GENDER RELATIONS IN HIV AND AIDS HOME-BASED CARE IN URIRI SUB-COUNTY, MIGORI COUNTY

DALMAS OCHIENG OMIA

A THESIS SUBMITTED TO THE INSTITUTE OF ANTHROPOLOGY, GENDER AND AFRICAN STUDIES IN FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY IN ANTHROPOLOGY OF THE UNIVERSITY OF NAIROBI.

2015

DECLARATION

This thesis is my original work and has not been presented to any other university or institution for the award of a degree.

Signature__________________ Date_____________________

Dalmas Ochieng Omia

This thesis has been submitted for examination with our approval as the university supervisors.

Signature ___________________ Date__________________

Dr. Charles O. Olungah

Signature _____________________ Date__________________

Dr. Salome Bukachi

DEDICATION

To Louise Muganda and our amazing son, Milan Leo Ochieng'.

To my mother Margaret Omia for the indefatigable encouragements, and to my late father, Andrew Omia for great inspiration into academia.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ACKNOWLDEGMENT

I wish to extend unmatched gratitude to my academic mentor, Dr. Owuor Olungah for his inexhaustible guidance. His input and re-direction from the point of inception of the thesis to its completion is inconceivably great and intellectually rich. To my second supervisor Dr. Salome Bukachi, the keenness with which you examined and re-routed the dimension of the work was both exhilarating and inspiring; my gratitude to you remains timeless.

To the faculty members at the Institute of Anthropology, Gender and African Studies, accept my sincere appreciation of your support especially at the time of proposal development and defence. Your ideas matured the approach with which I would pursue the subject matter of the study. My special cognisance goes to the former IAGAS Director Prof. Isaac Nyamongo, the Faculty Post Graduate Studies Committee Chairman, Prof. Simiyu Wandibba, who were proficient in organising a timely defence.

My unrivalled gratitude goes to the Sub-County Development Officer, the heads of St. Monica Health Centre, Uriri Sub-Sub-County hospital, Uriri World Changers, and RAPADO for your logistical support that enabled the execution of the fieldwork, my study informants for their cooperation throughout the study period. I salute you all for your openness and invaluable assistance, your informed generosity with ideas created the wealth of thoughts out of which the thesis was crafted. I wish to convey special cognizance to my workmates at ARRF, George, Mercy, Patrick, Rossalid, and those in administration for your encouragement during the fieldwork; may your actions be rewarded bountifully and all the best in your endeavours.

ABSTRACT

This was a cross-sectional study on gender relations in HIV and AIDS home-based care in Uriri Sub-County, Migori County, Western Kenya. The study examined the players in HIV and AIDS caregiving, the role played by caregivers to HIV and AIDS patients and the challenges faced by caregivers in HIV and AIDS care. The study population comprised all the caregivers and data were obtained through in-depth interviews, key informant interviews and case narratives. The study was guided by the gender relations theory and cultural production and reproduction. Data analysis was done using the constant comparative method which is consistent with the grounded theory approach. The findings indicate that home-based HIV and AIDS caregiving is a gender-segregated occupation, at the centre of which lie stereotypes and beliefs about the appropriate roles for males and females, hence, a large number of women and girls are kept in unpaid, voluntary HIV and AIDS caregiving while men are kept out of it. Males providing care against such dominant ideas were labelled ‘circumstantial’ ‘feminine’ and ‘atypical’ indicating incidences of denigration and ridicule to male care providers. Caregiving has resulted in social, physical and psychological stress and distress with women and young girls being disproportionately affected. Moreover, there are lost opportunities for education, careers and income among the caregivers besides their increased vulnerability to infection exacerbated by the lack of adequate training, mentoring and support. The study concludes that unequally distributed caregiving activities between males and females in Uriri Sub-County have resulted in feminisation of HIV and AIDS care sustained by gender status beliefs and stereotypes. The study recommends that the National and County governments should provide cash transfers to mitigate the disadvantages experienced by unpaid caregivers living in the rural areas with high levels of poverty. There should be a concerted effort to use the male champions to spearhead defeminisation of care as part of changing rigid attitudes and values that continue to reinforce gender essentialism and male primacy in division of labour in the context of caregiving. Moreover, an action research on “compensations for the under-valued” to quantify and give visibility to the contributions of home-based caregivers in mitigating the impact of HIV and AIDS in the households should be undertaken. This will be important in developing bottom-up approach in policy and programmatic interventions.

LIST OF ABBREVIATIONS AND ACROYNMS

AIDS	Acquired Immunodeficiency Syndrome
ARRF	African Research and Resource Forum
ART	Anti-Retroviral Therapy
ARV	Anti-Retroviral
BPfA	Beijing Platform for Action
CD4	Cluster of Differentiation
CEDAW	Convention on Elimination of All Forms of Discrimination Against Women
CHWs	Community Health Workers
CODESRIA	Council for Development of Social Science Research in Africa
CRC	Convention on the Rights of the Child
CSW	Commission on the Status of Women
ECLAC	Economic Commission of Latin America and the Caribbean
FANTA	Food and Nutrition Technical Assistance
GoK	Government of Kenya
HIV	Human Immunodeficiency Virus
HKFF	Henry Kaiser Family Foundation
ICESCR	International Covenant on Economic, Social and Cultural Rights
IDRC	International Development Research Centre
IDUs	Injecting Drug Users
ILO	International Labour Organization
IMAGES	International Man and Gender Equality Survey
ICRW	International Center for Research on Women
KAIS	Kenya AIDS Indicator Survey
KDHS	Kenya Demographic and Health Survey

KNASP	Kenya National AIDS Strategic Plan
KNBS	Kenya National Bureau of Statistics
MoPDN	Ministry of Planning and National Development
MSF	Medicines Sans Frontieres
NACC	National AIDS Control Council
NACSTI	National Commission for Science and Technology Innovation
NASCOP	National AIDS and STI Control Programme
NGOs	Non-Governmental Organisations
PEP	Post Exposure Prophylaxis
PLWHA	People Living With HIV and AIDS
PMTCT	Prevention of Mother-To-Child Transmission
RAPADO	Rural AIDS prevention and Development Organisation
SONY	South Nyanza Sugar Company
UK	United Kingdom
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV AND AIDS
UNDP	United Nations Development Programme
UNESCO	United Nations Education, Scientific and Cultural Organisation
UNFPA	United Nations Fund for Population Activities
UNGASS	United Nations General Assembly Special Session on HIV AND AIDS
UNICEF	United Nations Educational Fund
UNIFEM	United Nations Fund for Women
UNRISD	United Nations Research Institute for Social Development
US	United States
UWYC	Uriri World Youth Changers
VCTC	Voluntary Counselling and Testing Centre
VMMC	Voluntary Medical Male Circumcision

VSO	Voluntary Service Organisation
WHO	World Health Organization

CHAPTER ONE: BACKGROUND TO THE STUDY

1.1 Introduction

Acquired Immunodeficiency Syndrome (AIDS) is a fatal transmissible disease of the immune system caused by the Human Immunodeficiency Virus (HIV). AIDS is the final stage of HIV infection (Barnett and Whiteside, 2002:6). AIDS was first reported in 1981 by investigators in New York and California. Initially, most US AIDS cases were diagnosed in homosexuals, who contracted the virus primarily through sexual contact, or intravenous drug users who became infected by sharing contaminated hypodermic needles (UNAIDS, 2002). In 1983, French and American researchers isolated the causative agent, HIV, and by 1985 serological tests to detect the virus were developed (Mann, 2001; UNAIDS, 2002).

As per the UNAIDS (2009:16) AIDS Updates, by 2008, 33.4 million people worldwide were living with HIV and AIDS, of whom 15.7 million were women and 2.1 million were children under 15 years. Also, UNAIDS (2009) notes that the continuing rise in the population of people living with HIV reflects the combined effects of continued high rates of new infections and the beneficial impacts of anti-retroviral therapy. While the total number of new infections with HIV had dropped from the estimated 2.6 million at the height of the epidemic in 1997, by 2009 new infections had dropped to 1.9 million, which is an encouragement, but sub-Saharan Africa still remains the carrier of the heaviest burden, with 68% of total persons living with HIV/AIDS, that is,. the 34 million global 2010 estimate (UNAIDS, 2011).

According to the UNAIDS (2014), more than two-thirds (70%) of all people living with HIV, 24.7 million live in sub-Saharan Africa, including 91% of the world's HIV-positive children. In 2013, an estimated 1.5 million people in the region became newly infected. An estimated 1.1 million adults and children died of AIDS, accounting for 73% of the world's AIDS deaths in 2013 while in Asia and the Pacific, nearly 350,000 people became newly infected in 2013, bringing the total number of people living with HIV in that region to 4.8 million. AIDS claimed an estimated 250,000 lives in the region in 2013. Furthermore, approximately 12,000 people became newly infected in the Caribbean in 2013, bringing the total number of people living with HIV there to 250,000 (UNAIDS, 2014:11).

Throughout the world, caring for the young, the elderly, and the sick has traditionally been women's work, a reality resulting from assumptions made about the roles and responsibilities of women and girls. This gendered division of labour is amplified in the context of HIV and AIDS. In Africa alone, women account for two-thirds of all caregivers for people living with HIV (UN, 2004). Care has long been considered to be the 'natural' responsibility of women: around the world, it is still the case that women provide most of the unpaid care in households and communities (Budlender, 2010; Razavi and Staab, 2010).

In wealthy countries, health systems provide much of the care where sick people are taken into hospital or visited by health staff in their homes (Peacock & Westen, 2008). However, in the developing world, and especially in the areas hardest hit by HIV and

AIDS, a lethal mix of inadequate political will, failure by governments to fulfil commitments and the impact of structural adjustment policies of 1980s have left health systems without the capacity to undertake such care. Instead of the state assuming its responsibility to provide the care needed, the burden is taken up by family and community members, who look after the sick person at home (Peacock & Westen, 2008:2).

A large majority of home-based carers are women (Peacock & Westen, 2008; Budlender *et al*., 2001). In South Africa, for example, a national time-use survey found that women carry out eight times more care work for all illnesses than men (Budlender *et al*., 2001). In the family case of HIV and AIDS, a Henry Kaiser Family Foundation (HKFF) survey reported that over two-thirds of primary caregivers are women (HKFF, 2002:33). Women are also the principal carers of children who have lost parents to HIV and AIDS, for example, Desmond and Desmond (2006:7) found that in households where the mother has died, only 30 per cent of surviving fathers are present, whereas in those where the father has died, 71 per cent of surviving mothers are present and they continue to provide care to sick members of the family.

While commenting on the time-use by men from studies conducted in lower and middle-income countries, Budlender, (2008); IDRC, (2013); and Barker et al., (2011) state that the mean time spent by women on unpaid care ranges from two to ten times that of men. Their findings are supported by data from IMAGES that indicate that half of men who are fathers spent some time providing care for their children on a daily basis, however, self-reported time-use indicate that men’s time was typically far less than half of women’s time spent on the same activities (Barker et al., 2011). A study by European Union (2013) indicates that there are significant increases in men’s participation in caregiving in the global North by a marginal range of between 20 and 40 per cent as of 2010. In spite of the observed increases, the study concludes that no single country has achieved parity in caregiving including the Scandinavian countries that have used paternity leave and other policy practices to encourage men’s caregiving.

The disproportionate burden of care on females at the household and community level matters for several reasons since it can have a crushing impact on women and girls. At the most basic level, caring for people with such AIDS related opportunistic infections is extremely tiring (Seloilwe & Ndaba-Mbata, 2000:218). Fatigue renders carers more vulnerable to illness themselves, including to the opportunistic infections that plague those with HIV themselves. The stress of caring for someone who is dying increases susceptibility to psychological problems; carers of those sick with AIDS in Botswana, for example, report being emotionally drained by their roles (Seloilwe & Ndaba-Mbata, 2000:220).

Women who have to stay at home to perform care work are less able to seek other forms of paid work, and if they are already employed, they face enormous difficulties juggling their care duties with their work obligations and sometimes have to give up their jobs (Peacock & Westen, 2008:5). This weakens them economically and leaves them more dependent upon their husbands. In the long run, this perpetuates gender inequality in the household rendering women unable to participate in wealth creating activities.

In the recent World Development Report (World Bank, 2012) which focused on gender equality, it was affirmed that women constitute 40 per cent of the global paid workforce and half of the world’s food producers. Hence, women’s income has increased relative to that of men although it still lags behind in pay-gaps, hence, in the context of such developments, the politics of including men in the care giving work has to be explored as part of the process towards gender equality and releasing women to other productive ventures. This has to be done to ensure that the sick are not abandoned as women become occupied in paid labour.

Given the preceding context on men and women’s participation in caregiving, the study explored Gender dynamics of HIV and AIDS Home-based care in Uriri Sub-County, Migori County. This was of interest in light of the fact that caregiving in and of itself shapes gender regimes, systems of childrearing and care for the sick. In addition, caregiving may explain certain observed cycles of violence as well as cycle of poverty that result from differential expectations in the society. Understanding the patterns of caregiving and gender-role division offers a significant dimension of the overall study on women’s empowerment and sustainable development demands.

1.2 Problem Statement

The HIV and AIDS pandemic has meant that an increasing number of chronically ill people need ongoing assistance with care and support. VSO's (2003:34) Policy Paper, *Gendering AID*, notes that as the pandemic grows, so will the need for community and home based care, and this responsibility will continue to fall on women and girls. As public health services are downsized for the sake of cost-efficiency, the care role is passed to the home-sphere in which norms and expectations on women's traditional gender roles as housekeepers, nurturers and caregivers are reinforced in the context of HIV and AIDS patients' care (VSO, 2003). The roles currently played by men and boys as providers of such unremunerated and often unsafe care have been poorly documented and understood, including their willingness to perform this job. While there is positive evidence that some men are entering the HIV and AIDS caregiving job with a range of incentives and social supports (Peacock and Westen, 2008; Esu-Williams et al., 2004), long-term results from interventions to increase their numbers in the caregiving are still elusive. Women and girls perform these roles not because they are prepared to do the same but because social norms and practices prevalent in patriarchal societies place these duties within their domains.

Previous studies by Slater (2008), Slater and Wiggins (2005), Barnett *et al*. (2005), UNAIDS (2004) and VSO (2003) have observed the economic burden of HIV and AIDS at the household level based on the effects of structural adjustment policies of earlier decades that reduced the public sector mandate and capacity to respond to HIV and AIDS care. Studies have also looked into the economic burden of caring for HIV and AIDS orphans in high pandemic regions (Williamson, 2002; Slater, 2008) without interrogating the share of caregiving roles across the gender divide. These quantitative approaches in the analysis of socio-economic costs of HIV and AIDS have also failed to examine the hidden social and economic biases especially in caregiving, and as a result, unsustainable programmatic interventions have been developed where the unpaid community health workers are relied upon to bridge the gaps in care provision.

According to IDRC (2013), researchers and theorists have long argued for radical change in caregiving but most of that discussion has been centred on how to value, economically and socially, the care work that women and girls provide. Much less of that discussion has focused on how to create conditions necessary for men and boys to do more care work and be part of a global effort to value care work, regardless of who carries it. Moreover, there is a dearth of knowledge on the unequal sharing of HIV and AIDS care responsibilities between men and women, particularly, there exist a great information gap on how the social barriers preventing men and boys from taking part in caregiving manifest and persist in the context of HIV and AIDS. Thus, there was established need to document ethnographic accounts of gendered nature of division of labour in caregiving, the perpetuation and amplification of these unequal relations despite a universal call for egalitarianism in the share of HIv and AIDS caregiving through a cultural lens. To this end, the study explored gender relations in HIV and AIDS home-based care in Uriri Sub-County of Migori County. To address this broad objective, the study was guided by the following research questions:

i. Who are the players in HIV and AIDS caregiving in Uriri Sub-County?

ii. What roles are played by male and female caregivers of HIV and AIDS patients in Uriri Sub-county?

iii. What are the challenges faced by male and female caregivers of HIV and AIDS patients in Uriri Sub-County?

1.3 Objectives of the study

1.3.1 Overall objective

To assess the gender relations in HIV and AIDS home-based care in Uriri Sub-County, Migori County.

1.3.2 Specific objectives

i. To establish the players in HIV and AIDS caregiving in Uriri Sub-County.

ii. To describe the roles played by male and female caregivers to the HIV/AIDS patients in Uriri Sub-County.

iii. To find out the challenges faced by male and female caregivers in HIV/AIDS care in Uriri Sub-County.

1.4 Assumptions of the study

i. Males and females comprise home-based caregivers to HIV and AIDS patients in Uriri Sub-County.

ii. Home-based caregivers perform physical, nursing and counselling roles to HIV and AIDS patients in Uriri Sub-County.

iii. Home-based HIV and AIDS caregivers face socio-economic and psychological challenges in Uriri Sub-County.

1.5 Justification of the study

The findings of this study are imperative in providing evidence for modelling sustainable care provision services by the government and NGOs intervening in HIV and AIDS care. In developing home-based care programmes, it is vital to consider the perceived needs of persons living with HIV and AIDS and their direct informal caregivers in order to realize sustainable interventions. The results from this study serve as a basis for the development of a home-based care programme in resource-poor locations and could provide a model for such programmes in similar areas across Kenya where the HIV and AIDS continues to burden home-based caregivers.

Based on the findings, the strategies might include but not limited to programmatic approaches that can ease the burden of HIV and AIDS care such as social protection programmes for rural households infected and affected by HIV and AIDS. These interventions need to speak to the socio-cultural patterning of gender division of labour versus the need to share care responsibilities as part of global efforts towards valuing care and lessening the burden on women. The results, therefore, provide a gender lens and rights based perspective in the discussions that can inform such interventions in a more culture-aware and sustainable pattern.

Discussions and conversations carried out in this study are very significant in understanding men’s resistance to care work. However, discussions also reveal the benefits that can be derived by increasing men’s participation in HIV and AIDS care work. The debate in the findings proposes valuing of care work while at the same time defeminising notions that perpetuate men’s resistance to care-giving. In essence, the findings contribute to the notion that engaging men in caregiving may be the impetus needed to move from a limited and zero-sum notion of the patriarchal dividend to a greater gender equality dividend with benefits for women, children and men themselves in the context of HIV and AIDS caregiving. The findings therefore, scope beyond the normal assessment of economic burden to caregiving to proposing mechanisms of tackling social cues and cultural contestations such as, female legitimacy as caregivers in the society and care being innate to females, that have always worked against full integration of men in ‘direct’ caregiving beyond financial provision.

The study findings illuminate HIV and AIDS caregiving at the household and/or private domains by making visible its variables of costs in time, economy and opportunities practically and strategically. To this extent, the findings form a platform for bringing caregiving to the public domain calling for legal and policy reforms to attend to the burden borne by caregivers hardly who have been forced to step in due to inability of the public health system to undertake care provision to HIV and AIDS patients. Making the caregiver experiences visible will allow policies to provide a wholesome continuum of care for those living with HIV and AIDS and their families.

Similarly, the findings show that the discriminatory social norms upon which unequal gender division of labour has traditionally been anchored is a major impediment to the sustainable development in the long run hence the need to re-value and compensate tasks as care provision. In forging multi-sectoral responses to ameliorate the burden of caregiving, it is significant to understand the entrenched tendency of societies to segregate men and women into different work based on the gender ideologies and to assign different values to these differences, construct, which this study largely brings into focus.

Put into context, the study results make major contribution toward achievement of the Kenya AIDS Strategic Framework (for the period 2014-2018), premised on Kenya's Vision 2030 description of HIV and AIDS as "one of the greatest threats to socio-economic development in Kenya" and marks a change in the approach of managing the national response from doing "business as usual" to evidence and results-based multi-sectoral and decentralised planning by mainstreaming gender and human rights in all aspects of the response planning and service delivery.This is significant because the findings of the study project the muted voices of caregivers who should be the central focus of policy intervention and their lived experiences will be additive value toward improvement of the caregiving intervention programs already operational in the rural households.

The study is being conducted at a time that persistent global financial crisis has forced cash-drought on HIV and AIDS funding thus the need to improve the effectiveness of domestically developed mechanisms of dealing with the HIV and AIDS caregiving with the households being the foci. The findings remain important in informing strategic safety net programs such cash-transfers to HIV and AIDS caregivers suffering among other stress factors the double burden of living below the poverty line.

Academically, the study findings provide a rich source of data for scholars interested in studying feminization of patients' care and, specifically, HIV and AIDS care, through a gender lens within a rural set-up. More specifically, the findings illuminate emergent issues on the need to diffuse care to men as part of the shared responsibility versus the traditional perceptions of females as the only care givers. This has resulted from the care-crisis in the context of increased absorption of women into the paid labour and demands of modern education which has taken the women away from home. The study questions the stringent male role definitions, stigmatisation of males provisioning care within the households towards an understanding of the emerging rights based approaches of equity and gender equality, thereby ignoring the cultural reproduction of unequal gender roles.

1.6 Scope and Limitations of the study

This study was carried out in Uriri Sub-County of Migori County and it focused on gender dynamics in HIV and AIDS home-based care. The study established the players in care provision in HIV and AIDS care, the roles played by these care providers and the challenges faced by caregivers. The study was limited to caregivers of the HIV and AIDS patients within their households; therefore, the study did not concern itself with the challenges faced by HIV and AIDS care providers from the public and private organizations operational within the Sub-County. While the study concentrated on a geographically small area within Migori County, the findings of this study can still be mapped unto the other areas where the HIV and AIDS caregiving is continuously feminised across the Republic of Kenya.

While the study relied on qualitative methods of data collection, triangulation of methods (key informant, in-depth interviews and case narratives) were not only used to ensure that limitations of one method are compensated for but also a convergence of opinions on the objectives of the study is met. To this end, rich data that answer to the study questions and objectives were exhaustively collected. On the other hand, the limitations of gender relations theory to explain the reproduction of the observed unequal division of labour at the household levels across generations was taken care of through the use of cultural production and reproduction Theory. Hence, the two theories complimented each other not only to contextualise gender division of labour in caregiving but also to explain the cultural norms that perpetuate the observed gender stereotypes about essential “male” and “female” traits, status beliefs and perceptions of men and women in the context of HIV and AIDS caregiving.

Studies around HIV and AIDS are largely sensitive and involve a degree of reserved revelation by the study participants. This is because of the social stigma that is quite persistent in the communities. In the study, explanations were given to the extent that HIV and AIDS patients were only proxies for recruitment of their caregivers. Besides, the informants were given surety that no amount of identification that would reveal the source of information to the public would be used. Similarly, during the study, developing rapport and gaining the trust of caregivers was significant in digging out information on their experiences.

The study does not have any quantitative and comparative information on male and female labour participation in home-based HIV and AIDS caregiving. Thus, there is a limitation in that the extent to which the patterns on the nature of relationship between variables such as the male out-migration, death of a spouse or divorce would have influenced the dominance of females in caregiving.

1.7 Definition of terms

Care-givers: Females and males who undertake to provide care to the HIV and AIDS patients in Uriri Sub-County.

Challenges: In the study, these refer to the burdens/difficulties that assume socio-economic and psychological nature suffered by the caregivers in the process of doing their care work.

Cultural norms: The agreed-upon expectations and rules by which a culture guides the behaviour of its members in any given situation, in this case, what is considered ‘normal’ by the society with respect to the duties to be performed by males and females in care provision.

Gendered expectations: The pattern of masculine or feminine behaviour of an individual that is defined by a particular culture and that is largely determined by a child's upbringing which largely influence attitude towards care-giving.

Gendered norms: What society considers male and female behaviour and consistently taught to these groups, and it leads to the formation of gender roles, which are the roles males and females play in the context of care giving.

HIV and AIDS care: Physical, spiritual, palliative and psychosocial care given to HIV and AIDS patients at the households.

Home-based Care: Any form of assistance given to sick people within their homes including physical, psychosocial, palliative and spiritual interventions, financial and other necessities needed by the infirm. In the context of the study, provisioning of the material and social services above to HIV and AIDS patients was deemed as care-giving.

Social norms: The learned responsibilities, the domains and spheres of performing duties that have been taught to males and females in the society and caregiving in particular.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter reviews the literature relevant to the research problem. The literature is reviewed using the following headings: HIV and AIDS situation in Kenya, global financial crisis and burden of care, responsibility sharing in care provision, patriarchy and unequal roles in care-provision, systematic response to HIV and AIDS care, home-based care in HIV and AIDS context, and carers and their challenges. The chapter, finally, discusses the theoretical frameworks that guided the study.

2.2Global HIV and AIDS prevalence

According to UNAIDS (2014) there were 35 million [33.2 million–37.2 million] people living with HIV in 2013. The report indicates that since the start of the epidemic, around 78 million [71 million–87 million] people have become infected with HIV and 39 million [35 million–43 million] people have died of AIDS-related illnesses, however, new HIV infections New HIV infections were reported to fallen by 38% since 2001 (UNAIDS, 2014:1). Worldwide, 2.1 million [1.9 million–2.4 million] people became newly infected with HIV in 2013, down from 3.4 million [3.3 million–3.6 million] in 2001. New HIV infections among children have declined by 58% since 2001. Worldwide, 240 000 [210 000–280 000] children became newly infected with HIV in 2013, down from 580 000 [530 000–640 000] in 2001. AIDS-related deaths AIDS-related deaths have fallen by 35% since the peak in 2005. -In 2013, 1.5 million [1.4 million–1.7 million] people died from AIDS-related causes worldwide compared to 2.4 million [2.2 million–2.6 million] in 2005 (UNAIDS, 2014). Antiretroviral therapy In 2013, around 12.9 million people living with HIV had access to antiretroviral therapy. This represents 37% [35%-39%] of all people living with HIV. Thus, 38% [36%-40%] of all adults living with HIV are receiving treatment. However, just 24% [22%-26%] of all children living with HIV are receiving the life-saving medicines.

According to the *Gap Report*, almost 12.9 million people were receiving antiretroviral therapy globally at the end of 2013. The percentage of people living with HIV who are not receiving antiretroviral therapy (2) has been reduced from 90% [90–91%] in 2006 to 63% [61–65%] in 2013. Of these 12.9 million people, 5.6 million were added since 2010. The rapid increase in antiretroviral access has primarily occurred in a few countries. One-third of the increase in the number receiving antiretroviral therapy was in South Africa, followed by India at 7%, Uganda 6%, and in Nigeria, Mozambique, the United Republic of Tanzania and Zimbabwe 5%. Three of four people receiving HIV treatment are living in sub-Saharan Africa, where the need is most acute (UNAIDS, 2014).

Fewer people are dying of AIDS-related illnesses. In 2013 there were 1.5 million [1.4 million–1.7 million] AIDS-related deaths. AIDS-related deaths have fallen by 35% since 2005, when the highest number of deaths was recorded. In the past three years alone, AIDS-related deaths have fallen by 19%, which represents the largest decline in the past 10 years. In sub-Saharan Africa, the number of AIDS-related deaths fell by 39% between 2005 and 2013. The region still accounted for 74% of all the people dying from AIDS-related causes in 2013. In the Caribbean, it declined by 54% and in Latin America by 31%. More modest declines of 27% occurred during the same period in Asia and the

Pacific. In Oceania, AIDS-related deaths declined by 19% and in western and central Europe and North America, where mortality was already very low, by a further 2%. In contrast, the Middle East and North Africa experienced a significant increase in mortality from AIDS (66%), and eastern Europe and central Asia a more moderate increase of 5%. The number of AIDS-related deaths decreased significantly between 2009 and 2013 in several countries, including South Africa (51%), the Dominican Republic (37%), Ukraine (32%), Kenya (32%), Ethiopia (37%) and Cambodia (45%) (UNAIDS, 2014).

2.2.1 HIV and AIDS prevalence in Kenya

According to the Kenya AIDS indicator Survey (NASCOP, 2012), there are about 1.2 million people living with HIV out of a total population of 38.6 million people in the country. HIV prevalence among adults aged 15 to 64 years is 5.6%. The report also shows an HIV prevalence of 0.9% among children aged 18 months to 14 years with an estimated 104,000 children infected with HIV in Kenya. The country has seen a decline in HIV incidence rates among adults aged 15-49 from 0.62% in 2000 to 0.44 in 2013 possibly due to the scale up of various prevention and treatment programmes. In terms of absolute numbers, the new HIV infections among all adults 15+ declined by 15% nationally from 105,000 in 2000 to 88,620 in 2013 (NASCOP, 2014). Overall, there are marked gender disparities which characterize the epidemic with higher prevalence amongst women at 6.9% compared to men at 4.4% (NASCOP *et al*, 2013). These new estimates confirm a decline in HIV prevalence among both men and women at National level. Prevalence remains higher among women at 7.6% compared to men at 5.6%.

Kenya’s HIV epidemic is geographically diverse, ranging from a prevalence of 25.7 per cent in Homa-Bay County in Nyanza region to approximately 0.2 per cent in Wajir County in North Eastern region. Counties with the highest adult HIV prevalence in 2013 included Homa Bay at 25.7%, Siaya at 23.7%, Kisumu at 19.3%, Migori at 14.7%, Kisii at 8%, Nairobi at 8%, Turkana at 7.6%, and Mombasa at 7.4% (NASCOP, 2014:16).

Kenya has made impressive gains in promoting access to HIV Testing and Counselling(HTC) which has catalyzed achievement in interventions such as Prevention of Mother to Child Transmission (PMTCT), roll out of Voluntary Medical Male Circumcision (VMMC), Antiretroviral Treatment (ART) and increasing access to condoms. Overall, the KAIS (2012) report shows that 72% of adults aged 15-64 years reported having ever been tested for HIV, a marked increase from 34% in KAIS 2007. By the end of 2012, a total of 604,000 adults (548,588) and children (55,439) were on ART. The annual AIDS related deaths had dropped from 120,000 in 2003 to 62,000 in 2011, however, evidence in Kenya underscores the need to improve retention rates in a situation where 30% of the patients on Antiretroviral therapy were no longer enrolled in treatment after 60 months in 2012 (NASCOP, 2012).

2.2.2 Care as an analytical category

According to Esquivel (2011), the word care is loaded with moral overtones implying a duty based on love. These, she argues, have the effects of diminishing ‘care’ as an analytical category both socially and economically in social spheres.

Care has become prominent in the discourse of United Nations (UN) agencies, multilateral funding institutions, and donors. For instance, in 2009, the Commission on the Status of Women (CSW) chose ‘the equal sharing of responsibilities between women and men, including care giving in the context of HIV and AIDS’ as a priority theme for its work as evidenced in paragraphs four (4) and six (6) of its 53rd political declaration at the CSW meeting:

> *4. The Commission reiterates the 2001 Declaration of Commitment on HIV/AIDS and the 2006 Political Declaration on HIV/AIDS, which, inter alia, expressed concern that gender inequality increases women’s vulnerability to HIV/AIDS and the overall expansion and feminization of the pandemic, and also acknowledges that women and girls bear the disproportionate burden of caring for and supporting those infected and affected by HIV/AIDS.*
>
> *6. The Commission recognizes that gender inequalities still exist and are reflected in imbalances of power between women and men in all spheres of society. The Commission further recognizes that everyone benefits from gender equality and that the negative impacts of gender inequality are borne by society as a whole, and emphasizes, therefore, that men and boys, through taking responsibility themselves and working jointly in partnership with women and girls, are essential to achieving the goals of gender equality, development and peace. The Commission recognizes the capacity of men and boys in bringing about changes in attitudes, relationships and access to resources and decision-making which are critical for the promotion of gender equality and the full enjoyment of all human rights by women.*

While observing the effects of such declaration, Bedford (2010) posits that it triggered the visibility of care within the UN and supported various stakeholders to mobilize around care. Later, the Brasilia Consensus, the outcome of the 11th Regional Conference on Women in Latin America, established ‘care as a universal right, which requires strong policy measures to effectively achieve it, and the co-responsibility of the society as a whole, the state, and the private sector' (ECLAC 2010: 2, cited in Esquivel 2011).

The World Development Report (World Bank, 2013) on jobs applauds the adoption of the International Labour Organization's Domestic Workers Convention and Recommendation, a conquest that will help protect the most vulnerable group of care workers. The convention identified the shortage of care services as hindering female labour force participation and suggested that 'public provision or subsidization of childcare can reduce the costs women incur at home when they engage in market work' (World Bank 2012: 30).

Most recently, Carmona (2013: 2) has argued that the 'heavy and unequal care responsibilities are a major barrier to gender equality and to women's equal enjoyment of human rights, and in many cases, condemn women to poverty. This is captured by UNESC (2014) thus:

> *Recognise that caregiving is a critical societal function and therefore emphasize the need to value, reduce and redistribute unpaid care work establishing a very concrete and detailed policy agenda, which includes social protection policies, including accessible and affordable social services, including care services for children, persons with disabilities, older persons, and persons living with HIV and AIDS, and all others in need of care; the development of infrastructure, including access to environmentally sound time- and energy-saving technologies; employment policies, including family-friendly policies with maternity and*

> *paternity leave and benefits; and the promotion of the equal sharing of responsibilities and chores between men and women in caregiving and domestic work in order to reduce the domestic work burden of women and girls and to change the attitudes that reinforce the division of labour based on gender* (UN Economic and Social Council 2014:15).

This statement illustrates the enormous progress made in getting care on to the international development agenda as a public policy issue. Yet, in all cases, care continues to be considered as a women's issue, as if the fact that most caregivers are women means that care is a concern only for them. In other words, care remains 'woman-specific', as Daly and Lewis (2000:283) pointed out.

The examples above also show that the meanings of care are contested. Different understandings of care as a concept result in disagreements about how it needs to be addressed, and this has shaped different policy agendas (Eyben, 2012). Actors adopting a social justice perspective may consider care to be a 'right', while those adopting a social investment perspective may view care as a poverty-related issue (Williams, 2010).

Diagnoses that emphasize gender, class, and race inequalities in care provision highlight that women's costs of providing care. They call for the redistribution of care responsibilities, in particular through active state interventions with universal scope (United Nations Research Institute for Social Development (UNRISD), 2010). Diagnoses that focus on the role of care in the production of 'human capital', or the efficiency gains of women's partaking in the labour market when care services are publicly provided or subsidised, usually justify interventions that are focused on 'vulnerable' or dependent population groups. Such focused interventions may sideline women's (and others') equality claims (Jenson, 2010, cited in Razavi and Staab, 2012: 20).

2.2.3 Global financial strain and the burden of HIV and AIDS care

Since the mid-1980s, most developing countries have been pressured by the World Bank, the International Monetary Fund and other financial institutions to pursue neoliberal development policies characterized by a reduction in public spending, privatisation of public services, flexible labour laws, and an emphasis on attracting foreign investment (Marais, 2006). With clinics and hospital infrastructure crumbling, patient loads increasing and salaries decreasing, large numbers of doctors and nurses emigrated for better pay and working conditions (Marais, 2006:12). The net result was the relaying of care costs and associated roles to the communities and households with the patients given the continuously dilapidating hospital infrastructure and reduced manpower at the health centres.

The legacy of these international financial policies was made clear in a 2007 report from Médecins Sans Frontières. The report compares the number of health care providers per 100,000 inhabitants in Southern Africa against the US, the UK and WHO minimum standards and reveals that whereas the US and the UK have 247 and 222 doctors per 100,000 inhabitants, respectively, South Africa has on average 74 doctors per 100, 000 inhabitants and Lesotho has only five. On the other hand, Malawi and Mozambique have only two. The World Health Organisation’s minimum standard is 20. The number of nurses per 100, 000 people in the UK is 1,170, in the US 901, in South Africa 393, and 62 in Lesotho. As per the demands of the World Health Organisation, the minimum standard for nurses is 228 (MSF, 2007).

The results of the MSF (2007) survey indicate a massive departure of health care providers from the under-financed institutions in Africa making the burden of care to be passed to the resource-strained, untrained and unstructured community and home-based care provisions. Care provision in the households and communities tend to adopt the traditional gender division of labour, and since these duties fall under reproductive roles, women and girls are the most burdened (VSO, 2006).

The reason for government inaction is that governments failed to invest sufficiently in health care in general and AIDS care in particular (Avert, 2008). Even when prevalence rates had become shockingly high, many authorities delayed in making antiretroviral treatment available. Globally, millions of adults with advanced AIDS are dying or posing a heavy burden on their families. As the situation progresses through the illness trajectory, the burden is extended to public health systems because they are not receiving antiretroviral drugs (Avert, 2008). A large proportion of those infected with HIV are poor and, as it has been noted, most of those caring for them are women. The poor in general and poor women in particular have a muted voice in national decision-making in most of the developing world. This is because, the vast majority of policy-makers are men who often have little knowledge or interest in the problems faced by female carers (Marais, 2006; Avert, 2008).

Marais (2006) draws attention to the ways in which government policies on AIDS care reflect and reinforce class and gender inequalities and injustices: Home-based care appears to be a more realistic or affordable option because its true costs are hidden, deflected back into the domestic zones of the poor. In doing so, it adheres to the same polarising logic that defines society which is not only unjust; it also undermines the sustainability of care provision in the face of a crisis set to continue well into the future. AIDS is meshing with the routine distress endured by millions of Africans to pummelling effect, as it intensifies those hardships, and drives an even thicker wedge between the privileged and the deprived (Marais, 2006).

2.2.4 Shifting HIV and AIDS clinical care to home and community

In the mid to late 1990s, upon realizing that the public sectors of most poor, highly affected countries were ill equipped to handle AIDS-related morbidity, programmers and policy-makers considered ways to shift the locus of clinical care from the formal health services to the community. Initial efforts revolved around a principle of hospital-based outreach, whereby hospital staff travelled directly to patients' homes to provide care. Not surprisingly, however, these programmes were found to be time-consuming and expensive, especially in rural areas (Chela, 1995).

In many communities, meanwhile, new NGOs sprouted up and existing groups mobilized to provide support to families affected by the disease, in an effort to fill the care gap left by the retreating public sector. These groups were largely unable to provide clinical inputs, instead providing a range of care and support services to affected persons and families, including spiritual and emotional support, assistance with funeral expenses and some basic nursing care. Yet, given their limited resources, many of these community initiatives struggled, their networks and strategies often only able to reach a small segment of the affected population, especially in high prevalence countries.

In response to the growing need for a more programmatic approach to care for persons living with HIV and AIDS, the World Health Organization (WHO), in consultation with a wide group of experts, developed a framework for ‘Comprehensive Care Across a Continuum’ (van Praag, 1995; Osborne, 1996) later known simply as the ‘Care Continuum’ (WHO, 2000b). The intent of the model was to promote, create and sustain a ‘holistic’ approach to care and support for persons living with HIV and AIDS. The framework locates the person living with HIV and AIDS at the centre of a wide range of actors who are dynamically linked. The entry point to the ‘continuum’ is voluntary counseling and testing for HIV. ‘Home care’ is one element of this broader system of care provision, and it is an element perceived to be particularly relevant and important in resource-constrained settings (e.g., WHO, 2000a, 2002b; UNAIDS, 2002; UNAIDS *et al.*, 2004).

From the foregoing literature, most governments in developing countries, Kenya included, have not adequately invested in health care and AIDS care in particular. In the prevalent scenario, HIV and AIDS care burden has been passed on to poor families thus deflecting the costs of caregiving to households which have been described by Marais (2006) as domestic zones of care. Consequently, the government's laxity to invest in HIV and AIDS care programmes is seen to reinforce and promote gender inequality since caregiving basically fall on the face of women and girls in the households as part of their cultural gender roles thus forming grounds for feminization of HIV and AIDS care.

2.2.5 Responsibility sharing in the context of care-giving

Commitments on the equal sharing of responsibilities between women and men, including caregiving in the context of HIV and AIDS, have been made by Governments at the international level, including International Conference on Population and Development (1994), the Fourth World Conference on Women (1995), the World Summit for Social Development (1995), and the Twenty-Third Special Session of the General Assembly (2000), as well as in the outcomes of sessions of the Commission on the Status of Women since 1996. Similarly, the International human rights treaties, including the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) and the Convention on the Rights of the Child (CRC) also recognize the obligations that State parties have to promote equal sharing of responsibilities between women and men (ILO/UNAIDS/UNRISD, 2008:21). A unifying factor across these conventions is the need for role-sharing across genders, a strategy to lessen the burden on the females that is presently witnessed.

The Beijing Platform for Action recognised that HIV and AIDS pandemic bears negative consequences for women, specifically, it pushes women to perform the dual roles as mothers and caregivers, which in turn affect the women's economic contributions to households and women's health by extension (Commission on Status of Women, 2007). In order to address the burden of HIV and AIDS pandemic on women, Governments were called on to support and strengthen national capacity to create and improve gender-sensitive policies and programmes on HIV and AIDS, including the provision of resources and facilities to women who find themselves the principal caregivers. Moreover, it has been recommended that economic support should be accorded to those infected with HIV and AIDS or affected by the pandemic, and the survivors, particularly children and older persons (Commission on Status of Women, 2007).

The 2007 resolution of the Commission on the Status of Women on 'Women, the girl child and HIV and AIDS', expressed concern that women and girls bear the disproportionate burden to care for and support those infected and affected by HIV and AIDS and encouraged Governments to increase the provision of resources and facilities to women who find themselves having to provide care and/or economic support for those infected with HIV and AIDS or affected by the pandemic (CEDAW, 2007:152). The agreed conclusions on the elimination of all forms of discrimination and violence against the girl child also urged governments to identify and address the needs of girls heading households, including in the context of the HIV and AIDS pandemic, for protection, access to financial resources, and access to health care and support services, including affordable HIV and AIDS treatment (CEDAW, 2007:163).

2.2.6 Patriarchal stereotypes versus the unequal responsibility sharing

The underlying cause of the unequal sharing of responsibilities is the entrenched nature of patriarchy, which defines the status of women, children, the disabled, marginalized men and people of different races and classes (ILO/UNAIDS/UNRISD, 2008). Patriarchy is based on the presumption of the inferiority of women and the superiority of men. Thus, although all men are in positions of power and privilege, even those with diminished capacity for fulfilling traditional male roles, due to unemployment or other obstacles, benefit from the patriarchal dividend or the unequal sharing of power (Daly, 2008).

Norms and values, transmitted through stereotypes, are among the most important determinants of the unequal division of responsibilities between women and men (Daly, 2008). Stereotypes are oversimplified images of attributes that members of a group hold in common. Gender stereotypes endorse expectations that men are natural leaders and ideal breadwinners and imply that women will naturally gravitate towards responsibilities around personal relations and caring activities (Daly, 2008; ILO/UNAIDS/UNRISD, 2008). These views construct firm dividing lines between responsibilities and work that are seen as women's domain and those depicted as appropriate to men. In this context, the ideal location for men is perceived to be in the public sphere where they can be entrusted with power and authority while the private sphere is assigned to women (ILO/UNAIDS/UNRISD, 2008: 6). When these beliefs and practices are projected to healthcare arena, the women end up performing more duties than men since the care process is associated with reproductive work that is women's domain.

Both inside and outside the home, most activities have a notional label of male or female attached to them. Women are identified as ‘natural’ caregivers and caring is therefore seen as women’s work. Even when not widely held, such stereotypes often have saliency because many men and women may understand them to be socially acceptable, and conform publicly to practices that they may not agree with in private (Peacock, 2003). There is evidence, for example, that, in some settings, and particularly those with high HIV and AIDS prevalence, some men hide their involvement in the provision of care and support to those with HIV and AIDS because they fear they will be mocked for doing care work (Peacock, 2003).

Gender norms are a further key cause of the excessive care burden on women. Gender norms across the world expect women to bear the burden of caring for the ill, even when they also work. Many men believe that caring is “women’s work” and that it is beneath them, that their traditional role as breadwinners is more important and should exclude them from having to carry out domestic chores (ILO/UNAIDS/UNRISD, 2008). Studies show that these gender norms also operate in more insidious ways; even when men recognise that they should be providing care, their fear that they will be ostracised for doing “women’s work” stops them from providing care. In a survey carried out in Soweto, South Africa, men said they did not participate in caring activities even when they felt they should because of the fear that they would lose respect among their peers if they did so (Kruger, 2003).

Similarly, a study in Tanzania found that some male heads of households wanted to do more when their partners fell ill with AIDS but were prevented from doing so by "cultural definitions of maleness and the defined roles which determine masculinity (Aggleton & Warwick, 1998). Government policies often underpin these harmful gender norms. It has been documented that most governments have not done enough to reduce the total burden of HIV and AIDS. In most countries, for example, mothers are expected to take maternity leave to look after their newborn babies, but paternity leave is nearly always much shorter if it exists at all (Peacock & Westen, 2008). This entrenches an image of women, and not men, as carers. Even in places where child care grants are supposed to go to the carer irrespective of whether they are a man or a woman, many men report difficulties in accessing the grant (Peacock & Westen, 2008: 6).

Stereotypes posit a division of labour, responsibilities and capabilities between women and men. The persistence of deep-rooted stereotypes and patriarchal attitudes regarding the roles and responsibilities of women and men in the family and society are a root cause of the disadvantaged position of women in a number of areas, including in the home, the labour market and public life, and present a significant impediment to the achievement of gender equality. A focus on stereotypes illustrates that norms and values are critical in creating the existing situation as well as in challenging and changing it. In HIV and AIDS care, there is overwhelming evidence that these social constructs have been exploited to put women at the Centre of care work.

2.2.7 Towards redistribution of care work

Redistributing care provision between women and men within households means challenging the gender stereotypes that associate care with femininity. It means challenging the customary law, institutions, norms, and regulations in which these stereotypes are deeply embedded (Esquivel, 2011). This will involve challenging the distribution of tasks and roles that are socially defined as 'feminine'; for example, cooking and fetching water, the balance of maternity versus paternity leave, or the societal pressures on women to find ways to reconcile work and family responsibilities. As Eyben (2013: 2) points out, this means 'challenging the natural order'.

Changes in economic incentives also play a part in intra-household redistribution of care responsibilities. As long as gender wage gaps and labour opportunity gaps exist, the opportunity costs for women to assume unpaid care roles will remain lower than for men. This makes it economically 'rational' for families and households to maintain a male-breadwinner/female-caregiver arrangement. Indeed, these various areas of intervention underscore the fact that even in the intimacy and privacy of the household and family, care provision is indeed 'social' (Daly and Lewis, 2000).

Nevertheless, focusing action on redistribution of unpaid care work only at the household level would create the risk of overlooking family contexts in which the redistribution of responsibilities is not possible (because there is no other adult to share them with), or in which the care burden is so much that even when equally shared, the care needs are not met. For this reason, redistributing care means taking action beyond households.

2.2.8 HIV and AIDS caregiving as occupational segregation

Key contributors to this caregiving burden include global health worker shortages and regional migration, economic crisis and structural adjustment policies that have weakened public health and social security systems and transferred caregiving to households and communities and inadequate and delayed donor and government funding for HIV prevention and treatment (VSO, 2006; Peacock and Westen, 2008). But at the heart of women's disproportionate, inequitable HIV and AIDS caregiving burden lies gender inequality and the traditional gender roles and stereotypes that come into play in men's and women's responses to the epidemic.

When viewed this way, the unequal sharing of responsibilities between women and men results from and is sustained by the widespread existence of gender status beliefs and stereotypes, the difficulties associated with changing norms around the organization of family caregiving (Daly, 2008), inadequacies in policy, program approaches that have left a caregiving void into which women have stepped (or fallen) as almost exclusive default care providers, and a lack of political will.

Men's and boys' entry into HIV and AIDS care-giving in meaningful numbers would offer an important opportunity both to increase the equity and sustainability of national and community-level HIV and AIDS care-giving responses and mitigate health workforce shortages, especially for societies with high HIV prevalence (Reichenbach, 2007; Peacock and Westen, 2008).. However, the roles currently played by men and boys as providers of such unremunerated and often unsafe care have been poorly documented and understood, including their willingness to perform this job.

While there is positive evidence that some men are entering the HIV and AIDS care-giving job with a range of incentives and social supports (Peacock and Westen, 2008; Esu-Williams et al., 2004), long-term results from interventions to increase their numbers in HIV and AIDS care-giving are still elusive. Men's significant and sustained engagement in caregiving is by no means inevitable since HIV and AIDS care-giving appears to be a gender-segregated occupation. Making an impact in this vital area of health workforce planning requires a better understanding of the dynamics of gender segregation.

2.3 Home-based care in HIV and AIDS context

Community and home-based care is defined by the World Health Organisation (WHO, 2003: 4) as any form of care given to sick people within their homes and includes physical, psychosocial, palliative and spiritual interventions. Community and home based care has become the key response to the AIDS pandemic, and many people report that they preferred to be cared for in their home and communities. Indeed, a study in Zambia showed that 90 per cent of interviewees prefer home based care (Action Aid, 2001:11). However, this level of unrecognised and unsupported community and home based care is unsustainable in the long run (VSO, 2006).

Although this burden is currently more significant in Africa, this trend is growing across the developing world, as can be seen by studies that show that in Thailand, two-thirds of all adults with AIDS-related illnesses are nursed at home by parents predominantly by mothers (Godfred, 2006). If gender inequalities and the burden of community and home based care are not addressed comprehensively in Asia now, women and girls are likely to carry the unsustainable burden of care as the pandemic escalates (VSO, 2003: 34). Among many governments and communities today, home based care is perceived as ‘a cost effective response’ to the HIV and AIDS crisis because it is based on the unrecognised, under-valued and frequently unpaid work of women and girls.

The Alma Ata Declaration of 1978 affirms health as a basic human right, and yet many governments in developing countries are not meeting this obligation and are failing to provide adequate health care. Furthermore, African Heads of State agreed in 2001 to allocate 15 per cent of national budgets to health and this target has not been met either (VSO, 2006: 6). In some cases, this is as a result of factors such as external conditions limiting public sector spending and expansion, and the burden of debt repayments. It appears that many governments have been content to shift the burden of care to communities, particularly women and girls, essentially reneging on their roles as duty bearers in providing citizens’ rights to health care. As a result, the women and girls who provide community and home based care are subsidising the state, while being denied their right to health and appropriate compensation (VSO, 2006:19).

2.3.1 Caregivers in the context of HIV and AIDS

HIV and AIDS-related care generally refers to care for people living with HIV and AIDS who fall ill as well as care provided to children and/or families affected by HIV and AIDS. These distinct but overlapping care needs imply different strategies and tasks and many carers do both, often at the same time (UNAIDS, 2008: 63). Community caregivers include all people in the homes and communities who are responding to the health crisis and caring for the sick and dying.

Many terms are used to describe community caregivers, and they tend to be very context specific. Commonly, care-givers include: female primary caregivers, a patient's primary caregiver, usually family; grandmother, mother, sister, wife or community members, community nurses and health workers (VSO, 2006). Some are referred to as 'community volunteers' as they are volunteering, and are not in paid employment, however, others are working through organisations or the government. Some are formally recognised and perhaps supported, compensated or remunerated by an organisation or the state, while many others are simply caring for family and neighbours with no organisational support, compensation or remuneration (UNAIDS, 2000).

According to UNAIDS (2000), informal volunteers are referred to as friends and neighbours who care for sick people they know out of a sense of love or duty while formal volunteers are recognised as those who have been recruited, and supervised by an organisation. A significant number of caregivers are grandparents. To this extent, a study by HelpAge International (2004) shows that among older caregivers, it is the grandmothers, rather than the grandfathers, who tend to provide the care. At the far end of the spectrum, there are also a significant number of children providing care. Moreover, a UNAIDS (2000) report estimated that the least recognised caregivers were the children, when one parent dies there is frequently no one else to care for siblings and the second parent where there were two parents.

Both groups of caregivers are especially vulnerable as they are not in the traditional income earning age bracket, and are frequently not protected by policies or support programmes, as they are often invisible to authorities. In addition, while they can be excellent providers of love and support, they are often frail or simply young and inexperienced; and usually cannot provide adequate medical care. Furthermore, these groups are often not the targets of information sharing, further disempowering them. This burden means that many grandmothers and children are caregivers without the necessary skills and support, and at the same time they are having their retirement years and their childhood stolen from them (UNAIDS, 2000).

For caregivers who assume the role of parent for a child, they are likely to become the sole or main providers of all the emotional, material and financial support. For adults in need of care, carers are most commonly depended upon for emotional support, physical care and nursing care (Horizons, 2005). In the context of HIV, physical care extends to bathing, eating, dressing, as well as fetching water and gardening; nursing care includes pain management, treating wounds, and supervising the taking of medication. Caregivers also spend a significant amount of time advocating with hospitals and other administrative and governmental offices to gain recognition as the primary career for the people they care for, in order to carry out necessary administrative paperwork to cover benefits, as well as to assist families in arranging for burial fees, death certificates, and inheritance issues for spouses and children.

A full time caregiver may also bear extensive financial burdens for transport, treatment, food, and anything else the patient needs. Universal access to anti-retroviral therapy (ART) has the potential to reduce the HIV related burden of care as it enables people living with HIV to live healthy and productive lives for much longer, and to remain parents. However, while access to anti-retroviral therapy has been expanding, in 2007, an estimated 3 million people globally received access to ART, representing one third of those in need globally), there are an estimated five new infections for each new person accessing treatment (UNAIDS, 2008). The long term impact of HIV treatment on care needs, including co-morbidities and side effects, could present future challenges on both home carers, volunteer care workers and the formal health sector (Maher, 2008).

Evidence now abounds on the unequal AIDS related care work responsibilities which are assumed disproportionately by girls and women of all ages as compared to boys and men (UNAIDS/UNFPA/UNIFEM, 2004).

- In Southern Africa, numerous studies reveal that two thirds of primary caregivers in households surveyed are female, one quarter of these are over 60 years of age (Steinberg *et al*., 2002).

- A survey of 62 organisations, deploying a total of 2,635 volunteers in three Ugandan Sub-Counties, found that 68per cent of volunteers were female (Tumwine, 2007).
- Although the caregiving impact on women is most visible in Africa, the trend is growing across the developing world; in Thailand, two thirds of people living with HIV and AIDS are nursed at home by their parents, usually their mother (VSO, 2006).

Older women and married women are significantly affected. Care responsibilities fall to older women because a substantial proportion of people living with HIV and AIDS move back to their communities of origin at some stage of the illness to be cared for by their parents, and women take responsibility for their grandchildren if necessary (Knodel, 2001). Grandmothers and older women have traditionally always had a role in the care of children and of the sick but not on the current scale: the combination of deaths of parents and other caregivers of productive age and poverty-driven migration results overall in a shortage of prime-age adults.

Married women are affected significantly because studies have shown that for married men, where care normally takes place in the family and in the home, the carer is most likely to be their wife (Knodel, 2001). Men are less likely to be open about their HIV status and seek external support, even from home-based care programmes, relying on the commitment and discretion of their wives to care for them (Action Aid and VSO, 2008).

A lower percentage of the care burden, though still a significant share, of care work falls on younger women. And where children provide care for parents, two thirds are girls (VSO-RAISA, 2007). The impact of care work is far-reaching. The physical labour of fetching water, a task which principally falls to women and girls, the strength required to lift patients to help them to the toilet or to wash them, the cooking, cleaning and farming, and the lack of resources to spend on their own medication, all can have detrimental effects on the carer’s own health (Saengtienchai and Knodel, 2001). The physical and psycho-social impacts of caring on women’s well-being are rarely acknowledged, as women often ignore their own health concerns (WHO, 2003). Without proper training, information and supplies, there is also the risk of exposure to communicable opportunistic infections. Many carers are living with HIV themselves and need to take care of their own health concerns (VSO, 2003).

2.3.2 Caregivers and their roles in HIV and AIDS context

While the nature of home-based care has changed in recent years with increased access to antiretroviral therapy (ART), it remains as crucial as ever. Care and support services are needed from before diagnosis and throughout the course of HIV-related illness regardless of ability to access ART (VSO, 2003). Before treatment was available, caregivers gave much of their time to nursing bedridden sick people. Care-givers are more able to focus on providing a wide range of services including psychosocial, physical, socioeconomic, nutritional, and legal support, referrals to medical care, and support with ART adherence. Nevertheless, still less than 50% of those in need of ART globally are receiving it (Greenberg, 2012).

Primary caregivers looking after children, both living with HIV and those who have been orphaned or otherwise affected by the epidemic, also take on many caring responsibilities. These range from ensuring children's access to health care and education to providing adequate food, shelter, clothing, and other basic needs. Secondary caregivers are generally represented as non- or para-professional health care providers with basic training in primary health care, sanitation, and counseling for people living with HIV and other chronic illnesses, providing services in the sick person's home. In reality, caregivers do significantly more than this, acting as integrators of community and formal health systems, linking clients to primary health care and development support, and providing legal, social, and psychological counseling (Hayes, 2007).

Caregivers provide ongoing psychosocial counseling including bereavement counseling, succession planning support groups, and life skills support for people living with HIV, orphans and other vulnerable children. This often includes interventions targeted at key affected populations and survivors of violence (Greenberg, 2012).

Clinical, referral, and adherence support Caregivers provide adherence support for ART, Prevention of Mother-to-Child Transmission (PMTCT), TB and medications to prevent opportunistic infections. They assist clients to handle the side effects of some of these medications, are involved in tracking clients who are lost to follow up and provide bed care, wound care, and personal hygiene to bedridden people living with HIV (PLHIV).

Overall, caregivers perform a variety of roles that help people with HIV and AIDS adhere to treatment regimens, avoid unnecessary hospital admissions, reduce reliance on formal caregivers, remain at home longer, and maintain quality of life. Traditionally, family members have served as the primary caregivers for seriously ill individuals. Because HIV care involves more diverse social networks, many HIV-positive individuals have redefined family boundaries to include lovers, friends, and other chosen kin (Carlisle, 2000; Irving and Bor, 1995).

Findings from a 1997 national survey indicate that the typical caregiver devotes more than 20 hours per week to caregiving tasks (Caldwell, 2001). These tasks may include;

- Emotional support (e.g., comforting, empathizing, and providing encouragement)
- Help with activities of daily living (e.g., feeding, bathing, dressing, and toileting)
- Help with instrumental activities of daily living (e.g., cleaning the house, running errands, providing transportation)
- Management of financial and legal matters
- Health care advocacy (e.g., linking the care recipient with formal and informal services, communicating with health professionals)
- Nursing care (e.g., dispensing medications and monitoring use, administering injections among others.

2.4 Carers and their challenges

2.4.1 Financial costs in HIV and AIDS care

The increased financial costs related to caring for the sick ranges from costs incurred to provide immediate care (gloves, medicines, water, etc.) to financial outlays for medicines prescribed, over the counter, from clinical therapists or traditional healers and user fees for accessing health care services, transportation costs involved with attending clinics, rising food costs, and others (Horizons, 2004:12). Even with the free availability of anti-retroviral therapy, associated costs have often not declined; transport costs to health centers to obtain ART remain a key barrier, which impacts negatively on adherence, while food costs increase to ensure the efficacy of anti-retroviral therapy (HelpAge International, 2007).

Women face particular financial burdens in care-giving, particularly in diverting their time from other productive chores. Women produce 60-80 per cent of the food in most developing countries and, while women's employment in the informal sector and the impact on household economy is poorly documented and excluded from macro-economic modelling, studies have shown that the extra responsibilities of AIDS related care can divert their labour from productive agricultural work and so contribute to household food insecurity (UNAIDS, 2005:43).

Households with a sick family member face the opposing pressures to work fewer hours to spend more time caring, or to work more hours to earn more money to pay for increased expenditures. Gender differences in employment opportunities also impact on women’s caregiving responsibilities. If one of a working couple needs to spend time at home to care for a family member in need of care, the person with the most flexible working arrangement or lower income earning capacity, in both cases usually the woman, will be the person to sacrifice income earning opportunities for caregiving time (Saengtienchai and Knodel, 2001). Furthermore, women employed in the formal sector but without the flexibility of reducing their hours manage both their paid job and their role as primary carers in the home. One study found that a one in five Kenyan health worker was caring for an immediate family member living with HIV (Horizons, 2006: 8).

Women as volunteers in home-based care programmes have to sacrifice or manage competing demands for their household’s needs: farming, time with their family, especially children who need guidance with their school-assigned homework, and their own businesses (Tumwine, 2007). Gender-bias is found in the under-recognition and low value assigned to the care economy which is part of the unremunerated work performed by women. The care economy including AIDS related care work in the home is largely taken for granted in both governmental and non-governmental efforts to mitigate the impact of the disease. Both the importance of this caring work, and its costs for those who undertake it, go unrecognized in national accounts, and unaccounted for in national and international HIV and AIDS policy and programming (Ogden *et al*., 2006).

Accessing existing external financial support is also a challenge to carers. Many households in South Africa rely on pensions as unemployment is so high (Horizons, 2006). Where social grants are available, e.g., foster care grants, access can be problematic when guardians cannot trace their dependents' remaining living parents, i.e. an absent mother or father, to obtain signatures on the required documents or lack the necessary registration documents of themselves (Helpage International, 2007: 31). Strategies to pay for medical interventions and other care costs include taking on extra work, selling assets, taking children out of school to save on school fees, and most commonly borrowing money (Knodel *et al*., 2002:12).

In Thailand, almost half of parents who were primary carers of someone living with AIDS borrowed money, and many never expected to get out of debt (Knodel *et al.*, 2007). The financial cost to older carers is exacerbated by a loss of financial support from their adult child when they become sick, particularly in communities where there is a high co-residence rate between older parents and their children (Knodel, 2001). Economic pressures from the burden of care can lead to sexual risk taking by carers of all ages, increasing their susceptibility to HIV infection by engaging in income earning activities and survival strategies, including exchanging sex on an informal transactional basis (UNAIDS/UNIFEM/UNFPA, 2004).

A key issue raised by those who work with the concept of the care economy (Azari *et al.*, 2004; Budlender, 2004) is that, despite its value to the wider marketplace, this domain of unpaid labour remains invisible, and is not incorporated into national income accounting systems nor generally included in calculations of a country's overall Gross Domestic Product. And if unpaid care work remains invisible, so too does the unpaid care worker. For example, Elson (1991) posits that programmers and policy makers often assume that women can allocate their time easily between market work and household production. It is also taken for granted that women will be the ones to respond to crises or illnesses. This line of argument, therefore, asserts that making this unpaid work, and the unpaid workers, visible is of value to governments and policy makers in order to be able to capture the benefits of these activities, but also to be able to enumerate their costs. This will enable the unpaid contributions of women to the productive economy can be acknowledged and compensated.

2.4.2 Psycho-social impacts of care-giving

The emotional stress on carers of all ages and gender can be significant. Children without adult supervision, having experienced the grief of losing their parents, face the responsibility of feeding and clothing their siblings which puts them at risk of exploitation and harm. Parents caring for numerous children of their extended families and neighbours increase their worry and anxiety. The greater responsibility exacerbates poverty as having more mouths to feed means less food for those already in the family (Horizons, 2005).

Some adults care for their partners and loved ones and, for those that do not return to health, experience the pain of watching them die. Many of those in caregiving roles are also themselves living with HIV; this can cause additional psycho-social trauma for the caregiver. Many grandparents, parents and other carers often find that they have little time to grieve as they have to be emotionally and physically strong to support and look after the dependent children left behind (Saengtienchai and Knodel, 2001). The demanding nature of caring for both sick adults and for children means those carers can face social isolation (Horizons, 2005).

A significant challenge for older caregivers, both men and women, is that they are often at a time in their life when they expect to be cared for by their children, and they are emotionally, financially and physically inadequately prepared to fully provide for their newly acquired dependents (Horizons, 2005). Physical ailments affect many older caregivers, including strained muscles, fatigue, arthritis, high blood pressure, diabetes, and hearing, vision and mobility problems (Knodel, 2002).

Older women face age discrimination when they are considered to be beyond productive working age, impeding their income earning abilities, a situation further exacerbated for those who have lower levels of literacy and education than their male counterparts (Help Age International, 2007). Women are less likely than men to receive a pension from being in the formal employment sector except in countries like South Africa where there is a social pension. Age discrimination also occurs when older people are refused access to HIV services and information on the assumption that AIDS do not affect them. While the role of older caregivers, particularly older women, has been gaining increasing recognition through research at international level, national policies and programmes have been slower to respond to their needs (Horizons, 2005).

2.5 Theoretical frameworks

In the works of Christine et al. (1990), theories are examined as formulations of the relationships of the underlying principles of phenomena that have been observed and verified to some degree. A theory, therefore, provides a systematic way of dealing with a problem. The purpose of this sub-section is to make links between the two theories of gender relations and, cultural production and reproduction with the whole issue of gender relations in home-based HIV and AIDS care.

2.5.1 Gender Relations Theory

The gender relations theory was developed by Ruth Pearson (1992). According to her, the society views all activities that are carried out to be based on social roles and interactions of men and women. The theory asserts that gender roles are dictated by society through its norms and values. It defines a role as the expected behavior associated with a status (Pearson, 1992). Roles are performed according to social norms, shared rules that guide people's behaviour in specific situations. Social norms determine the privileges and responsibilities a status possesses. Females and males, mothers and fathers, daughters and sons are all statuses with different normative role requirements attached to them. The status of mother calls for expected roles involving love, nurturing, self-sacrifice, home-making, and availability. The status of father calls for expected roles of breadwinner, disciplinarian, home technology expert, and ultimate decision maker in the household.

Society allows for a degree of flexibility in acting out roles, but in times of rapid social change, acceptable role limits are often in a state of flux, producing uncertainty about what appropriate role behavior should be. People may experience anomie, normlessness, because traditional norms have changed and new ones have yet to be developed. When normative role behavior becomes too rigidly defined, our freedom of action is often compromised. These rigid definitions are associated with the development of stereotypes i.e., oversimplified conceptions that people who occupy the same status group share certain traits in common. Compared to males, for example, females are more likely to occupy statuses inside and outside their homes that are associated with less power, less prestige, and less pay or no pay (Pearson, 1992).

Rono (1999) posits that the notion of gender roles and activities have a strong ideological content based on the values and norms persistent in a society which are reflected in the gender division of labour. Based on such ideologies, society seems to have an ultimate authority on the precise nature of what women and men actually do, and their real contribution to production and reproduction which turns out to be biased against women (Pearson, 1992:12). Existential social structures with regard to division of labour determine the duty spheres of women and men in the society. Because of such bias, the performance of men and women in nearly all spheres of life such as business, environmental conservation, development projects and the like are bound to vary.

Proponents of gender relations theory, such as Rono (1999) and Emerek (1999) argue that women have been relegated to performing reproductive and undervalued roles within the households. These roles include those of caregiving since women have been brought up as good nurturers for children including the sick within the society. However, it should be understood that these care roles are performed alongside other reproductive duties that women and girls perform thus increasing the burden of work.

The gender relations theory has been used in assessing the working time and roles amongst European families (Emerek, 1999), engendering of poverty analysis in developing regions with specific focus on feminization of poverty (Chant, 2003) and in evaluating gender mainstreaming within the UNDP work environment (UNDP, 2006).

Whereas the this theory explains the observed labour patterns between males and females in the society, its association of these roles with social status/privileges in the society does not wholly speak to cultural transmission of roles across generations even when they are found detrimental to the wellbeing of males and females. Moreover, the theory fails to take into account the very pronounced economic and power-value attached to men’s roles that are largely located outside the domestic sphere. Hence, cultural production and reproduction theory was adopted as complimentary theory.

2.5.2 Cultural reproduction theory

In Bourdieu’s theory of social reproduction, cultural capital refers to transmissible parental cultural codes and practices capable of securing a return for their holders.

Cultural capital embodies the sum total of investments in aesthetic codes, practices and dispositions transmitted to children through the process of family socialization, or in Bourdieu’s term, habitus. Habitus is an important form of cultural inheritance. It reflects class position or the actors' location in a variety of fields and is geared to the perpetuation of structures of dominance (Bourdieu and Passeron, 1977: 204). Bourdieu believed that the education system was used solely to ‘reproduce’ the culture of the dominant class in order for the dominant class to continue to hold and release power (Jenks, 1993:2). According to Bourdieu, inequalities are recycled through the education system and other social institutions. Bourdieu’s theory of cultural reproduction is concerned with the link between original class membership and ultimate class membership, and how this link is mediated by the education system (Bourdieu, 1984).

Cultural reproduction theory bears important relations to a cluster of social, cultural and economic reproduction that developed in Anthropology and Sociology (Bilton, 1996). The theory concerns the ways that dominant ideologies, relations, and interests are reproduced, uncontested, through cultural and social institutions (Levinson and Holland, 1996; O’Connor, 2003). For example, reproduction theories implicate schools in the reproduction of hegemonic ideologies, forms of knowledge, skills, and attitudes needed to reproduce the relations of an existing social order (Levinson and Holland, 1996). According to the theory, human subjects are reduced to passive bearers of structural relationships including areas around division of labour (Willis, 1981).

Cultural reproduction often results in social reproduction or the process of transferring aspects of society, such as class, from generation to generation (Bilton, 1996). According to Sullivan (2001), the theory of cultural reproduction entails three fundamental propositions: 1) parental cultural capital is inherited by children. 2) Children's cultural capital is converted into educational credentials. 3) Educational credentials are a major mechanism of social reproduction in advanced capitalist societies. In the context of caregiving, the parental cultural capital remains significant in determining the gender division of labour at the household level.

2.5.3 Relevance of the theories to the study

The gender relations theory has been important in explaining the societal norms and practices toward gender division of labour in the society. To this end, the theory explains the connection between the women's dominance in caregiving roles relative to men even in the context of HIV and AIDS care. Women and girls are traditionally charged with the care and nursing roles that the HIV and AIDS patient requires, thus, the duty falls on the female members of the household due to gender division of labour that is predetermined. Carers are most commonly depended upon for emotional support, physical care and nursing care. At the core, the theory explains the norms and practices putting women at the centre of care provision and the roles they perform. The theory offers an explanation to social barriers that have prevented men and boys from taking part in the care-provision duties.

The theory is important in explaining the challenges faced by women caregivers in the context of HIV and AIDS. All the care takes place within the homes with little support from the health facilities or other intervention agencies that can provide the necessary information on safe and effective care provision. On the economic front, with the family’s source of economic support threatened and savings spent on care, household capacity to provide for other members’ basic needs declines. Economic pressure and the responsibilities of caring for parents and siblings can lead children especially the girls to withdraw from school to run the household, take care of the sick or support the family hence the girls fall deep into poverty i.e. inter-generational poverty is enhanced.

The cultural reproduction theory helps to contextualize the societal traditions and values/norms that are passed across generations with respect to the domains of men and women in labour activities. It points to cultural socialization as a major mechanism through which relations and activities (duties and roles of women and men) are transmitted thus explains to societal practices that place females at the centre of caregiving and by extension the culturally ‘appropriate attitudes and values’ that bar men from care-giving.

The cultural reproduction theory has helped to contextualise the perpetuation of gendered labour and societal values on work. This is the basis of institutionalised unequal share of work between males and females at the household and public spheres. This inequality is well exemplified in the care-giving context for the sick as is well documented in this study. Further, the theory explains men’s lived experiences and interactions with their fathers in a social learning process in which the socially ‘accepted’ gender roles are acquired and ingrained in the men’s daily behaviour through conceptualisation and valuation of work. In essence, the theory helps to explain issues as stigmatisation of male caregivers, their ridicule by males and females alike as being atypical.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter presents the context in which the study was conducted. It describes the research site, the study design, study population, sampling procedures and sample size, data collection methods and data analysis. The chapter finally discusses the ethical considerations that guided the study.

3.2 Research site

The study was carried out in Uriri Sub-County (figure 3.3) of Migori County (Figure 3.2). Uriri Sub-County borders Awendo to the North-East, Rongo Sub-County to the West and Ndhiwa Sub-County to the South (KNBS, 2009). It has two divisions i.e., Uriri and Oyani, and four locations, namely, Kanyamkago North, Kanyamkago South, Kanyamkago West and Kanyamkago East (KNBS, 2009). The Sub-County has a total population of 115, 751, out of whom 56, 348 are females and 59, 403 males (KNBS, 2009). According to GoK (2008), Uriri Sub-County has a population density of 282 persons per square kilometre.

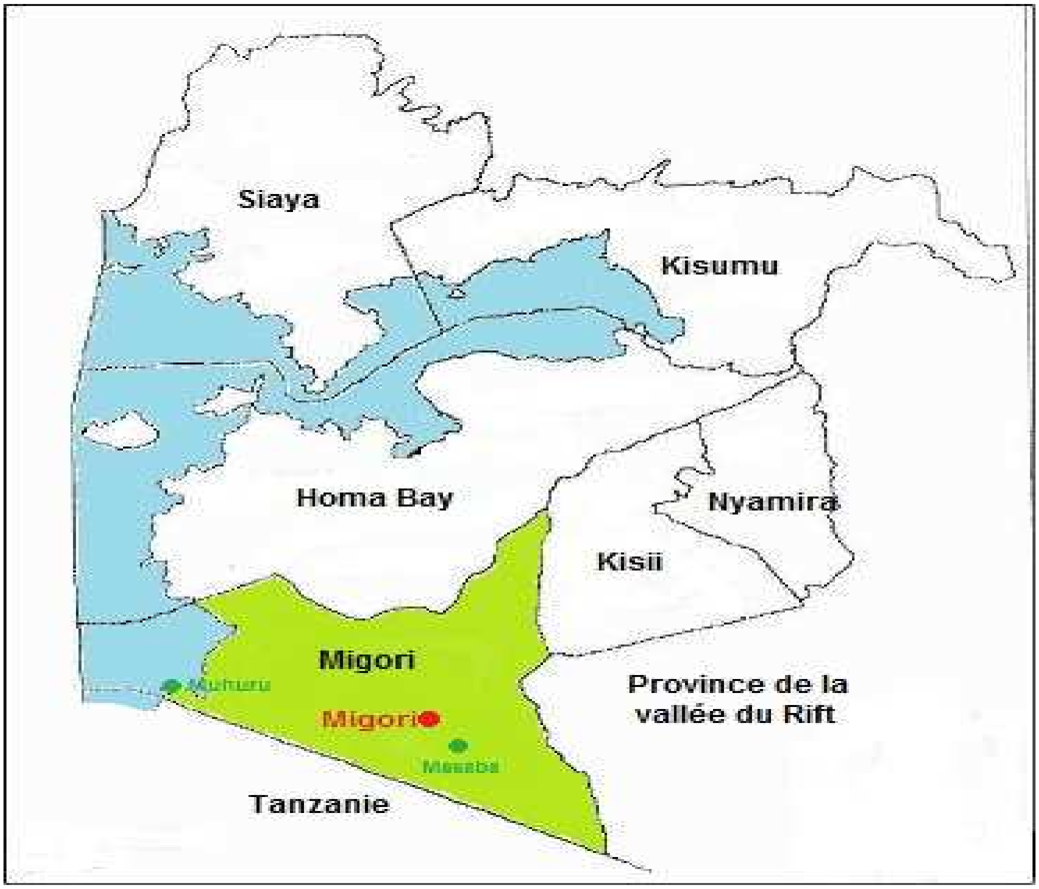
HIV and AIDS prevalence is high in Uriri Sub-County, at 15.5 per cent amongst married couples and 13 per cent amongst the youth (NASCOP, 2007). The KAIS (NASCOP,2012) report indicates a HIV and AIDS prevalence of 14.3% in Uriri Sub-County representing a 1.2% decline from the 2007 estimates but a high rate compared to the national average of 6.3%. High HIV and AIDS prevalence in the area means high demand for care-giving to the patients, of which, a lot of care occurs at the household level.

Uriri Sub-County has one sub-County hospital run by the government with a bed capacity of 10, four government run health centres spread across the four locations, one Faith Based Organization health centre and a dispensary. The nurse to patient ratio is estimated at 1: 4, 443 (GoK, 2008). By 2008, only 2, 595 People Living with HIV and AIDS (PLWHA) were provided with assisted home-based care (GoK, 2008). At the same time, KAIS (2007) reported the existence of four health centres across the Sub-County that are too ill-equipped and under-staffed to provide the care needs of HIV and AIDS patients. Figure 3.1 below shows the location of Migori County in Western Kenya.

Figure 3.1: Map of Kenya showing Migori County

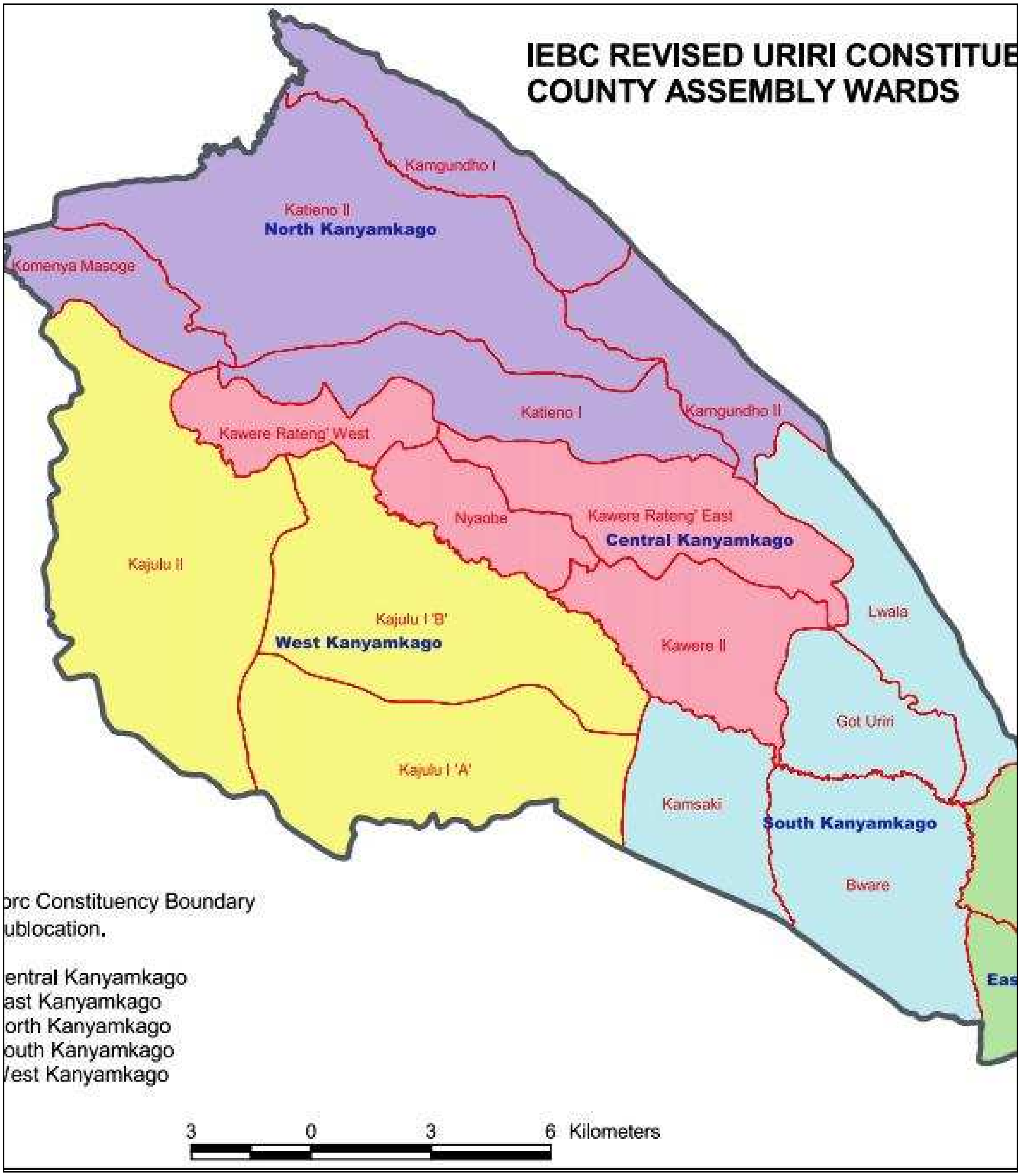
Source: GoK(2012)

Figure 3.2: Map of Migori County



Source: GoK (2012).

Figure 3.3: Map of Uriri Sub-County



Source: GoK (2012).

3.3 Study design

This was a cross-sectional descriptive study. The fieldwork spanned a period of 16 months as from January 2013 to April, 2014. In the study, qualitative data collection methods were employed to address the stated research questions. Specifically, data were collected using in-depth interviews, case narratives and key informant interviews. Given the exploratory nature of the study, triangulation of data collection methods was deemed necessary so as to compensate for limitations in single-line data collection approach.

To maximize on the data collection methods, the study began by conducting semi-structured in-depth interviews with informants on their experiences with caregiving. The information emerging from the informants during probing were useful in adjusting the interview guide to bring out insights that had not been originally envisaged at the proposal level. Having interacted with informants and understood the length of time spent on caregiving across the sample, case narratives were introduced at the 10th month to purposively selected informants from among the original group. Importantly, the method documented the cases of persons who spent more years in caregiving , had shown great passion during in-depth interviews to discuss their experiences and were still available for further inquiry. Having received information from the caregivers by way of case narratives and in-depth interviews, key informant interviews were conducted to rope-in expert opinions on the objectives of the study but also clarify some of the issues raised by the caregivers.

The data collected were analysed thematically along the line of the specific objectives. Caution was taken to ensure that emerging issues in the prism of caregiving and gender were adequately covered and explained. In the presentation, verbatim approach was adopted where direct quotations were used to amplify the informants' voices.

3.4 Study population and unit of analysis

The study population comprised all care-givers of HIV and AIDS patients within households in Uriri district spread across the four locations of Kanyamkago North, Kanyamkago East, Kanyamkago West and Kanyamkago Central. The unit of analysis was the individual care-giver defined as a male or female providing care to HIV and AIDS patient within Uriri Sub-County.

3.5 Sample size and Sampling procedures

In the study, 100 caregivers to HIV and AIDS were drawn for interviews. This number was based on the finite population of 1445 HIV and AIDS patients registered for ARV at Uriri Sub-County hospital. On the basis of the sample frame, ARV patients' register at the Sub-County Hospital, 100 patients from the Uriri Sub-County were drawn and clustered according to the locations where they come from with the help of Sub-County Community health outreach officer. Using the patients' register was a way of ensuring that caregivers eventually recruited for the study were those offering care to clinically confirmed HV and AIDS patient and not any other diseases or illnesses.

Contact was then established with the selected patients through the assistance of Uriri Sub-County community health focal person. In certain cases, the partnering Rural Aids

Prevention and Development Organisation (RAPADO) programs officer who closely works with the Sub-County community health officer on HIV and AIDS helped in locating the homes of the patients.

Once, the patient's place of residence was established and permission to visit granted, caregivers who reside with the HIV and AIDS patients were purposively selected and recruited as study participants. As an exclusion criteria, caregivers who only performed their roles on the basis of paid labour were left out of the final list of study participants. Similarly, patients registered for ARVs but admitted at the hospital and those patients who come from outside the Sub-County but receive their ARVs from Uriri Sub-County hospital were never followed for subsequent interviews with their caregivers. Finally, the HIV and AIDS patients living and managing their own conditions did not have their caregivers comprise the final list of the informants.

Whereas the study intended to follow study informants for in-depth interviews for a period of eighth moths, some of the selected informants declined to continue with the interviews on the subsequent visits. The first fourteen cases of withdrawal came within the second visit and this largely comprised the group that had expected to compensated upon consenting to the study. They also pointed out to previous surveys two years before where PLWHAs were promised continual assistance by community health workers and material gifts if they volunteered information but the benefits are yet to be realised. Similarly, there was a feeling amongst this group that academic studies had little bearing to their plight and the information that they gave at the first introductory meeting was all they could volunteer. For the remaining twenty-two informants, a number of HIV-positive caregivers (precisely 4) felt that the study would be emotionally draining to continue with over a long period of time given that no immediate intervention was in the offing, while another group largely comprising mothers (11 in number) working as casual labourers besides caregiving pointed to the need to be remunerated for information they had given over the last three months. Similarly, there was the last group of seven (grandmothers and young females) who reported being at the risk of losing financial support from relatives if they continued sharing their care burden in a study that had no monetary compensations. To this end, the study reached up to 64 caregivers on a consistent period of eight months through which visits were made to caregivers for interviews.

To get key informants' input, seven key informants were purposively selected for interviews based on their knowledge and work on HIV and AIDS care giving programmes, occupation as health officers at the selected district ARV-distribution health Centres, the position in the District HIV and AIDS Control Committees and being officials of NGOs dealing with HIV and AIDS prevention, care and treatment in Uriri Sub-County.

The informants to case narratives (numbering five) were purposively drawn from the sampled caregivers based on the length of time taken to provide care, their willingness and availability to delve more into discussing their experiences with caregiving. The narratives teased out the support that they have received in the process and the various challenges that they have faced in caregiving to HIV and AIDS patients.

3.5.1 Field entry

To conduct effective field work on a sensitive topic like HIV and AIDS and more so in a rural poor setting where monetary expectations from researchers has become the norm required strategic entry. First, it was important to go through the Sub-County community health officers and the RAPADO program's officer on AIDS who have worked with the community on a number of state and non-state driven interventions. These officers were important in creating trust and further explaining the nature of my study to the targeted study participants, more importantly, scaling down any monetary expectations from academic research that I was undertaking. Besides, they also explained that confidentiality of the patients remained intact and that my study would not in any way compromise the same given my interest in caregiving and eventual use of pseudonyms in the presentation of my findings.

During my first visit to the caregivers, I explained the scope of my study and its potential implications to the study participants, shared and interpreted the contents of the consent form while at the same time explained the voluntary nature of the study. It was at this point that we negotiated and scheduled for subsequent interviews largely observing timings that would minimise any interruptions to their schedules. These meetings were also used to clarify any issues raised by the informants regarding compensation or assistance to children/relatives by virtue of participating in the study.

3.6 Data Collection Methods

3.6.1 In-depth Interviews

These were semi-structured interviews conducted with 64 caregivers to HIV and AIDS patients across Uriri Sub-County as illustrated in table 3.1 below. The method was important in digging out data on the caregivers' experience in provision of care, defining who decides on the person to provide care in the household, the kind of support the carers have obtained from government and non-governmental quarters and the socio-economic challenges they have experienced as caregivers. The semi-structured nature of the method was significant in probing the cultural, social and economic dimensions of care-giving. Similarly, the method proved significant in yielding spontaneous responses and/or reactions which were significant in yielding the supplementary insights (emergent issues) into the study topic. The interviews were conducted with the help of an in-depth interview schedule (Appendix 2).

Table 3.1: Caregivers reached by Locations in Uriri Sub-County

Location	No. of caregivers originally reached (up to three visits)	No. of caregivers sustained throughout the study period
Kanyamkago North	22	14
Kanyamkago Central	28	21
Kanyamkago East	27	13
Kanyamkago South	23	16
Total	100	64

3.6.2 Key Informant Interviews

These were semi-structured interviews carried out with professionals amongst them: Head of the Uriri sub-county health management team under NASCOP, two-health officers in-charge of the district facilities (Uriri Sub-County hospital and St. Monica Mission Health Centre), a Community health worker trainer attached to a local NGO, heads of the Uriri Youth World Changers and Rural AIDS prevention and Development Organisation (RAPADO) and Sub-County Development Officers (CDO).

The key informants provided information on the observed continued shift toward home-based care provision in HIV and AIDS context from the government run-facilities, the division of labour in HIV and AIDS care provision within the households, the cultural expectations versus contemporary realities with respect to gender and labour division in caring for the sick, the role played by stakeholders across government and non-governmental quarters in aiding HIV and AIDS home based care. The inputs of the experts were important in analysing the applicability of various policy frameworks and programmatic interventions on HIV and AIDS care giving in the real socio-economic and cultural context. A key informant interview guide (Appendix 3) was used to collect the data.

3.6.3 Case Narratives

The fact that caregiving assumes multiple dimensions and is carried out over an extended period of time from HIV diagnosis in an individual to the point of death necessitated the use of case narratives. To this end, the case narratives were carried out with five caregivers who were willing to talk more about their experiences in the process of providing care to HIV and AIDS patients in their households. The narratives elicited information on the knowledge of the informants about care provision needs of HIV and AIDS patients (medical, physical, nutritional and psychological), the different roles they play in care-giving, the division of the roles in the households, challenges experienced over time and interaction with external (drawn from non-state and state actors) assistance aimed at reducing the burden of care. A case narrative guide (Appendix 4) was used to guide the process of inquiry.

3.6.4 Secondary data

The study relied on published and unpublished materials to inform the background and contextualise debate across the objectives in the process of reviewing literature. Some of the key materials used in this study include: KAIS (2007;2012), NASCOP(2012;2013), UNAIDS (2000-2014), ILO/UNAIDS/UNRISD (2008), WHO (2000a,b), Pearson (1992), Bourdieu (1977; 1984). Secondary data have also been used to situate the discussions emerging from study findings on previous studies.

3.7 Data processing and analysis

In research process, it is noted that: analysis of data reduces them to a more manageable form that permits the ethnographers to tell a story about the people or group that is the focus of their research; interpretation of that story permits ethnographers to describe to a reader what the story means (LeCompte and Schensul, 1999). Central to the endeavour of anthropology, is the intention to depict the lives and world views of other people and cultures. Analytical aids ensure that the ethnographer's personal experiences and insights have wider validity by integrating different perspectives and data sources in a holistic inquiry, and that analysis is on-going and progressive, interwoven with and shaped by data generation (Attride-Stirling, 2001). Sharkey and Larsen (2005) contend that analysis cannot be separated from theory or the overall aims of the research and is a process of asking questions of the data and checking how answers might be interpreted to make sense.

In this study, the audio-taped data collected through in-depth interviews, case narratives and key informant interviews were transcribed, translated and coded for analysis. Data transcription, translation and analysis were carried out concurrently with data collection. This was done in order to get feedback from the data being collected and to add new and pertinent information that was raised on the instruments being used and adjust accordingly as the data collection progressed. The interview schedule was therefore, constantly being reviewed. This was found to be very useful in eliciting a wealth of information from caregivers and experts.

The transcripts were imported into a qualitative data software known as Atlas-ti. Later, a code book was developed according to thematic categories emerging from the three objectives of the study. The analysis was further done along gender lines, particularly: perceptions and stereotypes regarding men and women in HIV and AIDS care-giving; household gender division of labour and care-giving practices. Code categories were also derived from close readings of the informants' narratives based on language and indigenous concepts that elicited indigenous categories of meaning and local knowledge about gender, caring, and HIV and AIDS. Thus, coding largely involved breaking the interview transcripts into discrete text units, interpreting their meaning and assigning a code, and deductively and inductively establishing the relationships among codes to form constructs.

Analysis was done using the constant comparative method which is consistent with the grounded theory approach (Strauss and Corbin, 1998). Constant comparison was done by reading the data over and over again and grouping statements into themes: gender expectations and labour division norms, caregiving roles, and, the challenges faced by caregivers. The analysis was to bring out salient issues as stated by the participants or seen in the field. A verbatim approach was used in data presentation where direct quotations and selected comments from informants were used to amplify the informants' voices in the discussions. The use of verbatim was not only for the purposes of emphasis and authenticity but also to ensure that the actual meanings or intentions of the informants' statements are not lost in translation.

3.8 Ethical considerations

Necessary ethical considerations and practices were undertaken to ensure that the study was conducted in line with sound research principles and regulations. A research permit was obtained from the National Commission for Science, Technology and Innovation (NACOSTI) and Kenyatta National Hospital/University of Nairobi Ethical Review Board

(Ref. KNH-ERC/A/98) before embarking on the fieldwork. The County administration was duly informed about the study and the duration.

During fieldwork, informants were duly briefed on the purpose, the target groups, selection procedures, duration of the study, and potential use of the research results. An informed consent form (Appendix 1) was signed by the informants as surety of their understanding and acceptance to be involved in the study.

Recruitments to participate in the study were based on informed consent of the caregivers upon being satisfied with the objectives of the study and accompanying explanations about their selection for the study. The rights of informants to disqualify themselves at any point of the study was explained, however, due measures was taken to encourage full and informed participation of the informants throughout the study.

During the interviews, the informants' consent was sought to allow for taping of deliberations which would later be transcribed for the sake of cross-checking with written notes during analysis. The study subjects were assured of their anonymity during publication of the research findings through the use of pseudonyms and coding of the locations. To the scientific community, the study results will be availed through publications in refereed journals and unpublished literature in the form of a thesis at the University of Nairobi libraries.

3.9 Ethical challenges and their solutions

Managing personal expectations around monetary benefits was a major challenge during the fieldwork. Informants needed to understand why such a significant study would be undertaken without immediate compensation to those in need of financial and referral assistance. Similarly, the informants needed to know if the study would put the caregivers under certain programmatic interventions that would ensure that their socio-economic challenges would be attended to. These issues presented the potential for ‘spoiling the field’ for other researchers in case the researcher used money to compensate for the volunteered information or potential for deception if the researcher promised a future programmatic safety net for the caregivers.

In all circumstances, emphasis was laid on the academic nature of the study and it was made clear that all information would be voluntary and their (informants’ views) subsequent use might offer the policy intervention approach necessary to address challenges. There was the issue of young girls below the age of 18 years providing care. While this had not been anticipated, the researcher undertook to explain the purpose of the study to their parents, some of whom were patients, before seeking the consent of the young girls to participate in the study.

CHAPTER FOUR: THE PROFILE OF HOME-BASED CAREGIVERS

4.1 Introduction

This chapter presents the demographic characteristics of HIV and AIDS caregivers within Uriri Sub-County as part of objective one of this study on HIV and AIDS caregiving players in Uriri Sub-County. Discussions have also been carried out on the implications of the reported socio-demographic profiles on HIV and AIDS care at the household.

4.1.1 Gender of caregivers

In the study, gender of the caregiver was deemed important in understanding the societal inclinations and practices around division of labour between males and females. Hence, gender and caregiving practices helped in contextualising disease care, specifically, HIV and AIDS care as a new focal arena for reproduction of societal gender division of labour. In addition, the share of duties between genders in caregiving was deemed important in assessing the interface between socio-cultural expectations and gender participation in caregiving. The findings indicate that most (77%) of the caregivers in the study were females while 23% were males as summarised in figure 4.1 below.

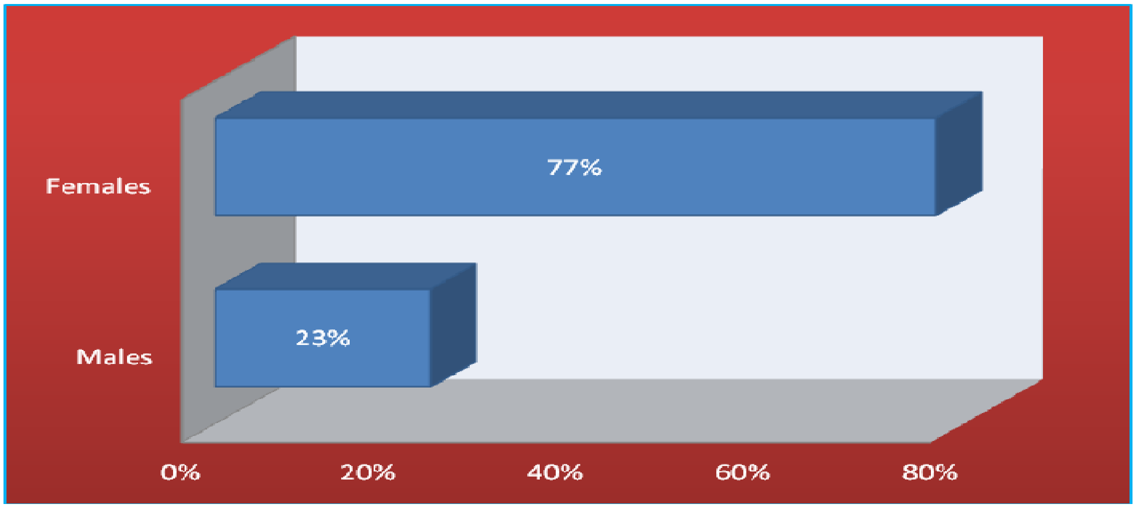


Figure 4.1: Gender of HIV and AIDS caregivers in Uriri Sub-County

By implication, caregiving within Uriri Sub-County largely remains a female domain despite the socio-economic burden that unequal sharing or care duties has had on the females. The findings indicate a tendency of the community in Uriri Sub-County to conform to the cultural expectations of females being born and socialised as nurturers in the society, a domain in which caregiving falls. Caregiving is viewed more as natural and moral to females in Uriri Sub-County due to cultural expectation. Conformity with such practices and expectations in a cultural setting is found to lend social legitimacy and relevance to certain social groups. A key informant in the study summed up the dominance of females in the care provision as follows:

> "The general feeling in the community is that caregiving is almost natural and identical with females while men shy away from such activities to avoid ridicule" **(Sub-County Development officer)**.

The findings on females' dominance on caregiving concur with those of UNAIDS (2008) which established that: In South Africa, 91% of caregivers are female and women carry out eight times more care work (for all illnesses) than men; 68% of volunteers working in three districts in Uganda are female; and two thirds of people living with HIV and AIDS in Thailand are nursed at home by a parent, usually their mother. In observing care patterns, Budlender (2010) concludes that care has long been considered to be the 'natural' responsibility of women who continue to provide most of the unpaid care in households and communities. In an earlier study, Budlender (2001) posits that in most countries, society expects wives, daughters, mothers, sisters and grandmothers, rather than men and boys, to care for sick family members. It can be argued that when such practices are reproduced over time, feminization of caregiving becomes almost naturally approved practice even in the context of HIV and AIDS despite its own burdens.

The disproportionate share of caregiving roles observed in Uriri speak to social rigidity in the division of labour within the households in which men and women are expected to work in culturally defined roles dominated by their gender. Therefore, the findings speak to Cultural Production theory in which dominant ideologies, relations, and interests around gender division of labour are reproduced through cultural and social institutions, in this case, the household where caregiving decisions and division of labour take place. In a previous study of schools as social institutions, Levinson and Holland (1996) stated that such institutions reproduce hegemonic ideologies, forms of knowledge, skills, and attitudes needed to reproduce the relations of an existing social order.

In its concluding recommendations on re-thinking HIV and AIDS care, the UN (2004) notes that, throughout the world, caring for the young, the elderly, and the sick has traditionally been women's work, a reality resulting from assumptions made about the roles and responsibilities of women and girls. This gendered division of labour is amplified in the context of HIV and AIDS. The report further states that in Africa alone, women account for two-thirds of all caregivers for people living with HIV (UN, 2004). In the context of this study therefore, the observed household labour organisation act to perpetuate segregation of men and women into chores, of which, women take the less valued duties such as caregiving.

4.1.2 Relationship between the patient and caregiver

Understanding the relationship between the caregiver and the patient remains significant in tracing the care-burden transfer by gender and generation from the hospital setting to the household arena. More importantly, it helps to explain whether the caregiver is exercising obligatory roles in the society or social voluntarism to the patient on the basis of social relations/ties between the parties. Given the secrecy and confidentiality with which HIV and AIDS is still treated, the patient's perceived trust is always invested in the caregiver, hence, the need to understand the relationship between the parties. In addition, understanding the relationships cross-generationally was deemed important in illuminating the socio-economic burden faced by the young and the aged caregivers who naturally fall out of the brackets of social safety nets and income respectively.

The findings indicate that spouses (husband and wife) accounted for a large number of caregivers at 46%, parents accounted for 32% of the total (fathers at 14.3% and mothers at 85.7%) , siblings (sister, brother, and cousins) comprised 14% while others (young girls and grandparents) comprised 8% of the caregivers as summarized in figure 4.2 below.

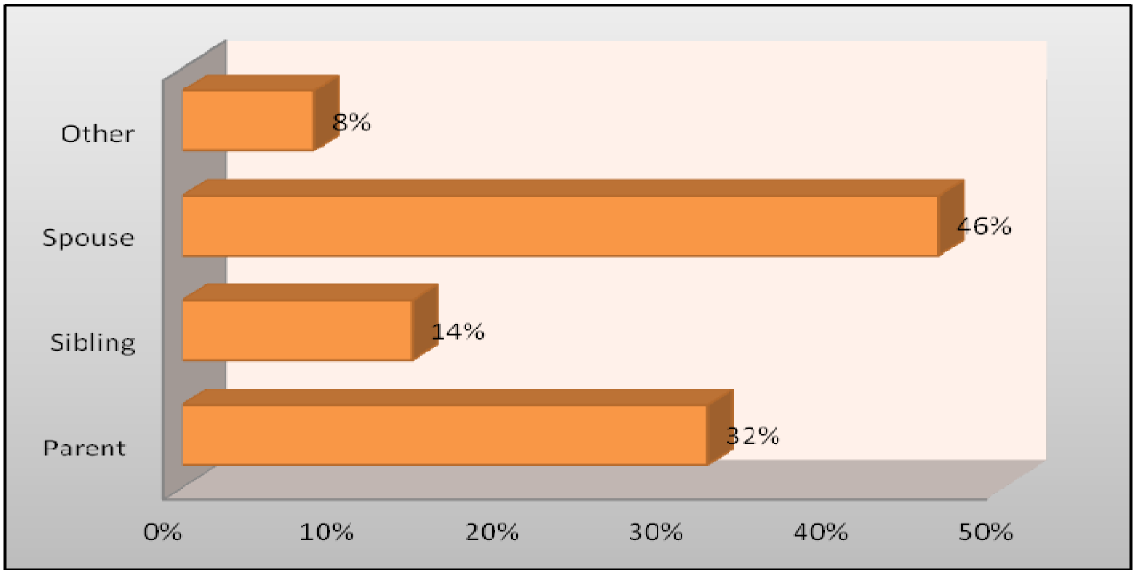


Figure 4.2: Relationship between caregiver and the patients

Inferentially therefore, spouses were found to be preferred for caregiving followed closely by parents, while statistically dismal in the study at 8%, the group comprising young girls and grandparents perform significant roles in caregiving and their consideration in the study have potential implication for any programmatic or policy intervention design. The gender and generational divide in the study compare closely to the study of Steinberg et al., (2002) in which it was estimated that two thirds of primary caregivers in households in South Africa are female, one quarter of whom are over 60 years of age and 7% of whom are under 18 years. Across all the categories of caregivers in Uriri Sub-County, females were found to be a dominant group resonating with the UN (2004) assertion that caring for the young, the elderly, and the sick has traditionally been women’s work, a reality resulting from assumptions made about the roles and responsibilities of women and girls.

According to Knodel & Vanlandingham (2001) study in Thailand, more than three-fourths received some care from a parent and for almost 60 %; a parent was a main caregiver. The vast majority of AIDS parents were at least aged 50 and more than half were 60 or over. In addition, a series of surveys in Uganda found similar levels of parental involvement as primary care givers (Ntozi and Nakayiwa, 1999). Likewise, studies in Zimbabwe also stress the important role of parents in caring for AIDS-afflicted adult children (Williams and Tumwekwase, 2001; WHO, 2001).

Several hypotheses have been offered to explain the possible source of support in caregiving, including substitution, supplementation, and task specificity. The substitution hypothesis argues that when closest relatives, presumably spouses and adult children, are not available in one's network, more distant relatives, friends, and formal helpers are substitutes in providing needed care (Shanas, 1979). As Shanas (1979: 4) explained, "Where old people have no children, a principle of family substitution seems to operate and brother, sisters, nephews and nieces often fulfill the roles and assume the obligations of children." The choice of caregivers is determined by an ordered preference regarding the primacy of relationship between the elder and the caregiver. In the context of HIV and AIDS care in Uriri district, substitution theory was manifest in circumstances where the patient had lost a spouse and has no grown up children to perform the care tasks.

Supplementation, argues that informal support influences one's use of formal care (Noelker & Bass, 1989). Primary caregivers, typically drawn from the informal support network, function as linkages between the elderly recipient and the formal care system. Informal caregivers may serve as mediators, referrals, or gatekeepers to formal care (Ward *et al.*, 1984). Formal support is viewed as a supplement rather than as a substitute to the extensive efforts of primary caregivers. On the other hand, task specificity posits that family, friends, and formal helpers are suited to different functions in support provision. They manage complementary components of a shared goal (Litwak, 1985). The task-specificity hypothesis outlines characteristics of primary groups, including proximity, length of commitment, commonality of lifestyle, and size that differentiate the marital dyad, other relatives, friends, and neighbors.

Relationship between the caregiver and patient is a significant determinant on the level of perceived burden. Studies by (Van Den Wijngaart *et al*., 2007) indicate that if the caregiver perceived the caregiving role as a responsibility as a threat, this will contribute toward a higher level of caregiving burden. Caregivers reporting a lower level of filial piety also reported a higher level of caregiving burden (Lai, 2007). Caregivers who have a more positive coping style, a higher level of perceived self-efficacy, social support, and instrumental support are more likely to have a reduced level of caregiving burden (Van Den Wijngaart *et al*., 2007).

4.1.3 Marital status of the caregiver

In the study, it was established that those patients who were married (57%) were largely cared for by their husbands or wives with children often performing back-up roles, those divorced/separated (20%) had their children or siblings as caregivers and so were the widowed a(13%), those who reported being single at 10% had their parents or grandparents providing care for them as summarized in figure 4.3 below. The caregivers in the study observed caregiving is a moral obligation expected of blood relatives, hence, children and spouses are by socially expected to provide care to the sick members of the family including HIV and AIDS patients as in the interviews below:

> "You cannot run away from your partner, caregiving is a proof of compassion and the community might judge you as being immoral if you walk away from a sickling husband" (**56 year old Female caregiver to a spouse**)
>
> " I am the only child in the house, my dad is long dead, my aunts and uncles say that I am obligated naturally to be mother's keeper, they can only assist from a distance" **(18 year old female caregiver to the mother).**

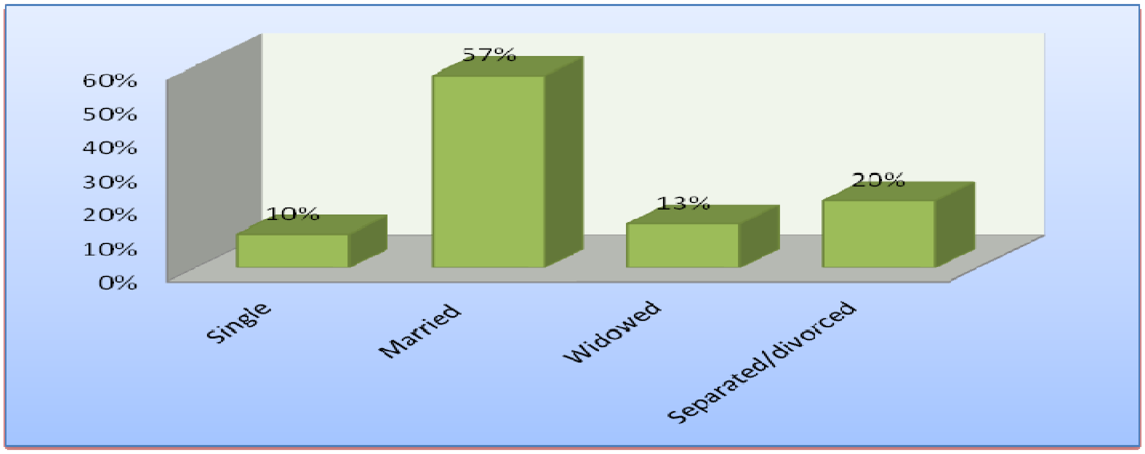


Figure 4.3: Marital status of the HIV and AIDS patients

While commenting on care taking place within the family, Knodel (2001) contends that married women are affected significantly because they are more likely to take care of their husbands and children. In the study amongst caregivers in Uriri Sub-County, it was established that spouses comprise 46% of caregivers a majority of whom are females at 77%, thus, it can only be deduced that the tendency to have caregiving fall on women and girls continues unabated. Furthermore, Action Aid and VSO (2008) contend that the increased burden on women as caregivers is a result of men being less likely to open up about their HIV status and seeking external support hence relying on the commitment and discretion of their wives to care for them within the home front.

4.1.4 Income levels of the caregivers

In the study, income level of the caregiver was of interest given its multifaceted relationship with challenges faced by caregivers. The findings indicate that caregivers who reported low income at between Kshs. 0 and 2,999 a month constituted 57% with more females (largely the children, grandmothers and the widowed) than males in the study comprising this group. A modest 26% of caregivers earned between Kshs. 3,000 and 5,999 a month. Informants who earned between 6,000 and 9,999 comprised 12% while those earning above Kshs. 10,000 comprised 5% as summarised in figure 4.4 blow.

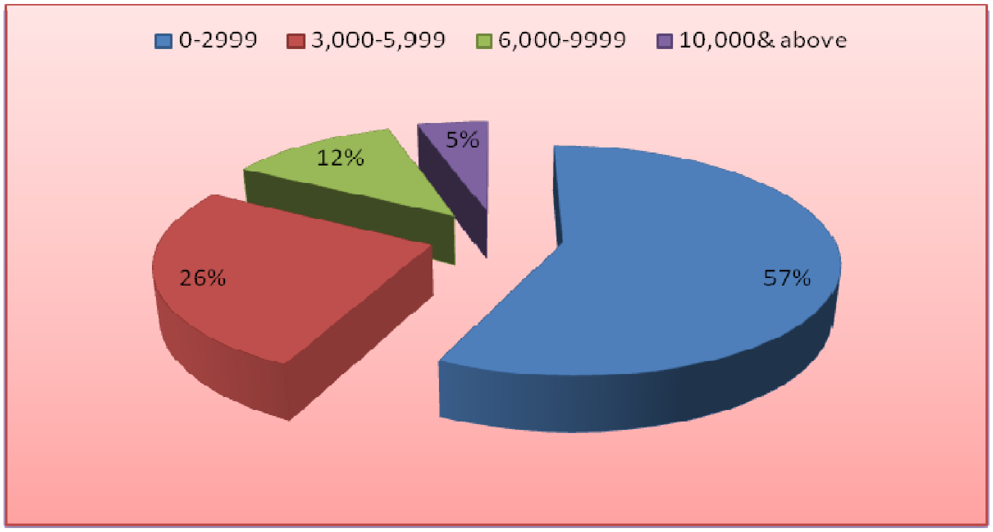


Figure 4.4: Income level of the caregivers

The caregivers found within the low income group depended on occasional sale of surplus production from subsistence crops in the family. Informants within this bracket reported financial strain (especially inability to afford transport in cases of opportunistic illnesses demanding treatment outside the home) as a major challenge in caregiving to the HIV and AIDS patients. A large number of them are literally out of employment and have completely no source of income. They are not part of the government driven cash transfer that has been used as safety net to cushion the most vulnerable members of society. As one of the caregivers observed, situations posed by opportunistic diseases may at times be financially straining as in the interview below:

> " Multiple opportunistic diseases means that you have to purchase more over-the-counter prescriptions for the patient and this can be draining cash-wise, you have to borrow money to meet these needs especially for those of us without meaningful income" (**56 year old female caregiver**)."

Compared to their counterparts in the low income bracket (Kshs. 0-2,999), caregivers in the bracket (Kshs. 3000-5,999) reported less financial strain in caregiving but more of care-crisis given the demands of paid labour outside the domestic sphere and/or household arena. Furthermore, those in the subsequent high income brackets in the study reported the challenges of double-work thus exhaustion and the psychological strain in caregiving.

Assessment of income levels in the context of caregiving in previous studies reveal that low personal and household incomes and limited financial resources can result in increased caregiver risk for negative outcomes, particularly if there are substantial out-of-pocket costs for care recipient needs (Stephens *et al.*, 2001). Caregivers who are unemployed or have low incomes may experience more distress because they may have fewer resources to meet care demands. Overall, studies by Clipp and George (1992) and Given et al., (2004) show that financial concerns cause particular distress for caregivers during long treatment periods as resources become depleted. Higher-income families, with greater financial resources to purchase needed care, might not become as distressed or burdened as those with limited resources (Davis-Ali *et al.*, 1993).

It is important to point out that caregiving itself might undercut caregivers' source of income when it largely feeds into paid working hours outside the household site where home-based care takes place unremunerated. In the study, those with low incomes reported the need to compliment income sources but were largely constrained by the large amount of time required to provide care needs before shifting to paid duties. Indeed, Pavalko and Woodbury (2004) while examining social roles in caregiving as a process posit that regardless of amount of care provided, caregivers may become increasingly more distressed if they are unable to participate in valued activities and interests. In another study, Cameron et al. (2002) state that caregivers who are employed report missed days, interruptions at work, leaves of absence, and reduced productivity because of their caregiving obligations. They have difficulty maintaining work roles while assisting family members. To this end, some studies note that the time required to competently care for a frail elderly relative often amounts to a full-time job (Schulz *et al*., 2003). Compared with coworkers who are not caregivers, family caregivers had to take more time off work, were interrupted at work more often regarding family matters, missed more days at work, took more time off without pay, and ultimately worked fewer hours than desired (Addington-Hall *et al.*, 1992).

4.1.5 Education level of caregivers

Education level of the caregiver as a variable was of interest in the study given its potential influence on caregiving information and demands across nutrition, medication and self-protection from opportunistic diseases that are largely abound during physical care. Education level is also a key determinant when packaging intervention information to help home-based caregivers. The findings indicate that those with primary education (complete) comprised 53%, primary (incomplete) was 17%. The caregivers with Secondary school (complete) comprised 6%, secondary (incomplete) comprised 12% similar to those with college level education. The findings are summarized in figure 4.5

below

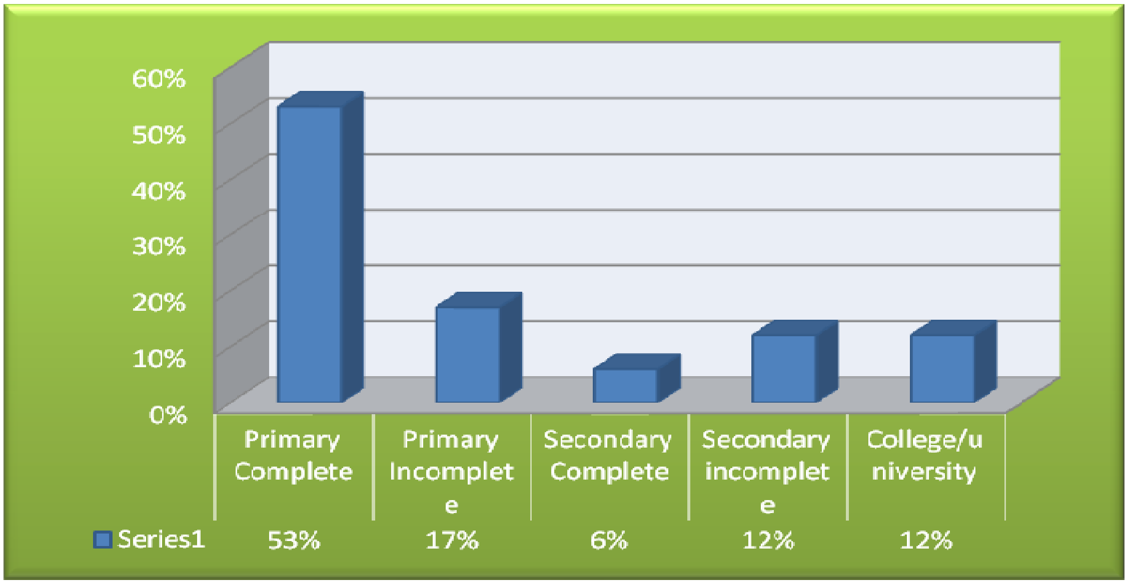


Figure 4.5: Education level of caregiver

Significantly, informants in the primary school bracket, completion status irrespective, reported poor understanding of the medication regimen, had strong attitude of care being a female chore in the community perhaps arising out of gender-role socialization in the community. Besides reporting poor nutritional knowledge for HIV and AIDS patients, informants with primary level of education viewed males' entry into caregiving as generally being financial provision to meet the daily living needs of the patient. This notion conforms to the tradition of the male as the family breadwinner whose responsibilities are largely situated outside the household chores arena such as caregiving as in the interviews below:

> "A woman in this community is often raised as a caregiver, whether to the children, an expectant relative or a sick person, so caregiving to my HIV positive daughter, however intensive and complicated, is a mirror of the feminine roles our community has socialized in me" (**61 year old female caregiver to an adult daughter**).

> "Caregiving is so sensitive to be left for men, it requires a sense of empathy and understanding, it is these qualities that make women and girls better caregivers in our community" (**32 year female caregiver to a sibling**).

On the other hand, informants with secondary school (complete) and college level of education reported relatively high knowledge of the medical, nutritional, and psychological demands of caregiving roles. Similarly, the groups were relatively less rigid about males and females cross-performing roles in caregiving with those with college level of education advocating for equal sharing of roles on the basis that men and women have become almost equal providers within the household in the current socio-economic settings as in the interviews below.

"I am a teacher and my job is demanding just like caregiving roles here in the house, I like the fact that my husband lends a hand in a number of physical tasks like lifting the patient when he is overwhelmed, taking him to the clinic and also helping in advising the patient on medical adherence, at times, he prepares meals and I see nothing unique in that because we are all working for a better welfare of the patient, traditions can frown but this is what works best for caregivers with remunerated occupation outside the home" (**46 year old female caregiver to a sister in-law**).

"Fetching water and cooking when my wife is in pain does not make me less of a man, I understand the circumstances better than the community members who ridicule my new feminine status..." (**42 year male old CBO worker and caregiver to the wife**).

In a previous meta-analysis study, Houts et al., (1996) noted that the model creativity, optimism, planning, and expert information (COPE) that train caregivers on how to design and carry out plans that focus on medical and psychosocial problems that are coordinated with care plans of health professionals was easily adaptable amongst those with post-primary education than those without any formal education or merely elementary levels. Moreover, there is a positive association between education and reduction in HIV risk. Better educated children are more likely to absorb prevention information and adopt safer behaviours (WFP, 2006). In the work of Glynn (2004), it is observed that completion of secondary school, especially among young women, may lower the risk of HIV infection. Yet, households that are food insecure are often forced to take children out of school in order to work to supplement the income lost as a result of their parents' illness and/or death as concluded by Greenblott (2006).

CHAPTER FIVE: GENDEREDNORMS IN HIV AND AIDS CAREGIVING

5.1 Introduction

This chapter presents and discusses prevalent gender norms around family division of labour in Uriri Sub-County in general and more specifically, the manifestation of these customary practices in the context of HIV and AIDS caregiving. This chapter seeks to tease out the social beliefs, practices and values around division of labour that determine the players in HIV and AIDS care within the home as a response to objective one of this study. Discussions are carried out along the following sub-thematic areas: gender division of labour around care, institutional reproduction of gendered labour, patriarchal dividend and unequal role sharing, premium on caregiving and finally, the atypical and circumstantial male caregiver in HIV and AIDS care.

5.2 Gender division of labour in caregiving

The findings indicate that a majority (77%) of females provide care relative to their male counterparts at 23% across all the study locations. Primarily, this practice is driven by socio-cultural definition of what duties, roles and responsibilities are ideal and culturally acceptable between males and females in the larger Luo community. Precisely, gendered division of labour is anchored on the cultural meanings of ‘males’ and ‘females’, which by extension, perpetuate some social rigidity on anticipated behaviours and roles in the society. Implicitly, the persistence of these societal norms tend to define the caregiving as a woman’s domain, thus, by their own form and construction, erect social barriers to men’s participation in caregiving as evidenced in the interviews below:

> "Tending to household chores such as caring for the children and the sick are largely women and girls' domains…these roles are feminine…the community might not socially approve of you (female) if you let men perform these roles…you may lack respect in the community if you shy away from these duties" (**63 year old mother caregiver to a son**).
>
> "We learnt about the division of labour from what our mothers used to do…these duties validates you as 'mother of the house' because a woman or a girl is born with the caring heart which is important in looking after the sick in the family" **(41 year old female caregiver to a spouse**).
>
> "Men are not supposed to compete with women in performing household tasks such as caregiving in our community, you will lose face, however, I am doing this because my wife is more often weak and I have no female relatives to come and perform these tasks..." (**37 year old male caregiver to a spouse).**
>
> "Women are considered natural nurses, persons trained to care for babies and more often look after the sick...the entry of HIV and AIDS has only heightened responsibilities in this arena that is still viewed as feminine duty" (**Head of advocacy at local NGO**).

From the voices of the informants above, it is apparent that the societal expectations and cross-generational norms have created bipolar spheres on the duties of males and females in Uriri Sub-County, with women, being dominant in the household chores. In interrogating household gender division of labour, Coltrane (2000) observed that women do the lion's share of unpaid labour within households which largely draws from cultural definition of their work space. Similarly, while examining labour patterns within the households, Bianchi et al. (2000) concluded that a decline in market labour inequalities is yet to be reflected in the highly gendered household division of labour. The findings also resonate with that of Berk (1985) reiterating that family still remains a site for reproducing rigid gender roles while at the same time devaluing the work of women. , Consequently, the strict division of labour in the context of caregiving to the sick in general and HIV and AIDS patients in particular fall on the shoulders of girls and women. It is also significant to note that caregiving does not in any way exempt the females in Uriri from performing other domestic and community duties. This is because caregiving is deemed ‘an obvious’ female chore naturally given and embedded to females through socialization by their mothers and grandmothers across generations. In a study by VSO (2006), it is posited that traditional gender norms and unequal gender relations create the mainstay upon which the burden of care is transferred to women and girls. These norms have created role boundaries between men and men, and by extension, one who excels in customarily defined roles is socially accepted as conforming to real femininity of masculinity. Indeed, caregivers in the study reported that society castigates females who cannot perform caregiving duties or even let their male counterparts be involved. Hence, it can be argued that the traditional gender norms provide social barriers to men and boys becoming caregivers.

A study by UNAIDS (2008) established that women account for two thirds of all caregivers for people living with HIV in Africa besides comprising 70 per cent of the world’s poor and two-thirds of the world’s illiterate. The report further posits that care provision in the households tends to adopt the traditional gender division of labour; and given that these duties fall under reproductive roles, women and girls are found to be the dominant caregivers. In the current study, a high number of caregivers are low income earners who double up as either grandmothers or young females pulled out of school to provide care to the sick. In essence, the traditional expectation of females as caregivers has roped in the vulnerable young females from school as well as the old persons who in themselves need care.

In the current study, discussions with the key informants revealed that the strict gender division of labour was not only a part of fulfillment of traditional prescriptions of roles between males and females but also a product of the societal stereotypes. The key informants observed that over time, men have been associated with energy-intensive productive work situated outside the domestic arena, in the context of monetarised economy, the value of men's input has become a measure of the amount of money they can bring into the household to cater for family needs. Thus, caregiving which remains unpaid is still stereotyped as womanly and domestic to warrant males' engagement despite its demanding nature.

> "We must agree that HIV and AIDS care demands shared responsibility between men and women so that the consequent burden of one gender is lessened. However, Uriri is largely rural and men who are found to perform feminine duties are always frowned upon and ridiculed as weak…there is more value in the man who gives money to the family than the one who helps in fetching water and other household chores…" (**NASCOP Programme Officer**).

> "Generally, caregiving demands some tenderness and relationship building between the caregiver and the patient…these core skills and traits are largely associated with females in the society….men in Uriri would not want to be 'de-masculinised' by engaging in primarily what the society has over the years

> reserved for women…the effect has been increased amount of work for females any time a family member is diagnosed with HIV...” **(Head of a local NGO).**

The observations of the key informants by inference confirm the thesis that societal values and norms while important in determining socially acceptable roles between females and males, also doubles up as faculties upon which unequal division of labour are transmitted. These views construct firm dividing lines between responsibilities and work that are seen as women’s domain and those depicted as appropriate to men. Generally viewed, women’s disproportionate responsibility for unpaid care work, and the persistent gender stereotypes underpin this unequal gender distribution of responsibilities.

Indeed, Daly (2008) while writing on general caregiving practices, contends that stereotypes sanctioned by social values largely influence the gender division of labour; a normative assertion which this study has confirmed. Similarly, the studies by (Daly, 2008; ILO/UNAIDS/UNRISD, 2008) assert that gender stereotypes endorse expectations that men are natural leaders and ideal breadwinners and imply that women will naturally gravitate towards responsibilities around personal relations and caring activities. Given the rural nature of Uriri Sub-County where customary practices and ideologies are still highly regarded, the social division of labour and the demarcation of male and female spheres naturally compound women and young girls’ care burden.

From the study, the discriminatory practices around household division of labour based on gender stereotypes promote and perpetuate the idea that women's place is in the home. This leads to women being assigned inferior status and rights which in essence cause and perpetuate this unequal distribution of work, rendering women's equal enjoyment of rights impossible. In deed,Huber (1991), she posits that gender division of labour is a central feature of gender inequality, both in its economic aspects and in the social construction of gender identities. Similarly, Chafetz (1991) observed that undergirding all systems of gender stratification is a gender-based division of labour, by which women are chiefly responsible for different tasks than are men. This occupational segregation continues to be apparent even in the context of HIV and AIDS care as observed in Uriri Sub-County.

5.3 Institutional reproduction of gendered roles

The study interrogated caregiving in the household especially in the context of HIV and AIDS as a new focal point for reproducing gendered and unequal division of labour in the society. Of interest was the need to understand how institutional (household caregiving) labour divisions morph into occupational segregation between genders. This was on the background that traditional roles and stereotypes are more likely to come into play as part of the HIV and AIDS epidemic response. Viewed from this lens, the unequal sharing of responsibilities are more likely to result from and be sustained by existing gender status beliefs and stereotypes compounded by difficulties associated with changing norms around family labour organisation.

Interviews with caregivers indicated that the entry of HIV and AIDS into the household does not alter any social structures around the definition of values, norms and expectations in the performance of males and females roles and duties in the society. While HIV and AIDS caregiving is perceived as labour intensive thus demand sharing of duties across genders, caregivers pointed out that, existing norms and values have literally reduced the males and females to passive bearers of structural relationships around areas of gender division of labour as exemplified in the quotes below:

> “Despite the burden in disease care-giving, there is nothing you can do to change the way men and women work around the family because these are women’s and girls’ duties in the household....men are supposed to lead the larger community and work outside the home” (**50 year old female caregiver to a sibling**).

> “I concur that we should share household chores at the moment given that men and women participate in productive labour, is not our custom as Luos to cook, fetch water, take care of the sick even when it is in the same household...I can only give money and help with mobility but get another lady to perform all other feminine tasks that come with caregiving"(**46 year old male caregiver to a wife**).

> “We have seen more female counsellors and nurses in our health centres in Uriri district, like we in this community believe, it is only a woman who has the patience to listen and understand the long-demand of caregiving especially medication that needs one to stay close to the patient. More often than not, it is the woman who stays at home and is therefore, the one who is naturally fitting this job...but since I have no grown girls to do these chores, I feel helpless and my wife needs care which I will do hoping that their people(wife's) will send a sister to take over from me ” (**40 year old male caregiver to a spouse**).

Two profound aspects of occupational segregation in caregiving emerge from the above findings: first; gender essentialism, in which case men and women are portrayed as having unchanging essence with women being natural nurturers to take care of the sick while men are more mechanical and situated outside the household, second; male primacy in which less valued responsibilities as caregiving and cooking do not befit the dominant status of males. In a previous study on gender, status and leadership, Ridgeway (2001) concluded that gender essentialism and male primacy are aspects of stereotyping that operate in gendered social systems which define men and women as different in socially significant ways. Social inequality is organized around these gender differences, in hierarchies where superior and inferior status is attached to men and women through stereotyping. These stereotypes and status beliefs act as barriers to women achieving positions of power and to men assuming positions of lesser social significance. To this extent, Charles and Grusky (2004) posit that by tying supposed innate traits to tasks, gender essentialism creates "occupational ghettos" which impede the crossover of men into female-identified jobs and vice versa.

While concurring with the notions of caregivers, key informants alluded to the fact that when societal existential structures become the basis of gender division of labour, the intensity and the burden of HIV and AIDS caregiving naturally become subset to cultural norms in defining the duty spheres of men and women in the society. This is because, caregiving irrespective of who performs it is still part of the undervalued reproductive work usually relegated to women in the community as evidenced in the interviews below:

> "Every time I try to explain to the members of a household looking after the sick (HIV/AIDS patient) to rotate in providing the duties across gender, there is an immediate reference to what is expected of men and women to do within a household...that men literally cannot be trained and succeed in women's community-given duties such as caring for the sick...people give references to neighbourhoods where women and young girls have cared for their sick relatives without changing the roles of men and boys just because there is a 'felt burden' on the female gender."**(Community Health Worker).**

> "I am not sure that the belief in gender equality or even the burden of HIV and AIDS caregiving can be enough reason to convince men and boys to share in providing perceived feminine roles in the household...this is a rural community and a large number of people would want to respect the provisions of customary practices that largely define duty boundaries between males and females" **(Sub-County Development Officer).**

The findings around gender division of labour speak to the tenets of both gender relations theory and the cultural production and reproduction Theory used in the study. For the former, the observed division of labour is a product of societal norms and values, hence, the notions surrounding gender roles in the context of caregiving are found to have strong ideological contents based on values and norms persistent in the society. To this extent, Pearson (1992) posits that, based on such ideologies, the society have an ultimate authority on the precise nature on what women and men actually do, and their real contribution to production and reproduction which turns out to be biased against women.

The cultural production theory contextualises the very transfer of parental cultural capital in the form of mothers and grandmothers socialising their daughters into caregivers and home nurturers hence, the household and the demand for HIV and AIDS care becoming new foci for reproducing the gendered labour. This practice concurs with Bourdieu's (1984) assertion that inequalities including those around division of labour are recycled through social institution part of which is the household where HIV and AIDS caregiving takes place.

The study established that more preference is given to customary norms than contemporary thinking on gender equality and its benefits while sharing roles in the household. To go back to norms only help to perpetuate unequal relations while also blurring the chances towards achieving a universal gender equity sharing and valuing of unpaid work especially within the household context. In a study on child caregiving by Peacock and Westen (2008) observed that in most countries, for example, mothers are expected to take maternity leave to look after their newborn babies, but paternity leave is nearly always much shorter if it exists at all. Further, they argue that even in places where child care grants are supposed to go to the carer irrespective of whether they are a man or a woman, many men report difficulties in accessing the grant. Put in the context of HIV and AIDS caregiving at the centre of this study, this practice entrenches an image of women, and not men, as carers.

The gender division of caregiving seems so deeply and historically ingrained in the social institutions such as the household in Uriri Sub-County. That care provision evolves out of the meanings and markers of manhood and womanhood as shaped by the community structures was evident in the study. In a study by IDRC (2013), in terms of caregiving in the global South, it is still women and girls who carry out the majority of unpaid domestic and care work (and this includes care of the children, the elderly and ill family members).

The findings of this study indicate that more females than males were involved in food gathering, preparation and serving to the patients than their male counterparts. Caregivers and experts agreed that the dominance of women in nutritional care conforms to the socio-cultural placement of women as family nurturers where food preparation forms part of the socially expected roles from the females as illustrated in the interviews below:

> "Food preparation is not for the males, he could buy and bring the food home...it is the duty of the woman or girls to ensure that the food is prepared though" **(43 year old female caregiver to a spouse**).

> "There is a general belief that the whole issue of food preparation for the family (sick or in normal circumstances) is the domain of women...given the demand of nutritional care to the patient, such stringent division of labour has only served to burden the women and girls the more" **(Sub-county Development Officer).**

The findings above show socialization and cultural expectations as key determinants of whom between males and females can undertake nutritional care roles. Female caregivers are seen to conform largely to social norms prevalent in the society to the extent of exempting their sons from getting involved in food preparation while at the same time questioning their social value i.e., relevance and legitimacy in circumstances where males take to the kitchen to perform roles already defined and categorised as women's domain in the community. In the light of the gender relations theory therefore, norms that are persistent in the society are being reflected in the gender division of labour (Rono, 1999). In this case, care-giving to HIV and AIDS patient does not seem to create exemptions to these prevalent values and norms in Uriri Sub-County. Similarly, the families of the caregivers are seen to perpetuate unequal share of duties in food preparation when male and female relations are indulged and dominant societal ideologies become major reference point in what O'Connor (2003) see as uncontested reproduction of labour relations.

It is important to point out that gender stereotypes that put the burden of care on women also negatively impact men. This results in challenged masculinity in which the men who cannot adequately provide the finances for their families face extreme social pressure to conform to the breadwinner theory. This pressure can reduce if the male contribution can also be valued on the basis of their ability to create time and provide care within the household. While observing intersection between feminine and masculine stereotypes in defining labour patterns and work valuations, Tamale (2002) observed that domesticity as an ideology is socially and culturally constructed and closely linked to patriarchy, subordinate/dominant hierarchical positioning in gender power relations, and an artificial private/public distinction that render the domestic roles of mother, wife, and homemaker as key constructions of women's identity in Africa. Essentially, targeting masculine and feminine stereotypes is a great step in changing the prevalent notions and traditions.

In the current study, patriarchal dividend was found to help in reinforcing the institutional bias in gender division of labour. Interviews with male caregivers and key informants revealed societal expectations around the valued roles of males…

> “As a man, I have always worked in the farm not cleaned the house, known that a responsible man is the one who provides shelter and other materials needs of the family, it is what makes a real man in the community, however, my wife's deteriorating condition forced me into undertaking house chores like cooking and laundry, activities associated with children and women in specific, I do not feel man enough every time I perform these tasks" (56 year old male caregiver to a wife)
>
> “Men can only do much in care-giving, we are community leaders not caregivers…when we perform caregiving duties, we are pushing ourselves as housekeepers which is less prestigious…I sacrifice a lot of ego to be seen always ferrying water on a bicycle and at times having to cook when she is down with malaria. I help because my wife can no longer perform such heavy tasks…and our only daughter is merely three years. Otherwise, these kinds of tasks are not a man’s domain…”**(49 year old male caregiver to a spouse).**
>
> "Males naturally have a prestigious placement in the society, beyond providing for the family, the undervalued household chores seen as feminine do not bother them…in HIV and AIDS care-giving, males expect their wives to care for them since men still remain heads of household but if the reverse (wife is sick) then most males would rather have any other female to perform the direct tasks" **(Head of a Health Centre in Uriri Sub-County).**

It is evident from the study findings that socialization, early life experiences and persistent structures that separate boys and men from the daily care of others serve to reinforce masculine view and burden women with care needs for the sick family members. While observing the penetration of patriarchal dividend in issues of gender and labour, Daly (2008) states that whereas not all men are in positions of power and privilege, even those with diminished capacity for fulfilling traditional male roles, due to unemployment or other obstacles, still benefit from the patriarchal dividend or the unequal sharing of power. Johnson (1997) suggests an incremental approach which posits that while patriarchal privilege permits men to avoid domestic and caregiving work, it is nevertheless possible for men and women to make small changes in how they as individuals participate in social systems to affect cultural systems in the longer term. Examples of this incremental strategy might be to involve men in non-personal care tasks (cooking, obtaining water, or gathering firewood) or in currently male-identified tasks (such as heavy lifting) as initial steps toward a more equal involvement of men and women in all caring tasks. These are further reinforced in the case narrative below.

Case Narrative 1: 37-year-old Male caregiver (3 years experience)

Juma is a local boda boda operator living in a two-roomed mud-walled house. He hasa sizeable herd of cattle and a motorcycle to his name basically summing up his asset. Juma has been married for the last five years with a three year old daughter. His wife was diagnosed with HIV in the year 2011 and has since then been in and out of the hospital with Juma as the caregiver. Juma himself took a test at the time the wife was diagnosed to be *seropositive* but turned out to be negative, the immediate pressure from the family and friends on him was to send the woman (infected woman) back to her people, a proposition that he declined. In the circumstances, the siblings refused to lend a hand in care-giving and saw him as courting death through unfaithful wife.

Given that the diagnosis was done when the CD4 T cells were already low, Juma's wife was introduced to ARVs to help prevent viral multiplication and advised on foodstuff to eat. Her condition meant that she could not at the time of starting the ARV therapy be able to perform a number of household chores. To complicate matters, the wife suffered bouts of malaria that weakened her but soon recuperated after medication.

Juma assumed the role of both the mother and the father to their three year old daughter. He would groom and bath the child late evenings after his work, prepare meals early in the morning to avoid being seen by the peers, which would in turn attract ridicule. Given that he has good water storage capacity, Juma would fill all the containers over the weekend to avoid daily fetching of water from the river as this would even lead to more public ridicule.

Juma reported that having to counsel his wife about her being positive was a tough undertaking and unmanly since it was replete with heavy emotions. When the emotions became unbearable, he eventually had to call in the wife's sister to help with that 'soft' part and also nurse the sister for two weeks until the wife fully got mobile. He has continued to take her to the hospital for regular tests on opportunistic infections as well as cook for the family when the wife feels exhausted.

While Juma does not complain about demanding nature of care-giving, he contends that it does not pay to stay at home like a woman and perform all those chores. He prefers being out there in the 'field' i.e., outside the home to make money and provide for the family. He is however, lucky that the wife finally got enrolled with RAPADO- a local

NGO where she can receive counselling on issues of positive living and share her predicament with other people who are living positively.

In this case, there is a typical image of coerced caregiver who has to perform the socially feminine duties after the natural flow of caregivers from the family side refused to offer their help based on their lay perceptions of the source of infection. These perceptions emanate from the patriarchal attitude that is reinforced by patrilocal post marital residence where Juma's wife is a stranger to the other extended family members. Since their knowledge of HIV discordance is low, they cannot come to terms with the simple fact that Juma is negative and his wife positive. They see the wife as having been of low morals and therefore, responsible for the disease that will ultimately also kill their brother or son.

While Juma is seen as being responsible as to undertake care duties, it is in the interest of retaining their young daughter and maintaining a 'glorified image' of married man in the community that drives his cause. This is far from the belief that there should be gender equality in sharing the roles in the household or a non-belief in stringent dichotomy in the roles of females and males in Uriri community. Juma himself noted thus:

> "It is for the love of my daughter and the need to be a family man that I have had to go out of my way irrespective of the rebuke in the community to take care of my wife. I am hopeful that she will get well again".

While Juma is more than willing to perform the financial roles, bathe the baby and even prepare the family meals when the wife is immobilised by opportunistic infections, the timings for the latter two activities is suspect and tend to be informed by stereotypical thinking that these are largely women's activities with potential to water down one's 'manliness' in the society. Similarly, his insistence that a female relative needs to counsel and attend to the emotional needs of the wife concurs with the argument that males in Uriri are not socialised as 'comforters' a soft task relegated to the females. This masked identity is in conformity with the societal expectations where a man's work is only valued when it is paid labour or outside the hearth-hold where women have their foothold. To be able to fit in the two worlds he finds himself, Juma has had to hide his "female side" by performing the feminised chores in the cover of darkness and behind the silent walls away from the public glare.

5.4 Premium on caregiving and gender participation

The value placed on caregiving roles was such an important construct to investigate in the study for among other reasons: its influence on the performance of the care tasks as part of social responsibility (cultural expectations) or obligatory performance, recognition and undervaluation of tasks, the issues of women's opportunity costs and male attitudes towards caregiving.

Findings point to the fact that a majority of females performed caregiving tasks alongside their domestic as well as those situated outside the household. This implies that the simple fact that females had their other priorities and demands does not constitute a justification to ignore caregiving roles, or justify some degree of assistance from the male gender. Female caregivers reported tending to the subsistence crops, creating time for social merry-go-round meetings, and retailing at the local market to supplement the family income besides undertaking the daily care demands as exemplified in the interviews below.

> ”Caregiving to the sick is an additional role to our routine duties, you have to go to the garden, market, and merry-go-round groups...besides, you have to ensure that the sick is taking proper medication, attend to their feelings/condition with a clear understanding that these are things that women have to do in the community” **(33-year -old female caregiver to a sibling**).
>
> ”At times I feel sick (strong headache) but I have to ensure that my husband feeds well and takes medicine in time because he has been sick for a long time...I do all this alone because I am a woman and I have to know what roles are expected of me” (**37-year-old female caregiver to a spouse**).
>
> “Though important in caregiving, most counselors happen to be females and the community health sensitization workshops are always led by women, thus, there is a general feeling that counsellingis a woman’s domain and only women should do that kind of job…it is feminine in the face of community…this has tended to leave out male caregivers and threatens their very entry into ‘informed’ caregiving” (**Head of advocacy at a local NGO**).

The cases above point to women’s undertaking of care duties more as part of their social responsibilities in the society and by extension cultural expectation of dutiful womanhood. It is clear that the obligations are met by the women in addition to their daily chores while at the same time ignoring the time and activity demands of women’s own engagement. In a study conducted by Global Coalition on Women and AIDS (2004), it was established that a large part of the caregiving is performed by women and young girls since this is construed as part of their social responsibility in the society. However, the work women do in the home is widely seen as unskilled and less valuable to society, meaning that men not only receive higher earnings, but also more status and recognition for their contribution. This situation renders many women socially and financially dependent on men, thereby restricting their agency and autonomy as observed by Razavi (2007).

Women caregivers who also work outside of the home face a double burden and are less likely to receive necessary rest, essentially working double shifts when their unpaid care work is taken into consideration. Time out of the formal work sector for caregiving also has long-term financial consequences, as the cumulative impact of care work affects total earning potential and contributions to retirement savings or pensions (Family Caregivers Alliance, 2015). As a result, this work is frequently severely underpaid and ineligible for accruing social security benefits (Meghan, 2013).

From the foregoing, the entry of HIV in the household means that women and girls pay a high opportunity cost when undertaking the unpaid care work for the HIV and AIDS-related illness as their ability to participate in income generation, education, and skill-building diminishes sharply. In essence, HIV and AIDS care in Uriri Sub-County has added to the triple work load that women have always performed in the society posing a great threat to young girls and women’s opportunities as elaborated by the key informants.

> “Women do perform caregiving work voluntarily; nobody rewards a woman who has to ensure that the house is clean, the medication regimen is followed, proper food is prepared for the sick person and other chores in the household are met...these duties are least recognised by men as important but they pose a big threat to young girls’ future and the ability of women to engage in income generating activities outside the home effectively” **(Sub-County Development Officer).**

> “Females are dominant in caregiving activities because of the diminished societal privileges on such activities, they are house-bound, and least valued despite the apparent significance and demand for the same to ensure a better welfare of the patient...the feministic tag around the tasks also tend to keep males away*”* **(Local NGO official).**

From the above voices, it is evident that gender-bias is found in the under-recognition and low value assigned to the care economy which is part of the unremunerated work performed by women. Hence, the care economy including AIDS related care work in the home is largely taken for granted in both governmental and non-governmental efforts to mitigate the impact of the disease. This is because, the programmatic and policy frameworks largely remain blind to the fact that women themselves might need care, are overstretched in undertaking care besides existing responsibilities and largely survive under situations of poverty in such places as Uriri Sub-County.

In this study, the perceptions of male caregivers on their involvement were of prime essence in contextualising the attitude and social value of their undertakings in care-giving. Interviews revealed that males, especially those with incomplete and complete primary level of education largely perceived caregiving as an activity not worthy of their time. Similarly, they contended that since women have always been trained as nurturers, they are best suited to undertake activities that require sympathy, empathy and relationship building rather than technical skills, the latter which would fit the males in the society as illustrated in the interviews below.

> **“**Providing care is just unmanly, I perform to my wife out of despair, most of the times I have had to send money to the sisters to come and look after her, I can only do little beyond ensuring that food and any monies for medication are available, imagine a grown up man washing beddings and clothes, it is such a tedious task and I have grown up not used to performing chores around the kitchen...when you sit the whole day to concentrate on this (caregiving), who will pay you anyway?” **(47 year old male caregiver to a spouse).**

> **“**Caregiving is time-intensive...it naturally delinks one from engaging in the community affairs, as a man, I need to be knowledgeable of what is going on in the ‘outside world’(current affairs, i.e,. politics) but here I am always doing a woman’s culturally prescribed duty without any reward. Those who encourage us to do it always say that we are doing it for our households so we do not deserve any pay or recognition for work that women have always excelled in.” (**58 year old male caregiver to a spouse).**

Key informants observed that while men would contribute a great deal to lessening the fatigue experienced by their female counterparts in care-giving by directly participating in care work, two issues remain a stumbling block. These are stereotyping of care work as feminine by those with low education level thus largely informed by community norms; and, the demand of double-work for those with high levels of education and engaged in formal employment. In both cases, there is always the strive to perform the ‘manly duties’ in the society of providing to the family while keeping away from largely female chores abound in direct-care-giving as illustrated in the interviews below.

> “Most men would rather work outside the home where the work is compensated and take the money back to their families to spend on the care needs...this is seen as more responsible than sitting with patients whole day to offer any counselling or medication, the latter are necessary but not valued as manly enough” **(Head of advocacy at a local NGO).**

> “There are male caregivers who happen to work in full-time employment with either the government or non-governmental sectors...the best they can do is to provide some capitation to the family care needs so that the patient is well taken care of...it is still relevant because some go to the extremes of hiring labour albeit females” **(Community Health Worker).**

While the attitudes towards care presented in the interviews above conform to its almost natural relegation as a feminine duty, the findings concur with those conducted on parental attitudes towards childcare in Europe by the International Social Survey Programme (2004). In that study, it was established that women frequently reduce their working hours to part-time when they have children. Men, in contrast, often maintain their full-time employment, take only short periods of parental leave or temporary cash benefits and concentrate instead on temporary efforts to solve the problems that arise between work and family life. Contextualised to the study in Uriri Sub-County, there is a prevalent norm that caregiving is largely a female’s domain and women socialized in the arena should perform such duties.

When the undervalued nature of caregiving is viewed from empowerment and sustainable development lenses, ultimately, the unequal distribution of unpaid care work undermines poverty eradication efforts given its intense and difficult nature. It creates a time poverty which affects women’s political and social empowerment. In addition, as men continue to shy away from the undervalued work; caregiving continues to be feminised under the guise of women’s expected social responsibility.

5.5 The ‘atypical’ and ‘circumstantial’ male caregivers

The study established that some male caregivers largely performed direct care roles unlike their counterparts who could only facilitate the process financially while relying on female relatives or occasional hired labour (females) to perform any direct roles. Of interest to the study was the motivation for undertaking care duties more directly by this category of males.

These male respondents while being caregivers, perceived the activities as being against gender grains in terms of societal expectations. They reported resistance from family members (largely females) and the community who generally viewed their work as non-masculine and a mere invasion into women's domains. Similarly, the male caregivers who double-up as professionals in other fields such as teaching did not escape the characterization of their roles as atypical despite reportedly receiving some training on caregiving to the sick family members as in the interviews below:

> “I do wash clothes, cook and see to it that my wife gets proper medication as prescribed because I am the only person around her...I have no sister nor mother

> around to do these duties...while I know the value of assisting in the process, my male friends still think I should call my wife's sister to do the kind of tasks I perform” **(34 year old male caregiver to a spouse).**
>
> “I have received some basic training on HIV and AIDS care, I understand its demands and the need to ensure that my wife receives proper nutritional and medical care...sometimes, I have to prepare meals and offer some counselling as well....these are responsibilities that are considered feminine by a majority of males in this community” **(32 year old male caregiver to a spouse).**
>
> “There is a likelihood that men who perform direct caregiving tasks have benefitted from some training or moved into the village with a young family where girls have not come of age to help with the process...more often they would like a community health worker to visit and help with physical care...there is a strong notion that caregiving is feminising them and barely earning these male caregivers the culturally defined respect based on the masculine construct and role divisions" **(Community Health Worker).**

The discourses of men who care as captured in the quotes above point to the awareness that their social networks, friends and relatives alike, do not value care work irrespective of who provides such duties. Consequently, while this group of care providers are already breaking rigid gender role divisions, a lot of caregiving roles are undertaken behind closed doors for fear of ridicule and being labelled ‘feminine’ males.

It was observed that, even in situations where men provided care for spouses and family members out of love and compassion, the fact is that their work remains unsupported and unrecognized by the community members who still viewed the group as going against the cultural grain. In the context of gender relations theory (Pearson, 1992; Emerek, 1999), therefore, these men are seen within the prism of undervalued reproductive work which is usually reserved for women and girls in the society thus atypical caregivers. Similarly, the works of these men might be viewed as breaking from the tenets advocated by cultural reproduction theory in Levinson and Holland (1996) study where the family as an institution is expected to perpetuate dominant ideologies, skills and attitudes, in this case, cultural definition of caregiving as feminine.

The resistance from some female members of the community to males' involvement in direct caregiving can only be explained in terms of the 'felt legitimacy' that caregiving confers to women and girls in the society. The notion that females are deemed dutiful and responsible upon caregiving irrespective of their own needs has presented the family setting as an agent of reproducing unequal relations between males and females occasioned by imbalanced gender division of labour. The case narrative below demonstrates the perseverance of cultural stereotyping around gender division of labour that has found its way into HIV and AIDS caregiving in Uriri Sub-County.

Case Narrative 2: 46 year old male caregiver of seven years

Peter (pseudonym) used to be a casual labourer with the Kenya Ports Authority (KPA) till the year 2008. Peter's wife was diagnosed with HIV and AIDS two years before the family relocated to their rural home in Uriri where Peter has been providing care:

> "I was least prepared to begin doing all the kitchen work that my wife used to perform before her health condition deteriorated. Having to bath our two children,

assist with laundry when she was physically weak, give her emotional encouragement and prepare meals for the family proved something that women and men in Uriri community did not approve of at all.

On a number of occasions, I was advised to look for a young lady as a second wife to help take care of my ailing wife. The fact that I had no constant income could not allow me to go for hired female caregiver either. This was a new task (caregiving) that I had to perform despite the obvious clash with cultural expectations of a man's roles and responsibilities in the society. I did this knowing that my wife's recovery to the extent of resuming her normal chores depended on my efforts not only to take her to clinic but also show her that I cared.

At the beginning, I kept everything in secret I was afraid of sharing my experiences with my colleagues at the carpentry workshop where I worked after coming back from Mombasa. I felt that they viewed me as a failed and weak man taking to women's tasks. Nobody would want to be constantly ridiculed about things they cannot change, so for a long time, I kept to myself.

“I got some relief when one of the female neighbors brought in a community health worker to counsel my wife and I on best caregiving practices. This is the time I learnt about the need to continue giving moral support to my wife who has been responding so well to ARVs. In fact, she has regained her normal body

> weight and can always do a lot on her own. I am only happy that I no longer have to fetch firewood and water let alone prepare meals for the family.”
>
> “I have since been enrolled with Uriri World Changers, a youth group that works with people who are living positively with HIV and AIDS in the Sub-County as a male champion. While caregiving is still predominantly female-driven in our community, men like me continue to share their experiences during training and we hope that in the near future, men who provide care will be less stigmatized."

From the above narrative, culturally defined male-traits were found to be substantially negative in allowing men to enter into caregiving spheres. For instance, the community ridicule of male caregivers suppresses men's public display of HIV and AIDS caregiving while peer pressure from family and friends function to stigmatize men who cross into feminine social identity of caregiving. Moreover, caregiving is viewed to include undesirable and low status tasks associated with women's labour in the household. Certain tasks such as cooking, laundry, fetching firewood and water do not attract the premium that is associated with men's roles in the community, hence, will often be loathed upon when performed by men.

The consistent quest and impression by women's intervention in the caregiving process cast the cultural image of women as natural caregivers with traits of nurturance, altruism and sympathy. Men's perceived lack of these traits is enough reason to ridicule those who dare cross into women's domain. Indeed, the UN Women (2014) in its report on women empowerment in post 2015 development agenda states that disproportionate care work within the homes is a result of persistent and powerful gender stereotypes of what constitutes feminine and masculine roles. Rono (1999) posits that the notion of gender roles and activities have a strong ideological content based on the values and norms persistent in a society which are reflected in the gender division of labour. Based on such ideologies, society seems to have an ultimate authority on the precise nature of what women and men actually do, and their real contribution to production and reproduction which turns out to be biased against women (Pearson, 1992:12).

The narrative also provides positive evidence that informed men by way of counsellingor other training on caregiving, have high willingness to provide care. This is evident in the dual perception of the male caregiver about the traditional work of women and circumstances which demand flexibility and input from men. In the work of Newman et al., (2011), they posit that establishing new social consensus that challenge the ideology inherent in gender essentialism, and the gender hierarchies inherent in male primacy would help to reduce the inequalities that pervade the distribution of gender responsibilities.

In general, it is striking that women continue to provide a larger amount of care than men across all the locations and households visited. The phenomenon is driven by gender-norms (culturally accepted) ideas about what it means to be a man or a woman in the Luo community. Gender norms, thus, prescribe care work as a women’s domain, creating social barriers to men assuming caregiving roles. Women's disproportionate responsibility for unpaid care work, and the persistent and powerful gender stereotypes that underpin this unequal distribution, represent a significant obstacle to achieving gender equality and women's rights. Such rights include the right to decent work, the right to education, the right to health and the right to participate in public life. At the same time, the gender stereotypes that put the burden of care on women also negatively impact on men, who experience social pressure to be the breadwinner, providing for the family financially rather than by caring for them more directly.

While caregiving in the HIV and AIDS context remains such an empathetic activity characterised by responsibilities and emotional connection in day-to-day practices, the very statistically definitive disconnect of men and boys from care provision observed in Uriri district paint a picture where caregiving is still deemed as secondary and feminine in all its forms and demands. The male-detachment from caregiving sustains views of manhood as synonymous with being providers and protectors, and as superior to all things feminine in the society. Similarly, the very undervaluation of care compounded with the feministic tag, feeds into the notion that production of goods and income is inherently more important than the creation of solidarity, role-sharing and meaningful social connection with others. In other words, men and boys are viewed to be manly when they care less for their own bodies and those of others from an illness irrespective.

Whereas substantive findings and discussions on the nature of caregiving responsibilities and gendered norms point to close relationship between historically ingrained practices and entrenchment in societal institutions, achieving realistic and sustainable change towards equality in caregiving demand an informed shift in social norms in Uriri district. More profoundly, tackling the markers and meanings of masculinities shaping the policies, workplaces, institutional and community structures should be prioritised to reach the goal of gender equality in care-giving. However, until such is achieved, the gendered norms and expectations on roles continue to feminise HIV and AIDS care in Uriri Sub-County.

In sum, the unequal distribution of unpaid care work in the household is highly reflective and determinative of power relations between women and men. Discriminatory gender stereotypes which promote the idea that a woman’s place is the home and assign them inferior status and rights, cause and perpetuate this unequal distribution of work, rendering women's access to equality and enjoyment of rights impossible.

CHAPTER SIX: CAREGIVING ROLES IN THE CONTEXT OF HIV AND AIDS

6.1 Introduction

This chapter presents and discusses the findings on the roles played by caregivers to HIV and AIDS patients in Uriri Sub-County in response to objective two of the current study. Roles assessment was premised on the understanding that people living with HIV and AIDS need access to a broad continuum of care throughout the course of their illness. For example, early counseling, as soon as people receive a diagnosis of HIV, can help them cope with the diagnosis. The patients are also advised on behavioural changes that assist in reducing future health problems and limit transmission of the virus.

As HIV progresses, weakened immune systems make people susceptible to a host of opportunistic infections and illnesses. Medical care to treat these infections and to relieve other common symptoms can increase the quality of, and sometimes, prolong life for people with AIDS. As people with AIDS near the end of life, a combination of practical and emotional support can help them prepare for death and offer consolation to surviving family members. The findings and discussions under this objective are presented under the following areas: Physical care, medical care, emotional care, nutritional and financial care roles.

6.2 Physical care

The care roles at this level set in at an advanced stage of HIV and AIDS infection. Therefore, the intensity of care required under physical cluster varies, depending on whether the person is mobile or bed ridden. The findings indicate that if the HIV positive person is at home and is bed ridden, the caregivers may need to be available for a large part of the day. In cases where the caregiver needs to undertake other duties outside the home, the common phenomenon would be asking the girls in the household to help with the caregiving. The caregivers who had bed-ridden patients reported having to help the patients with bathing, toilet assistance, turning on the bed (to avoid bedsores), providing water and nutrition as in the interviews below:

> **“**Sometimes the drugs do not work (the patient fails to respond to medication) and he (the patient) can stay weak for say two weeks while on gradual recovery, especially when it is a bout of diarrhoea and constant vomiting, in that case, I have to help clean the patient (bath), change clothes, and turn him around to avoid the bed-sores..." **(30-year- old female caregiver to a spouse).**

> "When my wife feels too weak to carry water to the bathroom, I do it besides doing her laundry, it has become almost a routine every time she is down with an infection" (**41- year-old male caregiver to a spouse**).

While taking the immobile patient to the health centre would be thought of as relief, the respondents reported having to stay by the side of the patients as the health workers tend to opportunistic infections. This was explained on the basis of lack of enough human resources to do the demanding physical care for bed-ridden patients. The respondents also expressed their inability to take their patients to the private hospitals where such care would come but at exorbitant costs as in the interviews below.

> “The nurses can only bring medication and check on clinical response of the patient....they are few and cannot go to the lengths of taking your patient to the bathroom and feeding the patient....sometimes, they demand that you stay in the

> hospital and respond to physical mobility needs of the patient...it is tedious and competes with your duties at home..." (**39-year-old female caregiver to a sister**).

> "Nobody leaves their sick relatives in the hospital anymore, there is only one nurse who has to take care of all the patients including women who have given birth, you have to be present to tend to your patient" (**45-year-old female caregiver and mother of three**).

The key informants revealed that physical caregiving roles have more women than men because, the nature of the activities involved naturally gravitate towards the socially ascribed feminine duties of nurturing . Men are only roped into physical care, then it is only when the patient requires assistance to reach the health centre. This is because such role is considered less 'intimate' where the man only offers what is deemed 'socially manly' by coming to the rescue of an energy-drained patient. Similarly, indirect physical roles such as purchasing supplies required by the patient and transporting the same home remain largely acceptable among men as demonstrated by two key informants below.

> "The physical care is energy-draining, intensive and tiring but a lot of the work is basically reproductive and socially relegated to women, only in exceptional circumstances can you see men take the patients for medication or even offer to help with water for cleaning...trying as much as possible to remain within the culturally acceptable masculine roles" **(Community Health Worker**).

> "Men would naturally tell you that they are not the household nurses (caregivers). Whatever assistance is required by the patient can always be handled by women. They can only come in where their physicality as men get to count otherwise they resist a lot of what they call 'sympathetic' chores largely found in physical care" **(Head of local NGO).**

The findings resonate with those of UNAIDS (2006) in Zimbabwe in which caregivers reported providing physical care for PLWA by assisting with activities of daily living (ADLs), cooking and physical exercise. Further, the findings indicate physical care roles as the most energy-demanding chores within the prism of care-giving to HIV and AIDS patients in Uriri sub-County. However, there is a tendency to relegate these duties to the spheres of women due to the prevalent social conceptualisation of the aforementioned. Gupta and Mehta (2006) contend that while it is obvious that physical care can be intensive with bed-ridden patients, more often, women and girls are left to perform these duties within the household despite their conditions as caregivers.

In a related study examining the stickiness in men's practices (Barker, 2014; IDRC, 2013) conclude that it is still women and girls who carry out the majority of unpaid domestic care work and this includes areas of care of the children, the elderly and ill family members. The present study thus confirms that the physical roles in the care provision are dominated by women and girls and men rarely participate.

While commenting on the gendered nature of the physical caregiving in HIV and AIDS context, (Charmes, 2006; Kes and Swaminathan, 2006) note that women feed and bathe the ill and take responsibility for household maintenance and reproduction tasks that include cooking, cleaning up after meals, washing and ironing clothes and maintaining an overall sanitary environment. The authors conclude that the time devoted to these tasks in households where there are chronically ill individuals is even more significant as more water is needed for frequent bathing and cleaning and more hours are spent for physical support. In the same vein, Pradha and Sundar (2006) posit that in the context of HIV and AIDS, women’s unpaid care work becomes both more essential and more taxing.

6.3 Psychological (emotional) care

Diagnosis with HIV often triggers psychological discomforts characterised by anger, denial, depression, anxiety and shock. In addition, emotional stress for HIV and AIDS patients could stem from thoughts about who to confide in, how lifestyle will change and if it will be possible to have children. Some persons living with HIV and AIDS may also experience guilt, viewing their infection as a punishment for being immoral, or for the worry they may cause to other people, and for possibly infecting others.

For the aforementioned reasons, emotional care is always deemed an important aspect of caregiving to the HIV and AIDS patients in order to ensure that the patients feel a degree of social acceptance within the household and community at large. In the study, caregivers reported having to talk to the patients about the significance of being optimistic in life and the fact that the patients’ value remained intact despite diagnosis with HIV. Similarly, the caregivers reported referring patients to some social groups and counselling centres where patients would get additional help as in the interviews below:

> “Once someone has been diagnosed with HIV, it is important to counsel the person so that they can understand that being positive does not in any way make them worthless...this is what I did to my brother and I have continued to support him in seeking further counselling at St. Theresa's hospital...)” (**56 year old male caregiver, father of four & primary school teacher**).

> “I have often talked to my husband positively about HIV and AIDS and on the importance of positive living, he has since accepted the situation and agreed to take medication in good time... to be compassionate with a patient at early stages earns you trust and this is something I value as a caregiver...)” (**43 year old female caregiver and trained community health worker**).

Key informants contended that emotional caregiving is a significant process towards social acceptance and affects how the positive person consequently carries him/herself without the guilt or sense of denial. In a lot of cases, the confidentiality, stigma and misunderstanding of the disease (HIV and AIDS) at times make the patients reveal their status only to those they can confide in, in this case, the caregiver. Therefore, experts were of the opinion that caregivers who mostly happen to be women in the context of Uriri Sub-County needed a degree of sensitization on HIV and AIDS which most of them lacked at the point of diagnosis.

> "Counselling or emotional care can go along away to define whether a patient accepts his/her status or not…either way it is important in subsequent treatment seeking practices and the lifestyle, which could either be risky or less risky for the patient,…it is therefore, important that any caregiver understands the need to discuss with the patient their fears and expectations during caregiving to enhance positive living chances" (**Clinical officer at Sub-County hospital**).

> "Emotional care is part of the coping strategy that the patient needs against the prevalent stigma in the community...it is a source of hope for the patient that their condition is not a death penalty and they can live as long as they keep to the medical prescriptions and socially accept their status...we train caregivers on effective counselling so as to improve healing outcomes of their patients" (**Head of advocacy at a local NGO**).

The findings above resonate with those of WHO (2007); counselling can be helpful in order to come to terms with the diagnosis and resulting feelings, and as a precursor to dealing with the virus itself. The WHO (2007) report further indicates that discussing the patient’s immediate emotional concerns is recommended as part of post-test counseling. Such steps could enable the patient to effectively absorb information regarding the consequences of their diagnosis, and they might make considered decisions about their next steps including preventing risky behavior and beginning treatment. In the previous studies (Perriens, 2000) andUNAIDS(2000) posit that individual counseling, meeting with other people infected with HIV in support groups, and support from community and family members can help people accept their situation, talk about their diagnosis, and cope with anxiety and depression.

Viewed from the perspectives of caregivers in the study, emotional caregiving is established as primary mechanisms through which initial references to extant networks around the available Voluntary Counselling and Testing Centres, treatment and advanced medication on (ARV) get introduced to the patient. This kind of awareness and information must be offered with a positive perspective to prevent stigma and increase social acceptance hence the consideration by males as a feminine chore. Given the significance of counselling, Gupta and Mehta (2006) recommend that counsellors, for instance the VCTC, should provide follow up counselling and ensure that the family members who are HIV-negative know how to remain so. Put to the context of care provider-counselling initiative, as was in the case of Uriri caregivers, it would only be significant that their limited knowledge in emotional care be corroborated with that of a trained community health worker so that the correct information is relayed to the patient and more sensitisation is done to bring males on board as emotional care providers.

6.4 Medical Care

Treatment often does not start upon diagnosis with HIV. The decision to start treatment for HIV is individual and considers a person's past medical history, the length of time they have been infected with HIV, CD-4 T cell count, and current health status. The common treatment known to caregivers in the study is anti-retroviral therapy, which often, stop viral replication and delay the development of AIDS. However, experts in the study pointed out that advanced knowledge on side effects of the ARVs amongst caregivers is necessary since these can be severe if not immediately observed and reported to the physician. The side effects largely include:, inflammation of the pancreas, liver toxicity, rash, gastrointestinal problems, elevated cholesterol level, abnormal body-fat distribution, and painful nerve damage as in the interviews below:

> “It is important that caregivers not only understand the medicine regimens(correct dosage and drug administration frequency) but also get some know-how on the side-effects of the medication that HIV and AIDS patients are treated to…this will give them a hint on when to take the patient for opportunistic disease diagnosis and timely treatment” (**Nurse Uriri Sub-County Hospital**).

> “While providing care, it is important that caregiver understands that advising the HIV positive person to go for CD-4 diagnosis is important in the introduction of treatment as well as change of medication to the patient depending on the outcomes, this knowledge gap remains hollow to a number of caregivers in Uriri most of whom are women with the basic primary education” **(Head of advocacy at a local NGO**).

Caregivers reported dressing wounds and treating other simple infections such as flue or occasional headaches. However, it was established that the medical care given was on the basis of caregivers’ experiences with other diseases and more often, they lacked basic knowledge on post-exposure prophylaxis as in the interviews below:

> "I started giving medical care to my sister without any training on medical regimens and precautions that I need to observe...I was only lucky when the community health worker visited and showed me the right procedures, that is when I realised that I had all along risked being infected...it was a relief..."**(49 year old male caregiver to a sibling).**

Treatment fatigue and defaulting of treatment were other issues of medical care that emerged from the study. The experts observed that since the government facilities where ARVs are sourced have not fully recognised counselling as part of treatment, medication default has become a common occurrence as soon as one’s condition shows marked physical improvement, thus, the relapse into viral up-shoot in the body. Other informants observed that this kind of medical care information needs to be passed on to the caregivers so that they can understand the issues of treatment endurance, side effects and social issues that surround the treatment of HIV related ailments. Moreover, the experts observed that the social acceptance of alcohol as stress-reliever amongst the patients on ARVs by some caregivers have served more to degrade the healing process.

> “There is little time spent between the clinicians and their patients including advice to caregivers limiting the interactions to mere prescriptions and medical dispensing services...the caregivers are hardly taught on the safe practices whether on the right dosage or adherence” **(Head of a local NGO in Uriri Sub-County).**

> “Cases of defaulting on medication have largely been reported on the observed physical improvement and mobility of the patients...some also default on medication because of inadequate food in the house and since most of the medicines are very strong, they should not be taken on empty stomachs. Further, there is lack of information as some patients are reported to take alcohol to reduce their stress levels” **(Female Nurse at a health centre in Uriri Sub-County).**

The health experts thus observed that with the advancement in ARVs, the need for medical expertise has increased especially from those who could speak in plain language to patients about co-morbidities and non-infectious, age-related illnesses exacerbated by HIV and, in some cases, HIV medications. These co-morbidities include heart and kidney disease, high blood pressure, cognitive impairments, depression, and non-AIDS related cancers affecting the anus, prostate, and colon.

While the findings paint medical care as being significant to the patients’ healing from opportunistic infections and longevity of life with a well-observed medical regimen, what was of interest to the study was the very division of labour around the same. The findings concur with those documented in HIV and AIDS Treatment in Practice (2003) stating that caregiving extend to purchasing, administering and supporting adherence to ARV drugs and medication for HIV related pain if the infected person is receiving treatment, as well as helping with nutrition, as the person’s diet may differ from other members of the household. Further, monitoring and recording progress, making notes of events such as toilet visits, fluid intake and symptom occurrence are other tasks that can be undertaken by family and home based care workers and volunteer (HIV & AIDS Treatment in

Practice, 2003). Further, Mupedziswa (2002) states that home-based caregivers increasingly are being asked to help patients manage sizable pill burdens, frequent and complicated dosing schedules, and therapy-related side effects.

6.5 Financial Care

The need for medication upon HIV advancement into AIDS always brings with it direct-financial implications. Furthermore, indirect costs are met in the acquisition of home-based care kits (gloves, soaps, detergents, bandages, cotton wools), transportation to the health centres, and meeting a variety of nutritionally prescribed foodstuff. Moreover, financial implications in the context of HIV and AIDS care is occasioned by hired labour providers or professional nurses/community health workers who are often expected to visit the patients at home.

In this study, financial provision was found to be common and easily acceptable to the males with college level of education and earning above Kshs. 10, 000 a month. Even the males below these clusters perceived financial obligations as manly and the 'best chore' or duty sphere that males should perform in caregiving. This can only be explained by the fact that financial provision largely resonates with socially defined 'responsible manhood' of being a family provider thus falling within the productive work common with males in Uriri district as shown in the interviews below:

> " Disease care is demanding and HIV and AIDS intensifies this monetary need, I always ensure that there is enough money to purchase food, hire a caregiver (fare and labour charges), buy medicine for the patient and meet other necessities as might be prescribed at the clinic" **(46 year old male caregiver to a sibling).**

> “In reality, I often receive money from my brother to take care of our sister, I have never seen him come into her room to help her walk around or feel her temperatures...the whole issue of patient-caregiver interaction is totally strange to men...but blame it on socialization” **(21 year old female caregiver to a sibling).**

Financial costs of care-giving can also be exacerbated in situations where the primary income earner in the family falls ill and is laid off or can no longer afford to work for regular income. In this case as evidenced in the study where most male HIV and AIDS patients were originally family breadwinners, the need to participate in income generating activities is passed on to females in the household who also double up as caregivers. This is necessitated by the medicinal and nutritional demand of the patient besides the need to send children to school as illustrated in the interviews below.

> “After my husband fell ill and could not continue with his masonry job, I was forced to open up a grain store in the local market because I wanted to be able to give him the correct diet and ensure that our children continue going to school without disruption)” **(37 year old caregiver and mother of four).**

> “I have to leave for casual work at the CDF projects after ensuring that my husband has taken his medicine..I have to do this because the one who used to provide at times gets so tired to go to work and there are some medicine that the doctor always prescribes for us to buy” **(28 year old caregiver and mother of one).**

The findings in this study testify to the multiple dimensions of financial need in HIV and AIDS care. More importantly, the findings bring out the inter-play in financial provisions across genders depends on who is affected. The guise of double-work and financing as an excuse for males’ lack of engagement in direct caregiving is both blind to the plight of female caregivers in the household and propagate feminisation of caregiving, thus reinforcing the tenets of gender relations theory (Pearson, 1992) of what is socially valued as male and females' work in the society. The latter findings of women as 'forced-income-earners' to the household upon HIV and AIDS entry serve to reinforce Peacock and Westen (2008) proposition that when HIV and AIDS enters the home, financial responsibilities and burdens also increase, therefore, widows, who have never worked outside their homes throughout their lives, have to enter the work force for the first time and are in a disadvantaged position.

In a study by Help Age International (2007), it is contended that even with the free availability of anti-retroviral therapy, associated costs have often not declined; transport costs to health centers to obtain ART remain a key barrier, which impacts negatively on adherence, while food costs increase to ensure the efficacy of anti-retroviral therapy. Moreover, even patients on medication require balanced diet and at times supplements, all if which have financial implications to be met by the caregiver.

6.6 Nutritional care

Good nutrition plays a significant role in the management of HIV and AIDS at all stages. HIV impairs nutritional status by undermining the immune system, as well as nutrient intake, absorption and use. Malnutrition can exacerbate the effects of HIV and hasten AIDS-related illnesses in people living with HIV. Adults living with HIV have 10−30% higher energy requirements than a healthy adult without HIV, and children living with HIV 50−100% higher than normal requirements (WHO, 2003).

Households that are below the poverty line cannot afford good nutrition and yet often try to provide the very best food possible. For instance, many caregivers reported originally spending scarce funds on liver rather than use more available beans and green grams on the assumption that since they are expensive, they must be more nutritious and would appeal to the patient’s appetite. Thus, more information on health and nutrition is required, so that caregivers of HIV positive members know which options (such as eggs, fermented milk) are both cost-effective and nutritious as illustrated in the interviews below:

> “I used to look for food like fish and meat thinking that these are the only varieties that would help with building the body...they proved expensive and financially draining....after the community health worker visited and advised that lentils, groundnuts even peas could do..I felt relieved and started preparing these varieties that I do not have to buy” **(49 year old caregiver and mother of four).**

> **“** I realised that the patient would respond well to locally available fruits as bananas, avocados and guavas...these when supplemented with other body building fruits and energy foods such as potatoes are good enough....they are better than buying things like eggplant and watermelons that are hardly available and expensive” **(37 year old caregiver and mother of two).**

Interviews with experts revealed that in addition to knowing the correct food for the HIV and AIDS patients, caregivers needed to understand the significance of supplying enough water and minerals to their patients. Water is deemed necessary in body functions and prevention of dehydration while minerals are deemed significant in blood formation, teeth and bone strengthening. Similarly, the experts noted that caregivers need the right information on food preparation when their patients have difficulties in eating occasioned by diarrhoea, oral thrush or sore mouth as illustrated in the interviews below.

> "Caregivers are always encouraged to give patients enough minerals and water, these are essential components of nutrition which most people giving care are not aware of...in rural areas as Uriri where food supplements are hard to come by, we encourage them to use dark-green leafy vegetables as pumpkin leaves and milk to get a lot of these minerals" **(Female nurse at a health centre in Uriri Sub-County).**

> "When patients are faced with opportunistic diseases causing sores in the mouth or issues of diarrhoea that might affect the eating habit of the patient, we encourage that caregivers give less spicy and hard to chew foods for the former and provide patients with home-made rehydration solutions and feed them on mashed foods that are easy to swallow for the latter**" (Head of a local NGO).**

The findings above show the necessity of a well-balanced diet for the HIV and AIDS patients. However, of utmost interest to this study was the very sharing of roles in the process of ensuring that the needed food is available, prepared and served to the patients. Indeed, Castleman et al. (2004) observe that patients who begin antiretroviral therapy without adequate nutrition have lower survival rates. Similarly, Friis (2006) states that adequate dietary intake and absorption are essential for achieving the full benefits of the treatment. Hence, he argues that antiretroviral therapy itself may increase appetite and it is possible to reduce some side-effects and promote adherence to the therapy if some of the medicines are taken with food. Given the importance of adherence in delaying viral resistance to first-line drugs, nutritional support becomes even more important in the longer run for sustaining antiretroviral treatment. Overall, the findings in the current study indicate that caregivers spend a substantial amount of time interacting with patients in the process of care within a wide range of activities such as housekeeping, personal hygiene, meal preparation, medical care, transportation, financial and moral support as captured in the case narrative below.

Case Narrative 3: Female caregiver (5 years of experience)

Rose (pseudonym), lives in abject poverty with her family. Their house is a two-roomed, mud-walled house, with rusty iron-sheets, mud floor with windows already caving-in. A few clothes, some poultry, ox-plough, water containers and a bicycle alongside the two-acre piece of land on which their house sits form the entire family asset.

Rose was married immediately after sitting her eighth grade examination (Kenya Certificate of Primary Education) at the age of 15 years. The husband, then a foreman at the South Nyanza Sugar Company (SONY) had a stable income of roughly Kshs 7000 a month. In the year 2009, the husband fell ill and after several hospital visits and tests was diagnosed with HIV. A year later, the husband was laid off work occasioned by his absenteeism from work over several occasions, thus, the couple had to vacate the company premises and relocate to their rural home slightly 30kms away.

With the sick-husband unable to work, five children to feed and no regular income in sight, their life became unbearable. While Rose was able to find some solace through RAPADO, a local NGO, the help was only in occasional access to medication for opportunistic infections the husband suffered pegged on funding availability at the NGO.

Rose decided to take up a cleaning job at a nearby private secondary school earning her 2000 shillings a month.

Working between 8.30am and 3pm daily, Rose has to go back and take care of her children and her ailing husband who suffers from consistent coughs, bouts of diarrhoea and occasional vomiting coupled with severe fatigue. At times, when the husband could not get up on his own, Rose took time off her work station to tend to him. Even more appalling is that Rose has never received any trainings in HIV and AIDS care, all activities are done on the advice of friends and own knowledge around household-hygiene.

> "There are several occasions when he gets overwhelmed by Malaria or serious stomach upsets to the extent that he cannot move around with ease, I have to take some time off work and attend to him".
>
> “What worries the most is whether I am doing the right thing in dressing wounds that result from rashes around his arms, I feel I might get infected as much and it even becomes depressing when try every remedy you know of and the situation does not change".

To get water, Rose and her children walk to the nearest stream around 1.5kms from their home. They visit the stream close to three times a day to get enough water for the family. On top of the physical exhaustion of collecting water from a distance, the weak husband has to be helped to the family pit-latrine situated around 300 metres from the house on occasions he feels so weak to walk on his own.

At the time of infection, the husband used to travel to the District hospital in the neighbouring Migori district (presently the County referral hospital) for medication. That proved expensive on the side of transport and the cost of medicine to treat the opportunistic infections. Similarly, a lot of money was required for x-ray tests and the CD4 tests. This led to the sale of the only two head of cattle that the family possessed.

> "Multiple laboratory tests overwhelmed all the savings we had, we still had to do more because we needed appropriate medication, the only logical thing to was to sell the heads of cattle to make ends meet"

Rose herself has begun wearing out on the intensity of the physical and emotional demands of care, her health is deteriorating and can hardly sustain her work at school without taking several sick-offs. In the current picture, their three daughters have to occasionally miss out on school to help perform Rose’s duties. There has been little help if any that the family receives from any formal (state) quarter.

> "More often, I feel drained both emotionally and physically, the opportunistic diseases keep recurring in the patient, I think my body is growing weak as well, in the last six months I have suffered malaria twice and very bad diarrhoea..." **(Rose**).

Rose presents a picture that cuts across the study objectives. In the first instance, Rose by nature of being female and spouse to the sick husband is socially expected to provide care to the ailing husband and the rest of the household members, roles which she immediately picks up. The assumption of these roles fall on the background of a perilous situations: Rose has received no training on care-giving to HIV and AIDS patient, the household income is already depleted in the clinical tests and transportation, she has to balance between her paid work and the unpaid care work at home all of which are compelling and essential for the household survival.

The fact that the care-giving is continuously being feminised is evident when Rose is forced to have her three daughters miss out on school to help with chores at the time when the husband is immobilised. The exemption of male children reinforces the narratives of defined spheres of males and females’ duties in Rose’s case. Therefore, out of the societal expectations and norms, she continues to be the family mother to her children and nurse to the ailing husband and engages in productive work to meet other material needs. It is significant to understand that all these engagements are undertaken despite the fact that she has already been infected hence needing some care as well.

The medical, physical and nutritional care roles have come out prominently in this case. Rose has to ensure that the drugs are available to the husband with a strict following of prescribed regimen. Given that the husband suffers multiple opportunistic infections, mostly diarrhoea and vomiting Rose has had to prepare foodstuffs in the forms that are easy to digest and rehydrate the patient, most of which she does based on own knowledge and understanding of the situation. Moreover, having to help the husband around the house and bathroom when immobilised presents a clear case of physical care that Rose has to contend with.

Considering the fact that Rose lost a stable income flow with the laying off of the husband, they have had to sell family property to acquire some medicines, for further tests and transportation to health facilities. Rose herself is now infected, provides care without any information and is facing economic and socio-emotional stress. This stress is most likely beginning to bear on the children who have both parents sick and occasionally have to miss school to assist in the household chores without any psycho-social counselling. Moreover, the situation has come with the schooling disruptive activities that young girls experience in the context of HIV and AIDS care-giving hence a great opportunity cost and bleak future. The roles played by caregivers are summarized in table 6.1 below.

Table 6.1: Summary of care roles performed by caregivers

Physical care • Bathing physically weak patients • Assistance to the toilets (Mobility to facilities) • Turning bed-ridden patients • Changing clothes to patients • Doing laundry and fetching water • Maintenance of bed hygiene	**Psychological care** • Counsellingpatients towards acceptance • Moral support to cope with anxiety • cross-referring patients to support groups • Displaying compassion towards de-stigmatisation
Medical care • Lay diagnosis of fever • Observing adherence to medical regimens • Dressing wounds and administering treatment on infections as flu • Recoding change in patient's condition and reaction to medicine • Making clinical referrals • Handling side effects of medication	**Financial and Nutritional care** Purchase of care kits Hiring of caregivers Purchase of food Facilitating transportation to the health facility Purchase of medication as per clinical prescription Food selection and preparation Observing fluid uptake by the patient Feeding patients when bed-ridden

CHAPTER SEVEN: CHALLENGES FACED BY HIV AND AIDS CAREGIVERS

7.1 Introduction

This chapter presents and discusses challenges faced by HIV and AIDS caregivers in Uriri Sub-County in response to objective three of this study. Assessing challenges was deemed important in contextualising programmatic interventions unique to the situation in Uriri in particular and providing the information upon which policy interventions can be hinged broadly. The findings and discussions on the objective have been carried out along the following sub-themes: Stress and HIV-positive persons as caregivers, financial burden of care, child caregivers and the opportunity costs, male caregivers and the identity crisis, information drought and care-giving, double-work load and care-giving, diminishing female availability and the care-crisis.

7.2 Social stress and HIV positive persons as caregivers

Stress in the context of HIV and AIDS caregiving manifests physically and emotionally. The situation of stress is aggravated when the caregiver also happens to be HIV positive and in need of care as well. In the study, both caregivers and experts observed that the demanding nature of caregiving coupled with activities such as carrying, lifting and bathing of patients; staying awake at night to attend to patients who are in the terminal stages of their illness and cleaning those with frequent bouts of diarrhoea among other ailments remain to be physically draining for any caregiver.

The aforementioned responsibilities force caregivers to stay emotionally and physically strong to support the care recipient. The demanding nature of caregiving for people living with AIDS means that caregivers can face social isolation as they come to concentrate on their new chores. In addition, HIV infection among the caregivers can place additional strain on caregivers, for example, the stresses of declining health and the added burden of taking care of PLWHA might contribute to psychological distress as illustrated in the interviews below:

> "There is increased work and one gets exhausted when opportunistic diseases become frequent and immobilises the patient, it forces you (caregiver) to turn the patient, bath the person and ensure that the patient sleeps well at night. You have to frequently wake up or permanently stay awake the whole night to give medication and attend to the patient as need arises...you are engaged both day and night” (**42-year-old female caregiver to a sibling**).
>
> “Caregivers always feel exhausted since care work only forms part of their daily chores...you can imagine a woman fetching water, cooking, bathing the sick and still having to work outside the home to earn some money to meet other household needs” (**Sub-County Development officer**).

The study respondents reported feeling anxious and worried about the deterioration in the physical state of their patients, which they are unable to arrest or reverse. This feeling was more acute amongst caregivers who are HIV positive, whom were constantly reminded of their own status and potential death. This group provided care on two grounds: first, caregiving naturally falls within their feminine roles and societal expectations, and two, while HIV positive, their visibly active physical conditions relative that of the patients is used as an excuse that they do not need care. These caregivers reported that this stress sometimes led to restlessness and nightmares. Compounding this emotional stress, women caregivers reported not able to voice their problems because of the socio-cultural norms that make it improper for them to complain.

> "When I witness the difficulties he finds in eating, the recurrence of opportunistic infections, I get worried about my own plight too, I can hardly sleep...I feel like I am destined to die but I cannot show such emotions since I do not want to negate his hope and expectations of living a little longer" (**56-year-old female caregiver to a spouse**).

> "A woman is naturally expected to take care of the sick and attend to his needs without complaining about her own situation in the community...HIV positive wife would still be expected to nurse her husband or risks being accused of insensitivity to his plight" (**Community Health worker**).

The findings in the study on the emotional stress and the continued care provision for the sick people in the household concur with the conclusions of D'Cruz (2004) amongst *seropositive* caregivers in Mumbai-India. In the study, she established that married women had to care for their *seropositiv*e husbands despite being positive themselves and in need of care, with the in-law's family providing little or no support. Further, she points out that the woman's natal family would ensure that they were not abandoned. Provision of care also depended on the interaction between the perceived source of infection, gender of the infected person. The narrative below gives an insight into the stress suffered by HIV-Positive caregivers in Uriri Sub-County.

Case Narrative 4: Female caregiver, 7 years experience

Lin is a 48 year old mother of five and a caregiver to her husband. Lin's husband was diagnosed HIV+ in the year 2006 but the situation worsened in 2009 when the he began developing multiple infections due to his resistance to first-line treatment drugs. Over the years, the husband's health has deteriorated forcing the family to sell most of their property to seek better medication for the recurring opportunistic diseases. To Lin, who was also diagnosed as HIV-positive in the year 2010 and put on treatment, caregiving has meant more household roles and chores in addition to stress about her own fate:

> "I keep wondering if this is the same thing that will happen to me, and more so, who will take care of me given that our children are still in primary school and not mature enough to work and provide food amongst other necessities for the family?"

Lin started providing care because that is what the community expects of a "good woman", who defies her own needs and prioritizes the welfare of the household members. "I am a woman and this is my family, the patient is my husband, I am naturally expected to provide and ensure that the family runs, otherwise, I will have failed in my roles, nobody likes such labelling just because your husband is sick". While her female friends including the family are aware Lin's own status as being positive, they never assist her even with physical tasks in cases where the husband is bed-ridden or too weak to walk without support.

Lin has had to miss work at the local nursery school on several occasions when she has to remain behind and take care of the husband. Besides, she reported missing out on a number of women group meetings when the care demands overwhelm her. "I miss out on my work a lot which nags me and sometimes when he gets bad, I tend to attend to his medical demands and forget even my own regimen; it is a stressful combination of events".

Lin's case presents the negative psychological consequences that family caregivers suffer as the patient’s illness progresses occasioned by stressful caregiving demands. Her own assertion of self-aggrandizement in performing expected feminine roles means that her condition of being HIV positive cannot be an excuse. The stressful caregiving experiences narrated by Lin resonate well with the findings of Given et al., (1994) among elderly caregivers in which they observed that family caregivers experience significant negative physical consequences as the patient’s illness progresses. They further established that elderly spouses who experience stressful caregiving demands have a 63 per cent higher mortality rate than their non-caregiving age-peers.

Her situation also presents the competitive demand between caregiving activities and that of paid work. While being a sole breadwinner in the current situation of husband indisposition, it would be expected that Lin is given more space to work and provide for the family, however, in the absence of assistance forthcoming from family members and lack of enough financial resources to afford hired caregiver, Lin has to exercise a cautious balance between providing a financially unrewarding care to the husband and attending to paid work. Indeed, Stephen et al. (2001) argue that caregivers who attempt to balance caregiving with their other activities, such as work, family, and leisure, may find it difficult to focus on the positive aspects of caregiving and often experience more negative reactions, such as an increased sense of burden. This followed the work of Pavalko and Woodburry (2000). Regardless of the amount of care provided, caregivers may become increasingly more distressed if they are unable to participate in valued activities and interests.

The diminishing income versus the need to continue providing effective treatment for opportunistic diseases presents a great source of stress for Lin. Her situation presents an overall low personal and household incomes and limited financial resources to fend for the children, the ailing husband and meet her own medical needs. The long-term illness has occasioned substantial out-of-pocket costs to care for the recipient's needs that compete with overall household demands. In a related study among cancer caregivers, Given et al., (2004) conclude that caregivers who are unemployed or have low incomes may experience more distress because they may have fewer resources to meet care demands. Overall, financial concerns cause particular distress for caregivers during long term treatment periods as resources become depleted as evidenced in the case of Lin.

7.3 Child and elderly caregivers

The study established that in severe cases, such as the death of one parent and competing demand to provide the material needs for other dependants, girls were found to be pulled out of school to help with the housework and to care for the their sick siblings compared to boys. The phenomenon might be occasioned by the community's belief that socialization of girls help to transform them into better nurturers than boys. Pulling out girls from school naturally cuts down on their schooling opportunity and the associated education outcomes. This is because, caregiving is performed alongside other domestic chores that already put strain on schooling time for the girl-child as illustrated in the interviews with key informants below.

> "It is often the case that girls will be preferred to boys in helping with care in the household...in HIV situation...they largely help with chores around the house including food preparation while their male counterparts maintain the school calendar" **(Sub-county Development Officer).**
>
> **"**The fact that girls are drawn into care-giving impacts negatively on their education and future life...they miss out on school and at times ending up dropping out...once this occurs, there is almost certainty that they won't get better jobs and even be able to raise decent families.." **(Head of advocacy at a local NGO**).

From the findings, it can be deduced that young girls often provide assistance to the primary adult caregivers and also assist in soliciting for food or material support. In homes where there is nobody else to care for the sick, children inevitably become the primary caregivers. This often happens when the children are still at very young age and when they are ill-equipped mentally and physically to cope with the burden of caring for a dying mother or father or both as exemplified by the key informant below.

> "Most girls become caregivers to their young siblings when their mothers who are expected to perform the same duties have to really struggle with some paid work outside the home to bring food to the family and meet the financial demands of care-giving" **(Community Health worker).**

The findings concur with those of Esplen (2009) who argues that care-giving in the context of poverty forces girls out of school to help with domestic activities or to take care of younger siblings when their mothers are sick or are out working. In the case of Uriri Sub-County, the widespread poverty further complicates the situation of young girls and permanently keep them away from school. In related studies in Swaziland, enrolment in school was found to have fallen by 36 per cent since the HIV and AIDS epidemic hit the country, and enrolment among girls had fallen more precipitously than among boys (Desmond *et al.*, 2000). Moreover, UNAIDS (2000) estimated that the least recognised caregivers were the children, when one parent dies, there is frequently no one else to care for siblings and the second parent where there were two parents. Socialization of girls as nurturers and home-keepers is seen to influence the preference of girls over boys, rather, the community views girls as persons who have been oriented in the social roles of caregiving and their entry into the same even at a younger age only serves to fulfil the cultural norms around social organisation of labour.

The pulling of children out of school violates the provisions of the International Covenant on Economic, Social and Cultural Rights (ICESCR, article 13; CEDAW article 10) on the rights to education on a broader level. In Kenya, the continued pulling of girls from school contravenes the Constitution of Kenya (2010) on the rights of the child where education is entrenched as a Fundamental Human Rights issue in the laws of Kenya (Article 10 (2) (b), 28, 43(1)(f)) with access to Basic Education clearly spelt in articles 53 1(b)(d), 54 (1)(b). Government has gone ahead to criminalize all harmful cultural activities/practices such as early marriages that would deter girls from realizing their full rights to education in Article (55d). In particular, Article (53b) states that " every child has a right to free and compulsory basic education". Since domestic work in the form of caregiving diminishes the time and energy girls can devote to schoolwork, networking, and extra-curricular activities, their progress and educational attainment relative to boys is naturally hindered.

In addition, while children can be excellent providers of love and support to the sick, they are often frail or simply young and inexperienced; and usually cannot provide adequate caregiving needs demanded by HIV and AIDS patients.

In observing the statistical trends around women's occupation across the globe, UN (2010) observes that girls are more likely than boys to perform unpaid work within their own household. In the less developed regions, many young girls aged 5-14 take on a large amount of household chores, including caregiving, cooking and cleaning, and older girls do so to an even greater extent. While boys also do household chores, their participation rate is not as high as that of girls. Moreover, girls generally work longer hours than boys, whether they are engaged in housework only, employment only or both. Long hours of work affect children’s ability to participate fully in education. Analysis shows that school attendance declines as the number of hours spent on household chores increases and declines more steeply for girls than for boys (UN, 2010).

In essence, the caregiving work performed by young girls has both immediate (practical) and strategic impacts on their choices. It helps to re-invigorate the pathway to the cycle of poverty since their ability to study and qualify for better livelihoods opportunities is curtailed at a young age as they take up the traditional gender roles of caregiving within the households. In the context of Uriri Sub-County, the socially prescribed roles of women and girls as caregivers undermine their rights and limit their socio-economic opportunities, capabilities and choices which in the long run constitute a prime impediment to gender equality and well-being. Such rights and opportunities include: right to education, the right to health, and the right to participate in public life. Moreover, the sudden uptake of caregiving poses the psycho-social stress due to lack of adequate counselling and understanding of HIV and AIDS situation and conditions among the children adding to their burden.

In the study, key informants pointed to the fact that young girls and grandparents ‘forced’ into care-giving by virtue of being the only surviving family members of the patient usually suffer the burden of having to provide encouragement (emotional), financial, physical and other material support needed by HIV and AIDS patients. Given the advanced age of the grandparents, they suffer a lot of physical strain when they become sole providers of the needs while frequently suffering common ailments of old age. Some of the difficulties faced are captured below by key informants:

> “Grandparents offering care are obviously physically weak, they will succumb to fatigue fast and give up on a number of physically-draining care roles. However, the thought of losing their younger generation forces them to stretch out and this

> coupled with old age illnesses put both physical and emotional strain on this group of caregivers” **(Sub-County Development officer)**

It is evident from the findings that HIV and AIDS caregiving in Uriri sub-County has continued to draw aged persons (especially the grandmothers) who in themselves need care. These aged grandmothers are relied upon by the patients (the bed-ridden ones) as chief providers of all the emotional, material and financial support. While examining the plight of the aged caregivers, Saengtienchai and Knodel (2001) posit that many grandparents often find that they have little time to grieve as they have to be emotionally and physically strong to support and look after the dependent children left behind. In subsequent study by Horizons (2005), it is concluded that many grandmothers face social isolation given the demanding nature of care-giving work. Eminent from the study in Uriri is the fact that physical stress caused by fatigue (care-chore-based) and emotional drain (fear of losing the loved ones) are common stress causers. The situation is captured in the case narrative below.

Case Narrative 5: 70 year old grandmother (6 years of experience)

Maria is a 70-year old widowed grandmother. She become a caregiver to her daughter in the year 2008 after the daughter was expelled from her matrimonial home once the husband succumbed to HIV and AIDS related complications. In her old age, Maria has to meet her personal needs, the ailing daughter’s and those of her grandchild who is in primary school.

Maria’s daughter was victimised by her in-laws who accused her of being responsible for the loss of their son. After the demise of the husband, she was banished from the home with her daughter despite the fact that she was already HIV positive too. She had no choice but to get back to her family of orientation and be cared for by her mother despite the poverty situation and the advanced age of the mother.

> "My daughter couldn't survive the pressure of the in-laws who accused her of being responsible for the husband's infection and eventual death, so I had to take her back as a good mother".

Maria notes that she has to take care of her daughter because if she does not, the society would blame her for running away from her feminine responsibility. Maria contends that as a mother and a woman in the society, she has to take care of her daughter’s needs. She posits that she was brought up in a society where caregiving to the sick and children is largely a woman’s affair, adding that a responsible woman would rather die trying to better the welfare of her children. In her routines, Maria reported having to assist the daughter with bathing whenever she is bed-ridden, she ensures that the daughter takes her medicine as directed at the health centre where she receives the ARVs and nurses the light wounds which were frequent at the time the daughter developed skin rushes and bedsores.

> "I might not have the energy and experience of performing strictly HIV and AIDS care but I have to ensure that her clothes are cleaned and her food is well prepared...when she is so weak, I will always go and fetch water and assist her with bath....it is more like I am doing the same things I used to do when she was so young".

Whenever she has to be away from the home for more than a day, the granddaughter has to be pulled out of school to care for the mother and watch over her if she is too weak. Maria notes that her daughter is nowadays increasingly getting weaker since she has developed the habit of resisting medication as prescribed by the health professionals.

Maria stated that at the beginning, she had no information at all on caring for HIV and AIDS patients. She relied on her social upbringing for a long time largely because she never wanted to share the nature of the daughter's illness with anyone given the stigma that is still prevalent in the community. This later changed once they started visiting the health centre for medication and after counselling. In addition, Maria reported that the care work has forced her to sell a large stock of her poultry to cater for the cost of medication that come with frequent opportunistic infections. She also has to purchase food supplements as recommended by the doctors. All these strains in her life have resulted in stress and she has of late been diagnosed with high blood pressure, a testimony to the strenuous nature of the care work.

> "Caregiving is costly, at times you are forced to buy food depending on what the doctor recommends, I have sold a lot of household possessions to cater for her medications as well, at my age I can only depend on farm products to generate the kind of money that goes into such caregiving activities, it is all straining that is what I can say".

Maria's case points to care as part of the gendered social relation in which women are normatively expected to perform the chore in the society irrespective of their socio-economic statuses. This case also points to the importance of maternal bond and elements of matriarchy in a patriarchal system. Maria is therefore, called upon to not only take care of her ailing daughter but to also bring up her grand-daughter. This implies that at times, the care is not only feminised but burdens the female side of the marriage relations. One would have expected that the daughter's mother-in-law steps in to care for her daughter in-law and her granddaughter if the marriage relations were binding to the extended family.

This relational nature of care is socially constructed as Maria emphasises an aspect of societal expectations of her with respect to care giving in the narrative. Thus, it can be argued that there is a normative dimension of care that is shaped by the upbringing in Uriri district. In Daly and Lewis (2000:284) study, they conclude that care as an analytical capacity serves to reveal important dimension of women's lives but more importantly capture more general properties of societal arrangements around personal needs and welfare. Put into the study context, social care provided by Maria illuminates how gender norms would mean that women remain the main caregivers in Uriri sub-County. These norms are largely grown out of societal expectations and nurturing of women and girls in the society. It also points to the saying that "blood is thicker than water" when Maria's daughter return home from her marriage to be part of her burden in old age.

The absence of outside assistance except on medical advice in the process of care giving contradicts Razavi's (2007) care diamond i.e., an analysis of how care responsibilities are distributed across four welfare pillars of families, the state, the market and the community. In the case of Maria, there is very little input from the community in terms of social advice but the family of Maria provides the bulk of care across all the dimensions. Even within the family as a responsible institution, the care provision is so gendered to the extent that females provide more care than males; hence, the norms in the society tend to exacerbate inequalities between women and men in relation to care work hence feminising the process.

Maria’s case also presents the other side of spectrum where the caregiver falls outside the income bracket and the fact that she is not protected by policies or support programmes, hence, she is generally invisible to the policy/intervention process. In addition, while she can offer effective care on the background of her experience and socialization, her frail nature does not allow her to provide energy-demanding physical care often needed by the bed-ridden patients. Moreover, the low level of education and general lack of information complicates her ability to provide medical care which includes clinical adherence to prescriptions and the observance of dosage frequencies and quantities.

The case also points to a myriad of responsibilities that care givers provide to HIV and AIDS patients. She reported helping the daughter with bath, cooking, cleaning and acquisition of medication, chores which form dimensions of care giving to the HIV and AIDS patients. In a study reported at www.caps.ucsf.edu, it is concluded that caregivers provide practical support such as shopping, housekeeping, and transportation to clinics, as well as more basic assistance such as help with bathing, going to the bathroom, and feeding. As symptoms worsen, caregivers are also likely to take on more clinical roles such as keeping track of medications, giving injections, inserting catheters, and cleaning wounds. This is evident where Maria reports having to dress the wounds when the daughter developed rashes and bedsores indicating deeper indulgence in the clinical caregiving, an activity which, most caregivers are not prepared to undertake since it does not often fall within the cultural socialization domains.

In the narrative, Maria exhibits incidences of failing health, physical exhaustion, financial strain and the fact that she has to ask the granddaughter at times to stay out of school to help with chores. Moreover, it is evident that care work is initiated without the necessary skills and support, at an advanced old-age of which she ought to have retired from labour-intensive activities. As a result, Maria experiences physical and psychosocial effects including stress, burnout and exhaustion affecting her individual well-being despite care giving being a social good that is advocated for by the society.

The findings confirm the conclusion made by Campbell (2004) that many caregivers suffer from the stressful nature of the work - which includes caring for dying people and orphans with little, if any equipment, supplies or support mechanisms. In addition, the frequent lack of training means that patients often receive poor standard of care, and this exacerbates the caregivers’ stress. The care provision as in the case of Maria violates her universal entitlement to quality health as espoused under articles 12 of ICESCR and CEDAW. Moreover, Akintola (2008) concludes that work done by caregivers can be arduous, stressful, emotionally draining and dangerous; hence, HIV and AIDS care givers always experience physical and mental strains that have adverse consequences on their own health.

7.4 Financial burden of care-giving

Financial costs of caregiving cut across the care domains and/or dimensions discussed in the second objective of this study. The informants reported high costs of purchasing the materials needed in physical care e.g., hand gloves, soaps, plastic bags etc, transportation to hospital during clinic visits, medicinal needs, hired labour and other nutritional demands that are not available within the household. The costs were more strenuous to the households that reported low income levels of less than Kshs 3, 000 a month. Given that these group forms the majority of caregivers in Uriri Sub-County, the meagre income levels compounded by high poverty situation in the district increases the financial strain as exemplified in the interviews below.

> "When you get some little money, it becomes quite hard to spread it around the competing needs...you are torn between buying bathing soaps, detergents and keeping the money for any medicinal need. Eventually, going to clinic too demands some cash for the '*boda boda'*(motorcycle transport), ultimately, you may not be able to buy personal effects like clothes" **(51-year-old female caregiver to a spouse).**

> **"**The financial burden is more apparent as the disease advances and a new treatment line is introduced...this comes with new medicine regimen which is often costly dependent on the opportunistic infections that are diagnosed...it is at this level that some patients end up defaulting on treatment or resorting to generic drugs that are cheap but hardly effective" **(Sub-County Development Officer).**

The findings above situate financial strain in medical expenses and the immediate household requirements that are deemed basic in any household. It also demonstrates the general low-income status as a condition that restricts the expenditures to competing priorities with personal needs more often becoming secondary. In the context of caring for the sick, a study by HORIZONS (2004) established that costs range from financial outlays for medicines prescribed over the counter, from clinical therapists or traditional healers and user fees for accessing health care services, transportation costs involved with attending clinics, and rising food costs. Thus, the entry of HIV and AIDS as established in Uriri Sub-County complicates the equation by introducing competitive financial needs in resources constrained environments.

This study established that grandparents and children provide care to the HIV and AIDS patient even though at a statistically low rate of 8% in Uriri sub-County. Important to underline is that this group naturally falls outside the income bracket but are forced to fend for money to provide for the care needs. In natural situations of co-residency, this group (young girls and grandmothers) would be expected to have financial support from active adults within the household, however, when active income group succumbs to HIV and AIDS, the dependency is abruptly reversed in circumstances that are devoid of any safety nets. Reflecting on the financial plight of young girls and aged women care providers in Uriri, the key informants noted that this group of caregivers has had to resort to selling family subsistence crops and other domestic animals to meet emergency medical needs as in the interviews below:

> "It is often the case that grandmothers can lease part of their land at a fee or sell some few heads of cattle if the costs of transportation and medication become quite a burden on them. This is something they do out of the desperate circumstances they find themselves. This is compounded by the fact that even though needy, a number of them do not benefit from the government driven social cash transfer for those above 65 years" **(NASCOP Officer).**
>
> "Some young girls would rather miss school and sell vegetables, family stock of grains to get money to buy food and medicine as instructed by their parents…at times you even find school-aged girls working for teachers and other employed people around to get enough cash to meet the financial needs of their ailing parent" **(Head of a local NGO).**

While previous findings by Knodel (2001) in communities of high co-residence conclude that the financial cost to older carers is exacerbated by a loss of financial support from their adult child when they become sick, the findings in this study assert that the very loss of financial flow to the adults triggers a reverse chain where money (directly in medical and transportation costs) or indirectly (through care material supplies) begin flowing from grandmothers and children to the immobilised active income earners.

In some households, the caregivers were found to be the only breadwinners as well as heads of the households and, therefore, responsible for the provision of finances. This was the case in situations where a widowed woman cared for a separated sibling (sister). Given the demand of care-giving, caregivers at times miss out on regular income generating activities to ensure the sick person is attended to at home. While care-giving took precedence over the paid productive work, more often, the caregivers reported having to contend with an increase in expenditure as a result of purchasing particular kinds of food for the sick, transporting them to health facilities, and the need for medicines as illustrated in the interviews below.

> "When my sister's situation deteriorates, I am forced to abandon my food kiosk business and look after her till she regains strength to be able to cook and do other things...despite that, I am aware that I have to look for school fees for my children...caring for a sick person in this condition is quite demanding but is my kin and I cannot let her to be on her own" **(43-year-old female caregiver to a sibling).**

> "There are often cases where caregivers pull out of regular work whether at the construction sites or other regular activities to look after their sick sibling...you can sense that social obligations towards bettering the welfare of the sick is given priority...the problem is that caregiving is more of a social obligation and does not pay so they end up in financial strains" **(Sub-County Development Officer).**

These findings serve to reaffirm the societal expectations of responsible womanhood even when it is at the cost of a woman's own economic needs. They point to the social pressure as a drive to sustain the care provision for the sick when in the real sense the unpaid care work restricts time available to the woman caregiver to work productively. In their study, Peacock and Westen (2008:5) posit that women who have to stay at home to perform care work are less able to seek other forms of paid work, and if they are already employed, they face enormous difficulties juggling their care duties with their work obligations and sometimes have to give up their jobs. In addition, Action Aid's (2013) recent report from studies in Nepal, Nigeria, Kenya, and Uganda makes clear not only that women's primary responsibility for unpaid care work is a concern for all women, but crucially that the amount, intensity, and drudgery of this work increases with poverty and social exclusion.

In its 2007 resolution, the Commission on the Status of Women on ‘Women, the girl child and HIV and AIDS’, expressed concern that women and girls bear the disproportionate burden to care for and support those infected and affected by HIV and AIDS. it therefore, encouraged Governments to increase the provision of resources and facilities to women who find themselves having to provide care and/or economic support for those infected with HIV and AIDS or affected by the pandemic (CEDAW, 2007:152). Thus, the HIV and AIDS care situation in Uriri is seen to be a new focal point for perpetuating the preference for unpaid work at the expense of paid labour. Women literally stop working to attend to their kin in an environment that escalates their poverty and makes their situation worse.

While examining the economic burden of care-giving amongst women in South Africa, Makina (2009) argues that heavy and intense burden of unpaid care work entrench and exacerbate poverty. As evidenced in this study, intensive unpaid care workloads create significant financial and opportunity costs and chronic time deficits, limiting women and girls’ opportunities to access and progress in education, increase subsistence agricultural production, participate in income-generating activities, or take a paid job.

7.5 Male caregivers and the ‘real male’ identity crisis

In this study, some of the male caregivers reported being depressed in their care-giving roles, this in part, was due to the ridicule from their peers in the community and the feeling that their children would not regard them as ‘real men’ given their roles in the domestic sphere. The experiences of this group of men served to assert an acute awareness of a number of males in the locality that their social networks and society in general do not value care work whether carried out by women or men. The ridicule is illustrated in the confessions below.

> “At the beginning I would come home and cook and wash clothes over the weekends when madam is not feeling well...my siblings were not amused and asked me to hire a house help to perform those ‘womanly stuff'. I could not withstand the social pressure for long so, I retreated to financial care alone and brought in a young woman to help with other care work” **(48-year-old male caregiver to a spouse).**

> “I have to do all these cleaning duties, get food from the market and cook when my wife is in bad shape...If I had the means to hire some lady or a sister to help me with this work it would be great, but for now, I am more of a woman than a man as my friends refer to me” **(36-year-old male caregiver to a spouse).**

> “It is not the fact that men cannot perform direct care chores in the house but the pressure and ridicule they face when they opt to perform these tasks from males and females alike make them feel odd in the community...men are not ‘kitchen people’ that is the belief” **(Community Health Worker).**

While women care receivers appreciated the diligence with which their spouses could perform a number of household chores alongside the demands of HIV and AIDS caregiving, they remained worried about the pressure and ridicule their male spouses received from relatives and the community. Further, they expressed fear that unmanly images would be cultivated among their male children who grow up observing their fathers cook and do the laundry as captured in the interviews below.

> "On several occasions, my wife has reported being labelled lazy by her peers just because she uses a malaria attack as an excuse not to prepare food for the husband, this characterization has gotten to the extent that she prefers one of her sisters to live with us and undertake household chores instead of me doing them and being ridicule by her peers" (**47-year -old male caregiver to a spouse)**

> "Sometimes it is the children who tease you as being "mommy" when they see you cook and clean around the house as the mother recuperates...this makes my wife a bit uneasy because she thinks we are nurturing our children the wrong way" (**33-year-old male caregiver to a spouse**).

The narratives of men in the study are not unique to the circumstances in caring for sick people when compared to earlier findings by Barker et al. (2012) amongst male child caregivers. In their study, it was established that men who cared consistently reported resistance from their families and female partners to their roles as caregivers, either in their homes or as professionals. Similarly, the male caregivers reported taking up their roles because of the life circumstances and external forces, not because of some greater than average belief in gender equality. In Uriri, the men who took up care-giving duties were either the primary spouses and needed their wives to confide in them or were the only surviving kinsmen of the HIV and AIDS patients without the financial muscle to hire caregivers.

The findings indicate that whether inside and outside the home, most activities have a notional label of male or female attached to them. Women are identified as ‘natural’ caregivers and caring is therefore, seen as women’s work. While there were few men providing care, the phenomenon cannot be seen to constitute a rejection of the rigid gender division of labour in Uriri since most of it took place behind closed doors for fear of being openly ridiculed and socially ostracised.

> "I just do everything behind the public limelight for fear of being viewed as a female-male, it is important for my family's welfare that I help in doing the chores but the society is yet to accept this fusion of male and female roles especially by a college graduate like me whom they view as a successful man in the society with informed authority to control the household and community affairs" (**40-year-old male caregiver to a sibling).**
>
> **"**I am always reminded to go home and help with fetching water while my wife lies in the house idling...they have no idea about her status but even if they knew, I doubt it would change their mind on what exactly a man should do" (**36-year-old male caregiver to a spouse**).

The findings show that the fear of social stigmatisation and ridicule remain the major barriers to males' engagement in direct care-giving to HIV and AIDS patient but where circumstances compel them to act, they often have to do the same in hiding. Peacock (2003) while examining societal notions and men's engagement in care posits that even when not widely held, such stereotypes often have saliency because many men and women may understand them to be socially acceptable, and conform publicly to practices that they may not agree with in private.

Similarly, in a survey carried out in Soweto South Africa men reported that they did not participate in caring activities even when they felt they should because of the fear that they would lose respect among their peers if they did so (Kruger, 2003). The study in

Uriri has re-affirmed similar notions where male caregivers resist a lot of direct care for fear of losing their status amongst their colleagues or the male community members.

The discourses of male caregivers in the study affirmed sensitive awareness that the social networks, whether family or society, hardly value care-giving irrespective of the gender undertaking it, thus, re-defining care work as an important and productive undertaking remains a key step in ensuring that caregivers receive the approval and support they need without undermining their rights and dignity in the society. Resolving such an impasse between the need to provide care and fear of denunciation demands the creation of immense awareness on the role that some men play in care-giving so as to encourage ‘open’ entry of men into care-giving. This consciousness-raising in itself would draw attention to the fact that men are not shaped permanently by gender norms but have the liberty to decide and take action in different ways.

7.6 Information drought and caregiving

Caregiving is both intensive and knowledge-driven practice. Understanding the emotional, medical and nutritional needs of the HIV and AIDS patients requires some degree of training. Similarly, the caregiver is expected to understand necessary precautions to avoid contamination and possible infections in the process of providing care and the whole issues surrounding post-exposure prophylaxis.

In this study, caregivers reported limited knowledge on care demands, and where such knowledge was reportedly available, it either emanated from the social groups at the church, occasional visit by the community health worker, or nursing advice picked during hospital visits. Largely though, the information used in care-giving to HIV and AIDS patients was derived from previous experience with other sick persons in the household and overall socialisation as shown in the confessions below:

> "I have always performed these tasks just like I used to handle sick children but I have never received any training, since I was born, I have always seen women perform care roles in this community so I am used to it" **(38-year-old female caregiver to a spouse).**
>
> "There is no formal training I have on caregiving to HIV and AIDS patients but I speak other women who handle similar cases so that I get to learn some common experiences and how to handle each sitaution as it arises)" **(28-year-old male caregiver to a sibling).**

The key informants observed that the transfer of care-giving from health facilities to domestic sphere has always ignored the socio-economic and psychological pre-care-giving information that caregivers may want to use as basic guideline. They pointed out that even after the development of the home-based care kit in 2002 (Home-based care for people living with HIV and AIDS), no efforts have been made to simplify and teach such care-giving information to those in the rural areas.

Such trainings, they opined, would ameliorate the emotional trauma amongst caregivers as well as improve the situation and mechanisms of care-giving. Furthermore, the experts pointed out that lack of financial motivation for community health workers who are supposed to act as care-information-banks has meant that just a few from the non-governmental actors are relied on by the community.

> "The care-giving knowledge is low amongst most caregivers since they do it for HIV patients as part of the household chores yet there is much more information they need to know about safety precautions, medication and the nutritional aspects of care-giving. This is complicated further by the fact that there are few counsellors in the health centres where people take the ARVs to meet the demand" **(NASCOP Officer).**

> "The problem has been the neglect of counselling and information dissemination on care-giving as part of healing and response to HIV in the health centres...more so, there is little effort made on reaching out to the caregivers with critical information on the essentials of HIV management and care" **(Clinical Officer at St. Monica health centre).**

The findings attest to the fact that care-giving especially at the household level still operates on the basis of lay knowledge, this in effect, has resulted into caregivers suffering the socio-emotional stress impacted on them by their daily interactions with the patients. Hence, house-based care remains largely unstructured, uninformed and generally of less concern to the state actors even as HIV epidemic takes toll on populations in the rural areas.

While examining the impact of abrupt relocation of care-giving to the communities in the face of resource-strains, WHO (2003) contends that the physical and psycho-social impacts of caring on women's well being are rarely acknowledged. As has been revealed in this study, some of the caregivers have ended up being infected due to the lack of information on safety issues and treatment of wounds. More often, these caregivers have been exposed to communicable opportunistic infections in the process of caring for the HIV and AIDS sufferers.

The information gap in Uriri Sub-County about caregiving remains alarming, at the risk of suffering the consequences of this neglect are the already over-stretched, unpaid and low-income women and girls who provide the bulk of care.

7.7 Increased workload for caregivers

The study findings point to the engagement of caregivers in multiple roles that cut across productive public duties and reproductive household chores. Such scenario serves to heighten the physical strain and psychological stress that caregivers suffer besides putting a time strain on the competing activities. The risk factor in this case that both the routine household chores and caregiving to the HIV and AIDS patients remain unrecognised, unpaid and undervalued. These chores when performed by women and young girls are regarded as socially legitimate and a source of women’s premium in the community. In such circumstances, women and young girls who form the bulk of care are forced to do ‘additional-shift’ of duties where monetary reward is available to meet other material needs in the household.

> “People think that caring for the sick is just like any household chores where a woman is nurturing and responding to social needs of household members, nobody considers it such important...it is tiring but the woman will still have to go to the market and sell something to get money badly needed for other household materials” **(NASCOP Officer).**

> "I wake up so early every morning to clear any work and attend to the needs of the patient before going to work at the Constituency Development Fund (CDF) office till 3pm...it is the paid work at CDF that gives us the extra cash to send children to school)" **(53-year-old female caregiver to a spouse).**

While culturally the issue of multiple workload for women even in the context of HIV and AIDS care cannot be largely contested given the classification of care as feminine, such debate is not sustainable and palatable in the realm of women's empowerment and sustainable development. This is because, women's participation in paid work is not in and of itself empowering if women are still bearing the primary responsibilities for work in the home. In a study by the World Bank (2012), it was concluded that constraints imposed by care responsibilities also contribute to the concentration of women in lower-quality, informal, and insecure jobs, due to the time women spend out of the workplace and their need for flexible work arrangements.

While considering the unrecognised labour of women in reproductive work specifically, the Beijing Platform for Action (1995 cited in Committee on the Status of Women, 2007) recognised that the HIV and AIDS pandemic bears negative consequences for women by pushing women to perform the dual roles as mothers and caregivers, which in turn affect the women's economic contributions to households and women's health by extension. UN (2010) states that in spite of the changes that have occurred in women's participation in the labour market, women continue to bear most of the responsibilities for the home: caring for children and other dependent household members, preparing meals and doing other housework. In all regions, women spend at least twice as much time as men on unpaid domestic work. Women who are employed spend an inordinate amount of time on the double burden of paid work and family responsibilities; when unpaid work is taken into account, women's total work hours are longer than men's in all regions.

In another study, Esplen (2009) asserts that women who cannot afford to pay for care for their dependants are often unable to take up paid work or are restricted to low-paid, low-status jobs. In the study, it was established that female caregivers had to squeeze out on their time to work outside the care-environment for monetary gains; however, such money would end up being spent on other household needs including the care-provision needs. Contextually, no savings are made for the future hence the beginning of economic poverty trap for the women caregivers.

In essence, the findings and discussions thereof show that the capacity of these women to save for old age is reduced thus increasing long-term financial uncertainty. Coping with paid work and unpaid work in HIV and AIDS care context leaves many women working a double-day which naturally squeezes their free time leading to fatigue. From the findings, the heavy and unequal unpaid care work tend to largely obstruct female care givers' access to decent work as enshrined in the (ICESCR article 6; CEDAW article 11) hence exacerbating women's poverty. The findings mirror the study by ECLAC (2007) in Latin America and the Caribbean where over half of women aged 20–24 cited their unpaid care work as their main reason for not seeking a job outside the home.

7.8 Diminishing female availability and the care-crisis

Emergent challenge in the study is the concept of care-crisis. This has been occasioned by the continued engagement of the girl-child in school given the free-primary schooling occasioned by government regulations and the women's preference for engaging in the productive sector to earn their own money. In either case, a scarcity of the community 'natural caregivers' is being cemented resulting into diminishing and/or fading availability of caregivers in the household. Even in circumstances where women have had to balance between their paying productive occupations and unpaid domestic chores that include care-giving, the effectiveness with which care should be approached remains threatened as in the interviews below.

> "School demands on young girls have literally squeezed the time that they can spend in helping with household chores....when you keep them at home for long, the children officers will come and take them back to school, it is something that is likely to affect the natural labour providers for care work at home" **(Community health worker).**

> "There have been so many openings for casual jobs in the multiple CDF projects, County projects and newly constructed sugar milling companies. Women have literally gone into working for long hours to earn money from these places, and the intensity of their occupation outside the house gravely affects their availability for care..." **(Sub-County Social Development Officer).**

While examining gender and care-giving in the context of gender equality, the World Bank (2012) indicates that women form 40 per cent of the global paid workforce and half of the world's food producers. As evidenced in this study, the increased involvement of women and girls in paid labour outside the home and in school, respectively, decreases the availability of this group for care-giving roles taking place within the domestic spheres. This is compounded by continued stress in public health facilities and greater commercialisation of healthcare hence increased user-fee, the increased demand for materials in care provision alongside competing individual needs.

While the increased engagement of women in the paid labour force would be naturally expected to shift the caregiving to men's domain or at least realise certain equivalent share of the caregiving work, this is not the case. Instead, it has meant that women more than men have to curve out part of their leisure or rest time to undertake a lot of domestic and unpaid chores such as caregiving. This is because there has been little change in the social markers of masculine roles and identities that still keep men and boys away from embracing caregiving as espoused in the interviews below.

> "Even when you have to work till midnight, you need to fulfil your social obligations as a woman which primarily lies in household chores....paid work comes second and that is what the community expects of any responsible woman" (**39 year old female caregiver to a spouse**).
>
> While women are moving towards gaining a degree of financial independence by venturing into paid labour under various County government projects, this entry into the men's domain has not excused the women from regular housework and caregiving neither has it meant a shift for me to cross into perceived women's labour domains" (**Sub-County Development Officer**)

The situation above points to women's disproportionate presence in providing core household work, such as cooking, cleaning, and the more tedious aspects of childcare including roles occasioned by HIV and AIDS. In a quantitative study on men and women's labour participation in the paid and unpaid labour, Milkie et al. (2009) conclude that mothers still work five more hours overall per week than fathers when paid and unpaid work are accounted for, with mothers working 73hours and fathers working 68 hours per week, respectively. Similarly, Sayer et al. (2009), while examining the role shifts across non-traditional domains, conclude that when women change their time use in a non-traditional direction, adding employment, men do not change in a non-traditional direction by adding housework.

The phenomenon observed in Uriri Sub-County speak to the concept of "stalled revolution" advanced by Hochschild (1989) while describing the excessive amounts of work for women in dual-earner households in American society because of fast-changing women and slow-changing men, coupled with a lack of social arrangements to ease the strain of parents in dual-earner households. He concludes that the arising of the second shift was an inevitable consequence of women joining the paid workforce with an uncooperative workplace and unchanging gender norms. In the case of Uriri, social norms are seen to play a major barrier in bringing men on board as alternates or equal providers of care.

Overall, the findings and discussions around challenges of caregiving in the study have elicited objective and subjective impacts across the physical, financial, psychological and social burdens associated with caregiving. The extent to which caregiving disrupts the daily routines and negatively affects resources in the households speak to the objective dimensions of such challenges, for example, the multiple-work of caregivers between paid and unpaid shifts, missed opportunities for young caregivers, intensified monetary expenditure, physical exhaustion and overall loss of income in the process of caregiving. On the other hand, subjective assessment of the challenges has scoped around the caregivers' perception of the caregiving demands, for example, the resentment of caregiving tasks, feelings of depression and that of being trapped by virtue of recipients being family members.

CHAPTER EIGHT: SUMMARY, CONCLUSION AND RECOMMENDATIONS

8.1 Summary

This study assessed the gender relations in HIV and AIDS home-based care in Uriri Sub-County situated in Migori County, Western Kenya. More precisely,, the study undertook to establish the players in HIV and AIDS care, the caregivers' roles and the challenges faced by HIV and AIDS caregivers in Uriri Sub-County.

Whereas both men and women were established to provide HIV and AIDS care, there were more women and young girls compared to men and boys in the home-based caregiving. The trend is informed by gendered norms and expectations that influence the division of labour within the households. Broadly, the socialisation of girls and boys into demarcated feminine and masculine values and roles have shaped females as nurturers and caregivers situated within the home where caregiving is located.

On the other hand, males are seen as providers and community leaders and providers whose roles are situated in the public domain. The reproduction of these roles occur within the family where strict gender division of labour begins, thus, girls and women largely socialized in nurturing assume greater responsibility in caregiving. Consequently, there has been the pulling of under-age girls and ‘very aged’ grandmothers into care-giving hence compromising their well-being. This pulling out seems to be a dominant undertaking based on societal expectation driven by traditional ideologies largely passed over from generation to generation as part of labour sharing.

Caregiving was established to have multiple roles among them: physical, medical, nutritional, emotional (psychological) and financial. While all the facets of care are significant in improving the welfare of the patient, most males identified strongly with financial care given that it largely falls within the valued productive input of a male in the household. Those (males) found to perform other care chores were deemed ‘atypical’, ‘unmanly’ and ‘circumstantial’ given the strong stereotypes that abound regarding the male-female roles divide.

Caregivers reported suffering from exhaustion especially when dealing with bed-ridden patients who demand intensive physical care. Similarly, psychological stress was another challenge largely reported by caregivers occasioned by the thought of ever losing their loved ones or the fate of their own health in the case of *seropositive* caregivers.

It was also established that entry into caregiving without adequate information on drug administration, the caregiving procedures including that of protecting oneself from infection and financial strain also contribute to the observed stress in caregiving. Further, young girls were found to lose on long term goals of benefitting from schooling which portends the risk of inter-generational poverty given their limited skills to compete for well-rewarding job opportunities. Besides, the societal construction of the expected images of masculinities was found to stigmatise and discourage men's engagement in caregiving by largely labelling men engaged in the process as atypical. Emergent in this context is the diminishing availability of young girls and women due to school demands and continued engagement in productive work respectively. The above two emerging demands pull the women and girls away from the homes and into the schools and the labour market in effect creating care-crisis.

8.2 Conclusion

Care is a constructive and matchless social good in the context of HIV and AIDS within Uriri Sub-County. However, the established, unrecognised and unevenly distributed care activities between males and females, with females dominating the discourse has resulted into feminisation of HIV and AIDS care. While the bias against women remains socio-structurally constituted and perpetuated, their impact and amelioration have remained missing topics in the debates about empowerment, women's rights and equality. More particularly, the debate has to shift to creating avenues by which young boys and men can get into household caregiving to share responsibilities with the females in carrying the burden, an entry that must take cognisance of the economics of caregiving and diminishing availability of young girls and women as natural caregivers.

From a Gender relations theory, feminisation of care established in the study, is a product of existential structures with regard to division of labour where the undervalued roles within the household are relegated to women and girls, unfortunately, this is where caregiving falls and the entry of HIV and AIDS has added to this burden of unrecognised and unpaid roles. Thus, the domination of females in care-giving has for the most part been explained by the community allegiance to social values. These are hinged on stringent division of labour where the domain of males remain outside the precincts of the household, thus, generally missing on socialisation as potential housekeepers and nurturers. Compounded by stereotypes, male care-giving remains undervalued and ridiculed making it a socially undesirable venture for most males in Uriri Sub-County.

The study, therefore, brings out the socio-cultural patterning of gendered division of labour in terms of values and norms that shape such labour regimes within the households. Essentially, such ethnographic accounts are significant in designing culturally-aware interventions aimed at encouraging egalitarian share of roles between males and females in caregiving.

8.3 Recommendations

Emanating from the above findings and in order to create a level playing field in the care of HIV and AIDS patients in resources constrained environments, certain undertakings need to be considered. Some of these considerations could be the following:

- Defeminisation of care should be spearheaded by the male champions already engaged in providing care to the HIV and AIDS patients as part of "freeing females" from the bondage of "natural caregivers" in the purview of customary norms. This cause should be supported by the local non-state and state actors in Uriri Sub-county.
- There is urgent need to institute measures that cushion the young girls who are pulled out of school to care for their parents and siblings. The first level of care, that of the community itself must be brought to bear in the care burden and a well planned training of Community Health Workers (CHWs) and well designed facilitation must be considered as part of the solution.
- The National and County governments should consider providing cash transfers to mitigate financial burden experienced by unpaid caregivers living in the rural areas

with high levels of poverty. Provision of high-quality care subsidies or tax credits (aimed at off-setting costs) to households affected by HIV and AIDS would ensure that women become active in the public sphere as was introduced in South Korea in 2001 through Elderly Care Insurance package.

- The sub-county and County HIV and AIDS control offices need to provide accurate information on HIV and AIDS care-giving needs among them pre-and post-test counselling, information on nutrition, medical care, anti-retroviral drugs including issues of hygiene and nutrition. This can be complemented by supporting peer-learning and networking among home-based care providers to facilitate the transfer of knowledge, strategies, lessons and good practices to home-based carers.

- The citizenry should hold the duty-bearers (legislators & policy implementers) to account for existing commitments to gender equality. This will go beyond supporting males to assume fair share in the care burden to demanding a commitment in resource allocation and shaping of public policies to respond to disease care situation (by increasing public investment to carers) in the country and rural areas in particular.
- There is need for an action research that is community driven on “compensations for the under-valued” to quantify and give visibility to the contributions of home-based caregivers in mitigating the impact of HIV and AIDS in the households. This will be important in developing bottom-up approach in policy and programmatic interventions.

REFERENCES

Action Aid (2001). *Care Provision in the Context of HIV and AIDS:Under the Mupundu Tree*. Available at: www.actionaid.org/publications.html. Retrieved on 15th November, 2011.

Action Aid and VSO (2008). *Walk the Talk on Women's Rights and HIV and AIDS.* Available at www.achwood.org.uk/doc/aamdg.pdf. Retrieved on 3rd January, 2012.

Addington-Hall, J. M., L.D. MacDonald, H.R.Anderson, J,Chamberlain, P. Freeling, J.M. Bland, and J. Raferty (1992). Randomized controlled trial of effects of coordinating care for terminally ill cancer patients. *British Medical Journal*, 305: 1317-1322.

Aggleton, P. and Warwick, I. (1998). *A Comparative Analysis of Findings from Multi-Site Studies of Household and Community Responses to HIV and AIDS in Developing Countries*. Geneva: UNAIDS.

Akintola O. (2008). Defying all Odds: Coping with the Challenges of Volunteer Caregiving for Patients with AIDS in South Africa. *Journal of Advanced Nursing*, 63(4):357–365.

Attride-Stirling, J. (2001). Thematic Networks: An Analytic Tool for Qualitative |Research. *Journal of Qualitative Research*, 3:385-405.

Avert (2008). *Worldwide AIDS Statistics.* Available at: http://www.avert.org/worldstats.htm. Retrieved on 12th January, 2012.

Azari, L., D. Braumer and L. Chen (2004). *Costing the Care Economy.*. New York: Columbia University Press.

Barker, G., J.M.Contreras, B. Heilman, A.K. Singh, R.K.Verma, R.K., and M. Nascimento, (2011). *Evolving Men: Initial Results from the International Men and Gender Equality Survey (IMAGES).* Wasington DC: International Center for Research on Women (ICRW).

Barnett, T., Whiteside, A., & Whiteside, A. (2002). *AIDS in the twenty-first century*. Palgrave:
McMillan.

Barnett, T. (2005). HIV/AIDS: Sex, Abstinence, and Behaviour Change. *The Lancet Infectious Diseases*, *5*(9), 590-593.

Bedford, K. (2010). *Harmonizing Global Care Policy*. Care and the Commission on the Status of Women', Gender and Development Programme, Paper Number 7, Geneva: UNRISD.

UN(1995). "Beijing Platform for Action adopted by the UN Fourth World Conference on Women: Action for Equality." Beijing: United Nations Fourth World Conference on Women.

Berk, Sarah F. (1985). *The Gender Factory: The Apportionment of Work in American Households*. New York: Plenum.

Bilton, T. (1996). *Introductory Sociology*,3rd Ed,. London: Macmillan.

Bourdiue, P. (1984). *Distinction: A social critique of the Judgment of Taste.* Harvard: Harvard University Press.

Bourdieu, P. and Passeron, J. C. (1977). *Reproduction in Education, Society and Culture*. Beverly Hills, CA: Sage Publishers.

Budlender, D., N.K. Chobokoane and Y. Mpetsheni (2001). A Survey of Time Use: How South African Men and Women spend their time. Statistics, South Africa, Pretoria South Africa'. *AIDS Care*, 14 (1): 41-55.

Budlender, D. (2004). *Why Should we Care about Unpaid Work?* A Guidebook prepared for the UNIFEM Southern Africa Region Office. Harare: UNIFEM.

Budlender, D. (2008). *The Statistical Evidence on Care and Non-care Work Across Six Countries*. Gender and Development Program Paper No. 4. Geneva: UNRISD.

Budlender, D. (2010). South Africa: When marriage and the nuclear family are not the norm' in D. Budlender (ed.) *Time Use Studies and Unpaid Care Work*.pp 44-72. Geneva: UNRISD.

Bianchi S.M., Melissa A M., Liana C.S.,, and John P. R. (2000). Is anyone doing the housework? Trends in the gender division of household labour. *Social Forces*, 79 (1): 191-228.

Caldwell A.M. (2001). Taking Time out for the Rest of your Life. *Quest*, 6(3): 1-6, 1999. Available at: www.mdausa.org:80/publications/Quest/q63respite.html. Retrieved on 13th May, 2015.

Carlile, C. (2000). The Search For Meaning in HIV and AIDS:The Carers'experience. Available at www.ncbi.nlm.nih.gov. Retrieved on 4th April, 2015.

Carmara, M. (2013). *Unpaid Care Work Poverty and Women Human Rights; Challenges and Opportunities for the Post 2015 Agenda*. New York: UN WOMEN.

Campbell, S. (2004). *Care of HIV/AIDS Patients in Developing Countries. Primary Health Care*. New Delhi: Sage.

Cameron J, R. Franche and A. Cheung (2002). Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. *Cancer*, 94(2):521-7.

Castleman T., E. Seumo-Fosso and B. Cogill (2004). *Food and Nutrition implications of Antiretroviral Therapy in Resource Limited Settings*. Washington, DC: Food and Nutrition Technical Assistance Project.

CEDAW (2007). *Agreed Conclusions of the Commission on the Status of Women on the Elimination of all Forms of Discrimination and violence against the Girl Child*. New York: UN Women.

Commission on the Status of Women (2007). Financing for Gender Equality and Empowerment of Women. E/2008/27-E/CN.6/2008/11; paragraph, 21(y). New York: UN Women.

Coltrane, S. (2000). Research on Household Labour: Modeling and Measuring the Social Embeddedness of Routine Family Work. *Journal of Marriage and the Family*, 62 (4): 1208-33.

Chafetz, P. (1991). *The Gender Division of Labour and the Reproduction of Female Disadvantages: Towards an Integrated Theory in Gender Family and Economy: the Triple Overlap*. Newbury Park CA. Sage.

Charles M., and Grusky D. B. (2004). *Occupational Ghettos: The Worldwide Segregation of Women and Men.* Stanford: Stanford University Press.

Charmes, J. (2006). *A Review of Empirical Evidence on Time Use in Africa from UN Sponsored Surveys*. Washington, DC:World Bank.

Chela, C. M. (1995). Assessing the cost-effectiveness of home based care in Zambia. *Paper presented at the 2nd International Conference on Home and Community Care for Persons Living with HIV/AIDS*; 24–27 May 1995. Montreal, Canada.

Chant, S. (2003). *Female Household Headship and the Feminisation of Poverty: facts, fictions and forward strategies*. Available at http://eprints.lse.ac.uk/574/. Retrieved on 12th October, 2014.

Clipp E., and George L. (1992). Patients with cancer and their spouse caregivers. *Cancer*,69 (4):1074-9.

Daly M. (2008). The equal Sharing of Responsibilities between Women and Men, including Caregiving in the context of HIV/AIDS.Paper presented at the Division for the Advancement of Women Expert Group Meeting on “Equal sharing of responsibilities between women and men ,including care-giving in the context of HIV/AIDS”. Geneva,15-22, August.

Daly, M. and Lewis J. (2000). ‘The Soncept of social care and the Analysis of Contemporary Welfare States’. *British Journal of Sociology*, 51(2): 281–98.

Davis-Ali S. M. Chesler andB. Chesney (1993). Recognizing cancer as a family disease: Worries and support reported by patients and spouses. *Soc Work Health Care*, 9(2):45-65.

D’Cruz, P. (2004). *Family Care in HIV/AIDS: Exploring Lived Experience*. New Delhi: Sage.

Desmond, C., and Desmond, K. (2006). HIV and AIDS and the Crisis of Care for our children. In Morrell and Richter (Eds.). *Baba: Men and Fatherhood in South Africa*, pp.: 229-274. Cape Town: HSRC Press.

Economic Commission for Latin America and the Caribbean (ECLAC) (2007). *Women’s Contribution in Latin America and the Caribbean*. Mexico City: ECLAC.

Elson, D. (1991). Male Bias in Macro-economics: the Case of Structural Adjustments in D. Elson (Ed.) *Male Bias in the Development Process, pp.:67-98*. Manchester. Manchester University Press.

Emerek, R. (1999). Atypical working time: examples from Denmark. *Paper presented to European Research Workshop on Families, Labour Markets and Gender Roles, European Foundation for the Improvement of Living and Working Conditions*. Dublin: Germany.

Esu-Williams E., K.Schenk, J.Motsepe , S. Geibel , and A. Zulu (2004). *Involving Young People in the Care and Support of People Living with HIV and AIDS in Zambia*. Washington DC: National Cancer Institute.

Esplen, E. (2009). ‘*Gender and care. Overview report*’. Institute of Development Studies: University of Sussex.

Esquivel, V. (2011). *The Care Economy in Latin America: Putting Care at the Centre of the Agenda, Undoing Knots*. Innovating for Change Series, Panama.: UNDP. .

Eyben, R. (2012). *The Hegemony Cracked: The Power Guide to Getting Care onto the Development Agenda*. Brighton: Institute of Development Studies.

Family Caregivers Alliance (2015). *Women and Caregiving: Facts and Figures.* Available at https://www.caregiver.org/women-and-caregiving-facts-and-figures. Retrieved 10th April, 2015.

Friis R. (2006). Micronutrients in HIV-positive Persons receiving highly active Antiretroviral therapy. *The American Journal of Clinical Nutrition*, 85:333-345.

Given B., P. Sherwood and C.W. Given (2004). *Family care during active cancer care*. Commissioned White paper. Washington DC: National Cancer Institute.

Given B., Given C.W., and Stommel M. (1994). Predictors of use of secondary carers used by the elderly following hospital discharge. *Journal of Aging Health*, 6(3):353-76.

Glynn J.R. (2004). Does Increased general Schooling Protect against HIV infection? A study in four African cities. *Tropical Medicine & International Health*, 9:4−14.

Godfred, P. (2006). *Cost of Care.* . New York: UNGASS.

GoK (2008). *Rongo District Development Plan,2008-2012.* Nairobi: Government Printer.

GoK (2012). *IEBC County Maps and Wards*. Nairobi: Government Printer.

Greenberg, J. (2012). *Past Due:Renumeration of Social Protection for Caregivers in the Context of HIV/AIDS*. London:.UK consortium of Aids And International Development.

Greenblott K., and Greenaway K. (2006). *OVC, HIV, food security and nutrition: a look at where we stand*. Washington DC: WFP.

Gupta S. and Mehta, A.K. (2006). *The Impact of HIV/AIDS on Women Care Givers in Situations of Poverty: Policy Issues.* New Delhi: UNIFEM.

HelpAge International . 2004. *The Cost of Care: Women and AIDS*. Geneva:UNAIDS.

HelpAge International (2007). *Building Bridges: Home-based Care Model for Supporting older Careers of People living with HIV/AIDS in Tanzania.* Dar es Salaam: HelpAge.

Henry Kaiser Family Foundation (2002). *Hitting Home: How Households Cope with the Impact of the HIV AND AIDS Epidemic. A Survey of Households Affected by HIV AND AIDS in South Africa.* The Henry Kaiser Family Foundation, Social Surveys, Memory Box Project. International Food Policy Research Institute.

Hochschild, A. (1989). *The Second Shift.* New York: Avon Books.

Horizons (2004). *Supporting Community Action on AIDS in Developing Countries.* Available at: www.popcouncil.org/publications. Retrieved on 12th November, 2011.

Horizons (2005). *Exploring the Role of Family Caregivers & Home-based Care Programs in meeting the Needs of People Living with HIV/AIDS*. Available at: www.popcouncil.org/publications. Retrieved 22nd November, 2011.

Horizons (2006). *Integrating Gender into HIV/AIDS Responses.* Available at: www.popcouncil.org/publications. Retrieved on 12th November, 2011.

Houts P., A. Nezu and C. Nezu C. (1996). The prepared Family Caregiver: A Problem-solving Approach to Family Caregiver Education. *Patient Education Counselling*, 27(1):63-73.

Huber, J. (1991). A Theory of Family, Economy, And Gender. In Rae L. Blumberg (Eds.) Gender, Family, and Economy, PP.: 447-478 . Newbury Park, CA: Sage.

IDRC (2013). *Women's Economic Empowerment and the Care Economy: A Scoping Study of the Literature.* Ottawa: International Development Research Centre.

ILO/UNAIDS/UNRISD (2008). *The Equal Sharing of Responsibilities between Women and Men, including Care-giving in the Context of HIV/AIDS.* Geneva: UNAIDS.

International Social Survey Programme (ISSP, 2004). *Family and Changing Gender Roles III (34 Countries).* Berlin: ISSP.

Irving, G., & Bor, R., (1995). Psychological distress among gay men supporting a lover or partner with AIDS: A pilot study. *AIDS Care*, 7, 605-618.

Jenks, C. (1993). *Cultural Reproduction.* New York: Routledge.

Johnson A.G. (1997). *The Gender Knot: Unraveling our Patriarchal Legacy*. Philadelphia: Temple University Press.

Kenya National Bureau of Statistics (2009). *National Housing and Population Census.* Nairobi: Government Printer.

Kes, A., and Hema S.(2006). "Gender, time-use and poverty in Sub-Saharan Africa." in Quentin Wodon and C. Mark Blackden (eds.), *Gender, Time Use, and Poverty in Sub-Saharan Africa.* Washington, DC: The World Bank.

Knodel, J. and Van-Landingham, M(2001). *The Role of Parents and Family Members in ART Treatment Adherence: Evidence From Thailand.* PSC Research Report 09-68. Available at: www.phishare.org/documents/AIDSELD. Retrieved on 6th January, 2012.

Knodel , J. (2002).*The Impact of an adult Child's Death due to AIDS on Older-aged Parents:Results from a direct Interview Survey*. Michigan: University of Michigan Population Studies Center at the Institute for Social Research.

Knodel, J., & Van-Landingham, M. (2002). The impact of the AIDS epidemic on older persons. *Aids*, *16*:S77-S83.

Kruger V. (2003). *Being willing to love and support them*. An Engender-Health Report on Focus Group Discussions held in Soweto by the HOPE Worldwide Men as Partners staff. Pretoria: HOPE worldwide.

Lai, D. W. L. (2007). Cultural Predictors of Caregiving Burden of Chinese-Canadian family caregivers. *Canadian Journal on Aging*, 26: 133-147.

Levinson, B. A., and Holland, D. C. (1996). The cultural production of the educated person: An introduction. In Bradley A. Levinson, Douglas E. Foley, and Dorothy C. Holland, (Eds.), *The cultural Production of the educated Person: Critical Ethnographies of Schooling and Local Practice*, pp 1-56. Albany: State University of New York Press.

Litwak, E. (1985). *Helping the Elderly: The Complementary Roles of Informal networks and Formal Systems*. New York: Guilford Press.

Maher, J. (2008).*The Impact of Increased Availability of ART on Programmes Responding to People Living with HIV*. Capetown: Southern Africa Partnership Programme.

Makina, A. (2009). Caring for People with HIV: States Policies and Their Dependence on Women's Unpaid Work. *Gender and Development*,17(2): 309–319.

Mann, J. (2001). AIDS in *One World: The Health and Survival of the Human Species in the 21st Century*. Santa Fe, NM: Health Press.

Marais, M. (2006). *A plague of inequality*., Johannesburg: Mail and Guardian.

Mbatha-Ndaba, D.R. and Seloilwe, E.S. (2000). Home-based care for the terminally ill in Botswana: Knowledge and perceptions. *International Nursing Review*, vol. 47 (4):218 – 223.

Médecins Sans Frontières (2007). *Help Wanted: Confronting the health care worker crisis to expand access to HIV/AIDS treatment.* Johannesburg: MSF.

Meghan, R. (2013). *Finally, Fairness for U.S. Home Care Workers*. Available at: http://www.hrw.org/newsdispatches-finally-fairness-us-home-care-workers. Retrieved on 14th September, 2014.

Milkie, M. A., Sara B. R., and Suzanne M. B. (2009). "Taking on the Second Shift: Time Allocations and Time Pressures of U.S. Parents with Preschoolers." *Social Forces*, 88(2): 487-518.

Mupedziswa R. (2002). AIDS and older Zimbabweans: Who will care for the carers? *South African Journal of Gerontology*, 6: 9–12.

Newman, C. (2008). *Alleviating Women's Burden of HIV Care in Lesotho*. AIDS:Intra-Health International.

Noelker, L. S., & Bass, D. M. (1989). Home care for elderly persons: Linkages between formal and informal caregivers. *Journal of Gerontology*,(44):63-70.

National AIDS Control Council (2011). *Sustainable Financing of AIDS in Kenya*. Nairobi: NACC.

NASCOP (2007): KAIS *Preliminary Report*. Nairobi: Government Printer.

National AIDS and STI Control Programme (2012). *Kenya AIDS Indicator Survey*. Nairobi: National AIDS and STI Control Programme.

National AIDS Control Council of Kenya, National AIDS and STI Control Programme (2013). *County HIV Profiles*. Nairobi: National AIDS Control Council of Kenya.

National AIDS Control Council of Kenya, National AIDS and STI Control Programme (2014). *Progress Towards Zero*. Nairobi: National AIDS Control Council of Kenya.

Ntozi, J. P. M. & Nakayiwa, S. (1999). AIDS in Uganda: how has the household coped with the epidemic. In J.C.Caldwell, I. O. Orubuloye, & J. P. M. Ntozi (Eds.), The Continuing African HIV/AIDS Epidemic, PP.: 212-334. Canberra: Health Transition Centre, National Centre for Epidemiology and Population Health, Australian National University.

Ogden, J., E. Simel and G. Caren (2006). "Expanding the care continuum for HIV/AIDS: Bringing carers into focus." *Health Policy and Planning*, 21(5): 333-342.

Osborne C. (1996). HIV/AIDS in Resource-poor Settings: comprehensive care across a continuum. *AIDS*, 10(3):S61-7.

Pavalko E. and Woodbury W. (2000). Social roles as process: Caregiving Careers and Women's Health. *Journal of Health and Social Behaviour*, 41(1):91-105.

Peacock, D. and Westen, M. (2008). 'Men and Care in the Context of HIV and AIDS: Structure, Political Will and Greater Male Involvement', paper presented at the United Nations Division for the Advancement of Women Expert Group Meeting on *"Equal sharing of responsibilities between women and men, including care-giving in the context of HIV/AIDS"*. Geneva: UNGASS.

Pearson, R. (1992). Gender Matters in Development Poverty and Development in the 1990s. In T. Allen and A. Thomas (Eds.) *Poverty and Development in the 1990s*. Oxford: Oxford University Press.

Perriens, J. (2000). *Key Elements in HIV/AIDS Care and Support: A Working Document*. Geneva: WHO and UNAIDS. Available at: www.who.int/HIV_AIDS_CARE. Retrieved on 14/04/2015.

Razavi, S. (2007). *The Political and Social Economy of Care in a Development Context*. Geneva: UNRISD.

Razavi, S. and Staab, S. (2012). *Global Variations in the Political and Social Economy of care: Worlds Apart*.London: Routledge.

Reichenbach, L. (2007). *Exploring the Gender Dimensions of the Global Health Workforce*. Boston: Harvard University Press.

Ridgeway, C. L. (2001). Gender, Status and Leadership. *Journal Social Issues*, **57:**637-655.

Rono, P. K. (1999). Women's and Men's Second-hand Clothes Businesses in two Secondary Towns in Kenya. *Institute of Development* StudiesUniversity of Nairobi Press.

Saengtienchai, C. and Knodel, J. E. (2001). *Parents providing Care to Adult Sons and Daughters with HIV/AIDS in Thailand.* Geneva: UNAIDS.

Sayer, Liana C., E. Paula , B. Michael, and M.B. Suzanne (2009). "How Long is the Second (Plus First) Shift? Gender Differences in Paid, Unpaid, and Total Work Time in Australia and the United States." *Journal of Comparative Family Studies*, 40: 523-545.

Secretary General's Task Force on Women, Girls and HIV/AIDS in Southern Africa 2003-2007. Geneva:UNAIDS.

Shanas, E. (1979). Social Myth as Hypothesis: The Case of the Family Relations of old People. *The Gerontologist*, 19:3-9.

Sharkey, S. and Larsen, J.A. (2005). Ethnographic Exploration: Participation and Meaning of Everyday Life in Holloway (Ed). *Qualitative Research in Health Care*. Maidenhead: Open University Press.

Slater, R. (2008). *Institutions and Instruments for tackling Chronic Poverty: The Case of Social Protection and HIV and AIDS*. Working Paper No. 127.. London: Overseas Development Institute.

Slater, R., and Wiggins, S. L. (2005). *Responding to HIV/AIDS in agriculture and related activities*. London: Overseas Development Institute.

Steinberg, M., S. Johnson, G. Schierhout , and D. Ndegwa (2002): *Hitting Home: How Households Cope with the Impact of the HIV/AIDS Epidemic in South Africa*. Pretoria: Henry J.Kaiser Family Foundation.

Stephens, M., A. Townsend , and L. Martire (2001). Balancing parent care with other roles: Inter-role Conflict of Adult Daughter Caregivers. *Journal of Gerentology*, 56:24-34.

Strauss, A. and Corbin, J. (1998). *Basics of Qualitative Research. Techniques and Procedures for Developing Grounded Theory* (2nd Ed). Thousand Oaks CA:, Sage.

Tamale, S. (2002). *Gender Trauma in Africa: Enhancing Women's Links to Resources*. Dakar: CODESRIA.

Tumwine, J. (2007). The Impact of HIV/AIDS on the Community-Based Natural Resources Management Practices in the Highlands of Kabale in South Western Uganda. Lessons from Uganda, Tanzania and Zambia. *Journal of International Development*, 7 (1):163-76.

UNAIDS (2000). *AIDS Palliative Care. UNAIDS Technical Update*. Geneva: UNAIDS.

UNAIDS (2002). *Report on the global HIV/AIDS epidemic*. Geneva: UNAIDS.

UNAIDS (2004). *Report of the Global AIDS Epidemic*. Geneva: UNAIDS.

UNAIDS (2005). *AIDS Epidemic Update*. Geneva: UNAIDS.

UNAIDS (2006). *The Global Coalition on Women and AIDS. Support women caregivers: Fight AIDS.* A UNAIDS initiative, issue (5). Retrieved at http://www.womenandaids.unaids.org\.

UNAIDS (2008).Caregiving in the Context of HIV/AIDS.. Geneva: UNAIDS.

UNAIDS (2009). *UNAIDS Action Framework: Universal Access for Men who have Sex with Men and Transgender People*. Geneva: UNAIDS.

UNAIDS(2010). Global Report: UNAIDS Report on the Global AIDS Epidemic 2010. Geneva: UNAIDS.

UNAIDS (2012). Global Report: UNAIDS Report on the Global AIDS Epidemic 2012. Geneva: UNAIDS.

UNAIDS, UNFPA and UNIFEM (2004). *Women and HIV/AIDS: Confronting the Crisis*. New York: UNIFEM.

UNDP (2006). *Evaluation of Gender Mainstreaming in UNDP*._New York: UNDP.

UNFPA/UNICEF (2003). *Finding Our Voices, Gendered & Sexual Identities and HIV AND AIDS in Education*. Nairobi: UNICEF.

United Nation (2004). *The Impact of Aids.* United Nations Department of Economic and Social Affairs Population Division. New York: UN.

UN Women (2008): The Equal Sharing of Responsibilities between Women and Men, Including Care giving in the Context of HIV/AIDS. New York: UNDAW.

United Nations Economic and Social Council (2014). *'Challenges and achievements in the implementation of 525 the Millennium Development Goals for women and girls. Agreed conclusions'*., New York: UN Women.

United Nations Research Institute for Social Development (2010). *Combating Poverty and Inequality: Structural Change, Social Policy and Politics*. Geneva: UNRISD.

Van Den Wijngaart, M. A. G., M. J. F. J., Vernooij-Dassen, and A.J.A Felling, (2007). The influence of stressors, appraisal, and personal conditions on the burden of spousal caregivers of persons with dementia. *Aging & Mental Health*, 11:626-636.

Van Praag, E. (1995). The Continuum of Care: Lessons from Developing Countries. *IAS Newsletter*,3:11-13.

VSO (2003). *Gendering AIDS: Women, Men, Empowerment and Mobilisation.* Available at www.vso.org/uk. Accessed on 18th November, 2011.

VSO (2006). *Reducing the Burden of HIV AIDS Care on Women and Girls.* Available at www.burder-of-care-tcm79-21029.pdf. Retrieved on 11th November, 2011.

VSO-RAISA (2007). *Gender and HIV/AIDS: A New Agenda for Change*:*Regional Conference Report, Challenges of care*. Available at: www.vso.org.uk. Retrieved on 23rd November, 2011.

Ward, R. A., S. Sherman, and M. LaCory (1984). Informal networks and knowledge of services for older persons. *Journal of Gerontology*, 19: 216-223.

Williams, A. and Tumweseke A. (2001). Multiple Impacts of the HIV/AIDS Epidemic on the Aged in Rural Uganda *Journal of Cross Cultural Gerontology, 8:447-563*.

Willis, P. (1981). *Cultural Production is Different From Social Reproduction*. London: Routledge.

WHO (*2000a*). *Key Elements in HIV/AIDS Care and Support.* Geneva: World Health Organization.

WHO *(2002b) Guidelines on Care and Support in Resource Limited Settings.* Geneva: World Health Organization.

World Health Organization (2007): *Engaging Men and Boys in changing Gender-Based Inequity in Health: Evidence from Programme Interventions*. Geneva: WHO.

World Bank (2012). *Gender Equality and Development.* Washington, DC: World Bank.

APPENDIX 1: Consent Form

Hello, my name is Dalmas Ochieng Omia, a doctorate degree student in Anthropology from the University of Nairobi. I am conducting research on feminization of HIV and AIDS scourge among caregivers in this district.

You have been purposively chosen to participate in the study given your role as a caregiver in this household. I want to assure you that all of your answers will be kept strictly in secret. To this extent, I will not keep a record of your name or address. You have the right to stop the interview at any time, or to skip any questions that you feel uncomfortable to answer. There is no right or wrong answer in this study. Some of the topics may be difficult to discuss, but many caregivers have found it useful to have the opportunity to talk.

Your participation is completely voluntary but your experiences could be very helpful to other caregivers in this district and the country at large towards formulation of a social protection programme. The interview takes approximately one hour to complete. Do you agree to be interviewed?

Please sign here as sign of your consent.

Sign_______________ Date _________________

Thank you for your cooperation.

APPENDIX 2: In-depth Interview Guide

Feminisation of HIV and AIDS care in Uriri District, Migori County

SECTION ONE: Demographic Profile of the Informants

Name of the informant (Optional) ________________________________

1. Age of caregiver

☐ >18 years ☐ 18-35 Years ☐ 36-53 Years ☐ 54 years and above

2. Gender of the patient

☐ Male ☐ Female

3. Relationship between the caregiver and the patient

☐ Parent ☐ Sibling ☐ Spouse

4. Marital status of the patient

☐ Single ☐ Married ☐ Divorced ☐ Widowed ☐ Separated

☐ Others (specify)

5. Occupation

☐ Government employed ☐ Private sector ☐ Private Business

☐ Unemployed ☐ Others (specify)

6. Income per month (in KES)

☐ 0-2,999 ☐ 3,000-5,999 ☐ 6,000 -9,999 ☐ 10,000 and above

6. Number of dependents in the household

☐ >2 ☐ < 4 ☐ 5 & above

7. Education background

Primary: ☐ Complete ☐ Incomplete

Secondary: ☐ Complete ☐ Incomplete

College/University: ☐ Complete ☐ Incomplete

8. Duration the care has been given

☐ 1-2 months ☐ 3-4 months ☐ >6 months

SECTION TWO: CARE-GIVING

Gendered Norms and Expectations in Labour Division

Introduction: Now I am going to ask you questions regarding the work that you have doing when taking care of the patient, in the first section of our interaction I would like to know how labour is generally shared in this community and within the family in specific.

i. What are some of the responsibilities of males and females in the house? (**Probe:** is their stringent division? What of cross-gender roles...)

ii. How is the decision to take these responsibilities reached? (**Probe:** who decides, what influences the decisions,...)

iii. Whose responsibility is it to take care of the sick in the family? (**Probe:** what roles are played by males and females? Who/what determines these roles? Who engages with the sick person the more?)

iv. Have you been able to maintain the above (iii) even in the context of HIV and AIDS care? (**Probe:** have roles remained the same, who has been burdened the more, what are emergent roles across genders in this context)

v. What generally is your feeling about the value of this care-giving role in the society? (**Probe:** Is it worth one’s time and space? Should it be compensated and how? Does the society regard it as important? Should it be a stand-alone work? Which gender should do more of it?)

vi. What is your feeling about men’s involvement in care-giving to HIV and AIDS patients? (**Probe**: Should they be brought on board? What would be their role? How would the household benefit? What have been the barriers to their inclusion?)

Care roles performed to HIV and AIDS patients

I would like us to discuss some of the tasks or duties that you have been doing in the process of caring for the patient at home.

i. Please take me through your daily care duties with the patient (**allow the informant to narrate as s/he pleases**)

ii. How do you decide on changing the tasks and routine about these roles? (**Probe**: Is it on the basis of one’s knowledge? Is it from a training experience? What are other determinants?)

iii. What are some of the things you do for the patient around: emotional distress, physical needs, medical needs, financial and nutritional needs? (**Probe as per the response**)

Care-giving challenges

Now, i would like us to go through some of the difficulties that you have experienced over time when giving care to your patient.

i. What would you share as some of the major problems of providing HIV and AIDS care at home? (**Probe in not mentioned**: stress both physical and emotional, information gap, risk of infection, involvement of young girls and older persons, balancing caregiving with other works etc)

APPENDIX 3: Key Informant Interview Guide

Feminisation of HIV/AIDS care in Uriri District, Migori County

i. What are some of the HIV and AIDS care responses practised in this Uriri Sub-County? (**Probe:** The government and non-governmental care response, the home-based care response etc)

ii. Picking on home-based care provision to HIV and AIDS patients, what in your opinion influences the care-response that a given household can adopt in the context of HIV and AIDS? (**Probe**: previous experience, lay knowledge , cultural dictates, others)

iii. What is the nature of gender division of labour around care giving in the Sub-County? (**Probe:** who performs what roles? What influences such division of labour? Which gender is burdened and why? Can the roles be shared? What value is there in sharing these roles?)

iv. Is there any training or information empowering mechanism to ensure that caregivers are equipped with comprehensive care provision knowledge? (**Probe**: who provides this information? What is the information package? How effective is it to caregivers?)

v. What are some of the challenges faced by caregivers to HIV and AIDS patients in Uriri Sub-County? (Probe: financial, psychological, social...what are possible responses to these challenges)

vi. How would you link HIV and AIDS care to female's poverty in the household and across generations?

APPENDIX 4: Case Narrative Guide

Please tell me about your experience with care-giving to HIV and AIDS patient within your household.

To be probed along:

i. The nature of the relationship between the carer and the patient

ii. When did the care begin and how long it has taken place

iii. The main care providers in the household and any assistances that the carers get

iv. The household observed economic strains due to care roles

v. How the household members have tried to cope with the situation

vi. Any incidences of contracting opportunistic diseases in the process of care

vii. Ways by which care provision has contributed to poverty in the household