeks?	Yes ○ No ○
341	Have you been seeing a doctor or other health worker for these symptoms?	Yes ○ No ○
342	During the last 12 months/year have you seen a traditional healer for these symptoms?	Yes ○ No ○
343	Are you currently taking any herbal or traditional remedy for your symptoms?	Yes ○ No ○

Diabetes

344	During the last 12 months/year have you been taking insulin or other blood sugar lowering medications?	Yes ○ No ○
345	During the last 2 weeks have you been taking insulin or other blood sugar lowering medications?	Yes ○ No ○
346	Have you been following a special diet, exercise regime or weight control program for diabetes during the last 2 weeks?	Yes ○ No ○

Cataract/Eye problems

347	In the last 5 years were you diagnosed with a cataract (cloudiness in the lens of the eye) in one or both of your eyes?	Yes ○ No ○ *If 'NO'* *Q349*
348	In the last 5 years have you had eye surgery to remove this cataract(s)?	Yes ○ No ○
349	In last 12 months have you experienced cloudy or blurry vision?	Yes ○ No ○
350	In last 12 months have you experienced vision problems with light, such as glare from bright lights or rings around lights?	Yes ○ No ○
351	Have you ever gone to the clinic because of eye problems?	Yes ○ No ○

Oral Health

352	Have you lost all your natural teeth?	Yes ○ No ○
353	During the last 12 months have you had any troubles with your mouth and/or teeth (this includes problems with swallowing)?	Yes ○ No ○ *If 'NO'* *Q357*
354	Have you received medication or treatment from a dentist during the last 12 months for mouth/teeth problems?	Yes ○ No ○
355	In last 12 months have you seen a traditional healer for your mouth/teeth problems (including problems with swallowing?	Yes ○ No ○
356	Are you currently taking any herbal or traditional remedy for your problems with mouth or teeth?	Yes ○ No ○

Injuries

357	During the last 12 months did you have an injury?	Yes ○ No ○ *If 'NO'* *Q400*
358	How did the injury happen? Was it an accident?	It was an accident ○ Someone else caused it deliberately (intentional) ○ I did it to myself (self-inflicted) ○
359	Did you receive medical treatment for the injury	Yes ○ No ○
360	Did you suffer a physical disability as a result of being injured?	Yes ○ No ○
361	In what way were you physically disabled? *(Tick only one)*	Unable to use hand/arm ☐ Difficulty using hand/arm ☐ Walk with a limp ☐ Loss of hearing ☐ Loss of vision ☐ Weakness/shortness of breath ☐ Inability to remember things ☐ Inability to chew ☐ OTHER _____
362	What caused the injury? *(Tick all mentioned)*	Fall ○ Stabbed ○ Gun shot ○ Fire or burn ○ Near-drowning ○ Poisoning ○ struck/hit by person/object ○ Animal bite ○ Electric shock ○ OTHER, SPECIFY _____

Section 4: Health care utilization & risk factors and behaviours

400	During the last 4 weeks, did you suffer from one of the following diseases or symptoms: ***Read the symptoms and record*** ***If no symptoms skip to 405***	Fever / malaria Yes ○ No ○ Gastro-intestinal problems (e.g. diarrhoea) Yes ○ No ○ Coughing/ respiratory problems Yes ○ No ○ Skin conditions such as (LOCAL NAMES) Yes ○ No ○ Trouble with mouth and/or teeth or swallowing Yes ○ No ○ Other Specify _____
401	For those symptoms, what did you do….? ***Tick all that apply***	Used own herbal medicine ☐ Saw a traditional healer/ herbalist ☐ Took medicine (self treatment) ☐ Visited the Pharmacy/chemist/shop ☐ Visited a government health centre /public clinic ☐ Visited a private or missionary health clinic ☐ Admitted to a government hospital ☐ Admitted to a private or missionary hospital ☐ Did nothing about the symptoms ☐ Other Specify _____
402	Where did you go first? ***Tick only one***	Traditional healer / herbalist /shrine ○ Pharmacy/chemist/shop ○ Government health centre /public clinic ○ Private or missionary health clinic ○ Government hospital ○ Private or missionary hospital ○ Others Specify _____
403	Did you have to pay for consultation and/or drugs?	Yes ○ No ○ ***If 'NO' Q405***
404	Who paid for the consultation and/or drugs?	Son/daughter ○ Spouse ○ Self ○ Other relative ○ Insurance ○ Was free ○ Other Specify _____
405	During the last 12 months, how often have you visited a clinic or hospital?	Not at all ○ Once or twice ○ Three to six times ○ More than six times ○ Don't know ○
406	When you visit the clinic or hospital how long, do you usually have to wait before it is your turn to be seen by a nurse or doctor?	Not long ○ Quite long ○ Very long ○
407	When you visit the clinic or hospital, do the health professionals usually give you enough time to explain to them what your health problem is?	Always ○ Sometimes ○ Never ○
408	When you visit the clinic or hospital, do the health professionals usually take the time to explain your health problem and treatment in a way that you understand?	Always ○ Sometimes ○ Never ○
409	Overall, are you satisfied with the services?	Satisfied ○ Indifferent ○ Dissatisfied ○
410	Do you ever go to traditional healers for treatment?	Yes ○ Never goes to traditional healer ○ ***If 'Never….' skip to Q412***
411	What are the reason(s) that you go to the traditional healers for treatment? ***Tick all that apply***	Closer distance ☐ Traditional healers are cheaper ☐ Traditional healers allow you to pay in goods ☐ Traditional healers will wait for your payment ☐ Traditional healers give better treatment ☐ Other Specify _____ ☐

Health centre/clinic, hospital stays

412	Were you ever hospitalized in the last year? If so, how many times?	Yes ○ If 'Yes', Number of admissions _____ No ○ *If 'NO' skip to Q450*
413	What type of hospital was it the last time you were hospitalized?	Public hospital ○ Private hospital ○ Charity or church run hospital ○ Old people's home or long term care facility ○ Other Specify _____
414	Which reason best describes why you were last hospitalized?	Specify reason hospitalized _____
1= communicable diseases, infections, malaria, infection TB, HIV; 2= nutritional deficiencies 3= acute conditions, (diarrhoea, flu, headaches, fever, cough and others); 4= injury; 5= surgery; 6= sleep problem; 7= occupational /work related condition/injury; 8= chronic pain in joints/arthritis (joints, back, neck); 9= diabetes or related complications; 10= problems with heart including unexplained pain in chest; 11= problems with mouth, teeth, swallowing; 12= problems with breathing; 13= high blood pressure, hypertension; 14= stroke/ sudden paralysis of one side of body; 15= generalized pain(stomach, muscle or other nonspecific pain); 16= depression, anxiety; 17= cancer; 87= other, specify		
415	Who paid for this hospitalization?	Son/daughter ○ Spouse ○ Self ○ Other relative ○ Insurance ○ Was free ○ Other, Specify _____

Section 4.5: Risk factors and preventive health behaviours

Tobacco use

450	Have you ever smoked tobacco or used smokeless tobacco?	Yes ○ No ○ *If 'NO' skip to Q454*
451	Do you currently use (smoke, sniff or chew) any tobacco products such as cigarettes, cigars, pipes, chewing tobacco or snuff?	Yes, daily ○ Yes, but not daily ○ No, not at all ○ *If 'Yes, not daily' OR 'No, not at all' SKIP TO Q454*
452	For how long have you been smoking or using tobacco daily?	Number of years _____
453	On average, how many cigarettes or pipes do you smoke or use each day?	Number of cigarettes _____

Alcohol

454	Have you ever consumed a drink that contains alcohol (such as beer, spirits, wine, etc.?)	Yes ○ No ○ *If 'NO' skip to Q458*
455	Have you consumed alcohol in the last 30 days/month?	Yes ○ No ○ *If 'NO' skip to Q458*
456	During the past 7 days, how many standard drinks of any alcoholic beverage did you have each day?	Number of drinks _____
457	In the last 12 months,/year how frequently [on how many days] on average have you had at least one alcoholic drink?	Less than once a month ○ 1 to 7 days per month ○ 1 to 4 days per week ○ 5 or more days per week ○

Nutrition

458	In the last 12 months, were you ever hungry, but didn't eat because you couldn't afford enough food?	Yes ○ No ○ *If 'NO' skip to next section*
459	In the last 12 months, how often did you eat less than you felt you should because there wasn't enough food?	Every week ○ Every month ○ Almost every month ○ Some months, but not every month ○ Only in 1 or 2 months ○ Never ○

Section 5: Anthropometric measurements

Interviewer to read: Now we would like to ask you to participate in a few tests to determine your health status. We would like to measure a few things, like your blood pressure, your weight and height etc. We will start with taking your blood pressure.

INTERVIEWER: Ask the respondent to release the arm and relax.

501	**Time 1:** Systolic ☐☐☐ Diastolic ☐☐☐ Pulse rate ☐☐☐
	INTERVIEWER: Ask the respondent to release the arm and relax. Wait for one minute before time 2. Do not ask the respondent questions.
502	**Time 2:** Systolic ☐☐☐ Diastolic ☐☐☐ Pulse rate ☐☐☐
	INTERVIEWER: Again, remind the respondent to relax and wait.
503	**Time 3:** Systolic ☐☐☐ Diastolic ☐☐☐ Pulse rate ☐☐☐

504	*Interviewer: Can respondent stand up?*	Yes ○ No ○

Interviewer to read: I would now like to measure how tall you are. To measure your height I need you to please take off your shoes. Put your feet and heels close together, stand straight and look forward standing with your back, head and heels touching the wall. Look straight ahead		
505	Measured height in centimetres	Height ☐☐☐ Not able to measure ○ refused ○
Now we want to measure your weight – could you please keep your shoes off and step on the scale.		
506	Measured weight in kilograms	Weight • Not able to measure ○ refused ○

Section 6: Care giving

Interviewer read: Now we would like to talk about people who live with you here in your household (resident); we mean those who share meals and usually stay here for at least four months a year. Please include people who may presently be in an institution due to their health (for example, in hospital) for a short time. Lets start by talking about resident adults (18+ years) to whom you may have provided care.

6.1: Physical, nursing care and financial assistance to resident adults and children

			Care giving to adults (18 years and above)	Care giving to children (less than 18 years)
601	Are you providing any physical or nursing care to any *adults/children* resident in your household? ***Interviewer: First ask Q601 to Q613 for care giving to adults and then start again from Q601 to Q613 for care giving to children***		Yes ○ No ○ ***If 'NO' skip to Q604*** If Yes how many? ☐☐☐	Yes ○ No ○ ***If 'NO' skip to Q604*** If Yes how many? ☐☐☐
602	Do you provide any care/ assistance such as with....?	Bathing (washing one's body) Eating (assistance with eating but not cooking) Dressing (putting on or taking off clothing) Toileting (getting to and using the toilet) Moving around (within or outside dwelling) Incontinence (help with hygiene problems) Preparing and giving medicines Taking care of wounds	Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Had no medicines ○ Yes ○ No ○ Had no wounds ○	Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Had no medicines ○ Yes ○ No ○ Had no wounds ○
603	Do you provide any physical assistance such as...?	Buying food Agricultural work Fetching water Cooking Taking to clinic or traditional healer Other	Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Specify_____	Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Specify_____
604	Are there any *adults/children* often sick and need care and treatment?		Yes ○ No ○ ***If 'NO' skip to Q611***	Yes ○ No ○ ***If 'NO' skip to Q611***
605	Can you tell me for what the *adults/children* need care and treatment for? ***If not 'HIV/AIDS RELATED' skip to Q607***		HIV/AIDS related ○ Health related reason, ○ Specify _____ Other reason, ○ Specify _____ Don't Know ○	HIV/AIDS related ○ Health related reason, ○ Specify _____ Other reason, ○ Specify _____ Don't Know ○
606	***Interviewer: Ask only If HIV/AIDS is mentioned in Q605*** How many *adults/children* with HIV infection do you take care of? ***If more than one adult or child needs care and treatment, ask the next questions about the adult or child in most need of care and treatment***			
607	Do you know the kind of treatment/medication (NAME) needs? ***DO NOT PROBE: Tick only one.***		ARV treatment ○ TB treatment ○ Knows it is for AIDS, but not name ○ Other, Specify _____	ARV treatment ○ TB treatment ○ Knows it is for AIDS, but not name ○ Other, Specify _____

			Care giving to adults (18 years and above)	Care giving to children (less than 18 years)
608	Does (NAME) need to take daily medication/ treatment from the clinic?		Yes ○ No ○ *If 'NO' skip to ➔ Q611*	Yes ○ No ○ **If 'NO' skip to ➔ Q611**
609	Do you need to remind (NAME) to go for their medical appointments and/or to take their medicines/(ARV)? ***(Interviewer: only mention ARV if ARV was mentioned in Q607)***		Yes ○ No ○	Yes ○ No ○
610	Do you accompany (NAME) going to the clinic/ hospital for follow up and /or ARV or TB treatment resupply? ***(Interviewer: ask only if ARV or TB is mentioned in Q607)***		Yes ○ No ○	Yes ○ No ○
611	Do you provide (NAME) with financial assistance such as……? ***Read and tick all that apply*** ***If all answers are NO skip TO Q613***	Paying for medicines Paying doctor or clinic or hospital fees Paying for food Paying for clothing Paying for transportation Paying for school expenses (of sick person's children) Other SPECIFY _____	Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Yes ○ No ○	Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Yes ○ No ○ Yes ○ No ○
612	Before (NAME) became ill, was s/he contributing to your household in cash or in kind or labour?		Yes ○ No ○	Yes ○ No ○
613	Overall, how difficult would you say it is for you to provide care, physical assistance or financial assistance to *adults/children*?		Very difficult ○ A little difficult ○ Not difficult ○	Very difficult ○ A little difficult ○ Not difficult ○

6.2 Care-giving to adults (18 and above) who have died in the last 24 months (2 years)

614	Has any adult resident member(s) of this household died in the last 24 months? ***Interviewer: If 'NO' deaths skip to Q701***	Yes ○ No ○ Number of deaths if Yes ☐☐☐
615	Of the resident adults who died in the last 24 months, how many were contributing an income/in cash or in kind to the household?	Number of adults contributing ☐☐☐
616	Were any of the persons who died the main income earner for your household?	Yes ○ No ○ Don't know ○
617	Did you provide care to any of the adults who died in the last 24 months? ***Interviewer: if provided care to more than one adult member, ask the next questions about the most recent death.***	Yes ○ No ○ *If 'NO' go to Q701*
618	What is the NAME and SEX of the person who died?	Name: _____ Sex: Male ○ Female ○
619	How old was (NAME) when they died?	Age in years ☐☐☐
620	What was your relationship to (NAME)?	Relationship type ☐☐☐
621	For how long was s/he sick before he/she died? ***If less than one month skip to Q625***	Number of months ☐☐☐
622	Where was (NAME) living during the time s/he needed care?	Outside DSA ○ Inside the DSA ○
623	Did you stay/live with (NAME) during his/her sickness?	Yes ○ No ○ *If 'No' skip to Q625*
624	How long did you stay/live with (NAME) during the time s/he needed care?	Number of Months ☐☐☐ Number of Days ☐☐☐

6.3 Assessment of satisfaction with care-givers role

Interviewer read: Now I am going to ask whether you faced some problems related to your health and well-being the time you provided care and support to adult resident members who died in this household in the last 24 months			
625	During the time that you provided care how much difficulty did you have with…..? *(Read responses and tick all that apply)*	Having enough energy to do extra work	Very much ○ some ○ None ○
		Taking care of your own ailments (if exist)	Very much ○ some ○ None ○
		Knowing the correct care to give for health problems	Very much ○ some ○ None ○
		Visiting family and relatives and friends	Very much ○ some ○ None ○
		Sharing feelings about care giving responsibility	Very much ○ some ○ None ○
		Knowing how to protect yourself from getting the illness/ disease	Very much ○ some ○ None ○
		Stigma or problems as a result of or associated with illness or death	Very much ○ some ○ None ○
626	Did the care you gave to adult household members give you the following …? *(Read and tick all that apply)*	A chance to keep busy and occupied	Yes ○ somewhat ○ No ○
		A chance to do things that makes use of your abilities	Yes ○ somewhat ○ No ○
		A chance to feel a sense of accomplishment despite the difficulties	Yes ○ somewhat ○ No ○
		A chance to do something useful for your sick household member	Yes ○ somewhat ○ No ○

Section 7: Receiving care

Interviewer to read: Now we will continue asking questions about the assistance and care you might have needed and received.

FINANCIAL ASSISTANCE

701	Do you receive financial assistance for……? *Read and record all that apply* *If all answers are 'NO' skip to Q705*	Paying for medicines Yes ○ No ○ Paying doctor or clinic or hospital fees Yes ○ No ○ Paying for food Yes ○ No ○ Paying for clothing Yes ○ No ○ Paying for transportation Yes ○ No ○ Paying school expenses (for offspring) Yes ○ No ○ Other SPECIFY _____
702	Who is/are the provider(s) of this financial assistance to you? *Record all answers given*	Spouse ☐ Son/daughter ☐ Grandson/daughter ☐ Sibling ☐ Other relative ☐ Community ☐ Neighbour/ Friend ☐ Government ☐ Church ☐ Insurance ☐ Other Specify _____
703	For how long have you been receiving this assistance?	Years ☐☐☐ Months ☐☐☐
704	Overall, how difficult would you say it has/ had been to receive financial assistance?	Very difficult ○ A little difficult ○ Not difficult ○
705	In the past, before you became ill, were you contributing to the household in cash or in kind or labour?	Yes ○ No ○ *If 'No' Skip to Q707*
706	Were you the main provider of cash or labour for the household?	Yes ○ No ○

GOVERNMENT GRANTS

707	Are you receiving any government grant meant for your use? *Tick only one. If 'No, none' Skip to Q709.*	Yes, Care Dependency ○ Yes, Disability ○ Yes, Old Age Pension ○ No, none ○ Other Specify _____
708	On what do you mainly use this grant you receive? *Tick only one*	Own upkeep ○ Care and support another household ○ Household expenses ○ Given to adult member of household ○ Other Specify_____
709	Are you receiving any government grant on behalf of some other member of your household? *Record all answers given*	Yes, Care Dependency ☐ Yes, Disability ☐ Yes, Old Age Pension ☐ Yes, Foster Care ☐ Yes, Child Support ☐ No, none ☐ Other Specify _____

PHYSICAL ASSISTANCE

710	Do you receive physical assistance such as……? *Read and tick all that apply* *If all answers to Q710 are 'NO' skip to Q713*	Buying food Yes ○ No ○ Agricultural work Yes ○ No ○ Fetching water Yes ○ No ○ Cooking Yes ○ No ○ Going to clinic or traditional healer Yes ○ No ○ Other SPECIFY_____

711	Who is/are the provider(s) of this assistance to you? *TICK ALL THAT APPLY*	Parent ☐ Spouse ☐ Son/daughter ☐ Grandson 16+ ☐ Grand daughter 16+ ☐ Grandson under 16 ☐ Granddaughter under 16 ☐ Community volunteer ☐ Neighbour ☐ Government ☐ Church ☐ Sibling ☐ Friend ☐ Other Specify _____
712	For how long have you been receiving this assistance?	Years ☐☐☐ Months ☐☐☐

NURSING CARE AND SUPPORT

713	Do you know your HIV Status?	Yes ○ No ○
714	Do you need care, support and/or treatment?	Yes ○ No ○
715	Are you receiving any care, support and/or treatment?	Yes ○ No ○ *If 'No' Skip to Q717*
716	Could you tell us why you need care, support and/or treatment? *Do not read the response categories. Tick only one.* *Complete next section as well if 'HIV/AIDS related' is mentioned*	HIV/AIDS related ○ TB related ○ Health related reason, Specify _____ Other reason, Specify _____ Don't know ○ Refused ○
717	Do you receive care/assistance with...? *Read and record all that apply*	Bathing (washing one's body) Yes ○ No ○ Eating (assistance with eating but not cooking) Yes ○ No ○ Dressing (putting on or taking off clothing) Yes ○ No ○ Toileting (getting to and using the toilet) Yes ○ No ○ Moving around (within or outside dwelling) Yes ○ No ○ Hygiene problems (bowel and bladder control) Yes ○ No ○
a.	Do you receive care/assistance with...?	Preparing and taking medicines Yes ○ No ○ Had no medicines ○

718	Overall how satisfied are you with the care/assistance you have received?	Satisfied ○ Indifferent ○ Not satisfied ○
719	Overall, how difficult would you say it has been for you to arrange this care/assistance?	Very difficult ○ A little difficult ○ Not difficult ○
720	Is there anything else you would like to tell us about the care/assistance you have received?	Yes ○ No ○
a.	**Record verbatim:**	

Interviewer: If 'HIV/AIDS related' was mentioned in Q716 Go to Q801, otherwise thank the respondent and end interview.

Section 8: HIV Experiences

EXPERIENCES OF LIVING WITH HIV/AIDS (only for respondents who know they are HIV infected)

Interviewer read: Now I would like to continue asking questions for this study about your health but the questions we will ask are now related to HIV and ARV treatment. We are asking these questions to get a better understanding about how this HIV affects older people but also the experience older people have with the ARV treatment.

801	How long ago did you learn that you have HIV?	Years Months
802	How was your health at the time you tested HIV positive?	Good ○ Moderate ○ Bad ○ *IF 'Good' Skip to Q804*
803	For how long had you been sick before you learnt that you have HIV?	Years Months
804	Since knowing that you have HIV, have you changed residence?	Yes ○ No ○ *IF 'NO' SKIP TO 806*
805	Did you move dwellings because of ….? *Read and record all that apply*	Needed care Yes ○ No ○ Fail to pay rent Yes ○ No ○ Stigma Yes ○ No ○ Feeling better Yes ○ No ○ Other (specify)_____
806	During the last 3 months how would you say your health was?	Good ○ Moderate ○ Bad ○ *IF 'Good' Skip to Q808*
807	What signs of illness did you experience during the last 3 months? *Read responses and tick all that apply*	Diarrhoea ☐ Itchy skin ☐ Herpes zoster ☐ Night sweats ☐ Vomiting ☐ Incontinence ☐ Feeling very weak ☐ Not able to sleep ☐ Confused ☐ Painful wounds ☐ Pain in the body ☐ Cough, chest pain ☐ Fever ☐ Could not eat because of nausea ☐ Could not eat because of pain when swallowing ☐ Others Specify _____
808	Before taking ARVs did you need any personal / nursing care?	Yes ○ No ○ Not yet on ARVs ○ *If 'Not yet on ARVs' End interview*
809	How long ago did you start ARVs treatment?	Years Months Weeks
810	Do you experience any of these problems with taking the ARVs? *Read and record all that apply*	Has side effects ☐ Sometimes forgets ☐ Needs certain kinds of food ☐ Other specify_____
811	Did you experience any serious side effects after starting ARV such as..? *Read and record all that apply* *If did not experience <u>any</u> side effects, Skip to Q815*	Skin conditions Yes ○ No ○ Yellow eyes Yes ○ No ○ Muscle weakness Yes ○ No ○ Pain in the muscle Yes ○ No ○ Nausea/ vomiting Yes ○ No ○ Diarrhoea Yes ○ No ○ Hallucinations Yes ○ No ○ Bad dreams Yes ○ No ○ Self hate Yes ○ No ○ Fears Yes ○ No ○ Sadness Yes ○ No ○ Unreasonable/irritable Yes ○ No ○ Other specify_____
812	How many weeks did these side effects last?	Weeks
813	Are you still experiencing these side effects?	Yes ○ No ○
814	Have you changed ARVs because of side effects?	Yes ○ No ○
815	Has your health improved since taking ARVs?	Very much ○ Same as before ○ Is worse ○
816	Does anyone living in the household ever remind you to take ARVs on time? *Tick only one*	Daily or almost daily ○ Several times a week ○ Only once in a while ○ Rarely or never ○ At first but not now ○ Other Specify _____
817	Does anyone accompany you when you go for follow up visits?	Yes, always ○ Yes, sometimes ○ Only when feeling sick ○ No ○ *If 'No' End interview*
818	Who usually accompanies you for follow up (and or resupply) visit?	Family member ○ Friend ○ Community volunteer ○

End time of interview |__|__| Hours |__|__| Mins

End of interview. Thank the respondent.

Appendix 8: Social grants, amounts and eligibility criteria in South Africa

Grant	Conditions for recipient	Age restriction	Amount*	Means tested
Old Age grant	• Must be SA citizen/permanent resident • Not being cared for in a state supported institution • Must not be in receipt of any other grant	• 60 years plus if female • 60 years plus if male	R1260	YES[g]
Disability grant	• Must be SA citizen/permanent resident • Must submit medical report confirming disability • Not being cared for in a state supported institution • Must not be in receipt of any other grant	• 18 years and over	R1260	YES
War Veteran's grant	• Must be SA citizen/permanent resident • Must have fought in World War II or Korean War • Must be disable (if not meeting age criterion) • Not being cared for in a state supported institution • Must not be in receipt of any other grant	• 60 years plus	R1280	YES
Care dependency grant	• Must be SA citizen/permanent resident • Must have a birth certificate • Must submit medical report confirming disability • Not being cared for in a state supported institution • Must not be in receipt of any other grant	• 1-18 years	R1260	YES
Grant in-aid	• Must require full-time attendance by another person owing to his/her physical or mental disabilities • Awarded as an additional grant to persons in receipt of Old age, War Veterans or Disability grants		R240	YES
Child Support grant	• Must be SA citizen/permanent resident • Must have a birth certificate	• Under 18 years	R290	YES
Foster Child grant	• Must be SA citizen/permanent resident • Must have a birth certificate • Must have court order indicating foster care status	• Under 18 years (may be extended to 21 on recommendation by a social worker)	R800	NO

Sources: "Grant for older persons." http://www.sassa.gov.za/Grant-for-older-persons-668.aspx. [Accessed 6th October 2013];
"Social security grants" http://m.mywage.co.za/main/decent-work/social-security/social-security-grants-1. [9th December 2013];
** Amounts as at October 2013. [g] There is a proposal currently to do away with means testing altogether.*
Table adapted from: Nyirenda and Newell, 2010. "Orphanhood and HIV risk in rural KwaZulu-Natal" in: Nzimande, N.B. (Ed.), State of the population of KwaZulu-Natal, pp. 159-186.