UNIVERSITY OF SOUTHAMPTON

FACULTY OF LAW, ARTS AND SOCIAL SCIENCES

School of Social Sciences

HIV/AIDS and older people: A case of Nairobi city slums, Kenya

by

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ABSTRACT

FACULTY OF LAW, ARTS AND SOCIAL SCIENCES
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Older people may be affected by HIV/AIDS indirectly through their role as caregivers to people who are suffering from AIDS and through caring for orphaned children. HIV/AIDS also poses a threat to old-age support due to the death of adults in economically active age who would have otherwise provided care and support to older people. This study sought to explore what older people perceive as their main HIV/AIDS concerns and to examine the association between providing care to someone with HIV/AIDS, and, socio-economic and health outcomes. The study was conducted in a demographic surveillance site covering two slum areas of Nairobi, Kenya using both quantitative and qualitative data. A total of 2,061 men and women aged 50 years and older were interviewed in a survey conducted by the author. The survey was supplemented by other datasets from the demographic surveillance systems and indepth interviews.

To understand the association between care-giving and socio-economic and health outcomes, HIV caregivers were compared with other caregivers and non-caregivers. HIV caregivers were found to live in larger households and in households with frequent in or out-migration of individual members compared with the comparison groups. They were also more likely to live in households with a large number of children below the age of 15 years. Whereas a high proportion of HIV caregivers were ranked highly in terms of wealth status, differences in per capita income and expenditure were not significant when household size and other factors were accounted for. The study found a dependence on salaries as a key source of income among HIV caregivers which presents a challenge for older people who are sometimes discriminated against in the labour market.

The groups were also compared on various self-reported health indicators namely functionality and disability, having a severe health problem and quality of life. Multiple regression analysis which controlled for age and various socio-economic characteristics found no significant differences between female HIV caregivers and the comparison groups, however, significant differences were observed among the males where HIV caregivers were more likely to report disability and having a severe health problem compared with non-caregivers. This finding highlights a gendered variation in outcome and is possibly an indication of the differences in gender-role expectation and coping strategies.

Another key finding from the study is that apart from the indirect ways through which HIV/AIDS affects older people, they are also concerned about HIV infection among people in their age group, a group that has received almost no attention among researchers and intervention policies and programs targeted at preventing the transmission of HIV/AIDS.

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DECLARATION OF AUTHORSHIP

I, **GLORIA CHEPNGENO LANGAT**

declare that the thesis entitled

HIV/AIDS and older people: A case of Nairobi city slums, Kenya

and the work presented in the thesis are both my own, and have been generated by me as a 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;
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- none of this work has been published before submission,

Signed:.....

Date.....14/11/08.....

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ABBREVIATIONS AND ACRONYMS

ADL	Activities of Daily Living
AIDS	Acquired Immune Deficiency Syndrome
AIM	AIDS Impact Model
APHRC	African Population and Health Research Centre
ART	Antiretroviral Therapy/Antiretroviral Treatment
BMI	Body Mass Index
CBO	Community Based Organization
CHW	Community Health Worker
DHS	Demographic and Health Surveys
DSA	Demographic Surveillance Area
DSS	Demographic Surveillance System
ERC	Ethical Review Committee
GBP	Great Britain Pound
GDP	Gross Domestic Product
HIV	Human Immunodeficiency Virus
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
IDI	In-depth Interviews
IEC	Information, Education and Communication
INDEPTH	International Network for the continuous Demographic Evaluation of Populations and their Health
KDHS	Kenya Demographic and Health Survey
KENSUP	Kenya Slum Upgrading Programme
KEMRI	Kenya Medical Research Institute
KENWA	Kenya Network for Women with AIDS
KSH	Kenya Shilling
KSPA	Kenya Service Provision Assessment
MDG	Millennium Development Goals
NACC	National AIDS Control Council
NASCOP	National AIDS /STI Control Programme
NGO	Non-governmental Organization
NUHDSS	Nairobi Urban Health Demographic Surveillance System
OVC	Orphans and Vulnerable Children
OR	Odds Ratio
PEPFAR	President's Emergency Plan for AIDS Relief
PLWHA	People Living With HIV/AIDS
PWR	Participatory Wealth Ranking
SAP	Structural Adjustment Programmes
SQL	Structured Query Language

STI	Sexually Transmitted Infections
TB	Tuberculosis
TBA	Traditional Birth Attendants
VCT	Voluntary Counselling and Testing
WHO	World Health Organization
WOFAK	Women Fighting AIDS in Kenya
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UPHD	Urban Poverty and Health Dynamics

CHAPTER ONE

1 INTRODUCTION

1.1 Statement of the problem

The estimates and projections of the global burden of disease indicate HIV/AIDS is, and will continue to be, among the top five leading causes of death. In addition, the proportion of deaths attributed to HIV/AIDS globally will increase from 5% in 2005 to 9% by 2030. HIV/AIDS is, however, the leading cause of illness and death in Africa. It accounted for 19% of deaths in 2005 and is projected to increase to 21% and then to 26% in the year 2015 and 2030 respectively (Mathers and Loncar, 2006; WHO, 2008). The consequence of HIV/AIDS manifests itself in various levels of the society from the macro level to household and individual levels in view of the fact that it is a very difficult and expensive condition to manage due to the prolonged incubation period coupled with a long duration and frequency of illness, and the multiplicity of infections that afflict HIV/AIDS patients, among other factors. Antiretroviral Therapy (ART) drugs, which restore and sustain the immune system of HIV/AIDS patients ultimately slowing the progression to full-blown AIDS, are still inaccessible to the majority of patients especially in sub-Saharan Africa (Weller and Williams, 2001). Moreover, the rollout of ART is also marred by broader issues such as financial shortfalls, logistical problems in service delivery, drug toxicities and adherence to treatment (Wood et al, 1997). The public healthcare systems in most countries in sub-Saharan Africa are unable either to provide tertiary care or a comprehensive home-based care to people infected with HIV/AIDS due to poor infrastructure and competing needs for scarce financial resources. The health system in many countries is also overwhelmed by the magnitude of the epidemic. In addition, most governments in sub-Saharan Africa spend only about 3% on healthcare as a percent of Gross Domestic Product (GDP) (Musgrove et al 2002).

In the absence of well developed healthcare systems in much of sub-Saharan Africa, the responsibility of care-giving to people infected with HIV/AIDS rests largely on informal caregivers who are mostly family members. The increased morbidity and eventual mortality of HIV/AIDS patients therefore, impacts on households and families who have to bear the burden of providing financial, health and emotional care to those infected (Ainsworth and Dayton, 2003; Knodel et al, 2002; Moller, 1997; Ndaba-Mbata

and Seloilwe, 2000). Older people largely assume the role of care-giving and support to their household or families members who are infected with HIV/AIDS. A study in Thailand indicates that about 70% of people ill with HIV/AIDS are cared for by older people (Knodel et al, 2001) while another study in Uganda showed that about 50% were cared for by older people (Ntozi, 1997). Older people also provide care and support to children orphaned after their parents succumb to HIV/AIDS (Nyambedha et al, 2003; Williams and Tumwekwase, 2001). HIV/AIDS mostly infects people in the reproductive age (UNAIDS, 2006). Death of adults of economically active age thus impacts on the current and future support for older people who have traditionally depended on their adult family members and continue to do so, largely due to the absence of formal social support systems across most countries in sub-Saharan Africa (Aboderin, 2006). The status of older people especially in the developing countries is characterized by extreme poverty coupled with poor health status (Lloyd-Sherlock, 2000). Kakwani and Subbarao (2005) in a multi-country study found the incidence of poverty significantly higher in households with older people compared with the countries' average. For instance, head count poverty among older people in Zambia was 80% compared with around 65% in all households. Only 3 out of the 15 countries reviewed had head count poverty among older people similar to the countries' average. The emergence of a new role as caregivers to people who are ill with HIV/AIDS and orphaned children occurring amidst a period of the life-course often marked by decreased economic activity, declining physical capability, and health, is, therefore, likely to increase older people's vulnerability and to impact on their financial, health and social wellbeing.

Much of what is known about HIV/AIDS and older people remains anecdotal and very little systematic research has been conducted (Ainsworth and Dayton, 2003; Anafri, 1995). Earlier studies that looked at the implications of HIV/AIDS epidemic focused more at individual level and less on the family, the community or other social systems. The focus was also only on the infected individual and less on the uninfected people who may be affected emotionally, economically, socially and physically by the illness and death of a person living with HIV/AIDS (PLWHA) (Bor et al, 1993; Ferreira, 2004). Orphans have also received relatively more attention, with the focus on older people being in relation to their role as foster parents to these orphans. Other forms of impact of HIV/AIDS on older people other than their role as foster parents have not

received much attention (Ferreira, 2004; McGrath et al, 1993; Williams and Tumwekwase, 2001).

Most of the studies on older people and HIV/AIDS have also focused on rural areas and very little is known about older people living in urban settings (Booysen and Arntz, 2003). The rapid rate of urbanization in most cities in sub-Saharan Africa, including Nairobi, has resulted in the mushrooming of slums and informal settlements with a very large proportion of urban residents living in extreme poverty. Nairobi which is the capital and also the commercial centre of the country and home to approximately 3 million inhabitants has among the highest HIV/AIDS prevalence rates in the country estimated at 9% among adults 15-49 years compared with the national average of 6.4% (National AIDS Control Council, 2005). Estimates indicated that between 60-80% of the city's population live in slums and informal settlements that occupy less than 6% of the total residential area (Government of Kenya and UNCHS, 2001; Matrix Development Consultants, 1993; UNHABITAT, 2005). These slums are characterised by poor living conditions, high unemployment rates, and poor health outcomes. HIV/AIDS prevalence is much higher in urban than rural areas and tends to be higher amongst the poor compared with other population sub-groups (UNAIDS, 2006). One explanatory factor is that people living in slum areas tend to engage in risky sexual behaviour. For instance, women in the slums of Nairobi exhibit higher levels of sexual activity compared with women in Nairobi as a whole and other urban areas of Kenya (APHRC, 2002). Slum residents are also more likely to engage in risky sexual behaviour compared with rural residents or Nairobi as a whole as they initiate sexual intercourse much earlier, are more likely to have multiple sexual partners and are less likely to take precaution against pregnancy and sexually transmitted infections (STIs) including HIV/AIDS (Zulu et al, 2002). Despite these slum challenges, urban areas still enjoy advantages relative to rural areas in terms of the economy, concentration of health facilities and related HIV/AIDS programs.

1.2 Study objectives

Older people in Africa have received little attention specifically on HIV/AIDS but also research in general, whereas the proportion and the number of older people continue to grow. This study intends to add to the literature on HIV/AIDS and older people by examining the association between HIV/AIDS and the wellbeing of older people living

in an urban slum setting in sub-Saharan Africa. Research on the impact of HIV/AIDS on older people is valuable to policies and programs on the care and management of people ill with HIV/AIDS in addition to those targeted at mitigating the impact of HIV/AIDS on individuals, households and the society as a whole. Such research would therefore, provide the basis for policies and intervention programs aimed at alleviating the impact of HIV/AIDS. The specific objectives of the study are to:

1. Explore what older people perceive as the main HIV/AIDS concerns facing people in their age groups;
2. Understand the role of older people as caregivers and the circumstances through which they find themselves providing care to someone ill due to HIV/AIDS; and
3. Examine the association between care-giving and (i) socio-economic status and (ii) health outcomes among older people.

The next section provides an overview of the situation and characteristics of older people in the developing countries with particular attention to older people in Africa.

1.3 Growth in the world's older population

Population ageing has been a major demographic phenomenon that has shaped the world's population during the last half of the 20th century and will continue to do so into the next millennium (Kinsella, 2000; United Nations, 2007). This occurs when there is an increase in the proportion of older people and a rise in the mean and median age of a population. Population ageing is a consequence of sustained decline in fertility rates, decline in mortality and a rise in life expectancy. The United Nations defines 60 years as the cut-off age for older people (Kinsella and Velkoff, 2001; United Nations, 2007). Globally, between 1975 and 2007 the proportion of those aged 60 years and older increased from around 9% to 11%. The rapid pace of population ageing being witnessed currently is set to continue whereby the increase will be more dramatic between 2025 and 2050 when the proportion of the world's population aged 60 years or older is set to increase from 15% to 22% (Table 1.1).

Table 1.1: Percentage and growth rate of older population by world regions 1950 – 2050

World regions[1]	Proportion aged 60+ (%)				
	1950	1975	2007	2025	2050
World	**8.2**	**8.6**	**10.7**	**15.7**	**21.7**
More developed regions	11.7	15.4	20.7	27.5	32.4
Less developed regions	6.4	6.2	8.4	12.8	20.0
Least developed countries	5.4	5.1	5.1	6.2	9.9
Africa	5.3	5.0	5.3	6.4	10.2
	Growth rate of population aged 60+ (%)				
	1950-55	1975-80	2005-10	2025-30	2045-50
World	**1.8**	**1.8**	**2.6**	**2.7**	**1.7**
More developed regions	1.8	0.8	1.8	1.1	0.3
Less developed regions	1.9	2.6	3.0	3.4	2.0
Least developed countries	1.3	2.2	2.9	3.3	3.5
Africa	1.6	2.7	2.8	2.8	3.5

Source: compiled from United Nations (2007) World Population Ageing 2007

Countries in the more developed regions will continue to have the highest percentage of people aged 60 years or older out of their total population, however, the growth rate of the population of older people has declined in the these countries due to persistent lower-than-replacement fertility experienced by successive birth cohorts. On the other hand, the most rapid increase in the population of older people is occurring in the developing world where most of the ageing process will take place in the near future. The ageing process in developing countries is occurring within a very short period of time and on a much larger population base than that experienced in the developed regions. Specifically, the increase is currently occurring at an annual growth rate of 3%, a rate 2 times that of the developed region (Table 1.1). In terms of aggregate numbers, the largest increase in the last half of the 20th century occurred in the developing world which accounted for two thirds of the annual increase in the number of older people. Currently, Asia is home to more than half of the world's older people (Légaré et al, 2003)

[1] Africa, Asia, Europe, Latin America and the Caribbean, North America and Oceania are classified into more developed and less developed groups based on demographic and socio-economic characteristics. The **less developed regions** are Africa, Asia excluding Japan, Latin America and the Caribbean and Oceania excluding New Zealand and Australia. The **least developed countries** consist of 48 countries 34 of which are in Africa, 9 in Asia, 5 in Oceania and 1 in the Caribbean.

The social, health, economic, and political gains made in the last century have contributed to the reduction in mortality and fertility as well as increase in the life expectancy. A rapid growth in the older population can have greater impact on a society given the very short time to adjust to the increase and to adopt its social and economic institutions to meet the challenge. The developing countries are faced with this situation as the rate of growth of the older population is very rapid and occurring over a very short period of time. Conversely, the gradual growth of the older population in the developed world, by and large, allowed the countries to prepare and adjust to the growing numbers. Moreover, population ageing in the developing countries is taking place amidst low levels of socio-economic development (United Nations, 2007).

1.4 Population Ageing in Africa

The proportion of older people in Africa, currently at about 5% due to very high levels of fertility and low life expectancy, is modest compared with the other regions of the world (United Nations, 2007). The aggregate proportion for the whole of Africa however does mask the diversity that exists within the different regions in the continent and also between countries. Northern Africa has, and will continue to have, the highest proportion of older people followed closely by Southern Africa. By 2050, the proportion of older people in Northern Africa will almost be twice that of the whole of Africa and almost three times the proportion in Middle Africa. The growth in the proportion of older people in Africa with the exception of Northern and Southern Africa has not been linear between the periods 1950-1975 and 1975-2000. This could be as a result of increase in fertility rates especially during the period 1950-1975 (United Nations, 2007). The low fertility and mortality rates in North Africa account for the higher proportion of older people compared with other regions (Légaré et al, 2003).

Although the proportion of older people in Africa is currently very low compared with countries in Europe, North America and parts of Asia, in absolute terms, the number of older people is quite high. Around 50 million people were aged 60 years and older in 2007 and the number of older people is projected to increase dramatically by 2025 (Table 1.2). The slow rate of growth and the low proportion of older people out of the total population conceal the attention that should be accorded to them including focusing on their needs (Benoît, 2001; Kinsella and Ferreira, 1997).

Table 1.2: Number of older people (60 years+) in Africa by regions 1950 – 2050 ('000s)

Africa Region[2]	1950	1975	2007	2025	2050
Northern Africa	2,979	5,593	13,649	27,141	60,646
Southern Africa	940	1,515	3,846	6,073	6,943
Western Africa	3,244	5,676	13,276	21,556	51,573
Middle Africa	1,546	2,365	5,240	8,005	18,708
Eastern Africa	3,123	5,654	14,045	22,983	55,015
Africa (Total)	**11,832**	**20,802**	**50,056**	**85,758**	**192,884**
Kenya	*386*	*663*	*1,480*	*2,766*	*8,223*

Source: compiled from United Nations (2007) World population ageing 2007

Ageing has received very little attention in Africa for a number of reasons. Continuing rates of high fertility and mortality and more recently HIV/AIDS are the priority issues in population and health policies of various countries. Thus policies on ageing still take a back seat. Out of 24 countries reviewed by HelpAge International, only 6 had working national policies on ageing (HelpAge International, 2002). However, the presence of policy documents is not enough, as some of the countries that have national policies are yet to implement them (Aboderin, 2005). The struggling economies of most African countries make ageing programmes a low priority in the development agenda whose main focus is on the majority youthful population. In addition, investment in young people often takes precedent over expenditure on older people (Benoît, 2001).

The assumption has been that the family, particularly in the predominantly rural societies are in a position to support the needs of older people and that the aged still fulfil an important traditional role, continue to command respect and social influence as elders. This assumption has led to lack of formal assistance given to older people (du Guerny, 1997). In the absence of formal social protection and lack of earned income, older people have no alternative other than to depend on their families. This could explain the living arrangements of older people where the majority co-reside with their family members in multi-generational households (Légaré et al, 2003; Lloyd-Sherlock, 2000). The traditional familial support is, however, no longer effective in supporting the

[2] **Northern Africa** – Algeria, Egypt, Libya, Morocco, Sudan, Tunisia and Western Sahara; **Southern Africa** – Botswana, Lesotho, Namibia, South Africa, and Swaziland; **Western Africa** – Benin, Burkina Faso; Cape Verde, Cote d'Ivoire, Gambia, Ghana, Guinea, Guinea-Bisau, Liberia, Mali, Mauritania, Niger, Nigeria, St. Helena, Senegal, Sierra Leone, Togo; **Eastern Africa** – Burundi, Comoros, Djibouti, Eritrea, Ethiopia, Kenya, Madagascar, Malawi, Mauritius, Mozambique, Reunion, Rwanda, Seychelles, Somalia, Uganda, Tanzania, Zambia, Zimbabwe; **Middle Africa** – Angola, Cameroon, Central Africa Republic, Chad, Congo, Equatorial Guinea, Gabon, Sao Tome and Principe

needs of older people. Several factors such as increasing unwillingness of young people to support their old kin, the weakening of societal norms and sanctions regarding care and respect for older people, and economic inability of young people to care for the old, have all led to diminishing intergenerational support and threatened the traditional safety net for older people. The decline in traditional support is even stronger in urban areas largely due to competing demands and also the influence of poverty (Aboderin, 2004; Kakwani and Subbarao, 2005; Légaré et al, 2003).

Older people in Africa are faced with a wide range of issues that affect their economic, health, and social wellbeing. Older people especially in sub-Saharan Africa are among the poorest people in society (HelpAge International, 2002; Kakwani and Subbarao, 2005). The reasons for their low economic status include both life-course and national level factors. Very few countries in Africa provide social protection to older people. Pensions cover a very small minority of the older population as most pension schemes are accessible only to workers in the public sector. Therefore, older people in the rural agricultural sectors and those in the urban areas working in the informal or private sector do not contribute to the pension scheme and hence have no access to pensions. Even for those older people who receive a pension, the value of the pension is often not sufficient to meet their basic living expenses (Kakwani and Subbarao, 2005; Lloyd-Sherlock, 2000). Countries such as South Africa, Botswana and Namibia provide non-contributory pensions and other forms of social protection to older people which most economies of countries in sub-Saharan Africa cannot afford. For example non-contributory pensions comprise 2 to 3% of the GDP of South Africa which is equivalent to the total health expenditure in some sub-Saharan African countries (Kakwani and Subbarao, 2005).

The diminishing capacity to engage in income generation in terms of both physical capacity and relevant skills in a changing labour market with no social protection to fall back on, increases older people's risk of poverty (Heslop and Gorman, 2002; Lloyd-Sherlock, 2000). A lifetime of low economic status would also mean older people are entering old age in poverty (Heslop and Gorman, 2002). Although older people in rural areas are generally thought to be poorer than their urban counterparts (Kakwani and Subbarao, 2005), older people in urban areas living in informal settlements or slums and those engaged in the informal sector are worse off. The reduction in economic activity

in the informal sector at older ages implies a lack of opportunity rather than a willingness to withdraw from the labour force (Lloyd-Sherlock, 2000). In addition, older people living in slums are disadvantaged due to the changing composition of the family and living arrangements of older people which is more dramatic in urban areas and also due to the chronic underemployment or unemployment (United Nations, 1977). Research on older people living in slum areas is therefore important.

Older people in Africa are also faced with a dual burden of communicable and age-related diseases. The socio-economic and environmental determinants of poor health outcomes that older people have been exposed to during the course of their lives continue to be a factor even during their old age. Low economic status prohibit access to appropriate healthcare thus increases vulnerability to poor health. The low per capita expenditure on health and other health policies such as cost recovery programs that include cost-sharing through out-of-pocket expenditure have made healthcare inaccessible for the majority poor. On the other hand, most health policies in sub-Saharan Africa do not focus on geriatric healthcare (Heslop and Gorman, 2002; Légaré et al, 2003; Lloyd-Sherlock, 2000).

HIV/AIDS has also led to diversion of resources to HIV programs away from other health programs that would otherwise have benefited older people. The extent of the HIV/AIDS infection among older people is less known because of lack of data and the assumption that the age group is less at risk of contracting HIV/AIDS, however, most of the impact on older people is indirect through their role of care-giving and support to persons infected with HIV/AIDS and to children orphaned as a result of their parent(s) dying of AIDS.

1.5 Structure of the thesis

The thesis is divided into 9 main chapters. Chapter two will review existing literature and present findings from previous studies conducted mainly in Asia and Africa on how HIV/AIDS affects older people. The focus will be on the social, health, and economic consequences for older people who are providing care to people ill due to HIV/AIDS and to orphaned children. A discussion on HIV/AIDS infection among older people is presented and includes broader forms of HIV/AIDS impact. The chapter concludes by presenting a pathway of the impact of HIV/AIDS on older people which has been informed by existing studies. The last section presents research gaps in the literature.

Chapter three sets the context under which the study was undertaken by giving an overview of the HIV/AIDS situation in Kenya and the strategies undertaken to reduce the spread of HIV and to mitigate the impact of the epidemic at both the macro and micro levels. A historical perspective of the growth and development of Nairobi city where the study took place is also presented in this chapter and discussed in the context of the rapid urbanization that is occurring amidst poor socio-economic and health outcomes among urban populations. The two slums where the study was conducted have an on-going longitudinal demographic surveillance project and this study formed part of a larger survey examining the interrelationship between migration, poverty and wellbeing of older people living in these two communities. A description of the study area, the on-going longitudinal project and socio-demographic characteristics of the population in the study area is therefore provided.

The research design in Chapter four describes the methods used for data collection, fieldwork activities, and the research protocol including data quality and research ethics issues. Definition of key terminologies and concepts are presented including an explanation of the various statistical methods of data analysis used in the study.

The fifth chapter explores what the study participants perceive as HIV/AIDS concerns or challenges facing older people. Logistic regression is then used to investigate the individual characteristics that are associated with reporting the main HIV/AIDS concerns highlighted. Chapter six then focuses on the nature and circumstances of older people who provide care to people with HIV-related illness. The type of care, duration, and the context of care-giving are described drawing mainly from qualitative data. Chapter seven and eight examine the association between care-giving and the likely impact upon socio-economic and health status respectively by comparing older people who are providing care with two comparison groups. An overall summary and conclusion of the thesis is presented in the last chapter highlighting the major contributions of the study. Suggestions for policy or programmatic recommendations and priority areas for future research are noted.

CHAPTER TWO

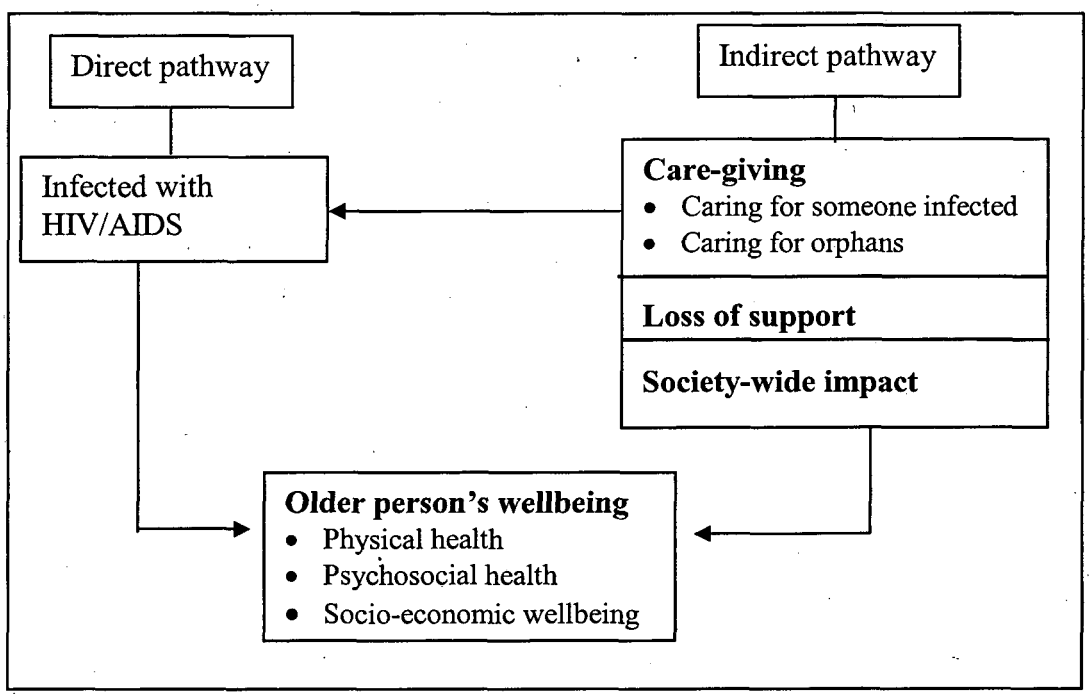
2 LITERATURE REVIEW

2.1 Introduction

The increasing proportion of older people in the global population and the HIV/AIDS pandemic have both emerged as key issues in the development agenda, throwing up new social, demographic, and economic challenges (HelpAge International, 2002; VanLandingham et al, 2000). Most studies assessing the impact of HIV on the family or household have not explicitly focused on how older people are impacted. A literature search for studies published in 2006 or earlier conducted in Asia and Africa to assess how HIV/AIDS affect older people identified a total of 16 studies. These studies vary both in scope and research design. A brief description of these studies including the sample size, methods of data collection, and key aspects of the research design are presented in Appendix 1. This chapter provides a synopsis of the findings from these studies as well as from more recently published studies available at the time of writing this thesis.

HIV/AIDS affects older people through various mechanisms broadly categorised into indirect and direct pathways (Figure 2.1). An indirect pathway occurs when older people become caregivers to people ill due to HIV/AIDS or if they care for orphaned children. Older people are also affected by loss of support they would have otherwise received from adult members of the family. Intergenerational reciprocity and the traditional roles and responsibilities of older people have been challenged by HIV/AIDS whereby the care and support that older people expect to receive from their adult children and other family members during their old age is under threat. The flow of reciprocal support has been reversed since older people are now taking care of the sick and orphans due to HIV/AIDS. Given that the majority of those infected with HIV/AIDS are people in the economically productive ages, older people risk losing both the current and potential future support they would have otherwise received from those infected (Knodel et al, 2001; Saengtienchai and Knodel, 2001; VanLandingham et al, 2000). Since HIV/AIDS impacts on the society both at the individual and societal level, older people are also affected as members of the wider community.

Figure 2.1: Direct and indirect pathways of the effect of HIV/AIDS on older people



Source: Author's own framework

A direct pathway on the other hand, refers to older people who are themselves infected with the HIV-virus. Care-giving to people infected with HIV/AIDS or orphans who may be HIV-positive also exposes older people to the risk of contracting HIV/AIDS through contact with bodily fluids although the chances are minimal. Epidemiological data report that the number of older people infected with HIV constitutes a substantially lower share of reported AIDS cases, thus the greatest impact upon this group is indirect (Knodel et al, 2002). Both the direct and indirect pathways have health, psychosocial, and economic implications on the older people. These mechanisms through which HIV/AIDS affect older people drawing from previous studies are therefore, discussed in the following sections.

2.2 Indirect pathway of HIV/AIDS impact on older people

2.2.1 Care-giving to people with HIV-related illness

In most developing countries, the less advanced healthcare systems including formal care and support programs for People Living with HIV/AIDS (PLWHA) means that they have had to rely on informal channels for care and support. Informal care at home mainly by family or non-relatives is a common feature of HIV/AIDS management in developing countries. Within the family, older people play a key role in care-giving for PLWHA. For instance in Thailand, older people provided care to 70% of those people

infected (Knodel et al, 2001) while Ntozi and Nakayiwa (1999) in a study conducted in six districts of Uganda found that close to two thirds of AIDS patients were cared for by their older parents. Different reasons have been advanced as to why older people assume the role of care-giving. These includes explanations such as they do it out of compassion, or as their responsibility as parents and heads of households. Being the only surviving kin and sometimes also as the only willing person due to fear of contagion and stigma surrounding HIV/AIDS (Ntozi and Nakayiwa, 1999; WHO, 2002).

Older people provide care for people who are either living with them in the same household or the care recipient may migrate from another location to reside near or with the older person. Adult children and other family members usually co-reside with their parents or relatives due to intergenerational support and obligation within the family system, a common characteristic of families in most developing countries (Aboderin, 2006). This influences the living arrangements of older people and their children or other family members and hence the subsequent role of caring for family members who get infected. In Thailand, about half of the HIV/AIDS people cared for by older people lived near or with their parents before being infected. This form of living arrangement is more prevalent in rural compared to urban areas. The chances of a HIV/AIDS person co-residing with their caregiver and subsequently being taken care of also varied with age and marital status of the PLWHA. The probability decreased with age and was more likely for those who were single, separated or divorced (Knodel et al, 2001; Saengtienchai and Knodel, 2001).

In some settings people with AIDS may migrate back to co-reside with or near their caregiver after being infected with HIV and especially at the terminal stage of the illness. This is especially so in rural areas where migrants return to their rural homes from cities and other urban or peri-urban centres (Dayton and Ainsworth, 2004; VanLandingham et al, 2000). About one third to two fifths of care recipients in Thailand returned home from a different location where they lived before becoming ill. The living arrangement of some of the people with AIDS also varies depending on the stage of the illness. At the asymptomatic stage, that is before showing any severe signs or symptoms of infection, those who reside elsewhere from their parents or older relatives continue to do so and only seek assistance when the illness is advanced. Some

might also migrate to reside with parents temporarily during a bout of illness and return back to their place of usual residence upon recovering (Knodel and VanLandingham, 2001).

The nature of care provided for people with HIV/AIDS ranges from care involving activities of daily living, to economic, health, moral and emotional support. The nature and intensity of care provided may vary according to the stage of the illness. During the extreme debilitating stage of the disease, a HIV/AIDS person requires more attention and support especially in basic routine needs such as feeding, bathing, laundry, use of toilet, and dressing. Forms of care relating to the health needs of the HIV/AIDS person include administering medication, seeking healthcare from modern and or traditional medicine, and consultation with heath personnel regarding the health of the HIV/AIDS person. Other health related tasks include facilitating and physically assisting in transportation when seeking care outside of home as well as performing physical therapy. Moral and emotional support also forms part of the care (Saengtienchai and Knodel, 2001).

The nature and intensity of care-giving provided by older people can be influenced by their living arrangements. Older people living in households with multiple members can receive help and in some cases the older person assumes the role of a secondary rather than the main caregiver. Being part of a large extended family can help ease the burden of care-giving (Ferreira et al, 2001; Saengtienchai and Knodel, 2001; VanLandingham et al, 2000). The level of stigma within the community can also determine whether the older person receives any assistance from informal social networks in the community (Ferreira et al, 2001; VanLandingham et al, 2000). The duration the older person provides care varies depending on for instance the stage of the illness at the time when the older person takes up the care-giving role, the severity of the illness and the living arrangement prior to and after the illness sets in. The duration of care-giving in Thailand was on average 3 months, with the care provided being more demanding at the terminal stage of the illness (Knodel and Im-em, 2003). Studies in Malawi and Botswana also found similar durations of care-giving where the duration was an average of four months and ranged from 3 to 8 months. Care-giving was also found to be an on and off task depending on the frequency of infection and stage of illness (Chimwaza and Watkins, 2004; Ndaba-Mbata and Seloilwe, 2000).

Availability of external support for instance from government agencies and non-governmental organizations provides some relief and mitigates the impact of HIV/AIDS on the caregivers and also influences the scope of care given to a HIV/AIDS person at home. Good quality and affordable public healthcare systems can lessen the burden of caring for the sick through, for instance, absorbing some of the health-related costs and reducing the incidence or severity of opportunistic infections. Certain communities as well as individuals might have better access to healthcare facilities and organizations that provide care. Rural areas in sub-Saharan Africa are said to have limited access because of the concentration of better health facilities and institutions in urban areas. In addition, urban areas have an over-concentration of organizations involved in interventions targeted at people infected and or affected by HIV/AIDS (Knodel and Zimmer, 2006). Areas hardest hit by the epidemic in terms of very high prevalence rates or areas that first recorded HIV/AIDS cases may also have a disproportionate concentration of HIV/AIDS-related programs and interventions (Kongsin, 2005). These existing programs are however also marred by challenges when delivering services.

An overwhelming proportion of external care and assistance programs focus mainly on the PLWHA ignoring the plight of others in the household who are affected indirectly such as the caregivers (HelpAge International, 1998; Ferreira et al, 2001). Home-based care support should ideally address the needs of caregivers by providing information, financial support, material support, skills training and professional support from health workers. Older people often have limited knowledge especially that which relates to the task of care-giving to people infected with HIV/AIDS. The caregivers therefore often find themselves ill-prepared to provide care and lack appropriate knowledge for example on how to manage some of the symptoms and complications associated with HIV/AIDS infection and how to protect themselves from cross-infection (Chimwaza and Watkins, 2004; Ndaba-Mbata and Seloilwe, 2000).

Women have been particularly singled out in the literature as the most affected as they frequently assume the primary role of care-giving (Ferreira et al, 2001; Wilson and Adamchak, 2001). Older women are seen as more likely to be the main caregiver for persons with HIV/AIDS and AIDS orphans compared to men because of traditional gender roles where women are responsible for care-giving in the family (Dayton and Ainsworth, 2004; HelpAge International, 1998; Knodel et al, 2001). These however,

vary from one setting to another and also depending on the nature of care provided. In Uganda, older women provide care for majority of PLWHA followed by siblings, spouses and children of the PLWHA. If married, men were more likely to be cared for by their spouse or their children while siblings were more likely to provide care for those in a younger age group between 15 to 29 years (Ntozi, 1997). In Botswana two thirds of the caregivers were found to be mothers of the ill persons (Ndaba-Mbata and Seloilwe, 2000). Among married couples, women are more likely to provide care to their spouse who has AIDS while the opposite is not true. In cases where the woman is infected or has AIDS and requires care, other female relatives or the parent is more likely to provide the care and not the spouse (Saengtienchai and Knodel, 2001; VanLandingham et al, 2000).

On the other hand, the care-giving roles performed by women vary from that of men. Women are usually more involved in personal care to the HIV/AIDS person while the men are involved in tasks that are more physical such as lifting and care that involves movement such as transportation to and from the hospital (Saengtienchai and Knodel, 2001). Men are also more likely to be the main income earner and given that labour participation for women is mostly in the informal sector in developing countries, they are more likely to adopt their caring roles to fit into their economic activity and in some cases divert time away from their economic activity or suspend it all together (Knodel and Im-Em, 2003).

2.2.1.1 Consequences of care-giving

Care-giving to someone with HIV/AIDS has physical, emotional, financial and health demands on the caregiver. Caring for a PLWHA because of the protracted duration of care-giving and also the debilitating nature of the illness can be very taxing for the caregiver (Dayton and Ainsworth, 2004; Knodel et al, 2003).

Economic implications of care-giving

Care-giving impacts on older people's economic situation through increased expenditures relating to care such as living and health expenses and also funeral costs in the event of death. Care-giving also impacts on the economic status of the caregiver through the opportunity cost resulting from diverting time away from their economic activities. Extra costs on living expenses arise if the person with HIV/AIDS was not a regular member of the household in which the older person lives (VanLandingham et al,

2000). Purchasing of different kinds of foodstuffs either through recommendation from health professionals or because the food is considered palatable to the HIV/AIDS person also has financial implications. In Thailand, food purchases accounted for a substantial proportion of the household budget compared with other expenses such as healthcare and transport (Knodel and Im-Em, 2003). Overall, care-related expenditure in households affected by HIV/AIDS is a source of economic burden. A study in Chad found monthly expenditure on healthcare to be close to 20 times higher in affected households compared with a comparison group that had not experienced any illness or death (Wyss et al, 2004). In addition, a large proportion of the expenditure in affected households is consumed by the ill person (Appleton, 2000; Bechu, 1998).

Another expenditure that can be a source of financial stress for caregivers is healthcare costs incurred by the person receiving care. In most instances, a large share of the expenditure goes on medical expenses with non-medical costs taking only a small proportion. Healthcare expenses include transportation to and from a health facility, payment for treatment, hospitalization and medication. Payment for drugs and remedies also takes up a large share of medical costs (Bechu, 1998; Wyss et al, 2004). Some households however spend very little direct costs on medical expenses because of the level of poverty and also owing to the absence of health facilities or those that are affordable in the community (Appleton, 2000). Expenditure on healthcare has been found to decline over time as the disease progresses either because of the realization of the futility of spending more on health or because over time the household exhausts all sources used to finance health (Bechu, 1998). Availability of subsidies in healthcare and other financial sources such as medical insurance can provide some relief (Knodel et al, 2001; Knodel and Im-Em, 2003). Lack of financial resources can compound the hardship of caring as it limits access to healthcare (WHO, 2002).

The task of care-giving is very demanding on the time of the caregiver and can result in some caregivers reducing the amount of time spent on other aspects of their life such as their economic activity. Several studies have found that those who are more involved in caring for the sick person are more likely to minimise or stop work completely (Chimwaza and Watkins, 2004; Ntozi, 1997; VanLandingham et al, 2000; Wyss et al, 2004). However, in other instances the person who is providing care to an ill person is sometimes the household member who is unemployed in this case no loss of income is

incurred (Ainsworth and Dayton, 2003; Booysen et al, 2002). The nature of economic activity that the older person is involved in also determines whether they can take time off or not. For example those working in the formal sector are less likely to be able to take time off. Households also sometimes have to assess the opportunity cost when deciding who should stop working and devote time to care-giving to the person with HIV/AIDS (Knodel and Im-Em, 2003). Loss of income from the ill household member especially if the person is the main income earner causes economic strain on the household. Loss of labour is also felt in agricultural communities or in family livelihood activities that rely on labour as well as skills of the ill person (Ainsworth and Dayton, 2003; Appleton, 2000; Booysen et al, 2002; Yamano and Jayne, 2002).

In order to cope with the financial demands of care-giving, older people may engage in a range of coping strategies such as the selling of household or individual assets, borrowing, and soliciting for help from other people or organizations. People of poor economic status are more likely to resort to these strategies to ease their economic burden. Selling of property or assets and borrowing is likely to lead older people into debt and the recovery process may be difficult and can lead to long term effects on their financial status (Ferreira et al, 2001; Knodel et al, 2001; Knodel and Im-Em, 2003). Making budgetary adjustments to fit the situation is another way of coping. This includes cutting back on food consumption even though this has adverse implications on the nutritional and health status of the caregivers (Ferreira et al, 2001; Knodel and Saengtienchai, 2002).

Returning to work or taking on extra work to be able to meet the costs of care-giving are some of the strategies taken by older people. However, this will depend on the skills that the person has and availability of employment opportunities. In addition, older people are often disadvantaged in the job market because of their physical and health status associated with the ageing process. Those already involved in an economic activity might opt to take on extra jobs or additional income generating activities (Knodel and Im-Em, 2003; VanLandingham et al, 2000).

Some older people receive financial assistance from diverse sources both informal and formal to meet the financial costs of care-giving to a person with HIV/AIDS. Informal sources include other family members or members of the community in which they live. Having a large family can therefore be advantageous as they can help offset some of the

costs (Ferreira et al, 2001; VanLandingham et al, 2000). The care recipient can also cover some of the costs either from their own economic activities, savings or insurance covers (Knodel et al, 2001; Knodel and Im-Em, 2003). Formal institutions that provide credit, welfare groups and insurance covers are also other sources where older people can access finances (Knodel and Im-Em, 2003; WHO, 2002).

The economic status of older people determines the nature and extent to which care-giving becomes a burden. Those who are poorer are more likely to report care-giving as being an economic burden when compared with those who are better off although they spend less in absolute terms (Knodel et al, 2001; Knodel and Saengtienchai, 2002). The poor are also more likely to run into debt, sell assets and use up savings to cover for expenses incurred when taking care of a HIV/AIDS person. The situation of economically disadvantaged caregivers is worsened because they are also more likely to stop or curtail work compared to those relatively better off probably because of the nature of economic activity they are involved in or because they cannot afford to hire outside help (Knodel and Im-Em, 2003; Saengtienchai and Knodel, 2001).

The level of socio-economic development of a country and its response to the HIV/AIDS pandemic can influence the financial impact of care-giving on older people. A well developed healthcare system and strategies to alleviate poverty and improve living standards can reduce the impact of HIV/AIDS. More specific strategies targeting older population and other policies on ageing also help alleviate the burden of care-giving. The existence of a non-contributory pension scheme for instance in South Africa that is beneficial to a large majority of older people is one such example (Ferreira et al, 2001; Knodel and Im-Em, 2003; Knodel and Saengtienchai, 2002).

Health consequence of care-giving

Care-giving to someone with HI/AIDS has consequences on the health of the older person who is providing care. The situation is further compounded given that it is difficult to distinguish the impact of caring from the more general process of ageing. Nonetheless, the health of a caregiver to a PLWHA can be affected owing to the physical stain of caring for a sick person as well as care that requires physically lifting the patient. Care-giving also involves additional workload in and outside the home. The effect on the health of caregivers is especially more severe during the terminal stage of HIV/AIDS (Ainsworth and Dayton, 2003; Saengtienchai and Knodel, 2001;

VanLandingham et al, 2000; WHO, 2002). Additionally, the effect on health can be more severe for primary caregivers compared with those who only assumed a secondary role in care-giving (Knodel and Saengtienchai, 2002). Examples of health problems that have been reported include anxiety or nervousness, insomnia, mental and emotional stress, fatigue, strained muscle, headache, stomach ache, joint pains, hypertension, swollen limbs, and malnutrition (Dayton and Ainsworth, 2004; Ferreira et al, 2001; Knodel and Im-Em, 2003; Knodel and Saengtienchai, 2002; WHO, 2002). Some studies have however, found that the effect on the health of older people does not persist and is only short-term as most people seem to recover afterwards. The body mass index (BMI) of older people taking care of AIDS patients in a study in Tanzania improved after the death of the HIV/AIDS person (Dayton and Ainsworth, 2004).

Diversion of household resources to the person with HIV/AIDS can be detrimental to the health of other household members including older people (Ainsworth and Dayton, 2003; Dayton and Ainsworth, 2004). The demands of care-giving and prioritizing the needs of the HIV/AIDS person can cause some caregivers to ignore their own health for example by not taking any action when ill. Care-giving also exposes caregivers to disease vectors especially to infectious diseases such as TB and also HIV/AIDS although contagion is reported to be minimal (Dayton and Ainsworth, 2004; VanLandingham et al, 2000).

Ability to access healthcare for both the HIV/AIDS patient and the older person who is providing care can lessen the adverse health effects of care-giving. The costs associated with healthcare are some of the barriers to access. Similar to the economic impact of care-giving on older people, the impact on health is worsened by poverty or poor economic status because it restricts access to healthcare thus increases their vulnerability to poor health outcomes (Dayton and Ainsworth, 2004). Older people also face age-related barriers in accessing healthcare due, for instance, to negative attitude of health workers towards older people and poor or lack of focus on geriatric medicine in healthcare systems especially in Africa (Keller et al, 2002). Poor health of the caregiver can in turn limit their ability to care for the ill person for instance performing activities that involve physical movement or transportation of the sick person to a health facility (Ferreira et al, 2001).

Social and emotional strains of care-giving

The reality of the imminent death, the debilitating state of the illness and a progressive decline is bound to take an emotional toll on the caregiver. Coupled with this is the anxiety and stress that result from the demands of care-giving. Care-giving can be isolating because it is involving and demanding on the caregiver sometimes resulting in the caregiver being cut-off from social activities (Ainsworth and Dayton, 2003; Chimwaza and Watkins, 2004; Ndaba-Mbata and Seloilwe, 2000). Some caregivers can also feel frustrated and incapacitated with their inability to provide what they consider to be the best possible care. Being angry at the PLWHA and blaming them for the predicament can also be a source of emotional stress (Bor et al, 1993; Knodel and Saengtienchai, 2002; Ntozi, 1997; Williams and Tumwekwase, 2001)). The emotional stress, if not managed well, can lead to depression. Thus caregivers often require emotional and social support during such times (Bor et al, 1993).

Anxieties brought about by fear of their children's future and the future of the family and community as a whole were expressed by older people in a Uganda study which also indicated that even those who have not been affected directly by illness or death of their own children were constantly worried. Older people were fearful that their children who were not infected might get infected in the future. They also expressed anxiety about their own future in the absence of support from their own children (Williams and Tumwekwase, 2001).

Tension and conflict within the family as a result of resources and time devoted to the person with HIV/AIDS and refusal by other family members to assist in care-giving can contribute to care-giving stress. Conflict and tension can arise from a reaction to the diagnosis, blaming each other including the PLWHA for the situation they find themselves or from fear and worry about the imminent death. Other factors that may contribute to tension and conflict include decisions on inheritance of the deceased property, the question of who is legally considered the next of kin or, the person to be charged with the responsibility of caring for orphaned children if any. In addition, existing conflict and disputes within the family can be triggered by an illness and death (Anafri, 1995; Bor et al, 1993; Williams and Tumwekwase, 2001). Having to make a choice between the needs of the ill members of the family and others can also be a source of stress and conflict (Ferreira et al, 2001; McGrath et al, 1993).

The level of stigma attached to HIV/AIDS can lead to social alienation, discrimination, and avoidance targeted at both the person with HIV/AIDS, the caregivers and sometimes extending to the rest of the family members. Stigmatization can also lead to verbal and physical abuse, abandonment and neglect (Ferreira et al, 2001; HelpAge International, 1998). Stigma arises from fear of contagion and the association of contracting HIV/AIDS with promiscuity. Hence, most caregivers including the PLWHA do not disclose their status for fear of being isolated or rejected. Some caregivers also deny that their care recipient is HIV positive and prefer to mention ailments such as malaria or tuberculosis (Anafri, 1995; Bor et al, 1993; Chimwaza and Watkins, 2004). Ferreira et al (2001) in a study in South Africa found that the HIV/AIDS status was known to members of the community for less than 20% of the cases while only half revealed their status to other members of their family. Most of the people who were providing care to PLWHA learnt of the HIV status from other sources such as health workers and not from the care recipient themselves.

Negative reaction has, however, been reported to dissipate over time (McGrath et al, 1993). However, the level of stigma and discrimination varies for instance in most countries of sub-Saharan Africa, HIV/AIDS is still stigmatizing in spite of widespread knowledge and information (Piot and Collseck, 2001). On the contrary, it is not widespread in some Asian countries such as Thailand. In a study conducted in three provinces with HIV prevalence rates above the national average to find out community reaction to persons with HIV/AIDS or their caregivers, less than a third of the respondents felt any disgust or condemnation towards persons with HIV/AIDS. This has been attributed to social acceptance of channels through which majority of the people contract HIV that is, commercial sex patronage and extra marital sex. Moreover, the Buddhist religious belief on non-discrimination, also helps in minimising stigma (Knodel and Saengtienchai, 2002). In the same vain, some caregivers seek solace in religion and spirituality in trying to cope with emotional stress. They therefore get comfort including counselling and encouragement from religious or spiritual leaders and fellow worshippers (Ferreira et al, 2001; Saengtienchai and Knodel, 2001).

Apart from religion, caregivers cope with emotional stress through accepting the situation and absolving the person with HIV/AIDS, self or anyone else of the blame. This way, they are able to face the challenging situation (Ferreira et al, 2001). Support

and comfort also comes from members of the community through for instance regular visits and providing material support (Chimwaza and Watkins, 2004; Knodel et al, 2001). In the study in western Kenya however, support from community members was minimal and most caregivers preferred to ask for help from people who are facing the same situation as they are deemed to be more understanding. Caregivers did not also want to appear bothersome by asking for help from other community members while others feared rejection (Nyambedha et al, 2003; Williams and Tumwekwase, 2001).

2.2.2 Caring for AIDS orphans

An older person caring for their grandchildren or younger relatives has always been routine in most African communities. Children are fostered to build alliances, in times of crisis, or to provide labour to the recipient household. High fertility, temporary migration of parents to urban areas, and for older people to provide informal education to younger people about traditions and customs are some of the reasons advanced to explain fostering. Children are also sent to live with grandparents to wean them off their mother, or to allow the mother sufficient time to care for younger siblings. Fostering is also a source of pride for older people (Foster, 2000; Isiugo-Abanihe, 1985). In South Africa, older people caring for young children has been influenced by apartheid and labour migration and the practice of fostering was, therefore, prevalent even before the era of HIV/AIDS (Hosegood and Timæus, 2006).

Older people fostering grandchildren or other children orphaned due to HIV/AIDS face economic, emotional, physical, health, and social challenges. Economic hardships in caring for the orphans are the most frequent problems mentioned by older foster carers. Providing for the children's schooling, food and medical expenses are some of the difficult tasks facing older caregivers. For instance in western Kenya, most of the orphaned children cared for by older people are of school going age with a mean age of 10.9 years (Nyambedha et al, 2003). Schooling is therefore the most frequent problem. Whereas free primary education is provided in Uganda, and also introduced more recently in Kenya, this only covers tuition fees and excludes scholastic materials. Other financial implications may arise from medical expenses especially for orphans who are HIV positive in addition to the risk of the caregiver contracting HIV (Kakooza, 2004; Nyambedha et al, 2003).

Older people come to care for AIDS orphans through different circumstances. An older person who was co-residing with an HIV/AIDS person plus his or her children will often continue to care for these children after the person with AIDS dies. An older person might also take care of a person with AIDS in the absence of his or her children. But upon their death, the children who were living elsewhere migrate and join the older person's household. There are also cases where older people take in orphans without having cared for the orphans' parents. Reasons given for providing care include willingness to care for the orphans and the feeling that it is their responsibility as grandparents (Dayton and Ainsworth, 2004; Nyambedha et al, 2003; Saengtienchai and Knodel, 2001; WHO, 2002). In Zimbabwe, older people caring for orphans mentioned reasons such as request by the deceased, and real or imagined abuse and neglect of the orphans by other relatives or caregivers (WHO, 2002). Other reasons such as unknown whereabouts of surviving parent or relatives have also been given as factors leading older people to care for orphans (Ferreira et al, 2001).

The restrictive nature of caring for orphans given that it is a full time responsibility and probably with limited financial support from others is a potential source of stress for older people (Nyambedha et al, 2003; Oburu, 2005). Apart from the financial, physical and emotional hardships that older people face when caring for orphans, the presence of children in the household has positive consequences such as being a source of inspiration, they are also a constant reminder of the positive aspects relating to the orphans' deceased parents (Ferreira et al, 2001; Nyambedha et al, 2003).

The number of children orphaned due to HIV/AIDS varies across countries due to fertility dynamics and other demographic factors. In Thailand for example, a low level of fertility means that most of those dying due to HIV/AIDS either have very few or no surviving children. Late age at first marriage for both men and women also influences the number of orphans left behind. Knodel and Saengtiechai (2002) found that close to half of the people with HIV/AIDS in their study had no surviving children whereas only 30% of those with children had more that one child. Most of the people infected with HIV/AIDS have also never married. In sub-Saharan Africa however, high fertility and early age at first marriage implies that PLWHA in the reproductive age of 15-49 years are most likely to leave behind at least one if not several orphans. In a study in Kayunga district of Uganda (Kakooza, 2004) more than two thirds of households that had

experienced a HIV related death were headed by persons 55 years and older and each of the households had at least one orphan. Most of the households had an average of 3 children each with one household having a total of 8 orphans. In a village in western Kenya, the older foster parents were each caring for an average of two orphaned children. One third of the children in the study area had also lost at least one parent (Nyambedha et al, 2003).

Another factor that can lessen the burden of orphans on older people is the presence of other relatives who too can care for the orphans. Ntozi and Nakayiwa (1999) found that less than 10% of the orphans in their sample covering 6 districts of Uganda were cared for by their grandparents while the majority were either with other relatives or a surviving parent. The patriarchal family system where descent, inheritance, and residence is through the male line, imply orphaned children are cared for by the father's relatives or parents. However, in Zimbabwe this tradition is slowly dying down as more and more orphaned children are being taken care of by maternal relatives. Nonetheless, the burden of care only shifts from one set of grandparents to another (WHO, 2002).

2.2.3 Impact of death of person with HIV/AIDS on older people

Older populations in developing countries and Africa in particular, largely depend on informal support from their family in the form of co-residency with those who are economically active, and remittances from those residing elsewhere. In addition, income from their own labour participation, liquidation of accumulated assets and use of savings are other sources of income. Pensions are almost none existent as only a small minority benefit from a pension scheme (Wilson and Admachak, 2001; Saengtienchai and Knodel, 2001). Loss of support and security for older people may result from the illness and death of their children or other adult family members. The loss of support from children is more severe among older people who lose more than one child (Knodel and Saengtiechai, 2002; May, 2003; Ferreira et al, 2001; WHO, 2002).

A larger proportion of older people live in multi-generational households. For instance, in Thailand close to half of the older people reside with or are near their children who are more likely the main source of financial support for the older people. Children residing elsewhere also send remittances to their older parents. A study comparing older people who had lost an adult child to AIDS with those who had experienced no loss found that those who had lost at least one child were more affected by the loss in terms

of the amount of financial assistance received from children even though they had other living children (Knodel et al, 2001; Knodel and Saengtienchai, 2002). Apart from losing direct income or remittances, older people also lose physical support provided by their children in performing household chores and helping out in family businesses including farming which is the main economic activity in rural areas (Knodel and Im-Em, 2003; WHO, 2002). Older people are therefore forced into wage employment or they continue to work into their old age to sustain themselves (Ainsworth and Dayton, 2003; Appleton, 2000). However, active participation in livelihood activities can be hampered by physical incapability especially in activities that require arduous labour (Ainsworth and Dayton, 2003; Nyambedha et al, 2003; Williams and Tumwekwase, 2001).

The most immediate effect of death of a person with HIV/AIDS is the funeral cost that older people have to incur (VanLandingham et al, 2000; Knodel and Saengtiechai, 2002; Knodel and Im-em, 2003). Costs of funerals vary between communities depending on how elaborate funeral ceremonies are. Most communities in Africa (see example van der Geest, 2000 and Chukwukere, 1981) and some in Asia are known to perform grand and extensive funeral ceremonies that can run for several days. In western Kenya the practice of having elaborate funerals is very common. A lot of financial resources are spent on funerals and related ceremonies (Nyambedha et al, 2003). Even among households not directly affected by death, a lot of time and resources are spent on funerals taking place not only in the immediate community but also in other communities owing to the extensive nature of kinship ties (Ainsworth and Dayton, 2003; Williams and Tumwekwase, 2001). Some communities however do not spend a lot on funerals (Bechu, 1998) and in some communities owing to the adverse effects of HIV/AIDS and increase in mortality, the duration of funerals has become shorter and less costly (Ntozi and Nakayiwa, 1999; Williams and Tumwekwase, 2001).

Older people might receive assistance towards the funeral costs from other family members or through contributions from members of the community, as was the case in Thailand, thus helping to minimise the direct costs incurred by older people towards the funeral (VanLandingham et al, 2000; Knodel and Saengtiechai, 2002). Making prior arrangements for the funeral such as taking an insurance cover also helps in minimising the cost (Booysen et al, 2002; Ferreira et al, 2001; Knodel and Im-Em, 2003). Although funeral insurance schemes are uncommon in Africa, informal insurance schemes have

become very popular in South Africa especially among low income earners (Roth, 2001). A study in Ethiopia and Tanzania found a growing number of well-defined funeral associations similar to formal micro-finance institutions. These funeral insurance schemes have evolved from indigenous self-help associations common in African societies (Dercon et al, 2006)

The extent to which the loss of adult child to HIV/AIDS has on the welfare and security of older people varies. The economic status of older person as well as that of the deceased person determines the extent of the impact. Older people of low economic status are likely to be more affected as their economic situation worsens and the impact is also likely to be long term. They are also more likely to use up their savings, sell assets and run into debt (Knodel et al, 2001; Knodel and Im-Em, 2003). If older parents were supporting the person who died financially they are less likely to experience any immediate effects. The older person's welfare may also recover following a death as the study in Tanzania showed an improvement in the health of older person after they assumed the role of household head previously occupied by the deceased. This could be due to the fact that they are able to control and allocate resources for their own welfare and needs (Ainsworth and Dayton, 2003).

2.2.4 Other forms of impact of HIV/AIDS on older people

HIV/AIDS impact is felt at various levels from the macro or sectoral level, to the household and down to the individual level. The previous section highlighted micro-level mechanisms through which HIV/AIDS affects older people. At the macro level, national economies are affected through a reduction in revenue resulting from decreased productivity, savings and investments due to illness and death of workers. This in turn also slows or even halts economic development. In addition to affecting the general population, national programs that are directly dependent on government revenue and those meant to benefit the older population are thus affected (Booysen et al, 2002; VanLandingham et al, 2000; Wyss et al, 2004). Economies of local communities are also affected by illness and death of economically well-off members who previously sustained the local economy and also provided social support to poor members of the community. The frequency of illness and death in the community can also dampen the initiative of people to engage in economic activities that would provide benefits in the long term or even in the short term, thus denying the community sources of revenue

(Williams and Tumwekwase, 2001). The estimated increase in mortality among adults may bring about a corresponding increase in the total dependency ratio.

Another form of impact arises when older people who already have disproportionate healthcare needs are forced to compete with other age groups for the limited healthcare resources. In addition, resources that would have been targeted at health problems facing older people are diverted to HIV/AIDS health programs. Reduction in government revenue collected will also impact on the amount of revenue spent on healthcare that would have benefited older people (Booysen et al, 2002).

2.3 Direct pathway of HIV/AIDS impact on older people

Although HIV/AIDS infection is considered a problem for people in their reproductive ages, little is known about infection among the older adult population. Older people are excluded from regular epidemiological data by virtue of not using antenatal clinics where most of the surveillance data in developing countries is collected. Therefore, data on the incidence and prevalence of HIV among older people is lacking (Chima et al, 2004). More recent studies however, show striking evidence of older people who are infected with HIV/AIDS (Goodroad, 2003; Macro International, 2008; Manfredi, 2002; NASCOP and Ministry of Health, 2008). In Kenya, current statistics indicate that HIV/AIDS prevalence among older people 50-54 years is around 8% whereas the prevalence rate among the age group 55-59 years is 4% (NASCOP and Ministry of Health, 2008; National AIDS/STD Control Program, 2005). In Swaziland, the DHS 2006/7 conducted a population-based HIV testing for all ages. HIV/AIDS prevalence among older people 50 years and older was 14% compared with 26% among those in the reproductive age of 15-49 years. Intrestingly, some of the older age groups especially men, had prevalence rates similar or higher than the national average. For instance, prevalence rate among men aged 50-54 years was 28% compared with about 20% among men in the 15-49 year age group (Central Statistical Office and Macro International, 2008). A study in Northwest Ethiopia also reported a high prevalence of HIV (5%) among older people (Kassu et al, 2004). Based on the emerging evidence therefore, the UNAIDS recommended that age-related HIV/AIDS statistics submitted to the UN body from 2005, should not be restricted only to 15-49 years but should also cover the older ages (UNAIDS, 2006). In spite of evidence to show that older people are also infected with HIV/AIDS, they have received less attention in research.

A number of factors account for the increase in the number of older people infected with HIV/AIDS. Despite the fact that sexual activity tends to decrease with age, it is still prevalent enough to be considered a risk factor for the spread of HIV among older people. They are also less likely to be perceived or to perceive themselves as being at risk of HIV thereby reducing the likelihood of adopting safer sex practices. For example older people are less likely to use condoms (Chima et al, 2004; Lieberman, 2000). Older people may engage in unprotected sex with young people or people of their generation with the assumption that these sexual partners are less risky and are therefore less likely to use protection. In addition, older people are unaware of the HIV prevalence among people of their age group and therefore least likely to practice HIV prevention (Ingstad et al, 1997; Williams and Tumwekwase, 2001). Given that older people are not suspected to be sexually active or to engage in risky sexual behaviour, information and education campaigns aimed at prevention and care is seldom targeted at them. Their vulnerability is therefore increased due to assumptions that they merit less attention. Older people are also excluded from prevention campaigns as most of the messages at targeted at young people who are considered at-risk groups (Chima et al, 2004; Ingstad et al, 1997; Williams and Tumwekwase, 2001; Wilson and Adamchak, 2001).

Diagnosing HIV infection among the older population is also a challenge. Healthcare professionals rarely suspect HIV/AIDS and other sexually transmitted diseases among older people and hence diagnostic testing for HIV is hardly carried out. While they may present with similar opportunistic infections as younger patients, they are often initially misdiagnosed as age-related conditions and very often undergo treatment for other age-related diseases. On the other hand, HIV symptoms can mimic symptoms of chronic and acute age-related diseases common among older people. By ignoring these early signs of HIV/AIDS, the diagnosis of HIV infection is made late in the course of disease (Lieberman, 2000; Sungkanuparph et al, 2004). Late or missed diagnosis can also explain the increase in the number of older people who are infected (Lieberman, 2000; Manfredi, 2002). Similarly, the proportion of older people who are HIV positive is set to increase due to survival chances of patients who are on treatment and also due to better care and understanding of the disease (Manfredi, 2002).

Management or treatment of older people infected with HIV/AIDS can be particularly challenging because at older ages the immune system tends to be compromised due to

other age-related conditions. HIV disease progression and mortality among older individuals is thought to be higher in comparison with those for younger patients. They experience progression more quickly and survive for a shorter period than their younger counterparts especially after developing an opportunistic illness (Adler et al, 1997; Chiao et al, 1999; Gebo and Moore, 2004; Goodroad, 2003). The more rapid progression of the disease among older people has been attributed to an inability of older persons to replace functional T-cells that are being destroyed. These findings suggest that improved survival in older HIV infected individuals will require more aggressive antiretroviral therapies as well as continued research to identify and preserve the immune system (Adler et al, 1997). In one study conducted in the US, HIV wasting syndrome, severe neutropenia or blood disorder and cancer were found to predict decreased survival among older HIV patients (Welch and Morse, 2002). Late diagnosis could also explain the shortened survival period among those aged 50 years and over as compared with the survival of younger patients (Goodroad, 2003).

Another mode of HIV/AIDS transmission among older people is through occupational risk for traditional healers including traditional birth attendants (TBAs), the majority of whom are older women. People do seek health advice and treatment from traditional healers either concurrently with the modern healthcare system or as an alternative. This is even more evident among those infected with HIV/AIDS and other STIs (Munk, 1997). A study in south eastern Nigeria found that over 60% of the population in the region relied on traditional healers for healthcare support (Peters et al, 2004). In a study in Zambia, 75% of the in-patients at the University Teaching Hospital in Lusaka and 68% of those attending HIV counselling and testing at a VCT centre had sought advice from traditional healers (Baggaley et al, 1996). HIV/AIDS-related risk factors include continuous usage of unsterilised instruments and cross-contamination with patients' blood and body fluid and limited HIV/AIDS knowledge relating to occupational safety. Other ways include use of bare hands as a diagnostic tool and for application of medicine, oral treatments such as sucking blood from their patient's body as part of disease management (Chipfakacha, 1997; Munk, 1997; Peters et al, 2004; Wilson and Adamchak, 2001). There are also other traditional practices which older people engage in that would put them at risk of infection for example a belief among the Tswana community in Botswana that an older person renews their youthfulness and vitality by

engaging in sex with younger people can increase cross-generation transmission of HIV (Ingstad et al, 1997).

Although general knowledge about HIV/AIDS is widespread among older people (Williams and Tumwekwase, 2001), they are equipped with limited relevant knowledge regarding caring for someone with HIV/AIDS thereby putting them at risk of infection. The role of care-giving does expose older people to HIV/AIDS infection even though the risk of exposure is very low. They can be exposed through contact with bodily fluids if they have open wounds in their hands and body. Older people with appropriate knowledge on how to avoid infection do not take precaution for fear of being seen as discriminating or showing disgust for the person with AIDS (Ferreira et al, 2001; Knodel and Saengtienchai, 2002; VanLandingham et al, 2000; WHO, 2002).

2.4 Summary and gaps in literature

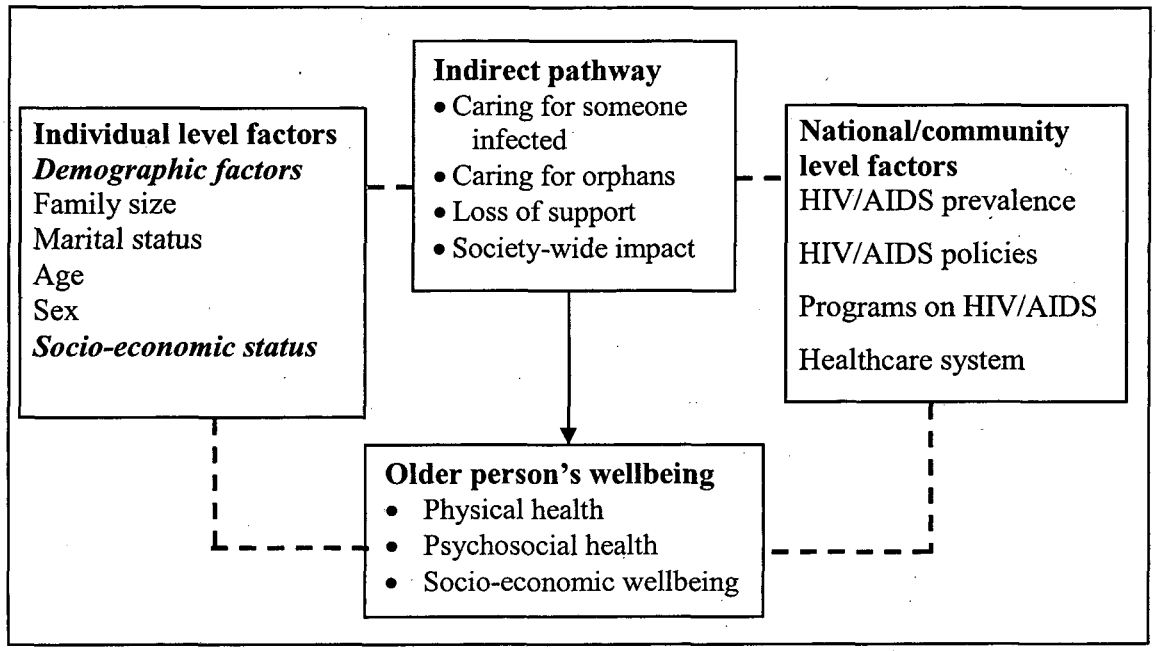
A review of the literature has highlighted how both the national, community and individual level factors contribute in mitigating the extent to which HIV/AIDS affects older people. As illustrated in Figure 2.2, the direct pathway through which HIV/AIDS affect older people is not negligible and cannot be ignored. However, these topics are beyond the scope of this study, which focuses mainly on the indirect pathway.

At the national or community level, the incidence and prevalence rate of HIV/AIDS has a direct bearing on the number of PLWHA. Thus a high prevalence rate would imply an increased chance of an older person providing care for someone ill with HIV/AIDS and also the frequency of such an event occurring. The availability and nature of response at the national and community level in the form of policy formulation and implementation programs both to reduce the incidence and to mitigate the impact of HIV/AIDS would influence the severity of impact of care-giving on older people. Knodel (2006) compared the level of HIV/AIDS impact in Thailand and Cambodia and found that older people in Cambodia, where there has been minimal national response to addressing HIV/AIDS, were more affected economically and received very little external support compared with those in Thailand.

At the national level also, a healthcare system with well developed infrastructure would provide health services for people living with HIV/AIDS. Management of opportunistic infections at health facilities reduces the duration of illness episodes as well as the

severity of illness. Other forms of palliative care and provision of ART also improve the quality of life for the PLWHA. The rollout of ART is dependant on well developed healthcare facilities and trained personnel and the existing national health policy on ART provision.

Figure 2.2: Intervening factors in indirect pathways of HIV/AIDS impact on older people



Source: Author's own framework

Community Based Organizations (CBOs) made up of faith-based organizations, support groups, networks and consortiums of PLWHA play an important role as they provide a wide range of services such as prevention, care, treatment, financial and psychosocial support to both those infected and affected by HIV/AIDS. Decentralization of national level HIV/AIDS programs to the grassroots level facilitate access by intended beneficiaries of the programs at the community level. The presence and how active CBOs are, both those initiated at the community level and at the national level, and the type of services they provide, determine the severity of impact both on those who are ill and also their caregivers.

At the individual level, demographic and socio-economic factors refer to the characteristics of both the PLWHA and their caregiver. These factors act to mitigate the severity of the impact of caring for PLWHA. The demographic and socio-economic characteristics of PLWHA do influence whether or not the person would end up under the care of an older person.

Previous studies in sub-Saharan Africa have been conducted in rural areas with none so far focusing on urban areas. None of the 13 studies conducted in Africa that were reviewed was carried out in an urban setting. How and whether HIV/AIDS impacts differently on older people living in urban areas is therefore unknown, given that the HIV/AIDS prevalence rate is higher in urban than in rural areas. The context under which older people in urban areas live is also likely to have a different influence on how they are affected by HIV/AIDS. This study therefore, aims to fill this gap.

CHAPTER THREE

3 STUDY CONTEXT AND SETTING

Chapter three provides pertinent background information of the country (Kenya) where the study was carried out in addition to a description of the study area. It first provides an overview of the HIV/AIDS situation in Kenya focusing on the levels and trends in HIV prevalence, the response undertaken to tackle the HIV/AIDS epidemic, and the care and support services available for people infected and or affected by HIV/AIDS at the national and also community level. The last sections in the chapter provides a description of Nairobi City by discussing its growth and development and more specifically the growth and conditions of informal settlements or slums located within the city followed by a description of the two slums where the study was conducted. The socio-demographic characteristics of the population in the two slums are presented.

3.1 HIV/AIDS in Kenya

3.1.1 Trends and prevalence of HIV/AIDS

The first case of HIV/AIDS in Kenya was reported in 1984. The prevalence rate rose steadily to peak at about 10% during the 1990s. The prevalence was much higher in Nyanza and Coast provinces where the peak was around 20 – 30% (see Figure 3.4 for provincial map of Kenya). HIV/AIDS prevalence began to decline after the 1990s as is evident by data from antenatal sentinel surveillance indicating a decline in HIV prevalence between 1998 -2000 although the decline did not occur in all the sites where sentinel surveillance was conducted. The decline can be attributed to changes in sexual behaviour and partly due to an increasing number of HIV-related deaths (Cheluget et al, 2006; National AIDS/STD Control Program, 2005). The 2003 KDHS survey indicate a national HIV/AIDS prevalence rate among adults 15-49 years to be 6.4% (Central Bureau of Statistics et al, 2004). Preliminary results from a recently conducted nationally-representative study show HIV/AIDS prevalence to have peaked slightly from 6.4% in 2003 to 7.8% in 2007. The western part of the country has consistently had very high prevalence rates. Nyanza province, located in western Kenya, currently has the highest prevalence rate in the country (15%) followed by Nairobi at 9% (Table 3.1). Urban areas in general also have a higher prevalence rate compared with the rural populations (NASCOP and Ministry of Health, 2008).

It is approximated that slightly more than 1 million people aged 15-49 years are infected with the virus (Table 3.1). In addition, about 100,000 children under the age of 15 years are estimated to be HIV positive, the majority of these children having become infected through mother-to-child transmission. The proportion among those infected with HIV who are aged 50 years and older is estimated at 5% (NASCOP and Ministry of Health, 2008; National AIDS/STD Control Program, 2005).

Table 3.1: Number of adults living with HIV/AIDS in 2003 and the prevalence rate by province, 2003 - 2007

Province	Number of PLWHA[1]	HIV Prevalence rate (%)	
		2003[1]	2007[2]
Nyanza	292,000	13.1	15.4
Nairobi	150,000	9.0	9.3
Coast	84,000	5.7	8.1
Central	124,000	5.6	4.2
Rift Valley	207,000	5.0	7.4
Western	85,000	4.5	5.7
Eastern	90,000	3.7	4.9
North Eastern	17,000	3.0	1.3
Total	**1,057,000**	**6.4**	**7.8**

Source: [1]NACC (2005) Kenya HIV/AIDS data booklet page 12; [2]NASCOP and Ministry of Health (2008) Kenya AIDS Indicator Survey 2007: Preliminary Report

The estimates of HIV/AIDS prevalence in Kenya are derived from sentinel surveillance sites and more recently population-based surveys. Sentinel sites are located in antenatal and STD clinics whereby pregnant women attending antenatal clinics are meant to represent the general sexually active population who are at risk of HIV infection while the clients to STD clinics provide estimates among high risk populations. The sentinel sites were purposively selected to reflect geographical, ethnic and socio-economic variations among the population (National AIDS/STD Control Program, 2005). However, the limitation of sentinel surveillance data from antenatal clinics is that they may not be representative as they can underestimate or overestimates HIV prevalence in the general population due to selectivity and geographical bias since surveillance sites are normally located in areas with operational and busy health facilities. The other limitation of sentinel sites based at antenatal clinics is that by default men and older people are excluded from the sample. Estimates from sentinel surveillance can be more

accurate if conducted regularly and from several sites. In addition, most sentinel surveillance sites are concentrated in urban areas (WHO, 2002).

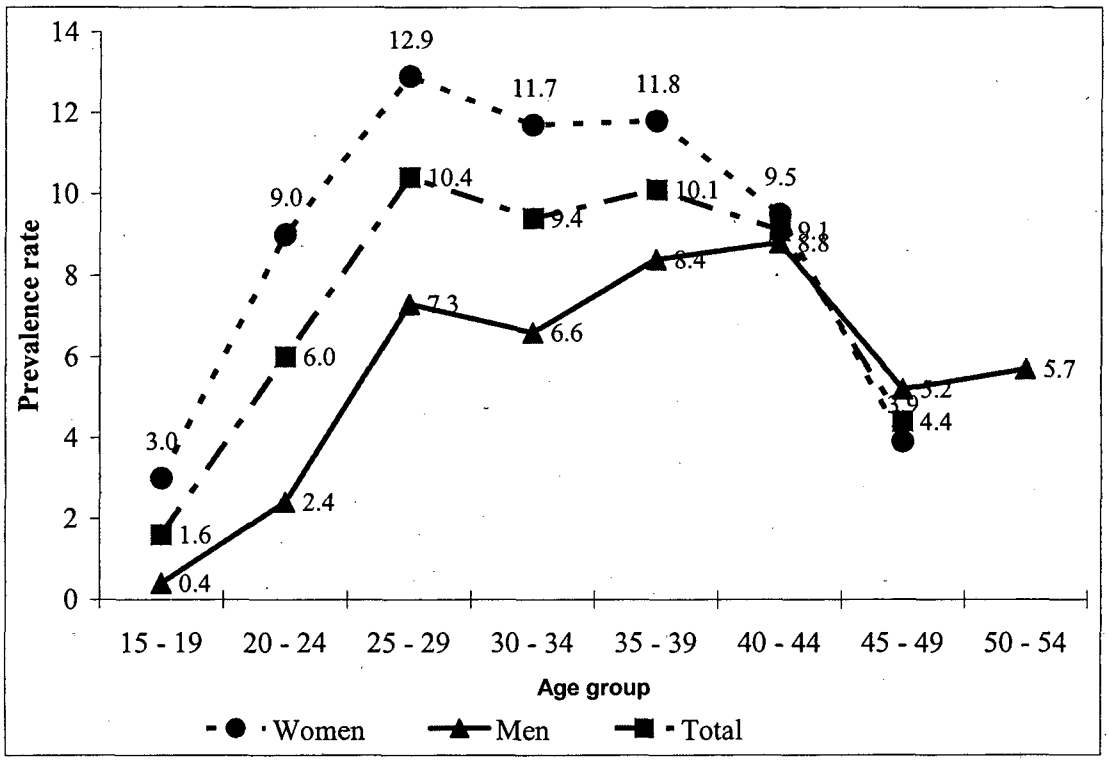
Population-based surveys on the other hand where HIV testing is done on a nationally probability sample provide better estimates as they are more representative, cover larger areas, and include men unlike antenatal surveillance data. However, they are costly and can be biased due to non-response. The 2003 Kenya Demographic and Health Survey (KDHS IV) for the first time conducted HIV testing to measure the prevalence of HIV among the general population in Kenya covering both males (15-54 years) and females 15-49 years (Central Bureau of Statistics et al, 2004; Cheluget et al, 2006). Following the newly available representative data the national HIV/AIDS prevalence rate which in 2001 was 10% was adjusted to 7% in 2003. Overall, the HIV prevalence estimates derived from the 2003 KDHS estimate showed lower prevalence rates at the national level than estimates derived from antenatal surveillance data. However, the KDHS estimates are similar to antenatal data for women aged 15-49 years in the geographical areas where antenatal sentinel surveillance is conducted (Brown et al, 2006).

The current HIV/AIDS statistics show a variation in the prevalence rates across different sub-groups of the population. Whereas only 25% of survey respondents aged 15-49 years were in urban areas, close to 40% of those HIV positive were urban residents. HIV is also much higher among formerly married women compared with those currently in union. For example women who are widowed had a prevalence rate of 30% while those divorced had a prevalence of 21% compared with only 8% among those currently married. Men who frequently travel away from home or spend nights away from home also had higher prevalence rate compared with those who rarely spend nights away from home (Central Bureau of Statistics et al, 2004).

There are also marked differences by gender and age. Women are reported to be more vulnerable to HIV/AIDS because of cultural, physiological and socio-economic reasons (Smith, 2002). This is reflected in the population currently infected with HIV/AIDS in Kenya where two thirds of those infected are women. In addition, the majority of new infections in Kenya are occurring among young women aged 15 – 24 years (National AIDS Control Council, 2005). Women generally have a higher prevalence rate compared with men across most age groups with the difference between the sexes being

more pronounced in the 25-29 age group, this is also the peak age of infection among women 15 – 49 years old (Figure 3.1).

Figure 3.1: HIV prevalence rate by sex and by age group (KDHS 2003)



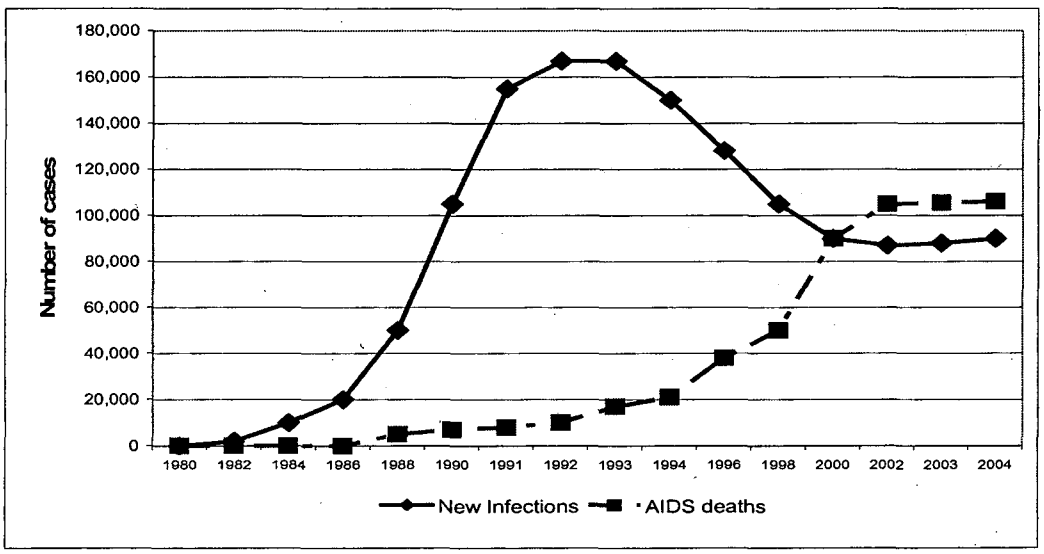
Source: Kenya Demographic and Health Survey, 2003

The prevalence rate among men is only slightly higher than the women among the older age group (45 – 49 years) with the prevalence rate among the men peaking at age 40 – 44 years at around 9% (Figure 3.1). Although HIV/AIDS statistics in Kenya does not include older people and HIV prevalence generally declines with increasing age, the jump in the prevalence rate among men in the age group 45-49 and 50-54 from 5.2% to 5.7% respectively, points to a need for the inclusion of older people in surveillance data. A comparison of countries where HIV testing was included in the DHS also found the prevalence rate among older men to peak in the late 30s and early 40s. More than 10% of older people aged 45-49 years in countries such as Swaziland, Zimbabwe and Malawi were HIV-positive (Macro International, 2008).

Estimates on the number of new infections and the number of deaths between the time the first case was reported and the year 2004 are presented in Figure 3.2. These estimates are derived from fitting the prevailing HIV prevalence rates on an

epidemiological-based model called AIDS Impact Model (AIM) using a software package called Spectrum. The models are simulated based on current and country-specific assumptions regarding HIV epidemic and a limited range of real data consequently introducing weaknesses in the derived models. Nonetheless, due to the absence of vital registration data on mortality and low coverage of HIV testing, the model provides estimates that are used to guide country HIV/AIDS policies and programs (Cheluget et al, 2006; Stover, 2004; Stover et al, 2006).

Figure 3.2: Trend in the number of new infections and AIDS-related deaths in Kenya



Source: NACC (2005) Kenya HIV/AIDS Data Booklet page 11

HIV/AIDS in Kenya is currently at the mortality stage where the number of new infections is lower than the number of deaths per year. As highlighted in Figure 3.2, the number of deaths or the death rate due to HIV/AIDS has been increasing rapidly in the last 10 years with most of the current deaths attributed to high infection rates during the 1990s. The current death rate is more than 3 times what was reported in the early 1990s. In the year 2004, about 105,000 deaths were attributed to HIV/AIDS which translates to about 300 deaths per day (National AIDS Control Council, 2005). The number of new HIV infections per year started to decline around 1992 after rising sharply from about 20,000 in 1986 to a high of about 180,000 in the period 1991 – 1992. The crossover between the number of new infections and deaths occurred after 1999 and this can also explain the low and declining prevalence rate currently being witnessed in the country. Whereas generally the prevalence rate and the number of new infections have been on

the decline, the number of AIDS cases and HIV/AIDS-related deaths would continue to be high. The need for care for PLWHA would therefore dominate as the consequence of previous high infection rates.

3.1.2 National response to HIV/AIDS

The government's response to HIV/AIDS from the onset of the epidemic was lukewarm until after 1996. The first major government response was in the drafting and passing of the sessional paper No.4 in 1997 where a policy framework for tackling the epidemic was outlined. This was also followed in 1999 by the declaration of HIV/AIDS as a national disaster marking the beginning of positive political commitment to tackling the epidemic (National AIDS/STD Control Program, 2005). The current government has also shown a lot of commitment, including substantial financial allocation to fighting HIV/AIDS. At the national level, the response to HIV/AIDS has been implemented through various ways. For instance, development of a policy framework, strategic plans on HIV/AIDS-related programmes, including institutional and legal frameworks.

3.1.2.1 Institutional support for HIV/AIDS

Institutions set up to address HIV/AIDS in Kenya include both government and non-governmental institutions such as the civil society, community based organizations and religious institutions. In line with the multi-sectoral approach, the government has set up AIDS control units in all ministries and key departments and institutions. Each unit addresses the challenges and impact of HIV/AIDS specific to the ministry or department (National AIDS Control Council, 2005). The two key government institutions set up to spearhead and coordinate HIV/AIDS activities in the country are, the National AIDS Control Council (NACC) and the National AIDS/STD Control Programme (NASCOP) both working in partnership with the umbrella objective of reducing the spread of HIV/AIDS and mitigating the impact of HIV/AIDS in Kenya.

NASCOP was established in 1987 first as an AIDS control programme and later in 1992 STD control was added to its activities when it became evident that STDs facilitate the spread of HIV/AIDS. NASCOP was established as a department under the Ministry of Health to coordinate the health and technical aspects of HIV/AIDS. For example, NASCOP sets the standards for effective provision of Voluntary Counseling and Testing (VCT) by setting and enforcing the quality and service provision guidelines.

The HIV sentinel surveillance system in Kenya is implemented by NASCOP. Currently there are a total of 38 sentinel surveillance sites.

NACC on the other hand was established in 1997 with the mandate "to provide policy and a strategic framework for mobilizing and coordinating resources for prevention of HIV transmission and provision of care and support to the infected and the affected in Kenya" (National AIDS Control Council, 2005). The creation of NACC was necessitated by the need for a multi-sectoral approach to addressing HIV/AIDS as opposed to coordination from the Ministry of Health through NASCOP. The bureaucratic bottlenecks within the Ministry of Health inhibited speedy implementation of activities and disbursement of funds hence a semi-autonomous institution was therefore deemed necessary (Republic of Kenya and Ministry of Health, 1997).

3.1.2.2 Strategic plans for HIV/AIDS in Kenya

The first 5-year strategic plan was set up by the ministry of Health in 1987 to cover the period 1987 – 1991. This was followed by the second strategic plan of 1992-1996 (National AIDS/STD Control Program, 2005). Several constraints were identified that prevented achievement of the targets that were set out in the first two strategic plans. The need for a multi-sectoral approach to addressing the epidemic was identified since HIV/AIDS was affecting not only the health sector but all the sectors and spheres of life. The priority areas for the current 5-year strategic plan covering the year 2005/6 – 2009/10 are:

- To reduce the spread of HIV;
- Improve the quality of life of those infected and affected; and
- To mitigate the socio-economic impact of the epidemic.

This strategic plan was set up in partnership with all stakeholders in HIV/AIDS including the government, the civil society and the private sector (National AIDS Control Council, 2005).

In addition to the strategic plans, the government has developed several national guidelines to streamline and guide activities and services relating to HIV/AIDS in the country. The guidelines on orphans and other children made vulnerable by HIV/AIDS is one such document that is aimed at guiding programmes for orphans and vulnerable children (OVCs) (Ministry of Home Affairs and National AIDS Control Council, 2003).

The development of the guidelines were necessitated by the lack of guidance on intervention programmes targeted at OVCs and the increasing number of OVCs in the country and the consequences they face as a result of HIV/AIDS. Also, the increasing number of uncoordinated and unregulated programmes that could potentially violate the rights of the OVCs through lack of adherence to ethical standards of practice, made the guidelines necessary. The guidelines highlight the priority areas of focus for programmes dealing with OVCs as well as the role of the various stakeholders both in the government and the non-governmental sectors (Ministry of Home Affairs and National AIDS Control Council, 2003).

The other major strategic document, the strategic plan of 2005/6 – 2009/10, is a guideline on the monitoring and evaluation of progress made in activities and programs. The guideline specifies the indicators to be monitored, sources of data to be used and the outputs or reports to be produced. Monitoring and evaluation of HIV/AIDS will mainly be integrated in the already existing framework such as using the demographic and health surveys, the sentinel surveillance systems and the service provision assessment surveys. Special surveys on information not routinely collected will also be undertaken (National AIDS Control Council, 2005). While other groups such as orphans and widows have been highlighted in the various strategic plans and policy documents on HIV/AIDS, older people have not been explicitly mentioned among the groups affected by HIV/AIDS or as a vulnerable group.

3.1.3 HIV/AIDS knowledge and prevention activities

Knowledge about the existence of HIV/AIDS is almost universal in Kenya (99%). Also widespread is the knowledge on the key ways through which one can protect themselves against HIV/AIDS as well as the mode of transmission (Central Bureau of Statistics et al, 2004). The media and Information, Education and Communication (IEC) campaigns have therefore paid off (Ministry of Health, 2005). The knowledge and prevention campaigns however, have been targeted only at younger people with older people left out of the campaigns. With 8% out of the total number of those infected aged 50 years and older (National AIDS/STD Control Program, 2005), prevention strategies should also be targeted at older people. The current prevention campaigns are now more focused on vulnerable groups such as young people, women and girls, migrant workers, uniformed forces (police and military) and commercial sex workers (National

AIDS/STD Control Program, 2005). Prevention of mother-to-child transmission is also one of the key strategies of reducing new infections (National AIDS/STD Control Program, 2005).The 'ABC' prevention campaign (abstinence, being faithful to one partner and condom use) has added a fourth component 'D' for diagnosis. Testing has been seen as a technique for preventing the spread of HIV/AIDS as well as a strategy for provision of care and treatment for those infected with HIV/AIDS (National AIDS Control Council, 2005).

The uptake of VCT services has been facilitated by the availability of treatment, care and support for persons infected with HIV/AIDS in addition to the media campaigns. HIV testing facilitates reduction in the number of new infections through promoting behaviour change both for those infected and those not infected and also by facilitating prevention of mother-to-child transmission. People infected with HIV will receive appropriate treatment, care and support once their status is known and through counselling they can have positive outlook to living with the virus (National AIDS Control Council, 2005). VCT has been stepped up through training of counsellors and through scaling up and expansion of VCT sites from 3 in the year 2000 to 555 sites by 2005 (National AIDS/STD Control Program, 2005). The target set out in the current strategic plan is to have at least 1 VCT site in each division, which in administrative hierarchy is the 4th lowest level, in order to reach people at the grassroots level (National AIDS Control Council, 2005). The quality of testing has also improved with the introduction of simple rapid testing kits which have improved the efficiency, confidentiality and accuracy of obtaining HIV results. The challenges facing VCTs include enforcing reliable standards and meeting the increasing demand for care and support. Other challenges include over concentration of services in certain areas especially urban areas and a lack of integration of other services such as family planning with VCT services. The government in collaboration with Family Health International has developed guidelines for VCT programs as well as a training curriculum for health workers and other VCT service providers (National AIDS Control Council, 2005).

3.1.4 Care and treatment for persons infected with HIV/AIDS

Comprehensive care of persons infected with HIV/AIDS should include medical treatment for opportunistic infections, provision of antiretroviral therapy (ART), home-based care, and psychosocial support. The current HIV/AIDS strategic plan seeks to

improve the quality of care of people infected with HIV/AIDS and it also seeks to mitigate the socio-economic impact of HIV/AIDS (National AIDS Control Council, 2005). The government has also set up guidelines for programmes that provide home-based care and support. The guidelines stipulate that the programmes should provide clinical care, nursing care, counselling/psychosocial care and social support. Requirements for setting up home-based care programmes as well as the type of personnel necessary to effectively deliver the services are highlighted. Indicators on monitoring and evaluation of home-based care programmes are also provided (National AIDS Control Council, 2005).

Treating opportunistic infections and providing palliative care is considered a basic-level of care and support services provided at health facilities for PLWHA. Advanced level of care and support includes, among other services, provision of antiretroviral therapy. Out of the 440 health facilities surveyed countrywide during the 2004 Kenya Service Provision Survey (KSPA), 65% provide treatment for opportunistic infections with more facilities in Nairobi (75%) offering this service. Provision of the main palliative care such as management of chronic diarrhoea is however lacking in most facilities. Less than half of the facilities in Nairobi offer management of chronic diarrhoea and the proportion is much lower (26%) at the national level (Muga et al, 2005).

Antiretroviral therapy (ART) which is a treatment regime for HIV/AIDS patients aimed at improving their quality of life and ultimately prolonging the life of a PLWHA, is available in only 7% of the facilities nationwide mostly in hospitals (52%) with very few of the lower level facilities offering the service. Most of the facilities that offer ART are also private run institutions or are managed by non-governmental organizations. Only 5% of the government health facilities provide ART. Across the provinces in Kenya, Nairobi province had the highest proportion of facilities offering ART (19%) followed by Eastern and Coast provinces (12% and 10% respectively) (Muga et al, 2005). In Nyanza province, although it has the highest HIV/AIDS prevalence rate of 15% (NASCOP and Ministry of Health, 2008), only 5% of the health facilities provide ART (Muga et al, 2005). The coverage for people on ART is currently at 20% and the number increased dramatically from 3% to 19.7% between 2003 and 2005 attributed mainly to the increased donor response through the Global Fund in

addition to the United States of America's President's Emergency Plan for AIDS Relief (PEPFAR).

Although there has been a positive response to the provision of care and treatment for PLWHA, a comprehensive care and support through the public sector is still not available to the majority of PLWHA. The services can be accessed through the private sector however the majority of poor people are not able to access these services due to cost barriers. The current national response to HIV/AIDS is very positive with a lot of measures put in place both to minimise the impact and reduce the spread of HIV/AIDS. Nevertheless, the bulk of the care and support for PLWHA still rests solely on family or households of those infected as the impact of strategies and measures outlined at the national level will be slow in filtering down to those infected and affected.

3.1.5 Community-based approaches to mitigate the impact HIV/AIDS

Community-based organizations (CBOs) provide valuable service in addressing the needs of those infected and affected by HIV/AIDS at the community level. The term CBOs is used here to collectively refer to organizations operating at the community level including faith-based organizations and PLWHA support networks. The majority of the CBOs are initiated and run by volunteers and private donations, and build on volunteerism and community-led response to a crisis. Over time some have expanded into fully fledged charities receiving support from governments, NGOs and other multilateral donor agencies. CBOs address the psychosocial, educational, nutritional, health, and material needs of PLWHA, OVCs including those affected by HIV/AIDS. Others provide home-based care training and services. CBOs targeting orphans provide support in the form of medical care, schooling and food. Some of the CBOs have also set up day-care programs and orphanages for OVCs (UNAIDS, 2001).

Within the study area, the Kariobangi Community Health program, an organization run by the Catholic Church is one such example of CBO working in Korogocho. It has provided HIV/AIDS services in the slums since 1990 and its main program involves training volunteer community health workers to care for PLWHA and runs a hospice for PLWHA (UNAIDS, 2001). Other examples of CBOs include Women Fighting AIDS in Kenya (WOFAK) and Kenya Network for Women with AIDS (KENWA) who provide material and psychosocial support for women living with HIV/AIDS and also offer training in home-based care. The other broader activities include advocating for the

needs and rights of people infected and those affected by HIV/AIDS. These networks focus mainly on women although their activities have extended to include children and men especially those within the social networks of women living with HIV/AIDS. Larger institutions such as donor agencies and multilateral organizations running HIV/AIDS programs in the study area, work mainly through partnerships with CBOs. For instance JHPIEGO, an international NGO, seeks to link PLWHA with a range of healthcare services and support groups, and strengthen major health facilities in the community by providing basic infection prevention supplies.

CBOs are best situated and have the potential of providing HIV/AIDS related services at the grassroots level because of their familiarity with the community they serve, they are also within reach and with limited social barriers. They also serve as links to mainstream or national-level health and social programs. The bureaucracy associated with top-down public health approaches make CBOs ideal for tackling HIV/AIDS at community level. The community ownership and cultural sensitivity of the programs also make CBOs more effective in addressing HIV/AIDS (Kloos et al, 2008; Thurman et al, 2007).

In spite of these advantages however, CBOs are faced with several challenges. First, the existing CBOs can hardly meet the demand for care and support even among their registered clients due to the diverse unmet needs and the overwhelming number of people in need of support. Their services are therefore reserved only for the neediest leaving several people disheartened. The support received from these organizations apart from being inadequate, is also irregular and sometimes one-off (Thurman et al, 2007). Furthermore, only people who have disclosed their HIV status benefit from the services (Neville and Rubin, 2007). The other problem is the lack of coordination of activities by CBOs resulting in duplication of services and sometimes different CBOs serving the same beneficiaries. A lack of basic training and managerial skills limits the capacity of CBOs coupled with the absence of monitoring and evaluation mechanisms are other major challenges (Amuyunzu-Nyamongo et al, 2007; Kloos et al, 2008). Therefore the bulk of care and treatment for PLWHA with its financial and social implications rests mainly on the family or households. CBOs mainly build on care and support largely provided at home by relatives and friends.

3.2 Growth and development of Nairobi City

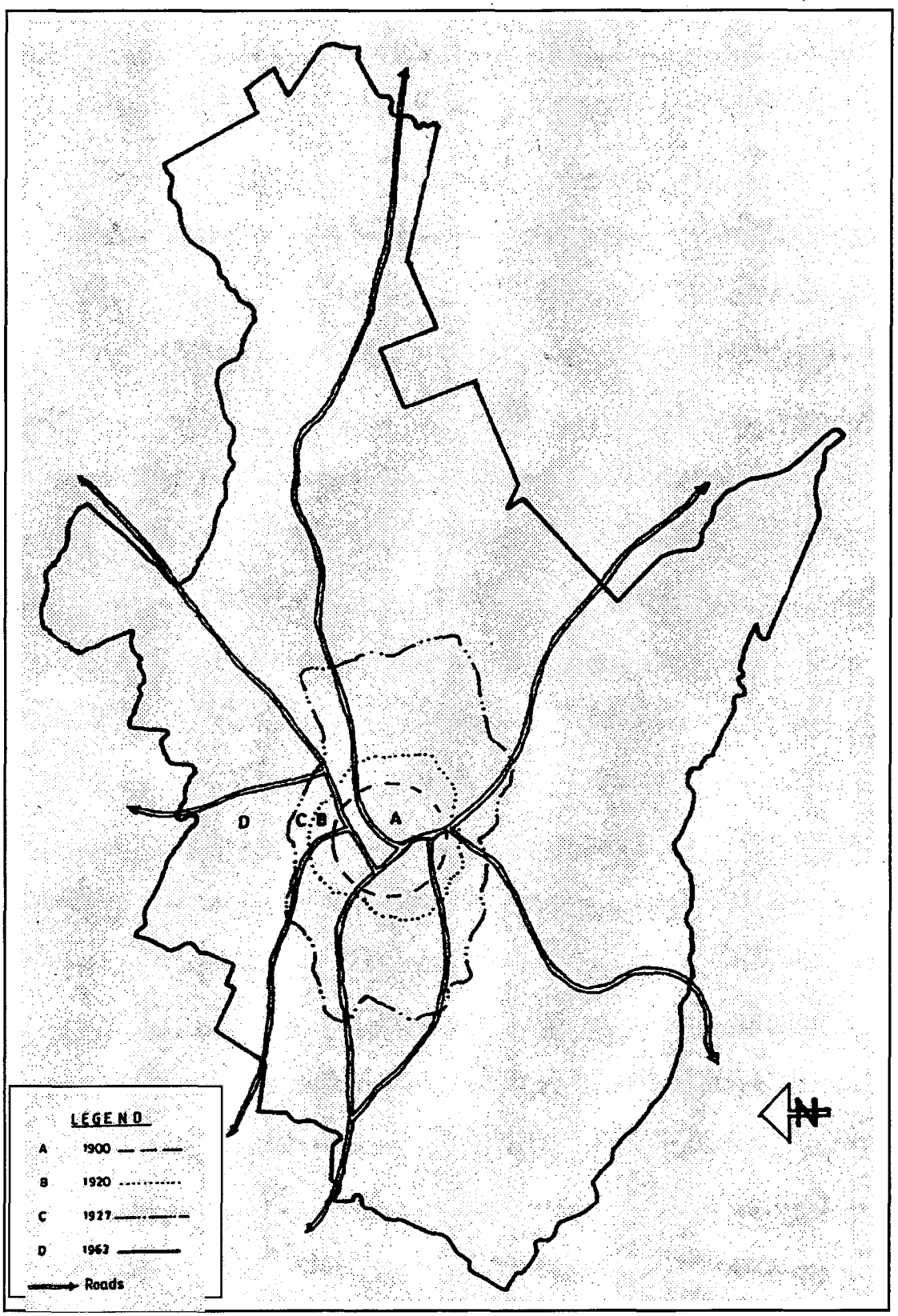
The study is carried out in two slum communities, Viwandani and Korogocho, located in the city of Nairobi, Kenya. Slums and informal settlements which began growing in 1902 when the city was officially founded, is home to about 60-80% of Nairobi's population and 71% of the total urban population in Kenya (Government of Kenya and UNCHS, 2001; Matrix Development Consultants, 1993; UNHABITAT, 2005). Urbanization levels rose from 8% in 1969 to 19% in 1999. However the rate of urbanization in Kenya has declined between inter-censual period of 1979-89 and 1989-99 from 5.2% to 3.2% respectively. Most of the increase in population in the coming decades will be attributed to natural increase due to the large proportion of the population in the reproductive age while migration will play a minor role (Central Bureau of Statistics, 2002).

The city of Nairobi first emerged as a depot for transporters in 1896 and three years later became a railway station during the construction of the railway line linking the hinterland of East Africa with the coastal sea port of Mombasa, on the shores of the Indian Ocean. Nairobi's temperate tropical climate and the altitude were deemed conducive for settlement as opposed to the humid and malaria prone low-lying areas. In 1905, it was upgraded to an administrative capital which was previously based in Mombasa and by 1906 it had a total population of 11,000 people. Nairobi was declared the capital of the colonial government in 1907 and upgraded to a city status in 1950 (Deng and Turkstra, 2004; Mitullah W, 2003).

Nairobi has since grown both in physical size and in the size of its population. The city boundaries and hence the land area has been adjusted 4 times from 1,813 hectares in 1900 to the current size of 68,945 hectares as illustrated by the map in Figure 3.3. The population of Nairobi according to the latest census (1999) stands at 2.8 million and it is estimated to increase to 3.2 million by 2010. The inter-censual period of 1989-99 saw an increase of close to 1 million people. The declining productivity from agriculture as well as the rising population land density in the rural areas has fuelled the urbanization rates in most African countries. The gap between urban and rural areas in availability of social services, employment and higher wages has also contributed to the influx of migrants into the urban areas (Government of Kenya and UNCHS, 2001).

Currently, Nairobi is not only the administrative capital city of Kenya but it is also the cultural, industrial and education centre. It is also an international and regional centre for commerce, transport, and economic as well as non-economic corporations. Over two thirds of the national GDP is generated in the urban centres while Nairobi generates over 45% (Deng and Turkstra, 2004; UNHABITAT, 2005).

Figure 3.3: Changes in size and boundary of Nairobi city 1900 - present



Source: Matrix Development Consultants (1993)

The growth of slum communities in Nairobi has resulted from a host of factors that are both historical and contemporary in nature. The development of slum areas during the pre-independence period was attributed to displacement of indigenous population to create room for urban settlements and insufficient housing for indigenous population. Independence from colonial rule in 1963 was another landmark in the growth of slums and informal settlements (Matrix Development Consultants, 1993; Mitullah W, 2003).

The population growth rate in Nairobi after independence resulted mainly from relaxation of migration rules that existed during colonial administration. This led to the inability of the city to provide adequate housing for its residents and hence contributed to the growth of slums and informal settlements. The post-colonial government's initiative to provide housing has been met with obstacles and hence inability to satisfy the demand. The housing projects initiated in the 1960s and 70s were composed largely of large housing estates that were considered expensive, economically not viable and mostly benefited the higher and middle income groups. The government halted provision of housing following the Structural Adjustment Programs (SAPs) implemented in the late 1980s which saw a reduction in public subsidies thereby affecting government housing projects previously heavily subsidised. The economic decline during the 1980s and 90s also contributed to a reduction and eventual halting of new government-initiated housing projects (Government of Kenya and UNCHS, 2001).

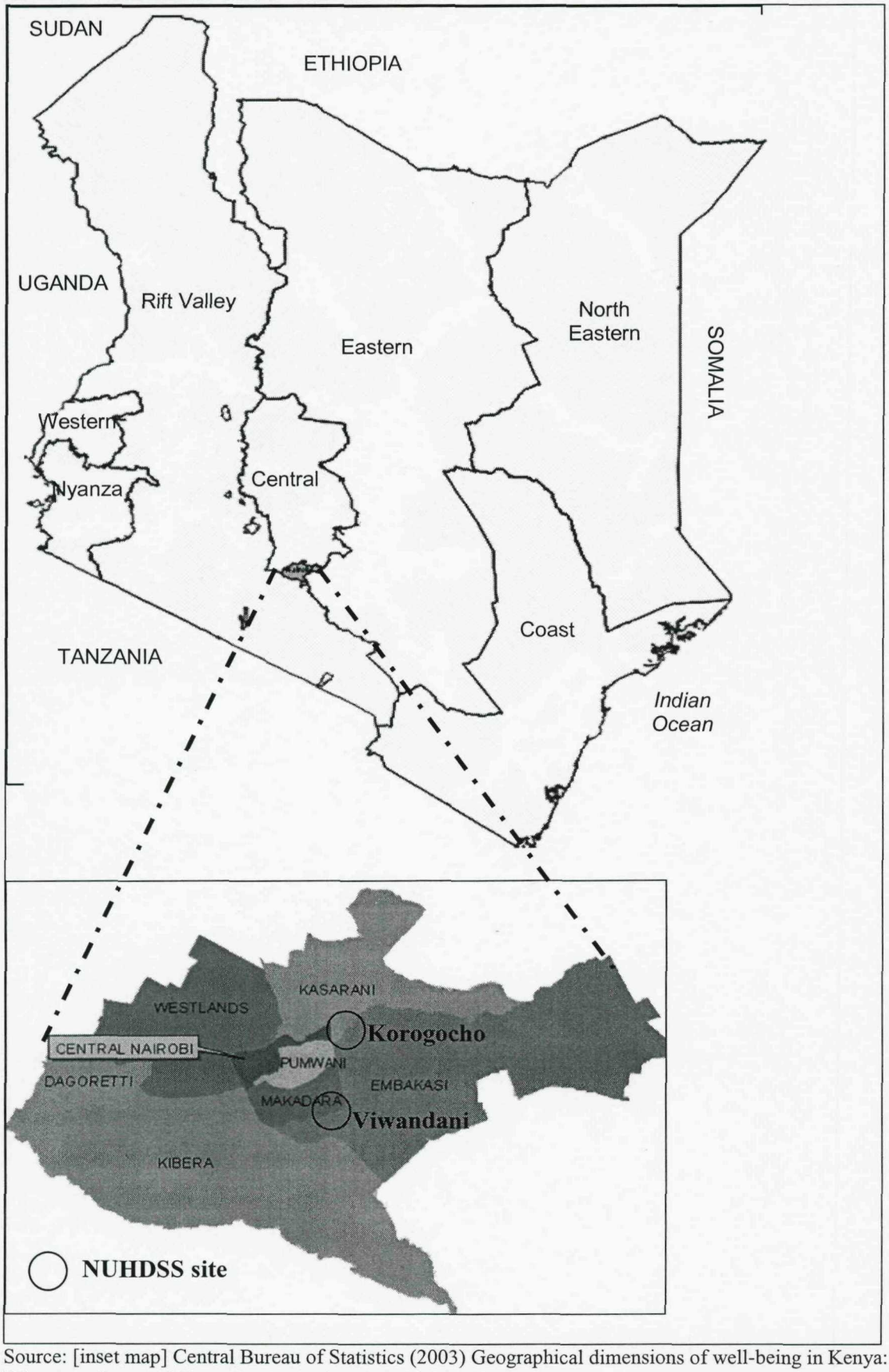
Most of the slums are located on public land which is not designated as residential areas while some are built illegally on privately owned undeveloped land. Some of the informal settlements have legal titles for the land but the structures on the land have not been approved by the planning authorities and have been constructed with disregard to building regulations. Interestingly, many of the occupants of public land are not entirely squatters as they possess temporary occupation licences issued by the local government (Deng and Turkstra, 2004; Matrix Development Consultants, 1993). The majority of the informal settlements in Nairobi are located in the eastern part of the city mostly along river valleys unsuitable for human settlement. The location of slums is also defined by the proximity to industrial sites that are accessible for the residents seeking employment.

The government's initial policy was to eradicate slums through demolition. However, following condemnation from various sources and being a signatory to UN conventions

that seek to protect the rights of slum dwellers, the government abandoned its slum clearing policy (Government of Kenya and UNCHS, 2001; Matrix Development Consultants, 1993). Very few attempts have been made to improve slums or the living conditions among slum residents. There is a lack of coordination among the various government ministries responsible for slums. While housing is a responsibility of the Ministry of Lands and Housing, the local authority is in charge of provision of social services. However, most local authorities are cash strapped and are weakened by very strong control from the central government which in turn relies on funding from donor agencies that influence expenditure and priority areas. Previous attempts to upgrade slums have been ad hoc, uncoordinated, and small-scaled while others have not benefited the poor (UNHABITAT, 2005). Recent development within the government has showed renewed efforts to upgrade slums which are in line with several Millennium Development Goals (MDGs) (targets for goal 1 - eradicating extreme poverty and hunger, and goal 7 - ensuring environmental sustainability). The Kenya Slum Upgrading Programme (KENSUP) drafted in 2000 with funding and technical support from UN-HABITAT is one such initiative.

Kenya has a centralised political and administrative system of government and the country is divided into 8 administrative provinces. Nairobi city is both an administrative province and district and it is further sub-divided into 8 administrative divisions (Figure 3.4). Korogocho location one of the sites of this study is 49.2 hectares in size and is located in the eastern part of the city and falls under Kasarani division where several informal settlements such as Mathare, Kariobangi, Kahawa and Karindudu are also located. Viwandani, the other site, falls under Makadara division which is an industrial zone and settlements in Viwandani do not date back further than 1981 as the city council previously used to demolish any structures in the area as soon as they were erected. Most settlements in Viwandani are in vacant plots behind large factories or below electricity power lines where officially no construction is authorised (Deng and Turkstra, 2004; Matrix Development Consultants, 1993).

Figure 3.4: Map showing Kenya's province boundaries and (inset)Nairobi's division boundaries and NUHDSS sites



Source: [inset map] Central Bureau of Statistics (2003) Geographical dimensions of well-being in Kenya: Where are the poor? From districts to locations Volume I

3.3 The Nairobi Urban Health and Demographic Surveillance System (NUHDSS)

The African Population and Health Research Centre (APHRC)[3] conducts a Demographic Surveillance System (DSS) in the two slums, Korogocho and Viwandani, where this study was conducted. DSS sites are important tools for research and for monitoring the determinants of demographic dynamics and the long term impact of diseases and cause-specific morbidity and mortality in the absence of efficient vital registration systems, as well as health information systems, a characteristic of most developing countries. Over 30 such DSS sites have come together under an umbrella organization called INDEPTH, which provides opportunities for networking and synergy (Phillips, McLeod and Pence, 2000; Baiden, Hodgson and Binka, 2006).

The DSS is known as the Nairobi Urban Health and Demographic Surveillance System (NUHDSS). The core function of the NUHDSS is to monitor population dynamics, that is, fertility, mortality and migration of the population under surveillance by recording all the births, death and movements occurring to this population. Information on associated social and economic factors to explain the observed changes in the population size is also collected. In addition, the NUHDSS also acts as platform for conducting other panel and cross-sectional surveys within the defined geographical setting. The NUHDSS monitors the entire population within the demarcated geographical area or Demographic Surveillance Area (DSA). This study was a cross-sectional study nested on the NUHDSS.

3.3.1 Setting up of the NUHDSS, eligibility and membership criteria

An initial census or baseline to register the defacto population that will be visited periodically was carried out in August and September of 2002. A usual resident was defined as any person who spends the majority of his/her time in that household. Persons who usually live in police barracks, prisons, university, boarding school, etc. were considered as living in those institutions and were, therefore, not usual residents of

[3] The African Population and Health Research Center (APHRC) is a non-profit, non-governmental international organization that conducts high quality and policy-relevant research on population and health issues facing sub-Saharan Africa. APHRC's research focuses on four major themes: Urbanization and wellbeing; Population and reproductive health; Health challenges and systems; and Education (www.aphrc.org)

the household. Before the initial census was conducted, all the rooms and structures located in the DSA including business units, health facilities, schools and utilities such as toilets were numbered and assigned unique identifiers with the usage specified. Geographical maps indicating the locations of all the structures were also drawn to facilitate identification of rooms and structures and to determine the precise boundary of the DSA.

A DSS has to set up clearly defined eligibility criteria for inclusion or exclusion of individuals in the DSS (INDEPTH network, 2002). All individuals who were usual residents during the initial census automatically became DSS members. Individuals who were visitors during the initial census and were still present during the first round were also considered as DSS members. After the initial census, individuals became DSS members either through in-migration or through birth. The birth should have occurred to a female DSS member. If a birth occurs to a visitor, that birth will not be considered a DSS event and the child would therefore not become a DSS member. Visitors who have been resident in the DSA for 90 days or more are registered as DSS members through in-migration. A person ceases to be a DSS member either through death or out-migration. A resident is out-migrated only after having stayed outside the DSA continuously for 90 days or more. After the initial census, the enumerated population was visited every three months or 90 days and later the cycle was changed to 120 days. The initial census is therefore considered as round 0 with the subsequent updates or cycle being round one and so on. The visitation cycle was changed from 90 days to 4 months or 120 days after the second round. This study was therefore conducted among 2,771 older people who were registered as DSS members during the round (round 12) preceding the survey.

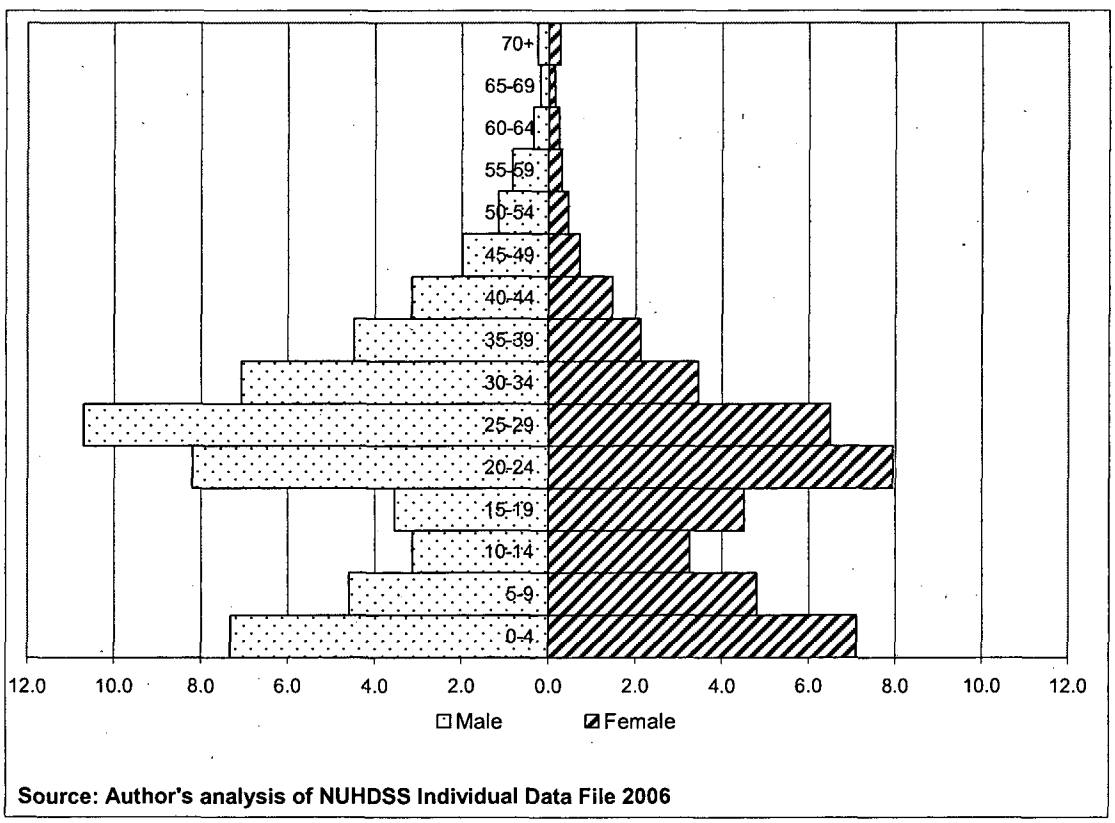
3.4 Demographic and socio-economic characteristics of NUHDSS population

The total population resident at the end of the 12th round was 55,281. The NUHDSS population is generally very highly mobile with an annual attrition rate of about 20%. However, the size remains almost constant or increases slightly given that the number of in-migrants still outnumber out-migrants (Zulu et al, 2006). The median age for the entire population is 23 years which is higher compared with the national average of 18 years and where almost half of the country's population is 15 years or younger (Central Bureau of Statistics, 2002).

3.4.1 Age and sex distribution

The age and sex distribution of the NUHDSS residents is presented using a population pyramid in Figure 3.5. The population in these slums is made up largely of people in their economically active ages. Evidently, almost two thirds of the population is aged between 15-49 years. The pyramid, having a huge bulge in the middle ages and narrower at the bottom, does not depict a typical triangular-shaped age distribution for a youthful population. It is, however, consistent with the structure of most urban population in sub-Saharan Africa (Adepoju, 1995; UNHABITAT, 1996; UNHABITAT, 2005).

Figure 3.5: Age and sex distribution of NUHDSS population



Source: Author's analysis of NUHDSS Individual Data File 2006

The low proportion of young people in the age groups 10-14 and 15-19 years is also a major demographic feature for this population. Teenagers especially those aged 10-14 years make up a relatively smaller proportion (6%) compared with other younger age groups (0-9 years). This has been attributed to parents or guardians sending their children to boarding schools or to schools located in rural areas when they attain the school-going age (Otieno and Bocquier, 2006). The NUHDSS operation definition of usual residents, which excludes people who are away continuously for 90 days or more

for instance in boarding schools and other residential institutions, also accounts for the low proportion of those in the school-going ages of 10 – 19 years.

Older people (50+ years) constitute 5% of the total population the majority of whom, fall in the age group 50-54 (46%) hence a median age of 56 years. However, the age distribution among the older people contrasts between the two sexes. Specifically, the men are relatively younger compared with the women. While almost half of the women population is aged 60 years or older (44%) only about 29% of the men are in this age group.

The other feature of the NUHDSS population is a high sex ratio. The overall ratio of males to females is about 124:100 which is typical for most cities in Africa where males outnumber females (O'Connor, 1983). The sex ratio in Nairobi has consistently been high and for instance during the 1962 census was 154:100 which fell to 138:100 by 1979. Although the proportion of women migrants has been on an increase forcing the sex ratio to gradually fall, men still outnumber women among migrants to urban areas (Gould and Oucho, 1993) including migrants into the NUHDSS (Zulu et al, 2006). The sex distribution among older people is even more skewed where two thirds of the population is male. These differences point both to the historical rural-urban migration patterns and gender variations that typically characterised earlier migrants to the city. The majority of the current older people in Nairobi migrated to the city during pre-independence period and immediately following independence when there was a strong bias towards single male labour migrants (Byerlee, 1974).

3.4.2 Household size

A household in the NUHDSS is defined as a social unit whose members (one or more) live together in one or more rooms within the same structure. A household is therefore made up of a group of people (irrespective of how they are related to each other) who share the same dwelling units within a given structure and ideally consume or make some contribution to food and other shared resources. By convention, if a family unit is spread over two distinct structures, then its members living in the other structure will be registered as a separate household. Approximately 22,000 households were registered at the end of 12th round of data collection. Households in the NUHDSS typically occupy one room or dwelling unit. The average number of people in one household is 2.5 while households with older people are slightly larger (2.9) (see Table 3.2).

Table 3.2: Basic demographic characteristics of NUHDSS

	Total NUHDSS population	Older people (50 years+)
Total resident population	55,281	2,771
Total number of households	21,793	2,498
Average household size (persons)	2.5	2.9
Ethnic groups (%)		
Kikuyu/Embu/Meru	32.2	43.5
Kamba	22.8	17.2
Kisii	4.7	1.5
Luhya	14.0	12.4
Luo	16.9	11.6
Somali/Borana	7.0	10.4
Other ethnic groups	2.6	3.5
Highest education level for adults 18+ years (%)		
No education	4.9	26.3
Primary	60.6	56.8
Secondary or higher	33.4	16.0
Unknown	1.2	1.0
N	*35,679*	*2,645*
Total	100.0	100.0

Source: Author's analysis of NUHDSS Membership and Individual Data Files, 2006

3.4.3 Ethnic groups

The ethnic distribution for the total population and among older people is presented in Table 3.2. Overall, the dominant ethnic groups are those that originate from the Central and Eastern provinces of Kenya (see Figure 3.4 for provincial map of Kenya) as the Kikuyu, Embu and Meru make up about a third of the population followed closely by the Kamba (23%). The ethnic distribution in these slums does not reflect the country's ethnic composition nor is it representative of slums in Nairobi (APHRC, 2002). Generally, most slums in Nairobi depict unique spatial segregated pattern based on ethnicity which can be accounted by chain migration where the presence of kin and relatives provide a base for new migrants, hence encouraging migrants from a specific place of origin to predominantly settle in one area (Byerlee, 1974). Among the older people however, the Kikuyu, Embu and Meru make up almost half (43%) of the population. This may be reflective of the composition of earlier migrants to the city

where communities from provinces in close proximity to Nairobi dominated (O'Connor, 1983).

3.4.4 Education attainment

Education is important in facilitating employment opportunities in urban areas hence rural-urban migrants are usually characterised by people with some formal education compared with those less likely to migrate (Gould and Oucho, 1993). Therefore, a large majority of the population 18 years or older has been to school (94%) the bulk having attained primary level of education. On the contrary, slightly more than a quarter of older people have never been to school (26%) compared with only 5% overall (Table 3.2).

3.4.5 Participation in income generating activities

An income generating activity is defined in the NUHDSS as any activity done for income either in form of cash or payment in kind. Livelihood information is periodically collected in the NUHDSS and the information seeks to capture all income generating activities of DSS members aged 12 years or older. Other information collected includes, household expenditure in major items such as food, rent and selected durable goods as well as information on transfers and remittances either in cash or kind to or from the household. Out of the population that was sampled for the livelihood module, 60% reported to have been engaged in an income generating activity in the 4 months preceding the date of interview (Table 3.3).

Table 3.3: Proportion currently working and sector of employment by age

Work status	Females	Males	Total
Currently working (%)	42.2	73.5	60.1
Employment Sector (%)			
Other sectors	22.3	21.4	21.6
Private sector	18.5	48.6	39.6
Household enterprises	59.3	30.0	38.8
Total	100.0	100.0	100.0
N	*1,865*	*3,140*	*5,005*

Source: Author's analysis of NUHDSS Livelihood Data File, 2006

Employment in the public sector in Kenya has reduced drastically especially during the 1990s after the implementation of the structural adjustment programmes in the late 1980s. The bulk of the workforce has thus been absorbed by the private and informal sectors with the majority ending up in the informal sector which includes those in self-employment or engaged in family businesses (Bocquier, 2005). This is also reflected in the study area as shown by the type of sector of employment (Table 3.3). The private sector and household enterprises are the largest employers of those currently working. Less than 2% of those who are employed reported to work in the public sector (included in 'other' category). Even though almost two fifth of those currently working reported to be in the private sector, this may not reflect employment security or entitlement to benefits such as health insurance and pensions. Bouquier (2005) by analyzing the trends in the labour market in Kenya shows that whereas the formal sector is still a major employer especially in Nairobi the majority of the employees in this sector are either employed as casuals or informally without contracts or benefits.

3.5 Summary

This chapter has provided a description of the study area and the HIV/AIDS situation in Kenya. The HIV prevalence in the country has been on the decline over the last 10 years from a high of 10% to the current level of 6.4% resulting from a concerted effort to educate the public about HIV/AIDS. While prevention is still a priority for the government, the immediate area of concern is to mitigate the impact of the epidemic including improving the quality of life of PLWHA and those affected by HIV/AIDS. However, the bulk of the responsibility for care and support for those infected continue to rest on the family or informal caregivers. Efforts by the government and other

stakeholders to assist those infected or affected by HIV/AIDS is yet to be felt by the majority. The study setting, informal urban slum settlement, provides a perspective for researching on HIV/AIDS in an urbanising context. The next chapter presents the methodological aspects of the study.

CHAPTER FOUR

4 RESEARCH DESIGN AND METHODOLOGY

The overall goal of this study is to understand how HIV/AIDS affects older people living in the slums of Nairobi by addressing the following research questions:

1. What do older people perceive as the main HIV/AIDS concerns facing older people in their community?
2. What circumstances lead older people to provide care to someone ill due to HIV/AIDS and what specific role do they play as caregivers?
3. What is the association between being caregivers and, socio-economic and health outcomes?

This chapter discusses the study design and measurements in addressing these research questions above. The first part of the chapter presents who the study's target population are and the operational definitions of key measurement concepts. A description of the fieldwork process and procedures are then discussed followed by the methods used for data analysis.

4.1 Target population and measurement of key concepts

4.1.1 Older person

The target population for the study is older people living in Korogocho and Viwandani slums of Nairobi, Kenya. An older person was defined as anyone, male or female, aged 50 years or older. While the UN uses 60 years and older as the cut-off age for older people in most of its publications, there is no global consensus on the chronological age for defining older people. The age 60 or 65 is used generally in developed countries and this mostly corresponds to the age set by governments as the retirement age or age when a person is eligible for pension. The cut-off age of 50 years was selected in this study to define older people due to the low life expectancy in Kenya which in 2006 was estimated at 53.2 years for men and 57.7 years for women (Kenya National Bureau of Statistics, 2007). This implies that the number of people surviving beyond 60 years is small. Setting the minimum age for eligibility at 50 years therefore allowed a sufficient number of participants for the survey. The cut-off age of 50 years was also set based on the retirement age for most countries in sub-Saharan Africa. For Kenya in particular, the

age at which a pensions contributor is eligible to withdraw pension is 50 years while the official retirement age is set at 55 years.

The Demographic Surveillance System (DSS) provided a sampling frame for identifying older people for the study. All people 50 years and older who were registered as resident members in the DSS during the round preceding the survey were eligible for interview hence the survey was a complete census of all persons who met the age and residency criteria for selection. A total of 2,771 men and women were eligible to participate in the survey.

4.1.2 Care-giving

A caregiver is someone providing informal and unpaid assistance to a person with a chronic illness who is unable to provide for themselves. The care is considered informal because the caregiver has not undergone any formal training in care-giving similar for instance to caregivers in the formal healthcare system (Hunt, 2003). The choice of operational definition of care-giving influences the number of individuals identified as caregivers and consequently the degree of impact care-giving has on the caregiver in terms of psychosocial, health and economic consequences. In broad terms care-giving includes both instrumental and emotional care provided by the caregiver (Hunt, 2003; Kramer, 2002).

A broad definition of care-giving was adopted for this study where provision of care to someone ill is defined as providing at least one form of care or a combination of financial, psychosocial, health-related care, and personal or nursing care. **Financial care** includes catering for financial needs such as for daily subsistence or paying for medical expenses. **Instrumental care** consists of doing household work such as cooking, laundry which the caregiver would not usually be doing for the care recipient if the person was not ill. Assisting the ill person with bathing, feeding, dressing or help with use of the toilet is classified as **nursing care**. This normally occurs when the care recipient is severely ill and sometimes confined to a bed. **Health-related care** included making decision about where and when to seek treatment, accompanying the person receiving care to hospital or consulting with health professionals on their behalf whereas **psychosocial** support or care involves provided counselling, encouragement and spending time with the ill person. These forms of care are not mutually exclusive and can be provided simultaneously.

The information on care-giving is derived from a question asking participants whether they were providing care to someone with a chronic illness during the time of the interview or if they had provided care during the three years preceding the survey. Chronic illness was defined as any illness that persisted for 3 months or longer. About 11% (216) of older people reported to be providing or to have provided care to someone with a chronic illness.

4.1.3 HIV/AIDS case diagnosis

HIV compromises the body's immune system hence the body becomes susceptible to opportunistic infections caused by bacteria, viruses, fungi and parasites which would otherwise not develop in a healthy immune system. A HIV positive person may by asymptomatic for several months or years before showing signs of the infection. The stage where a person begins to show signs or symptoms of infection is known as the symptomatic stage. A person is diagnosed with AIDS when the immune response system is severely damaged and the person suffers from opportunistic infections. Therefore, AIDS clinical manifestation involves a wide range of infections and disease-symptoms. Laboratory diagnosis for the presence of the HIV virus in the body on the other hand, tests for the presence of antibodies (Grant and De Cock, 2001).

The sensitive nature of HIV/AIDS together with the stigma and secrecy surrounding the disease makes direct reference to HIV/AIDS difficult especially in a setting where HIV/AIDS is still stigmatising. The level of stigma towards people infected with HIV/AIDS is still relatively high in Kenya according to the recent Kenya Demographic and Health Survey (KDHS). Questions on attitude towards people living with the virus were asked during the survey and only 27% of the women and 40% of the men expressed acceptance towards people living with the virus (Central Bureau of Statistics et al, 2004). Further, unlike other DSS sites in Africa for instance Rakai in Uganda, Karonga in Malawi and KwaZulu Natal in South Africa where HIV testing is conducted for all residents, the NUHDSS does not collect HIV serological testing on its population. This study therefore used an indirect approach without making a direct reference to HIV/AIDS.

An adaptation of the WHO's AIDS case definition is used. The WHO categorises a person as having developed AIDS if he or she presents with at least 2 of the major signs in combination with at least one of the minor signs. The major signs consist of weight

loss of at least 10% of body weight, chronic diarrhoea for more than a month, and prolonged fever. Six other conditions listed as minor signs are; persistent cough, pruritic dermatitis, herpes zoster, oropharyngeal candidiasis, herpes simplex infection and disease of the lymph nodes. The list of illnesses or conditions was expanded in a revised version of the WHO definition also referred to as Abidjan Definition in 1994 to include meningitis, pulmonary tuberculosis, Kaposi sarcoma, neurological impairment, pneumonia, and invasive cervical cancer. The method has not been modified or improved since it was last updated in 1994 probably because of improvement and widespread laboratory testing and the setting up of surveillance sites in health facilities and clinics using laboratory diagnosis (Grant and De Cock, 2001). The WHO diagnosis is mostly in use in resource-poor settings and in the absence of diagnostic facilities or laboratory testing and in areas where HIV prevalence approaches 10% (Centers for Disease Control and Prevention, 1992; Pan American Health Organization, 2001). The method has been tested in a number of settings for its sensitivity (probability that the test is positive in patients with HIV/AIDS) and specificity (probability that the test is negative in patients without HIV/AIDS) with varying results. In Zambia, the indicator was tested on paediatric patients and the results indicated specificity of 69% and sensitivity of 64% (Chintu et al, 1993) while a study in Rwanda found specificity of 92% and sensitivity of 55%(Lepage et al, 1989). Overall, the WHO definition has very high specificity but low sensitivity.

During the study, participants who responded 'YES' to either currently caring for someone with a chronic illness or having cared in the three years preceding the survey were asked to mention the illness or condition the person receiving care was suffering from. Interviewers were encouraged to record more than one illness or condition. In order to isolate people receiving care who have HIV/AIDS, those who were reported to have been suffering at least one of the major signs according to the WHO definition namely; prolonged fever, diarrhoea, persistent cough, tuberculosis, or pneumonia, were categorised as having a HIV/AIDS-related illness. The presences of these major conditions or illness usually indicate advanced progression from asymptomatic HIV stage to full-blown AIDS (Grant and De Cock, 2001). Out of the 216 older people who reported to be caring or to have cared for someone with a chronic illness, 41% (88) were classified as caring for someone with a HIV-related illness. Only 10 of the participants mentioned outright that the person under their care had been diagnosed with HIV/AIDS.

Older people who were providing care to someone with a HIV-related illness were therefore categorized as HIV caregivers whereas those who were providing care to people with other illness are referred herewith as other-caregivers (128). Non-caregivers are therefore older people who had not provided care to anyone with a chronic illness over the three-year period preceding the survey (1,845).

4.1.4 Socio-economic and health indicators

One of the research questions in this study seeks to find out if there is an association between caring for someone with a HIV/AIDS-related illness and socio-economic and health outcomes. This is addressed by comparing HIV caregivers with other-caregivers and non-caregivers. The socio-economic indicators used are presented in Table 4.1. Details on how these indicators were computed are discussed in detail in Chapter 7.

Table 4.1: Socio-economic indicators

Type of variable	Socio-economic indicators
Money-metric measurements	Income Expenditure
Non-monetary measures	Wealth or asset index Participatory wealth assessment
Coping strategies	Sources of income Sale of household assets
Other outcomes	Household size and composition

Care-giving to someone with a prolonged illness like HIV/AIDS is likely to affect income through loss in productivity and earnings from the ill person if he or she was contributing to the household income. The loss in income also occurs when caregivers reallocate their time to care-giving which would otherwise be used for generating income. A reduction in income will in turn impact upon expenditure. Care-giving affected expenditure through reallocation of expenditure budget to illness-related overheads including medical costs. Given that care-giving may result in expenses which would have otherwise not be incurred by the caregiver or household, therefore, an increase in the total expenditure budget may occur. Faced with changes in income and expenditure, those affected may react by employing coping strategies to meet any shortfalls. Such strategies may include the sale of assets or borrowing to supplement income which may temporarily increase the amount of income earned. A drawn out

care-giving situation ultimately affects the wealth status of those who are providing care.

In addition to the socio-economic indicators discussed above, the health of HIV caregivers is also compared with other-caregivers and non-caregivers. The indicators used to measure health status are self-reported functionality and disability, severe health problem and quality of life, details of which are presented in chapter 8.

4.2 Mixed methodology research design

This study employed a mixed methodology approach, a research design which integrates qualitative and quantitative methodological approaches in various stages of the research process. Most research in social sciences and other behavioural and health sciences is increasingly using mixed methodology designs which is gradually being recognised as a distinct research design (Creswell et al., 2003; Creswell, 2003; Teddlie and Tashakkori, 2003). Hence, this study integrated qualitative and quantitative methods in addressing the research objectives at the data collection and analysis stages.

The multifaceted and contextual nature of the research problem stipulated a mixed methodology approach. Apart from the clinical or medical aspect, HIV/AIDS also affects the psychosocial, behavioural and economic dimensions of life for both the PLWHA and his or her family including their social networks. Therefore, use of different data collection strategies and analysis provides a better understanding of the research problem as the research question is addressed from different perspectives using different methods. Integrating different methods enhances the richness of the data by providing greater depth and breath thus strengthening the quality of data interpretation and findings (Creswell et al., 2003; Tashakkori and Teddlie, 1998; Teddlie and Tashakkori, 2003).

Mixed methods designs have other advantages in that it draws on the strength of one method while offsetting the weaknesses inherent in another method (Creswell, 2003; Tashakkori and Teddlie, 1998). For instance, quantitative surveys are advantageous in that they allow for the collection of data that can be manipulated using inferential statistical techniques to understand relationships and association between individual attributes and occurrence of certain events. The findings can also be generalized to a wider population or setting. The wording and sequence of the questions in a survey are

standardised across all the respondents thus allowing for relative uniformity in the ways the questions are asked and understood by respondents (Robson, 2002).

Mixed methods design is also used for triangulation or convergence of research findings although this is seen as a weakness in that some of the findings from the different data collection methods can contradict rather than complement findings from another method. However this can help in uncovering the diversity in the phenomenon under study and also allows for evaluation of conceptual and theoretical assumptions underlying the research problem (Stake, 2005; Teddlie and Tashakkori, 2003).

In this study therefore, qualitative methodology was used mainly to answer the 'how' and 'why' questions and to address contextual questions pertaining to the study area in addition to explaining and interpreting finding from the quantitative data. Specifically, the quantitative survey on older people was mainly used to address the question on what is perceived as the main HIV/AIDS concerns facing older people in their community and the factors associated with these concerns and to examine the socio-economic and health factors associated with care-giving. The qualitative study on the other hand informed on the circumstances that lead older people to provide care to someone ill due to HIV/AIDS and to illustrate care-giving tasks.

4.2.1 Concurrent nested mixed methods design

The data collection strategy used for the study was a concurrent nested design where the quantitative and qualitative data are collected simultaneously during the same data collection phase. This design is denoted as "QUAN + QUAL" in methodology literature to indicate that both data methods have the same importance or equal precedence in addressing the research problem (Morse, 2003). The sequence in data collection and priority given to either method has implications on the overall research purpose and data analysis strategy. QUAN + QUAL strategies are designed for confirmatory as opposed to exploratory studies. Where a research problem under study is less known or if the purpose of the study was to generate a theory, the sequence would be a QUAL → QUANT where a qualitative study would first be conducted, the data analysed and the findings used to inform the design of a quantitative study. For this study however, the qualitative method and the quantitative survey were meant to address different aspects of the research as mentioned in the section above (Creswell, 2003; Morse, 2003; Tashakkori and Teddlie, 1998; Teddlie and Tashakkori, 2003).

The other reason for collecting both the quantitative and qualitative data concurrently was to minimise recall bias given that the research questions in the qualitative study made frequent reference to responses given during the quantitative survey. The qualitative respondents were asked specific questions based on the responses they provided in the survey regarding the care they were providing to someone with a chronic illness. Additionally, the data collection for this study was done concurrently with other NUHDSS surveys which also formed part of the data used in the analysis. Specifically, the socio-economic data is derived from the household amenities and livelihood survey which was collected simultaneously with the older people survey. Concurrent quantitative and qualitative data collection was also necessary due to the nature of the phenomenon under study. Care-giving is a dynamic process, therefore, the situation at a given point in time may be quite different after some time has lapsed due, for instance, to changes in the health condition of the person receiving care as well as the caregivers' circumstances may also change. Given that the study was cross-sectional in nature, quantitative and qualitative data collection processes were therefore conducted simultaneously to minimise on time-varying factors (Creswell et al., 2003; Creswell, 2003; Morse, 2003).

4.3 Survey on social, health, and overall wellbeing of older people (Survey of Older People)

A quantitative module designed by the author for this study was nested on a larger cross-sectional survey conducted by the African Population and Health Centre (APHRC) in Korogocho and Viwandani slums that sought to study the overall wellbeing of older people living in these two communities and how it related to their migration and poverty status. This Survey of older people is part of a larger 5-year programme titled Urbanization, Poverty and Health Dynamics in sub-Saharan Africa (UPHD) to investigate the linkage between migration, poverty and health consequences at each stage of the life-course among people living in slum settlements (APHRC, 2008).

The survey was conducted using face-to-face interview method between November 2006 and January 2007. In the study area, the virtually non-existent postal mailing addresses or system, coupled with low levels of literacy which is especially lower for older people, necessitated an interviewer-administered procedure for collecting data.

This also allowed a speedy and timely duration in completing the whole survey given that the questionnaire was relatively long, thus requiring a sustained attention from the respondents. A face-to-face interview also allows the interviewer to judge the respondents' accuracy, commitment and truthfulness in participating in the survey (Robson, 2002).

A copy of the complete English version of the questionnaire is provided in appendix 7. The questionnaire is divided into 11 modules or sections. The modules in the questionnaire that are specifically relevant to this study are sections 8, 9, and 11 which focus on caring for people who are ill, caring for orphans, and HIV/AIDS attitudes and perceptions respectively. The main objectives of these sections were to investigate possible mechanisms through which HIV/AIDS affects older people and to provide a baseline for follow-up studies looking at changes over time. These sections have been informed largely by research conducted in Africa and Asia that have looked at the impact of HIV/AIDS on older people. These studies are: the Socio-Economic Impact of Morbidity and Mortality on Households Study carried out in the Free State province of South Africa by the School of Medicine, Health Policy and Practice, University of East Anglia (Bachmann and Booysen, 2003), and the Socio-demographic Impact of AIDS Epidemic on Older People in Thailand by the Population Studies Center, University of Michigan (Knodel, 2005).

4.3.1.1 Data collection teams, recruitment and training

Field interviewers with data collection experience and who had previously worked in projects implemented in the NUHDSS were recruited and trained for a period of one week. The training process involved both classroom-type instructions and workshops. A training manual with detailed information on the objectives of the study, the study rationale and a detailed description of the content of the questionnaire was used to guide the training. The manual also contain information and procedures on how to conduct an interview, guidelines on interviewer conduct during fieldwork and also how to handle and approach respondents. In order to standardise field procedures, the field workers were asked to stick to the guidelines provided in the training manual and to consult with the office team before varying any protocol. The training also consisted of role playing between the trainees to familiarise with the questionnaire. Any difficulties regarding the questionnaire and various uncharacteristic interview scenarios which could arise during

the actual fieldwork were discussed. The training and the data collection was co-ordinated by the author in conjuction with APHRC research staff.

The whole data collection team comprised 28 field workers grouped into 5 teams working in designated areas or zones and each team consisted of an average of 5 interviewers and 1 team leader. Each interviewer was assigned a list of eligible respondents and was expected to interview an average of 3 respondents per day. The list contained the exact physical location of respondents and other personal details such as the name, age and sex. The role of the interviewer was to locate the eligible respondents, conduct the interview and edit their own questionnaires before handing them over to the team leader. The team leader was in charge of assigning work to the field interviewers in their team, editing the questionnaires, carrying out spot checks and overall supervision of the team. A site supervisor - one for each of the two slums and a field coordinator in charge of all field activities nested on the NUHDSS also provided overall supervision and were in charge of liaison with the office team.

4.3.2 Field work procedures and data collection

The fieldwork preparation, data collection and data processing covered a period of 15 months from January 2006 to March 2007. The timeline of the main field activities is presented in Table 4.2 below.

Table 4.2: Schedule of field activities

Time	Duration	Major activity
Older people survey		
January 2006 - June 2006	6 months	Fieldwork preparation & design of questionnaires
August 2006	1 month	Application of ethical approval
September 2006	2 weeks	Translation of Questionnaires from English to Kiswahili
October 2006	3 days	Recruitment of field interviewers
	1 week	Training
	1 day	Pre-test of questionnaire
	1 day	Revision of questionnaire
November 2006 - January 2007	12 weeks	Data collection
December 2006 - March 2007	5 weeks	Data entry and editing
Qualitative Interviews		
January 2007	1 week	Selection of study participants
	3 days	Training of qualitative interviewers
	2 weeks	Data collection
January 2007 - February 2007	3 weeks	Transcription of interviews

4.3.2.1 Questionnaire pre-testing

The questionnaire was pre-tested for content and consistency before it was fielded. The other objectives of the pre-test were to ensure the translations reflected the exact meaning from the original language, to check the skip patterns and to provide an estimate on the duration it would take to conduct a single interview. The pre-test exercise was also part of training for the interviewers to understand and familiarize themselves with the questionnaire. Each trainee was required to complete a minimum of two interviews. The pre-test was conducted in slum communities in the neighbourhood of the demographic surveillance area (DSA) and with similar physical and socio-economic characteristics as the DSA.

4.3.2.2 Actual data collection

All the interviews were conducted at the respondents' home or house. The language used during the interview was Kiswahili which was the most commonly used language in a linguistically heterogeneous and cosmopolitan setting. Kiswahili is the most widely spoken language across several countries in Eastern Africa and is also the national language in Kenya spoken by more than 90% of the population in urban areas being also the medium for daily commercial, cultural and social urban life. The questionnaire was therefore translated from English to Kiswahili and the translation was checked for accuracy by translating it back to English and field tested during the pre-test exercise.

Although two thirds of the field interviewers were female, the interviewers were randomly assigned to respondents without taking into consideration their own or the respondents' sex. Sex-of-interviewer effect has been known to affect the outcome of gender-related attitudinal questions (Kane and Macaulay, 1993), and also responses to questions on sensitive issues such as sexual behaviour (Wilson et al, 2002). At the end of each interview, the interviewers were asked to make an overall assessment of the interview on certain key aspects and to indicate specific questions which they or the respondent found difficult and or embarrassing. The questions on respondents' perception on their individual risk to HIV/AIDS were reported to have been embarrassing to ask by both male and female interviewers irrespective of the sex of the respondent.

In order to minimise non-response, the interviewers were asked to make a minimum of three scheduled visits in trying to locate the respondent. Interviewers were encouraged

to inquire from neighbours or other household members the most appropriate time to locate the respondent. Some interviews where therefore held early in the morning or very late in the evening as long as it did not compromise the interviewers' welfare and security. The fieldworkers worked for 6 days a week and in order to maximise on the best time to find respondents at home, the off-days were scheduled between Monday and Friday as weekends were considered primetime for doing interviews.

4.3.2.3 Data entry, cleaning and data management

The data entry was done using a Visual Basic as a front-end and with Structured Query Language (SQL) software as the back-end. The SQL Server platform is an ideal software for handling relational databases and hence for managing longitudinal data. Information collected for this study is linked to previously collected information pertaining to a particular individual or household. While most of the editing was done in the field by the interviewers and the team leaders, the data management system is configured with built in consistency checks that relate information collected at different points in time and also performs consistency checks for a particular set of data. The first line of data cleaning was therefore performed during data entry where inconsistent data is sent back to the field for verifications.

4.4 Qualitative In-depth interviews

The objective of the qualitative interviews was to provide an in-depth look into the role of care-giving and the contextual issues of providing care in an urban slum setting. The qualitative interview was designed and supervised by the author. The interviews were semi-structured with predetermined topics for discussion. An interview guide (Appendix 9) with topics to be discussed and additional probes was used during the interview although the discussion was conducted in a conversational and informal style. The semi-structured nature of the interview was to allow flexibility and adaptation to responses which vary from one interview to another. This also allowed the interviewer to follow-up on interesting responses and to probe for clarification or elaboration from the interviewee. Semi-structured interviews also provide focus, maximising on the interview time and ensure similar issues are addressed across all the participants in the study allowing for cross-case comparisons (Mason, 2002).

The topics covered on the guide included:

- Accounts on the routine tasks of caring for someone who is ill for a prolonged period,
- What constitutes typical and non-typical days and difficulties faced in providing routine care with specific reference to challenges associated with being an older person,
- The support received, either directed at the ill person or the older person who is providing care, from within their households or both formal and informal external support, and the adequacy of the support,
- The specific challenges of caring for a person with prolonged illness within an urban slum setting in comparison with other settings such as non-slum urban areas and the rural areas, and,
- Topics specific to HIV/AIDS and related care and support were asked to respondents who were explicit on that their care recipient had HIV/AIDS.

In-depth interviews were conducted with 31 participants out of a sample of 38 individuals selected from the quantitative survey. Out of the 7 selected individuals who were not interviewed, 3 respondents could not be found at home after several attempts to locate them, 1 refused to be interviewed citing too much commitment towards her patient who had just been re-admitted to hospital. The patients for two other selected individuals had died therefore one of the caregivers had travelled out of Nairobi for the funeral while the other person was too distressed to be interviewed as the patient had just died two days before the researchers visit to the household. One man who could only be found for a few hours on Sundays was however drunk on two occasions when the field interviewers visited his home and was therefore not in a position to be interviewed although he consented to be interviewed on these two occasions. Biographical information for the 31 indepth interview participants is presented in Appendix 4 which indicates their sex, age, marital status, ethnicity, education level, employment status and summary information on their care-giving experience.

4.4.1 Selection of participants

The participants for the qualitative interview were selected from the quantitative survey respondents through strategic and purposive sampling based on their specific

experiences of caring for someone chronically ill. This sampling method was used to capture the variety of experiences and provide an understanding of the diversity in care-giving. Individuals who had had non-typical experiences such as consecutive or concurrent episodes of care-giving to ill people over the 3-year reference period were selected. The participants were also selected based on their relationship with the care recipient. Typical cases were older people caring for their adult children, while atypical cases included those caring for their spouses, non-relatives and those caring for children under the age of 15 years. Other characteristics were sex and marital status of the caregiver. Table 4.3 present a summary of the number of IDI participants corresponding to the different characteristics taken into account while selecting the participants.

Table 4.3: Number of qualitative interview participants by sex and care-giving experience compared across place of residence

	Place of residence	
Individual Characteristics	Korogocho	Viwandani
Sex		
Male	7	8
Female	13	3
No. of experiences		
Single experience	13	4
Multiple experience	7	7
Relationship to ill person		
Parent	9	7
Child	1	0
Spouse	2	0
Not related	5	1
Other blood relation	3	3
No. of couples	1	3
Total number of interviews	20	11

Source: Author's analysis of Qualitative Indepth Interview Data, 2007

4.4.2 Indepth interview data collection and processing

The field interviews were conducted by the author, with the help of 4 qualitative researchers with previous extensive experience in collecting qualitative data. The field assistants have received training and worked with various projects implemented by institutions such as APHRC, Family Health International and the Population Council. They therefore did not require extensive training on conducting qualitative interviews. A 3-day meeting was held with the field interviewers to discuss the objectives of the study, the interview guide and the field procedures. The interview guide was also translated from English to Kiswahili by the team during this meeting. One of the field

interviewers was male and the rest were female. An analysis of the responses by gender of the interviewer showed no effect or variation by gender and additionally, during the data collection no respondent raised any objection regarding the sex of the interviewer.

The respondents were located with the help of field interviewers and field assistants who had participated in the quantitative survey. Almost all the interviews took place in the respondents' home with the exception of two that were conducted in the respondents' business premises within the DSA and not far from the respondents' house. All except 3 of the interviews were audio-taped using tape recorders, digital recorders and sometimes both were used with one acting as a backup. The three interviews not audio-taped were because the respondents did not consent to the interview being recorded although they did not object to notes being taken. Most of the interviews were conducted in Kiswahili except for 4 interviews where the respondent felt comfortable having the interview in their own ethnic language and this occurred in cases where the field interviewer and the respondent were from the same ethnic group.

The author transcribed all the Kiswahili interviews verbatim directly to English. The transcription was done as soon as the interview was complete and while data collection was on-going to allow for clarification and confirmation with the interviewers who conducted the interview. The field notes were used to identify non-verbal signs and also to obtain information on the observations made by the field interviewers during the interviews. Daily meetings and consultations were held between the researcher and the field interviewers to discuss each of the interviews and also for clarifying issues arising during transcription. The meetings were also used as debriefing sessions given the emotional nature of the subject under study.

During the 3-day meeting before the data collection commenced, the field interviewers indicated that on several occasions they had had to use their own financial resources to buy food items to give to respondents in various studies they had undertaken especially in the slums. While the official position of APHRC for any study nested on the NUHDSS is that no compensation should be provided to respondents, additional allowance was paid to the field interviewers to use at their own discretion should any situation arise where they felt they had to buy anything for the respondents. In such instances, such items were provided at the end of the interview so as not to appear as an incentive to participate in the study. The interviewers also made it clear to the

respondents that the items were provided by them and neither by the project nor on behalf of APHRC. Since the number of qualitative interview participants was small, the chances of the word getting that the field interviewers were providing tokens or gifts was minimal.

4.5 Supplementary NUHDSS data

Routine data and other surveys conducted under the on-going NUHDSS were incorporated to supplement the qualitative and quantitative survey of older people. Socio-demographic information for older people namely age, ethnicity, and education level was part of the existing data (Individual data file). Other datasets retrieved from the NUHDSS database include information on characteristics of older people's households such as age of other household members (Membership data file) and information pertaining to in-and-out migration of members (Migration file). Information on household amenities and livelihood comes from data collected over the same period as the quantitative survey of older people (September – December 2006) where all households with older people were sampled. The data collected included type of housing material, access to utilities such as toilets, water, electricity, fuel used for cooking or lighting, household possession of duration assets in addition to total household income and expenditure. A copy of the English version of the household livelihood questionnaire is attached as Appendix 8.

4.6 Data quality and research ethics

Efforts to ensure quality data was collected entailed close supervision by APHRC research staff including the author, the site leaders and the team leaders to ensure that field workers applied the skills acquired and adhered to procedures of data collection. Supervision and quality checks were also enforced through spot-check interviews, editing of completed questionnaires, and through regular meetings between the field teams and the investigators. At data entry stage, about 5% of the questionnaires were double-entered to check for accuracy.

Surveying older people can present problems due to cognitive, visual, auditory and level of concentration normally associated with ageing. Even though these problems are usually associated with much older respondents unlike this study participants whose mean age was 56 years, nevertheless the interviewers were asked to assess the

respondents' comprehension of issues discussed, the extent of digression and level of concentration and attentiveness during the interview on a 5-point Likert scale. Less than 5% of the respondents were reported as bad or very bad in comprehending the issues discussed and less than 1% had problems with concentration during the interview. The only major problem was with respondents digressing from the discussion as 22% were reported to have digressed to a great or very great extent.

4.6.1 Response rate and non-response bias

A high response rate in surveys and other studies is important as it allows generalization of the findings to a wider population and also minimises non-response bias. Several measures were put in place to minimise non-response during data collection. The field interviewers where trained and given tips on how to build rapport with the respondents and how to use persuasion at the same time not to infringe on the respondents' rights of choosing to participate in the study. Prior to commencement of data collection, activities were conducted to promote awareness of the survey specifically, a meeting was held with a welfare group set up by older people in one of the communities that looks into issues affecting older people in that community. Other measures included making several attempts in locating an eligible respondent as well as making interview appointments when the time was most convenient for both the interviewer and the respondents. Data collection took place during the month of November – December which is usually a holiday season in Kenya and a time when several urban residents in Nairobi travel out of the city to the rural areas to spend the Christmas vacation. To counter this, the data collection period was extended to include two weeks in January in an attempt to capture those respondents who had travelled outside the city over the Christmas period.

The response rate for the quantitative survey was about 76%. The final result of interview for the 2,771 target participants 50 years or older is presented in Table 4.4.

Table 4.4: Final interview results and response rate

Final result of interview	Percentage (%)
Completed interviews	75.8
No competent respondent at home	3.5
Entire household absent	0.6
Refused to be interviewed	4.6
Whereabouts unknown	7.1
Access to dwelling unit denied/blocked	0.1
Incapacitated	0.1
Other reasons	8.2
Total	100
N	2,771

Source: Author's analysis of Survey of Older People 2006/2007

Most of the non-response was either because the respondent could not be found at home after several repeated visits (3.5%) or the entire household or respondent could not traced at their last known address (7%) either having relocated to a different address within the DSA or out-migrated to locations outside the DSA. A large proportion of non-response was for other reasons (8%) other than the options provided on the questionnaire. The interviewers however, did not specify the reasons given for the majority of these cases coded as 'other'.

The response rate for the household amenities and livelihood survey was similar to the quantitative survey. About 76% of households with older people had complete interviews and only 1% refused to participate in the livelihood survey. Contact with a competent household member could not be established for various reasons in the reminder of the households (23%).

4.6.2 Informed consent

As part of research ethics, informed consent must be obtained from research participants either verbally or in writing. The purpose of the study was explained to the respondents including how the research findings will be used. The respondents were assured of confidentiality in the information they provide and that no harm is intended to happen to them through participating in the study. The respondents were also informed of the estimated duration of the interview and that they had an option of choosing not to respond to particular questions in spite of having accepted to participate in the study. Respondents who accepted to participate in the study were asked to sign a consent form. Several respondents accepted to participate in the study but declined to sign the consent form citing mainly their inability to read and write as a reason for not signing. Only

35% accepted to sign a consent form while 45% were willing to sign but declined because of inability to read or write. The remaining percentage (19%) refused to sign although they had no difficulty with reading or writing. A copy of the informed consent statement is included as the first page of the two quantitative questionnaires in Appendix 7 and 8, and also the first page of the indepth interview guide (Appendix 9).

Additional information was provided to respondents selected for the qualitative interviews where they were informed that some of topics of discussion might be distressing to them and permission to take down notes and audio record the discussion was sought. They were also informed that they could choose not to have certain information recorded. Only 3 out of the 31 qualitative interview respondents declined to have the interviews audio-taped.

While every effort is made to ensure that the respondents consent to be interviewed out of their own free will, whether the respondents completely comprehend the information given to them to allow them make a fully informed choice remains a concern. The understanding and comprehension of what the research entailed may not be very clear especially to respondents who are illiterate or with low level of education (Wiles et al, 2005). The other concern relating to informed consent was the discussion of third parties, in this case the person who is ill, without their explicit consent. While most of the discussion about older people caring for ill persons revolves around the older person, some sections in the quantitative survey and also the qualitative interview discusses the ill person. In this case the older person is consenting as a proxy for the ill person. There is however, no clear cut regulations on who is the actual research subject even in medical research where for example clinicians consent to participate in a study researching their patients' medical records (Alderson and Goodey, 2007; Veatch, 1997).

4.6.3 Confidentiality

All the respondents were assured that the information they provided would be confidential. In addition, all identification information such as names and other identifiers were removed from the data and the interview transcripts. Coded identifiers were used in the analysis and presentation of findings. Confidentiality was also maintained during the process of conducting the interviews. Whilst an ideal setting during data collection should provide an environment that is conducive in ensuring that the discussion takes place in confidence especially when discussing sensitive and

private matters, this was sometimes not guaranteed given the type of housing and living conditions in the study area. The congested and clustered structures coupled with the type of material used for housing means that it is possible to hear and follow conversations taking place next door. The respondents seem wary of this as was evident in two incidences during the qualitative interview. In one instance, when the interviewer asked the following question which the respondent considered confidential *'How did you find out that your daughter had HIV/AIDS?'* to which the respondent said *'let us talk softly because the houses have got no privacy and somebody could be listening to our conversation.'* In another instance, a respondent terminated the interview after the neighbour came back home.

4.6.4 Research fatigue

The NUHDSS study has been running for 4 years since it was initiated in 2002 and in addition to the nested studies done by APHRC, other organizations conduct studies among the same population. The feeling of being over-researched and research fatigue cannot be underestimated especially in a resource-poor setting where needs and expectations are quite high. Although respondents may not decline outright to participate in the survey, they can respond in a non-committal way out of politeness or boredom (Robson, 2002) especially if they perceive the questions to be irrelevant or of little interest to them. At the end of the interviews most respondents would ask how the study is going to benefit them for example *'we have done a lot of interviews and there are no fruits to the research', 'what is the benefit of the research, after all those years of being interviewed it is becoming tiresome'* and *'why ask so many questions now and then without benefit?'*.

4.6.5 Research and ethical approval

In Kenya, the permit to conduct the research and the ethical approval are issued by different institutions from two different government ministries. The research permit is issued by the Ministry of Education, Science and Technology. APHRC currently has a three-year research permit that covers all research activities and projects conducted wholly by APHRC or in collaboration with other institutions (Appendix 2). The ethical approval is however issued by the Kenya Medical Research Institute (KEMRI) with mandate from the Ministry of Health. KEMRI is responsible for carrying out health science research in Kenya and in coordinating human research activities in the country.

The Ethical Review Committee (ERC) chaired by the Director of the Centre for Clinical Research is in charge of reviewing all research proposals involving humans. The research proposal for this study was reviewed by the ERC and an ethical clearance was issued (Appendix 3).

4.7 Methods for data analysis

4.7.1 Quantitative data analysis methods

The quantitative data has been analysed cross-sectionally given that this study was cross-sectional in nature nested in the NUHDSS longitudinal framework. Various descriptive statistics were used to assess the distribution, frequency of responses and the range of values for all the variables used in the study. Bivariate analyses to examine relationship between variables were conducted and chi-square test is used to assess the independence of variables. Linear and logistics regression were used to measure the association between dependent continuous and binary variables respectively and explanatory factors. These statistical methods are described below.

4.7.1.1 Linear regression analysis

Regression is used to examine the nature and strength of a relationship between two or more variables and to determine if the relationship is in agreement with what is hypothesised. Regression analysis involves fitting the best line to explain how the variation in a dependent variable (Y) depends on the variation in an independent or explanatory variable (X). The line is expressed using an equation thus:

$$\hat{Y} = a + bx + e$$

Where:

a (intercept point) = $\bar{y} - b\bar{x}$ where $\bar{y}$ is the mean of all y values and $\bar{x}$ is the mean of all x values

$$\text{b (slope or gradient)} = \frac{\sum x^2 - \frac{(\sum x)^2}{n}}{\sum xy - \frac{(\sum x)(\sum y)}{n}}$$

e = error term expressing the variation not accounted for by relationship between the dependent and independent variables.

The regression equation indicates the average magnitude of the expected change in Y given a change in X. The observed values are used in calculating the regression line by minimising the deviation of each data point from the line. The values of the dependent variable (Y) are then predicted using the know values (X). Regression equation is ideally used for internal-level data therefore categorical variables are included by converting the variables into dummies or binary variables of 1 or 0.

The equation above refers to a simple linear regression of a response variable and one independent variable. A multiple linear regression equation involving more than one independent variable is denoted by

$$\hat{Y} = a + b_1X_2 + b_2X_2 \ldots\ldots + b_nX_n$$

The independent variables each has different measurement units therefore the units are standardised to have a mean 0 and a variance of 1 to allow for comparability in that the computed values in the equation indicate relative rather than the absolute value of each independent variable in the equation.

The correlation coefficient R^2 is used to determine how good the regression line is as a predictor of Y. It is the proportion of variation in Y which is explained by the linear relationship between X and Y. A strong R^2 which is close to 1.0 means the predicted values of Y based on the values of X are close. In multiple regression, R^2 shows the proportion of the variance in the dependent variable that is explained by all the independent variables.

$$R^2 = \frac{\text{total variance} - \text{residual variance}}{\text{totalvariance}}$$

Regression analysis is performed on data which has a normal distribution and simple random sampling of the dependent variable. In a multiple regression there should be no interaction between the categories of the independent variables. Further, the independent variables should not be highly correlated.

4.7.1.2 Chi-square test

The chi-square test (χ^2) for independence tests whether two variables are independent from each other. It therefore tests the null hypothesis that there is no association between two variables. The test computes values expected in a cell of a contingency

table or a cross-tabulation if there was no association between the two values. Numerical values or counts are used in the cells and not percentages or ratio, and the expected value in each cell should be five or greater. The values are then compared with the observed values to see if there is a significant difference between the observed and the expected.

$$\text{expected value} = \frac{\text{column total} \times \text{row total}}{\text{overal total}}$$

The chi-square test statistic formula is

$$\sum \frac{(O-E)^2}{E}$$ where O = observed values and E = expected values

To determine if the chi-square test statistic is significant the computed value is compared with the critical value in the chi-square distribution table based on the set level of significance and the number of degrees of freedom (the number of categories in minus 1). The null hypothesis is rejected if the test statistic is greater than the critical value and the alternative hypothesis stating that there is an association between the variables is accepted.

4.7.1.3 Logistic regression analysis

Logistic regression is a method used to analysis data where the dependent variable is dichotomous. The dependent variable is first transformed into a logit variable which is the natural log of the odds of the event (dependent variable) occurring or not. Therefore, logistic regression estimates the probability of the event occurring. The logit model is denoted by:

$$\log\left(\frac{p}{1-p}\right) = a + b_1x_1 + b_2x_2 + ...b_jx_j$$

Maximum likelihood estimation is applied in estimating the logit coefficients by seeking to maximise the log likelihood that the observed values of the dependent variable may be predicted from the observed values of the independent variables. This occurs through an interative process of repeated estimation until a convergence is reached where the log likelihood doesn't change significantly.

Logistic regression is similar to linear regression in that logit coefficients are the same as coefficients of linear regression. However, logistic regression does not assume a linear relationship between the independent variables and the dependent nor does it require normally distributed variables.

4.7.2 Qualitative data analysis methods

The qualitative data was first transcribed before it was coded and indexed using the QSR NUD*IST (Non numerical Unstructured Data Indexing Searching and Theorizing) computer software for coding and analysing qualitative data. The first coding done was cross-sectional and categorical coding which refers to similar coding applied to all the cases consistent with the research questions. The initial coding allowed for easy retrieval and further analysis of the data. Other preliminary analytical techniques include writing summaries and memos which were also initiated while data collection was on-going (Mason, 2002; Miles and Huberman, 1994; Onwueghbuzie and Teddlie, 2003; Tashakkori and Teddlie, 1998).

The data analysis for the qualitative data followed two approaches, variable-oriented and case-oriented approach. Variable-oriented compared the inter-correlation between variables while the case-oriented approach evaluates individual cases by analyzing the case-profiles, looking at various associations and effects of a case in a holistic style. Both approaches also applied comparative analysis by searching for similarities and mutual exclusiveness within categories and through cross-cases analysis (Miles and Huberman, 1994).

Data display techniques including charts, matrices and networks are used for analysis and presentation of findings. Matrices are cross tabulation of variables or cases which provide a visual display of associations and relationships between variables across several cases or within a single case. Networks which are mostly used for case-oriented analysis allow for visual display of interconnections and flow of events across cases as well as within a single case (Mason, 2002; Miles and Huberman, 1994).

CHAPTER FIVE

5 PERCEPTION OF HIV/AIDS AMONG OLDER PEOPLE

Existing literature which was reviewed in chapter 2, highlights various pathways both direct and indirect, through which HIV/AIDS may affect older people (Barnett and Whiteside, 2002; Dayton and Ainsworth, 2004; Nyambedha et al, 2003; VanLandingham et al, 2000; Zimmer and Dayton, 2005). A large number of studies which have evaluated the impact of HIV have been based on theoretical assessment and very little empirical research has been conducted to seek the views and opinions of older people themselves and to explore how they perceive HIV/AIDS as a threat to their generation. This chapter seeks to fill this gap in knowledge by exploring what older people perceive as their main concerns with regards to HIV/AIDS and the factors associated with reporting these concerns. The information is drawn from a survey question asking the respondents to list what they consider as HIV/AIDS concerns facing older people. The question posed was *"What are the main concerns of older people in the community regarding the HIV/AIDS problem - any other concern?"*, only spontaneous responses were recorded. The term 'concern' was purposively used to capture both the direct and indirect effects of HIV/AIDS on older people as opposed to the term 'risk', which has widely been used in the HIV/AIDS literature to connote direct impact or infection especially in studies investigating the association between behaviour that increases the chances of being infected with HIV and perceived risk.

5.1 Factors associated with perception

Different approaches, mostly borrowing from the field of psychology and sociology, have been applied to study variation in how individuals perceive a phenomenon (Sjoberg, 2000). Perception of threats such as HIV/AIDS can be objectively estimated by the public through logical assessment or through subjective reasoning. Subjectivity is influenced by social, psychological and cultural factors and can result for instance, in some threats which have low probability of occurring being perceived as serious threats while those with high probability may be rated as minor threats (Slovic and Peters, 2006). In general, perception of risk may be influenced by factors external to the individual or by factors operating at the individual level.

Proponents of external factors, including the cultural theory of risk, argue that social relationships and environmental factors act to shape how an individual perceives a

hazard (Sjoberg, 2000). Individuals exist within a social structure therefore, the cultural, environmental factors and institutions in the society shape their values and attitudes including how they perceive a threat. As a result, individual opinion and attitude regarding social issues is shaped by the cultural norms of the society in which they live (Oltedal et al, 2004). Since the advent of HIV/AIDS, numerous (mis)information has emerged in the public discourse around HIV to try and make sense of the new threat. These discussions have been shaped by cultural values and beliefs in the processes of deciphering complex information pertaining to HIV/AIDS and constructed into locally understood knowledge (Douglas, 1992).

The structures that exist within a community may impede or allow communication channels to filter to the individual, thus, influencing the level of perceived severity to a threat. These organizational structures also act as communication agents in that they filter what is communicated, evaluate the threat, attach values, and provide an interpretation thus influencing how the recipients of the information perceive the threat. Examples of agents include the media, opinion leaders, social groups and personal networks. Information within a community may flow through social networks where people share information and form similar beliefs, attitudes or opinions. Networks also act as agents of communication and can facilitate or constrain information flow through filtering and influencing the attitude or behaviour of its members (Scherer and Cho, 2003). For instance, social networks have been found to be resourceful in the communication of family planning and more recently HIV/AIDS information from one member of the network to another. This information being relayed may or may not be factual (Rutenberg and Watkins, 1997; Watkins, 2004). The media, both print and electronic, also plays a role in influencing how the public perceive a threat based on the amount of attention and publicity given to the threat and what aspects of the threat they choose to highlight (Sjoberg, 2000). By and large, coverage of HIV/AIDS in the media has been quite extensive especially in providing information and educating the public. Conversely, the media has also played a role in perpetuating misinformation and stereotypes about HIV/AIDS. For instance the portrayal of homosexuals with regards to HIV/AIDS and the lack of sympathy towards those infected (Clarke, 2006). The level of importance accorded to HIV/AIDS as a newsworthy item and the specific issues that receive attention varies from country to country and over time (Makgoba, 2002).

At the individual level, perception may be associated with demographic factors such as age and gender (Glendon et al, 1997). Individuals differ in the way they perceive a threat. Others may be extremely worried while some may be indifferent and calm (Chauvin et al, 2007). Having less or no control over the occurrence of a hazard as opposed to someone else in control may also account for variation between individuals. Similarly, a person may perceive a hazard they participate in voluntarily to be less of a threat compared with non-voluntary participation. Other factors that may explain variation among individuals include the nature or type of hazard in question. There may be similarity or little variation on how individuals perceive threats that are not considered controversial or have been in the public domain for a relatively longer duration. A new type of threat is perceived differently because of lack of accurate information about the threat. For instance, a new health scare would generate public debate as a topical issue thus influencing exchange of information and opinion about the threat. A new threat with little information may be perceived as a more serious threat in particular if there is mistrust between the public and experts or suspicions about the source of information (Sjoberg, 2000).

The public or lay people may also perceive a threat differently from professional experts on the hazard or threat. While experts may define a threat in technical and probability terms, lay people's perception may be influenced by psychological and cultural factors. Conversely, the variation in perception between experts and the public may be due to valid concerns raised by the public that were otherwise omitted by the experts in their assessment of the threat. Experts may also define and understand a threat in a different way from lay people who consider several dimensions such as the social and cultural factors when evaluating the threat (Chauvin et al, 2007). For instance, with regard to HIV/AIDS, there is mistrust of experts or professionals by the public as is evidenced by some of the misconceptions pertaining to modes of HIV transmission or the efficacy of condoms (Douglas, 1992).

Negative affective feelings such as worry, fear and dread are brought to mind when a person thinks about a risk or hazard. The psychometric model which indicates an association between affect and perception is one such example. Affective reaction to a hazard is normally quicker and faster and, occurs almost instantaneously guiding the mental process, thus, stirring thoughts about the hazard and the resulting judgement. For

this reason, rational or objective risk appraisal, where an individual makes an assessment based on the probabilities of a risk through logical reasoning, requires time to consciously process the information and assess a situation before arriving at a conclusion. Evoking feelings and emotions surrounding a risk on the other hand, is often easier and quicker. Knowledge of a threat can also influence how worried, anxious, or fearful an individual may be towards that particular threat. Similarly, having direct or indirect experience with a threat may result in more realistic perception of the threat. The threat may also be perceived to be severe if the individual or someone they know has been directly or indirectly affected by the threat (Slovic and Peters, 2006). Familiarity with a phenomenon on the other hand, can create complacency where the threat is no longer perceived as a serious concern and becomes part of everyday life (Dudley et al, 2002).

In order to understand the variation among older people in what they perceive as HIV/AIDS concerns, the association between individual-level characteristics, personal experiences, and social interaction, with reported HIV/AIDS concerns is explored. People who have been affected by HIV/AIDS either directly or indirectly are hypothesised to be more likely to report HIV concerns compared with those with no personal experience. In addition, individuals who interact with other community members and participate in community-level activities are more likely to be exposed to or exchange HIV/AIDS information compared with those less likely to interact frequently with other community members and are therefore more likely to report HIV/AIDS concerns.

5.2 Description of variables used

Dependent variable - The information is drawn from a question asking the respondents to list what they consider to be the main HIV/AIDS concerns facing older people. The question allowed for multiple responses and only spontaneous responses were recorded. A pre-coded list of possible response-options was provided in the questionnaire, however the options were not read out to the respondents. The list of the response options were as follows:

A. Caring for persons infected with HIV/AIDS
B. Caring for orphaned children
C. Loss of support from adult children
D. Being infected with HIV/AIDS

E. Loss/reduction of community support to older people
F. Other (specify)

The responses were recoded into dichotomous variables '1' if mentioned and '0' otherwise. Logistic regression analysis is used to estimate the effect of the explanatory variables on the probability of reporting a HIV/AIDS concern. Only variables that were significant (5% level) at the bivariate level are used as explanatory variables in the multiple logistic model.

Explanatory variables

Table 5.1 below describe the variables used in the analysis, the frequency distribution of responses and the corresponding number of cases. The variables are grouped into four clusters: Socio-demographic; socio-economic; personal experiences and social interaction. The *socio-demographic* variables measured are sex, age, marital status and ethnicity whereas the *socio-economic* variables are education and type of livelihood activity. Education attainment and working outside of home are expected to influence access to information and may be related to a person having a better understanding of HIV/AIDS impact. *Personal experience* related to HIV/AIDS is modelled using four variables: household composition, living with grandchildren, living with adult child and ever affected by HIV/AIDS which was derived from a question asking respondents if they have personally been affected by HIV/AIDS. Those who responded '*yes*' were asked to list how they had personally been affected. The questioned allowed for multiple responses and only spontaneous responses were recorded. Personal experience is expected to heighten the saliency of HIV/AIDS as a threat making it easier to recall or imagine an outcome.

The fourth cluster of variables, *social interaction,* is measured using the number of close friends an older person has, involvement in community activities, participation in social group meetings, and contact with community leaders. Older people who interact with people other than members of their household are expected to perceive HIV/AIDS differently based on the assumption that social interaction would facilitate learning through exchange and evaluation of information. More frequent interaction will thus lead to exposure to HIV/AIDS information.

Table 5.1: Description of explanatory variables

Variable	Categories	%	N	Description
Socio-demographic variables				
Gender	Female	36.9	*761*	Dichotomous variable of
	Males	63.1	*1,300*	females and males
Age	50 – 54	41.7	*859*	Age was categorised into
	55 – 59	24.1	*496*	5-year age groups: *50-54, 55-59* and then *60* years
	60+	34.3	*706*	or older
Marital status	Not in union	32.1	*661*	Recoded into 2 dummy
	Currently married	67.9	*1,400*	variables: *currently married* and those *not in union* who included the never married, widowed, divorced and separated
Ethnic group	Kamba	16.0	*330*	The variable consists of 5
	Kikuyu	44.1	*909*	groups comprising the
	Luhya	12.0	*248*	major ethnic groups:
	Luo	12.0	*248*	*Kamba, Kikuyu, Luhya,*
	Other groups	15.8	*326*	and *Luo* and the other smaller ethnicities combined into one group coded as *other*
Socio-economic variables				
Education level	no education	28.9	*573*	Refers to the highest
	Primary	56.1	*1,113*	education level attained
	Secondary+	15.0	*297*	coded as *primary, secondary and higher* while those never been to school coded as *no education*
Type of current employment	Not employed	6.8	*141*	The type of employment has been categorized into five main groups[4] :
	own business	43.3	*893*	
	Informal employment	25.6	*527*	
	Formal employment	18.4	*379*	
	Other	5.9	*121*	
HIV/AIDS-Related personal experiences				
Household composition	skip generation	32.9	*677*	computed using the age of the members of households with older people categorized into 4
	single member	5.5	*113*	
	mixed generation	53.0	*1,093*	
	older people only	8.6	*178*	

[4] *own business* - self-employed individuals running their own enterprises and may employ other workers to work in their enterprise; *Informal employment* - mainly temporary and irregular and the mode of payment is mainly a daily or per job basis. *Formal employment* - longer durations with more regular payments either weekly or monthly basis. *Informal and formal employment* - differs mainly in terms of the duration of employment and the mode of payments. The *other* - combines both those engaged in urban agriculture farming along road reserves and other open spaces within the city and those foraging for recyclable waste materials at nearby dumpsites.

				groups: *'skip generation'* consist of older people living alone with children aged below 15 years; *'mixed generation'* has children below 15 years, adult 15 – 49 years and older people; *'older people'* households had 2 or more older people and no other agegroup; and *'single member'* households had only one older person living alone.
Lives with grand children in household	No 1 or more	80.9 19.1	*1,658* *392*	Usually lives with at least one grandchild in the household coded '0' if none and '1' if lives with at least one child
Lives with adult child in household	No 1 or more	85.9 14.1	*1,699* *278*	Usually lives with at least one of their adult children aged 15 years or older in the household coded '0' if none and '1' if lives with at least one child
Personally affected by HIV/AIDS	Never affected cared for orphans care for PLWHA Lost support Infected with HIV	82.5 12.6 7.7 15.6 0.8	*1,701* *260* *158* *322* *17*	The responses were recoded into dichotomous variables '1' if mentioned and '0' otherwise.
Social interaction				
Number of friends	no friends 1 – 2 3+	4.9 46.3 48.9	*99* *940* *993*	The variable is derived from the question '*How many people do you have whom you consider as close friends?*' The variable was recoded into 3 categorical variables; *no friends, 1 – 2* and *3 or over*
Frequency of voluntary work within community	Never 1 - 2 times a week 1 - 2 times a month 1 - 2 times last 4mths	60.8 11.5 14.6 13.1	*1,252* *237* *301* *269*	To gauge involvement and participation of older people in the community, the respondents were asked '*How often in the*

Frequency of attending social group meetings	Never	51.7	*1,065*	*last 4 months have you (i) met with a community leader, (ii) attended any group, club, society, union or organizational meeting, and (iii) worked with other people in your neighbourhood to fix or improve something or resolve a community issue?'* The three variables were recoded into four categories: *never, once or twice a week, once or twice per month* and *once or twice in last 4 months*
	1 - 2 times a week	16.9	*347*	
	1 - 2 times a month	21.8	*448*	
	1 - 2 times last 4mths	9.7	*199*	
Frequency of attending community meetings	Never	59.3	*1,220*	
	1 - 2 times a week	15.4	*318*	
	1 - 2 times a month	16.0	*329*	
	1 - 2 times last 4mths	9.3	*192*	

5.3 What are older people worried about?

An overwhelming majority of older people (97%) acknowledged HIV/AIDS as a concern among older people living in the urban slums. Indirect forms of HIV/AIDS impact were the most cited concerns. Overall, caring for children orphaned due to HIV/AIDS (65%), caring for people living with HIV/AIDS (PLWHA) (48%), and loss of support from adult children through illness or death (37%) were the three most cited HIV/AIDS concerns. Loss of support to older people at community level was also mentioned by a sizable proportion (17%). Direct impact through HIV infection among older people, which has received little attention in HIV/AIDS impact studies, also featured prominently as a concern among the study participants (39%). Other HIV concerns mentioned, albeit by a small proportion of older people (less than 1%), included young people engaging in risky sexual practices and whether older people can influence them against these risky practices. Bereavement due to HIV/AIDS resulting from death of loved ones such as friends, relatives, and spouses was also reported as a concern. The responses are not mutually exclusive as respondents could mention more than one concern. The concerns mentioned by less than 2% of the respondents refer to open-ended responses that were coded under the 'other' category. The low frequency of these concerns may reflect interview bias towards the set of pre-coded categories rather than a lack of prominence as HIV/AIDS concerns for older people. Table 5.2 below presents the concerns raised compared across gender, bivariate analysis was carried out.

Table 5.2: Percentage of older people who reported specific HIV/AIDS concern compared by sex of the older person

HIV/AIDS Concern [1]	Women	Men	Total
Indirect impact	**92.0**	**89.6**	**90.5**
Caring for orphaned children*	67.8	62.8	64.7
Caring for person infected	48.8	47.8	48.1
Loss of support from adult children	37.1	36.1	36.4
Loss of support in the community	15.2	17.8	16.9
Losing friends to HIV	0.3	0.3	0.3
Losing relatives to HIV	0.5	0.5	0.5
Prevention of HIV/AIDS*	0.4	1.2	0.9
Educating young people about HIV	0.3	0.5	0.4
Other concerns	1.6	1.5	1.6
Direct impact* **	**31.8**	**41.7**	**38.1**
Older people being infected***	31.1	41.2	37.5
Losing spouse or partner to HIV	0.7	1.0	0.9
Does not know	2.4	2.5	2.5
N	*761*	*1,300*	*2,061*

[1] Respondents could mention more than one response
χ^2 test for between gender difference: Significance levels * <0.001; **<0.01 *<0.05**
Source: Author's analysis of Survey of Older People Data, 2006/2007

Several studies have highlighted gender differences in perception of risk or hazards with women being seen to perceive higher risks and to express greater concerns than men (Gustafson, 1998). However, there was little or no difference by gender on most of the HIV/AIDS concerns mentioned except for caring for orphans and direct HIV/AIDS impact. Older women were significantly more likely to cite caring for orphans as a major concern compared with men (χ^2=5.17, p=0.023). Grandparents, particularly grandmothers, have traditionally played a key role in rearing their grandchildren (Isiugo-Abanihe, 1985; Madhavan, 2004). Therefore, this social role could explain why older women are more likely to mention caring for orphans as a concern compared to older men. Conversely, a significantly (χ^2=20.5, p=0.000) higher proportion of men cited older people being infected with HIV/AIDS as a concern compared with women. This may be because sexual activity among older men tends to be more culturally tolerated unlike older women (van der Geest, 2001).

During the study, the participants were encouraged to mention as many concerns as they could. Table 5.3 compared men and women based on the total number of HIV/AIDS concerns mentioned. On average, most of the older people mentioned at least two

concerns; mainly caring for orphans and caring for people infected with HIV/AIDS while less than a third (32%) reported only one concern. The same proportion of men and women cited only one concern, however, there was a slight difference in the specific concern mentioned with a higher proportion of men mentioning HIV/AIDS infection among older people as a concern together with 'other' concerns compared with women. Overall, a higher proportion of men (4%) cited more than 4 concerns compared with women (2%). Details on the number of concerns mentioned by gender are presented in Table 5.3 below.

Table 5.3: Percentage distribution of older people by number of HIV/AIDS concerns mentioned compared by sex

Number of concerns	Women	Men	Total
No concern	2.4	2.5	2.5
One concern	31.8	31.8	31.8
Caring for orphans	13.1	9.7	11.0
Caring for people infected	5.9	5.0	5.3
Loss of support	2.1	3.5	3.0
HIV infection	6.8	8.9	8.1
Other concerns	3.8	4.7	4.4
Multiple concerns			
2 concerns	36.1	34.4	35.0
3concerns	20.8	20.3	20.5
4 concerns	7.5	6.9	7.1
5 concerns	1.5	4.2	3.2
Total	**100.0**	**100.0**	**100.0**
N	***761***	***1,300***	***2,061***

Source: Author's analysis of Survey of Older People Data, 2006/2007

Based on the assumption that individual-level characteristics, personal experiences and social interaction are associated with what older people perceive as HIV/AIDS concerns facing their age group, logistic regression models on the odds of reporting the four most cited concerns: caring for orphaned children, caring for people infected with HIV/AIDS, loss of support, and infection among older people, are estimated below. Only factors that were significantly associated at the bivarate level are included in the multiple logistic model.

5.3.1 Caring for orphaned children

Providing care to orphaned children has been highlighted as a major issue facing older people by most studies investigating the impact of HIV/AIDS on older people in sub-Saharan Africa (Bongaarts and Zimmer, 2002; Hosegood and Timæus, 2006; Ntozi and Zirimenya, 1999; Nyambedha et al, 2003). This was also the most commonly cited concern by the study participants. Table 5.4 presents the bivariate distribution and the odds of reporting orphans as a concern. Age, marital status, education and type of employment showed no significant discriminating effect at the bivariate level. Gender of the older person although significant at the bivariate level, had no effect on the odds of reporting caring for orphans when other factors were controlled for.

According to Table 5.4, older people from the Kikuyu (OR, 0.75 95% CI 0.56, 0.99), Luhya (OR, 0.66 95% CI 0.46, 0.94) and Luo (OR, 0.55 95% CI 0.39, 0.79) ethnic groups were significantly less likely to cite caring for orphans as a concern compared with Kambas. The results regarding ethnic variation are surprising with regards to the hypothesis that frequent exposure to a threat or hazard is likely to heighten recall given that lower incidence of orphanhood due to HIV/AIDS has been recorded among the Kamba ethnic group relative to the other groups particularly the Luos (National AIDS/STD Control Program, 2005).

Personal experiences such as type of living arrangement and having ever been affected by HIV/AIDS were significantly associated with reporting orphans as a concern. Older people living alone, in mixed households, or living only with other older people, were less likely to cite caring for orphans as a concern compared with those living in skip generation households. Similarly, having ever provided care to orphans increased the odds of mentioning orphans as a concern by 1.70 compared with older people who have not been affected (OR, 1.70 95% CI 1.04, 2.78).

The frequency of participating in community activities and the number of close friends an older person has had strong association with citing caring for orphans as a concern. Older people who met a community leader once or twice in the last 4 months were significantly more likely to cite orphans as a concern than those who did not meet with a community leader. Having a close friend also increased the odds of mentioning caring for orphans as a concern compared with older people with no close friends.

Table 5.4: Results of bivariate distribution and logistic regression analysis on the odds of reporting caring for orphans as a HIV/AIDS concern

	% reporting caring for orphans	Odds Ratio	P-value significance
Gender			
Female (ref)	67.8	1.00	-
Male	62.8	0.88	NS
Ethnic group			
Kamba (ref)	70.6	1.00	-
Kikuyu	65.7	0.75	*
Luhya	61.7	0.66	*
Luo	57.3	0.55	***
Other	63.8	0.75	NS
Ever affected by HIV/AIDS			
Not affected (ref)	64.2	1.00	-
Other type of impact	63.5	0.96	NS
cared for orphans	76.0	1.70	*
Number of close friends			
no friends (ref)	48.5	1.00	-
1 – 2	66.0	1.86	***
3+	65.7	1.85	***
Frequency of talks with a community leader			
Never (ref)	63.5	1.00	-
1 – 2 times a week	60.4	0.89	NS
1 – 2 times a month	68.7	1.25	NS
1 – 2 times last 4 months	72.4	1.56	**
Type of household			
Skip generation (ref)	80.5	1.00	-
Mixed generation	63.8	0.49	**
Older people only	62.9	0.46	*
Single member household	64.0	0.51	*
Lives with grandchildren in household			
No (ref)	63.4	1.00	-
Yes	69.6	1.03	NS
Model χ^2		53.77	
Df		16	
p-value		0.000	
N		2,021	
R^2		0.20	

Significance levels * <0.001; **<0.01 *<0.05 NS – Not significant**
Source: Author's analysis of Survey of Older People Data, 2006/2007

5.3.2 Caring for people infected with HIV/AIDS

Care-giving to people infected with HIV/AIDS was the second most cited concern facing older people. There was little variation among older people who cited this as a concern by age, gender, marital status, education level and type of employment (Table 5.5). Only ethnicity, personal experience and frequency of meeting with a community leader were significantly associated with the odds of citing caring for a PLWHA as a concern. Personal experience of caring for a PLWHA and frequently meeting with a community leader were both strongly associated with higher odds of reporting care-giving to a PLWHA as a concern for older people. Again, similar to those who reported caring for orphans as a concern, older people from the Luo ethnic group (OR, 0.64 95% CI 0.46, 0.89) were significantly less likely to report this concern compared with the Kamba.

Table 5.5: Results of bivariate distribution and logistic regression analysis on the odds of reporting caring for persons infected as a HIV/AIDS concern

	% reporting caring for PLWHA	Odds Ratio	P-value significance
Ethnic group			
Kamba (ref)	51.5	1.00	-
Kikuyu	49.0	0.91	NS
Luhya	49.2	0.90	NS
Luo	41.1	0.64	**
Other	46.9	0.89	NS
Ever affected by HIV/AIDS			
Not affected (ref)	46.7	1.00	-
Other types of impact	50.5	1.15	NS
cared for person with HIV	60.8	1.74	***
Frequency of talks with a community leader			
Never (ref)	46.1	1.00	-
1 – 2 times a week	50.9	1.19	NS
1 – 2 times a month	52.3	1.26	NS
1 – 2 times last 4 months	50.0	1.15	NS
Model χ^2		23.85	
Df		9	
p-value		0.0046	
N		2,059	
R^2		0.8	

Significance levels * <0.001; **<0.01 *<0.05 NS – Not significant**
Source: Author's analysis of Survey of Older People Data, 2006/2007

5.3.3 Loss of support from adult children

In most traditional societies, the material, social, and psychological support for older people is largely a responsibility of their family and kin. The majority of older people in the developing countries continue to rely on this traditional support especially for their material wellbeing due to lack of formal social protection. Pensions are also inaccessible to the majority of older people (Heslop and Gorman, 2002). Loss of support from adult children who fall ill and eventually succumb to HIV/AIDS was therefore viewed as a major concern by older people. The results of the model on the odds of citing loss of support as a concern are presented in Table 5.6. None of the demographic variables, age, gender, and marital status showed any significant association with the dependent variable whereas personal experience and participation in community-level activities were strongly associated with citing loss of support as a concern facing older people. Having at least one close friend increased the odds of reporting loss of support as a concern. Similarly older people who participated in fixing or solving a community problem at least once in the last 4 months had significantly higher odds of citing this concern. The odds were 1.79, 1.85 and 1.51 for older people who attending a meeting at least a week, twice a month and twice in the last 4 months respectively compared with older people who did not take part in any such activity. Attending a social group meeting at least once in the last 4 months also had a similar effect albeit the association was marginally significant.

Co-residence between older people and their adult children can be an indication of reciprocal exchanges between the two generations. Conversely, co-residence can also indicate a unidirectional exchange from the young to the old or vice versa. In a study looking at living arrangements of older people in the developing world, older people with higher socio-economic indicators were shown to be less likely to live in extended families and also less likely to co-reside with adult children implying financial independence of older people in this kind of living arrangement (Bongaarts and Zimmer, 2002). Therefore, a strong association was observed between co-residing and citing loss of support from adult children as a HIV/AIDS concern. Older people living with at least one of their adult children in the same household had significantly higher odds of reporting loss of support as a concern compared with those not living with an adult child (OR, 1.51 95% CI 1.15, 1.99). Within an urban slum setting, co-residence may indicate inability to afford renting more space rather than preference to live with

adult children in the same household. Consequently, older people co-residing with their adult children are likely to be dependent on them for material support (Lloyd-Sherlock, 2005).

Table 5.6: Results of bivariate distribution and logistic regression analysis on the odds of reporting loss of support for older people as a HIV/AIDS concern

	% reporting loss of support for older people	Odds Ratio	P-value significance
Type of employment			
not employed (ref)	34.0	1.00	-
runs own business	37.4	1.21	NS
informal employment	37.8	1.15	NS
formal employment	28.5	1.03	NS
Other type of employment	51.2	1.79	*
Number of close friends			
No friends (ref)	13.1	1.00	-
1 – 2	40.6	4.67	***
3+	34.9	3.89	***
Frequency of voluntary work within community			
Never (ref)	33.5	1.00	-
1 – 2 times a week	44.7	1.79	***
1 – 2 times a month	43.9	1.85	***
1 – 2 times last 4 months	34.6	1.52	*
Frequency of attending social group meetings			
Never (ref)	34.6	1.00	-
1 – 2 times a week	38.1	1.07	NS
1 – 2 times a month	44.7	1.43	*
1 – 2 times last 4 months	31.8	0.93	NS
lives with adult child in household			
No (ref)	34.8	1.00	-
Yes	43.5	1.51	**
Model χ^2		177.08	
Df		21	
p-value		0.0000	
N		1,952	
R^2		0.28	

Significance levels * <0.001; **<0.01, *<0.05, NS – Not significant**
Source: Author's analysis of Survey of Older People Data, 2006/2007

5.3.4 HIV/AIDS infection among older people

High HIV/AIDS prevalence has been evident among populations considered to be high-risk groups and adults in their reproductive ages of 15-49 years. Older people have largely been considered less at risk of contracting the disease and have received very little attention from researchers and service providers. HIV/AIDS infection, however, featured as a major concern facing older people living in the slums. There was also great variation among older people on whether they considered HIV infection a concern (Table 5.7). Ethnicity, level of education and type of employment were all significantly associated with citing HIV infection as a concern. Older people from the Kamba ethnic group were more likely to cite this concern compared with all the other ethnic groups. The Luos had significantly lower odds when compared with the Kamba (OR 0.48, 95% CI 0.33, 0.70). Higher education attainment and being in employment was positively associated with older people citing concerns about HIV infection. Having at least primary education increased the odds by 1.29 while having secondary education or higher increased the odds by 1.43 compared with older people who have never been to school. Older people working in the informal (OR 2.24, 95% CI 1.33, 3.77) and formal sector (OR 2.46, 95% CI 1.44, 4.24).of employment had significantly higher odds of citing HIV infection amongst older people as a concern compared with those not employed.

Participating in community activities and having a large network of close friends were strongly associated with the dependent variable. Having met with a community leader at least once a week, once a month or at least once in the preceding 4 months significantly increased the odds of citing HIV infection as a concern by 2.24 (95% CI 1.58, 3.18), 3.42 (95% CI 2.40, 4.86) and 2.03 (95% CI 1.38, 2.99) respectively compared with older people who had not met with a community leader at all. Similarly, participating in fixing or solving a community problem in the preceding 4 months also had similar association even though the association was marginally significant. Older people with at least one close friend were more likely to mention HIV infection as a concern compared with those who reported having no close friends. Being male and in a marital union was associated with reported HIV infection at the bivarate level, however, this association did not remain significant when other factors were controlled.

Table 5.7: Results of bivariate distribution and logistic regression analysis on the odds of reporting HIV infection among older people as a concern

	% reporting infection among older people	Odds Ratio	P-value significance
Gender			
Female (ref)	31.1	1.00	-
Male	41.2	1.08	NS
Marital status			
Currently married (ref)	33.1	1.00	-
Not currently in union	39.5	0.88	NS
Ethnic group			
Kamba (ref)	47.0	1.00	-
Kikuyu	34.5	0.75	*
Luhya	46.0	0.90	NS
Luo	29.8	0.48	***
Other	35.3	0.99	NS
Level of education			
No education (ref)	31.6	1.00	-
Primary	38.8	1.29	*
secondary+	45.8	1.43	*
Type of employment			
not employed (ref)	19.9	1.00	-
runs own business	32.4	1.32	NS
informal employment	45.7	2.24	**
formal employment	47.8	2.46	***
Other type of employment	27.3	1.06	NS
Number of close friends			
No friends (ref)	25.3	1.00	-
1 – 2	38.5	1.77	*
3+	37.6	1.85	*
Frequency of voluntary work within community			
Never (ref)	32.6	1.00	-
1 – 2 times a week	46.4	1.44	*
1 – 2 times a month	42.2	1.10	NS
1 – 2 times last 4 months	46.8	1.41	*
Frequency of talks with a community leader			
Never (ref)	41.0	1.00	-
1 – 2 times a week	32.4	2.24	***
1 – 2 times a month	35.3	3.42	***
1 – 2 times last 4 months	37.8	2.03	***
Model χ^2		184.55	
Df		0.0000	
p-value		26	
N		1,954	
R^2		0.22	

Significance levels * <0.001; **<0.01 *<0.05 NS- Not significant**
Source: Author's analysis of Survey of Older People Data, 2006/2007

5.4 Discussion and conclusion

Older people in the slums perceive similar concerns arising from HIV/AIDS to those that have widely been reported in HIV impact literature namely caring for children orphaned by HIV/AIDS, caring for PLWHA and loss of support from adult children. The recognition of HIV/AIDS infection as a threat facing the older generation by older people themselves is of great interest. In spite of this, older people have received less attention in research and in service provision programmes and initiatives. A number of plausible factors can account for HIV/AIDS vulnerability among older people. Sexual activity with younger people poses a risk of cross-generation infection. The assumption that older people are not sexually active or that they do not engage in risky sexual behaviour implies they are seldom the target for prevention and care information and education campaigns. In addition, HIV/AIDS care and prevention messages are packaged for younger audiences thus presenting a communication barrier among older people (Chima et al, 2004; Ingstad et al, 1997; Williams and Tumwekwase, 2001). Other factors such as late or missed diagnosis can also explain the increasing number of older people who are infected (Manfredi, 2004; Uphold et al, 2004). The proportion of older people who are HIV positive is set to increase due to survival chances of patients who are on treatment and also due to better care and understanding of the disease (Manfredi, 2002). Another mode of HIV/AIDS transmission among older people is through occupational risk for instance traditional healers, traditional midwifery, and care-giving to those infected with HIV. Older people should therefore, be targeted in prevention interventions and the notion that older people are not at risk of HIV infection should be dispelled.

This chapter sought to understand the factors associated with perception of HIV/AIDS threats facing older people. Whereas older people differed in what they perceived as concerns, the extent of variation depended on the specific concern. Nonetheless, the association between social interaction and personal experiences, and the likelihood of citing a HIV/AIDS concern was consistent across the four major concerns namely: caring for orphans; caring for PLWHA; loss of support for older people; and HIV infection among older people. Attending social group meetings regularly, participating in voluntary work in the community, and interacting with community leaders more frequently increased the odds of mentioning the key HIV/AIDS concerns facing older

people. The number of close friends a person has was also significantly associated with reporting HIV/AIDS concern.

The role of social interaction and social networks in diffusion of information and knowledge has been widely documented and applied in various disciplines. Participating in community activities provides an opportunity for individuals to interact with others whereby they exchange and evaluate information. Individuals who are members of a social network are more likely to access information compared with those not part of any network. Topical issues which may include HIV/AIDS are part of everyday conversation when people are gathered together in groups or meetings. They are therefore likely to talk about the disease in general, how it manifests itself in their everyday life and that of their friends and relatives. It therefore provides an opportunity to learn about the disease, its implication as well as consequences. Social interaction and exchange of information can also occur in the workplace which may explain the association between being in employment and reporting a HIV/AIDS concern.

Information and knowledge in the community can also flow through community leaders. Older people who regularly interact with community leaders were more likely to cite HIV/AIDS concerns. Leaders in the community who also double up as opinion leaders can disseminate knowledge both in the formal or official capacity as leaders and informally through personal contact with individuals in the community. Leaders may have access to various sources of information and their experience including exposure in the community enable them to influence others attitude and knowledge.

Personal experience was strongly significant in influencing older people to report a HIV/AIDS concern. Older people who have ever cared for orphans, cared for a person with HIV/AIDS, or were living with their adult children in the same households were more likely to report a similar HIV/AIDS concern. Personal encounter with a threat results in emotional or affective feelings to the threat including accurate understanding thus combining both subjective and objective perception of the threat. Personal experience amplifies perception of a hazard as familiarity with the hazard leads to better knowledge about the hazard and the resulting consequences thus influencing how a threat is perceived (Slovic et al, 2004).

This chapter has pointed to the factors closely associated with perceived HIV/AIDS-related threat facing older people. It should be noted however, that factors influencing perception of a threat are highly complex and multifaceted, and, therefore, this chapter was not exhaustive in exploring all the possible factors that could explain variation among older people in their perception of HIV/AIDS. The next chapter focuses on one of the risks identified by older people, care-giving to PLWHA.

CHAPTER SIX

6 CHARACTERISTICS OF THE COMPARISON GROUPS, AND THE NATURE AND TYPE OF CARE PROVIDED BY HIV CAREGIVERS

6.1 Introduction

Care-giving to someone ill with HIV/AIDS impacts negatively on the health and economic wellbeing of the caregiver. One methodological approach used in studies assessing the impact of HIV/AIDS, a form of quasi-experimental design where cases are compared with a comparison group, (Barnett and Whiteside, 2000; Beegle and Weerdt, 2007) is used in this study. The cases, defined here as older people who have provided care to someone with a HIV-related illness (HIV caregivers), are compared with two groups: older people who provided care to someone with a non HIV-related illness (Other caregivers); and the other group being those who have not provided care (Non-caregivers) over the 3-year period preceding the survey. Only one explanatory variable, having cared for someone with a HIV-related illness, is used as a distinction between the cases and the comparison groups. Some studies on HIV/AIDS impact have selected comparison groups through matching cases and comparison group using for instance Propensity Score Matching (Canning et al, 2006; Donovan and Bailey, 2005) to identify various characteristics or variables in pairing the cases with the comparison groups. This procedure is used mainly in studies where the selection of the cases is non-random. However, in this study both the cases and the comparison groups had a random chance of being selected or included in the study.

The cross-sectional nature of the study cannot adequately measure causality between HIV/AIDS with health and economic status, hence, the objective is to assess if there are any significant differences between the cases and the two comparison groups. One limitation of comparison studies is the threat to internal validity and selectivity if the groups differ in some ways other than those indicated by the explanatory variable (in this case, having cared for someone with a HIV-related illness) (Beegle and Weerdt, 2007; Robson, 2002). To address this limitation, observable confounding factors are controlled for at the analysis stage. Another limitation, is the inability to detect whether the comparison groups have not been affected in any way through spill-over effect. A shock affecting a group of individuals or households can spread across households and community resulting in under-estimation of the impact if the comparison groups are negatively affected or over-estimation if positively affected (Beegle and Weerdt, 2007).

The chapter first compares the socio-demographic characteristics of the three comparison groups: HIV caregivers, other caregivers and non-caregivers. The next sections provide a profile of the care recipients who are ill due to HIV/AIDS with respect to their caregivers and the context under which the care-giving takes place. Specifically, the duration of care, the forms of care provided, and the factors leading HIV caregivers to provide care are discussed. The prevailing conditions of care-giving in an urban slum setting contrasted with other settings are examined followed in the last section by a summary and discussion. The chapter uses data from both the older people survey and the qualitative study.

6.2 Comparison of HIV caregivers, other caregivers and non-caregivers

6.2.1 Age, education and marital status

Table 6.1 presents the age, education and marital status for the three groups. Among the women, HIV caregivers and other caregivers have very similar mean age (56.3 and 56.6 respectively) which is significantly different from non-caregivers with a mean age of about 62 years. The three groups were also significantly different in terms of the highest education level attained. For instance, a higher proportion of HIV caregivers (17%) had secondary education or higher unlike only 8% of other caregivers and 5% of non-caregivers. There was no significant difference between the comparison groups of women with regards to marital status.

The men's groups, however, were not significantly different in age and marital status. Unlike the women where a higher proportion of HIV caregivers had secondary education or higher, only 14% of the HIV caregivers had secondary education or higher compared with other caregivers (21%) and non-caregivers (20%).

Table 6.1: Socio-demographic characteristics of HIV caregivers, other caregivers and non-caregivers

	HIV caregivers	Other-caregivers	Non-caregivers	Total
		Women		
Mean Age* **	56.3	56.6	61.6	61.1
Level of education* **				
No education	41.7	21.1	49.9	47.9
Primary	41.7	71.1	44.9	46.1
Secondary+	16.7	7.9	5.2	6.0
Marital Status				
Not married	60.5	71.1	69.2	68.9
Currently married	39.5	29.0	30.8	31.1
N	*38*	*38*	*685*	*761*
		Men		
Mean Age	57.7	57.2	58.1	58.0
Level of education* **				
No education	8.0	3.4	20.0	18.4
Primary	78.0	75.3	59.9	61.7
Secondary+	14.0	21.4	20.1	20.0
Marital Status				
Not married	10.0	4.4	11.0	10.5
Currently married	90.0	95.6	89.0	89.5
Total	100	100	100	100
N	*50*	*90*	*1,160*	*1,300*

χ^2 test for between care-giving differences and F-test significance levels * <0.001; **<0.01 *<0.05**
Source: Author's analysis of NUHDSS Individual Data File, 2007

6.2.2 Household size and composition

Despite the fact that large households may enjoy economies of scale in consumption of goods and services such as rent and electricity of which the consumption by one member of the household does not exclude consumption by others and also benefit through pooling of resources and labour (Deaton, 1997), large households are also disadvantaged. For instance, intra-household resource allocations may not benefit all the members equally. In addition, the composition of the household members in terms of their age, sex, education, skills and health conditions has implications on overall welfare of its members. With regards to HIV/AIDS, the significance of the size, composition and dynamics of a household has been noted in various studies that have reported very high mobility in affected households as well as differences in size and composition

compared with other households (Ntozi, 1997; Ntozi and Zirimenya, 1999; Urassa et al, 2001).

The size and composition of households for HIV caregivers, other caregivers and non-caregivers are compared in Table 6.2. HIV caregivers are significantly more likely to be in larger size households compared with other caregivers and non-caregivers. About 34% of HIV caregivers live in households with 5 people or more compared with only 25% of non-caregivers and 20% of other caregivers. Whereas co-residence between young people or grandchildren with older people is a common feature in sub-Saharan Africa (Bicego et al, 2003), HIV caregivers were significantly more likely to be living in households with children 15 years or younger and to be living in the same household with at least one grandchild, compared with the two comparison groups. HIV caregivers lived in households with on average 1.23 children aged below 15 years unlike 0.73 for other caregivers or 0.90 for non-caregivers. Similarly, HIV caregivers lived on average with 0.74 grandchildren unlike 0.37 and 0.34 for other caregivers and non-caregivers respectively. A large proportion of these children are orphans (not shown) supporting the extensively documented evidence of a growing number of orphans in sub-Saharan Africa especially due to HIV/AIDS and the role older people play in caring for these children (Zimmer and Dayton, 2005). The presence of young dependants in the household has both immediate and long-term implications on their welfare and also that of the older person who in most instances is responsible for their wellbeing.

Table 6.2: Comparison of HIV caregivers, other caregivers and non-caregivers household size and composition

Household characteristics	HIV caregivers	Other caregivers	Non-caregivers	Total
Household size*				
0 – 2	44.3	60.2	53.5	53.6
3 – 4	21.6	19.5	20.9	20.8
5+	34.1	20.3	25.6	25.6
Mean household size	*3.85*	*2.98*	*3.22*	*3.23*
Young dependants (0-15 years) in the household***				
No	48.9	70.3	62.2	62.1
Yes	51.1	29.7	37.8	37.9
Average number of young dependants	*1.23*	*0.73*	*0.90*	*0.89*
Grandchildren in the household***				
No	68.2	83.6	81.3	80.9
Yes	31.9	16.5	18.7	18.9
Average number of grandchildren	*0.74*	*0.37*	*0.34*	*0.36*
Working age adults (15-49 years) in household				
None	37.5	48.4	45.5	45.3
1	31.8	26.6	25.3	25.6
2+	30.7	25.0	29.3	29.1
Average number of working age adults	*1.17*	*0.98*	*1.14*	*1.13*
Total	100	100	100	100
N	*88*	*128*	*1,845*	*2,061*

χ^2 test statistic of between care-giving differences: significance levels * <0.001; **<0.01 *<0.05**
Source: Author's analysis of NUHDSS Membership Data File, 2007

6.2.3 Movement of household members

The DSS registers people who have lived in the DSA for at least 90 days as in-migrants while out-migrants are members who have lived continuously outside the DSA for at least 90 days. Table 6.3 shows the proportion of older people in households that registered in and out-migration, during the 3-year period immediately preceding the survey comparing HIV caregivers and the two comparison groups. The 3-year period is

divided into three 12-month periods each corresponding to 4 rounds of data collection. Migration event in a household was defined as having registered at least one person joining or leaving the household over the 12-month period. The definition did not take into account repeated visits hence it is highly possible to have the same person counted as both an in-and-out migrant.

HIV caregivers registered a relatively higher movement of people in and out of their households compared with the comparison groups. At the start of the three-year period, there was very little difference between the HIV caregivers and the two comparison groups in proportions that registered either in or out-migration from their households. The difference was minimal between HIV caregivers and other caregivers. For instance, 38% of HIV caregivers were in households that registered an in-migration during this period compared with about 40% of other caregivers. Similarly, 15% registered an out-migration compared with 16% of HIV caregivers over the same period. In the second year preceding the survey, however, a significantly higher proportion of HIV caregivers lived in households that registered in and out migration compared with the other two comparison groups. A similar pattern is also evident in the year preceding the survey. Overall, the three groups of older people recorded a gradual increase in the size of their households over this 3-year period and HIV caregivers were in relatively larger households especially in the last two years prior to the survey compared with the other 2 groups of older people.

Table 6.3: Percentage of older people in households registering in and outward mobility and average household size over a 3-year period by care-giving status

	Period of observation preceding survey		
	Year I (Sept 17, 2003 – Sept 20, 2004)	**Year II** (Sept 25, 2004 – Sept 26, 2005)	**Year III** (Sept 27, 2005 – Aug 11, 2006)
	In-migration (in and outside the surveillance area)		
HIV caregivers	38.3	47.6	29.6
Other caregivers	39.8	32.0	19.5
Non-caregivers	36.3	26.8	18.7
	Out-migration (Outside the surveillance area)		
HIV caregivers	16.1	25.0	12.5
Other caregivers	15.3	15.2	10.2
Non-caregivers	12.2	12.8	7.3
	Average household size		
HIV caregivers	2.88	3.14	3.35
Other caregivers	2.56	2.62	2.79
Non-caregivers	2.79	2.94	3.09
N	*1,900*	*2,010*	*2,061*

Source: Author's analysis of NUHDSS Migration Data File, 2007

A number of plausible explanations could account for relatively high mobility in HIV caregivers' households compared with the other two groups of older people. One is the mobility of people in need of care. Additionally, new members who may include other older people, both family and non-family, may join the household to assist in caring for the ill person. New members may also join the household to offset actual or potential loss of labour or economic productivity resulting from the illness or care-related activities. Having adults in the household can be beneficial in contributing to the households' income and also in providing valuable support towards the care of an ailing member. However, a large dependency ratio can be detrimental to the welfare of vulnerable members and a source of burden or strain on older people who are mostly breadwinners in their households.

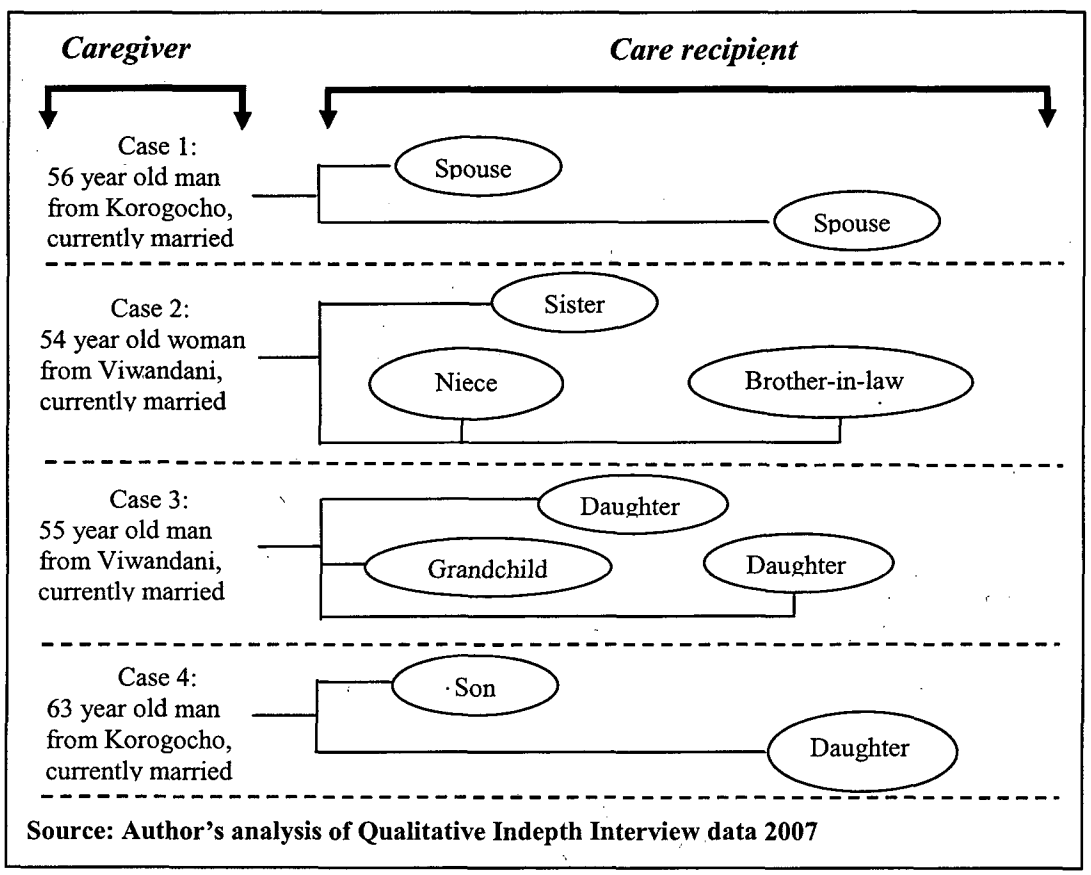
6.3 The attributes and context of HIV care-giving

During the survey, caregivers were asked if they had provided care to more than one person over the 3-year reference period preceding the survey. More than a third (36%) of the HIV caregivers reported having provided care to more than one person with a HIV-related illness. The care episodes were provided either concurrently (44%) or during different time periods.

6.3.1 Pathways to multiple care experiences

Different pathways lead to multiple care-giving episodes as illustrated by the 4 case examples from the qualitative study presented graphically in Figure 6.1. The chart shows the relationship of the caregiver with multiple care-giving episodes and the care recipients demonstrating the many different pathways through which an older person provides care to multiple cases. The mode of HIV transmission; namely, mother-to-child transmission and heterosexual transmission within marital unions influence the chances of either concurrent or successive multiple care episodes as illustrated by cases 1, 2, and 3. Case 1 has been married more than once and has cared for two of his spouses at different episodes. Case 2 cared for a couple almost concurrently and then later cared for the couple's child, while case 3 cared for two of her children one of whom had a child who was also ailing. The first two cases illustrate a possible marital or heterosexual transmission of HIV while case 3 and also case 2 point to mother-to-child transmission. An older person can also provide care to two or more people unrelated in terms of HIV transmission as shown by Case 4, who provided care to two of his children at different times during the three years.

Figure 6.1: Key pathways to multiple care-giving episodes



Source: Author's analysis of Qualitative Indepth Interview data 2007

6.3.2 Socio-demographic characteristics of care recipients with HIV-related illness

An older persons' level of involvement in care-giving may be influenced by a number of factors such as their age, sex, marital status and relationship to the person receiving care (Knodel et al, 2001). For instance, young unmarried adult children previously living with their caregiver before becoming ill, may be completely dependent on the older person and may also be in receipt of care for a longer duration compared with the situation if they were married and leaving elsewhere for part of the illness period. The age of the care recipient may be a factor in the care, for example children less than 15 years may demand more intensive and full time care during the entire duration of the illness compared with adults. Therefore, the consequence of care-giving and how it impacts on the wellbeing of the caregiver may be influenced by such factors associated with the care recipients. The care recipients' socio-demographic information discussed below refers to one care-giving episode for each HIV-caregiver. As noted in section 6.3.1 above, about 36% of HIV caregivers had more than one care-giving episode over the 3-year period. Therefore, information for the most recent care-giving episode was collected for these caregivers with multiple episodes.

6.3.2.1 Age, sex and marital status of care recipient with HIV-related illnesses

Increasing evidence indicates that the majority of people living with HIV/AIDS in sub-Saharan Africa are female and comprise 59% of PLWHA (UNAIDS, 2006). Similarly, Nairobi also depicts a higher prevalence rate among females compared with males by about 4 percentage points (National AIDS Control Council, 2005). This sex differential in HIV prevalence is, consequently, reflected in the sex distribution of the care recipients in the study area of which more than half were female (53%) (Table 6.4). Similar findings have also been noted in other studies on older caregivers for people with HIV/AIDS. For instance, a WHO study in Zimbabwe found that 61% of people receiving care were females (WHO, 2002), while a study in South Africa found a disproportionate number of females (39 out of 43) compared with males (Ferreira et al, 2001). Conversely, young males make up the majority of care recipients in Thailand where only 26% of those receiving care were females (Wachter et al, 2003), a consequence of the course of the epidemic in South-East Asian countries which first spread among single males and injectable drug users although recently the proportion of married females among those infected is on the rise (UNAIDS, 2006).

Table 6.4: Percentage distribution of care recipients according to their age, sex, and marital status

Characteristics	*Number*	Percentage
Age group		
0-14	*12*	13.6
15-49	*61*	69.3
50+	*15*	17.1
Sex		
Male	*41*	46.6
Females	*47*	53.4
Marital status (only if 12 years or older; N=81)		
Married	*33*	40.7
Never married	*24*	29.6
Formerly married	*24*	29.6
Total	*88*	100.0

Source: Author's analysis of Survey of Older People's Data 2006/2007

Table 6.4 also show that two fifths (41%) of the care recipients in the study were currently married and more than two thirds (69%) were aged between 15 – 49 years, the reproductive age group where the bulk of the HIV/AIDS cases fall both nationally and within urban areas. Interestingly, about one sixth (17%) of the care recipients were 50 years or older and the majority of whom (10 out of 15) were currently married. Only 4 of these older people in receipt of care were cared for by their spouses while the rest were siblings (3), other relatives (5) or not related (3) to their caregiver. This age group is normally considered a low risk group and have been excluded from surveillance data and routine HIV testing. The proportion aged 50 years and older out of the total number of those infected with HIV/AIDS in Kenya, estimated to be 8%, might therefore be an underestimation (National AIDS Control Council, 2005). A higher proportion of older people among those infected (15%) have been recorded in the US where there has been more systematic reporting of HIV among older age groups (Goodroad, 2003).

The proportion of children below 15 years out of the total number of PLWHA in Kenya is currently estimated to be 10% (National AIDS Control Council, 2005). This has increased over the years corresponding to the increase in the proportion of pregnant women infected with HIV given that vertical transmission from mother-to-child accounts for about 90 percent of HIV infection among children below 15 years. Hence about 14% of the care recipients in the study were below 15 years and were mainly

grandchildren (n=5) or biological children (n=4) of their caregivers. Only 1 out of the children was below the age of one year, 5 were between 2 and 4 years old while the remaining 6 children were 5 years or older with the oldest being 13 years.

The sex, age and marital status of the care recipient are compared by gender of their caregiver in Table 6.5. A higher proportion of women were providing care to males, children below 15 years, and those aged 50 years or older compared with male caregivers although these differences were not statistically significant (χ^2=0.98, p=0.322 and χ^2=2.70, p=0.259 respectively). Men who were caring for children under the age of 15 years were mostly parents of the child (4 out of 6) while older women were either grandparents or other relatives to the children. Men and women caregivers also differed significantly (χ^2=26.04, p=0.000) based on the marital status of their care recipient. Almost half of the care recipients cared for by women were formerly married (46%) unlike the men who were more likely to provide care to those currently married (48%). This difference is due to the high proportion of men caring for their spouses. Men generally marry women who are younger and this is also reflected in ages of the spouses cared for by men caregivers where 7 out of 9 were aged between 15 – 49 years. The difference in marital status of care recipients by gender of the caregiver can also be due the higher risk of marital dissolution among HIV positive women compared with men (Porter et al, 2004) and the propensity of formerly married women who are ailing to migrate out of their spouse's home (Ntozi, 1997) most probably in search of care and support from their biological parents. Evidently, 10 out of the 16 formerly married care recipients who were cared for by women were female and almost all (7) were children of their caregiver.

Table 6.5: Comparison of male and female caregivers by the age, sex and marital status of their care recipients

Characteristics of care recipient	Women	Men	Total
Sex (%)			
Male	52.6	42.0	46.6
Female	47.4	58.0	53.4
Age group (%)			
0-14	15.8	12.0	13.6
15-49	47.4	60.0	54.5
50+	36.8	28.0	31.8
Marital status (%)**			
Married	31.4	47.8	40.7
Never married	22.9	34.8	29.6
Formerly married	45.7	17.4	29.6
Total	100	100	100
N	*38*	*50*	*88*

χ^2 test for between gender differences: significance levels * <0.001; **<0.01 *<0.05**
Source: Author's analysis of Survey of Older People Data, 2006/2007

6.3.2.2 Living arrangement and relationship of caregiver to care recipient

The type of relationship between the caregiver and the care recipient and their living arrangements are presented in Table 6.6 compared across the gender and place of residence of the caregiver. The diverse forms of relationship between the caregiver and the care recipient indicate support for persons with HIV/AIDS go beyond a parent – child relationship to include spouses and other kin. Forty three percent of the older people were providing care for their own children with a large majority of these children (31 out of 38) being in the reproductive age of 15 – 49 years. A similar proportion of older people (43%) were caring for other relatives such as their siblings, grandchildren, in-laws, nephews or nieces. This also points to the importance and utility of the extended family ties and kinship in times of shocks such as illness. Although there have been debates on the ability of the extended family to act as a 'safety net' in the face of HIV/AIDS (Ankrah, 1993; Ntozi, 1997; Seeley et al, 1993), reliance on the extended family members to provide care is still important in the absence of public social support systems especially among poor-resource communities.

The living arrangement of the care recipient influences the type of care provided by the caregiver. Living in the same household or in close proximity to the care recipient may imply more involvement on a day-to-day basis in addition to providing more than one

form of care. About half of the care recipients (49%) were living in the same household with their caregiver, one quarter were in another household within the DSA and a similar proportion living outside the DSA. There was a significant difference in the living arrangement by gender of the caregiver (χ^2=29.89, p=0.000) and also between the two slums (χ^2=23.40, p=0.000) where the study was conducted. Care recipients for male caregivers and those living in Viwandani were more likely to live outside the DSA mostly in the rural areas, reflection of the gendered nature of split family migration where usually male members of a rural household migrate to the urban areas and maintain linkages through social and economic ties (Agesa, 2004).

Table 6.6: Comparison of caregivers' gender and place of residence by the type of relationship and living arrangements of the care recipients

	Women	Men	Korogocho	Viwandani	Total
Relationship of caregiver to care recipient (%)					
Parent	42.1	44.0	42.6	44.1	43.2
Spouse	7.9	18.0	13.0	14.7	13.6
Other[5]	50.0	38.0	44.4	41.2	43.2
Household care recipients' lived at the time of care * (%)**					
Same household	52.6	46.0	53.7	41.2	48.9
Other household within DSA	36.8	16.0	33.3	11.8	25.0
Outside DSA	10.5	38.0	13.0	47.1	26.1
Care recipients in same household before care (%)					
No	21.1	14.0	13.0	23.5	17.0
Yes	78.9	86.0	87.0	76.5	83.0
Total	100.0	100.0	100.0	100.0	100.0
N	*38*	*50*	*54*	*34*	*88*

χ^2 test for between gender and site differences: significance levels * <0.001; **<0.01 *<0.05**
Source: Author's analysis of Survey of Older People Data, 2006/2007

[5] Women caregivers not providing care to either their children or spouses (18 cases) were caring for their sibling (2), in-laws (2), grandchildren (2), nieces/nephews (3), while a large number were not related to their care recipient (8). Among the men (14 cases), 5 were caring for their siblings, 1 was caring for an in-law, 2 were caring for their grandchildren, 2 were caring for their niece/nephews while 4 were not related.

The migration of people living with HIV/AIDS from urban to rural areas or from larger cities to smaller towns during advanced stages of the illness has been widely documented (Clark et al, 2007; Ellis and Muschkin, 1996; Knodel and VanLandingham, 2001). However, the reverse movement namely from rural to urban or smaller cities to larger metropolis during the early stages of the illness has also been noted (Ellis, 1996). Failing health status, access to better healthcare facilities, dwindling financial resources, and the desire to be near family or friends are some of the reasons attributed to the migration with the underlying reason being the need to access care and support especially from informal and family sources. About 18% (n=15) of the care recipients changed residence as a result of the illness, of which 13 moved into the same household as their caregiver while the remaining two moved outside the DSA. A higher proportion of those who changed residence were care recipients in Viwandani slum and those cared for by women half (7 out of 15) of whom were formerly married moving back to their parents' home for care.

Although a quarter of the care recipients usually live outside the DSA, there is constant movement of the caregiver and mostly the care recipient between the DSA and their usual place of residence, mostly in the rural areas. The frequent circular movement in and out of the slums by both the caregiver and the care recipient have financial implications on the caregiver through, for example, costs associated with travel and additional household expenses incurred due to the care recipient either migrating permanently or temporarily to join the older person's household. The two excerpts below from the qualitative study illustrate the mobility of the care recipients and the caregiver respectively:

> *Interviewer*: So she is not here with you, when was she here?
> *Respondent*: From February to November 2006
> *Interviewer*: So you were with her from February to November 2006?
> *Respondent*: Yes. She had been sick for a long time while at 'home' (rural home), because in 2005 around July that is when I noticed she was sickly. So from July 2005 until February 2006 that is when she came here to take her to hospital (VM016).
>
> *Interviewer*: Okay. So, on a normal day, does he live here with you?
> *Respondent*: He was living here with me but right now he is at 'home' (rural areas).
> *Interviewer*: He is at 'home'?
> *Respondent*: Yes.
> *Interviewer*: So right now you are only sending money?

Respondent: I also go there personally. One month cannot lapse without me going there (KM022).

6.4 Type of care provided by caregivers

The qualitative study respondents were asked to describe the type of care-related activities they provided for the care recipient. Information was collected on both the routine care and occasional care provided. The data in this section is drawn from the qualitative study. The type of care is categorised into four key forms: financial, psychosocial, instrumental care, and personal or nursing care. Table 6.7 presents the tallies on the number of indepth interview (IDI) participants who reported to provide a specific form of care compared across gender. The type of care provided is not mutually exclusive therefore each caregiver provided more than one form or type of care.

Table 6.7: Number of caregivers by the type of care they provide compared across gender of caregiver

Type of care provided[1]	Women	Men	Total
Financial	10	14	24
All expenses	*7*	*11*	*18*
Occasional expenses	*3*	*3*	*6*
Psychosocial care	15	7	22
Instrumental care	12	3	15
Personal or nursing care	11	4	15
Other forms of care	6	9	15
Hospital visits	*2*	*4*	*6*
Other health related	*2*	*3*	*5*
Other types of care	*1*	*4*	*5*
N	16	15	31

[1]**Respondents could mention more than one type of care provided**
Source: Author's analysis of Qualitative Indepth Interview Data, 2007

6.4.1 Financial care

Financial support was provided by almost all the men (14 out of 15) rather than the women (10 out of 16). The support ranged from occasional assistance, to include taking care of all living expenses such as food, rent and medical expenses including related expenses such as transport costs when seeking healthcare. The caregivers frequently mentioned *"food and bus fare for going to hospital" "my work was to look for food and medicine"* or "*I helped a lot with money.*" Financial care for care recipients aged 14

years or younger also included scholastic expenses for those attending school. Providing for all expenses is not only limited to cases where the caregiver lived in the same household as the care recipient as illustrated by two case studies below where the care recipient lived in a different household from the caregiver but within the same DSA:

Case study one: KF031 is a 56 year old widow living in Korogocho. She took care of her friend aged over 50 years, now deceased who lived several structures away from her. She decided to take care of her because they were very good friends and had known each other over the years. Her friend was never married but was a single parent and lived with her children. KF031 took over all the financial responsibility of her friend's household after she became ill. She was also in charge of the medical expenses, nursing care and providing psychosocial support.

Case study two: VM011 is a 59 years old widower and lives in Viwandani. He earns his living through manning community toilets about 200 metres from his house. He is taking care of his son who has been ailing for the last 7 years. His son sleeps in a room in a different structure from where he lives that he rented out for him. He talked to the owner of the room who agreed to charge him 500 shillings (£4) while the other tenants in the same structure pay 700 shillings (£6). He is the one responsible for taking care of all his son's needs. He plans his meals, pays for the medical expenses and also monitors his condition all the time. At night since he is not there, he arranges for his brother's child to sleep in the same room as his son and the respondent can, therefore, be alerted should his son require anything or his condition worsens

Caregivers who provide care to recipients living outside the DSA remit cash regularly for general use but mainly for medical expenses. Both the caregiver and the care recipient frequently travel between the DSA and care recipient's usual place of residence and this would consequently have financial implication on the caregiver for instance costs resulting from additional living expenses during such visits as shown by the example below:

Interviewer: How long does she stay here?
Respondent: She doesn't stay for long, may be for a month and then she goes back.... She just comes for medicine and for any other help that we can give her...Like medicine, clothes...
Interviewer: And for how long has she been sick?
Respondent: Something like 3 years. I do not know exactly how long but it is something close to that.
Interviewer: Now, what kind of care do you give her when she comes?
Respondent: She can come and stay for a few days or a month...We give her money to buy the medicine.
Interviewer: What about food?

Respondent: Food is okay because she eats whatever we eat but sometimes buying fruits is a problem which makes her unhappy. You know fruits are like medicine for someone who is sick....Sometimes she needs something and we do not have the money, so we cannot take care of her properly. Sometimes the money we have is not enough. We take care of her depending on what we are able to do (VM013).

Financial responsibility is not only limited to the care recipient but can include his or her dependants such as the spouse but more often the children. The person who is ill, together with his or her dependants may live in the older persons' household or, the older person will provide care to the ill persons' entire household while living in a different location. This is illustrated by the examples below:

Interviewer: So you were taking care of her in terms of medicine, food...
Respondent: and also her children. She had 3 children.
Interviewer: Okay. So you told me that you cared for this child's mother before you started caring for her ill child. ...How long was the mother sick?
Respondent: She was sick for about 3, 4 years probably 5 because when she started to feel unwell... I don't know because when she started staying with me ... when she left where she had rented a house...
Interviewer: She had rented a house somewhere?
Respondent: Yes she had rented a house somewhere else. She brought her children and told me 'Dad, I am sick and because I am overwhelmed and I am not able to pay rent and we also fail to get food' I told them 'welcome, stay here in my house because you have been staying very far and if someone gets sick I wouldn't even know' (VM018).

Respondent: She is a bit better right now. There was a time when she was so badly off. In fact, food was a problem. I would cook food and give to my child to take it to her. Her child used to come to eat here. She was not able to get food for her so I had to do that.
Interviewer: So she doesn't stay here?
Respondent: I told her to stay in another house in Lunga Lunga (a neighbouring slum).
Interviewer: What about when she was badly off?
Respondent: When she is badly off, I tell her to come here.
Interviewer: So she was badly off, the two weeks when she has been here?
Respondent: Yes, when she is badly off she stays with me (VF014).

6.4.2 Psychosocial care

Almost all the women caregivers mentioned providing psychosocial support compared with less than half the men. Due to the stigma and discrimination normally associated with HIV/AIDS, the caregivers are aware of the situation that the care recipients find themselves in and therefore attempt to safeguard their feelings by showing them love, reassuring them that they are not to blame for the illness and also making them feel part

of the family or community as illustrated by the following quotes from indepth interview participants:

> "... I used to try to talk to him a lot. That is even something we have been taught and trying to bring him close to me so that he doesn't feel like he is alone. For example, if I was running late, I would tell one of my sons to warm up some food and take it to him. I would also go to see him later and at bedtime, I would leave him feeling better. So he would feel like he had his family nearby (KF008)".
>
> "When she came here, she had TB. I took her to hospital and when she was tested it was confirmed to be TB... We took her to Kenyatta (national referral hospital in Nairobi) for tests. My husband talked with the doctor who told him that she had the HIV virus. The doctor said she shouldn't be told because it would affect her negatively. But I think she already knew because her partner had gone to the doctor to be tested and she really didn't care about her illness although she would be in deep thought sometimes. So I started talking to her and showing her how much I loved her. I told her that being sick does not mean death (VF014)."
>
> "I used to talk with her to encourage her because you know when one is sick they can have many negative thoughts, but when you talk to them they feel better and the [negative] thoughts go away. We used to talk and I could encourage her to be strong (VM016)."

The caregivers mentioned avoiding confrontation or upsetting the care recipient and making them feel cheerful, as vital when caring for a person with a chronic and terminal condition. The caregivers also encouraged their ill person to live positively with their condition and not to give up, for example, one caregiver mentioned making statements such as *"do not worry, even if it is AIDS or TB, there is treatment and you will be treated* (KM001)*"* as ways of counselling the care recipient. Some of the caregivers also mentioned encouraging their care recipient to join support groups or to register with community- based organization that provide care and support to PLWHA. Caregivers who personally suspected the illness to be HIV-related also counselled the care recipient and encouraged them to go for a HIV test as shown in the excerpts below:

> *Interviewer*: How were you caring for him when he was sick, what assistance were you giving him?
> *Respondent*: The first thing I did was to enrol him with the Catholic doctors, they are the ones who assisted him a lot. They have doctors who normally visit [the sick], so I sent him there ...
> *Interviewer*: So you only came in and introduced him to this 'sponsor"?
> *Respondent*: Yes, I 'Introduced' him so after he joined my role sort of reduced and the rest was just to counsel him (KM001).
>
> *Interviewer*: You said *Child1* had AIDS

Respondent: Yes
Interviewer: And *Child2* had a chest problem and nothing else?
Respondent: You know…they tell you when you have tested. Like *Child3* I told her to take the test, which she did….but if you have not tested you cannot know…but I have been talking to *Child2* to go for HIV test (VF010).

Caregivers also discussed the end of life with the care recipient. Religion and spirituality form a major part of the psychosocial care especially for encouraging the ill person to live positively and to accept their situation including the imminent death. In some instances, the care recipients also brought up the topic and discussed their verbal wills with their caregiver, for instance, those with children would discuss their preference on who should take care of their children as shown in the case below:

Interviewer: Is there any other essential care you gave her during this time she was ill that you haven't mentioned?
Respondent: The important thing … lets say buying her meat, chicken… soup…
Interviewer: Was she able to eat?
Respondent: Yes she used to eat until the last minute except when she was so overwhelmed because it reached a point when she was so overwhelmed… and she came and told me 'Dad, I am dying and these children are yours' she uttered these words when I was with her and my tears came down. I told her… she told me 'Dad I will leave but these children are yours'. She left me the children.
Interviewer: She gave the children to you?
Respondent: She gave the children to me. What I am saying are words that came from her mouth (VM018).

A few of the caregivers also discussed sexual matters, for example, advising the care recipient to change their sexual behaviour. One caregiver also discussed the dangers of re-infection with other strains of HIV/AIDS and urged the person receiving care to use protection even though they were already infected. To illustrate some of these issues, an excerpt from an interview with an older person taking care of his son is presented below. The respondent uses phrases such as *'things to do with women'* and *'things of the world'* as euphemism for sexual intercourse.

Interviewer: What about psychologically? Would you talk to him and tell him not to have worries?
Respondent: I told him that even though he doesn't have a wife because she died, he shouldn't worry too much. I told him that if he starts thinking too much about a wife and things to do with women, he is going to die very quickly. I told him he should know that he can die at any moment and he listened to what I said and he is still alive even now.
Interviewer: Those times when his condition would worsen, is there any additional care that you would offer him?

Respondent: You know you have to pray to God. If you have a sick person, you have to pray even if you take them to hospital. So we told him to pray. Even if you are taking medicine, you have to ask God to help you. So we would tell him not to think so much about the things of the world because this world has brought him a lot of troubles and he accepted this (KM003).

6.4.3 Instrumental care

Cooking, doing laundry and general cleaning around the house were the main types of instrumental care that caregivers reported providing. Most of the women provided this form of care (70%) compared with men (20%). Men who reported performing instrumental care were either not living with the spouse in the same household, were widowed or those who were providing care to their spouses. Older people, especially men rely on other people who are sometimes hired to perform some of the tasks they are unable to do as shown by the excerpts below:

Interviewer: When X is sick are you the one who washes his clothes?
Respondent: No, he just takes his clothes and washes them. I tell him that I cannot wash his clothes. Also the mother of this young child who normally shares the same room with him is like his mother. So I ask her to help me with washing X's clothes.
Interviewer: and is there anybody else in your family who helps you to take care of X?
Respondent: The one who helps him is his sister. Sometimes I give her money and she cooks for X. You know, I don't cook here so I give her everything and she cooks for him. I just make sure that the food is brought here but you know she has a husband (laughing).
Interviewer: Oh, she is staying with her husband?
Respondent: Yes. You know if you are married...I just pleaded with her together with the husband to help me because I cannot cook (VM011).

6.4.4 Personal or nursing care

Nursing care such as feeding, bathing, and helping the care recipient with toileting are types of care normally provided when the ill person is bedridden. More women reported providing nursing care (69%) compared with men (27%). Traditional norms relating to division of labour across gender lines including work relating to personal or nursing care persist among most ethnic communities in sub-Saharan Africa. In addition, the gender of the caregiver varies with respect to that of the care recipient as well as the nature of their relationship. For instance, women are excluded from caring for adult males except for spouses. The rationale was mainly to ensure modesty and avoid embarrassment on the part of both the caregiver and care recipient (MacNeil, 1996; Ntozi, 1997). The absence of a large choice of kin in urban areas however, may make

such norms difficult to practice. On the other hand this could also indicate changes in traditionally ascribed norms relating to gender care-giving in the context of HIV/AIDS.

Although nursing care is normally provided to PLWHA during the last stage of illness, a number of the caregivers reported episodes where the care recipient is bedridden and then recovers to the extent of having the ability to perform activities of daily living by themselves sometimes even returning to work. The examples below indicate the intermittent nature of care-giving.

> *Interviewer*: What do you normally do?
> *Respondent*: I wash her clothes, I wash her…
> *Interviewer*: Wash her everyday?
> *Respondent*: Not everyday only when she is critically ill (KF025)

> *Interviewer*: So you normally go and assist her daily…
> *Respondent*: Yes, that is a must every single week. But in terms of washing her, I only do that when she is critically ill.
> *Interviewer*: Only when critically ill?
> *Respondent*: Yes. Otherwise when she has strength she will wash herself and even go and collect water by herself, do her cooking. Even now if I take you to see her you will not believe it's the same person we are talking about (KF029).

6.4.5 Other forms of care provided

Accompanying the care recipient to hospital on a regular basis and making scheduled visits if the person is admitted featured as a major care-giving activity for both older men and women. Other health-related care activities include liaising with health workers, sourcing for medical supplies and monitoring the care recipient's drug prescription which is imperative especially for TB and ART medication where strict adherence is crucial for efficacy. The following quotes illustrate these types of care.

> I used to take her to hospital where she would be given drugs to take for a certain period of time and when the drugs are finished, we go for another dose (VF017).

> *Interviewer*: Has he gotten any treatment?
> *Respondent*: I took him to hospital and I took him there for his blood to be tested, after testing he was found like that….. (infected with the HIV virus).
> *Interviewer*: So lets say on a day that is not ordinary, for example, when he is too ill, that is during a day when it is not ordinary, what assistance do you give him or what do you normally do?
> *Respondent*: When he is too ill I sit with him and ask him how he is feeling, I ask which medicine he has taken and if there is any medicine he has not swallowed, I ask him to take. If we have run out of a certain drug, I ensure that

we get the medicine because he has to have it. If his condition worsens, we carry him and take him to hospital (KM022).

Interviewer: And did you take him to Mbagathi hospital (Infectious disease hospital within the city) then?
Respondent: He went to Mbagathi on his own. I gave him money and he went.
Interviewer: Even the first time?
Respondent: I was the one who took him the first time. You know you have to go with him because of the queue (VM011).

One of the caregivers caring for a child aged less than 15 years said taking the child to school and going to the school periodically to check on the child were also part of the routine care.

Interviewer: Is there any other care you give her during the day?
Respondent: You know when she goes to school I have to keep checking on her to see how she is doing.
Interviewer: So you have to follow her to school and see how she is doing?
Respondent: Yes I have to see how she is doing.... sometimes she cannot go on her own so I have to take her everyday (VF019).

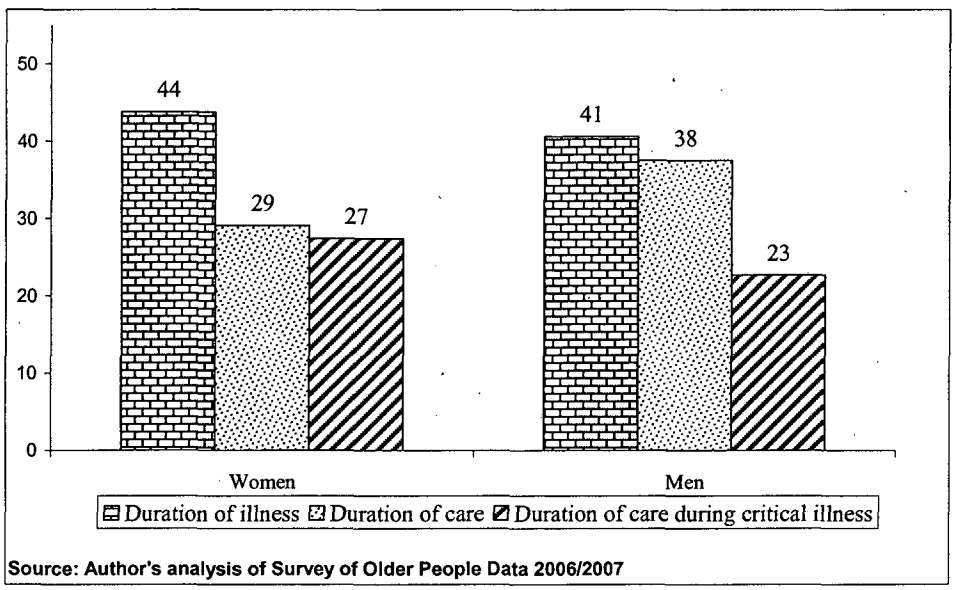
Caregivers also reported the following; spending time with the ill person and keeping them company especially when their condition deteriorates, and keeping watch during the night to ensure they are comfortable and in case they require any assistance, as other key tasks relating to care-giving. Caregivers whose care recipients live outside the DSA mentioned enquiring about their health and situation regularly in addition to making both scheduled and unscheduled visits to see them.

6.5 Duration of care-giving

The social, health and economic impact of care-giving may vary depending on the duration the caregiver provides care, which is in turn associated with the length of time the care recipient has been ill, their living arrangements, HIV/AIDS progression and severity of the illness (Chimwaza and Watkins, 2004; Knodel and Saengtienchai, 2002). Figures 6.2 presents the mean duration of illness and care compared against the gender of the HIV caregivers. The information is drawn from the older people survey. Men on average provide care for longer durations compared with women (38 months vs 29 months respectively). Men unlike women also provide care for almost the entire duration of illness. However, the average duration of care is slightly higher for women during periods when the care recipient is critically ill (27 months vs 23 months respectively).

This variation in duration of care and timing between men and women may arise from gender differences in care-giving roles with women mainly providing nursing and assistance with instrumental care while men mainly provide financial care. For this reason, the demand for financial care may begin at the onset of the illness due, for instance, to medical expenses and the need for support towards living expenses during bouts of illness. The type of care PLWHA need and receive does vary depending on the stage of the illness with the demand for personal or nursing care arising during the symptomatic or last stage of the infection. At the early stage of the infection, the care recipient require little or no nursing care since they may be able to independently perform activities of daily living (ADL) unlike at advanced stages of the illness or during periods of critical illness. As a result, women caregivers provide care mainly during critical illness (Figure 6.2).

Figure 6.2: Mean duration of illness and care (Months) by gender of the caregiver

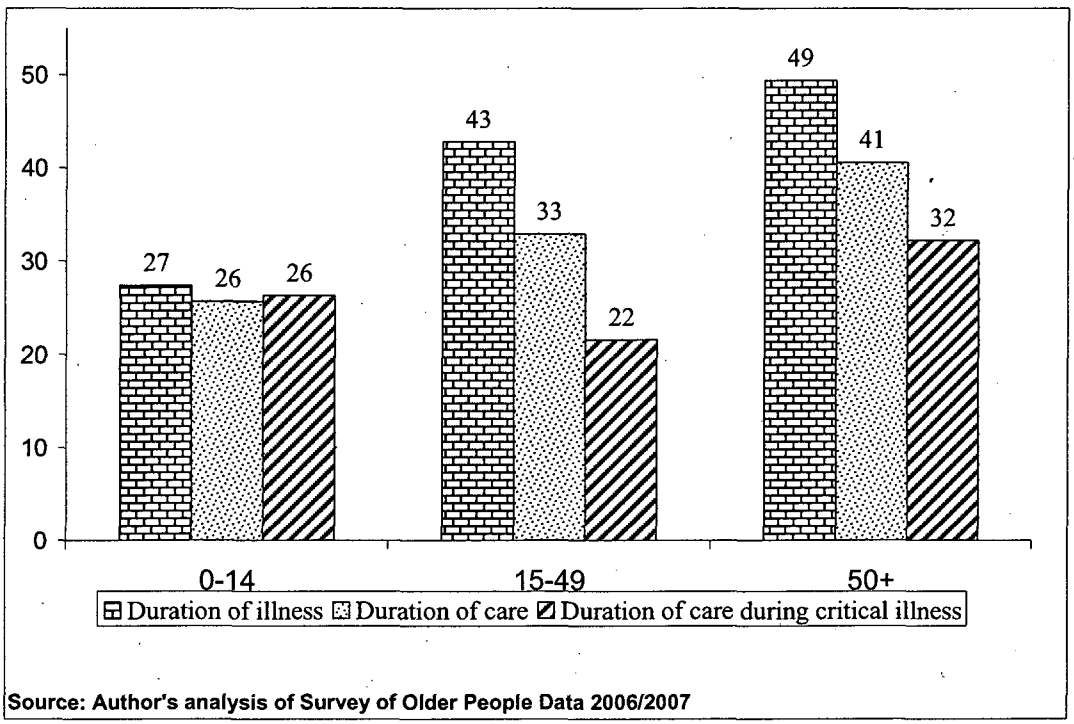


Source: Author's analysis of Survey of Older People Data 2006/2007

Figure 6.3 illustrates the difference in mean duration of illness and care by the age of the care recipient. Children below 15 years receive care almost the entire duration of the illness indicating the demanding nature of care-giving or the vulnerability of children during illness thereby requiring care almost the entire illness duration. It is also evident that HIV positive children in sub-Saharan Africa and especially in poor-resource

settings, progress more rapidly to full blown AIDS unlike adults, therefore, they present with severe illnesses almost the entire period of illness (Spira et al, 1999).

Figure 6.3: Mean duration of illness and care (Months) by age and sex of the care recipient



Source: Author's analysis of Survey of Older People Data 2006/2007

Table 6.8 compared the duration of care according to the time when the care was provided and also the outcome of the care. Slightly more than half (52%) of the caregivers were providing care at the time of the interview. Out of those who had stopped providing care, 33% of the cases recovered from the illness while the others (67%) terminated with the death of the care recipient. The duration of illness and care was significantly different for those receiving care at the time of the interview compared with those cared for previously (χ^2=25.98, p=0.000 and χ^2=17.14, p=0.000 respectively). Cases that resulted in death had been ill for an average of 19 months unlike 42 months for those receiving care at the time of the interview. Consequently, the average duration of care for those receiving care at the time of the interview was almost 2.5 times longer than cases that resulted in death.

Table 6.8: Percentage of caregivers who were providing care by duration of care-giving (months) and outcome of illness

	Period when care was provided						Total	
	Currently care-giving		Provided care within preceding 3 years					
			Terminated in recovery		Terminated in death			
Duration of illness* **	%	*N*	%	*N*	%	*N*	%	*N*
0 – 23	19.6	(9)	85.7	(12)	53.6	(15)	53.49	(46)
24+	80.4	(37)	14.3	(2)	46.4	(13)	46.51	(40)
Mean	*42.04*		*12.07*		*18.68*		*33.28*	
Median	*60.0*		*5.5*		*12.0*		*36.0*	
Duration of total care* **								
0 – 23	34.1	(15)	85.7	(12)	54.2	(13)	40.9	(36)
24+	65.9	(29)	14.3	(2)	45.8	(11)	59.1	(52)
Mean	*33.65*		*10.14*		*18.58*		*29.84*	
Median	*36.0*		*4.5*		*11.5*		*24.0*	
Duration of care during critical illness* **								
0 – 6	38.5	(15)	100.0	(14)	67.9	(19)	53.95	(41)
7+	61.5	(24)	0.0	(0)	32.1	(9)	46.05	(35)
Mean	*50.70*		*1.69*		*13.32*		*23.44*	
Median	*60.0*		*1.0*		*8.0*		*12.0*	
Total	100.0	(46)	100.0	(14)	100.0	(28)	100	(88)

χ^2 test for between period care-giving significance levels * <0.001; **<0.01 *<0.05**
Source: Author's analysis of Survey of Older People Data, 2006/2007

The shorter duration of care for cases that resulted in death may indicate cases where the caregiver starts providing care when the disease was at an advanced stage. This is supported by similar studies where persons ill with HIV/AIDS were found to seek external care usually at the advanced stage of the illness when they are physically and financially unable to care for themselves. On average, PLWHA migrating from elsewhere to be cared for by older people were found to receive care for shorter durations compared with those living near or with the older people before the onset of the illness (Knodel and Saengtienchai, 2002). The shorter duration of care for cases that resulted in death may also be a pointer to the quality of care received by the ill person. Differences in duration of care were observed among older people in Cambodia and Thailand where on average those with lower economic status provided care for shorter durations compared with older people with higher economic status (Knodel, 2006). The

capacity of the caregiver, including financial ability to provide adequate care and support, can contribute to quality of care thus prolonging the life of the care recipient resulting in longer duration of care. Access to comprehensive quality care and support for HIV/AIDS patients contributes to the delay in disease progression, reduction in morbidity incidence and opportunistic infections with the overall effect of prolonging the life of the PLWHA (Kitahata et al, 2002). Below is a case example from an indepth interview respondent who provided care to multiple cases over the 3-year reference period. The case illustrates how the duration of care is influenced by the stage of the illness when the caregiver starts providing care and differences in treatment seeking behaviour.

Case study three: VF010 lives with the husband together with three of their children and several grandchildren in Viwandani. Their household occupies two adjacent rooms. She has provided care to three of her children over the three-year period and was currently taking care of two and one was deceased. The deceased child (Child I) previously lived with her spouse in the rural areas and came to live with the respondent in 2004 when she was already ill. She said that *"Child I's husband came and told me Child I was very sick and by then Child II was also sick and I could not leave her to go and visit Child 1. Her husband doesn't have an income... So I told him to bring Child I to stay here with me so that I could take care of both, Child I and Child II."* She was taken to various health facilities and her condition was not improving. She died after receiving care for a period of 8 months. Child II started getting ill about the same time in 2004 while Child III's illness started in 2005. For the two children currently receiving care, the respondent took them to a hospital specialised in TB and HIV treatment and their conditions have been stable. The respondent receives material and educational support towards the care for child II and III from a CBO and the medical costs excluding transportation are provided at subsidised costs in government health facilities. When asked to compare the three care experiences the respondent said *"You know, when Child I was admitted in hospital X they did not tell me what the problem was. If they had told me I would have taken her to Hospital Y where I took Child II and she could be alive today."*

The caregiver, therefore, started providing care to Child I when the illness was at an advanced stage thus explaining the shorter duration of care. The two children currently being cared for have received specialised care and the caregiver has also benefited from support in the form of material and knowledge and information on how to care for PLWHA from a care and support CBO.

6.6 Reasons for care-giving

Studies have indicated a large majority of PLWHA are usually cared for by their parents. In Uganda, between 1992 and 1995, the proportion of PLWHA cared for by their parents increased from 35.2 to 40.4 (Ntozi et al, 1997) while about two thirds of PLWHA in Thailand were cared for by an older person (Knodel and Saengtienchai, 2002). Other potential caregivers to PLWHA include their siblings, spouses and other relatives. In order to determine the circumstances leading older people to provide care, the indepth interview respondents were asked to give reasons why they provided care. Table 6.9 presents the tally of caregivers by the reasons given for care-giving categorised into key themes and compared across gender of caregiver and their relationship to the care recipient. Several respondents gave multiple reasons.

Table 6.9: Number of caregivers by reasons given for care-giving compared across gender of caregiver and type of relationship to care recipient

Reasons for care-giving [1]	Gender of caregiver		Type of relationship to care recipient			
	Male	Female	Parent	Spouse	Other	Total
Parental responsibility	11	4	7	0	8	15
Responsibility as the oldest family member	9	3	2	0	10	12
Care recipient rejected or discriminated upon by other relatives	6	8	2	0	12	14
Willingness to care	13	10	5	2	16	23
No one else to care	5	6	4	0	7	11
Inability of others to provide care	7	3	3	2	5	10
Other reasons	7	5	5	2	5	12
N	*13*	*12*	*9*	*2*	*14*	*25*

[1]**Respondents could mention more than one reason for care-giving**
Source: Author's analysis of Qualitative Indepth Interview Data, 2007

6.6.1 Care as parental or family responsibility

Most of the caregivers view caring as a personal responsibility towards either their children or other family members. Caregivers who are providing care to their children felt care-giving was their responsibility as heads of their families and also as parents. Most of those who mentioned care as a parental responsibility were men (11 out of 15). The respondents mentioned this parental role as a matter of fact, for instance *"I took care of him because he is my child* (VM015)"or *"because they are my blood and since I gave birth to her...* (VM018)." Caring was seen as inevitable by some respondents as they have almost no choice on whether to provide care or not as one respondent pointed out on discovering her child was HIV positive: *"I got shocked at first but I had to compose myself because I knew the problems had already come and there was nothing I could do. This is my daughter after all (VF017)"*. Responsibility over their children also extends to those living elsewhere and even those already married as pointed by the respondent below:

> *Respondent:* When they are in my house, even if they were at their husband's before, they are still mine. That is a problem. There is none (problem) that passed me by...My family, this one came, then another one came, all of them are mine. It is not that I will wait for their husbands to come for them. Its not that I will wait for their families (matrimonial family) to come and take care of them, if I see you getting sick, I will take you to hospital until your family decides to come and take you or to come and see you (KM028).

Older people caring for other relatives also see it as their responsibility towards the extended family, especially if the older person is male and the oldest in the family. The oldest male member of a family is usually designated as the head in most patrilineal and patrilocal traditional extended families in sub-Saharan Africa. This practice is still common among some of the contemporary extended family systems (Landau and Griffiths, 1981). Relatives, therefore, turn to the head of the family at times of need who in turn feel obliged to assist. Several older people mentioned their obligation towards members of their extended family as a reason for providing care as shown in the example below from a respondent from Viwandani who has had multiple experiences of care-giving to members of his extended family.

> *Interviewer*: You had said something important. That when your relatives become sick they come to you for help, why you only? Don't you have any other relatives or are you the only one here?

Respondent: I am the oldest in my family. We were born boys but the ones who were born before me are all dead. Four have died.

Interviewer: So you are the oldest remaining.
Respondent: Now the children keep coming here. I have older sisters but I am the first born son. I was born in-between sisters. ... Our last born is a boy. He is the eighth born. I was born in-between girls. There were four older boys who died and they left children behind. You see?

Interviewer: They cannot go to your younger brother?
Respondent: No, I am the one who is now like their father. If someone is sick, they come here. I am like their father. I am like their mother because I was born in the middle. And you know when girls get married many times their children have to go back to their parents. So they keep coming here. We have even rented another house here so that when they come, they have a place to sleep (VM013).

Other relatives may not be able to provide care due to physical or financial hardships forcing the older person to take up the responsibility. For example, a 54 year old man living in Viwandani slum explains below why he had to take care of his sister and how his other relatives were not in a position to provide care to her.

For 2 years before I brought her here, she was living with my mother in Kisii (a District in Western Kenya) and she had been admitted in Kisii General Hospital... She improved and was discharged but she got sick again. I brought her here and took her to St. Marys Hospital (a Catholic Church hospital in Nairobi). She was treated and improved but she got sick again and I took her back [to St. Marys Hospital]. She was married but left the husband 5 years ago and was living with my mother... My step brothers and my sisters living in Kisii took her to hospital but are married and have their own homes. My mother is very old... the only thing she could do was to check on her and see if she is alive or not. That is why I brought her here.... I felt I was responsible in taking care because I am her only brother although we have stepbrothers (VM012).

Older people with multiple experiences felt that caring for a second and subsequent person follows naturally after having cared for the first one either because they are already living together in the same household or in most cases the people who are eventually cared for are related by birth or through marriage. An example of an older person taking care of his grandchild aged below 15 years said *"I was taking care of the mother and the father and since they gave birth to this child and the child was alone after the parents died so... [I decided to take care of her]* (VM019)".

6.6.2 Rejection and neglect by other family members

PLWHA often face stigma and discrimination from their community including their own family forcing the PLWHA to conceal their HIV status out of fear of rejection. Stigma and discrimination can also be a barrier towards receiving adequate care and support when PLWHA are shunned and neglected by potential care providers including informal providers such as friends and family. A number of older people reported providing care to those who have been neglected or rejected by other family members. This was mentioned mainly by those who were providing care for other relatives and non-relatives.

Stigma and discrimination towards PLWHA is displayed in various forms from very subtle to overt negative attitude or verbal attack. PLWHA may therefore perceive negative attitude or because of fearing rejection, are forced to shun certain members of their family while preferring others or in some instances non-family members to provide care. The PLWHA may be abandoned or cared for half- heartedly forcing them to seek care elsewhere. One respondent who cared for his niece said "*She was sharing a house with another girl whom she worked with but when she started becoming sick, the roommate left her. So she ended up staying in the house alone... we would go check on her, give her food and pay her rent until she died* (VM013)."

Stigma and discrimination associated with HIV/AIDS largely has its roots in the mode through which HIV is mainly transmitted and in the history of the epidemic. HIV is mainly a sexually transmitted infection and the disease first appeared among high risk groups such as prostitutes. HIV/AIDS has, therefore, been perceived to be a consequence of commercial sex work or patronage, a practice which is largely discriminated aganist. The PLWHA is thus blamed for having contracted the disease or the infection is seen as a form of punishment for the persons behaviour (Parker et al, 2002). This reason was commonly cited by the respondents as a reason for rejection and lack of interest by others to provide care for the care recipients as expressed below:

> That stigma was there because even in our 'home' we were given nicknames by people because of these two sisters of mine. Even the church where we used to go, we had to stop going because people were discriminating against us. The church elder said 'this disease is killing members of such and such a family' so we decided instead of going to church to listen to being preached about ... [we would rather not go at all]. They were saying that we are promiscuous (VM019).

Married women are often blamed for being the source of HIV infection in a relationship, especially by the man's relatives more so when the man is deceased (Rakwar et al, 1999). This sometimes leads to abandonment or the woman is ostracised forcing her to seek help elsewhere most often from their biological parents or relative, explaining the high proportion of formerly married women among the care recipients.

HIV/AIDS has been associated with urban areas with rural residents perceiving themselves at a lower or no risk compared with their urban counterparts. They also perceive urban residents as contributing to the spread of HIV in rural areas (Coast, 2005). Family members based in rural areas may, therefore, be reluctant or unwilling to take up the responsibility of providing care to their kin living in urban area who become ill. The fear of rejection by family members in the rural home may also prevent people who are ill from seeking care and support. This rural-urban dichotomy is illustrated by the excerpts below. The first respondent depicts how family members living in the rural area were unwilling to provide care while the second example shows how PLWHA may shy away from seeking help in rural areas.

> Those ones in the rural areas do not come. They know that someone is sick but they do not come to see them. They leave you with the burden. When people in the reserve (rural areas) know that someone is sick, they do not bother with them saying the person was engaged in prostitution and so put the blame on them and may be the person was not engaged in any prostitution.... It was just bad luck. May be a friend (sexual partner) gave you the disease and this friend got the disease from another friend (VM013).
>
> You know when someone is sick, they require very many things. I used to talk to him a lot to see whether he could be taken upcountry. I was trying to organize for him to go upcountry but he said that his biggest problem would be to be taken there. He said if he went, he would die faster than if he stayed here. He said he never went home when he was still strong, so why should he go now when he cannot help himself in any way? (KF008).

Interestingly, one respondent mentioned the expectation or perception by other family members that their care recipient will be cared for by formal or charitable institutions as a reason for neglecting or abandoning the person. The respondent while giving reasons why other family members were unwilling to provide care said *"He told me that he knows it's because of the disease he is infected with.... He says his family told him they know when someone gets sick here (urban/slum area) they get 'sponsors'"* adding that *"He does not have children because his wife died and the children who are there [at 'home'] are his brother's children and they cannot come here to assist him or care for*

him in any way (KF026)." While no extensive study has been conducted on the preference for institutional or formal care for PLWHA, an exploratory study conducted in Kenya earlier on in the epidemic to assess community attitudes towards PLWHA found that while people generally 'empathise with the plight' of PLWHA, they preferred hospital to family care citing limited knowledge and lack of financial resources by informal caregivers and the need for professional care (Olenja, 1999).

6.6.3 Compassion, willingness to care and other reasons

The feeling of compassion towards the care recipient and willingness to care featured prominently as reasons for care among almost all the caregivers. Having humane feelings, love towards the person who is ill and empathising with their pain were some of the reasons highlighted. Not blaming the ill person and the understanding that anyone can get infected stirs the caregivers not to stigmatise or refuse to care for a person with HIV/AIDS. Some respondents acknowledged other potential caregivers within their own families or the family of the care recipients who would have been in a better position to provide care but were unwilling to do so. The excerpt below from one interview best illustrates the feelings of compassion and willingness to care.

> *Interviewer*: What made you personally decide to help this child?
> *Respondent*: What made me do this is my humane heart. I saw the baby has been cast aside in the father's home, I am the first born in our home and there was no one I could take this child to and since I was taking care of the mother as well, feeding her...
> *Interviewer*: Didn't you have other relatives who would have helped you take care of this child?
> *Respondent*: I have a sister and, in fact, I used to take care of her child. She abandoned the child when she was 2 and half years and came to Nairobi to roam. That is the one we would have assisted each other. But she has not been given the same gift as I have. In fact she lives in this village, if I left this child before she has eaten anything I will find her in that same condition.
> *Interviewer*: So you said whatever happens you had made your decision?
> *Respondent*: Yes I made that decision.
> *Respondent*: I saw that illness is not anyone's wish. There is nowhere anyone wrote a letter like an 'application', even you today you are okay but you don't know about tomorrow (VM019).

The idea of treating others as their own child or family also acted as a guiding principle to some of the caregivers taking care of distant or non-relatives. One caregiver taking care of a non-relative 50 years and older said *"You know X was a friend of mine, she was not from my 'family'.....It is because of that humane feeling and as a parent, although she was almost my age I imagine 'What if she was my daughter? Won't*

someone care for her? (KF030)". Willingness to provide care was reported as very key, especially to a person with HIV due to the nature of care they demand and the difficulties involved as one respondent who had multiple experiences over the 3-year period pointed out *"You would not have wanted to even get close to them if you do not have a humane heart because of the 'rashes', wounds all over....* (VM019)". Caring for PLWHA also requires time and patience. Some caregivers took it upon themselves to care because they felt other people may provide care half-heartedly as the following caregiver whose child was previously cared for by community health workers explained:

> *Interviewer*: So to conclude, I would like to know what happened for you to start caring for this child of yours, you yourself taking care of him. Why did you decide to take care of him and not someone else...
> *Respondent*: It was because I saw that there was no one else who could care for him and when this people (volunteers) from the project (CBO) came and started caring for him, I saw that the person was not volunteering willingly. ...Then I thought someone else taking care of my child would be a problem, I thought it would be difficult because I had seen it before right here, like those other two who are gone [dead], you can see that their condition is bad but then you wait for the person taking care of them to come but... [they never come on time] (KF020)

The decision by the care recipient as to whom they preferred to be their caregiver and proximity to health facilities in the city were other reasons cited. The care recipient may choose someone whom he or she feels comfortable with or someone they believe will provide them the best care and support. Being the only available next of kin and having no one else to provide care was also commonly mentioned as pointed out by the following excerpt from a caregiver taking care of her nephew.

> *Respondent*: This person was sick, he does not demand a lot. He was a young man and I am an old woman so I used to care for him like my own son. He was a son to my sister.
> *Interviewer*: He was your sister's son?
> *Respondent*: Yes. He came to live with me. My sister died a long time ago so I was caring for him. He stayed with me for 7 years.
> *Interviewer*: So, by caring for him, did it affect your life in any way?
> *Respondent*: It did not affect my life because I took care of him as best as I could until his time came (death).
> *Interviewer*: What about for all the 7 years when he was ill?
> *Respondent*: Of course we had problems....There was no danger because it was my love for him that made me decide to care for him and I decided that there is no point of discriminating someone like him and he has been brought to my house, he has no one else.... There was no one to care for him in the place where

he was staying previously. So people decided that 'let us take him to live with his aunt so that she can take care of him'. I did not see anything wrong with that (KF031).

6.7 Care-giving in slums in contrast with other settings

The living conditions in slums such as poor housing structures, inadequate access to safe drinking water, lack of sanitation, severe overcrowding and insecurity could have direct bearing on the caregivers' role of providing care. The indepth interview participants were asked about their experience and challenges in the day by day tasks of care-giving. This was discussed with reference to other setting such as rural or non-slum areas and both advantages and disadvantages of care-giving in city slums were discussed.

Caregivers who considered the city to be advantageous felt it was easier and convenient to access health facilities and related services unlike the rural areas where such facilities are inaccessible due to distance and unreliable transport system. For instance, in case of emergencies, it is much easier and faster to take a sick person to hospital as opposed to rural areas. Drugs and other medical supplies can also be easily purchased from various outlets in urban areas sometimes at lower prices relative to outlets located in rural areas. HIV/AIDS care and support services were also reported to be more accessible in urban than rural areas.

> *Interviewer*: Are these challenges different from the older people in other environments like rural areas?
> *Respondent*: They are different. In Nairobi it is easier and faster to get a sick person to hospital for treatment. In rural area health facilities are far and it takes some time to get to a health facility (VF010).

> The rural area is a bit better. You can just go to your garden and get food there. You will just eat without having to spend money. It not like here. But here, medicines are more accessible. But there is no money here. We just stay because we don't have any other option. The rural area is better off (KF026).

> *Respondent*: back home there are more problems than here.
> *Interviewer*: More problems that here?
> *Respondent*: Yes, You know at home hospitals are far away, and you cannot get as much help as you would here. Like.... the rural areas have problems. If you do not have money, and with no volunteers (CHWs) to assist you ... I tell you the person (sick person) would not last one month [alive] (KF030).

The rural area was thought to be better than urban areas in terms of the costs and means of obtaining food. The caregivers mentioned purchasing food and commented that nutritious food was one of the difficult aspects of care-giving owing to the high costs in the city compared with rural areas. Being able to farm and grow own foodstuffs was, therefore, pointed out as one of the main advantages of care-giving in a rural setting as this reduces the cost of care. Apart from growing own food, the cost of purchasing food in rural areas was thought to be cheaper.

> Yes there is a difference because back home there is food ...there is food from the garden and you know some diseases require food that is fresh and also that is sufficient. Here, there is no food, food here is hard [to get]. You see? There at 'home' when someone is sick and is asked to eat kales or other foods like the traditional vegetables, it will be found in the garden but here, there is no place you can find such (KM001).
>
> *Interviewer*: So do you think someone your age, would it be better to help these children here or when they are at 'home'? Is there a difference?
> *Respondent*: There is a difference because if I had these children at home they would get bananas from the farm, there we have kales in the garden, you just go and pluck them and eat ... but now here when I am as broke as I am ... is there anything I can give them? Nothing, if it is at 'home', I can go and tell them 'that banana over there...' even if it is has not ripen properly, I tell them 'cut it so that we can eat' (VM018).

However, some respondents felt rural areas as opposed to urban were more challenging for instance due to landlessness or scarcity of land. One caregiver said *"if you do not have a farm, you will have problems similar to the ones here* (KF025)." Disparity in rural areas with some areas not easily habitable due to harsh climatic conditions was another factor pointed out by those who favoured urban to rural areas. Therefore, these caregivers felt the cost of food in urban areas to be relatively cheaper with better access to a variety of foodstuffs as expressed in the excerpts below.

> Even here, for food, you can see that we have a market right here, you can easily get vegetables here and you prepare for your patient very quickly. But there it is very (stressing) difficult to get, you see? (KF020)
>
> Here in Nairobi they can say they have problems but they can walk around and get food for 5 shillings, 10, and he is able to eat but back home (exclaims), he will just be in pain waiting for the wife to return from the farm (laughter) to come and prepare him something to put here (pointing to the stomach), and they have spent the whole day in the farm, and what is produced from the farm he might not have. So the problems are mostly back home (KM028).

The cash-based economy in urban areas, where payment is required on demand for almost all basic utilities such as water and toilet facilities, makes care-giving in the city

more expensive compared with rural areas. Access to adequate water for domestic use was deemed more difficult especially when the care recipient is bed-ridden and requires assistance with Activities of Daily Living (ADL) such as bathing and washing. Such views are articulated in the responses below.

> They are different. In Nairobi it is easier and faster to get a sick person to hospital for treatment. In rural area health facilities are far and it takes some time to get to a health facility. In rural area you don't depend on jobs...people have land where they plant crops so food is available. But in Nairobi all food stuffs are bought and if you don't have money to buy, you will not have food. Here everything is money (VF010).

> *Respondent*: Here there are a lot of problems it is not like the rural areas.
> *Interviewer*: Why?
> *Respondent*: You know when someone is at 'home'... here you cannot get free things, but there someone can just give you things like maize, beans, but in Nairobi, no one can give you such things...The other problem is where to stay, here it is a rental house and probably that one at home is staying in her own house. You know here in Nairobi, we do not have [own] houses, they are for rental and you may not be able to pay the rent. 'So there is a very big difference' (KF024).

The type of housing in the slum and lack of access to toilet facilities also pose challenges to those who are providing care. Households without access to their own toilet facility have to pay per visit and the costs may be increased by having a sick person in the household with greater than usual need to use the toilet. Accessing toilet facilities at night is also difficult due to poor lighting and distance to the toilets which are normally located far away and at the edge of the slum. Insecurity in the slum also contributes to the challenges of care-giving especially during the night sometimes limiting the contact and the amount of care that the caregiver provides specifically to the care recipients living in other households or different structures from the caregiver. The following two excerpts express these challenges of care-giving in a slum setting.

> *Interviewer*: What about at night? Didn't he have any needs at night?
> *Respondent*: He had some at night. He needed to go to the toilet and I have to take him there so that he doesn't fall inside there. And the toilet is also far. It is outside and you have to pay two shillings for it. It was locked at night, so he really needed the toilet... That problem of the toilet is the one I had (VM015).

> There is a difference because the estate (non-slum residential areas) is not like here. The estate is better off. This place has a lot of problems. Sometimes you could not even go out at seven. Yet when I have to see the ill person at night, I have to request my son to take me [there] (KF027).

The rudimentary materials used for housing can worsen the condition of the care recipient because of the inability and the costs of trying to keep the house warm. The caregivers have to incur additional costs from buying charcoal or kerosene in order to heat up the houses. The small size of most dwelling units and the limited space can be a source of constraint to care-giving as some caregivers are forced to live in a different house from the care recipient.

> It would have been different because ... for example the toilet here... you need to pay to use the toilet, you need to pay for water but if you were at 'home' you would have your traditional toilet and for water, you will just be fetching it in the river, you see? Here we live in houses made of iron sheets... but if you were at home you would just light a fire easily but here you need to have a charcoal stove or a kerosene stove. So we are not able to keep the house warm. ... even the toilet... you see, if you are to remove the 2 shillings every time... and such a child needs to go to the toilet every now and then (VM019).
>
> *Interviewer*: you also said it is different for those in rural areas?
> *Respondent*: Yes because they have food, they have people to stay with, they can even take care of a sick person for more than 10 years and the person does not die quickly. The person can even be taken outside to bask in the sun, you know they feel cold sometimes. The most important is food because having a full stomach is really important (KF031).

Older people who are providing care in the urban areas do not have a wide choice of people who can assist the caregiver due to the small family or household sizes. This is in contrast to rural areas where family members live in close proximity to each other and hence are more likely to give a hand at times of need. Neighbours, for example, in rural areas may also be willing to help because they may have the ability to do so unlike in the slums where people are more hard pressed by their personal needs.

> *Interviewer*: Okay. You live here in Nairobi and you have a patient. Do you think the problems you are undergoing here are the same as those back 'home' or they different?
> *Respondent*: There is a difference. Back home this old man who has a patient will have people, neighbours, his parents, his grandparents, uncles, in-laws, everyone will come together to assist him on that task and sometimes he will find his patient has been cared for in his absence, he can leave and go somewhere else and his patient will be taken care of, even given a bathe (KF023).

Some older people who view HIV/AIDS as an urban problem pointed out that the slums have a higher prevalence rate and also higher mortality unlike the rural or non-slum areas. The level of poverty in the slum prohibits access to better healthcare and also contributes to the HIV problem in the slums.

Interviewer: What about those living in the rural areas? Is there a difference?
Respondent: There is a difference because in the rural areas, there are not very many ways of spreading this disease. And people in rural areas do not usually engage in immoral behaviour and things like that. So in rural areas, the ones who are sick are the ones who have brought this disease from here and taken it there. Some people from the rural areas....
Interviewer: The ones in the rural areas, do they have the same problems like the ones who are here and they are taking care of people who are sick for long?
Respondent: The ones in the reserve do not have a lot of problems like the ones who are here. You know in the reserve, people live like a family, you see?
Interviewer: Yes.
Respondent: But here, we do not live like a family. In the reserve you are like a family. You find that the one who has built next to you is your brother, another one is an uncle... but here, you find that you do not even know the person who is your next door neighbour (VM013).

Overall, the caregivers highlighted more disadvantages than advantages of living in an urban area and caring for someone ill with the majority favouring the rural areas. The decision, however, of choosing between taking care of someone in the slum or going to the rural areas may not be an option for these caregivers as the urban slum may be the only 'home' available to them.

6.8 Summary and discussion

Older people not only provide care for their own biological children who get infected but the care extends to other relatives and non-relatives. The extended family system is crucial especially in resource-poor settings as they act as a safety net in the absence of public-sector support in the event of shocks such as severe illness. Older people by virtue of their age, usually hold the helm of the extended family with the accompanying responsibility of providing not only leadership roles, but care and support to members of the family who become ill due to HIV/AIDS. Adults in the reproductive age of 15 – 49 years form the majority of care recipients. However, the presence of older people among those in receipt of care, albeit small, draws attention to a new dimension to the epidemic where older people have been viewed largely as a group affected and not infected by HIV/AIDS. Despite the fact that older people continue to play the role of caregivers for persons ill due to HIV/AIDS, a role which they consider integral and their responsibility as heads of families, infection among this age group is also a reality.

While the proportion of older people who are providing care to people with HIV/AIDS may appear small relative to the population of older people, caregivers are likely to have multiple experiences of care-giving due to the mode of HIV transmission. Heterosexual

intercourse and vertical transmission from mother-to-child are the main routes of transmission of HIV in sub-Saharan Africa. This, therefore, increase the likelihood of an older person providing care to multiple cases over a short period of time because of the chances of caring for both partners in a marital union or, mother and child.

HIV caregivers may provide care to someone living outside the DSA usually in the rural areas due to split migration, a common feature of rural-urban migration in sub-Saharan Africa, where one part of the household migrates to the urban areas with the other half remaining in the rural areas. PLWHA in need of care do migrate to the city either permanently or on routine basis especially due to the concentration of healthcare facilities and HIV/AIDS services in Nairobi. The caregiver also does maintain contact and continue providing care through sending remittance and making routine visits outside the DSA. This type of arrangement is more prevalent in Viwandani compared to Korogocho a relatively more-established slum.

Caregivers' willingness to provide care supersedes their individual comfort and welfare. Whereas there has been improvement in access and continuum of care and support services for PLWHA in Kenya, households and caregivers strive to provide quality of care to the best of their ability in order to increase the survival and healthy life expectancy for PLWHA. This is bound to increase the social and economic burden of care-giving and thus impact on the wellbeing of the caregiver. In addition, HIV caregivers live in larger households and are also more likely to live with children aged below 15 years. Most of the HIV caregivers reported that they provided care not only to the care recipients but to the care recipients' dependants also. The children continue to live with the HIV caregiver after caring for their ailing parents or relocate from elsewhere following the death or illness of their parent(s) or guardians. This, therefore, may explain why HIV caregivers live in comparatively larger size households than other caregivers or those who have not provided care. Larger households have implications on intra-household resource allocation which is usually detrimental to vulnerable household members while a large number of children in the household implies a large dependency ratio. The next chapter therefore, examines the association between care-giving to someone with HIV-related illness and the socio-economic status.

CHAPTER SEVEN

7 SOCIO-ECONOMIC DIFFERENTIAL BETWEEN HIV CAREGIVERS, OTHER CAREGIVERS AND NON-CAREGIVERS

7.1 Introduction

Care-giving to someone with a chronic illness results in additional financial costs on the caregiver which can lead to negative economic consequences. Direct costs arise from expenditure on goods and services relating to care and indirect costs are associated with income forfeited by the care recipient or the caregiver through loss of employment or reduced productivity causing financial strain on the caregiver (Bachmann and Booysen, 2003; Barnett and Whiteside, 2002; Bechu, 1998; Kongsin, 2005; Naidu and Harris, 2005). This chapter seeks to investigate the association between care-giving to someone with a HIV-related illness and the socio-economic status of their caregiver. Prior to comparing the different groups based on their socio-economic status, a discussion of the indicators used to measure socio-economic status is first presented.

7.2 Measurement of socio-economic status

Commonly used indicators to measure socio-economic status are income, expenditure, ownership of assets, occupation, and other dimensions such as education attainment. The indicators can also be measured in absolute or relative terms (Falkingham and Namazie, 2002). The choice of indicators to use is influenced by various factors such as the availability of data or the practicality associated with collecting the relevant information. Other factors to take into consideration are the validity and reliability of the measure especially its applicability to the population being studied and comparability of the measure across different settings. Differentiating between households or individuals according to economic status and welfare in resource-poor settings such as slums where the entire population is living in absolute poverty can be challenging.

The standard money-metric measures, (income and expenditure) and non-monetary measures (Wealth index and Participatory Wealth Ranking) are used in this chapter to compare the economic wellbeing of HIV caregivers with other caregivers and those older people who have not provided care. These measures are used to complement each other taking into account the limitations and strengths of each method (Filmer and

Pritchett, 2001; Gwatkin, 2003; Montgomery et al, 2000; Morris et al, 2000; Prakongsai, 2006). The indicators are discussed below.

7.2.1 Socio-economic indicators

Wealth or asset index

Asset or wealth index, a proxy for measuring welfare, has increasingly been applied to assess socio-economic status either as an alternative or substitute to money-metric measures or especially in the absence of income or expenditure data (Montgomery et al, 2000). The use of the indicator as a measure of socio-economic status has been advanced by ORC Macro to evaluate inequity in health status using the Demographic and Health Survey (DHS) data (Falkingham and Namazie, 2002; Rutstein and Johnson, 2004). The wealth index has increasing appeal since it requires a minimum amount of data to compute, the variables used are easy to collect, less time consuming and subject to less reporting bias compared with money-metric measures. It is also less sensitive to fluctuations over a relatively short period (Filmer and Pritchett, 2001; Gwatkin, 2003; Prakongsai, 2006; Sahn and Stifel, 2003).

The index is computed using a set of indicator variables that reflect economic status more notably ownership of durable assets, characteristics of housing and access to or use of various utility items. The assumption being, the higher the monetary value of a particular asset the less likely a household or individual will own it (Gwatkin, 2003; Nandy, 2008). The choice of the assets or indicator variables to use is context specific but should be as comprehensive as possible to allow for better differentiation and avoid a disproportionate share of households or individuals concentrated within a particular index (Gwatkin, 2003; Morris et al, 2000; Nandy, 2008).

Various methods have been used to derive the weights that reflect the relative importance or value of the different indicator variables. One way is to assign weights manually or arbitrarily relying on the subjective knowledge of the researcher. The other most widely used and preferred method is the use of statistical techniques to assign weights and compute the scores or the index. Using statistical techniques is preferred as it allows comparison over time and across different studies. This is also the preferred method in studies where data on the value of the assets are not collected due to difficulty in assessing the quality of the item or assigning the actual market value (Filmer and Pritchett, 2001; Nandy, 2008; Prakongsai, 2006).

Computation of the wealth index

The wealth index used here was computed at the household level as most of the variables collected had the household as the reference unit. The indicator variables are classified into three broad categories: housing quality (materials used for flooring and walls); utility items (type of toilet, water source, source of lighting, cooking fuel); and household durable assets (19 items). The other indicator variable included was place where the household usually does its cooking. Assets owned by less than 1% of the population (vehicle, motorcycle, refrigerator, fan and electric stove) and the type of roof where 99% of the households had the same material used for roofing were excluded from the initial variable selection.

Principal components analysis (PCA) is used to derive the wealth index for each household. PCA simplify or reduce a matrix combination of many correlated variables into a smaller new set of uncorrelated variables or principal components (PC). The first PC which is used to derive the index, summarises the largest amount of information common to all the variables (Manly, 2005). The best fit model in computing the index followed an elimination process of variables that least accounts for the variance of the first PC while increasing the percent of total variance explained. As the total number of indicator variables included in the analysis reduces, the percent of total variance explained by the first PC increases while the total number of principal components extracted (Engenvalues greater than 1) also reduces. The model selected for analysis (PCA 4) has the first principal component explaining 31% of the variance of the 26 indicator variables used (Appendix 5). Overall, the distribution of the index is highly positively skewed as shown by the box and whisker plots in Appendix 6. The distribution also becomes more skewed as fewer indicator variables are included in the analysis. Although the PCA assumption that the observed variables are normally distributed is not met (Statacorp, 2007), the variables used have the expected correlation. There is a very high positive correlation between the various durable items. For instance, sharing a toilet with other households is also negatively associated with ownership of durable assets while the inverse is true, that is, having own toilet is positively associated with owning durable assets. Having a floor made of natural earth and walls made of mud or plastic sheets are also negatively correlated with ownership of durable assets.

Table 7.1 presents the factor scores for each of the indicator variables used to compute the wealth index. Having electronic equipments, for instance television (0.99), DVD recorder (1.10), iron (1.05), a phone (0.84), and radio (0.79) are important in accounting for a higher wealth index. Conversely, having a floor made of natural earth or having mud or plastic walls have negative scores thus reducing the overall index. In order to interpret the index, the individuals were divided into 3 equal sized groups of very poor, less poor and least poor. Dividing the individuals into four or five equal sized groups is not feasible since the index is highly skewed. To assess the reliability of the index in classifying the individuals according to their welfare status (Filmer and Pritchett, 2001), the indicator variables are compared across the three groups: very poor, less poor and least poor in Table 7.1.

An internally coherent index should differentiate the population based on the factor scores, that is, the least poor individuals should have indicator variables with higher scores and the converse should be true for very poor individuals. Noticeably, ownership of durable assets is only concentrated in the least poor group. Computation of the index was done at the household level and given that the analysis for this study is done at the individual level, therefore, each older person was assigned their respective household index.

Table 7.1: Factor scores, percentage distribution of indicator variables for total population by wealth grouping

Indicator variables	% own	Scoring factor	Wealth groupings		
			Very poor	Less poor	Least Poor
Television	4.3	0.988	0.000	0.000	1.000
Radio	17.4	0.795	0.000	0.000	1.000
DVD recorder	1.2	1.105	0.000	0.000	1.000
Sewing machine	0.8	1.008	0.000	0.000	1.000
Iron	1.0	1.056	0.000	0.000	1.000
Phone	6.9	0.842	0.000	0.000	1.000
Sofa	12.5	0.828	0.000	0.000	1.000
Table	21.9	0.766	0.000	0.000	1.000
Torch	11.7	0.822	0.000	0.000	1.000
Lamp	14.4	0.795	0.000	0.000	1.000
Kerosene stove	19.0	0.779	0.000	0.000	1.000
Wall clock	7.8	0.872	0.000	0.000	1.000
Mattress	24.0	0.744	0.000	0.000	1.000
Blankets	24.3	0.740	0.000	0.000	1.000
Bed	24.0	0.741	0.000	0.000	1.000
Cows	19.5	0.129	0.000	0.286	0.714
Goats	21.2	0.100	0.036	0.345	0.618
Chicken	26.0	0.113	0.062	0.347	0.592
Other livestock	31.8	0.114	0.076	0.386	0.538
Kerosene or charcoal for cooking	97.5	-0.063	0.351	0.321	0.328
Gas or electricity for cooking	1.5	0.109	0.000	0.435	0.565
Natural floor	41.3	-0.103	0.612	0.150	0.238
Cemented, PVC or wooden floor	58.6	0.101	0.156	0.446	0.398
Mud, tin or plastic walls	47.3	-0.058	0.618	0.108	0.274
Mud walls plastered with cement	16.7	0.050	0.026	0.620	0.353
Brick or wooden walls	36.0	0.033	0.133	0.468	0.399

Source: Author's analysis of Household Amenities and Livelihood Data File, 2006

Income and expenditure

Income allows people to obtain goods and services and expenditure refers to resources actually consumed. Therefore, higher levels of income or expenditure are a reflection of higher socio-economic position (Morris et al, 2000; Prakongsai, 2006). Income and expenditure data are difficult to obtain due to the need to collect detailed information in order to capture accurate estimates. Income is subject to seasonal fluctuation especially in developing countries where most people are either self-employed or in informal employment and rely on multiple and constantly changing sources of income (Montgomery et al, 2000; Morris et al, 2000; Prakongsai, 2006). There is also a tendency for people to conceal financial data (Nandy, 2008; Sahn and Stifel, 2003).

Expenditure data is often preferred to income because of the difficulty in collection income relative to expenditure (Filmer and Pritchett, 2001; Sahn and Stifel, 2003). Households or individuals also tend to smooth out expenditure over time as a mechanism to allow for variability or seasonality in income hence, making expenditure less subject to fluctuation compared to income. In addition, collection of expenditure data in developing countries is much easier unlike in developed countries where consumptions patterns are highly complex (Deaton, 1997).

In this study, information on income and expenditure was collected at household level and referred to the total earnings and expenses incurred in the 30 days preceding the interview. A shorter recall period means that respondents will provide better estimates for each of the expense items as opposed to longer periods where certain purchases may not be included. In this regards, expenditure estimates tends to be larger for shorter compared with longer reference periods. The same is true for information on income. Hence, the 30-day reference period was selected to minimise measurement errors associated with recall questions. This, however, introduces a limitation as the reference month's income or expenditure may not be indicative of average income or expenditure.

In order to collect comprehensive or better estimates for income and expenditure, during data collection the questions were disaggregated into different components as opposed to aggregate totals. Therefore, income included both primary and secondary sources namely income from savings, borrowing, agriculture, and monetary or non-monetary transfers to the household. Income from each adult household member was also included. The various sources of income were summed up to compute the average monthly income for the household. Expenditure covered both food and non-food major items expended by the household. The reference period varied depending on frequency of purchase. For instance, monthly estimates were collected for items such as rent and electricity usually paid for on monthly basis whereas weekly estimates were collected for food, cooking fuel, water and transport costs. All the expenses were totalled up to compute the average monthly expenditure for the household. At the analysis stage, per capita monthly income and expenditure was computed and each older person was assigned the household's value.

Participatory wealth ranking (PWR)

Participatory assessment of socio-economic status is a method whereby respondents or community members themselves define the wealth status of households in their community using local reference group to rate the relative status of theirs or other households in their community. PWR is therefore a subjective method where individuals evaluate economic status based on their own local perspectives or understanding of poverty and wellbeing taking into account multiple dimensions, and participants' knowledge and familiarity with their welfare or quality of life relative to others in the local community (Adams et al, 1997; Feulefack and Zeller, 2005). PWR is a comparatively new approach to measuring socio-economic status unlike other standard measurements despite the extensive application of participatory techniques in development research. Use of participatory approaches has not received extensive recognition and validation to determine its effectiveness (Feulefack and Zeller, 2005; Hargreaves et al, 2007) although findings from a few studies point to comparability with standard socio-economic measurements in achieving desired outcomes (Hargreaves et al, 2007; Kebede, 2005).

Various techniques for instance, participatory mapping, pile sorting, matrix ranking and scoring, are applied to stratify or rank the households or individuals (Falkingham and Namazie, 2002; Hargreaves et al, 2007). One approach for ranking households involves focus groups or group discussions with a selection of key informants or persons knowledgeable about the community. The groups first discuss the local meanings of poverty or wealth and then using maps and score cards and a set of pre-determined criteria assign scores to households in the community. The final scores are derived from averages from different groups ranking the same households (Adams et al, 1997; Hargreaves et al, 2007; Hargreaves et al, 2007). Another approach, also used in this study, involves visual aids and self-assessment by individuals with reference to others in the community. The approach used is called 'Ladder-of-life' (Cantril, 1965) where the respondent is shown a picture of a ladder with 10 steps and asked the following question:

> "Now, I would like you to tell me how your household compares with other households in this community with respect to the general wellbeing. If all households in the community were placed on a ladder from ONE to TEN where the richest is on number TEN and the poorest on number ONE, where would you place your household?"

This was therefore a quick way of assessing the participants' evaluation of their socio-economic status, however, the criteria used by the individuals or the basis of determining wealth or wellbeing was not explored. The older people were divided into three groups. Majoirty of the respondents tended to place themselves in the middle 'steps' of the ladder.

Other socio-economic indicators used

In order to offset unexpected expenditure or cater for income deficits, households or individuals may sell durable goods and other assets as a coping strategy. Therefore, the sale of household assets is another indicator that was used to compare respondents. Information on assets is drawn from a list of 21 items made up of electronic goods, household furniture and utility items read out to respondents asking whether the household had sold the item in the past year. The question captures assets owned by the household not only in their current place of residence but includes assets in other locations such as rural homes. Assets owned in other locations were included because the majority of urban residents usually maintain close ties and investments with a rural home as an insurance in the event of shocks such as unemployment and also to maximise benefits associated with both settings (Agesa, 2004).

7.2.2 Comparison of the main socio-economic indicators

The four indicators; wealth index, PWR, income, and expenditure are compared to assess how these indicators are related. The objective of the comparison is not to determine the superior measure out of the four indicators since the indicators reflect and measure different aspects of wellbeing. Rather, it is meant to assess if the ranking of individuals based on the four indicators is consistent. The comparison is done by first grouping the individuals into approximately three equal bands namely: very poor, less poor and least poor for each indicator. The three bands of individuals based on each indicator are then compared using a pairwise cross-classification as presented in Table 7.2.

The idea is that if all individuals were classified in the same category for the paired measures, only the shaded cells would be filled with the rest having zero and the percentage of individuals in identical ranking would sum up to 100%. A similar percentage of individuals are cross-classified in the same ranking across almost all the paired indicators with the exception of income and expenditure where two thirds (65%)

of the individuals were in the same ranking. The other method used to compare the indicators is spearman's rank correlation coefficient to test the degree to which the 4 indicators produce the same ranking. The association between the 4 indicators show the expected positive correlation. Wealth index is however weakly correlated with income, expenditure or PWR. Other studies (Filmer and Pritchett, 2001; Sahn and Stifel, 2003) have also reported weak correlation between wealth index and money-metric measures especially in poorer countries. The weak correlation between the methods could point to each method reflecting different aspects of household wealth or wellbeing with wealth index indicating a balance between income and expenditure over a long period (Filmer and Pritchett, 2001; Montgomery et al, 2000; Prakongsai, 2006). Despite the weak correlation, however, the wealth index is thought to be a reliable measure similar to standard money-metric measures in predicting health or other outcomes such as education (Filmer and Pritchett, 2001; Gwatkin, 2003).

Table 7.2: Cross-classification and correlation of wealth index, income, expenditure and participatory wealth ranking

	Very poor	Less poor	Least poor	Percent in identical ranking	Correlation coefficient	*N*
	Per capita income					
Wealth index						
Very poor	14.4	12.8	8.0			*528*
Less poor	11.4	9.8	10.6			*475*
Least poor	8.3	11.0	13.7	38.0	0.19	*493*
	Per capita expenditure					
Wealth index						
Very poor	14.3	12.2	8.2			*540*
Less poor	10.9	10.7	10.7			*503*
Least poor	8.2	10.5	14.3	39.4	0.19	*513*
	Participatory wealth ranking					
Wealth index						
Very poor	10.3	17.8	6.5			*544*
Less poor	6.5	16.4	9.4			*509*
Least poor	6.5	16.6	10.1	36.7	0.16	*523*
	Per capita income					
Participatory wealth ranking						
Very poor	10.5	8.0	4.2			*340*
Less poor	17.8	17.3	16.3			*769*
Least poor	5.8	8.3	11.8	39.6	0.24	*387*
	Per capita expenditure					
Participatory wealth ranking						
Very poor	9.3	7.5	6.3			*360*
Less poor	17.4	17.4	16.3			*795*
Least poor	6.8	8.5	10.5	37.3	0.12	*401*
	Per capita income					
Per capita expenditure						
Very poor	24.7	7.8	0.7			*495*
Less poor	8.1	16.7	8.4			*497*
Least poor	1.3	9.2	23.2	64.6	0.76	*502*

Source: Author's analysis of Household Amenities and Livelihood Data File, 2006

Income and expenditure are highly positively correlated. The distribution for both measures is also positively skewed as depicted graphically using histograms and box and whisker plots in Figures 7.1 and 7.2 and the summary statistics in Table 7.3. With the exception of outliers, a small inter-quartile range indicates little variability for the distribution of both income and expenditure. The amount of income earned usually differs with the expenditure due to the tendency of households to smooth out

expenditure as an insurance against fluctuation and seasonality of income (Deaton, 1997). Evidently, average expenditure is lower than income with three quarters of the respondents reporting higher incomes compared with expenditure.

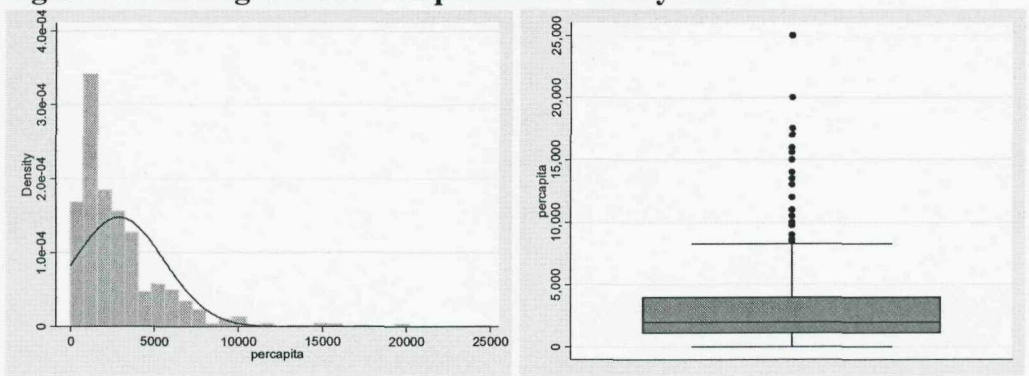
Table 7.3: Summary statistics for income and expenditure (KSHS)

Statistic	Per capita income[1]	Per capita expenditure[1]
Mean	2,893.39	2,017.07
Median	2,000.00	1,334.00
Standard deviation	2,695.63	2,220.78
Inter-quartile range	2,910.00	1,578.00
Skewness	2.58	3.86
Kurtosis	13.63	25.06
N	*1,556*	

[1] GBP (£) was equivalent to 133 – 137 Kenya shillings at the time of the survey

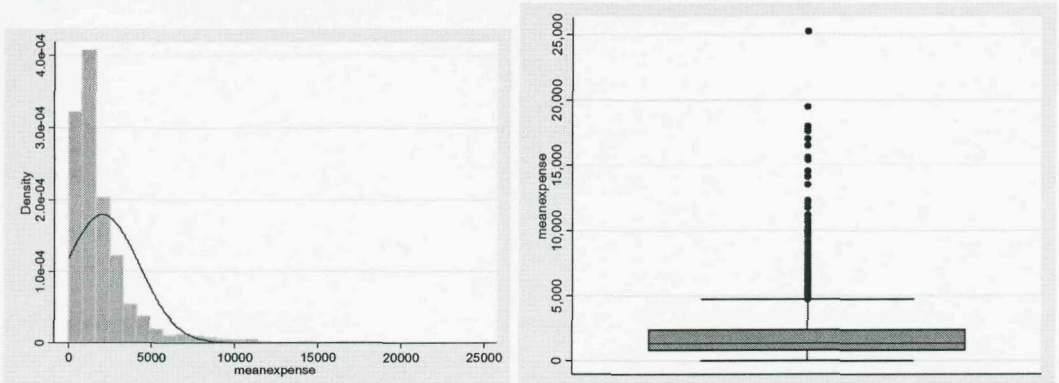
Source: Author's analysis of Household Amenities and Livelihood Data File, 2006

Figure 7.1: Histogram and box plots for monthly income



Source: Author's analysis of Household Amenities and Livelihood Data File, 2006

Figure 7.2: Histogram and box plots for monthly expenditure



Source: Author's analysis of Household Amenities and Livelihood Data File, 2006

Overall, all the indicators show the expected positive correlation and are hence consistent in measuring socio-economic status. The next section compares older people

who are HIV caregivers with other caregivers and non-caregivers based on the indicators discussed above.

7.3 Results on socio-economic differentials

7.3.1 Differentiation based on non-metric measures of wealth

The three groups of older people are compared based on wealth index, a marker of the households' welfare over a longer period of time (Falkingham and Namazie, 2002) and based on participatory wealth ranking (PWR) in Table 7.4. The population is divided into approximately three equal groups. Both indicators rank older people who are providing care, irrespective of the illness, to be better off compared with non-caregivers. For example, a higher proportion of non-caregivers (35%) were in households ranked in the bottom based on the wealth index compared to HIV caregivers (28%) and other caregivers (26%). Conversely, only 33% of non-caregivers were ranked in the top category compared with 37% of HIV caregivers and 39% of other caregivers. A similar pattern also emerged with how their households ranked on the PWR indicator. Only a quarter of non-caregivers were in households ranked among the top unlike a third of other caregivers (33%) and more than a third of HIV caregivers (36%).

Table 7.4: Comparison of wealth index and participatory wealth ranking by care-giving status

	HIV caregivers	**Other caregivers**	**Non caregivers**	Total	*N*
Wealth index (%)					
Bottom	27.8	25.6	35.4	34.5	*544*
Middle	34.7	34.9	32.0	32.3	*509*
Top	37.5	39.5	32.6	33.2	*523*
Participatory wealth ranking (%)					
1- 2	22.2	25.6	23.2	23.3	*367*
3	19.4	24.4	28.4	27.8	*438*
4	22.2	17.4	23.3	23.0	*362*
5 – 10	36.1	32.6	25.0	26.0	*409*
Total	100	100	100	100	
N	*72*	*86*	*1,418*	*1,576*	

Source: Author's analysis of Household Amenities and Livelihood Data File, 2006

Care-giving to someone with a chronic illness requires fairly enormous financial resources to cope with the responsibility. Care-giving, therefore, may be selective of those willing and with the ability to meet the financial demands of care. The fact that

older people who are providing care are sought out by the care recipients due to their resource or financial ability as indicated in the previous chapter (Chapter 6) is a pointer to the differences in wealth status between HIV caregivers, other caregivers and non-caregivers. The care-recipients may therefore be migrating from a relatively poorer to a non-poor household.

The family and kinship relations which forms the extended family network characteristic of African societies provide valuable support where members share responsibility in absorbing shocks experienced by its members. Relatively well-off family members usually share their resources with those undergoing stress by providing direct support including supporting multiple extended family members. Those in need, therefore, rely on relatives who are capable of accommodating their needs. The extended family network therefore continues to be pivotal in spite of changes in social and cultural contexts for instance urbanization on which it operates (Ankrah, 1993).

7.3.2 Differentiation based on income and expenditure

Care-giving to someone ill affects household income directly through losses resulting from non-participation in income generating activities by either the caregiver or by the care recipient. This sequentially impacts on household expenditure or consumption. Conversely, care-giving imposes additional expenses through for instance increase in the number of dependants or extra healthcare costs. Summary statistics on income and expenditure comparing HIV caregivers, other caregivers and non-caregivers is presented in Table 7.5.

In aggregate terms, households with HIV caregivers had higher average income and expenditure compared with other caregivers and non-caregivers. The average monthly income for HIV caregivers was approximately Ksh2,000 (GBP 15) higher than the income for households with other caregivers and also for non-caregivers. Similarly, the average expenditure was slightly higher for HIV caregivers compared to the comparison groups. In view of the fact that HIV caregivers are in larger households, the differences in aggregate income and expenditure almost disappears when per capita equivalence is factored in (Table 7.5). Thus, average per capita income and expenditure is higher for other caregivers compared with HIV caregivers and non-caregivers. Whereas larger households can still enjoy similar or better standards of wellbeing compared with smaller ones with similar per capita income or expenditure due to economies of scale, a

large household imposes a strain on its resources which have to be shared between the large number of people especially if the majority of the members are economically inactive. While the present analysis does not take into account inequality and inequity in intra-household allocation of resources, nonetheless, in households which are providing care to someone ill with HIV/AIDS, it's highly likely to devote a substantial proportion of resources in favour of the ill person. Intra-household distribution can therefore be to the detriment of other members of the household such as older people.

Table 7.5: Comparison of aggregate and per capita income and expenditure by care-giving status (Kenya shilling)

Income and expenditure statistic[1]	HIV caregivers	Other-caregivers	Non-caregivers	Total
Aggregate income				
Mean	8,442.86	6,778.46	6,568.76	6,667.06
Median	6,000.00	6,000.00	5,700.00	6,000.00
Range	45,000.00	18,000.00	32,000.00	45,000.00
Inter-quartile range	5,000.00	5,000.00	4,000.00	4,000.00
Per capita income				
Mean	3,006.01	3,189.74	2,870.40	2,893.39
Median	1,916.50	2,400.00	2,000.00	2,000.00
Range	16,000.00	17,500.00	25,000.00	25,000.00
Inter-quartile range	3,100.00	3,000.00	2,875.00	2,910.00
Aggregate expenditure				
Mean	5,647.40	5,362.32	4,627.69	4,714.20
Median	4,261.25	4,112.50	3,677.50	3,750.00
Range	22,435.00	25,800.00	37,385.00	37,385.00
Inter-quartile range	3,787.50	3,985.00	3,197.50	3,275.00
Per capita expenditure				
Mean	2,147.85	2,537.62	1,979.11	2,017.07
Median	1,293.00	1,737.00	1,312.00	1,334.00
Range	14,305.00	17,820.00	25,250.00	25,250.00
Inter-quartile range	1,938.00	1,907.50	1,543.00	1,578.00
Mean household size	3.85	2.98	3.27	3.28
N	*72*	*86*	*1,418*	*1,575*

[1] GBP (£) was equivalent to 133 – 137 KSH at the time of the survey

Source: Author's analysis of Household Amenities and Livelihood Data File, 2006

To determine the association between care-giving to someone with HIV/AIDS and income and expenditure, multiple linear regression models controlling for other explanatory factors were performed. To make up for the positively skewed distribution

of income and expenditure, a logarithmic transformation was carried out to normalise the distribution. The results of multiple regression showing the regression coefficients, standard errors and significance levels are presented in Table 7.6 and 7.7 for per capita income and expenditure respectively.

Table 7.6: Multiple linear regression model of log of per capita income

	Coefficient (standard error)	t-statistic	P-value significance
Gender			
Women (Ref)			
Men	0.171 (0.041)	4.20	***
Level of education			
No education (Ref)			
Primary	0.109 (0.041)	2.67	***
Secondary or higher	0.232 (0.060)	3.84	***
Work status			
Formal employment (Ref)			
Not working	-0.152 (0.086)	-1.76	NS
Informal employment	-0.148 (0.054)	-2.74	**
Runs own business	-0.161 (0.058)	-2.79	**
No of adults in working age-group (15-49 years)	0.028 (0.021)	1.32	NS
Mean household size	-0.205 (0.012)	-17.45	***
Care-giving status			
Non-caregivers (Ref)			
Other caregivers	0.072 (0.078)	0.92	NS
HIV caregivers	0.096 (0.083)	1.16	NS
Constant	8.265 (0.066)	124.39	
Adjusted R^2	0.42		
No. of cases	1,429		

Significance levels * <0.001; **<0.01, *<0.05, NS – Not significant**
Source: Author's analysis of Household Amenities and Livelihood Data File, 2006

Table 7.7: Multiple linear regression model of log of per capita expenditure

Independent variables	Coefficient (standard error)	t-statistic	P-value significance
Gender			
Women (Ref)			
Men	0.097 (0.039)	2.49	*
Level of education			
No education (Ref)			
Primary	0.078 (0.039)	2.00	*
Secondary or higher	0.159 (0.058)	2.75	***
Work status			
Formal employment (Ref)			
Not working	-0.392 (0.082)	-4.82	***
Informal employment	-0.225 (0.051)	-4.46	***
Runs own business	-0.189 (0.055)	-3.51	***
No of adults in working age-group (15-49 years)	0.011 (0.020)	0.57	NS
Mean household size	-0.184 (0.011)	-16.41	***
Care-giving status			
Non-caregivers (Ref)			
Other caregivers	0.125 (0.073)	1.72	NS
HIV caregivers	0.075 (0.079)	0.95	NS
Constant	7.568 (0.063)	125.43	
Adjusted R^2	0.39		
No. of cases	1,506		

Significance levels * <0.001; **<0.01, *<0.05, NS – Not significant**
Source: Author's analysis of Household Amenities and Livelihood Data File, 2006

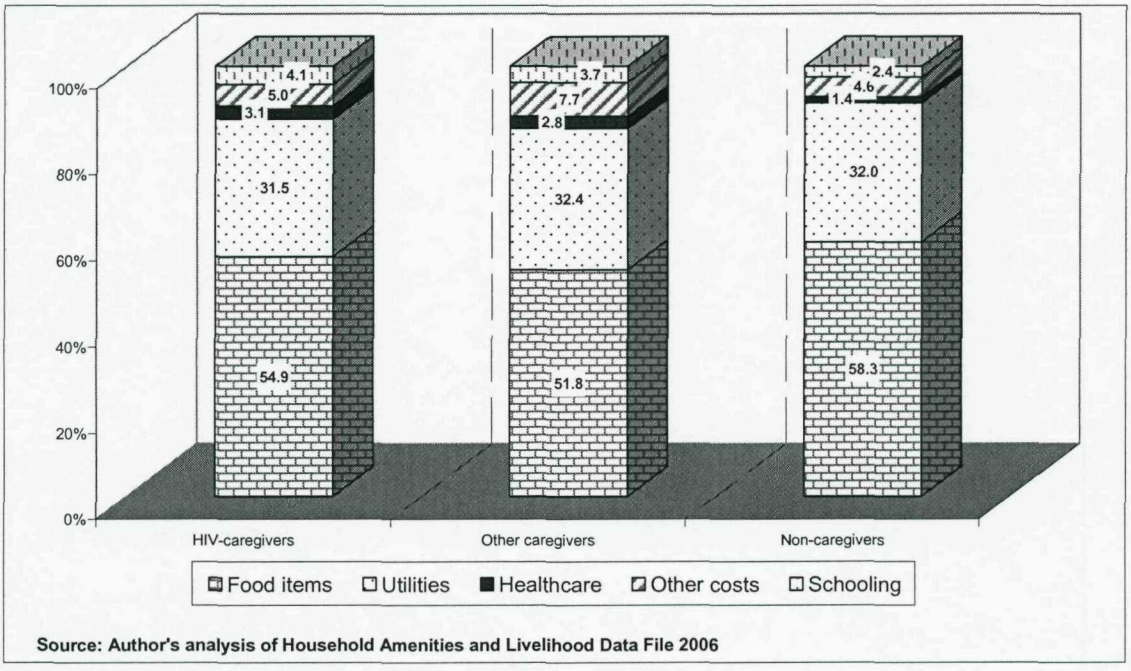
The explanatory variables included in the two models are gender, level of education, type of employment, household size and number of people in the household of working age 15 – 49 years. Controlled for these factors, the differences in income and expenditure between HIV caregivers and other caregivers on the one hand and with non-caregivers was not significant at the 5% level.

Allocation of expenditure account

The percentage of total expenditure allocated to specific items is presented in Figure 7.3 comparing HIV caregivers with the comparison groups. Typical of resource-poor settings where a large portion of expenditure is devoted to essential items specifically food (Pinstrup-Andersen, 1985), more than half of total expenditure is spent on food items and an additional one third is devoted to essential items such as rent, energy for

cooking or lighting and water, across all the three comparison groups. The differences, however, across these groups is that HIV caregivers and other caregivers live in households spending a higher proportion of expenditure budget on scholastic items, health and other miscellaneous items compared with older people who were not providing care. Only the difference in the proportion of expenditure devoted to healthcare between HIV caregivers and non-caregivers was statistically significant. Both HIV caregivers and other caregivers' households spent on average similar proportion of expenditure on scholastic items and on healthcare.

Figure 7.3: Household expenditure comparing HIV caregivers, other caregivers and non-caregivers



Source: Author's analysis of Household Amenities and Livelihood Data File 2006

The similarity in the proportion of expenditure spent on healthcare between HIV caregivers and other caregivers, where on average both spent 3% out of the total budget, may reflect the considerably subsidised healthcare provided by government or NGO hospitals and clinics for HIV/AIDS/TB care. The Kenya government has approximately over the last 5 years gradually increased the amount of financial expenditure allocated to HIV/AIDS through financial support from Global Fund. For instance it increased by 70% between 2000/01 and 2004/2005 financial year with treatment and care comprising more than half of the HIV/AIDS budget (Institute of Policy Analysis & Research, 2004). The number of comprehensive care centres offering management of opportunistic infections and ARTs located in government facilities including sub-district hospitals has also been scaled up (WHO, 2005). Almost all the indepth interview

respondents reported receiving medical aid channelled through community based organizations or directly from government health facilities. The excerpts below provide examples of cases that received medical support from CBOs and government health facilities.

> *Respondent:* The first thing I did was to enrol him with the Catholic doctors. They assisted him a lot. They [Catholic Mission] have doctors who normally visit the sick at home... giving food... and medicine for free. He [the patient] was not paying even a cent (KM001).
>
> *Interviewer:* Okay. What about treatment? Was there any problem?
> *Respondent*: No. He was given medicine for free.
> *Interviewer*: Was he given the medicine free meaning you did not have to buy any?
> *Respondent*: We were told to buy some and he was given some.
> *Interviewer*: Let me ask you, where did he get this treatment from, which hospital?
> *Respondent*: It is from Mbagathi District Hospital [Government hospital] (KF004).

> *Interviewer*: How about financially, how was it taking care of her financially, were you the one buying the medicines?
> *Respondent*: No the medicines were given by the government. The only cost I incurred was paying for the bed occupancy at the hospital. That is all I paid and a little amount for medicines (VM016).

Despite the fact that treatment and care of HIV/AIDS patients has been scaled up in recent past, the delay in diagnosis and treatment by HIV-positive people means that the majority do not benefit from existing medical care and therapies the entire duration of the illness. Most patients seek testing and treatment only at advanced stages of immuno-suppression and disease progression due to delays caused by a range of social, personal and physical barriers to obtaining care.

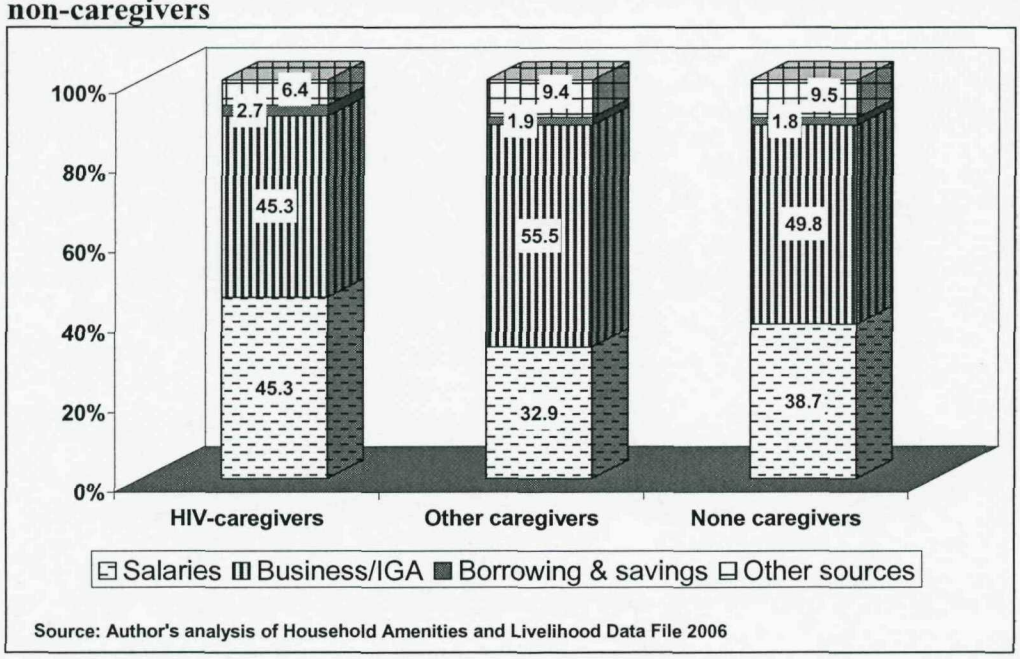
Sources of income

When faced with economic hardships or shocks, households do employ various coping strategies in order to minimise income losses, loss of labour or to cover for unexpected financial costs (Bachmann and Booysen, 2003; Barnett and Whiteside, 2002). The prolonged nature of HIV/AIDS illness and the resulting financial demand and losses, imply that those affected adopt coping strategies to mitigate and absorb the outcome. Such strategies include use of savings, borrowing, and selling of household assets. Nonetheless, these strategies are dependent on the prior wealth of the household (Barnett and Whiteside, 2002; Nkurunziza and Rakodi, 2005). These strategies might

follow a sequence where savings and available cash are used up first before resorting to selling assets or alternatively multiple strategies are used simultaneously (Sauerborn et al, 1996). Figure 7.4 compares the main sources of income for HIV caregivers and the comparison groups.

A large share of income for HIV caregivers comes from salaries and wages (45%) compared with other caregivers (33%) and non-caregivers (39%). This may be a reflection of the dominant type of employment among HIV caregivers where the majority are in formal employment (30%) compared with only 19% of other caregivers and a similar percentage of those who were not providing care. Working in the formal sector implies regular wages and explicit job contracts which provide secure longer-term employment and source of income unlike the informal sector which is largely unprotected nor regulated by labour laws, often offering low and irregular income, and lack legal or social protection. The proportion of income from borrowing and savings was 1% point higher among HIV caregivers compared with the comparison groups. Having access to credit or loans either from formal or informal sources can be an indication of ability to pay and therefore reflecting financial capacity. On the one hand however, indebtedness can have negative consequences if faced with difficulty in servicing the debts or when forced to cut back on spending on essentials items such as food or healthcare.

Figure 7.4: Sources of income comparing HIV caregivers, other caregivers and non-caregivers



HIV caregivers are also compared with the comparison groups on ownership and sale of assets (Table 7.8). The assets are divided into two categories; electronic equipment and, various durable assets that include household furniture and other utilities items. The level of asset ownership is relatively low across all the three groups. Additionally, there was no significant difference between the three groups in terms of ownership or the type of assets owned.

Table 7.8: Percentage distribution of older people owning and selling assets by care-giving status

	HIV caregivers	Other caregivers	Non-caregivers	Total
[§] Owns electronic goods	20.8	25.6	18.2	18.7
[+] Owns other durable items	29.2	29.1	25.6	25.9
Sold assets	4.2	3.5	1.8	2.0
N	*72*	*86*	*1,418*	*1,575*

[§] TV, radio, DVD player, Sewing machine, iron, fan, phone, gas/electric stove
[+] Sofa, table, torch, lamp, kerosene stove, wall clock, mattress, blankets, bed
Source: Author's analysis of Household Amenities and Livelihood Data File 2006

Information on the sale of assets referred to the year preceding the survey. The items reported sold were mainly mobile phones, bicycles and radios. A similar proportion of HIV caregivers and other caregivers sold assets (4%) compared with only 2% of non-

caregivers, although the difference was not statistically significant. Selling of assets as a strategy to cope with financial hardships may not be a viable option for this population since above all, ownership is low and proceeds from the sale of these assets may not be substantial due to low re-sale value (Naidu and Harris, 2005).

7.3.3 Challenges in the labour market

Participation in the labour-market either directly through employment or self-employment in the informal sector is very crucial especially in a cash-based economy associated with urban areas and where labour is a crucial asset in guaranteeing a source of income (Odhiambo and Manda, 2003). In addition, there is a great need among older people to engage in employment due to the absence of pensions and or formal old age support coupled with a declining intergenerational support. Older people are therefore forced to work out of necessity and non-participation in the labour market could be an indication of reduced opportunities in employment rather than the wish to withdraw voluntarily (Lloyd-Sherlock, 2005). Care-giving can be in conflict with labour market participation. Balancing work and care-giving responsibilities can be challenging as the two roles compete for the caregivers' time and energy resulting in disruption of employment (Covinsky et al, 2001) with some studies pointing to women being more affected compared to men (Evandrou and Glaser, 2003). In this study, a higher proportion of HIV caregivers (27%) were not working at the time of interview compared with other caregivers (23%) and non-caregivers (21%). Not working may indicate competing demands with care-giving. The case study below demonstrates the challenges one HIV-caregiver faced resulting in her loss of job and inability to maintain an income generating activity.

Case study: VF019 lives in a 6-member household in Viwandani. She has had multiple experiences of providing care and is currently caring for her 8-year old niece whom she has cared for since the age of one month after caring for both the child's parents who are now deceased. She is responsible for all the child's needs including her schooling and medical expenses. She previously worked as a cleaner/cook at a nearby school but lost the job due to care commitments. Her current caring experience is too demanding as she is forced to remain in the vicinity of the home and the child's school all day long. Her household's main source of income is casual jobs done by her 54 year old husband who however had not secured a steady job for a period of 4 months. Finding jobs for both her and her husband has been difficult. She says *'When my husband goes to look for work he is told that he has exceeded the age limit, "you will disturb the Indians* [who own or run most of the industrial plants]*." Even me, I am told "mum, you have exceeded the age limit"'* When asked to compare her previous care-giving episode and how it has affected her life she points out that *'I see both being similar because I am tied down at home in both experiences. That one made me lose my job, this one... I tried to run a business and I realised I will kill this child very fast so I had better take care of her. So 'it is the same.'* She has therefore not been able to keep both her job and her income generating activity which she started after losing the job. Securing employment in the formal sector has been difficult and she attributes it to her age.

Other studies have also found caregivers to be significantly less likely to participate in the labour market compared with non-caregivers and are forced to make adjustments at work which may include reducing the time allocated to working, taking unanticipated and frequent time-off from work and otherwise withdrawing from employment all together (Stone and Short, 1990; Wakabayashi and Donato, 2005). Scaling down or terminating employment has implications on income and does lead to financial hardships, consequently affecting care-giving ability due to the financial burden associated with care-giving. Re-entry into the labour market can be difficult and sometimes impossible especially for older unskilled workers or those with health problems. The situation is further compounded by macro-economic factors such as very high unemployment rates and saturated labour markets.

The IDI participants highlighted various ways care-giving interferes with employment or income generating activities. They reported that care-giving is time-consuming and require the caregivers' constant and sometimes uninterrupted attention especially when the care recipients' condition is critical as one respondent said; *'I am always around and if I was to go anywhere, I have to be very fast but when they are bedridden I don't*

go anywhere [at all] (VF010)'. The caregivers are also less likely to receive support in the workplace to accommodate their care-giving role. A male caregiver who is a casual worker employed as a security guard said *'If I miss work, my employer will not understand and employers nowadays want you to report to work without fail (VM015).'* Caregivers who have to travel far from the community in search mainly of casual jobs are forced to forfeit the jobs as illustrated below by one participant.

> *Interviewer:* Now, I would like to ask a question about your situation now, I think you have done well to take care of this child but has taking care of this child 'affected' your life in 'general"?
> *Respondent:* It has affected me because I cannot now go for causal work located very far away because I have to be near so that she does not miss her medication. Even now going to certain places, I have to take her with me. .... I cannot even sell vegetables because all my thoughts are devoted to this child to ensure that she is comfortable (VM019).

The financial demands of care-giving can also divert resources or capital meant for income generating sometimes leading to complete collapse of the enterprises.

> *Interviewer:* What are the challenges you faced in caring for your daughter who was living with HIV/AIDS in relation to her special needs?
> *Respondent:* I got many problems because even the small business I had started had to close down. I had started some business of selling vegetables and this could not last. I did not have time to be there and also the money for the stock was spent on treatment. There were also school-going children who were forced to stay away from school, this is one problem. I was also required to go out and look for food for the other children but I could not leave her on her own. I had to look after her (VF017).

The participants also highlighted the challenges that older people face while seeking or in retaining jobs. Discrimination based on age is rampant often sighting older people's low productivity and inability to perform manual duties. The situation of older people is made worse by their lack of or low education attained and lack of up-to-date or competitive skills. They are, therefore, more vulnerable to downsizing and job-cuts in an environment where employment opportunities are shrinking. The poor and deteriorating health status of older people also plays a role in aggravating participation in the labour market. The following excerpts illustrate how age is a factor in securing or sustaining both formal and informal employment.

> *Respondent:* When this son of mine called me at night I thought that if I could get employment so that when illness strikes, I can have money to assist him but now there is no place that can hire me, I cannot be hired anywhere. So there are problems.

Interviewer: so the problem of older people is that they cannot get employment?
Respondent: It is a problem because if I come and ask you if I could wash your clothes, you will have doubts that the clothes would be washed properly (laughter).
Interviewer: I will just see that you cannot do it?
Respondent: Yes, you will doubt whether the clothes would be clean (KF002).

Respondent: We only knit *(items for sale)* after getting an order from the pastor of the church. If we have no order, we stay like that. Like last year, we had none. Sometimes I go to Eastleigh to look for work.
Interviewer: For washing?
Respondent: Yes, washing but nowadays, I don't have the strength to wash and you have to walk for such long distances. And touching water all the time is not good. So now I am just trying to knit *(items for sale)* but it is not doing very well. Another problem is that I do not have strength. As days go by, I see my strength diminishing even more. If I was able, I would .... If I wasn't old, I would have the strength to look for work (KF027).

Interviewer: What are the specific challenges faced by older people when providing care to someone who is ill for a long time?
Respondent: Financial problem ..... So, when someone is ill for long it becomes a burden to the family and especially to older people who cannot get employment in these industries. Who can employ an old man when there are many young men? (VM012).

The competitive urban job market thus makes it increasingly difficult for older people to secure employment.

7.4 Conclusion

Various indicators to measure socio-economic welfare are used to compare HIV caregivers, other caregivers and non-caregivers. Overall, HIV caregivers have better economic status compared with those not providing care. HIV caregivers were rated to be in wealthier households as measured by the wealth index and the participatory wealth ranking. Older people who provide care may, therefore, not be a random sample but reflects selection effect of people with the financial ability to provide care. This therefore, entrusts older people with a lot of responsibility towards people in need which may in the immediate or longer term disadvantage them. The diverse nature of relationships between the caregiver and the care recipient also draws our attention to the role of older people not only as heads of their immediate family but also the extended family network. The responsibility is not only limited to social roles but also includes financial commitment. Despite being portrayed as needy or recipients of care and support within their households (Aboderin, 2006), older people are heads of their

households not only in terms of seniority or status, but in providing for the economic welfare as well (Bongaarts and Zimmer, 2002; HelpAge International, 2002).

Caregivers usually employ various strategies to cope with the economic shock of care-giving to someone with prolonged illness. However, their ability to keep up with the challenge might be unsustainable in the long run as the coping strategies may provide only temporary relief. For instance, a higher proportion of households with HIV caregivers sold assets during the one year preceding the survey compared with non-caregivers. Inability to replenish resources and savings might compromise both the immediate and long-term welfare. This might, therefore, have permanent effect and increase the likelihood of pushing households that are relatively non-poor into poverty and those already poor into destitution.

The economic consequences of care-giving have a rippling effect. Indeed, all the consequences of care-giving may not be felt immediately as long-term effects begin to manifest at later stages. The fact that older people who are providing care to someone with a HIV-related illness on average live in larger households and more importantly with young children below the age of 15 years compared with non-caregivers implies longer-term financial obligation beyond the duration of the care-recipients' illness.

Whereas some studies have indicated that the financial situation of those who are providing care recovers in the long-term, older people might not be able to recover from the economic shock given their declining ability to generate wealth and to participate in the labour market. A higher proportion of households with HIV caregivers compared with other caregivers or non-caregivers rely on salaries as their main source of income. This might not be sustainable in the longer term given the challenges older people face in their attempt to continue participating in the labour market due to age-discrimination and competition with younger people for limited job opportunities. This places them at a precarious position especially in urban areas where labour-force participation is crucial for survival and where a substantial share of income is spent on food. The majority of the older people do not have access to pension or formal social security support therefore the ability to earn an income is crucial in avoiding falling into extreme poverty or destitution.

CHAPTER EIGHT

8 HEALTH DIFFERENTIALS BETWEEN HIV CAREGIVERS, OTHER CAREGIVERS AND NON-CAREGIVERS

8.1 Introduction

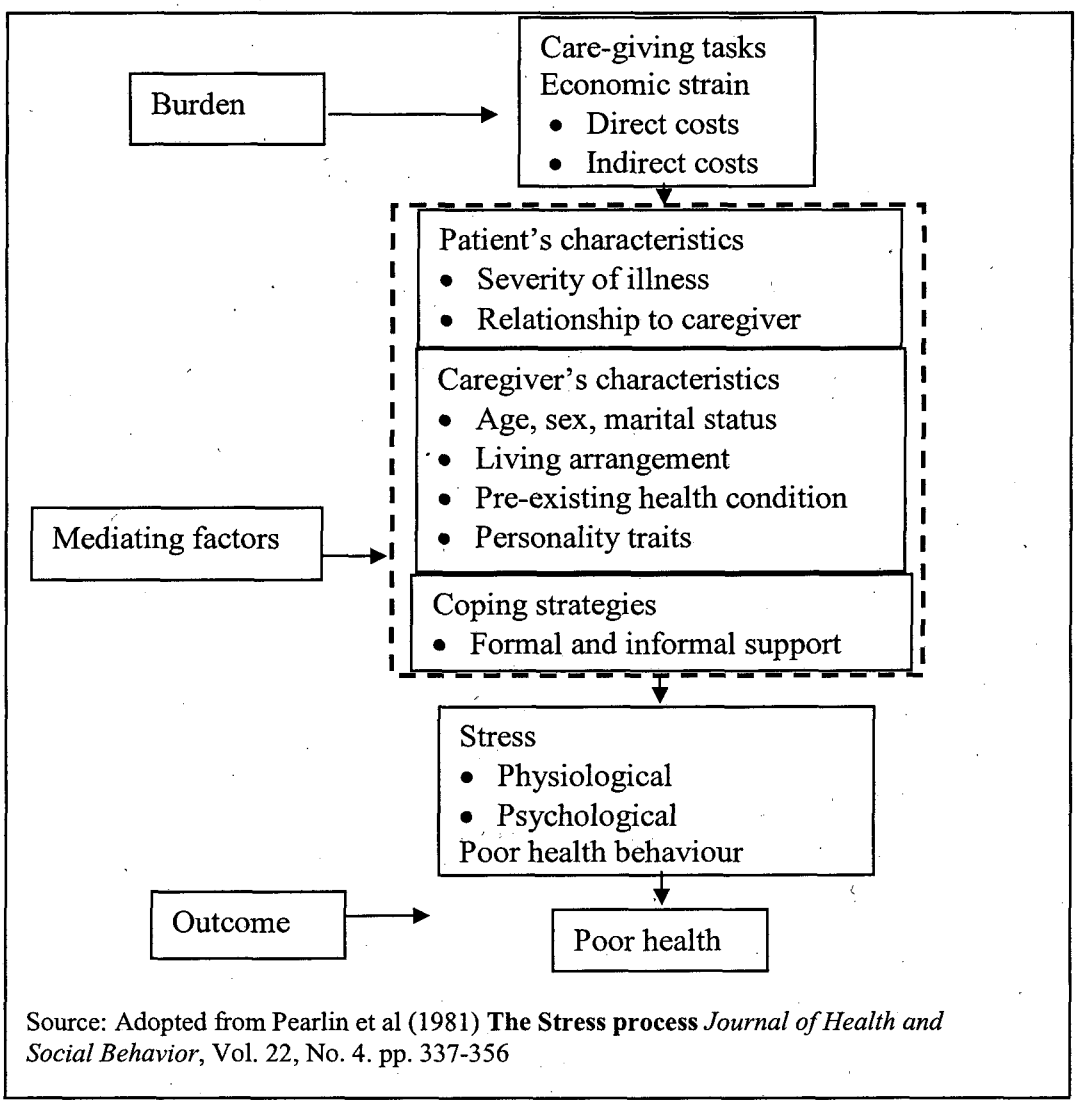
This chapter compares the self-reported health of HIV caregivers with other caregivers and non-caregivers. Care-giving can be hazardous to the health of the caregiver as numerous studies have identified a positive relationship between care-giving and negative psychological outcomes and reported health problems (Chappell and Reid, 2002; Grant, 1999; Nijboer et al, 1998; Schulz and Beach, 1999; Vitaliano et al, 2003). The extent of psychological and health impact on the caregiver may vary depending on the chronic ailments of the care recipient (Haley et al, 2001). Caring for someone with HIV/AIDS is likely to have worse health outcomes compared with other chronic ailments due to the multiplicity of infections that afflict HIV/AIDS patients (Grant and De Cock, 2001) and the stigma attached to HIV/AIDS which is bound to compound the negative consequences associated with caring for someone with HIV/AIDS (Piot and Collseck, 2001).

The conceptual model in Figure 8.1 presents the mechanisms through which care-giving impacts on the health of the caregiver. The model is adopted from the stress process developed by Pearlin et al (1981). According to the model, the *burden* associated with care-giving arises from the actual tasks and duties relating to care and in many cases also includes financial costs that are paid for by the caregiver. The resulting *outcome* from prolonged exposure to the burden is chronic stress which leads to negative physiological effects, as well as psychological distress. The burden and preoccupation with care-giving diverts the attention of the caregiver from caring for his/her own health. In addition, caregivers engage in risky health behaviour such as poor eating habits, lack of exercise, smoking, and alcohol abuse (Grant, 1999; Vitaliano et al, 2003).

Factors such as the care recipients' or caregivers individual characteristics and other external factors act to *mitigate* the occurrence of or the intensity of the health impacts of care-giving, thus making some caregivers more vulnerable than others. Socio-demographic characteristics of the caregivers such as age, sex, ethnicity, living arrangements, and relationship with the care recipient do influence the health outcomes. Other factors such as the caregivers' prior health status, presence of co-morbidities and

economic resources interact with care-giving to affect the health outcome. The stress associated with care-giving can activate or reactivate already existing chronic health conditions or lead to rapid disease progression in a person already ill (Vitaliano et al, 2003). The caregivers' psychosocial traits such as their personality, their coping behaviour including the availability of social support networks may act positively to lessen the negative consequences of care-giving (Nijboer et al, 1998; Vitaliano et al, 2003). The type of care provided, the nature of care-giving activities and the amount of time and resources devoted to caring may act to lessen the burden and thus minimise the overall impact on health outcomes (Nijboer et al, 1998).

Figure 8.1: Conceptual model on care-giving effect on health



Source: Adopted from Pearlin et al (1981) **The Stress process** *Journal of Health and Social Behavior*, Vol. 22, No. 4. pp. 337-356

Caregivers can also expose themselves to infectious diseases either from the care recipient or when accompanying the care recipient to health facilities (Grant, 1999). The age of the caregiver may be a factor in the extent to which care-giving affects the

caregiver. Older caregivers may be more vulnerable due to an already compromised physiological functioning thus increasing their risk for health problems (Schulz and Beach, 1999).

Care-giving can also have a positive effect on the health of the caregiver although the actual mechanism through which it influences health outcomes has been inconclusive. This can occur when caregivers view care-giving positively and derive meaning, a sense of purpose or self-worth in the activity which can increase the caregivers' ability to meet the challenge and decrease the feelings of viewing the experience as a burden. These can ultimately lead to a positive effect on health outcomes (Nijboer et al, 1998; Vitaliano et al, 2003). Based on this background, therefore, the health of the three groups of older people is contrasted.

8.2 Health indicators

Health status of older people is usually measured in two broad terms either as the presence or absence of disease on the one hand or the extent of functional disability on the other. These two broad health indicators: functionality and disability; illness and morbidity; and in addition, Quality of Life (QOL) are thus used to compare the health of HIV caregivers, other caregivers and non-caregivers. The definition of these indicators and how they are generated is discussed below. The instrument used to assess health is part of the WHO multi-country *Study* on Global *AGEing* and Adult Health (SAGE) that covers a broad range of assessment of health and wellbeing (Appendix 7). SAGE questions are an adaptation of the World Health Survey (WHS) and various other field-tested instruments including the US Health and Retirement Survey (HRS) and the UK English Longitudinal Study of Ageing (ELSA) (WHO, 2008).

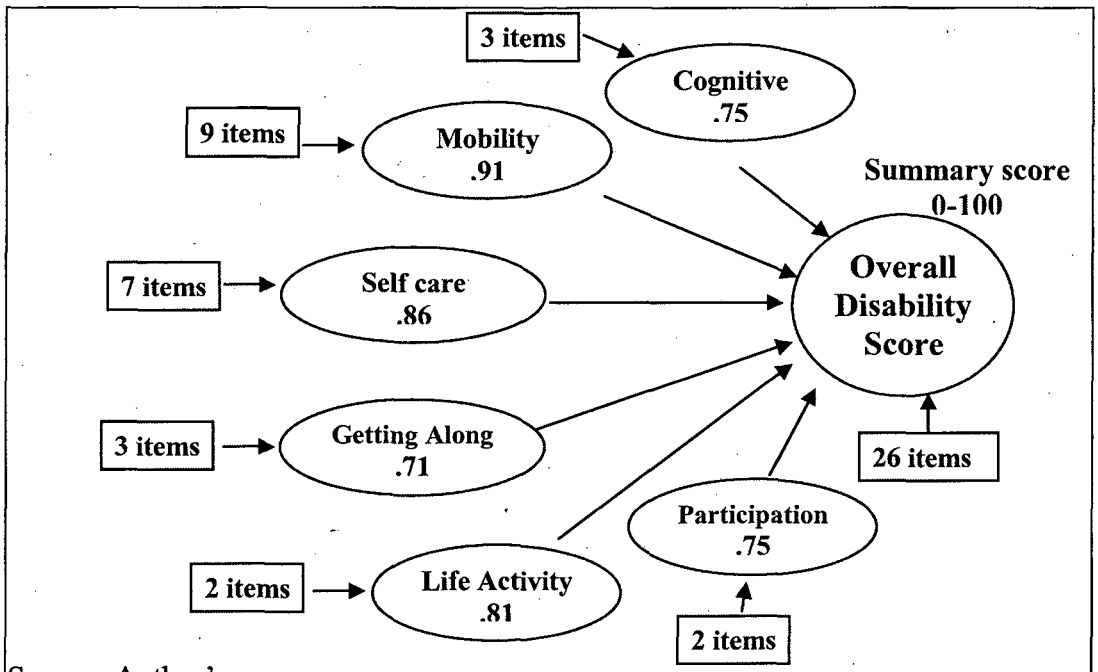
8.2.1 Description of health indicators

8.2.1.1 Functionality and disability

Disability can be defined in both medical and social terms. WHO's medical definition refers to disability as impairments in the ability to complete multiple daily tasks ranging from mild to severe forms. A wider definition of disability considers the way the society imposes barriers, thus affecting the lives of people with a disability (Eliopoulos, 1997; Hooyman and Kiyak, 1996). Disability is defined here as the inability to perform various daily tasks leading to limitations in fulfilment of roles that are considered normal. The WHO Disability Assessment measure (WHODAS) is used to assess

functionality and disability. WHODAS is multidimensional and assesses day to day functioning at the physical, personal and social levels based on six different domains: understanding and communication (cognition); getting around (mobility); self care (hygiene, dressing, eating alone); interpersonal interactions (getting along); life activity (domestic responsibilities and work); and participation in society (community activities). Cognition, self-care and mobility relate to physiological functioning while getting along and life activity refers to personal level of functioning. Only one domain, participation in society, measures functioning at societal level. Loss of functionality can occur suddenly and affect all the six domains simultaneously for example after suffering a stroke. In other instances, loss of functionality is gradual and the disability initially affects participation in society. As disability increases, more domains are affected and ultimately, the ability to perform self care is affecting. The different domains and the number of items that constitute each domain are presented graphically in Figure 8.2.

Figure 8.2: Health domains and correlation with overall disability score



Source: Author's own

Items refer to the number of questions asked to assess the specific domains. The responses to items were coded on a 5-point Likert scale ranging from none (1) to extreme difficulty (5). However, to compute the score, the items were re-coded on a scale of 0 – 4. A standardised score for each of the domains is generated by averaging

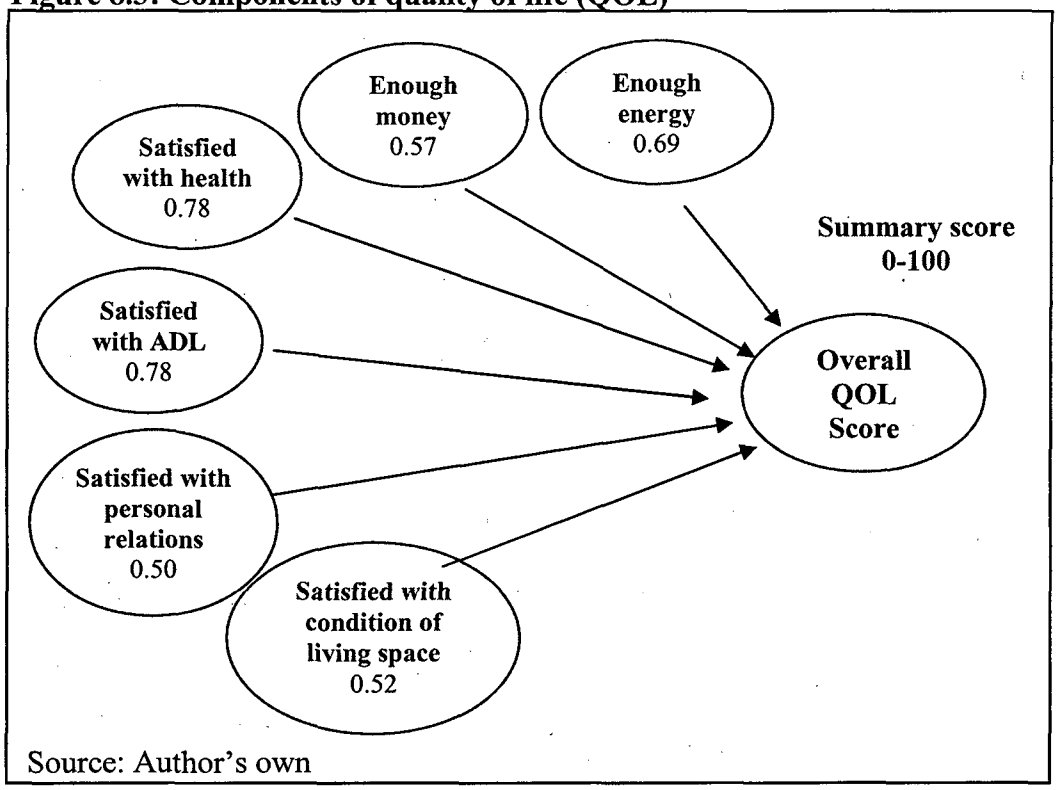
responses to the items that constitute the domain and then converting to a percentage of the highest possible score obtained. The overall disability score is an aggregate of the six domains and each domain was awarded equal weight. The final score as well as the scores for specific domains range from 0 to 100 with higher scores indicating more functional impairment. There is very strong correlation between each of the domains and the overall disability score as shown by Pearsons correlation coefficient in Figure 8.2. The strong correlation, therefore, validates use of the overall disability score given that a weak correlation with one of the domains may limit use of the overall score.

8.2.1.2 Overall quality of life

The WHO Quality of Life (WHO QOL) measurement is used to assess overall quality of life which is defined 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"(The Whoqol Group, 1993). It is a subjective measure that encompasses a broader aspect of quality of life beyond physical health status to include psychological state, social relations, financial and environmental facets of life (The Whoqol Group, 1993; The Whoqol Group, 1998). The QOL score was computed using 6-items shown in Figure 8.3.

The 6-items were coded on a 5-point Likert scale ranging from none (1) to extreme difficulty (5). The QOL score was computed similar to the disability score above where the items were re-coded on a scale of 0 – 4 and a standardised score was generated by aggregating the 6–items and computing a percent of the highest possible score. The final score, therefore ranges from 0 – 100 with a higher score indicating greater dissatisfaction with quality of life. Figure 8.3 also indicates the correlation coefficient for each of the 6 items and the overall score. All the items were strongly correlated with the QOL score with items relating to physical health having a higher degree of correlation compared with items on social relations, finances, and satisfaction with conditions of living space.

Figure 8.3: Components of quality of life (QOL)



Source: Author's own

8.2.1.3 Illness and morbidity

In view of the fact that care-giving predisposes the caregiver to poor health including susceptibility to illness and morbidity as discussed in section 8.1 above, the assumption is that caregivers are more likely to report having a health problem compared with non-caregivers. To assess the presence of disease or general poor health the respondents were asked the following question *"what do you consider to be the most severe health problem you have currently?"* If respondents mentioned more than one health problem, they were asked to state one they considered to be the most severe. The question was pre-coded with a list of approximately 20 response options comprising communicable diseases, acute illnesses, injuries and a range of other age-related health problems.

8.3 Results on differentials in health status

Men and women tend to report feelings of distress differently with women more likely to report higher levels of distress or health outcomes compared with men. Between-gender comparison would therefore often conclude that women have more distress or poorer health outcomes compared with men even though men and women may undergo the same level of stress or health outcome (Lutzky and Knight, 1994). Traditional expectations where men are not expected to display their emotions or distress may result

in men either not reporting their distress or downplaying the effects. Consequently, men tend to report lower levels of health problems relative to women (Anderson and Gerdenio, 1994). For these reasons therefore, within-gender comparisons of health status for HIV caregivers, other-caregivers and non-caregivers is carried out.

8.3.1 Differentials in functionality and disability

Functionality is particularly relevant among older people given that the rate of decline is progressive with increasing age. Functional disability is also a sign or symptom of underlying illnesses and is usually associated with specific diseases or impairments of body systems or organs. Caring for someone with a chronic condition can be a risk factor as it can impact on functioning or lead to an acceleration of decline in functionality. Therefore, HIV caregivers and their comparison groups are compared across the various domains which constitute the disability score as well as the overall score. Table 8.1 and 8.2 presents the level of disability across the various domains for men and women respectively. The computed disability score for each domain and the overall score which range from 0-100 has been categorised into 3 groups: no disability (0 score), moderate disability (1 – 50) and severe disability (51-100).

Among the men, HIV caregivers were more likely to report moderate to severe disability across most of the functionality domains compared with other caregivers and non-caregivers. Specifically, HIV caregivers were significantly more likely to report severe disability in physiological functioning compared with the comparison groups. For instance, 20% of HIV caregivers had severe disability with mobility compared with less than 10% of other caregivers and non-caregivers. There were no significant differences between the three comparison groups with regards to functionality at the societal level especially between HIV caregivers and other caregivers.

The women showed mixed results across the different functionality domains. A higher proportion of HIV caregivers had severe disability for cognitive and mobility domains compared with the other two comparison groups although the differences are not statistically significant. Conversely, HIV caregivers were significantly different from other caregivers and non-caregivers with regards to self-care where none of the HIV caregivers had severe disability unlike 5% and 4% of other caregivers and non-caregivers respectively. Tasks relating to care-giving especially those undertaken by

women such as instrumental and nursing care may self-select individuals who are at least physically able, as a pre-requisite for care-giving.

Table 8.1: Percent distribution of level of disability on various domains for men by care-giving status

Functionality and disability domain	HIV caregivers	Other-caregivers	Non-caregivers	Total
Cognitive				
No disability	24.0	41.1	42.8	42.0
Moderate disability	66.0	55.6	51.9	52.7
Severe disability	10.0	3.3	5.3	5.3
Mobility* **				
No disability	10.0	18.9	29.0	27.5
Moderate disability	70.0	72.2	64.3	65.1
Severe disability	20.0	8.9	6.7	7.4
Self care				
No disability	50.0	62.2	53.0	53.5
Moderate disability	48.0	37.8	45.6	45.2
Severe disability	2.0	0.0	1.4	1.3
Getting along*				
No disability	78.0	82.2	69.0	70.2
Moderate disability	20.0	17.8	29.1	27.9
Severe disability	2.0	0.0	2.0	1.9
Life activity				
No disability	64.0	74.4	61.2	62.2
Moderate disability	32.0	25.6	36.6	35.6
Severe disability	4.0	0.0	2.2	2.2
Participation in society				
No disability	84.0	84.4	75.0	76.0
Moderate disability	16.0	15.6	23.0	22.2
Severe disability	0.0	0.0	2.0	1.8
Overall disability*				
No disability	4.0	18.9	22.7	21.7
Moderate disability	92.0	81.1	75.2	76.2
Severe disability	4.0	0.0	2.2	2.1
Total	**100.0**	**100.0**	**100.0**	**100.0**
N	***50***	***90***	***1,160***	***1,300***

χ^2 test for between care-giving status differences: Significance levels *** <0.001; **<0.01, *<0.05
Source: Author's analysis of Survey of Older People Data, 2006/2007

Table 8.2: Percent distribution of level of disability on various domains for women by care-giving status

Functionality and disability domain	HIV caregivers	Other-caregivers	Non-caregivers	Total
Cognitive				
No disability	31.6	34.2	28.8	29.2
Moderate disability	52.6	55.3	60.0	59.4
Severe disability	15.8	10.5	11.2	11.4
Mobility				
No disability	13.2	5.3	11.4	11.2
Moderate disability	50.0	73.7	61.8	61.8
Severe disability	36.8	21.1	26.9	27.1
Self care* **				
No disability	39.5	63.2	33.4	35.2
Moderate disability	60.5	31.6	62.6	61.0
Severe disability	0.0	5.3	3.9	3.8
Getting along				
No disability	68.4	81.6	59.1	60.7
Moderate disability	29.0	18.4	36.2	35.0
Severe disability	2.6	0.0	4.7	4.3
Life activity				
No disability	55.3	55.3	44.4	45.5
Moderate disability	39.5	34.2	49.3	48.1
Severe disability	5.3	10.5	6.3	6.4
Participation in society				
No disability	73.7	76.3	62.6	63.9
Moderate disability	21.1	18.4	31.5	30.4
Severe disability	5.3	5.3	5.8	5.8
Overall disability				
No disability	7.9	5.3	9.1	8.8
Moderate disability	86.8	81.6	83.4	83.4
Severe disability	5.3	13.2	7.6	7.8
Total	**100.0**	**100.0**	**100.0**	**100.0**
N	***38***	***38***	***685***	***761***

χ^2 test for between care-giving status differences: Significance levels *** <0.001; **<0.01, *<0.05
Source: Author's analysis of Survey of Older People Data, 2006/2007

Multiple linear regression is used to identify determinants of the various health domains as well as the overall disability score. Age, the level of education, household per capita income and wealth status (PWR) are controlled for in the models presented in Table 8.3. Separate models are run for men and women. Similar to bivariate analysis, the differences among the three groups of women were not significant in almost all the functionality domains when age and other socio-economic characteristics are controlled for except for mobility. HIV caregivers had higher disability scores for mobility compared with non-caregivers. The difference in self care at the bivariate level where

HIV caregivers did not report severe disability was however not significant when other factors are controlled for.

Table 8.3: Results of multiple linear regression models of functionality and disability domains for women and men

Functionality and disability domains[6]	Women			Men		
	Coefficient (standard error)	t – statistic	P-value sign	Coefficient (standard error)	T – statistic	P-value sign
Cognitive						
Non-caregivers (Ref)						
Other caregivers	-0.239 (4.571)	-0.05	NS	4.163 (2.768)	1.5	NS
HIV caregivers	-0.726 (3.993)	-0.18	NS	7.057 (3.375)	2.09	*
Constant	-2.036 (10.909)			3.566 (8.120)		
Adjusted R^2	0.13			0.07		
Mobility						
Non-caregivers (Ref)						
Other caregivers	7.466 (4.818)	1.55	NS	6.900 (2.723)	2.53	**
HIV caregivers	8.202 (4.208)	1.98	*	10.950 (3.320)	3.3	***
Constant	-19.965 (11.497)			-9.016 (7.988)		
Adjusted R^2	0.17			0.14		
Self care						
Non-caregivers (Ref)						
Other caregivers	-0.406 (3.256)	-0.12	NS	-1.470 (1.791)	-0.82	NS
HIV caregivers	-4.106 (2.844)	-1.44	NS	2.529 (2.184)	1.16	NS
Constant	2.614 (7.770)			-5.288 (5.253)		
Adjusted R^2	0.14			0.11		
Getting along						
Non-caregivers (Ref)						
Other caregivers	-6.429 (3.994)	-1.61	NS	-3.944 (2.296)	-1.72	NS
HIV caregivers	-4.112 (3.488)	-1.18	NS	-2.953 (2.799)	-1.05	NS
Constant	5.309 (9.530)			-3.943 (6.735)		
Adjusted R^2	0.08			0.04		
Life activity						
Non-caregivers (Ref)						
Other caregivers	4.006 (4.358)	0.92	NS	-5.273 (2.304)	-2.29	*
HIV caregivers	-2.557 (3.807)	-0.67	NS	4.078 (2.810)	1.45	NS
Constant	-5.538 (10.400)			-4.968 (6.759)		
Adjusted R^2	0.12			0.09		
Participation in society						
Non-caregivers (Ref)						
Other caregivers	1.322 (4.781)	0.28	NS	-2.856 (2.467)	-1.16	NS
HIV caregivers	-2.261 (4.176)	-0.54	NS	-2.901 (3.009)	-0.96	NS
Constant	2.359 (11.408)			-1.662 (7.238)		
Adjusted R^2	0.11			0.05		
Overall disability score						
Non-caregivers (Ref)						
Other caregivers	3.197 (3.371)	0.95	NS	1.805 (1.946)	0.93	NS
HIV caregivers	2.192 (2.945)	0.74	NS	5.655 (2.373)	2.38	*
Constant	-5.226 (8.045)			-4.316 (5.709)		
Adjusted R^2	0.19			0.13		
N	*582*			*967*		

Significance levels * <0.001; **<0.01, *<0.05, NS- Not significant**
Source: Author's analysis of Survey of Older People Data, 2006/2007

[6] **Age, level of education, household per capita income and wealth status (PWR) are controlled for in the models but the results are not shown in the table**

Among the men, HIV caregivers were significantly more likely to report disability in the cognitive and mobility functionality domain as well as in the overall disability compared with non-caregivers.

8.3.2 Differentials in illness and morbidity

HIV caregivers are also compared with the comparison groups based on whether they reported having a severe health problem. This is presented in Table 8.5 along with whether treatment was sought for the health problem. A higher proportion of both men and women who were HIV caregivers reported having a severe health problem at the time of the interview compared with other caregivers and non-caregivers. In contrast to women however, the difference among the men was statistically significant (χ^2=76.15, df=4, P =0.000) at the 5% level. Five out of six (84%) HIV caregivers reported to have a severe health problem compared with less than a third of other caregivers (31%) and less than half (43%) of those who were not providing care.

The difficulty reported by majority of those with severe health problem among the women was chronic health conditions with the proportion slightly higher for other caregivers (72%) followed by non-caregivers (59%). Among the men however, a significantly higher proportion of both HIV caregivers and other-caregivers were more likely to report a communicable or acute health problem compared with non-caregivers. The study participants were only reporting the most severe health problem they had at the time of the survey. Therefore, having a communicable or acute illness does not rule out the presence of chronic conditions. Also, some studies have found caregivers to be significantly more prone to infectious diseases due to stress and low immune response. Co-morbidities among caregivers compared with non-caregivers has also been found to be high (Kiecolt-Glaser et al, 1991).

Caregivers often neglect their own health and may not seek healthcare when they are ill due to preoccupation with care-giving and not allocating time to take care of their own health (Cancer journal for clinicians, 2006). The differences in the proportion who sought care for the severe health problem in the 3 months before the survey between the cases and their comparison groups was however, not statistically significant for both men and women although among the men a smaller proportion of HIV caregivers (45%) sought healthcare compared with other caregivers (58%) and non-caregivers (56%).

Table 8.4: Percentage distribution of reported severe health problem and treatment seeking by care-giving status

	HIV caregivers	Other caregivers	Non-caregivers
		Women	
Has a severe health problem	78.9	65.8	68.9
N	*38*	*38*	*685*
Type of severe health problem			
Communicable & acute illness	20.0	8.0	16.5
Chronic condition	53.3	72.0	59.1
Other health problems	26.7	20.0	24.4
Sought care for health problem	56.7	44.0	61.7
N	*30*	*25*	*472*
		Men	
Has a severe health problem* **	84.0	68.9	43.2
N	*50*	*90*	*1,160*
Type of severe health problem* **			
Communicable & acute illness	40.5	45.2	23.8
Chronic condition	33.3	30.7	50.3
Other health problems	26.2	24.2	26.0
Sought care for health problem	45.2	58.1	56.5
N	*42*	*62*	*501*
Total	100	100	100

χ^2 test for between care-giving status difference: significance levels *** <0.001; **<0.01 *<0.05
Source: Author's analysis of Survey of Older People Data, 2006/2007

Logistic regression was used to determine the association between care-giving and reporting a severe health problem while controlling for age and various socio-economic characteristics. The models are shown in Table 8.5 and separate models are presented for women and men. There was no difference between the three groups of women when age and socio-economic characteristics were controlled for. On the contrary, men who are HIV caregivers had significantly higher odds of reporting a severe health problem compared with non-caregivers. Specifically, HIV caregivers were almost 8 times more likely to report a severe health problem compared with non-caregivers.

Table 8.5: Results of logistic regression analysis on the odds of reporting a severe health problem among men and women

	Women		Men	
	Odds Ratio	**P-value significance**	**Odds ratio**	**P-value significance**
Age	1.062	***	1.044	***
Education level				
No education (ref)	1.000		1.000	
Primary	0.693	NS	0.795	NS
Secondary+	1.535	NS	0.789	NS
Per capita income	1.061	NS	0.916	NS
Household rating (PWR)	0.917	NS	0.951	NS
Care-giving status				
Non-caregivers (Ref)	1.000		1.000	
Other caregivers	0.753	NS	3.558	***
HIV caregivers	1.824	NS	7.651	***
Model χ^2	46.9		68.1	
Df	7		7	
P-value	0.000		0.000	
Adjusted R^2	0.067		0.057	
N	*582*		*967*	

Significance levels * <0.001; **<0.01, *<0.05, NS - Not significant**
Source: Author's analysis of Survey of Older People Data, 2006/2007

8.3.3 Differentials in quality of life (QOL)

Care-giving not only affects the physical health of the caregiver but the burden associated with care-giving is expected to affect the caregiver's outlook towards broader aspects of life leading to dissatisfaction with their emotional, social, and financial circumstances of their lives (Glozman, 2004). Table 8.6 and 8.7 presents the level of satisfaction with specific components of QOL and the overall satisfaction comparing HIV caregivers with the comparison groups for women and men respectively. Among the women, the three comparison groups were not significantly different on how they rated their satisfaction with most of the QOL aspects. The only significant difference between the three groups was how they rated their satisfaction with having enough energy for everyday life. Both HIV caregivers and other caregivers were more likely to be satisfied with the amount of energy they had for everyday life compared with non-caregivers. About 16% of HIV caregivers and other caregivers reported to be very

dissatisfied with having enough energy for everyday life unlike about a quarter of non-caregivers (24%). This is not surprising given that care-giving requires enormous amount of physical, mental, and emotional energy to meet the challenges relating to care (Vitaliano et al, 2004).

The results for men presented in Table 8.7 showed significant differences in the level of satisfaction across most of the QOL components according to care-giving status. A higher proportion of HIV caregivers were very dissatisfied with almost all the QOL components including overall dissatisfaction with quality of life compared with other caregivers and non-caregivers.

Care-giving often results in strained relationship either between the caregiver and the care recipient or with family and non-family members. The conflict could relate to finances, disagreements in the division of roles, expectations by either party, strategy of care, or feelings of lack of appreciation on the part of the caregiver (Vitaliano et al, 2004). In this regard, a higher proportion of HIV caregivers both men and women, were dissatisfied with personal relationships with the differences among the male groups statistically significant.

Table 8.6: Percent distribution of level of satisfaction on various QOL domains for women by care-giving status

	HIV caregivers	Other-caregivers	Non-caregivers	Total
Enough energy* **				
Satisfied	10.5	26.3	7.9	8.9
Dissatisfied	73.7	57.9	68.3	68.1
Very dissatisfied	15.8	15.8	23.8	23.0
Enough money				
Satisfied	2.6	0.0	2.5	2.4
Dissatisfied	13.2	26.3	24.8	24.3
Very dissatisfied	84.2	73.7	72.7	73.3
Own health				
Satisfied	5.3	10.5	7.7	7.8
Dissatisfied	71.1	68.4	68.0	68.2
Very dissatisfied	23.7	21.1	24.2	24.1
Activities of Daily Living (ADL)				
Satisfied	7.9	10.5	7.0	7.2
Dissatisfied	65.8	68.4	70.2	69.9
Very dissatisfied	26.3	21.1	22.8	22.9
Personal relationships				
Satisfied	29.0	26.3	18.7	19.6
Dissatisfied	60.5	68.4	75.3	74.2
Very dissatisfied	10.5	5.3	6.0	6.2
Conditions of living space				
Satisfied	13.2	10.5	11.2	11.3
Dissatisfied	60.5	55.3	63.9	63.3
Very dissatisfied	26.3	34.2	24.8	25.4
Overall quality of life				
Satisfied	2.6	0.0	0.2	0.3
Dissatisfied	65.8	71.1	68.5	68.5
Very dissatisfied	31.6	29.0	31.4	31.3
Total	**100.0**	**100.0**	**100.0**	**100.0**
N	***38***	***38***	***685***	***761***

Significance levels * <0.001; **<0.01, *<0.05, NS - Not significant**
Source: Author's analysis of Survey of Older People Data, 2006/2007

Table 8.7: Percent distribution of level of satisfaction on various QOL domains for men by care-giving status

	HIV caregivers	Other-caregivers	Non-caregivers	Total
Enough energy* **				
Satisfied	38.0	34.4	18.4	20.2
Dissatisfied	44.0	63.3	72.1	70.4
Very dissatisfied	18.0	2.2	9.6	9.4
Enough money* **				
Satisfied	4.0	0.0	2.8	2.7
Dissatisfied	34.0	36.7	40.3	39.8
Very dissatisfied	62.0	63.3	56.9	57.5
Own health** **				
Satisfied	20.0	23.3	12.2	13.2
Dissatisfied	60.0	62.2	77.7	75.9
Very dissatisfied	20.0	14.4	10.2	10.9
Activities of Daily Living (ADL)* **				
Satisfied	32.0	22.2	12.1	13.5
Dissatisfied	50.0	71.1	78.2	76.6
Very dissatisfied	18.0	6.7	9.7	9.9
Personal relationships* **				
Satisfied	50.0	32.2	23.2	24.9
Dissatisfied	42.0	67.8	73.2	71.6
Very dissatisfied	8.0	0.0	3.6	3.5
Conditions of living space				
Satisfied	24.0	14.4	14.4	14.8
Dissatisfied	48.0	58.9	63.5	62.5
Very dissatisfied	28.0	26.7	22.2	22.7
Overall quality of life				
Satisfied	0.0	0.0	0.9	0.8
Dissatisfied	78.0	87.8	87.2	86.9
Very dissatisfied	22.0	12.2	12.0	12.4
Total	**100.0**	**100.0**	**100.0**	**100.0**
N	***50***	***90***	***1,160***	***1,300***

Significance levels * <0.001; **<0.01, *<0.05, NS - Not significant**
Source: Author's analysis of Survey of Older People Data, 2006/2007

The differences in satisfaction with the quality of life according to care-giving status observed in the bivarate analysis however did not remain significant when age and socio-economic characteristics were controlled for in the multiple linear regression analysis presented in Table 8.8 below. Marginal significant differences were observed only among women with regards to satisfaction with money to meet basic needs where HIV caregivers were more likely to report dissatisfaction compared with those who were not providing care.

Table 8.8: Results of multiple linear regression models of overall quality of life score for women and men

Quality of life domains[7]	Women			Men		
	Coefficient (standard error)	t - statistic	P-value sign	Coefficient (standard error)	t – statistic	P-value sign
Energy for everyday life						
Non-caregivers (Ref)						
Other caregivers	-0.153 (0.194)	-0.78	NS	-0.051 (0.127)	-0.40	NS
HIV caregivers	-0.024 (0.170)	-0.14	NS	0.081 (0.155)	0.52	NS
Constant	0.533 (0.464)			0.226 (0.372)		
Adjusted R^2	0.15			0.08		
Enough money						
Non-caregivers (Ref)						
Other caregivers	0.246 (0.191)	1.29	NS	0.179 (0.131)	1.37	NS
HIV caregivers	0.351 (0.167)	2.10	*	0.132 (0.160)	0.82	NS
Constant	2.951 (0.456)			2.120 (0.385)		
Adjusted R^2	0.07			0.03		
Satisfied with own health						
Non-caregivers (Ref)						
Other caregivers	0.051 (0.200)	0.26	NS	0.060 (0.127)	0.47	NS
HIV caregivers	0.163 (0.174)	0.94	NS	0.277 (0.155)	1.79	NS
Constant	1.030 (0.477)			1.234 (0.372)		
Adjusted R^2	0.09			0.04		
Satisfied with ADL						
Non-caregivers (Ref)						
Other caregivers	-0.050 (0.196)	-0.25	NS	-0.129 (0.121)	-1.07	NS
HIV caregivers	0.208 (0.171)	1.22	NS	0.122 (0.148)	0.82	NS
Constant	1.065 (0.468)			1.155 (0.355)		
Adjusted R^2	0.11			0.05		
Satisfied with personal relations						
Non-caregivers (Ref)						
Other caregivers	-0.054 (0.172)	-0.32	NS	-0.010 (0.112)	-0.09	NS
HIV caregivers	-0.086 (0.150)	-0.57	NS	-0.141 (0.136)	-1.04	NS
Constant	1.235 (0.410)			1.811 (0.328)		
Adjusted R^2	0.02			0.07		
Satisfied with conditions of living space						
Non-caregivers (Ref)						
Other caregivers	0.225 (0.221)	1.02	NS	0.284 (0.154)	1.85	NS
HIV caregivers	-0.125 (0.193)	-0.65	NS	0.066 (0.187)	0.35	NS
Constant	2.313 (0.528)			1.934 (0.451)		
Adjusted R^2	0.02			0.01		
Overall quality of life						
Non-caregivers (Ref)						
Other caregivers	1.163 (3.026)	0.38	NS	1.381 (1.994)	0.69	NS
HIV caregivers	1.985 (2.643)	0.75	NS	2.143 (2.432)	0.88	NS
Constant	37.531 (7.222)			34.832 (5.851)		
Adjusted R^2	0.13			0.05		
N	582			967		

Significance levels * <0.001; **<0.01, *<0.05, NS - Not significant**
Source: Author's analysis of Survey of Older People Data, 2006/2007

[7] **Age, level of education, household per capita income and wealth status (PWR) are controlled for in the models but the results are not shown in the table**

8.4 Discussion

HIV caregivers, other caregivers, and non-caregivers have been contrasted based on various health indicators; functional disability, illness and morbidity, and quality of life. The assumption was that caregivers would present with poorer health outcomes compared with non-caregivers. In particular, it was assumed that HIV caregivers would be worse off due to factors such as stigma towards people with HIV/AIDS coupled with the long debilitating nature of the disease AIDS. Caring for someone with a chronic debilitating condition necessitates both physical and psychosocial adjustment to the new situation. However, variation does exist among caregivers as some are able to adjust or adapt to the situation with minimal psychosocial effects while for others psychosocial disturbance is manifested in severe poor health outcomes (Chappell and Reid, 2002).

Women who were providing care to someone with an HIV-related illness did not differ significantly from other caregivers or non-caregivers in terms of overall disability scores, in their rating of quality of life, or in reporting a severe health problem. On the contrary, men who were HIV caregivers were significantly more likely to report poor health across all the indicators compared with other caregivers and non-caregivers. A longitudinal study by Schulz (1991) also found similar findings which indicated that female caregivers reported higher psychological effects over time compared with male cargivers however, the condition for the females remained stable over time whereas for the male caregivers, although lower initially, their health condition deteriorated significantly faster.

Although studies which have compared health outcomes between men and women caregivers report mixed findings, more studies however point to worse outcomes for women compared with men, with women reporting poorer health outcomes and perceiving higher levels of burden from care-giving compared with men. This gender differences has however been challenged as 'a research artefact rather than a fact' (Kramer, 2002; Miller and Cafasso, 1992) especially in self-reported health outcomes. Men are thought to downplay their health problems and hence under-report symptoms, caregiver strain, or distress especially in interview situations. Men are also socialised to be self-reliant, in control, courageous, and to portray self-confidence when faced with challenges or complex situations. Consequently, they are expected not to show feelings such as fear, anxiety, grief, or frustration and should be able to endure stress and bear

pain and hence tackle care-giving tasks with control or stoically. However, there is little evidence that men are less emotionally sensitive to care-giving and related burden or stress. This societal or cultural expectation therefore may fuel frustration and elevate stress when the expectations are not met (Kim et al, 2006; Mullan, 1998; Stoller, 2002).The true level of health problems for men in respect to women is therefore, rarely measured (Brown et al, 2007; Fuller-Jonap and Haley, 1995; Mullan, 1998).

Men have also been underrepresented in studies on informal caregivers (Kramer, 2002). A review of literature to understand the difference in the association between care-giving and health outcomes between men and women provides various plausible explanations which mainly highlight gender differences in socialization and cultural expectations.

The other explanation of the differentials between men and women may arise from gender variation in coping strategies. Unlike women, men do not utilise or seek informal support networks. This therefore, deters them from seeking support or discussing their problem or difficulties relating to care-giving (Ashley and Kleinpeter, 2002; Kramer, 2002; Neary, 1993). Informal support has been found to have a mediating effect in caregiver burden and strain. Caregivers who receive psychosocial support when providing care often perceived less burden resulting in better health outcomes. This indicates a strong association between wellbeing and social support, but the relationship is dependent on nature and quality of the support (Fuller-Jonap and Haley, 1995; Mullan, 1998).

According to traditional gender-role socialization, nursing, psychosocial, and domestic tasks relating to care-giving are perceived as women's tasks hence men who have to take up or learn these tasks may be faced with distress or anxiety if they view the role of care-giving to be in conflict with their socialised expectation on gender roles. Women on the other hand would be more competent or familiar with these tasks without feeling overloaded or frustrated and may therefore perceive care-giving as part of their gender-role expectations with minimal negative effect on their health (Fuller-Jonap and Haley, 1995; Kim et al, 2006; Mullan, 1998; Neary, 1993). Additionally, cultural expectations where men are expected to be in control and to show more endurance may lead to elevated levels of stress among men caregivers leading to poorer health outcomes (Kramer, 2002; Stoller, 2002).

The findings from this study therefore highlights the variation that exist among caregivers in the extent to which caregiving may impact on health outcomes in line with Pearlin's et al (1981) stress process discussed in section 8.1 above where a range of factors act to mediate the effects of caregiving on health. The sex of the caregiver therefore acts as a mediating factor.

CHAPTER NINE

9 SUMMARY AND CONCLUSION

This chapter provides a summary of the thesis by highlighting the key findings and a discussion of the implications of the findings for policy and programmes targeting older people and HIV/AIDS. The limitations of the study are also noted as well as suggestions of priorities for future research.

Until recently, older people have not been linked with HIV/AIDS since the focus has been mainly on people of reproductive age who are considered at higher risk of infection. Over time, almost 25 years into the HIV epidemic, it is now emerging that older people are affected both directly and indirectly. Older people in high-prevalence countries where the main transmission route is through heterosexual sex are just as vulnerable as other sub-groups. Indirectly, older people are also affected by HIV/AIDS. In most developing countries and particularly in Africa they rely on their adult children for economic support and care due to the absence of social pensions and other social services targeted at older people. This intergenerational support is also coming under threat given that the economically active adults are the ones getting infected and dying. The other way in which HIV/AIDS affects older people is through their role as caregivers to people who are ill with HIV/AIDS. This study therefore, aimed to investigate how HIV/AIDS affects older people living in the slums of Nairobi, Kenya.

Urban areas in most developing countries, in contrast to rural areas, enjoy advantages in terms of access to social services, employment opportunities, and related infrastructure. Among other factors, high unemployment rates in rural areas have contributed to rural-urban migration resulting in very high and rapid rates of urbanization ultimately outstripping the provision of services such as housing and employment opportunities. A consequence of this high level of rural-urban migration has been the urbanization of poverty, which is manifest in the proliferation of slums and informal settlements. The slums in Kenya are home to about 60-80% of Nairobi's population and 71% of the total urban population (Government of Kenya and UNCHS, 2001; Matrix Development Consultants, 1993; UNHABITAT, 2005). Coupled with this phenomenon is the growing recognition of the permanence of urban population and the increasing number of older people living in urban areas. Consequently, the broader aim of conducting this study

was to highlight the plight of slum dwellers and contribute to the growing body of evidence which is showing how disadvantaged the slum residents are relative to other urban dwellers and rural residents.

The study adds to the limited number of studies conducted on older people and HIV/AIDS and it makes a methodological contribution to research investigating the effects of HIV/AIDS on older people. The data come from a population-based cross-sectional survey (sample size 2,016) and a qualitative study carried out in two slum areas where a Demographic Surveillance System (DSS) is being conducted by the African Population and Health Research Centre (APHRC). Triangulation of methods is known to yield valuable insights as it allows for understanding of both the depth and breadth of issues under study.

The DSS provided a framework for conducting a population-wide study rather than relying on opportunistic samples from healthcare facilities or clientele of care and support CBOs/NGOs to recruit participants thereby minimising selection bias associated with opportunistic samples. Such samples often exclude individuals who are not accessing the particular services or facilities therefore certain groups are not represented. Care and support programmes also mainly target people infected and rarely focus on those indirectly affected by HIV/AIDS. A population-based study therefore yields relatively larger samples compared with one drawing from opportunistic samples.

The study first sought to establish what the study participants perceive as HIV/AIDS concerns facing older people living in the slums. The findings indicate that older people are concerned about having to care for orphans, followed by caring for people who are infected, and losing both material and social support in their old age due to the disproportionate number of young people in productive ages dying from HIV/AIDS. One surprising finding is that a substantial proportion of older people are concerned with HIV/AIDS infection among people in their age group. The perception among researchers and other players in HIV/AIDS is that older people do not perceive themselves as being at risk of infection while at the same time they have largely been ignored in research and intervention programs targeted at preventing the transmission of HIV/AIDS.

Other concerns facing older people are loss of adults to HIV/AIDS who ideally should play the role of fostering the community and caring for the vulnerable members of the society including older people. The study went further to investigate factors associated with reporting these HIV/AIDS concerns among older people and whether it is related to individual socio-demographic characteristics, personal experience with HIV/AIDS, or the level of participation and interaction with people outside of the household.

Being personally affected by HIV/AIDS was significantly associated with reporting HIV/AIDS concern among older people. For instance older people who are living with children who are orphans were more likely to report orphans as a concern. The role of social networks and informal interaction with people outside of the household was also important in reporting HIV/AIDS concerns. This is consistent with studies on family planning that have identified diffusion of information through informal channels to be crucial in accessing information and also influencing behaviour. Gender variation in what is considered HIV/AIDS concern was evident in reporting orphans and infection among older people where women were more likely to report caring for orphans while men on the other hand were more concerned with HIV/AIDS infection among older people.

The study focused on one of the forms through which HIV/AIDS affects older people—caring for someone ill due to HIV/AIDS— to assess the association between care-giving with socio-economic and health outcomes. Use of comparison groups allows for measurement of the degree of effects and differentiation with a general population of similar demographic status in the defined geographical area. Older people who were caring for, or had cared for, someone with a HIV/AIDS-related illness were compared with two comparison groups namely, other caregivers and non-caregivers. Caregivers were identified as those who had provided financial, personal care, emotional support, and or health-related care to someone with a chronic health condition over a three-year period. Clinical diagnosis and the WHO AIDS-case definition, which identifies the following conditions or illness - tuberculosis, weight loss, diarrhoea, fever and pneumonia - as characterising an HIV/AIDS case were adopted to identify HIV caregivers. About 5% of older people (88) had cared for someone with an AIDS-related illness over the 3-year period preceding the survey.

The study included both older men and women aged 50 years and older. Women mainly provided personal care while men mainly provided financial care. Both men and women reported that they provided health-related care and emotional support. The gender roles were however not clearly demarcated as some of the men also provided personal care and women were responsible for financial care. Involvement of men as givers of personal care may indicate a changing context of norms and challenges to the traditional gender roles relating to care-giving in the context of HIV/AIDS epidemic. The urban context also presents situations which render traditional gender norms in care-giving unfeasible. Where nuclear rather than extended family prevails, this implies that there is a shortage of kin to allow distribution of responsibility. The rural-urban migration pattern which is predominantly male resulting in split-households consequently presents a different demographic setting from rural communities.

Older people provide care not only to their biological children but also care for other relatives such as siblings, grandchildren and sons or daughter-in-laws. Reliance on kin for material support is a common characteristic of low income communities since there are no alternative support systems. These strong social and financial ties with individuals or families across space result in migration of people in search of care. While slum residents have poorer social and economic outcomes compared with non-slum residents, they still enjoy advantages such as access and proximity to health services, albeit marginally, compared with their rural counterparts. The urban advantage, therefore, acts as a pull-factor for people in need of care and to those who wish to access the services available in the city.

Care-giving is not limited to a single episode but to multiple and sometimes concurrent episodes. This indicates clustering of HIV/AIDS infection and care. A combination of high HIV prevalence and a generalised HIV epidemic creates situations of repeated or multiple care-giving episodes. Vertical HIV or mother-to-child transmission gives rise to an increased likelihood of care-giving to both an infected mother and her infected child. Recent studies point to an increased risk of infection due to unsafe extra-marital sex and self-perceived low risk of infection among married couples. Hence, HIV infection within marriage also presents a situation of multiple care-giving episodes.

The economic burden of care-giving to someone with a chronic illness such as HIV/AIDS results from direct expenditure on healthcare, loss of income, or

opportunities costs. Asset depletion and indebtedness may be used as strategies to cope with the unexpected expenditure and income loss. Standard money-metric measures (income and expenditure) and non-monetary measures (wealth index and participatory wealth ranking) were used to compare the economic wellbeing of HIV caregivers with other caregivers and non-caregivers. The three comparison groups were also evaluated based on their household size and composition, and sale of assets. Descriptive statistics and multiple linear regression were used to examine the association between care-giving to someone with HIV/AIDS with the economic indicators.

On the whole, households with HIV caregivers had higher incomes and expenditure and were rated wealthier than households with other caregivers and especially non-caregivers. This may indicate a selection effect where older people with financial capacity to provide care end up as caregivers. The relative economic advantage of HIV caregivers however becomes insignificant since they are more likely to live in larger households and to live with children below 15 years compared with other caregivers and non-caregivers. This has implications on intra-household resource allocation and expenditure as evident by a substantial share of expenditure devoted to scholastic material in a household with HIV caregivers and also other-caregivers. The well-being of individual members in the household including the older person is therefore compromised. In the longer term, the economic welfare of households with HIV caregivers may not be sustainable due to large household sizes comprising mainly of children. Additionally, reliance on salaries, which is the main source of income for HIV caregivers is not sustainable due to the reduction in labour-force participation among older people and the age-discrimination they face in the job market.

The stress and burden relating to care-giving impacts on the caregiver and can result in both physiological and psychological negative health outcomes. Men who were providing care to someone with HIV/AIDS had significantly poorer health compared with other male caregivers and non-caregivers. Male HIV caregivers had higher disability scores and were more likely to report having a severe health problem compared with the comparison groups. On the contrary, female HIV caregivers did not differ significantly from other female caregivers or non-caregivers across all the health indicators used in the analysis. The difference between men and women in the association between care-giving and negative health outcomes may arise from gender

variation in socialisation and cultural expectations. Men have been socialised to show courage, to be self-reliant, to display confidence, and not to show any weakness or display emotions when faced with a challenge. This does not however mean that they are less likely to be emotionally affected or stressed when undergoing difficult situations such as care-giving compared to women. Consequently, they may not resort to external help or assistance for psychosocial support. The pressure and expectation confronting male caregivers who have limited support may account for the poor health outcomes.

9.1 Limitations of the study

This study aimed to establish the association between caring for someone with HIV/AIDS illness and health and economic outcomes. The causal relationship between care-giving and these outcomes cannot however be determined due to the cross-sectional nature of the study. In addition, the impact of HIV/AIDS manifests itself over a longer period and the full extent of the effects can only be measured if individuals are observed over a longer period. The cross-sectional design also only captures events immediately preceding the study. Effects of care-giving to a person with HIV/AIDS may vary depending on various factors such as the duration of care-giving and the stage of the illness.

The other limitation of the study is that it did not take into account heterogeneity among caregivers. This diversity results from variation in care-giving experiences, care receivers' characteristics as well as inherent individual differences among caregivers all of which can influence the health and economic outcomes of care-giving. The sample size of HIV caregivers did not however allow for stratification or differentiation based on these intervening factors. The study was also not able to isolate if the observed health or economic outcomes were attributed exclusively to care-giving or other personal or macro-level factors. Although attempts were made to control for some of the factors during analysis, variables that account for differences were not exhaustive.

The stigma and discrimination surrounding HIV/AIDS, lack of disclosure of serological status, and the low uptake of HIV-testing compel many studies on HIV/AIDS to use covert or indirect approaches in identification of cases. This was the case with this study also. The majority of HIV caregivers were identified using the WHO AIDS case definition which relies on the presence of opportunistic infections to make the

diagnosis. The covert nature of the study therefore makes it difficult to comprehensively study care-giving to people with a stigmatized condition. One of the comparison groups used in the study (other caregivers) may contain HIV caregivers.

Household dissolution and out-migration of members as a result of being affected by HIV/AIDS has been reported in several studies. Such households dissolve because of being adversely affected and are therefore unable to cope. This study was however not able to capture this type of household given the cross-sectional nature of the study and the fact that only people who were currently resident in the DSA at the time of the interview were eligible to participate in the study.

9.2 Policy and programme implications

HIV/AIDS prevention campaigns need to be intensified and sustained in order to curb the spread of HIV by reducing the incidence rate. This includes encouraging and facilitating counselling and testing for HIV as it promotes behaviour change for the infected and uninfected and it also facilitates prevention of mother-to-child transmission. Additionally, comprehensive care for PLWHA including access and monitoring of antiretroviral therapy (ART) should be scaled-up and strengthened in order to improve the health of those infected and reduce the intensity and need for care.

Informal care-giving to people ill with HIV/AIDS will, however, continue to play a very crucial role and fill a void brought about by the inability of the formal healthcare system to meet the needs of PLWHA. Older people will continue to bear the brunt of this burden. To alleviate the burden of care-giving, there is need for practical and other forms of support. While the current National Strategic Plan for HIV/AIDS seeks to improve the quality of life of those infected and affected; and to mitigate the socio-economic impact of the epidemic, details on how these objectives are to be implemented are not clearly stated.

This study recommends the introduction of a cash transfer system to assist older people who are caregivers as this will assist in alleviating financial challenges. Such programs have been successful in countries such as South Africa, Botswana, Namibia and Lesotho. Older people can be identified with the help of Community Based Organizations (CBOs). These organizations are best placed to provide HIV/AIDS-related care and support services in the community as they are within the reach of those

infected and affected by HIV/AIDS and therefore provide a link between national programs and those affected. There is also a need for CBOs that specifically target older people.

Support groups for PLWHA have been very successful in meeting the needs of its members. Informal caregivers do face a similar situation with PLWHA such as feelings of impending death, grief, isolation, helplessness, and hopelessness. Support groups for older people who are caregivers would provide a forum to bring caregivers together to share their experiences. They can therefore benefit from how to deal with challenging issues such as how they feel about care-giving, fear of contagion and infection, grief, changes in their lives, and health concerns. These groups can act as a platform for advocating for the needs of caregivers and in raising awareness in the community of the challenges facing members of the group.

This study has highlighted the role of older men as caregivers. There is a need therefore to acknowledge at the policy and programme level the role that older men play. Interventions targeted at people affected by HIV/AIDS should include men. This may entail having gender-neutral or gender-specific interventions that focus on men. Women have been seen as the *face of HIV/AIDS care* and support with several studies pointing out that older women are disproportionately affected as they are solely responsible for the care of persons infected with HIV/AIDS. The higher life expectancy of women compared with men also leads to over-representation of women in HIV/AIDS care studies. These factors therefore have led to the over-emphasis of studies and interventions on women.

Care-giving should not only be viewed as provision of personal care and domestic tasks, but should have a broader multi-dimensional definition that encompasses all aspects of care. To be able to comprehensively mitigate the impact of HIV/AIDS on caregivers, there is need to acknowledge and understand the role and challenges in care-giving faced by both male and female caregivers.

Caregivers take up the role of care-giving with little or no preparedness. While there is willingness at the national level to assist those affected by HIV/AIDS as indicated in the National Strategic Plan for HIV/AIDS, the majority of the caregivers are not aware of what action to take or where to go for help or support. Public campaigns should

therefore be initiated to educate the public on where they need to go for help or the steps to take when faced with the task of care-giving. For instance, Kenya' National AIDS Control Council (NACC) has set up offices at the constituency level and constituency AIDS control committees whose role is to monitor HIV/AIDS activities at the constituency level. These offices can therefore act as resource centres for the public.

9.3 Priority for further research

The gaps or limitations highlighted in this study provide pointers to areas that should be given priority in future research on older people and HIV/AIDS. These include studies of a longitudinal nature which might provide a better picture in order to fully measure the health and economic impact of HIV/AIDS and to understand the timings and sequencing of events for an epidemic with a long incubation period. A longitudinal study will also enable the isolation of intervening factors that may impact on the outcome being observed thereby identifying factors that are directly attributed to being affected by HIV/AIDS. Action-oriented research can also be incorporated in studies with longitudinal designs in order to understand the effectiveness of different interventions aimed at mitigating the impact of HIV/AIDS. The negative health and economic outcomes of care-giving may fluctuate over time, recur, or emerge at a later time hence a longitudinal study would capture these events and their timings. Researchers however need to be aware of the limitation that may complicate longitudinal studies, for instance high costs and loss to follow up.

The generalisability of findings from this study may be limited to the slum areas of Nairobi which are similar with respect to economic and health characteristics (APHRC, 2002). It is therefore recommended that similar studies be replicated in other settings for instance rural areas or non-slum areas of the city. Another priority area for research is male caregivers who unlike women have been relatively understudied. Therefore more research is needed to gain better insights on their role as caregivers, such as their perception on care-giving, the challenges they face in care-giving, and their needs as caregivers.

Another gap in research on older people and HIV/AIDS is the direct form of impact where older people themselves are infected with HIV/AIDS. Routine data collection on HIV/AIDS should therefore include older people. For instance, the Demographic and Health Surveys can have a sub-sample focusing on older people for testing and also

collecting information on their knowledge, attitudes, and practice regarding sexual behaviour and HIV/AIDS. In this regard, Swaziland and Kenya are among the very few countries that have included testing of older people in their most recent population-based surveys. Other systems that are meant to monitor HIV/AIDS in Kenya include Behavioural Sexual Surveillance surveys which are conducted every two years on selected populations. These surveys should also include older people. Even though older people are left out of sentinel surveillance on HIV prevalence conducted through antenatal clinics, small scale studies focusing on testing and related studies on older people can be commissioned. Other avenues for collecting information on older people are the demographic surveillance systems (DSS) which can provide a framework for HIV testing, monitoring, and HIV-related surveys on older people. Currently, there are at least five such systems in Kenya.

Appendix 1: Studies on Impact of HIV/AIDS on Older People

	Country of study	Investigators and Institutions	Project title and objectives of study	Year	Type of study	Methods of data collection	Sample size	Age defining older people	Selection of cases
1	Thailand	J. Knodel et al Population Studies Center University of Michigan	National study on the "Socio-demographic Impact of AIDS on Older Persons" 8 provinces covering both rural and urban. Focus: *morbidity and mortality*	1999	Cross-sectional	Quantitative	768 AIDS cases	50+	Purposive sampling using staff of local hospitals as key informants & respondents; persons who had died due to AIDS or were living with AIDS
			Bangkok city and 3 provinces Focus: *morbidity and mortality*	1999	Cross-sectional	Qualitative	20 parents	50+	Purposive sampling using staff of local hospitals as key informants; persons who had died due to AIDS or were living with AIDS
			Study in 3 provinces Focus: *morbidity and mortality*	2000	Cross-sectional	Quantitative	649 AIDS parents (394 interviews)	50+	Staff of local hospitals as key informants; persons who had died due to AIDS or were living with AIDS

	Country of study	Investigators and Institutions	Project title and objectives of study	Year	Type of study	Methods of data collection	Sample size	Age defining older people	Selection of cases
2	Cambodia	J. Knodel et al Population Studies Center University of Michigan	"Survey of Elderly in Cambodia" The Impact of AIDS on Older-age Parents in Cambodia covering Phnom Penh and 5 other provinces both rural and urban Focus: *morbidity and mortality*	2004 - 2005	Cross-sectional	Quantitative	1273 older people	60+	Stratified representative sampling
3	India	A. Bhardwaj AVNI Health Foundation, Mumbai India	Impact of HIV/AIDS *Focus: morbidity and mortality*	2006					
4	Tanzania	J. Appleton	participatory rural appraisal (PRA) exercise for a community fisheries project *Focus: mortality*	1992	Cross-sectional	Qualitative – case studies, focus group discussions			Purposive sampling
5	Tanzania	Ainsworth et al Policy Research Division World Bank	"The economic impact of fatal adult illness due to AIDS and other causes in sub-Saharan Africa" measure the impact of prime-aged adult deaths on the welfare of surviving household members in the Kagera region (KHDS) Focus: *mortality*	1991 - 1994	Longitudinal study	Quantitative	565	50+	Stratified sampling; selection of households which reported an adult death due to illness or with a sick adult too sick work or both
6	Uganda	Williams et al University of Queensland Australia and MRC (UK), Uganda	multiple impacts of HIV/AIDS on older persons *Focus: mortality*	1996-1997	Longitudinal study	Qualitative	30	60+	Random sampling

	Country of study	Investigators and Institutions	Project title and objectives of study	Year	Type of study	Methods of data collection	Sample size	Age defining older people	Selection of cases
7	South Africa	Ferreira et al University of Cape Town South Africa	Inform on the design and implementation of an intervention study in 4 townships near Cape Town *Focus: morbidity and mortality*	1999 - 2001	Longitudinal study	Qualitative	43	50+	Purposive sampling of mulit-generational households with child with AIDS, AIDS orphans or both & the older person is aware of status
8	Kenya	Nyambedha et al Maseno University, Kenya	Foster parenting (role as grandparents) *Focus: mortality*	1999 - 2000	Cross-sectional	Quantitative and Qualitative	100	55+	Purposive sampling
9	South Africa	Victoria Hosegood and Ian Timaeus	The impact of adult mortality on the living arrangements of older people in rural South Africa *Focus: Mortality*	2000 - 2002	Longitudinal study	Quantitative	3,657 older people	60+ for women & 65+ for men	All households with older people living in the surveillance area
10	Zimbabwe	WHO	"Impact of AIDS on older people in Africa" designed to develop a methodology to examine the impact of HIV/AIDS on older caregivers. National study covering all 6 provinces & included both rural & urban; ethnicity taken into consideration *Focus: morbidity and mortality*	2001	Cross-sectional	Quantitative and Qualitative	685 older people	50+	Purposive sampling using community health workers, nurses, and volunteer HIV/AIDS care providers to locate older persons providing care to a sick person due to AIDS or did so in the past
11	Kenya	Horizons Program and Plan International Kenya	Exploratory study on the roles of older people in caring for PLWHA and AIDS-affected children, the challenges and their coping mechanism *Focus: morbidity and mortality*	2003	Cross-sectional	Qualitative	61	50+	Purposive sampling

	Country of study	Investigators and Institutions	Project title and objectives of study	Year	Type of study	Methods of data collection	Sample size	Age defining older people	Selection of cases
12	Uganda	J. Kakooza Makerere Institute for Social Research (MISR) Makerere University	The role, constraints and consequences of older people as providers of basic education for their grandchildren who are orphaned by HIV/AIDS-related death; 6 counties in Kayunga district *Focus: mortality*	2004	Cross-sectional	Quantitative and Qualitative	94	50+	Random sampling of districts & households; selected households either experienced death or caring for orphans
13	Botswana	Ingstad et al	AIDS and the elderly person *Focus: HIV/AIDS infection and prevention*		Cross-sectional	Qualitative	346	60+	Purposive sampling
14	South Africa	S. Madhavan et al University of Colorado at Boulder	Impact of mortality and morbidity on older people *Focus: morbidity and mortality*	2005	Cross-sectional	Qualitative	60	60+	Purposive sampling
15	Togo	A. M. Moore University of North Texas	Comparative analysis of AIDS and malaria death. *Focus: mortality*	2006	On-going				
16	South Africa	Chantal	Growing old with AIDS: Targeting older people for a change [Social Aspects of HIV/AIDS]	2006	On-going				

Source: Authors own compilation

Appendix 2: Research Permit

CONDITIONS

1. You must report to the District Commissioner of the area before embarking on your research. Failure to do that may lead to the cancellation of your permit.
2. Government Officers will not be interviewed without prior appointment.
3. No questionnaire will be used unless it has been approved.
4. Excavation, filming and collection of biological specimens are subject to further permission from the relevant Government Ministries.
5. You are required to submit at least four (4) bound copies of your final report.
6. The Government of Kenya reserves the right to modify the conditions of this permit including its cancellation without notice.

GPK 7092—6m—11/96

REPUBLIC OF KENYA

RESEARCH CLEARANCE PERMIT

(CONDITIONS—*see* back page)

PAGE 2

THIS IS TO CERTIFY THAT:

Prof./Dr./Mr./Mrs./Miss ALEX CHIKA EZEH

of (Address) P.O. Box 10787-00100 NAIROBI

has been permitted to conduct research in KASARANI AND MAKANDARA Location,

NAIROBI District,

NAIROBI Province,

on the topic INTERVENTIONS TO REDUCE INFANT MORTALITY AMONG SLUM RESIDENTS OF NAIROBI CITY.

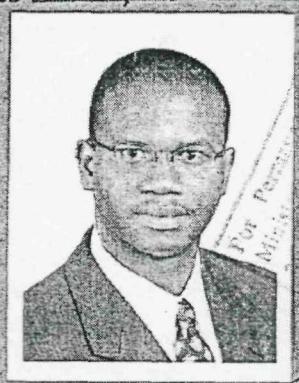
for a period ending 30th September 2006

PAGE 3

Research permit No. MOEST 13/3/297

Date of issue 13-10-03

Fee received KSH.1000.00



A.G. KAARIA

Applicant's Signature

FOR: *Permanent Secretary, ~~Office of the President~~*
MINISTRY OF EDUCATION

Appendix 3: Ethical Approval Letter

KENYA MEDICAL RESEARCH INSTITUTE

P.O. Box 54840-00200 NAIROBI, Kenya
Tel: +254 (020) 2722541, 2713349, 0722-205901, 0733-400003, Fax +254 (020) 2720030,
E-mail: director@kemri.org; info@kemri.org Website: www.kemri.org

KEMRI/RES/7/3/1 **22nd Aug 2006**

Dr. Alex Ezeh,
African Population and Health Research Center (APHRC)
Shelter Afrique Center
PO Box 10787, 00100
NAIROBI.

Dear Sir,

Re: NON-SSC Protocol – **Migration, Poverty and the wellbeing of older people, by Alex Ezeh *et al***

Thank you for your letter dated August 28th 2006. We acknowledge receipt of the scientific approval of the protocol.

The Committee is satisfied that the issue raised at the 136th meeting of the KEMRI/National Ethical Review Committee held on 22nd Aug 2006 has been adequately addressed.

The study is hereby granted approval. You are responsible for reporting to the Ethical Review Committee any changes to the protocol or in the Informed Consent Document. This includes changes to research design or procedures that could introduce new or more than minimum risk to human subjects.

You may embark on your study.

R.C.M. Kithinji
For: Secretary,
KEMRI/National Ethical Review Committee

Appendix 4: Socio-demographic characteristics of Indepth interview participants

ID code	Place of residence	Sex	Age	Ethnic group	Marital status	Highest education level	working at time of interview	Usual/last work activity	Household size	Care-giving at time of interview	No. of care experiences	Caregivers relationship to index care recipient	Age of index care recipient
KM001	Korogocho	Male	84	Kikuyu	Married	No education	No	Formal employment	2	No	Multiple	Parent	38
KF002	Korogocho	Female	64	Kikuyu	Married	No education	No	Formal employment	2	No	Multiple	Parent	38
KM003	Korogocho	Male	52	Kikuyu	Married	Primary	Yes	Urban farming	6	Yes	Single	Parent	17
KF004	Korogocho	Female	51	Kikuyu	Married	Primary	Yes	Urban farming	6	Yes	Single	Parent	17
KF005	Korogocho	Female	58	Kikuyu	Widowed	Primary	Yes	Own business/ enterprise	4	Yes	Single	Grandparent	3
KF006	Korogocho	Female	63	Kikuyu	Widowed	No education	No	Rural farming	7	Yes	Single	Parent	33
KM007	Korogocho	Male	57	Kikuyu	Married	Primary	Yes	Own business/ enterprise	2	No	Single	Parent	20
KF008	Korogocho	Female	58	Kikuyu	Divorced/ separated	No education	No	Own business/ enterprise	4	No	Multiple	Other relation	98
VM009	Viwandani	Male	62	Luhya	Married	Primary	Yes	Informal employment	10	Yes	Multiple	Parent	37
VF010	Viwandani	Female	54	Luhya	Married	No education	No	Own business/ enterprise	10	Yes	Multiple	Parent	34

ID code	Place of residence	Sex	Age	Ethnic group	Marital status	Highest education level	working at time of interview	Usual/last work activity	Household size	Care-giving at time of interview	No. of care experiences	Caregivers relationship to index care recipient	Age of index care recipient
VM011	Viwandani	Male	59	Kamba	Widowed	Primary	No	Formal employment	3	Yes	Multiple	Parent	25
VM012	Viwandani	Male	54	Kisii	Married	Secondary or higher	Yes	Formal employment	2	Yes	Multiple	Sister	49
VM013	Viwandani	Male	62	Kikuyu	Married	Primary	Yes	Informal employment	5	No	Multiple	Uncle	22
VF014	Viwandani	Female	50	Kikuyu	Married	Primary	No	Own business/ enterprise	5	Yes	Multiple	Auntie	22
VM015	Viwandani	Male	55	Luhya	Married	Primary	Yes	Formal employment	1	Yes	Single	Grandparent	6
VM016	Viwandani	Male	54	Kamba	Married	Primary	Yes	Informal employment	2	Yes	Single	Parent	24
VF017	Viwandani	Female	52	Kikuyu	Divorced/ separated	Primary	Yes	Own business/ enterprise	2	No	Multiple	Parent	23
VM018	Viwandani	Male	63	Kikuyu	Married	Primary	Yes	Informal employment	3	No	Multiple	Parent	38
VM019	Viwandani	Male	54	Kikuyu	Married	Primary	Yes	Formal employment	6	Yes	Multiple	Uncle	4
KF020	Korogocho	Female	63	Kikuyu	Never married	Primary	Yes	Own business/ enterprise	3	Yes	Single	Parent	30
KM021	Viwandani	Male	69	Kamba	Married	No education	Yes	Own business/ enterprise	1	Yes	Single	Spouse	42

ID code	Place of residence	Sex	Age	Ethnic group	Marital status	Highest education level	working at time of interview	Usual/last work activity	Household size	Care-giving at time of interview	No. of care experiences	Caregivers relationship to index care recipient	Age of index care recipient
KM022	Korogocho	Male	55	Luo	Married	Primary	Yes	Own business/ enterprise	2	Yes	Multiple	Sibling	58
KF023	Korogocho	Male	56	Luhya	Married	Primary	Yes	Own business/ enterprise	4	Yes	Multiple	Spouse	36
KF024	Korogocho	Female	52	Kikuyu	Divorced/ separated	Secondary or higher	No	Informal employment	10	Yes	Single	Child	69
KF025	Korogocho	Female	66	Kikuyu	Divorced/ separated	Primary	No	Own business/ enterprise	10	Yes	Single	Parent	49
KF026	Korogocho	Female	66	Kikuyu	Married	Primary	Yes	Formal employment	5	Yes	Multiple	Other relation	98
KF027	Korogocho	Female	60	Kamba	widowed	Secondary or higher	No	Informal employment	6	Yes	Multiple	Other relation	33
KM028	Korogocho	Male	63	Kikuyu	Married	No education	No	Other type of employment	4	Yes	Multiple	Parent	34
KF029	Korogocho	Female	55	Luhya	widowed	Primary	Yes	Formal employment	2	Yes	Single	Other relation	28
KF030	Korogocho	Female	50	Kamba	Married	Primary	Yes	Informal employment	2	No	Single	Other relation	54
KF031	Korogocho	Female	56	Kikuyu	widowed	No education	Yes	Own business/ enterprise	4	No	Multiple	Sibling	24

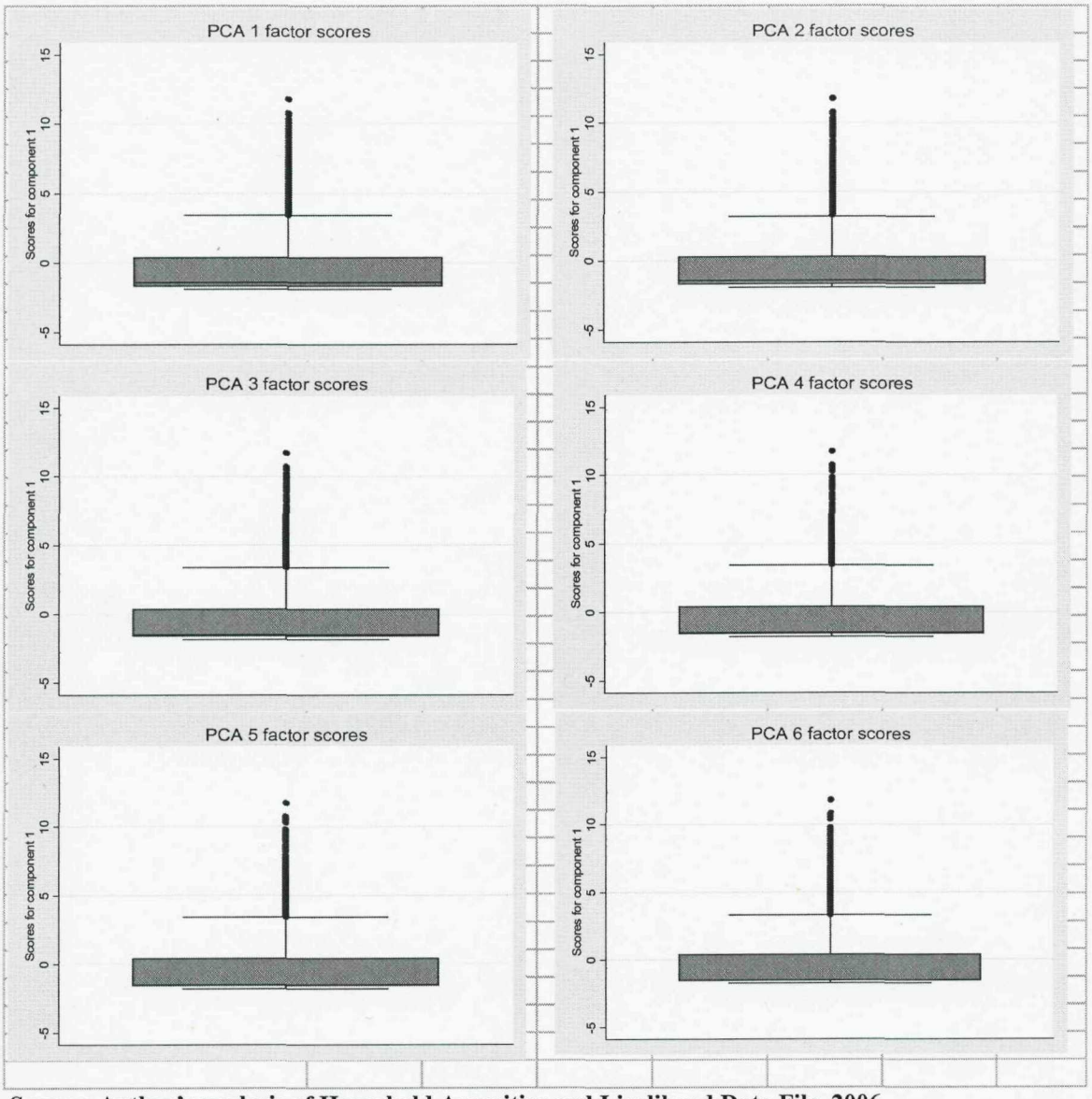
Source: Author's analysis of NUHDSS Individual Data File 2006 and Qualitative Indepth Interview Data 2007

Appendix 5: Variable selection and factor scores for first principal component

Indicator variables	PCA 1	PCA 2	PCA 3	PCA 4	PCA 5	PCA 6	PCA 7	PCA 8
Television	0.2012	0.2011	0.2001	0.2009	0.2009	0.2013	0.2014	0.2230
Radio	0.3003	0.3004	0.3008	0.3014	0.3014	0.3016	0.3020	0.3195
DVD recorder	0.1212	0.1212	0.1199	0.1205	0.1206	0.1210	0.1211	0.1362
Sewing machine	0.0927	0.0927	0.0925	0.0925	0.0925	0.0927	0.0926	0.1024
Iron	0.1053	0.1053	0.1045	0.1046	0.1044	0.1048	0.1049	0.1184
Phone	0.2131	0.2130	0.2123	0.2130	0.2129	0.2131	0.2131	0.2319
Sofa	0.2733	0.2733	0.2731	0.2735	0.2736	0.2739	0.2745	0.2952
Table	0.3155	0.3156	0.3164	0.3171	0.3172	0.3177	0.3189	0.3323
Torch	0.2630	0.2631	0.2634	0.2642	0.2644	0.2646	0.2650	0.2830
Lamp	0.2789	0.2789	0.2796	0.2795	0.2797	0.2798	0.2800	0.2975
Kerosene stove	0.3034	0.3034	0.3042	0.3057	0.3057	0.3063	0.3074	0.3227
Wall clock	0.2335	0.2335	0.2332	0.2337	0.2337	0.2340	0.2339	0.2539
Mattress	0.3160	0.3161	0.3170	0.3179	0.3179	0.3184	0.3194	0.3295
Blankets	0.3152	0.3153	0.3162	0.3172	0.3172	0.3176	0.3188	0.3285
Bed	0.3145	0.3145	0.3155	0.3164	0.3164	0.3168	0.3180	
Cows	0.0536	0.0537	0.0545	0.0512	0.0510	0.0499	0.0482	
Goats	0.0427	0.0428	0.0435	0.0409	0.0409	0.0403	0.0393	
Chicken	0.0511	0.0512	0.0519	0.0496	0.0495	0.0490	0.0487	
Other livestock	0.0553	0.0555	0.0561	0.0533	0.0532	0.0526	0.0518	
Kerosene or candles for lighting	-0.0120	-0.0114	-0.0107	-0.0098				
Gass or electricity for lighting	0.0153	0.0152	0.0142	0.0132				
Kerosene or candles for lighting	-0.0305	-0.0302						
Gass or electricity for lighting	0.0305	0.0302						
Shared toilet not paid per use	-0.0396	-0.0395	-0.0403					
shared toilet paid per use	0.0355	0.0356	0.0368					
Own toilet	0.0136	0.0132	0.0126					
Natural floor	-0.0553	-0.0552	-0.0529	-0.0505	-0.0503	-0.0464		
Cemented, PVC or wooden floor	0.0546	0.0545	0.0522	0.0498	0.0496	0.0457		
Mud, tin or plastic walls	-0.0335	-0.0335	-0.0322	-0.0291	-0.0288			
Mud walls plasted with cement	0.0198	0.0199	0.0184	0.0188	0.0185			
Brick or wooden walls	0.0195	0.0194	0.0192	0.0157	0.0156			
Number of original variables	33	31	29	26	24	21	19	14
Principal components extracted	9	8	8	6	5	4	3	2
Eigenvalue of the 1st PC	8.09	8.09	8.08	8.06	8.06	8.05	8.02	7.19
Percent of variance of 1st PC	0.25	0.26	0.28	0.31	0.34	0.38	0.42	0.51

Source: Author's analysis of Household Amenities and Livelihood Data File, 2006

Appendix 6: Box plots for Index for principal component analysis



Source: Author's analysis of Household Amenities and Livelihood Data File, 2006

Appendix 7: Questionnaire for the survey on social, health, and overall wellbeing of older people

AFRICAN POPULATION AND HEALTH RESEARCH CENTRE AND WHO/INDEPTH
SURVEY ON SOCIAL, HEALTH AND OVERALL WELLBEING OF OLDER PEOPLE (50+ YEARS)

1.0 IDENTIFICATION INFORMATION

1.1 FIELD WORKER'S CODE

1.2 DATE OF INTERVIEW (DD/MM/YYYY)

1.3 RESPONDENT'S ID

1.4 RESPONDENT'S DATE OF BIRTH (DD/MM/YYYY)

1.5 RESPONDENT'S SEX **(F=Female; M=Male)**

1.6 RESPONDENT'S FULL NAME _____

1.7 ID OF ROOM WHERE RESPONDENT SLEEPS

1.8 INDICATE VIGNETTE TYPE A=Set A B=Set B C=Set C D=Set D N=No vignette [N]

1.0 INTRODUCTION AND CONSENT

Hello, my name is _____ and I work with the African Population and Health Research Centre. We are conducting a survey to better understand the health and well-being of older people in this community Specifically we would like to know about your health, your economic challenges, the care and support you need or receive, and the experiences you go through such as caring for people who are ill, caring for younger children and so on. The results of this study will be presented to institutions, including the government, that are involved in decision making and provision of services targeted at older people with the intention that they will use the information to improve the wellbeing of older people. All the responses you provide are confidential and will be used for the purposes of this study only. This interview is not expected to cause you any harm or discomfort. However, if you feel uncomfortable with certain questions you can choose not to answer them. We, however, hope you will participate in this survey since your views are very important. This interview will take about XX minutes of your time.

1.9 Do you accept to participate in the study? **(Y=YES; N=NO; IF 'YES' SKIP TO 1.11)**

1.10 IF THE RESPONDENT DOES NOT ACCEPT TO BE INTERVIEWED ASK: To help better inform our work in the future, could you please tell me the main reason why you do not want to participate in this study? .....

(FW: IF REASON IS RELATED TO TIME BEING INCONVENIENT FOR RESPONDENT, PLEASE MAKE APPOINTMENT TO COME BACK AND DO THE INTERVIEW).
OTHERWISE THANK RESPONDENT FOR HIS/HER TIME AND END THE INTERVIEW.

1.11 IF THE RESPONDENT ACCEPTS TO BE INTERVIEWED: Thank you for agreeing to participate in our study. Could you please sign here to show that you have accepted to participate in the study.

Respondent's Signature.....

0= IF RESPONDENT REFUSES TO SIGN 1= IF RESPONDENT SIGNS

1.12 FINAL RESULT OF INTERVIEW **(CODE SHEET A[7])**

1.13 START TIME (24 HR-FORMAT)

OFFICE/FIELD CHECK DETAILS

1.14 FIELD SUPERVISOR'S/TEAM LEADER'S CODE

1.15 DATA ENTRY CLERK'S CODE

2.0 MARITAL STATUS

2.1 Are you currently married or living with a man/woman? (Y=YES; N=NO) **[IF NO, SKIP TO 2.3]** ☐

2.2 How would you best describe your type of marriage - did you have a religious ceremony, a civil registration, customary or traditional ceremony or just living together? 1=religious ceremony, 2=civil registration only, 3=customary/traditional marriage only, 4=just living together? **[SKIP TO 2.5]** ☐

2.3 Have you ever been married or lived with a man/woman? (N=NO; Y=YES) **[IF NO, SKIP TO 3.0]** ☐

2.4 How did your last marriage/union end? Are you widowed, divorced, or separated? (W=WIDOWED; D=DIVORCED; S=SEPARATED) ☐

2.5 How many times have you been married or lived with a man/woman in your lifetime? [INCLUDE CURRENT SPOUSE FOR THOSE CURRENTLY MARRIED/LIVING WITH A MAN/WOMAN]. ☐☐

2.6 How old were you when you got married or started living with a man/woman for the first time? ☐☐

[CHECK 2.3, IF YES SKIP TO 2.16];
IF A MAN (IF 1.5 IS MALE) AND CURRENTLY MARRIED/LIVING TOGETHER (IF 2.1 IS YES), [SKIP TO 2.12]

DETAILS ABOUT CURRENT/MOST RECENT SPOUSE FOR WOMEN CURRENTLY MARRIED/LIVING TOGETHER

2.7 Does your husband/partner usually live in this household? (Y=YES; N=NO) **[IF YES SKIP TO 2.9]** ☐

2.8 Where does he live? **[CODE SHEET A[5]]** ☐

2.9 In what year and month did you get married/living together with your current husband/partner?

MONTH ☐☐ YEAR ☐☐☐☐

2.10 Does your husband/partner have any other wife/wives besides yourself? (N=NO; Y=YES) ☐
[IF "NO", SKIP TO 3.0]

2.11 How many other wives does he have? NUMBER ☐☐
[SKIP TO 3.0]

DETAILS ABOUT CURRENT/MOST RECENT SPOUSE FOR MEN CURRENTLY MARRIED/LIVING TOGETHER

2.12 How many wives/partners do you currently have? ☐☐

2.13 [IF MORE THAN ONE] Are you living with your wife/partner in this household? (N=NO; Y=YES)
[IF HAS ONLY ONE] Does your wife/partner usually live in this household? (N=NO; Y=YES) ☐
[IF Y SKIP TO 2.15]

2.14 [IF HAS MORE THAN ONE] Where does your most recent wife live? **[CODE SHEET A[5]]** ☐

2.15 In what month and year did you get married/living together started with your (MOST) recent wife/partner?

MONTH ☐☐ YEAR ☐☐☐☐
[SKIP TO 3.0]

2.16 In what month and year did you get separated/divorced/widowed in your most recent marriage/union?

MONTH ☐☐ YEAR ☐☐☐☐

3.0 CHILD BEARING HISTORY, CARE AND SUPPORT

Now I would like to ask about all the births/children you have had during your life including any children whom you raised as your own and are now grown up. We will also talk about children who are deceased if any. It may be painful to talk about this but it is important that we get the right information.

3.1 Have you ever given birth/Have you ever had any children of your own? ☐
(Y=YES; N=NO; If 'NO' skip to 3.3)

3.2 In total, how many children have you given birth to/have you had, including those that have died? ☐☐

3.3 Do you have any children you did not give birth to but whom you raised as your own? **(Y=YES; N=NO)** ☐
[If 'NO' in 3.1 & 'NO' in 3.3; SKIP TO 3.21]

3.4 In total how many children did you not give birth to but raised as your own? ☐☐

Now I would like us to talk about all your biological children including any children you may have raised as your own even if you did not give birth to them. We are interested in both those who are still alive and those who have passed away. We will begin by talking about your biological children first starting with the first one you had.

3.5	3.6	3.7	3.8	3.9	3.10	3.11	3.12	3.13	3.14	3.15	3.16	3.17	3.18
					IF 12 YRS OR OLDER			IF ALIVE			IF DEAD		
What name was given to your first (next) child?	Is (NAME) *male (M)* or female (F)?	Is (NAME) still alive or not? ***(Y=Alive; N=Dead)***	In what month and year was (NAME) born? ***(If 'Alive' skip to 3.10)***	If (NAME) DIED, In what month and year did (NAME) die?	Has/ was (NAME) ever/been married? ***IF YES*** What is/was (NAME)'s marital status?	How many children does/ did (NAME) have, if any? IF NO ENTER 00	Where did (NAME)/does (NAME) currently live? ***(CODE SHEET A[5])***	How frequently do you see each other with (NAME)? (UNITS W=WEEK, M=MONTH, Y=YEAR	On average, how much money do you receive from (NAME) each month?	In what other ways does (NAME) support you? 1=No other support 2=Household chores 3=Health care 4=2&3 5=Other	Did (NAME) die of injury or illness? [1=INJURY; 2=ILLNESS] IF 2 SKIP TO 3.18	(If died of illness) Did you regularly provide care to (NAME) at the time of his/her illness? (Y=YES; N=NO)	Did (NAME) regularly contribute financially towards your upkeep/ support before their death? (Y=YES; N=NO)
1			M Y	M Y				U #					
2			M Y	M Y				U #					
3			M Y	M Y				U #					
4			M Y	M Y				U #					
5			M Y	M Y				U #					
6			M Y	M Y				U #					

3.5	3.6	3.7	3.8	3.9	3.10	3.11	3.12	3.13	3.14	3.15	3.16	3.17	3.18
					IF 12 YRS OR OLDER			IF ALIVE			IF DEAD		
What name was given to your first (next) child?	Is (NAME) male (M) or female (F)?	Is (NAME) still alive or not? *(Y=Alive; N=Dead)*	In what month and year was (NAME) born? *(If 'Alive' skip to 3.10)*	If (NAME) DIED, In what month and year did (NAME) die?	Has/ was (NAME) ever/been married? *IF YES* What is/was (NAME)'s marital status?	How many children does/ did (NAME) have, if any? IF NO ENTER 00	Where did (NAME)/does (NAME) currently live? *(CODE SHEET A[5])*	How frequently do you see each other with (NAME)? (UNITS W=WEEK, M=MONTH, Y=YEAR	On average, how much money do you receive from (NAME) each month?	In what other ways does (NAME) support you? 1=No other support 2=Household chores 3=Health care 4=2&3 5=Other	Did (NAME) die of injury or illness? [1=INJURY; 2=ILLNESS] IF 2 SKIP TO 3.18	*(If died of illness)* Did you regularly provide care to (NAME) at the time of his/her illness? (Y=YES; N=NO)	Did (NAME) regularly contribute financially towards your upkeep/ support before their death? (Y=YES; N=NO)
6			M Y	M Y				U #					
7			M Y	M Y				U #					
8			M Y	M Y				U #					
Now I would like us to talk about the children you did not give birth to but raised as your own, both those who are alive and those who have passed away. Starting with the eldest/oldest.													
1			M Y	M Y									
2			M Y	M Y									
3			M Y	M Y									

I would like to ask you some questions about the support you provide to your children and the support that you may receive from others.

3.19 *Do you provide any of your children with financial support or assistance?* **(Y=YES; N=NO)** ☐

3.20 Do you assist any of your children in/by .....

	Yes	No
a. Caring for their children	Y	N
b. Doing domestic chores for them	Y	N
c. Providing material support (food, clothing..)	Y	N
d. Providing advice or counseling	Y	N
e. Other (specify)	Y	N

3.21 Who normally provides the most assistance to you with work around the house such as cooking, cleaning, collecting water and so on? **RECORD RELATIONSHIP TO RESPOPNDENT (CODE SHEET A[3])**

3.22 Do you usually require assistance to get somewhere outside the community, for example going to town, to the market etc? ☐ **(Y=YES; N=NO; If 'NO' skip to 3.24)**

3.23 Suppose you wanted to go somewhere outside the community, who normally assists you or accompanies you to places outside the community? ☐☐☐
RECORD RELATIONSHIP TO RESPOPNDENT (CODE SHEET A[3])

3.24 Do you receive any kind of assistance or support from any of your relatives (other than children)? ☐
(Y=YES; N=NO; If 'NO' skip to 3.26)

3.25 What type of assistance or support do you receive from your relatives?

CIRCLE ALL MENTIONED

Financial ....A
Material support (food, clothing) ....B
Shelter or rent payment C
Assist in domestic chores ....D
Advice or counsel ....E
Emotional support ....F
Other (Specify) ....G _____
Other (Specify) ....H _____
Other (Specify) .....I _____

3.26 Are you aware of any organizations or groups that provide assistance such as financial, material, or emotional support to older people in this community? ☐ **(Y=YES; N=NO; If 'NO' skip to 4.0)**

3.27 Which are these groups or organizations that provide assistance to older people?

CIRCLE ALL MENTIONED

Catholic Church/Sisters ....A
Muslim groups ....B
Redeemed Gospel Church C
TAK (Tekataka Afya Korogocho) ....D
Women's Groups ....E
KENWA\ Orphans\ HIV\AIDS ....F
Government/DO/Chief ....G
Other (Specify) ....H _____
Other (Specify) .....I _____
Other (Specify) .....J _____

3.28 Have you received assistance from any of these groups or organizations in the last 12 months? ☐
(Y=YES; N=NO; If 'NO' skip to 4.0)

3.29 From which groups or organizations have you received the most assistance?

CIRCLE ONLY ONE

Catholic Church/Sisters ..1
Muslim groups ..2
Redeemed Gospel Church ..3
TAK (Takataka Afya Korogocho) ..4
Women's Groups ..5
KENWA\ Orphans\ HIV\AIDS ..6
Government/DO/Chief ..7
Other (Specify) ..8

3.30 What is the main type of assistance or support have you received from this organization or group?

CIRCLE ALL MENTIONED

Financial ..1
Material support (food, clothing) ..2
Shelter or rent payment ..3
Support for the OVC ..4
Care and support for PLWHA ..5
Other (Specify) ..6

3.31 How often do you receive assistance from this organization of group?

W=WEEKLY; M=MONTHLY; Y=YEARLY; O=OTHER ☐ NO. OF TIMES ☐☐

Other (Specify) _____

4.0 LINKS WITH PLACE OF ORIGIN

4.1 What is the name of the area where you consider as your place of origin?

(RECORD THE PROVINCE/DISTRICT/LOCATION/VILLAGE OR ESTATE)

(P).....(D).....(L).....(V/E).....

4.2 RECORD CODE FOR AREA OF ORIGIN MENTIONED IN 4.1 **(CODE SHEET A[5])** ☐

[IF ANSWER IS 1, 2, 3 or 4, SKIP TO 4.7A]

4.3 When was the last time you visited your place of origin?

MONTH ☐ YEAR ☐☐☐☐

[IF ANSWER IS NEVER RECORD 88 IN MONTH AND 8888 IN YEAR AND SKIP TO 4.5]

4.4 In the last 12 months, how many times have you visited your place of origin? ☐

4.5 When was the last time you had visitors from your place of origin?

MONTH ☐ YEAR ☐☐☐☐

[IF ANSWER IS NEVER RECORD 88 IN MONTH AND 8888 IN YEAR AND SKIP TO 4.7]

4.6 In the last 12 months, how many times have you had visitors from your place of origin? ☐☐

4.7 4.7A. Do the following family members live at your place of origin?				4.7B In the last 12 months, did you have the following family members as visitors?		
	YES	NO			YES	NO
A. Parent/parent-in-laws	Y	N	**If YES ASK -->**	A. Parent/parent-in-laws	Y	N
B. Spouse/partner	Y	N	**If YES ASK -->**	B. Spouse/partner	Y	N
C. Siblings/in-laws	Y	N	**If YES ASK -->**	C. Siblings/in-laws	Y	N
D. Child/Children	Y	N	**If YES ASK -->**	D. Child/Children	Y	N

4.8 Do you have a piece of land anywhere outside Nairobi? **(Y=YES; N=NO)** ☐

4.9 Do you have a house anywhere outside Nairobi? **(Y=YES; N=NO)** ☐

4.10 Do you intend to move away from Korogocho/Viwandani any time in the future? ☐

(Y=YES; N=NO; If 'YES skip to 4.12)

4.11 What is the most important reason why you don't intend to move away from Korogocho/Viwandani?

CIRCLE ONLY ONE RESPONSE

Has no land anywhere else ...1
Has no house anywhere else ...2
Family disputes/ Other disputes at origin 3
Dispossessed of land ownership.....4
Has property in Nairobi ...5
Has family/social networks in Nairobi ...6
Lack finances to migrate back ...7
Conflict of culture e.g intermarriage.....8
Living condition is better here ..10
Rent is affordable/cheap ..11
Get used to the area ..12
Convenient to me/my family members work place ..16
Have no other choice ..17
Other (Specify) ..18

_____

[SKIP TO SECTION 5.0]

4.12 Where do you intend to move to?

CIRCLE ONLY ONE RESPONSE

Place of origin/Place of birth ...1
Another rural place in Kenya ...2
Another urban place in Kenya ...3
Another slum in Nairobi.....4
Outside Kenya ...5
Don't know/Unsure of where to go ...6

4.13 How long from now do you intend to move away from Korogocho or Viwandani?

W=WEEK; M=MONTH; Y=YEAR; D=DON'T KNOW ☐ Duration ☐☐

5.0 WORK HISTORY AND BENEFITS

Now I would like to ask you some questions about any work that you may be doing now or have done in the past.

5.1 As you know, some people take jobs for which they are paid in cash or kind. Other people sell things, have a small business, or work on the family farm or family business. Are you currently working or doing any of these activities (not including housework)? (Y=YES; N=NO; IF 'YES' SKIP TO 5.6) ☐

5.2 What is the main reason you are not currently working or engaged in any income generating activity?

CIRCLE ONE RESPONSE

Homemaker / caring for family 1
Cannot find a job 2
Do voluntary work (not paid) 3
Seasonality of work 4
_____ (specify) Health problems/Disabled 5
Have to take care of someone with disability/health condition 6
Do not have the need to work 7
My family/spouse doesn't want me to work 8
Retired / too old to work 9
Laid off / made redundant 10
Vacation / sick leave / voluntary and temporary time off 11
_____ Other, specify: ...98

5.3 When was the last time you were engaged in an income generating activity?

MONTH ☐☐ YEAR ☐☐☐☐

[IF NEVER WORKED RECORD NA=NOT APPLICABLE IN 'MONTH' THEN ASK 5.4 OTHERWISE SKIP TO 5.5]

5.4 What is the main reason that you have never worked?

CIRCLE ONE RESPONSE

Homemaker / caring for family 1
Could not find a job 2
Do voluntary work (not paid) 3
_____ (Specify) Health problems/Disabled 4
Have to take care of someone with disability/health condition 5
Do not have the economic need 6
Parents / spouse did not let him/her 7
Other, specify: ...8

5.5 Are you actively looking for work at this time? (Y=YES; N=NO) ☐

(IF ANSWER IS NO AND 5.3 IS NA, SKIP TO 5.16; IF ANSWER IS NO AND 5.3 IS NOT NA, SKIP TO 5.7)

5.6 **[NOT CURRENTLY WORKING & LOOKING]** When people become older, they would like to retire from active employment. Why would you like to work at present?

[CURRENTLY WORKING] When people become older, they would like to retire from active employment. *Why are you currently working?*

CIRCLE ALL MENTIONED

- Need the income for self 1
- Need income to support spouse 2
- Need income to support children 3
- Need income to support grand children 4
- Need income to support other family members 5
- Want to/need to be active 6
- Want to feel useful 7
- Not reached retirement age 8
- Other (Specify) 9

5.7 **[CURRENTLY WORKING]** Now I will ask you some questions about your current work. What is your main occupation currently?

[NOT CURRENTLY WORKING] Now I will ask you some questions about your most recent work. What was your main occupation?

- Public.....1
- Private company.....2
- Business.....3
- EPZ.....4
- NGO/international organization.....5
- Domestic.....6
- Family business.....7
- Agriculture, Nairobi.....8
- Other 9

5.8 Do/did you usually work throughout the year, seasonally, or only once in a while? ☐
(1=Work Throughout the year; 2=Seasonally/Part of the year; 3=Once in a while)

5.9 On average, how many days in a week do/did you work in your main job? DAYS ☐

5.10 *On average, how many hours a day do/did you work in your main job?* HOURS ☐☐

5.11 Are/were you paid a salary monthly **(1)**, weekly **(2)**, daily **(3)** or per job done **(4)**? ☐

5.12 Have you ever made any contribution to NSSF or any other pensions or retirement scheme? ☐
(Y=YES; N=NO; D=DON'T KNOW; If 'N' or 'D' skip to 5.15)

5.13 Which pension scheme have you contributed to? **RECORD ALL MENTIONED**

- NSSF ..A..
- Other schemes (specify)...B.. _____
- Other schemes (specify)...C.. _____

5.14 Have you been paid your pension or gratuities? **(Y=YES; N=NO)** ☐

5.15 At what age did you start working for pay? **(DON'T KNOW =98)** ☐☐

5.16 What would you say is your main source of livelihood currently?

CIRCLE ONE RESPONSE

- Own and/or spouse's work 1
- Own savings/investments 2
- Pension/retirement benefit 3
- Support from children 4
- Support from other relatives 5
- Donations/welfare 6
- Other(Specify) 8

6.0 HEALTH CARE UTILIZATION

6.1 In the last 3 months, have you gone to seek health care outside the home? ☐
(Y=YES; N=NO; If 'NO' skip to 6.4)

6.2 Where did you go to seek health care?

NAME OF FACILITY/PROVIDER

_____

_____

Govt health center/dispensary.....1
Private Health center/dispensary.....2
Pharmacist/Drug store.....3
Government hospital.....4
Private hospital.....5
Traditional healer/herbalists.....6
Religious / Prayer houses.....7
Other (specify).....8

6.3 Have you spent on the following health related costs in the last 3 months? (RECORD '00000' IF FOR FREE)

6.6.1 Consultation	☐☐☐☐☐
6.6.2 Hospitalization	☐☐☐☐☐
6.6.3 Medicine/drugs	☐☐☐☐☐
6.6.4 Transportation to health facility	☐☐☐☐☐
6.6.5 Other (specify) _____	☐☐☐☐☐

		6.4A Have you ever been diagnosed with/told you have.....		6.4B [IF 'YES' IN 6.4A] How long ago was this diagnosis made?		6.4C [IF 'YES' IN 6.4A] Are you currently on treatment for ...	
		YES	NO			YES	NO
6.4.1	Arthritis	1	2 → IF NO SKIP TO 6.4.2	☐☐	Months	1	2
6.4.2	Stroke	1	2 → IF NO SKIP TO 6.4.3	☐☐	Months	1	2
6.4.3	Angina	1	2 → IF NO SKIP TO 6.4.4	☐☐	Months	1	2
6.4.4	Diabetes	1	2 → IF NO SKIP TO 6.4.5	☐☐	Months	1	2
6.4.5	Chronic lung disease	1	2 → IF NO SKIP TO 6.4.6	☐☐	Months	1	2
6.4.6	Asthma	1	2 → IF NO SKIP TO 6.4.7	☐☐	Months	1	2
6.4.7	Hypertension	1	2 → IF NO SKIP TO 6.4.8	☐☐	Months	1	2
6.4.8	Tuberculosis	1	2 → IF NO SKIP TO 6.4.9	☐☐	Months	1	2
6.4.9	Cataracts	1	2 → IF NO SKIP TO 6.4.10	☐☐	Months	1	2
6.4.10	Depression	1	2 → IF NO SKIP TO 6.4.11	☐☐	Months	1	2
6.4.11	Dementia	1	2 → SKIP TO 6.5	☐☐	Months	1	2

6.5 What do you consider to be the most severe health problem you have currently?

CIRCLE ONE RESPONSE

Communicable disease (malaria, tuberculosis, HIV/AIDS, other).....1
Acute conditions (diarrhea, flu, headaches, cough, other).....2
Injury or disability as a result of injury.....3
Post-Surgery complications.....4
Sleep problems.....5
Chronic pain in joints/arthritis (joints, back, neck).....6
Diabetes or related complications.....7
Problems with heart including unexplained pain in chest.....8
Problems with mouth, teeth or swallowing.....9
Problems with breathing.....10
High blood pressure / hypertension.....11
Stroke/sudden paralysis of one side of body.....12
Generalized pain (stomach, muscle or other non specific pain).....13
Depression or anxiety.....14
Cancer.....15
Poor sight.....16
Hearing Loss.....17
Other (specify).....98

6.6 In the last 3 months, have you gone to seek health care outside of home for this problem? ☐
(Y=YES; N=NO; If 'NO' skip to 6.10)

6.7 Where did you go to seek health care? NAME OF FACILITY/PROVIDER

Govt health center/dispensary	1	Government hospital	....5 _____
Private Health center/dispensary	2	Traditional healer/herbalists	....6 _____
Pharmacist/Drug store	3	Religious / Prayer houses	7
Private hospital	4	Other (specify)	....8 _____

6.8 What was the outcome of the last visit to seek care for this health problem? Did your condition greatly improve, slightly improve, no change, slightly worsened or greatly worsened? ☐
Greatly improved (1), slightly improved (2) No change (3) Slightly worsened (4), Greatly worsened (5)

6.9 In total, how much have you spent on the health care for this problem in the last 3 months?
(RECORD '00000' IF FOR FREE)

6.6.1 Consultation	☐☐☐☐☐
6.6.2 *Hospitalization*	☐☐☐☐☐
6.6.3 Medicine/drugs	☐☐☐☐☐
6.6.4 Transportation to seek treatment	☐☐☐☐☐
6.6.5 Lab, X-Ray etc	☐☐☐☐☐
6.6.6 Other (specify) _____	☐☐☐☐☐

[IF ANSWER IS "YES" IN 6.6, SKIP TO 6.11]

6.10 What is/was the main reason why you did not seek health care outside the home/when you needed it?
CIRCLE ONE RESPONSE

Could not afford the cost of the visit	1	The health care provider's skills are inadequate	7
No transport available	2	You did not know where to go	8
Could not afford the cost of transport	3	You tried but were denied health care	9
Was previously badly treated	4	You thought you were not sick enough	10
Could not take time off work or had other commitments	5	You did not need health care	11
The health care provider's drugs or equipment are inadequate	6	Other (specify) _____	99

6.11 Are there times in the past 3 months when you needed health care but you did not get it?
(Y=YES; N=NO; If 'NO' skip to 7.0)

6.12 What is/was the main reason why you did not seek health care outside the home/when you needed it?
CIRCLE ONE RESPONSE

Could not afford the cost of the visit	1	The health care provider's skills are inadequate	7
No transport available	2	You did not know where to go	8
Could not afford the cost of transport	3	You tried but were denied health care	9
Was previously badly treated	4	You thought you were not sick enough	10
Could not take time off work or had other commitments	5	You did not need health care	11
The health care provider's drugs or equipment are inadequate	6	Other (specify)	99

6.13 In the last 12 months did you ever feel that you were treated differently by health care providers for any of the following reasons.

6.13A. Because of your ...	Y=YES	N=NO		6.13B. If YES were you treated better or worse? B=Better	W=Worse
Sex	Y	N	**IF YES ASK ---->**	B	W
Age	Y	N	**IF YES ASK ---->**	B	W
Social class	Y	N	**IF YES ASK ---->**	B	W
Lack of money	Y	N	**IF YES ASK ---->**	B	W
Ethnic group	Y	N	**IF YES ASK ---->**	B	W

7.0 HEALTH STATE DESCRIPTIONS

7.1 START TIME (24 HR FORMAT) ☐☐☐☐

I would like to ask you questions about your health and well-being. I know some of these questions may be sensitive or difficult to answer, but please try to provide an answer to the best of your knowledge. I will ask about your overall health, including both your physical and your mental health. Some of the questions may sound similar or repetitive, but I need to ask all of the questions so we have complete understanding of your health.

7.2 In general, how would you rate your health today, would you say your health is Very good (1), Good (2), Moderate (3), Bad (4), or Very bad (5)? ☐

7.3 Overall in the last 30 days, how much difficulty did you have with work or household activities. Would you say No difficulty (1), Mild difficulty (2), Moderate (3), Severe (4) or Extreme/cannot do anything (5)? ☐

Now 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, 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 average, in the last 30 days, 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. I would like you to provide me your response whether you have No difficulty, Mild difficulty, Moderate difficulty, Severe difficulty or Extreme difficulty regarding the following functions of your body. **(CIRCLE APPROPRIATE CODE)**

	NONE	MILD	MODERATE	SEVERE	EXTREME/ CAN'T DO
Mobility					
7.4 Overall in the last 30 days how much difficulty did you have with moving around?	1	2	3	4	5
7.5 Overall in the last 30 days how much difficulty did you have in vigorous activities (such as walking fast)?	1	2	3	4	5
Self-Care					
7.6 Overall in the last 30 days how much difficulty did you have with self-care, such as bathing or dressing?	1	2	3	4	5
7.7 Overall in the last 30 days how much difficulty did you have in taking care of and maintaining your general appearance (e.g. grooming, looking tidy)	1	2	3	4	5
7.8 Overall in the last 30 days how much of bodily aches or pains did you have?	1	2	3	4	5
7.9 Overall in the last 30 days how much bodily discomfort did you have?	1	2	3	4	5
Cognition					
7.10 Overall in the last 30 days how much difficulty did you have with concentrating or remembering things?	1	2	3	4	5
7.11 Overall in the last 30 days 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					
7.12 Overall in the last 30 days how much difficulty did you have with personal relationships or participation in the community?	1	2	3	4	5
7.13 Overall in the last 30 days how much difficulty did you have in dealing with conflicts and tensions with others?	1	2	3	4	5

	(CIRCLE APPROPRIATE CODE)				
	NONE	MILD	MODERATE	SEVERE	EXTREME/ CANNOT
Breathing					
7.14 Overall in the last 30 days how much of a problem did you have with breathing, such as shortness of breath when not doing anything?	1	2	3	4	5
7.15 Overall in the last 30 days how much of a problem did you have with shortness of breath when doing mild activity, such as climbing uphill for 20 meters or climbing stairs?	1	2	3	4	5
Sleep and Energy					
7.16 Overall in the last 30 days 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?	1	2	3	4	5
7.17 Overall in the last 30 days how much of a problem did you have due to not feeling rested and refreshed during the day (e.g. feeling tired, not having energy)?	1	2	3	4	5
Affect					
7.18 Overall in the last 30 days how much of a problem did you have with feeling sad, low or depressed?	1	2	3	4	5
7.19 Overall in the last 30 days how much of a problem did you have with worry or anxiety?	1	2	3	4	5
Vision					
7.20 When was the last time you had your eyes examined by a health care professional? (1=Never; 2=Within the last 12 months; 3=1-2 years ago; 4=3-4 years ago; 5=5 or more years ago)					☐
7.21 Do you use eyeglasses or contact lenses to see far away (for example across the street)? (Y=YES; N=NO)					☐
7.22 Do you use eyeglasses or contact lenses to see up close (for example at arms length, like when you are reading)? (Y=YES; N=NO)					☐
	NONE	MILD	MODERATE	SEVERE	CANNOT DO
7.23 Overall in the last 30 days how much difficulty did you have in seeing and recognising a person or object you know across the road (from a distance of about 20 meters)?	1	2	3	4	5
7.24 Overall in the last 30 days how much difficulty did you have in seeing and recognising an object at arm's length (for example reading)?	1	2	3	4	5
Hearing (respondent should answer when wearing hearing aid if one is used)					
7.25 Do you wear a hearing aid? (Y=YES; N=NO)					☐
	NONE	MILD	MODERATE	SEVERE	EXTREME/ CANNOT
7.26 Overall in the last 30 days how much difficulty did you have in hearing someone talking on the other side of the room in a normal voice (even with hearing aid on if you use one)?	1	2	3	4	5
7.27 How much difficulty did you have in hearing what is said in a conversation with one other person in a quiet room (even with your hearing aid on if you use one)?	1	2	3	4	5

FUNCTIONING ASSESSMENT

The 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.

(CIRCLE APPROPRIATE CODE)

	NONE	MILD	MODERATE	SEVERE	EXTREME /CANNOT	N/A
7.28 In the last 30 days, how much difficulty did you have in standing for long periods (such as 30 minutes)?	1	2	3	4	5	9
7.29 In the last 30 days, how much difficulty did you have in taking care of your household responsibilities?	1	2	3	4	5	9
7.30 In the last 30 days, 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	9
7.31 In the last 30 days, how much difficulty did you have 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	9
7.32 In the last 30 days, how much difficulty did you have in concentrating on doing something for 10 minutes?	1	2	3	4	5	9
7.33 In the last 30 days, how much difficulty did you have in walking a long distance such as a KM (or equivalent)?	1	2	3	4	5	9
7.34 In the last 30 days, how much difficulty did you have in washing (bathing) your whole body?	1	2	3	4	5	9
7.35 In the last 30 days, how much difficulty did you have in getting dressed (including, for example, putting on your shoes and socks)?	1	2	3	4	5	9
7.36 In the last 30 days, how much difficulty did you have relating with people you do not know?	1	2	3	4	5	9
7.37 In the last 30 days, how much difficulty did you have in maintaining a friendship?	1	2	3	4	5	9
7.38 In the last 30 days, how much difficulty did you have in your day to day work?	1	2	3	4	5	9
7.39 In the last 30 days, how much have you been emotionally affected by your health condition(s)?	1	2	3	4	5	9

7.40 Besides any vision (eyeglasses, contact lenses) or hearing aids, do you use any other assistive devices (such as a cane, walker, or other devices) to help you with any difficulties you may have? ☐

(Y=YES; N=NO)

(IF YES Please Specify)

7.41 Do you have any difficulty in feeding as a result of loosing your teeth? ☐

(Y=YES; N=NO)

SUBJECTIVE WELLBEING AND QUALITY OF LIFE

Now, I would like to ask for your thoughts about your life and life situation. By telling me whether you Completely, Mostly, Moderately, A little, or Not at all agree with the statement.

	(CIRCLE APPROPRIATE CODE)				
	COMPLETELY	MOSTLY	MODERATELY	A LITTLE	NONE AT ALL
7.42 Do you have enough energy for everyday life?	1	2	3	4	5
7.43 Do you have enough money to meet your basic needs?	1	2	3	4	5

Please tell us how satisfied you are with the following issues. By telling me whether you are Very Satisfied, Satisfied, Neither Satisfied nor Dissatisfied, Dissatisfied, or Very Dissatisfied

	VERY SATISFIED	SATISFIED	NEITHER SATISFIED NOR DISSATISFIED	DISSATISFIED	VERY DISSATISFIED
7.44 How satisfied are you with your health?	1	2	3	4	5
7.45 How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
7.46 How satisfied are you with your personal relationships?	1	2	3	4	5
7.47 How satisfied are you with the conditions of your living place?	1	2	3	4	5
7.48 Taking all things together, how satisfied are you with your life as a whole these days?	1	2	3	4	5

7.49 How would you rate your overall quality of life. Is it Very Good (1), Good (2), Moderate (3), Bad (4), or Very Bad (5)? Don't Know (8). ☐

7.50 Taking all things together, how would you say you are these days? Are you Very happy (1), Happy (2), Neither happy nor unhappy (3), Unhappy (4), or Very unhappy (5)? IF DON'T KNOW (8) ☐

7.51 END TIME (24 HR-FORMAT) ☐☐☐☐

7.52 INDICATE VIGNETTE TYPE ☐

A=Set A B=Set B C=Set C D=Set D N=No Vignette

8.0 CARING FOR PERSONS WITH PROLONGED ILLNESS

In the following questions, I would like to find out how families and households cope and support each other through prolonged illnesses. People who are ill may need care and assistance from others. This includes both *daily personal care at home, assistance outside the house such as to go see a doctor, going to buy medicines,* health care, emotional well-being or other personal activities.

I would like to ask you some questions about this type of care given to people who have had prolonged illness that is, people who have been ill continuously for three months or more.

8.1 Are you currently taking care of someone who has had a prolonged illness? ☐
(Y=YES; N=NO; IF 'NO' skip to 8.4)

8.2 How many people who have a prolonged illness are you currently caring for? ☐

8.3 **(IF MORE THAN ONE IN 8.2)** Please give me the name of the person who got ill most recently.
(OTHERWISE ASK) Please give me the name of the person you are currently providing care to?

_____ ☐

8.4 [IF CURRENTLY CARING] Other than those you are caring for, in the past 3 years, have you cared for someone who had a prolonged illness?

[IF NOT CURRENTLY CARING] in the past 3 years, have you cared for someone who had a prolonged illness?
(Y=YES; N=NO; IF 'NO' skip to FILTER 1)

8.5 [IF CURRENTLY CARING] Apart from those you are currently caring for, how many people have you cared for in the past 3 years?
[IF NOT CURRENTLY CARING] how many people have you cared for in the past 3 years? ☐

8.6 **(IF MORE THAN ONE IN 8.5)** Please give me the name of the person who started getting ill later than the others.
(OTHERWISE ASK) Please give me the name of the person whom you provided care.

_____

8.7 In what month and year did you start providing care to (PERSON MENTIONED IN 8.6)?

MONTH ☐ YEAR ☐☐☐☐

[FILTER 1: CHECK 8.1 AND 8.4, IF ANS IS 'NO' IN 8.1 AND 'NO' IN 8.4, SKIP TO SECTION 9;
IF 'YES' IN 8.1 AND 'NO' IN 8.4 ASK ABOUT THE PERSON MENTIONED IN 8.3; OR
IF 'NO' IN 8.1 AND 'YES' IN 8.4 ASK ABOUT THE PERSON MENTIONED IN 8.6]
IF 'YES' IN 8.1 AND 'YES' IN 8.4 ASK ABOUT THE PERSON MENTIONED IN 8.3]

I would like us to talk briefly about _____ (NAME OF PERSON)

8.8 What is your relationship to (NAME)? **(CODE SHEET A[1])** ☐☐☐

8.9 How old is (NAME)?/How old was (NAME) at the time you started providing care to him/her? ☐☐

8.10 Where is (NAME) currently residing?/Where was (NAME) residing at the time you were caring for him/her? **(CODE SHEET A[5])** ☐

8.11 Before you started providing care, was (NAME) living at the location (MENTIONED IN 8.10) ☐
(Y=YES; N=NO)

8.12 **IF NAME WAS 12 YEARS OR OLDER:** At the time you provided care, what is/was (NAME)'s marital status? ☐

(**N**=Never married; **M**=Married; **L**=Living together; **W**=Widowed; **D**=Divorced; **S**=Separated/Not living together)

8.13 What main illness is/was (NAME) suffering from? Any other? _____

8.14 For how long has/was (NAME) been ill?
M=MONTHS; Y=YEARS; D=DON'T KNOW ☐ DURATION ☐☐

8.15 For how long has/was (NAME) critically ill that he/she needed someone to provide a lot of personal care?
W=WEEKS; M=MONTHS; Y=YEARS; D=DON'T KNOW ☐ DURATION ☐☐

CARING ROLE

8.16 For how long have you been caring for/did you provide care to (NAME)?
M=MONTHS; Y=YEARS; D=DON'T KNOW ☐ DURATION ☐☐

8.17 Is there anyone else assisting you/who assisted you in providing care to (NAME)? ☐
(Y=YES; N=NO; If 'NO' skip to 8.20)

8.18 Between you and the other people or person, who is/was the main person who provides/provided care? ☐
(1=Respondent; 2=Someone else; If '1' skip to 8.20)

8.19 What is this other person's relationship to (NAME)? **(CODE SHEET A[1])** ☐☐☐

	NONE	MILD	MODERATE	SEVERE	EXTREME
As a result of providing care to (NAME), how much difficulty have you had/did you have with:					
8.20 Getting enough sleep?	1	2	3	4	5
8.21 Eating enough food?	1	2	3	4	5
8.22 Having enough time to do other extra work?	1	2	3	4	5
8.23 Having muscle aches and pains?	1	2	3	4	5

MEDICAL COSTS

8.24 Has/did (NAME) gone/go to seek treatment for his/her illness in the last 12 months (of the illness)? ☐
(Y=YES; N=NO; D=DON'T KNOW)
(IF 'YES' AND CURRENTLY CARING SKIP TO 8.26. IF CARE WAS IN THE PAST SKIP TO 8.27)

8.25 What is the main reason why (NAME) has not gone/did not go to seek treatment? [8] ☐
(SKIP TO 8.27)

8.26 Is (NAME) currently on treatment? **(Y=YES; N=NO; D=DON'T KNOW)** ☐

8.27 Has/did (NAME) incurred any medical costs in the last 12 months? **(Y=YES; N=NO; IF 'NO' SKIP TO 8.37)** ☐

8.28 How much has been spent for (NAME) on the following costs during the last 12 months? (RECORD '00000' IF NONE)

8.28.1 Consultation	☐☐☐☐☐
8.28.2 Hospitalization	☐☐☐☐☐
8.28.3 Medicine/drugs	☐☐☐☐☐
8.28.4 Transportation for treatment	☐☐☐☐☐
8.28.5 Other (specify) _____	☐☐☐☐☐

8.29 Have you personally contributed financially to meet the medical costs incurred by (NAME)? ☐
(Y=YES; N=NO; IF 'NO' SKIP TO 8.35)

8.30 About how much would you say you have contributed to meet the medical costs: Would you say it is all or nearly all **(1)**, over half **(2)**, half **(3)**, less than half (4), or, very little or nothing at all (5)? ☐

8 Reasons for not seeking care

1=Lack of funds	4=Self treatment/Use home remedies	7=Fear/embarrassment
2=Religion	5=Didn't think treatment would help	8=Other
3=Facility too far	6=Did seek treatment but could not help	

8.31 As a result of the medical expenses, have you had/did you have to borrow any money to cover these expenses? **(Y=YES; N=NO)** ☐

8.32 As a result of the medical expenses, have you had/did you have to sell any items or assets to cover these expenses? **(Y=YES; N=NO; If 'NO' skip to 8.34)** ☐

8.33 What asset(s) have you sold/did you sell?

- Household utensils/Clothing ....A
- Furniture(table/chair/stool/sofa) ....B
- Electronic household appliances C
- Production tools/Equipment ....D
- Livestock ....E
- _____ Other (Specify) ....F
- _____ Other (Specify) ....G

8.34 What has been your main source for the money you have contributed to meet the costs of (NAME's) medical expenses?

- Own income generating activity 1
- Savings/Investments 2
- Pension/retirement benefits 3
- Donations from friends/relatives 4
- Sell of assets/property 5
- _____ Other (Specify) 6

8.35 What or who has been the primary source of finances used to pay (NAME's) medical bills? ☐☐ **(CODE SHEET A [10])**

8.36 What would you say is/was the most costly medical expense?

- Consultation 1
- Hospitalization 2
- Medicine/drugs 3
- Transportation 4
- _____ Other (specify) 8

INCOME LOSS

8.37 Is/was (NAME) engaged in any livelihood activity/at the time of providing care? **(Y=YES; N=NO If 'YES' skip to 8.39)** ☐

8.38 Was (NAME) engaged in any livelihood activity at least 4 months before s/he became ill? **(Y=YES; N=NO; If 'NO' skip to 8.41)** ☐

8.39 Does/did (NAME) contribute to your household income/upkeep? **(Y=YES; N=NO; If 'NO' skip to 8.41)** ☐

8.40 About how much would you say (NAME) contributed/contributes to your household income/upkeep: Would you say it was/is all or nearly all **(1)**, over half **(2)**, half **(3)**, less than half **(4)**, or, very little/nothing at all **(5)**? ☐

8.41 Has/did the caring responsibility interfered/interfere with your livelihood activities? **(Y=YES; N=NO)** ☐

8.42 What is the main reason why the caring responsibility interfered/did not interfere with your livelihood activities?

- Was not working/Not looking for work 1
- Caring tasks took too much time 2
- Care required constant presence 3
- Lost job/laid off because of caring 4
- Health problems/Disabled 5
- Retired / too old to work 6
- Livelihood activity not too demanding 7
- _____ Other, specify: 8

8.43 Have/did you tried/try to engage in (another) an income generating activity to cope with the financial costs of caring for (NAME) since (NAME) fell sick? **(Y=YES; N=NO)** ☐

(CHECK QUESTION 8.1, IF CURRENTLY CARING SKIP TO SECTION 9 OTHERWISE ASK QUESTION 8.44)

FUNERAL COSTS

8.44 Did (NAME) survive the illness? **(1=YES; 2=NO; If 'YES' skip to SECTION 9)** ☐

Now I would like to talk briefly about (NAME's) death. I know it may be painful to talk about this but it is important that we get the right information

8.45 How long after (NAME) became ill did he/she die from the illness?

M=MONTHS; Y=YEARS; D=DON'T KNOW ☐ DURATION ☐☐

8.46 Where was (NAME) buried? Was s/he buried in Nairobi **(1)**, other urban area of Kenya **(2)**, rural Kenya **(3)** *or elsewhere* **(4, *specify*)**? _____ ☐

8.47 How long after the death of (NAME) did the burial take place?

D=Days; W=WEEKS; M=MONTHS; D=DON'T KNOW ☐ DURATION ☐☐

8.48 Did you contribute financially to meet the funeral costs incurred by (NAME)'s death? ☐

(Y=YES; N=NO; IF 'NO' SKIP TO 8.53)

8.49 *About how much would you say you have contributed to meet the funeral costs: Would you say it was* all or nearly all **(1)**, over half **(2)**, half **(3)**, less than half (4), or, very little or nothing at all (5)? ☐

8.50 As a result of the funeral expenses, did you have to borrow any money to cover the funeral expenses? ☐

(Y=YES; N=NO)

8.51 As a result of the funeral expenses, have you had/did you have to sell any item or asset to cover the funeral expenses? ☐

(Y=YES; N=NO; If 'NO' skip to 8.53)

8.52 What asset(s) have you sold/did you sell?

Household utensils/Clothing .....A
Furniture(table/chair/stool/sofa) .....B
Electronic household appliances C
Production tools/Equipment .....D
Livestock .....E
_____ Other (Specify) .....F
_____ Other (Specify) .....G

8.53 What or who has been the primary source of finances used to offset (NAME's) funeral costs? ☐

(CODE SHEET A [19])

8.54 What would you say was the most costly funeral item?

Transportation 1
Mortuary fees 2
Food 3
Coffin 4
_____ Other (specify) 8

OTHER COSTS AND SOCIAL SUPPORT

8.55 What would you say is/was the most difficult task of providing care to (NAME)?

Personal care (dressing/bathing/feeding) 1
Physical (lifting, transportation, moving around) 2
Heath care (hospital visits, giving medicines) 3
Financial (medical, funeral, foodstuff) 4
Being helpless/Unable to assist 5
Don't know/cannot determine 6
Emotional (Bearing with the suffering) 7
_____ Other (specify) 8

8.56 What would you say is/was the most costly item/aspect of providing care to (NAME)?

Foodstuff/groceries 1
Medical costs 2
Funeral costs 3
Don't know/cannot determine 4
Other (specify) 8

8.57 Are there any activities/social roles that you have been unable to perform because of providing care to (NAME)? (Y=YES; N=NO) ☐

8.58 As a result of providing care to (NAME), has it resulted in any friction between members of your household or family? (Y=YES; N=NO) ☐

8.59 Do you/did you or (NAME) experience any negative reaction from neighbours/community members as a result of his/her illness? (Y=YES; N=NO) ☐

The next few questions ask about what help or assistance you as a person who has provided care, received from other people or groups to assist you in providing care to (NAME) during their illness.

	Personal care	Physical care	Health care	Financial care	Emotional care	Other
8.60 What sort of help do/did you receive from your family/relatives during (NAME's) illness. **PROBE:** Any other help?	A	B	C	D	E	F
8.61 What sort of help do/did you receive from your neigbours/community during (NAME's) illness. **PROBE:** Any other help?	A	B	C	D	E	F
8.62 What sort of help do/did you receive from any NGO/CBOs during (NAME's) illness. **PROBE:** Any other help?	A	B	C	D	E	F
8.63 What sort of help do/did you receive from any religious groups/organizations during (NAME's) illness. **PROBE:** Any other help?	A	B	C	D	E	F

8.64 Who would you say was the most helpful to you during (NAME's) illness? [10] ☐

9 CARING FOR CHILDREN UNDER 15 YEARS

9.1 Are you currently taking care of children who are not your biological children and who are less than 15 years of age? (Y=YES; N=NO; If 'NO' skip to SECTION 10) ☐

9.2 In total, how many children under the age of 15 years are you taking care of? ☐☐

9.3 Why did you end up caring for the children under your care?

CIRCLE ONLY ONE REASON

No other person to care for them 1
No one else willing to care for them 2
Out of choice 3
Children are orphaned 4
Parent(s) living elsewhere 5
Parent (s) refused to care for them 6
Other, specify: 8
Other, specify: 9

9.4 How many of the children whom you are caring for living with you in this household? ☐☐
(If ANS for 9.2 is EQUAL to ANS for 9.4, skip to 9.6)

9.5 How many of these children are living elsewhere? ☐☐

CHARACTERISTICS OF CHILDREN

Now I would like us to talk about the children under the age of 15 years who are currently living with you

9.6	9.7	9.8	9.9	9.10	9.11	9.12	9.13	9.14	9.15	9.16	9.17	9.19
NAME OF CHILD	SEX: Male (M) Female (F)	Is (NAME'S) mother alive? (Y=YES; N=NO; D=DON'T KNOW)	IF ALIVE Where does (NAME'S) mother live? (CODE SHEET A[5])	Is (NAME'S) father alive? (Y=YES; N=NO; D=DON'T KNOW)	IF ALIVE Where does (NAME'S) father live? (CODE SHEET A[5])	For how long have (NAME) been living with you? (in years)	What is your relation-ship to (NAME)? (CODE SHEET A)	IF (NAME) > 5 years Is (NAME) currently attending school? (Y=Yes; N=No) If NO GO TO 9.16	What grade is (NAME) in?	How would you best describe (NAME's) health? 1=Very Good 2=Good 3=Neither good nor bad 4=Poor 5=very poor	How often does (NAME) feel unhappy or sad? 1=Often 2=Sometimes 3=Rarely 4=Never 5=DK	How often does (NAME) act disobediently at home? 1=Often 2=Sometimes 3=Rarely 4=Never 5=DK
1	☐	☐	☐	☐	☐	☐☐	☐☐☐	☐	☐	☐	☐	☐
2	☐	☐	☐	☐	☐	☐☐	☐☐☐	☐	☐	☐	☐	☐
3	☐	☐	☐	☐	☐	☐☐	☐☐☐	☐	☐	☐	☐	☐
4	☐	☐	☐	☐	☐	☐☐	☐☐☐	☐	☐	☐	☐	☐
5	☐	☐	☐	☐	☐	☐☐	☐☐☐	☐	☐	☐	☐	☐
6	☐	☐	☐	☐	☐	☐☐	☐☐☐	☐	☐	☐	☐	☐

10.0 SOCIAL NETWORKING

I would like to ask you about social aspects of your life and also get your opinion on the community life in general. I will start with the social aspects of your life.

TYPE OF NETWORK and COMMUNITY INVOLVEMENT

10.1 How many people do you have whom you consider as close friends? ☐☐

10.2 Suppose you had a financial problem, whom would you turn to first for help? How is this person related to you? **RECORD RELATIONSHIP** **(CODE SHEET A[1])** ☐☐☐

10.3 Where does this person live? **(RECORD CODE OF PLACE OF RESIDENCE)** **(CODE SHEET A[5])** ☐

10.4 Suppose you needed to confide in someone you trust, whom would you turn to first? How is this person related to you? **RECORD RELATIONSHIP** **(CODE SHEET A[1])** ☐☐☐

10.5 Where does this person live? **(RECORD CODE OF PLACE OF RESIDENCE)** **(CODE SHEET A[5])** ☐

10.6 Do you belong to a self-help group such as merry-go-rounds or welfare organization? **(Y=YES; N=NO)** ☐

10.7 How often in the last 4 months have you met with a community leader?
1. Never 2.Once or Twice a week 3. Once or twice per month
4. Once or twice in last 4 months 5. Other (specify) ..... ☐

10.8 How often in the last 4 months have you attended any group, club, society, union or organizational meeting?
1. Never 2.Once or Twice a week 3. Once or twice per month
4. Once or twice in last 4 months 5. Other (specify) ..... ☐

10.9 How often in the last 4 months have you worked with other people in your neighborhood to fix or improve something or resolve a community issue?
1. Never 2.Once or Twice a week 3. Once or twice per month
4. Once or twice in last 4 months 5. Other (specify) ..... ☐

10.10 What is your religious affiliation?
1. Roman Catholic 2. Protestant/Other Christian 3. Muslim ☐
4. No religion 5. Other (specify) .....

10.11 Not including weddings and funerals, how often do you attend religious services?
1. More than once per week 2. Once per week 3. Once or twice a month
4. Only on special occasions 5. Once a year or less often 6. Never ☐

COMMUNITY PERCEPTION AND SECURITY

Now we have a few questions about safety in the area where you live

	VERY SAFE	SAFE	NEITHER SAFE NOR UNSAFE	UNSAFE	VERY UNSAFE
10.12 In general, how safe from crime and violence do you feel when you are alone at home? Would you say you feel very safe, safe, neither safe nor unsafe, unsafe, or very unsafe?	1	2	3	4	5
10.13 How safe do you feel when walking down a road in the community alone after dark? Would you say you feel very safe, safe, neither safe nor unsafe, unsafe, or very unsafe?	1	2	3	4	5

10.15 First, think about people in your neighbourhood. Generally speaking, would you say that you can trust nearly all of them, some of them, few of them, none of them?

1= Nearly all of them 2=Some of them
3= Few of them 4=None of them ☐

10.16 In the last 12 months, have you or anyone in your household been the victim of a crime such as robbery, assault or mugging? **(Y=YES; N=NO; IF 'NO' SKIP TO SECTION 11)** ☐

10.17 What type of crime have you or your family members been victims of? **PROBE:** Any other crime?

CIRCLE ALL MENTIONED

Robbery ..A
Assault ..B
Mugging ..C
Rape ..D
_____ Other (Specify) ..E
_____ Other (Specify) ..F

11.0 HIV/AIDS ATTITUDE AND PERCEPTION

Now I would like us to talk about HIV/AIDS, a disease that is affecting all our lives irrespective of our education, economic status, age or ethnic group.

11.1 What are the main concerns of elderly people in community regarding the HIV/AIDS problem? **PROBE:** Any other concern?

CIRCLE ALL MENTIONED

Caring for persons infected with HIV/AIDS..... ..A
Caring for orphaned children..... ..B
Loss of support from adult children..... ..C
Being infected with HIV/AIDS..... ..D
Loss/reduction of community support to older people ....E
Other (spy) _____ ..F
Other (spy) _____ ..G

11.2 Have you personally been affected by HIV/AIDS? **(Y=YES; N=NO; If 'NO' Skip to 11.4)** ☐

11.3 How have you been personally affected by HIV/AIDS?

CIRCLE ALL MENTIONED

Caring/cared for someone infected with HIV/AIDS..... ..A
Caring for orphaned children..... ..B
Loss of support from adult children who died of sick of AIDS..... ..C
Infected with HIV/AIDS..... ..D
Loss/reduction of community support to older people ....E
Loss of spouse to AIDS ....F
Other (spy) _____ ..G
Other (spy) _____ ..H

11.4 *Now I would like to ask you some personal questions on how you feel about HIV/AIDS.*

Do you think your chances of contracting HIV/AIDS are small **(1)**, moderate **(2)**, great **(3)** no risk at all **(4)** **or** Has HIV/AIDS **(5)** **[IF '5' SKIP TO 11.9]** ☐

11.5 Why do you think you have NO RISK AT ALL/SMALL chance of contracting HIV/AIDS?

CIRCLE ALL MENTIONED

Abstain from sex..... A
Use condoms..... B
Have only one sex partner..... C
Spouse has not other sex partners..... D
Avoid/no blood transfusion..... E
Avoid unsterilised body piercing..... F
Use own body piercing/shaving instruments..... G
Other _____ H
Other _____ I
Other _____ J

11.6 Why do you think you have a MODERATE/GREAT chance of contracting HIV/AIDS? **CIRCLE ALL MENTIONED**	Do not use condoms ..... A More than one sex partner ..... B Many sex partners ..... C *Spouse has/suspected to have other sex partners* ..... D Had blood transfusion ..... E Had injection/body piercing ..... F Interacted with someone with AIDS ..... G Lost weight ..... H Have weak body resistance ..... I Other _____ J Does Not Know ..... K
11.7 If a relative of yours becomes sick with the virus that causes HIV/AIDS, would you be willing to care for him or her in your own home? **(Y=YES, N=NO, D=DON'T KNOW/UNSURE)**	
11.8 If a married man becomes sick with HIV/AIDS, who should mainly be responsible for providing care to him? **RECORD ONLY ONE RESPONSE**	Spouse ..... 1 Parents ..... 2 Brother/Sister ..... 3 Parent-in-law ..... 4 Brother/sister-in-law ..... 5 Other family members ..... 6 Friends ..... 7 Government facilities ..... 8 NGOs/CBOs ..... 9 Religious group ..... 10 The community ..... 11 Other _____ 12
11.9 If an unmarried man becomes sick with HIV/AIDS, who should mainly be responsible for providing care to him? **RECORD ONLY ONE RESPONSE**	Spouse ..... 1 Parents ..... 2 Brother/Sister ..... 3 Parent-in-law ..... 4 Brother/sister-in-law ..... 5 Other family members ..... 6 Friends ..... 7 Government facilities ..... 8 NGOs/CBOs ..... 9 Religious group ..... 10 The community ..... 11 Other _____ 98
11.10 If a married woman becomes sick with HIV/AIDS, who should mainly be responsible for providing care to her? **RECORD ONLY ONE RESPONSE**	Spouse ..... 1 Parents ..... 2 Brother/Sister ..... 3 Parent-in-law ..... 4 Brother/sister-in-law ..... 5 Other family members ..... 6 Friends ..... 7 Government facilities ..... 8 NGOs/CBOs ..... 9 Religious group ..... 10 The community ..... 11 Other _____ 98

11.11 If an unmarried woman becomes sick with HIV/AIDS, who should be the main person who should provide care to her?

RECORD ONLY ONE RESPONSE

Spouse	1
Parents	2
Brother/Sister	3
Parent-in-law	4
Brother/sister-in-law	5
Other family members	6
Friends	7
Government facilities	8
NGOs/CBOs	9
Religious group	10
The community	11
Other _____	98

11.12 I don't want to know the results, but have you ever been tested to see if you have the virus that causes AIDS? **(Y=YES; N=NO; D=DON'T KNOW; IF 'YES' skip to 11.9)** ☐

11.13 Would you be willing to be tested for HIV/AIDS? ☐
(Y=YES; N=NO; D=DON'T KNOW; IF 'YES' skip to 11.9)

11.14 Why are you unsure/not willing to be tested for HIV/AIDS?

CIRCLE ALL MENTIONED

Risk of contacting HIV is low	A
Risk of contacting HIV is high	B
Testing has no benefit	C
Spouse/partner does not approve	D
Not ready / fear of knowing the status	E
Do not know place for testing	F
Other _____	G
Other _____	H

11.15 Would you say there are older people infected with HIV/AIDS in this community? **(Y=YES; N=NO)** ☐

11.16 We have now come to the end of our discussion, Do you have any comments or questions you would like to ask me? _____

_____

_____

_____

11.17 END TIME (24 HR-FORMAT) ☐☐☐☐
END THE INTERVIEW BY THANKING THE RESPONDENT

INTERVIEWER ASSESSMENT

INTERVIEWER, PLEASE COMPLETE THE QUESTIONS BELOW BASED ON YOUR OWN OBSERVATION AND ASSESSMENT OF THE ENTIRE INTERVIEW PROCESS AND OF THE RESPONDENT

12.1 What is your assessment of the respondent's cooperation? ☐
1=Very good 2=Good 3=Moderate 4=Bad 5=Very bad

12.2 What is your evaluation of the accuracy and completeness of the respondent's answers? ☐
1=Very high 2=High 3=Average 4=Low 5=Very low

12.3 What is your assessment of the respondent's comprehension of issues discussed? ☐
1=Very good 2=Good 3=Moderate 4=Bad 5=Very bad

12.4 What is your assessment of the respondent's concentration and attentiveness during the interview? ☐
1=Good 2=Moderate 3=Bad 4=Very bad

12.5 What is your assessment on the extent of the respondent digressing during the interview ? ☐
1=To a very great extent; 2=To a great extent; 3=Neither great nor small extent
4=To a small extent; 5=To a very small extent

12.6 Questions with doubtful answers **(Explain)**

12.7 Questions needing follow-up or clarification from supervisor **(Explain)**

12.8 What questions did respondent find difficult, embarrassing or confusing? **(Explain)**

12.11 What questions did you the interviewer find difficult, embarrassing or confusing? **(Explain)**

12.12 **INTERVIEWER NOTES**

Appendix 8: Household amenities and livelihood questionnaire

AFRICAN POPULATION AND HEALTH RESEARCH CENTER
NAIROBI URBAN DEMOGRAPHIC SURVEILLANCE SYSTEM (NUDSS)
HOUSEHOLD AMENITIES AND LIVELIHOODS FORM

1. BACKGROUND

1.1. START TIME ☐☐☐☐
1.2. FIELD WORKER'S CODE ☐☐
1.3. DATE OF INTERVIEW ☐☐☐☐☐☐☐☐
1.4. HOUSEHOLD HEAD NAME.....
1.5. ID OF ROOM WHERE HOUSEHOLD HEADS SLEEPS ☐☐☐☐☐☐☐☐☐☐
1.6. HOUSEHOLD ID ☐☐☐☐☐☐☐☐☐☐☐☐
1.7. NUMBER OF ROOMS USED BY HOUSEHOLD FOR SLEEPING IN THIS STRUCTURE ☐☐
1.8 NUMBER OF ROOMS USED BY HOUSEHOLD FOR SLEEPING IN ANOTHER STRUCTURE ☐☐
1.9 TOTAL NUMBER OF RENTABLE ROOMS USED BY THIS HOUSEHOLD IN THIS STRUCTURE ☐☐
1.10 TOTAL NUMBER OF RENTABLE ROOMS USED BY THIS HOUSEHOLD IN ANOTHER STRUCTURE ☐☐
1.11 TOTAL NUMBER OF PEOPLE IN HOUSEHOLD ☐☐

INTRODUCTION AND CONSENT

Hello, my name is _____ and I work with the African Population and Health Research Centre. As you may be aware, we visit households in this community every four months to collect information on health and other related issues so that we can understand the health and well-being of members of this community. Specifically, we would like to know a bit about the nature of amenities and facilities as well as the household income, expenditure and the coping strategies that your household has in case of a problem. The results from this study will be presented to institutions including the government, that are involved in the provision of services targeted at people living in informal settlements. All the responses you provide are confidential and will be used for the purposes of this study only. This interview is not expected to cause you any harm and if you feel uncomfortable with certain questions you can choose not to answer . However, we hope that you will participate in this survey since your views are important. This interview will take about 30 minutes of your time.

1.12. Do you accept to participate in the study? **[1=YES; 2=NO; IF YES SKIP TO 1.14]** ☐

1.13. IF THE RESPONDENT DOES NOT ACCEPT TO BE INTERVIEWED: Why don't you want to participate in in this interview? ☐
1=Too busy/Do not have time; 2= Tired of Research; 3= Research not beneficial;
4= Not interested; 6=Other (specify) _____
Thank you for your time. **[IF NO IN 1.10, COMPLETE 1.15-1.19 AND SKIP TO 8.0]**

1.14. *IF THE RESPONDENT ACCEPTS TO BE INTERVIEWED: Thank you for agreeing to participate in this study.*

RESPONDENT'S PARTICULARS AND OTHER INTERVIEW DETAILS

1.15. FW: IS RESPONDENT REFERENCE PERSON NAMED IN **1.4? 1=YES; 2=NO** **[IF 1, SKIP TO 1.22]** ☐
1.16. What is your name? .....
1.17. FW: DOES RESPONDENT LIVE IN THIS HOUSEHOLD? 1=YES; 2=NO **[IF 2, SKIP TO 1.19]** ☐
1.18. FW: RECORD RESPONDENT'S LINE NUMBER IN HOUSEHOLD LISTING
1.19. How are you related to (NAME OF INDIVIDUAL IN Q1.4)? (CODESHEET A[1]) ☐☐☐

OFFICE/FIELD CHECKER'S DETAILS

1.20. FIELD SUPERVISOR/TEAM LEADER'S CODE ☐☐
1.21. DATA ENTRY CLERK'S CODE ☐☐

	HOUSEHOLD LIVING ARRANGEMENT AND DURATION OF STAY	
	I will start by asking you some questions regarding the duration that your household has lived in this community as well as the living arrangement of your household so that I can have a better understanding of your household.	
1.22	How long has your household lived in Korogocho/Viwandani? M =MONTHS; Y=YEARS; N=NO DURATION GIVEN FOR DURATION: 98=DON'T KNOW; 97=REFUSAL	☐ DURATION ☐☐
1.23	Does your household fully support or is it fully supported by another household located here in Viwandani/Korogocho? (DSA) 1=YES SUPPORTS 2=YES DEPENDS 3=NO 8=DON'T KNOW **[IF "3" OR "8", SKIP TO 2.0]**	☐
1.24	In what way is your household related to the other household?	.....
1.25	HOUSEHOLD HEAD ROOM ID FOR DEPENDENT/ SUPPORTING HOUSEHOLD	☐☐☐☐☐☐☐☐☐☐☐
1.26	HOUSEHOLD ID FOR DEPENDENT/ SUPPORTING HOUSEHOLD	☐☐☐☐☐☐☐☐☐☐☐☐
2.0.	**HOUSEHOLD AMENITIES**	
	Now, I would like to ask you some questions regarding the nature of amenities and facilities that your household has. The aim of these questions is to understand your household's wellbeing. **[CIRCLE THE APPROPRIATE RESPONSES]**	
2.1.	SOURCE OF DRINKING WATER: What is the main source of drinking water for members of your household?	Buying water from: Taps 01 Tanks 02 Hawkers 03 Piped water Piped into residence/compound/ plot 11 Public tap 12 Well water Well on residence/plot 20 Public well 21 Surface water River/stream 31 Pond/lake 32 Rainwater 41 Other_____(specify) 96
2.2.	What kind of toilet facility do your household members **aged 2- 4 years** usually use? (IF LATRINE: PROBE FOR THE TYPE)	Flush Toilet Own flush toilet 11 Shared flush toilet 12 Pit toilet/latrine Own traditional pit toilet 21 Shared traditional pit toilet 22 Ventilated improved pit toilet Own (VIP) latrine 23 Shared (VIP) latrine 24 Flush trench toilet 31 Toilet without pit/working flush 41 No facility/bush/field 51 Flying toilet 61 Other_____(specify) 96 Not applicable 99

2.3.	What kind of toilet facility do your household members aged **5 years and above** usually use? (IF LATRINE: PROBE FOR THE TYPE) **[IF 11, 21, 23, 51 OR 61 SKIP to 2.6]**	Flush Toilet Own flush toilet Shared flush toilet Pit toilet/latrine Own traditional pit toilet Shared traditional pit toilet Ventilated improved pit toilet Own (VIP) latrine Shared (VIP) latrine Flush trench toilet Toilet without pit/working flush No facility/bush/field Flying toilet Other_____(specify)	 11 12 21 22 23 24 31 41 51 61 96
2.4.	Do you pay to use the toilet facility? **[1=YES; 2=NO]**	**[IF NO SKIP TO 2.6]**	☐
2.5.	What is the pattern of payment?	Per use Daily Monthly Other_____(specify)	01 02 03 96
2.6.	MAIN MATERIAL OF THE FLOOR **FW: OBSERVE AND RECORD MAIN FLOOR MATERIAL. IF NOT SURE ASK RESPONDENT**	Natural floor [Earth/Mud/dung/sand] Rudimentary floor [Wood planks] Finished floor Vinyl (PVC) Cement Polished wood/tiles/carpets Other _____(specify)	11 21 31 32 33 96
2.7.	MAIN MATERIAL OF THE ROOF **FW: OBSERVE AND RECORD MAIN ROOF MATERIAL. IF NOT SURE ASK RESPONDENT**	Grass/thatch Plastic sheets Cardboard sheets Wood/timber Metal sheets/tin Iron sheet (corrugated) Tiles Other_____(specify)	01 02 03 04 05 06 07 96
2.8.	MAIN MATERIAL OF THE WALL **FW: OBSERVE AND RECORD MAIN WALL MATERIAL. IF NOT SURE ASK RESPONDENT**	Mud Wood/timber Iron sheets (mabati) Burnt Bricks Stone/quarry stones Concrete blocks Cardboard sheets Cemented mud Carton/plastic Tin/metal sheets Other _____(specify)	01 02 03 04 05 06 07 08 09 10 96

2.9.	Where does your/this household do most of its cooking? **[IF 05, SKIP TO 2.11]**	Open air/outside or small shade outside Separate kitchen (distinct room) Room also used for sleeping Room used for other purposes Household does not cook Other _____(specify)	01 02 03 04 05 96
2.10	What is the main source of cooking fuel used by the household?	Kerosene/paraffin Gas KPLC electricity Electricity from other sources Charcoal Firewood Animal waste Crop residue/saw dust Briquettes/mud charcoal Other _____(specify)	01 02 03 04 05 06 07 08 09 96
2.11	What is the main source of lighting for your/this household?	Kerosene/Paraffin Gas KPLC electricity Electricity from other sources Candles Firewood Other _____(specify)	01 02 03 04 05 06 96
2.12	What is the main method of garbage disposal used by your household?	Garbage dump In the river On the road In drainage/trench In private pits In public pits Garbage disposal services Vacant/abandoned house Burning No designated place/all over Other_____(specify)	01 02 03 04 05 06 07 08 09 10 96
2.13	Is your household renting or does it own this dwelling unit/the rooms in which it is living in this structure?	Owned Purchase Constructed Inherited Renting from Individual Government Local authority Parastatal Private company Free of charge Other _____(specify)	 01 02 03 04 05 06 07 08 09 96

3.0.	HOUSEHOLD POSSESSIONS												
	[1= YES, 2= NO AND 8= DON'T KNOW] [CIRCLE THE APPROPRIATE RESPONSES]	Q 3.1 Does this household own (.) that is kept here?			Q 3.2 Does this household own (.) that is kept in another place?			Q 3.3 In the past ONE year, did this household buy (.) that is/was kept here?			Q 3.4 In the past ONE year, did this household buy (.) that is/was kept in another place?			Q 3.5 In the past ONE year, did this household sell (.) that is/was kept here?			Q 3.6 In the past ONE year, did you sell (.) that is/was kept in another place?		
A	A Vehicle ..... A	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
B	A motorcycle ..... B	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
C	A bicycle C	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
D	A refrigerator ..... D	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
E	A television ..... E	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
F	A radio/Stereo ..... F	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
G	A DVD/VCD/VCR ..... G	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
H	A Sewing machine ..... H	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
I	An electric iron I	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
J	A fan ..... J	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
K	Telephone/Mobile phone ... K	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
L	An electric/gas stove L	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
M	Sofa set ..... M	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
N	Table ..... N	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
O	A Torch ..... O	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
P	Kerosene lamp with glass . P	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
Q	Kerosene stove ..... Q	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
R	Wall Clock ..... R	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
S	Mattress ..... S	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
T	Blankets ..... T	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8
U	Bed ..... U	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8	1	2	8

3.7. Does your household own any Livestock or Poultry that is kept here, upcountry or somewhere else? ☐
[1= YES, 2= NO AND 8= DON'T KNOW] ***[IF NO OR DON'T KNOW SKIP TO 3.12.]***

	[CIRCLE THE APPROPRIATE RESPONSES] 3.8. Does your household own (.)? **[1= YES, 2= NO AND 8= DON'T KNOW]** ***[IF NO OR DON'T KNOW SKIP TO NEXT LIVESTOCK]***				3.9 How many do you own?	3.10 Where are the (.) domesticated? **1= In this community** **2= Upcountry or some other place** **3= In both places**			3.11. How does today's number of (.) compare with ONE year ago? **1= Less now** **2= The same** **3= More now** **8= Don't Know**			
A	Cattle?	1	2	8		1	2	3	1	2	3	8
B	Goats/Sheep?	1	2	8		1	2	3	1	2	3	8
C	Pigs?	1	2	8		1	2	3	1	2	3	8
D	Chickens/Ducks?	1	2	8		1	2	3	1	2	3	8
E	Donkeys?	1	2	8		1	2	3	1	2	3	8
F	Other Livestock or Poultry (specify _____	1	2	8		1	2	3	1	2	3	8

3.12. Which is the main commodity that your household uses to clean its teeth? **[1= Tooth Paste; 2= Herbs/Chewing Stick; 3= Salt; 6= Other]** _____ **(Specify)** ☐

4.0. HOUSEHOLD INCOME AND EXPENDITURE

4.1. [ENSURE THAT THE RESPONDENT PROVIDES A **TOTAL** OF ALL INCOMES FROM ALL SOURCES]
I know that it is usually difficult to state exactly how much income a household makes over time. I would like you to tell me your best estimate of the TOTAL income that this household had in the last 30 days? _____

4.2.

	How much did this household receive or retrieve from (.) in the last 30 days?	AMOUNT
A	**SALARIED/WAGE EMPLOYMENT**	
B	**BUSINESS**	
C	**SAVINGS**	
D	**AGRICULTURE**	
E	**BORROWING**	
F	**FINANCIAL GIFT/SUPPORT FROM ANY SOURCE**	
G	**ANY OTHER SOURCE OF INCOME IN THE LAST ONE MONTH** _____(Specify)	

4.3 How much in total did your household spend on the following items?

	ITEM	EXPENDITURE
A	FOOD **(Last 7 days)**	
B	ENERGY (paraffin, charcoal) **(Last 7 days)**	
C	WATER **(Last 7 days)**	
D	TRANSPORT **(Last 7 days)**	
E	FINANCIAL GIFT/SUPPORT TO OTHERS **(Last 7 days)**	
F	ELECTRICITY **(Last Month)**	
G	HEALTH CARE **(Last 30 days)**	
H	RELIGIOUS OBLIGATIONS **(Last 30 days)**	
I	RENT **(Last Month)**	
J	SCHOOL RELATED EXPENSES **(Last 30 days)** (School Fees, Scholastic Materials)	
K	Other **(Last 7 days)** _____	

5.0. FOOD PRODUCTION AND CONSUMPTION

5.1 Did your household grow crops during the last 12 months? **[IF NO OR DON'T KNOW SKIP TO Q5.4]** ☐
[1= YES, 2= NO AND 8= DON'T KNOW]

5.2 Where did you grow the crops? ☐
[1= Within same DSA Nairobi slum 2= Other DSA Nairobi slum 3= Non-DSA Nairobi slum
4= Nairobi non-slum 5= Other urban area of Kenya 6= Rural Kenya 7= Outside Kenya
8= Do not Know]

5.3 Were the crops sold or used for household consumption? ☐
[1= For household consumption only 2= For sale only 3= For both consumption and sale
8= Do not Know]

5.4 Do you grow or buy most of the staple food that you eat in your household? ☐
[1=Buy all the food 2=Mostly buy food 3=Grow all the food 4=Mostly grow all the food
8= Do not Know] [IF 3, SKIP TO Q5.6]

5.5 How often do you purchase the following staple foods?

	STAPLE FOOD	FREQUENCY
A	Ugali (Maize Meal)	☐
B	Githeri (Beans & Maize)	☐
C	Sukuma (Kales)	☐

[1= DAILY, 2= TWICE A WEEK, 3= WEEKLY
4= FORTNIGHTLY, 5= MONTHLY,
6= LESS FREQUENTLY THAN A MONTH, 8= DON'T KNOW]

5.6 Did any special event occur in your household in the last two days (for example, family event, guests invited)? **[1= YES, 2= NO AND 8= DON'T KNOW]** **[IF YES SKIP TO 5.8]** ☐

5.7 How many meals were served to the household members during the last two days? **[SKIP TO 5.9]** ☐☐

5.8 How many meals were served to the household members during the 2 days preceding the special event? ☐☐

5.9 Were there any special events in the last seven days (for example family event, guests invited)? ☐
[1= YES, 2= NO AND 8= DON'T KNOW]

(IF YES IN 5.9, THEN 5.10 SHOULD REFER TO THE WEEK PRECEDING THE SPECIAL EVENT)

5.10. During the last seven days, for how many days were the following foods served in a main meal eaten by the household?
[DO NOT INCLUDE LEFT OVERS THAT ARE SOLD ON THE STREETS IN THE COMMUNITY]

	LUXURY FOOD	NUMBER OF DAYS SERVED	
A	Chapati	☐	**[8= DON'T KNOW]**
B	Meat, Fish, Chicken	☐	**[EXCLUDE LEFT OVERS LIKE "MGONGO WAZI" "HELICOPTER" "KATAKATA", "BYE BYE" "FIRESTONE" "MAHORI" "MUTURA" etc]**
C	Bread	☐	**[EXCLUDE LEFT OVERS LIKE "ANYONA", "NGAE" etc]**

The following questions relate to whether your household was able to afford the food you needed

5.11. Which of these statements **best** describes the food eaten by your household during the last 30 days? ☐

1. Your household had enough of the kinds of food it wanted to eat **[IF 1 SKIP TO 5.15]**
2. Your household had enough food, but not always the kinds of food it wanted
3. Sometimes your household did not have enough food to eat
4. Your household often did not have enough food to eat
8. Don't know

Now I am going to read several statements that people usually make about their food situation. Please tell me whether each of these statements was often true, sometimes true, or never true for your household in the last month

5.12. "The food that you bought finished and you didn't have money to get more."
Was that often true, sometimes true, or never true for your household in the last 30 days? ☐
[1= Often true 2= Sometimes true 3= Never true 6= Refused 8= Don't Know]

5.13. "During the past 30 days, children in your household failed to eat for a whole day/slept hungry because there wasn't enough money for food." Was that often, sometimes, or never true for you/your household? ☐
[1= Often true 2= Sometimes true 3= Never true 6= Refused 8= Don't Know 9= Not Applicable]

5.14. "During the past 30 days, you or other adult(s) in your household failed to eat for a whole day because *there wasn't enough food." Was that often, sometimes, or never true for you/your household?* ☐
[1= Often true 2= Sometimes true 3= Never true 6= Refused 8= Don't Know]

I would like to ask you some questions about how you would use extra income. I just want you to imagine this situation. We are not going to provide the money to you. We are just using this as an example.

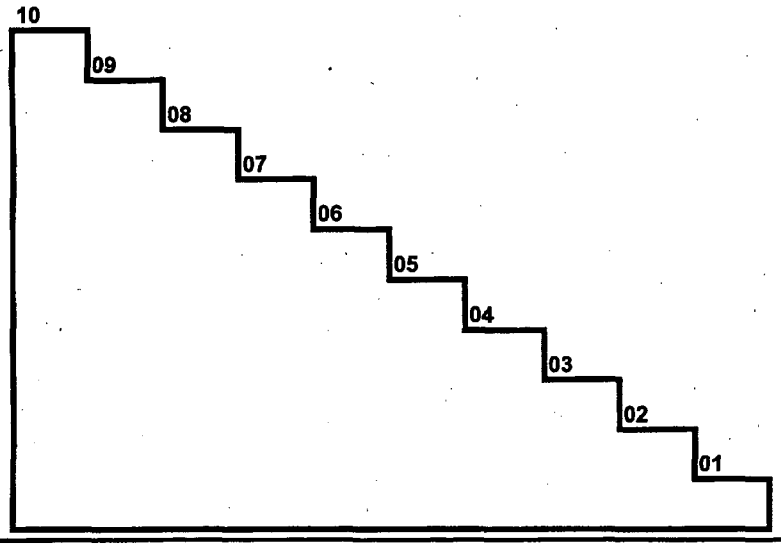
5.15. If your household received additional Ksh. 2000 each month, would you change anything about what your household eats? **[1= YES, 2= NO AND 8= DON'T KNOW], IF NO OR DON'T KNOW SKIP TO 6.0** ☐

5.16. What is the main change that you would make to your household's food consumption? ☐
1= Buy more food items of what is being eaten 2= Buy more nutritious food items
3= Buy greater variety of food 4= Other _____(Specify)

6.0.	HOUSEHOLD SHOCKS EXPERIENCED				
	[CIRCLE THE APPROPRIATE RESPONSES] 6.1. Has your household or any member experienced (.) problem in the last one year? [1= YES 2= NO 8= DON'T KNOW, IF 2 or 8 SKIP TO THE NEXT SHOCK]				6.2. How many such events have occurred in this household in the last one year?
A	FIRE	1	2	8	
B	FLOODS	1	2	8	
C	MUGGING	1	2	8	
D	THEFT	1	2	8	
E	EVICTION	1	2	8	
F	DEMOLITION	1	2	8	
G	SEVERE ILLNESS	1	2	8	
H	DEATH	1	2	8	
I	RAPE	1	2	8	
J	STABBING	1	2	8	
K	LAY-OFF	1	2	8	

Before I conclude, I would like to ask you a general question about your household in this community

7.1. Now, I would like you to tell me how your household compares to other households in this community with respect to the general wellbeing. If all households in the community were placed on a ladder from ONE to TEN **[SHOW THE RESPONDENT THE LADDER]**, where the richest is on number TEN and the poorest on number ONE, where would you place your household? ☐☐



8.0. END OF INTERVIEW

8.1. I would like to thank you for taking your time to answer the questions that I asked you. As I said at the beginning, the information you have given me will help a lot in understanding how people's movements affect their wellbeing I have now come to the end of the interview. Do you have any questions for me? ☐
1=YES; 2= NO; **[IF 2 SKIP TO Q8.3]**

8.2. FW: RECORD QUESTIONS AND COMMENTS RAISED BY RESPONDENT
.....
.....

8.3. FW: RECORD COMMENTS ABOUT THE INTERVIEW
.....
.....

8.4. RESULT OF INTERVIEW (CODESHEET A7) ☐

8.5. **END TIME (24 HRS)** ☐☐☐☐

Appendix 9: In-depth interview guide

AFRICAN POPULATION AND HEALTH RESEARCH CENTER
OLDER PEOPLE PROVIDING CARE TO PERSONS WHO ARE ILL
IN-DEPTH INTERVIEW GUIDE

IDENTIFICATION

Date of interview (DD/MM/YY):__ __/ __ __/ __ __

Name of Interviewer: .....

Name of respondent: .....

ID of respondent: .....

Name of ill person.....

Current experience: **YES** Q **NO** Q

Multiple experiences: **YES** Q **NO** Q

INTRODUCTION AND CONSENT

Hello, my name is _____ and I work for the African Population and Health Research Centre. We are following up on an interview we had with you a few weeks ago to better understand some of the problems you encounter in caring for ill relatives and family. Specifically I would like us to have a further discussion regarding the care you provide or provided to _____. The information that you and others provide will be summarised and presented to people involved in decision-making and provision of services targeted at older people so that they may be better informed of how they can improve the wellbeing of older people in this and other similar communities. All the responses you provide are confidential and will be used for the purposes of this study only. Some of the questions may be sensitive and we hope that you will bear with us but if you feel uncomfortable answering certain questions you can choose not to answer. However, we hope that you will participate in this survey since your views are important. This interview will take about 45 minutes of your time.

Do you accept to participate in the study? **YES** Q **NO** Q

IF THE RESPONDENT DOESN'T ACCEPT: Record the reason for not accepting to participate and thank the respondent for his or her time
IF THE RESPONDENT ACCEPTS TO BE INTERVIEWED: Thank you for agreeing to participate in our study. Could you please sign here or put a mark to show that you have accepted to participate in the study?
Respondent's Signature.....
PERMISSION TO TAPE-RECORD: I do not want to trust my memory so I will ask your permission to take down notes and tape-record our discussion. Once I have listened to your views from the tape and noted down your views, I will destroy the tapes. If you feel uncomfortable having any portion of the interview recorded, please inform me to switch off the tape.

Do you accept to have the discussion recorded? **YES** Q **NO** Q

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AFRICAN POPULATION AND HEALTH RESEARCH CENTER
OLDER PEOPLE PROVIDING CARE TO PERSONS WHO ARE ILL
IN-DEPTH INTERVIEW GUIDE

ROUTINE OF CARE-GIVING

1. Do you know what is/was wrong with (NAME)? How long has he/she been ill? Has (NAME) received any treatment?
2. What type of care do you provide for (NAME)? Anything else?

   PROBE: Financial, social, and psychological, anything else?
3. Would you please describe the care you provide to (NAME) on a typical day?

   PROBE: Normal routine during the day and during the night.

   How a non-typical day is like—what makes it non-typical?

   Special care provided to (NAME) but perhaps not every day

   Other special needs that (NAME) requires outside of normal routine care
4. Have there been occasions when you have not been able to provide care for (NAME)? Please explain what happened on those occasions and why you were unable to provide care.

   PROBE: How the issues were resolved and the consequences of not being able to provide the needed care.

CHALLENGES OF CARE-GIVING

5. What do you consider to have been/be the most difficult aspect of providing care? Why do you say that?

   PROBE: Challenges or difficulties relating to healthcare including, financial, stigma, discrimination, competing needs or demands. Anything else?
6. (NAME) is lucky to have you providing care for him/her. Now I want to ask about yourself, how has providing care for (NAME) affected your life in general?

   PROBE: Financial, social, and psychological, anything else?
7. What are the specific challenges faced by older people when providing care to persons who are ill for a long time?

   PROBE: Why older people face these challenges and how is it different from younger people in similar situations

   Differences with older people in other settings such as rural areas, non-slum areas etc

   What needs to be done to ease these challenges faced by older people?

FAMILY, COMMUNITY AND INSTITUTIONAL SUPPORT

8. Do you get any support from anyone in caring for (NAME)? Please tell me who gives you support and how.

   PROBE: Support from family, neighbours, community members, church

[If no support] Why no support was received

9. Are you aware of [other] institutions (NGOs/CBOs) within this community that provide care to person's who are ill or families taking care of an ill person?

   PROBE: Names and type of the institutions and the nature of support they provide, the target group, criteria for participation/recruitment, the catchment area

   Whether respondent has received assistance from these organizations and the nature of assistance received

   Adequacy of assistance received and how it can be improved

   If no assistance received ask for reasons why

10. Have you or your household received any negative reaction from anyone in relation to (NAME)'s illness or the care you are providing to (NAME)?

    PROBE: Negative reaction from family, neighbours, community members, religious groups

    How the negative reaction was displayed and possible reasons or causes

IF RESPONDENT MENTIONS (NAME) IS SUFFERING FROM HIV/AIDS

11. How did you find out that (NAME) had HIV/AIDS?

12. Does someone living with HIV/AIDS require special things (does he/she have special needs)? Please explain.

    PROBE: Nutritional needs, health needs, spiritual, psychosocial

13. What are the challenges you have faced in caring for a person living with HIV/AIDS in relation to their special needs? Please explain

    PROBE: Financial, stigma, discrimination, fear of contagion etc

14. Have you received assistance from organizations or institutions that provide support to persons affected or infected with HIV/AIDS?

    PROBE: Names and type of the institutions

    The nature of support they provide

    Also Probe: Information and education on HIV/AIDS, caring for a HIV/AIDS person etc

    Adequacy of assistance received and how it can be improved

    If no assistance received ask for reasons why no help has been sought from organizations or institutions that provide support to persons affected or infected

15. What are the specific challenges faced by older people who are providing care to persons with HIV/AIDS?

    PROBE: Why older people face these challenges and how different it is from younger people in similar situations

    Differences with older people in other settings such as rural areas, non-slum areas etc

    What needs to be done to ease these challenges faced by older people

16. What circumstances led you to provide care to (NAME)? Anything else?

PROBE: Presence of other relatives and friends?

Willingness, stigma or fear from other relatives or friends

RESPONDENTS WITH MULTIPLE EXPERIENCES

17. You also indicated that you have cared for more than one person with chronic illness in the past. Do you know what is/was wrong with (NAME)? How long was this other person ill? Did he/she receive any treatment?

18. How different has it been caring for the other person and this person?

PROBE: Differences in the routine of providing care

Differences in the challenges faced - relating to healthcare including, financial, stigma, discrimination, competing needs or demands

Differences in the support received - family, community, institutional

REFERENCES

Aboderin, I. (2004) "Modernisation and ageing theory revisited: current explanations of recent developing world and historical Western shifts in material family support for older people" *Ageing & Society* Vol 24, No. 01 page 29 - 50.

Aboderin I. (2005). "Understanding and responding to ageing, health, poverty and social change in sub-Saharan Africa: A strategic framework and plan for research" In Research on Ageing, Health and Poverty in Africa: Forging Directions for the Future .

Aboderin, I. (2006). *Intergenerational support and old age in Africa.* New Jersey: New Brunswick.

Adams, A. M., Evans, T. G., Mohammed, R., and Farnsworth, J. (1997) "Socioeconomic Stratification by Wealth Ranking: Is it Valid?" *World Development* Vol 25, No. 1165 - 1172.

Adepoju, J. (1995) "Emigration Dynamics in sub-Saharan Africa" *International Migration.Special Issue: Emigration Dynamics in Developing Countries* Vol 33, No. 4 page 315 - 390.

Adler, W. H., Baskar, P., V, Chrest, F. J., Dorsey-Cooper, B., Winchurch, R. A., and Nagel, J. E. (1997) "HIV infection and aging: mechanisms to explain the accelerated rate of progression in the older patient" *Mechanisms of Ageing and Development* Vol 96, No. 1-3 page 137 - 155.

Agesa, R. (2004) "One Family, Two Households: Rural to Urban Migration in Kenya" *Review of Economics of the Household* Vol 2, No. 2 page 161 - 178.

Ainsworth, M. and Dayton, J. (2003) "The Impact of the AIDS Epidemic on the Health of Older Persons in Northwestern Tanzania" *World Development* Vol 31, No. 1 page 131 - 148.

Alderson, P. and Goodey, C. (2007) "Theories of consent" *British Medical Journal* Vol 7, No. 317(7168) page 1313 - 1315.

Amuyunzu-Nyamongo, M., Okeng'O, L., Wagura, A., and Mwenzwa, E. (2007) "Putting on a brave face: The experiences of women living with HIV and AIDS in informal settlements of Nairobi, Kenya" *AIDS Care* Vol 19, No. 1 supp 1 page 25 - 34.

Anafri, J. K. (1995) "The condition and care of AIDS victims in Ghana : AIDS sufferers and their relations" *Health Transition Review* Vol 5, No. Supplement page 253 - 263.

Anderson, K. M. and Gerdenio, M. (1994) "Gender differences in reported stress response to the loma prieta earthquake" *Sex Roles* Vol 30, No. 9 page 1573 - 2762.

Ankrah, E. M. (1993) "The impact of HIV/AIDS on the family and other significant relationships: the African clan revisited" *AIDS Care* Vol 5, No. 1 page 5 - 22.

APHRC (2002) "Population and health dynamics in Nairobi's informal settlements: Report of the Nairobi cross-sectional slum survey (NCSS) 2000" African Population and Health Research Centre

APHRC (2008) Urbanization, Poverty and Health Dynamics in sub-Saharan Africa http://www.who.int/healthinfo/statistics/bodprojections2030/en/index.html

Appleton, J. (2000) "'At my age I should be sitting under that tree': the impact of AIDS on Tanzanian lakeshore communities" *Gender and Development* Vol 8, No. 2 page 19 - 27.

Ashley, N. R. and Kleinpeter, C. H. (2002) "Gender differences in coping strategies of spousal dementia caregivers" *Journal of Human Behavior in the Social Environment* Vol 6, No. 2 page 29 - 46.

Bachmann, M. and Booysen, F. R. (2003) "Health and economic impact of HIV/AIDS on South African households: a cohort study" *BMC Public Health* Vol 3, No. 14 page 1471 - 2458.

Baggaley, R., Sulwe, J., Burnett, A., and Ndovi, M. (1996) "Forging links between the formal and traditional in Zambia. Special report: traditional healers" *AIDS Analysis Africa* Vol 6, No. 1 page 2 - 13.

Barnett, T. and Whiteside A. (2000). *Guidelines for studies of the social and economic impact of HIV/AIDS.* Geneva, Switzerland: UNAIDS.

Barnett, T. and Whiteside, A. (2002) 'Poverty and HIV/AIDS: Impact, coping and mitigation policy ' in Giovanni,A.C. (eds) *AIDS, public policy and child well-being* Florence: UNICEF Innocenti Research Centre,

Bechu, N. (1998) 'The impact of AIDS on the economy of families in Côte d'Ivoire: Changes in consumption among AIDS-affected households' in Ainsworth,M., Fransen, L., and Over, M. (eds) *Confronting AIDS: Evidence from the Developing World* Luxembourg: European Commission,

Beegle, K. and Weerdt, J. (2007) "Methodological Issues in the Study of the Socioeconomic Consequences of HIV/AIDS" World Bank

Benoît K. (2001). "Population and ageing in Africa: A policy dilemma?" In IUSSP Conference. Salvador, Brazil

Bicego, G., Rutstein, S., and Johnson, K. (2003) "Dimensions of the emerging orphan crisis in sub-Saharan Africa" *Social Science and Medicine* Vol 56, No. 1235 - 1247.

Bocquier, P. (2005) "Informal Sector Versus Informal Contracts in Nairobi, Kenya" Working papers. Developpement Institutions & Analyses de Long terme

Bongaarts, J. and Zimmer, Z. (2002) "Living Arrangements of Older Adults in the Developing World: An Analysis of Demographic and Health Survey Household Surveys" *Journals of Gerontology Series B: Psychological Sciences and Social Sciences* Vol 57, No. 3 page S145 - S157.

Booysen, F. R., Bachmann, M., Van Rensburg, H. C. J., Engelbrecht, M., Steyn, F., and Meyer, K. (2002) "The Socio-Economic Impact of HIV/AIDS on Households in South Africa: Pilot Study in Welkom and Qwaqwa, Free State Province" University of the Free State

Booysen, F. R. and Arntz, T. (2003) "The methodology of HIV/AIDS impact studies: a review of current practices" *Social Science & Medicine* Vol 56, No. 12 page 2391 - 2405.

Bor, R., Elford, J., Hart, G., and Sherr, L. (1993a) "The family and HIV disease" *AIDS Care* Vol 5, No. 1 page 3 - 4.

Bor, R., Miller, R., and Goldman, E. (1993b) "HIV/AIDS and the family: a review of research in the first decade" *Journal of Family Therapy* Vol 15, No. 2 page 187 - 205.

Brown, J. W., Chen, S. l., Mitchell, C., and Province, A. (2007) "Help-seeking by older husbands caring for wives with dementia" *Journal of Advanced Nursing* Vol 59, No. 4 page 352 - 360.

Brown, T., Grassly, N. C., Garnett, G., and Stanecki, K. (2006) "Improving projections at the country level: the UNAIDS Estimation and Projection Package 2005" *Sexually Transmitted Infections* Vol 82, No. suppl_3 page iii34 - iii40.

Byerlee, D. (1974) "Rural-Urban Migration in Africa: Theory, Policy and Research Implications" *International Migration Review* Vol 8, No. 4 page 543 - 566.

Cancer journal for clinicians (2006) "Family caregivers often neglect their own mental health" *CA: A Cancer Journal for Clinicians* Vol 56, No. 1 page 5 - 6.

Canning, D., Mahal, A., Mahal, A., Odumosu, K., and Okonkwo, P. (2006) "Assessing the Economic Impact of HIV/AIDS on Nigerian Households: A Propensity Score Matching Approach" PGDA Working Papers. Program on the Global Demography of Aging

Cantril, H. (1965). *Pattern of human concerns.* New Brunswick, New Jersey: Rutgers University Press.

Centers for Disease Control and Prevention (1992) "1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults" Morbidity and Mortality Weekly Report. 41(RR-17) Centers for Disease Control and Prevention

Central Bureau of Statistics (2002a) "1999 Population and housing census: volume I" Government of Kenya Nairobi

Central Bureau of Statistics (2002b) "The 1999 population and housing census: The popular report" Government of Kenya Nairobi

Central Bureau of Statistics, Ministry of Health, and Macro, O. R. C. (2004) "Kenya demographic and health survey 2003" Demographic and health surveys. CBS, MOH, and ORC Macro

Central Statistical Office and Macro International, I. (2008) "Swaziland Demographic and Health Survey 2006-07" Demographic and Health Surveys. Central Statistical Office and Macro International Inc

Chappell, N. L. and Reid, R. C. (2002) "Burden and Well-Being Among Caregivers: Examining the Distinction" *The Gerontologist* Vol 42, No. 6 page 772 - 780.

Chauvin, B., Hermand, D., and Mullet, E. (2007) "Risk Perception and Personality Facets" *Risk Analysis* Vol 27, No. 1 page 171 - 185.

Cheluget, B., Baltazar, G., Orege, P., Ibrahim, M., Marum, L. H., and Stover, J. (2006) "Evidence for population level declines in adult HIV prevalence in Kenya" *Sexually Transmitted Infections* Vol 82, No. suppl_1 page i21 - i26.

Chiao, E. Y., Ries, K. M., and Sande, M. A. (1999) "AIDS and the elderly" *Clinical Infectious Diseases* Vol 28, No. 4 page 740 - 745.

Chima R., Chima, I., and Azie, U. (2004). "Ageing and HIV/AIDS: Impact, Responses and Weak links" In African Conference on Ageing. Johannesburg, South Africa 18-9-2004.

Chimwaza and Watkins (2004) "Giving care to people with symptoms of AIDS in rural sub-Saharan Africa" *AIDS Care* Vol 16, No. 7 page 795 - 807.

Chintu, C., Malek, A., Nyumbu, M., Luo, C., Masona, J., DuPont, H. L., and Zumla, A. (1993) "AIDS and the urban family: its impact in Kampala, Uganda" *International Journal of STD & AIDS* Vol 4, No. 2 page 83 - 85.

Chipfakacha, V. G. (1997) "STD/HIV/AIDS knowledge, beliefs and practices of traditional healers in Botswana" *AIDS Care* Vol 9, No. 4 page 417 - 425.

Clark S. J., Collinson, M., Kahn, K., Drullinger, K., and Tollman, S. (2007). "Returning Home to Die: Circular Labor Migration and Mortality in Northeast South Africa" In Migration and Wellbeing in Developing Countries Population Association of America (PAA) 2007 Annual Meeting. 29-3-2007.

Clarke, J. N. (2006) "Homophobia out of the closet in the media portrayal of HIV/AIDS 1991, 1996 and 2001: Celebrity, heterosexism and the silent victims" *Critical Public Health* Vol 16, No. 4 page 317 - 330.

Coast E. (2005). "Sexual behaviour and perceptions of risk: male rural-urban migrants in Tanzania" In The behavioural dimension of the HIV epidemic: risks, perceptions and

behaviours International Union for the Scientific Study of Population XXV International Population Conference. Tours, France 18-7-2005.

Covinsky, K. E., Eng, C., Lui, L. Y., Sands, L. P., Sehgal, A. R., Walter, L. C., Wieland, D., Eleazer, G. P., and Yaffe, K. (2001) "Reduced Employment in Caregivers of Frail Elders: Impact of Ethnicity, Patient Clinical Characteristics, and Caregiver Characteristics" *Journals of Gerontology Series A: Biological Sciences and Medical Sciences* Vol 56, No. 11 page M707 - M713.

Creswell, J. W. (2003). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches.* Sage Publications, Inc.

Creswell, J. W., Guttman, M., and Plano-Clark, V. (2003) 'Advanced Mixed Methods Research Design' in Tashakkori, A. and Teddlie, C. B. (eds) *Handbook of Mixed Methods in Social & Behavioral Research* Sage Publications, Inc, 209-240.

Dayton, J. and Ainsworth, M. (2004) "The elderly and AIDS: Coping with the impact of adult death in Tanzania" *Social Science & Medicine* Vol 59, No. 10 page 2161 - 2172.

Deaton, A. (1997). *The Analysis of Household Surveys: A Microeconometric Approach to Development Policy.* Baltimore: Published for the World Bank [by] Johns Hopkins University Press.

Deng, N. and Turkstra, J. (2004) "Urban poverty and slums, Intra-city differential study of Nairobi" Global urban observatory, UNHABITAT

Dercon, S., De Weerdt, J., Bold, T., and Pankhurst, A. (2006) "Group-based funeral insurance in Ethiopia and Tanzania" *World Development* Vol 34, No. 4 page 685 - 703.

Donovan, C. and Bailey, L. (2005) "Understanding Rwandan Agricultural Households' Strategies to Deal with Prime Age Illness and Death: A Propensity Score Matching Approach" International Development Collaborative Working Papers. Department of Agricultural Economics, Michigan State University

Douglas, M. (1992). *Risk and blame: Essays in cultural theory.* London: Routledge.

du Guerny J. (1997). "The Rural Elderly and the Ageing of Rural Populations" In World Congress of Gerontology/Inter-Agency Meeting for the International Year of Older Persons 1999

Dudley, C., O'Sullivan, L. F., and Moreau, D. (2002) "Does Familiarity Breed Complacency? Hiv Knowledge, Personal Contact, and Sexual Risk Behavior of Psychiatrically Referred Latino Adolescent Girls" *Hispanic Journal of Behavioral Sciences* Vol 24, No. 3 page 353 - 368.

Eliopoulos, C. (1997). *Gerontological Nursing.* New York: Lippincott-Raven Publishers.

Ellis, M. (1996) "The post diagnosis mobility of people with AIDS" *Environment and Planning A* Vol 28, No. 6 page 999 - 1017.

Ellis, M. and Muschkin, C. (1996) "Migration of persons with AIDS--A search for support from elderly parents?" *Social Science & Medicine* Vol 43, No. 7 page 1109 - 1118.

Evandrou, M. and Glaser, K. (2003) "Combining work and family life: the pension penalty of caring" *Ageing & Society* Vol 23, No. 05 page 583 - 601.

Falkingham, J. and Namazie, C. (2002) "Measuring health and poverty: A review of approaches to indentifying the poor" Health Systems Resource Centre

Ferreira M. (2004a). "HIV/AIDS and family well-being in southern Africa: towards an analysis of policies and responsiveness" In Social Policy and Development Policy Workshop. Windhoek, Namibia 28-1-2004a.

Ferreira M. (2004b). "Older caregivers in African households affected by HIV/AIDS: supporting the caregivers and promoting family well-being" In African Conference on Ageing. Johannesburg, South Africa 18-9-2004b.

Ferreira, M., Keikelame, M. J., and Mosaval, Y. (2001) "Older women as carers to children and grandchildren affected by AIDS: a study towards supporting the carers" Institute of Ageing in Africa

Feulefack, J. F. and Zeller, M. (2005) "How Accurate Is Participatory Wealth Ranking (PWR) in Targeting the Poor? A Case Study from Bangladesh" "The Global Food & Product Chain—Dynamics, Innovations, Conflicts, Strategies". Georg-August-University G¨ottingen, Institute of Rural Development, Germany

Filmer, D. and Pritchett, L. H. (2001) "Estimating Wealth Effects without Expenditure Data-or Tears: An Application to Educational Enrolments in States of India" *Demography* Vol 38, No. 1 page 115 - 132.

Foster, G. (2000) "The capacity of the extended family safety net for orphans in Africa" *Psychology, Health and Medicine* Vol 5, No. 1 page 55 - 62.

Fuller-Jonap, F. and Haley, W. E. (1995) "Mental and physical health of male caregivers of a spouse with Alzheimer's disease" *Journal of Aging & Health* Vol 7, No. 1 page 99 - 118.

Gebo, K. A. and Moore, R. D. (2004) "Treatment of HIV infection in the older patient" *Expert Review of Anti-infective Therapy* Vol 2, No. 5 page 733 - 743.

Glendon, A. I., Dorn, L., Davies, D. R., Matthews, G., and Taylor, R. G. (1997) "Age and Gender Differences in Perceived Accident Likelihood and Driver Competences" *Insurance: Mathematics and Economics* Vol 20, No. 273 - 274.

Glozman, J. M. (2004) "Quality of life of caregivers" *Neuropsychology Review* Vol 14, No. 4 page 183 - 196.

Goodroad, B. K. (2003) "HIV and AIDS in people older than 50. A continuing concern" *Journal of Gerontological Nursing* Vol 29, No. 4 page 18 - 24.

Gould, W. T. S. and Oucho, J. O. (1993) 'Internal migration, urbanisation and population distribution' in *Demographic Change in Sub-Saharan Africa* Washington D.C.: National Academy Press, 256-296.

Government of Kenya and UNCHS (2001) "Nairobi Situation Analysis" UNCHS

Grant, A. D. and De Cock, K. M. (2001) "ABC of AIDS: HIV infection and AIDS in the developing world" *British Medical Journal* Vol 322, No. 7300 page 1475 - 1478.

Grant, I. (1999) "Caregiving May Be Hazardous to Your Health" *Psychosomatic Medicine* Vol 61, No. 4 page 420 - 423.

Gustafson, P. E. (1998) "Gender Differences in Risk Perception: Theoretical and Methodological Perspectives" *Risk Analysis* Vol 18, No. 805 - 811.

Gwatkin, D. R. (2003) "How well do health programmes reach the poor?" *The Lancet* Vol 361, No. 9357 page 540 - 541.

Haley, W. E., LaMonde, L. A., Han, B., Narramore, S., and Schonwetter, R. (2001) "Family caregiving in hospice: Effects on psychological and health functioning among spousal caregivers of hospice patients with lung cancer or dementia" *Hospice Journal* Vol 15, No. 4 page 1 - 18.

Hargreaves, J. R., Morison, L. A., Gear, J., Porter, J. D. H., Makhubele, M. B., Kim, J. C., Busza, J., Watts, C., and Pronyk, P. M. (2007a) "'Hearing the voices of the poor': Assigning poverty lines on the basis of local perceptions of poverty; a quantitative analysis of qualitative data from participatory wealth ranking in rural South Africa" *World Development* Vol 35, No. 2 page 212 - 229.

Hargreaves, J., Morison, L., Gear, J., Kim, J., Makhubele, M., Porter, J., Watts, C., and Pronyk, P. (2007b) "Assessing household wealth in health studies in developing countries: a comparison of participatory wealth ranking and survey techniques from rural South Africa" *Emerging Themes in Epidemiology* Vol 4, No. 1 page 4 - 12.

HelpAge International (1998) "The Impact of HIV/AIDS on Older People in Cambodia"

HelpAge International (2002) "State of the world's older people 2002" HelpAge International

Heslop, A. and Gorman, M. (2002) "Chronic Poverty and Older People in the Developing World" Chronic Poverty Research Centre. 10

Hooyman, N. and Kiyak A. (1996). *Social gerontology: A multi-disciplinary perspective.* Needham Heights, MA: Simon & Schuster Company.

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* Washington, D. C.: The National Academies Press, 250-275.

Hunt, C. K. (2003) "Concepts in Caregiver Research" *Journal of Nursing Scholarship* Vol 35, No. 1 page 27 - 32.

Ingstad, B., Bruuns, F. J., and Tlou, S. (1997) "AIDS and the elderly Tswana: The concept of pollution and consequences for AIDS prevention" *Journal of Cross-Cultural Gerontology* Vol 12, No. 4 page 357 - 372.

Institute of Policy Analysis & Research (2004) "Funding the Fight Against HIV/AIDS: Budgetary Analysis of Kenya.s HIV/AIDS Activity Prioritization and Financing" *Policy Briefs* Vol 10, No. *8* page 1 - 4.

Isiugo-Abanihe, U. C. (1985) "Child Fosterage in West Africa" *Population and Development Review* Vol 11, No. 1 page 53 - 73.

Kakooza J. (2004). "HIV/AIDS and the changing role of the aged.Understanding The Role, Constraints And Consequences for the Elderly as Providers of Education to Children Orphaned By HIV/AIDS" In African Conference on Ageing. Johannesburg, South Africa 18-9-2004.

Kakwani, N. and Subbarao, K. (2005) "Ageing and poverty in Africa and the role of social pensions" Social Protection Discussion Paper Series. 0521 The World Bank

Kane, E. W. and Macaulay, L. J. (1993) "Interviewer Gender and Gender Attitudes" *The Public Opinion Quarterly* Vol 57, No. 1 page 1 - 28.

Kassu, A., Mekonnen, A., Bekele, A., Abseno, N., Melese, E., and Ota, F. (2004) "HIV and Syphilis Infection among Elderly People in Northwest Ethiopia" *Japanese Journal of Infectious Diseases* Vol 57, No. 6 page 264 - 267.

Kebede, B. (2005) "Community Wealth-Ranking and Household Surveys: An Integrative Approach" Q-Squared Working Paper No 13.

Keller, I., Makipaa, A., Kalenscher, T., and Kalache, A. (2002) "Global survey on geriatrics in the medical curriculum" Ageing and Life Course Programme. World Health Organization

Kenya National Bureau of Statistics (2007) "Kenya facts and figures 2007" Government press

Kiecolt-Glaser, J. K., Dura, J. R., Speicher, C. E., Trask, O. J., and Glaser, R. (1991) "Spousal caregivers of dementia victims: longitudinal changes in immunity and health" *Psychosomatic Medicine* Vol 53, No. 4 page 345 - 362.

Kim, Y., Loscalzo, M. J., Wellisch, D. K., and Spillers, R. L. (2006) "Gender differences in caregiving stress among caregivers of cancer survivors" *Psycho-Oncology* Vol 15, No. 12 page 1086 - 1092.

Kinsella, K. (2000) "Demographic Dimensions of Global Aging" *JOURNAL OF FAMILY ISSUES* Vol 21, No. 5 page 541 - 558.

Kinsella, K. and Ferreira, M. (1997) "Ageing trends: South Africa" International Brief. U.S. Department of Commerce

Kinsella, K. and Velkoff, V. A. (2001) "An Aging World" U.S. Census Bureau Series. P95/01-1 U.S. Government Printing Office

Kitahata, M. M., Tegger, M. K., Wagner, E. H., and Holmes, K. K. (2002) "Comprehensive health care for people infected with HIV in developing countries" *British Medical Journal* Vol 325, No. 7370 page 954 - 957.

Kloos, H., Wuhib, T., Mariam, D. H., and Lindtjorn, B. (2008) "Community-based organizations in HIV/AIDS prevention, patient care and control in Ethiopia" *The Ethiopian Journal of Health Development* Vol 17, No. Special issue page 3 - 31.

Knodel, J., VanLandingham, M., Saengtienchai, C., and Im-em, W. (2001) "Older people and AIDS: quantitative evidence of the impact in Thailand" *Social Science & Medicine* Vol 52, No. 9 page 1313 - 1327.

Knodel, J. E. (2005) "Researching the Impact of the AIDS Epidemic on Older-age Parents in Africa: Lessons from Studies in Thailand" *Generations Review* Vol 15, No. 2 page 16 - 22.

Knodel, J. E. (2006) "Poverty and the impact of AIDS on older person: Evidence from Cambodia and Thailand" Research Report. Population Studies Centre, University of Michigan

Knodel, J. E. and Zimmer, Z. (2006) "The impact of AIDS on older-age parents in Cambodia" Research Report. Population Studies Centre, University of Michigan

Knodel, J. E. and Im-Em, W. (2003) "The Economic Consequences for Parents of Losing an Adult Child to AIDS: Evidence from Thailand" PSC Research Report. 02-504 Population Studies Center

Knodel, J. E. and Saengtienchai, C. (2002) "AIDS and older persons: The View from Thailand" PSC Research Report. 02-497 Population Studies Center

Knodel, J. E. and VanLandingham, M. (2001) "Return Migration in the Context of Parental Assistance in the AIDS Epidemic: The Thai Experience" PSC Research Report. 01-492 Population Studies Center

Knodel, J. E., VanLandingham, M., Saengtienchai, C., Im-Em, W., and Kespichayawattana, J. (2003) "Data Collection Strategies for Studying the Impacts of AIDS on Older Parents: Lessons from Research in Thailand" 03-537 Population Studies Center

Knodel, J. E., Watkins, S., and VanLandingham, M. (2002) "AIDS and older persons: An International Perspective" PSC Research Report. 02-495 Population Studies Center

Kongsin, S. (2005) "The economic impact of HIV/AIDS mortality on households in Upper-North Thailand: Phayao case study" Faculty of Medicine, University of London Department of Public Health and Policy, London School of Hygiene and Tropical Medicine

Kramer, B. J. (2002) 'Men caregivers: an oberview' in Kramer,B.J. and Thompson, E. H. J. (eds) *Men as caregivers: Theory, research, and service implication* New York: Springer Publishing Company, 3-19.

Landau, J. and Griffiths, J. (1981) "The South African Family in Transition: Training and Therapeutic Implications" *Journal of Marital and Family Therapy* Vol 7, No. 3 page 339 - 344.

Légaré, J., Ibrahima, M., and Sossa, O. (2003) "Population Ageing: A Challenge for Developing Countries" International Federation on Ageing

Lepage, P., van de Perre, P., Dabis, F., Commenges, D., Orbinski, J., Hitimana, D. G., Bazubagira, A., van Goethem, C., and Butzler, J. P. (1989) "Evaluation and simplification of the World Health Organization clinical case definition for paediatric AIDS" *AIDS* Vol 3, No. 4 page 221 - 225.

Lieberman, R. (2000) "HIV in older Americans: an epidemiologic perspective" *Journal of Midwifery & Women's Health* Vol 45, No. 2 page 176 - 182.

Lloyd-Sherlock, P. (2005) "living arrangements of older persons and poverty" Bulletin 42 - 43. Department of Economic and Social Affairs Population Division

Lloyd-Sherlock, P. (2000) "Old Age and Poverty in Developing Countries: New Policy Challenges" *World Development* Vol 28, No. 12 page 2157 - 2168.

Lutzky, S. M. and Knight, B. G. (1994) "Explaining Gender Differences in Caregiver Distress: The Roles of Emotional Attentiveness and Coping Styles" *psychology and aging* Vol 9, No. 4 page 513 - 519.

MacNeil, J. M. (1996) "Use of Culture Care Theory with Baganda Women as AIDS Caregivers" *Journal of Transcultural Nursing* Vol 7, No. 2 page 14 - 20.

Macro International, I. (2008) "HIV prevalence estimates from the Demographic and Health Surveys" Macro International, Inc.

Madhavan, S. (2004) "Fosterage patterns in the age of AIDS: continuity and change" *Social Science and Medicine* Vol 58, No. 1443 - 1454.

Makgoba, M. W. (2002) "Politics, the media and science in HIV/AIDS: the peril of pseudoscience" *Vaccine* Vol 20, No. 15 page 1899 - 1904.

Manfredi, R. (2002) " HIV Disease and Advanced Age: An Increasing Therapeutic Challenge" *Drugs & Aging* Vol 19, No. 9 page 647 - 669.

Manly, B. F. J. (2005). *Multivariate Statistical Methods: A Primer.* London: Chapman & Hall/CRC.

Mason, J. (2002). *Qualitative Researching.* Sage Publications, Inc.

Mathers, C. D. and Loncar, D. (2006) "Projections of global mortality and burden of disease from 2002 to 2030" *PLoS Medicine* Vol 3, No. 11 page e442 -

Matrix Development Consultants (1993) "Nairobi's informal settlements: An inventory" A Report Prepared for USAID/REDSO/ ESA. Nairobi: USAID.

McGrath, J. W., Ankrah, E. M., Schumann, D. A., Nkumbi, S., and Lubega, M. (1993) "AIDS and the urban family: its impact in Kampala, Uganda" *AIDS Care.5(1):55-70,* Vol

Miles, M. B. and Huberman M. (1994). *Qualitative Data Analysis: An Expanded Sourcebook.* Sage Publications, Inc.

Miller, B. and Cafasso, L. (1992) "Gender differences in caregiving: fact or artifact?" *The Gerontologist* Vol 32, No. 4 page 498 - 507.

Ministry of Health (2005) "Behavioural surveillance survey 2002: Summary report, HIV/AIDS and sexually transmitted infection in Kenya" National AIDS/STD Control Programme

Ministry of Home Affairs and National AIDS Control Council (2003) "National programme guidelines on orphans and other children made vulnerable by HIV/AIDS" Republic of Kenya

Mitullah W (2003) "Urban slums reports: The case of Nairobi, Kenya" UNHABITAT

Moller, V. (1997) "AIDS: The `Grandmothers' Disease' in Southern Africa" *Ageing and Society* Vol 17, No. 4 page 461 - 464.

Montgomery, M. R., Gragnolati, M., Burke, K. A., and Paredes, E. (2000) "Measuring Living Standards with Proxy Variables" *Demography* Vol 37, No. 2 page 155 - 174.

Morris, S. S., Carletto, C., Hoddinott, J., and Christiaensen, L. J. M. (2000) "Validity of rapid estimates of household wealth and income for health surveys in rural Africa" *Journal of Epidemiology and Community Health* Vol 54, No. 5 page 381 - 387.

Morse, J. (2003) 'Principles of Mixed-and Multi-Method Research Design' in Tashakkori,A. and Teddlie, C. B. (eds) *Handbook of Mixed Methods in Social & Behavioral Research* Sage Publications, Inc, 189-208.

Muga, R., Ndavi, P., Kizito, P., Buluma, R., Lumumba, V., Ametepi, P., Fronczak, N., and Fort, A. (2005) "Kenya HIV/AIDS service provision assessment survey 2004" Service Provision Assessment Survey. National Coordinating Agency for Population and Development, Ministry of Health, Central Bureau of Statistics, and ORC Macro

Mullan, J. T. (1998) "Aging and informal caregiving to people with HIV/AIDS" *Research on Aging* Vol 20, No. 6 page 712 - 738.

Munk, K. (1997) "Traditional healers, traditional hospitals and HIV / AIDS: a case study in KwaZulu-Natal" *AIDS Analysis Africa* Vol 7, No. 6 page 10 - 12.

Naidu, V. and Harris, G. (2005) "The impact of HIV/AIDS morbidity and mortality on households - a review of household studies" *The South African Journal of Economics* Vol 73, No. s1 page 533 - 544.

Nandy, S. (2008) "`Misunderestimating' Chronic Poverty?: Exploring Chronic Poverty in Developing Countries Using Cross-Sectional Demographic and Health Data" *Global Social Policy* Vol 8, No. 1 page 45 - 79.

NASCOP and Ministry of Health (2008) "Kenya AIDS indicator survey 2007: Preliminary report" Government of Kenya

National AIDS Control Council (2005a). *Kenya HIV/AIDS data booklet.* Nairobi: Government of Kenya.

National AIDS Control Council (2005b). *Kenya national HIV/AIDS strategic plan 2005/6 - 2009/10: A call to action.* Nairobi: Government of Kenya.

National AIDS Control Council (2005c). *Monitoring and evaluation implementation manual.* Nairobi: Government of Kenya.

National AIDS Control Council (2005d) "NACC Restructured to meet its mandate" Maisha newsletter Government of Kenya Nairobi

National AIDS/STD Control Program (2005). *AIDS in Kenya: Trends, interventions and impact.* Nairobi: Government of Kenya.

Ndaba-Mbata, R. D. and Seloilwe, E. S. (2000) "Home-based care of the terminally ill in Botswana: knowledge and perceptions" *International Nursing Review* Vol 47, No. 4 page 218 - 223.

Neary, M. A. (1993) "Type of elder impairment: Impact on caregiver burden, health outcomes and social support" *Clinical Gerontologist* Vol 13, No. 2 page 47 - 59.

Neville, M. A. and Rubin, D. L. (2007) "Factors Leading to Self-Disclosure of a Positive HIV Diagnosis in Nairobi, Kenya: People Living With HIV/AIDS in the Sub-Sahara" *Qualitative Health Research* Vol 17, No. 5 page 586 - 598.

Nijboer, C., Tempelaar, R., Sanderman, R., and Mattanja, T. R. (1998) "Cancer and caregiving: the impact on the caregiver's health" *Psycho-Oncology* Vol 7, No. 1 page 3 - 13.

Nkurunziza, E. and Rakodi, C. (2005) "Urban families under pressure: conceptual and methodological issues in the study of poverty, HIV/AIDS and livelihood strategies" Working Paper. International Development Department

Ntozi, J. P. M. (1997a) "AIDS morbidity and the role of the family in patient care in Uganda" *Health Transition Review* Vol 7, No. Supplement page 1 - 22.

Ntozi, J. P. M. (1997b) "Widowhood, remarriage and migration during the HIV/AIDS epidemic in Uganda" *Health Transition Review* Vol 7, No. Supplement page 125 - 144.

Ntozi, J. P. M., Lubaale, Y. M. A., and Nakanaabi, I. M. (1997) "AIDS mortality in Uganda: circumstances, factors and impact of death" *Health Transition Review* Vol 7, No. Supplement page 207 - 224.

Ntozi, J. P. M. and Nakayiwa, S. (1999) 'AIDS in Uganda: how has the household coped with the epidemic' in Caldwell,J.C., Orubuloye, I. O., and Ntozi, J. P. M. (eds) *The Continuing African HIV/AIDS Epidemic* Canberra: Health Transition Centre, National Centre for Epidemiology and Population Health, Australian National University,

Ntozi, J. P. M. and Zirimenya, S. (1999) 'Changes in household composition and family structure during the AIDS epidemic in Uganda' in Caldwell,J.C., Orubuloye, I. O., and Ntozi, J. P. M. (eds) *The Continuing African HIV/AIDS Epidemic* Health Transition Centre, National Centre for Epidemiology and Population Health, Australian National University, *193-209.*

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* Vol 18, No. 1 page 33 - 52.

O'Connor, A. M. (1983). *The African City.* London: Hutchinson.

Oburu, P. O. (2005) "Caregiving stress and adjustment problems of Kenyan orphans raised by grandmothers" *Infant and Child Development* Vol 14, No. 2 page 199 - 210.

Odhiambo, W. and Manda, K. D. (2003) "Urban poverty and labour force participation in Kenya" Kenya Institute for Public Policy Research and Analysis (KIPPRA)

Olenja, J. M. (1999) "Assessing Community Attitude Towards Home-Based Care for People with AIDS (PWAS) in Kenya" *Journal of Community Health* Vol 24, No. 3 page 187 - 199.

Oltedal, S., Moen, B.-E., Klempe, H., and Rundmo, T. (2004) "Explaining risk perception. An evaluation of cultural theory" Rotunde publikasjoner

Onwueghbuzie, A. and Teddlie, C. B. (2003) 'A Framework for Analyzing Data in Mixed Methods Research' in Tashakkori,A. and Teddlie, C. B. (eds) *Handbook of Mixed Methods in Social & Behavioral Research* Sage Publications, Inc, 351-384.

Otieno, A. T. A. and Bocquier, P. (2006) "An Event History Analysis of Factors Influencing Entry into Parenthood In Nairobi" *African Population Studies* Vol 19, No. 2 page 43 - 62.

Pan American Health Organization (2001) "Case Definition: Acquired Immunodeficiency Syndrome (AIDS)" *Epidemiological Bulletin* Vol 22, No. 2 page

Parker, R., Aggleton, P., Attawell, K., Pulerwitz, J., and Brown, L. (2002) "HIV/AIDS-related stigma and discrimination: A conceptual framework and an agenda for action" The Population Council

Peters, E. J., Immananagha, K. K., Essien, O. E., and Ekott, J. U. (2004) "Traditional healers' practices and the spread of HIV/AIDS in south eastern Nigeria" *Tropical Doctor* Vol 34, No. 2 page 79 - 82.

Pinstrup-Andersen, P. E. R. (1985) "Food prices and the poor in developing countries" *European Review of Agricultural Economics* Vol 12, No. 1 page 69 - 81.

Piot, P. and Collseck, A. M. (2001) "International response to the HIV/AIDS epidemic: planning for success" *Bulletin of the World Health Organization* Vol 79, No. 12 page 1106 - 1112.

Porter, L., Hao, L., Bishai, D., Serwadda, D., Wawer, M. J., Lutalo, T., Gray, R., and Team, T. R. P. (2004) "HIV Status and Union Dissolution in Sub-Saharan Africa: The Case of Rakai, Uganda" *Demography* Vol 41, No. 3 page 465 - 482.

Prakongsai, P. (2006) "An Application of the Asset Index for Measuring Household Living Standards in Thailand" SSRN eLibrary. Social Science Research Network

Rakwar, J., Kidula, N., Fonck, K., Kirui, P., Ndinya-Achola, J., and Temmerman, M. (1999) "HIV/STD: the women to blame? Knowledge and attitudes among STD clinic attendees in the second decade of HIV/AIDS" *International Journal of STD & AIDS* Vol 10, No. 543 - 547.

Republic of Kenya and Ministry of Health (1997) "Sessional paper No. 4 of 1997 on AIDS in Kenya"

Robson, C. (2002). *Real World Research: A Resource for Social Scientists and Practitioner-Researchers.* Blackwell Publishing Limited.

Roth, J. (2001) "Informal microinsurance schemes - the case of funeral insurance in South Africa" *Small Enterprise Development* Vol 12, No. 39 - 50.

Rutenberg, N. and Watkins, S. C. (1997) "The Buzz Outside the Clinics: Conversations and Contraception in Nyanza Province, Kenya" *Studies in Family Planning* Vol 28, No. 4 page 290 - 307.

Rutstein, S. O. and Johnson, K. (2004) "The DHS Wealth Index" Comparative reports. CR6 MEASURE DHS+ & ORC Macro

Saengtienchai, C. and Knodel, J. E. (2001) "Parents providing care to adult sons and daughters with HIV/AIDS in Thailand" UNAIDS *Best Practice* Collection. UNAIDS

Sahn, D. E. and Stifel, D. (2003) "Exploring Alternative Measures of Welfare in the Absence of Expenditure Data" *The Review of Income and Wealth* Vol 49, No. 463 - 489.

Sauerborn, R., Adams, A., and Hien, M. (1996) "Household strategies to cope with the economic costs of illness" *Social Science & Medicine* Vol 43, No. 3 page 291 - 301.

Scherer, C. W. and Cho, H. (2003) "A Social Network Contagion Theory of Risk Perception" *Risk Analysis* Vol 23, No. 2 page 261 - 267.

Schulz, R. and Beach, S. R. (1999) "Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study" *JAMA: The Journal of the American Medical Association* Vol 282, No. 23 page 2215 - 2219.

Seeley, J., Kajura, E., Bachengana, C., Okongo, M., Wagner, U., and Mulder, D. (1993) "The extended family and support for people with AIDS in a rural population in south west Uganda: a safety net with holes?" *AIDS Care* Vol 5, No. 1 page 117 - 122.

Sjoberg, L. (2000) "Factors in Risk Perception" *Risk Analysis* Vol 20, No. 1 page 1 - 12.

Slovic, P., Finucane, M. L., Peters, E., and MacGregor, D. G. (2004) "Risk as Analysis and Risk as Feelings: Some Thoughts about Affect, Reason, Risk, and Rationality" *Risk Analysis* Vol 24, No. 311 - 322.

Slovic, P. and Peters, E. (2006) "Risk Perception and Affect" *Current Directions in Psychological Science* Vol 15, No. 6 page 322 - 325.

Smith, M. K. (2002) "Gender, poverty, and intergenerational vulnerability to HIV/AIDS" *Gender and Development* Vol 10, No. 3 page 63 - 70.

Spira, R., Lepage, P., Msellati, P., Van de Perre, P., Leroy, V., Simonon, A., Karita, E., and Dabis, F. (1999) "Natural History of Human Immunodefiency Virus Type 1 Infection in Children: A Five-Year Prospective Study in Rwanda" *Pediatrics* Vol 104, No. 5 page e56 - e65.

Stake, R. E. (2005). *Multiple Case Study Analysis.* The Guilford Press.

Statacorp (2007). *Stata Multivariate Statistics Reference Manual.* College Station, Texas: Stata Press.

Stoller, E. P. (2002) 'Theoretical perspective on caregiving men' in Kramer,B.J. and Thompson, E. H. J. (eds) *Men as caregivers: Theory, research, and service implication* New York: Springer Publishing Company, 51-68.

Stone, R. I. and Short, P. F. (1990) "The competing demands of employment and informal caregiving to disabled elders" *Medical Care* Vol 28, No. 6 page 513 - 526.

Stover, J. (2004) "Projecting the demographic consequences of adult HIV prevalence trends: the Spectrum Projection Package" *Sexually Transmitted Infections* Vol 80, No. suppl_1 page i14 - i18.

Stover, J., Walker, N., Grassly, N. C., and Marston, M. (2006) "Projecting the demographic impact of AIDS and the number of people in need of treatment: updates to the Spectrum projection package" *Sexually Transmitted Infections* Vol 82, No. suppl_3 page iii45 - iii50.

Sungkanuparph, S., Manosuthi, W., Kiertiburanakul, S., and Vibhagool, A. (2004) "Clinical experience with high success rate of antiretroviral therapy in elderly HIV-infected patients" *Age and Ageing* Vol 33, No. 5 page 520 - 521.

Tashakkori, A. and Teddlie C. B. (1998). *Mixed Methodology: Combining Qualitative and Quantitative Approaches.* Sage Publications, Inc.

Teddlie, C. B. and Tashakkori, A. (2003) 'Major Issues and Controversies in the Use of Mixed Methods in the Social and Behavioral Sciences' in Tashakkori,A. and Teddlie, C. B. (eds) *Handbook of Mixed Methods in Social & Behavioral Research* Sage Publications, Inc, 3-50.

The Whoqol Group (1993) "Study protocol for the World Health Organization project to develop a Quality of Life assessment instrument (WHOQOL)" *Quality of Life Research* Vol 2, No. 2 page 153 - 159.

The Whoqol Group (1998) "The World Health Organization quality of life assessment (WHOQOL): Development and general psychometric properties" *Social Science & Medicine* Vol 46, No. 12 page 1569 - 1585.

Thurman, T. R., Hoffman, A., Chatterji, M., and Brown, L. (2007) "A Case Study: Community-Based HIV/AIDS prevention, care, and support program" MEASURE Evaluation and Pathfinder International

UNAIDS (2001) "Reaching out, scaling up. Eight case studies of home and community care for and by people with HIV / AIDS" UNAIDS Best Practice Collection. UNAIDS

UNAIDS (2006) "2006 Report on the global AIDS epidemic: A UNAIDS 10th anniversary special edition" Report on the global AIDS epidemic. Joint United Nations Programme on HIV/AIDS

UNHABITAT (1996) "An urbanizing world: Global report on human settlements 1996" Oxford university press

UNHABITAT (2005) "Kenya urban sector profile:" Regional urban sector profile study (RUSPS). UNHABITAT

United Nations (1977). *The aging in slums and uncontrolled settlements.* New York: Department of Economic and Social Affairs, United Nations.

United Nations (2007). *World population ageing, 2007.* New York: United Nations.

Urassa, M., Boerma, J. T., Isingo, R., Ngalula, J., Ng'weshemi, J., Mwaluko, G., and Zaba, B. (2001) "The impact of HIV/AIDS on mortality and household mobility in rural Tanzania" *AIDS* Vol 15, No. 15 page 2017 - 2023.

van der Geest, S. (2001) ""No strength": sex and old age in a rural town in Ghana" *Social Science and Medicine* Vol 53, No. 1383 - 1396.

VanLandingham, M., Knodel, J. E., Im-Em, W., and Saengtienchai, C. (2000) "The Impacts of HIV/AIDS on Older Populations in Developing Countries: Some Observations Based on the Thai Case" *Journal of family studies* Vol 21, No. 6 page 777 - 805.

Veatch, R. M. (1997) "Consent, Confidentiality, and Research" *The New England Journal of Medicine* Vol 336, No. 12 page 869 - 870.

Vitaliano, P. P., Young, H. M., and Zhang, J. (2004) "Is caregiving a risk factor for illness?" *Current Directions in Psychological Science* Vol 13, No. 1 page 13 - 16.

Vitaliano, P. P., Zhang, J., and Scanlan, J. M. (2003) "Is Caregiving Hazardous to One's Physical Health? A Meta-Analysis" *Psychological Bulletin* Vol 129, No. 6 page 946 - 972.

Wachter, K. W., Knodel, J. E., and VanLandingham, M. (2003) "Parental bereavement: heterogeneous impacts of AIDS in Thailand" *Journal of Econometrics* Vol 112, No. 1 page 193 - 206.

Wakabayashi, C. and Donato, K. (2005) "The Consequences of Caregiving: Effects on Womens Employment and Earnings" *Population Research and Policy Review* Vol 24, No. 467 - 488.

Watkins, S. C. (2004) "Navigating the AIDS Epidemic in Rural Malawi" *Population and Development Review* Vol 30, No. 4 page 673 - 705.

Welch, K. and Morse, A. (2002) "Predictors of survival in older men with AIDS" *Geriatric Nursing* Vol 23, No. 2 page 62 - 68.

Weller, I. V. D. and Williams, I. G. (2001) "ABC of AIDS: Antiretroviral drugs" *British Medical Journal* Vol 322, No. 7299 page 1410 - 1412.

WHO (2002a) "Impact of AIDS on older people in Africa: Zimbabwe Case Study" World Health Organization

WHO (2002b) "WHO Report on Global Surveillance of Epidemic-prone Infectious Diseases - Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (HIV/AIDS)"

WHO (2005) "Summary country profile for HIV/AIDS treatment scale-up" World Health Organization

WHO (2008a) Projections of mortality and burden of disease to 2030 http://www.who.int/healthinfo/statistics/bodprojections2030/en/index.html

WHO (2008b) WHO Study on global AGEing and adult health (SAGE) http://www.who.int/healthinfo/systems/sage/en/index.html

Wiles, R., Heath, S., Crow, G., and Charles, V. (2005) "Informed Consent in Social Research: A Literature Review" National Centre for Research Methods Paper Series. NCRM/001 ESRC National Centre for Research Methods

Williams, A. and Tumwekwase, G. (2001) "Multiple impacts of the HIV/AIDS epidemic on the aged in rural Uganda" *Journal of Cross-Cultural Gerontology* Vol 16, No. 3 page 221 - 236.

Wilson, A. O. and Adamchak, D. J. (2001) "The grandmothers' disease--the impact of AIDS on Africa's older women" *Age and Ageing* Vol 30, No. 1 page 8 - 10.

Wilson, S. R., Brown, N. L., Mejia, C., and Lavori, P. W. (2002) "Effects of Interviewer Characteristics on Reported Sexual Behavior of California Latino Couples" *Hispanic Journal of Behavioral Sciences* Vol 24, No. 1 page 38 - 62.

Wood, C. G. A., Whittet, S., and Bradbeer, C. S. (1997) "ABC of palliative care: HIV infection and AIDS" *British Medical Journal* Vol 315, No. 7120 page 1433 - 1436.

Wyss, Hutton, and N'Diekhor (2004) "Costs attributable to AIDS at household level in Chad" *AIDS Care* Vol 16, No. 7 page 808 - 816.

Yamano, T. and Jayne, T. S. (2002) "Measuring the impacts of prime-age adult death on rural households in Kenya" 2002-26 Department of Agricultural Economics Michigan State University

Zimmer, Z. and Dayton, J. (2005) "Older adults in sub-Saharan Africa living with children and grandchildren" *Population Studies* Vol 59, No. 3 page 295 - 312.

Zulu, E. M., Dodoo, F. A., and Ezeh, C. A. (2002) "Sexual risk-taking in the slums of Nairobi, Kenya, 1993-98" *Population Studies* Vol 56, No. 3 page 311 - 323.

Zulu E. M., Konseiga, A., and Mberu, B. (2006). "Migration and the Urbanization of Poverty in sub-Saharan Africa: The Case of Nairobi City, Kenya" In Population Association of America Annual General Meeting. Los Angeles 30-3-2006.