SOCIO-ECONOMIC CHALLENGES AND COPING MECHANISMS OF HOME BASED CAREGIVERS FOR PEOPLE LIVING WITH HIV/AIDS IN NJORO SUB-COUNTY, KENYA

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A Project Report Submitted to Graduate School in Partial Fulfillment of the Award of the Degree of Masters of Education in (Guidance and Counseling) of Egerton University.

EGERTON UNIVERSITY

MAY, 2015

DECLARATION AND RECOMMENDATION

DECLARATION

This project report is my original work and to the best of my knowledge has not been presented before for an award of a degree in any other university

Signature …………………………. Date …………………………….

Purity Wanjiku Njau

Reg. No: EM16/2559/10

RECOMMENDATION

This project report has been submitted for examination with my approval as University Supervisor:

Signature …………………………. Date …………………………….

Prof. Mary Kariuki

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ABSTRACT

AIDS scourge has put to test the capacity of Kenya’s health delivery system to meet the ever-increasing number and needs of AIDS related illnesses and complications for equitable and humane treatment. This has led the government to rely on home-based care to fill the gap. Home-based care giving is well-recognized as the majority of care work due to illness takes place in the homes for a number of reasons, including the lack of a coordinated public policy addressing care needs, limited health infrastructure and human resources, and the preference of patients. The purpose of the study was to determine the socio-economic challenges and coping mechanisms of home based caregivers for people living with HIV/AIDS in Njoro Sub-county. The specific objectives were; to examine the types of support provided by home based caregivers for people living with HIV/AIDS; to determine the social challenges faced by home based caregivers for people living with HIV/AIDS; and, to explore the coping mechanisms used by home based caregivers for people living with HIV/ AIDS. The study used Coping theory and Behavioral theory as they deemed relevant to this study. The study employed descriptive survey research design which sought to obtain information that describes existing phenomena by asking individuals about their perceptions, attitudes, behavior or values. Purposive sampling was used to identify 420 home based caregivers who were registered with the local administration to receive relief of which Simple random sampling was used to obtain a study sample of 103 from a population of 420 who are registered. A questionnaire was used to collect data and the Statistical Package for Social Science (SPSS) version 22.0 aided in the analysis. The data generated from the study was analyzed by descriptive statistics. From the study findings 76 (73.8%) were females and 27 (26.2%) were males. This indicates that caregiving seems to attract more women than men. From the study it was established that the most common social challenge faced by caregivers was stigma and discrimination as it was indicated by 87% of the home based caregivers. This had an influence on their interaction and it influenced emotional and psychological support being offered to the people living with HIV. Also majority (91.3%) of the caregivers indicated that lack of finances was a major economic challenge faced when taking care of HIV/AIDS victims. From the study findings this study recommends that policies on home based caregivers should be developed to accommodate the challenges faced by this group which provide alternative health care at home that ease pressure on health care facilities.

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LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	**:**	Acquired Immune Deficiency Syndrome
ARVs	**:**	Anti Retroviral Drugs
CBOs	**:**	Community Based Organizations
CDC	**:**	Center for Disease Control
CHBC	**:**	Community Home Based Care
CHWs	**:**	Community Health Workers
DICGs	**:**	Direct Informal Caregivers
FHI	**:**	Family Health International
HBCGS	**:**	Home Based Caregivers
HIV	**:**	Human Immuno Deficiency Virus
IEC	**:**	Information, Education and Communication
NACC	**:**	National AIDS Control Council
NASCOP	**:**	National AIDS and STDs Control Programme
NGO	**:**	Non Governmental Organization
OVC	**:**	Orphans and Vulnerable Children
PLHIV	**:**	People Living With HIV
UNAIDS	**:**	Joint United Nations Programme on HIV/AIDS
UNICEF	**:**	United Nations Children Fund
USAID	**:**	United States Agency for International Development

CHAPTER ONE

INTRODUCTION

1.1 Background of the Study

HIV/AIDS is a global pandemic that affects individuals, families, and entire communities around the world and has profound social and economic implications. In 2012, the pandemic killed an estimated 3 million people, and an additional 40 million were living with the infection (UNAIDS, 2012). The epidemic primarily affects the world's poorest people in countries with the greatest gender inequities, disparities in income, and access to productive resources (World Health Organization, 2012). HIV/AIDS is primarily a heterosexual epidemic in developing countries, yet sex between men remains a critical aspect of the epidemic in middle and high-income countries (Akintola, 2004). Internationally, an estimated 33.3 million people are living with HIV (NASCOP, 2012). The burden of the epidemic continues to lie disproportionately heavily within lower- and middle-income contexts. Approximately 15 million people living with HIV who need treatment are in these contexts, and of these, only a third (5.2 million) have access to the necessary facilities and resources (WHO,2012). Sub-Saharan Africa remains the region most severely affected by the epidemic: Approximately 68% of all people currently living with HIV, 69% of new infections and 72% of AIDS-related deaths occur in sub-Saharan Africa (WHO,2012). Furthermore, HIV has been recognised as a major humanitarian crisis in this context, as well as a significant threat to socio-economic development.(UNAIDS, 2012).

With regard to the prevalence of this disease, recent studies indicate that South Africa has one of the highest rates within Sub-Saharan Africa. It is estimated that one out of every five adults in South Africa is HIV positive and that out of a population of 40 million, 4.2 million are currently living with the virus (Uys and Cameron,2013). In Kenya the current HIV prevalence rates are estimated at 25 % in urban areas, 27 % in semi-urban and 12 % in rural areas. Current estimates suggest that there are over 1.2 million people infected with HIV/AIDS. In Kenya, and more than 1.5 million have so far died of the disease, leaving behind over 1 million orphans in the rural areas where the socio-economic conditions are worsening due to poverty and unemployment (UNAIDS, 2013). In addition, a large number of children are living with parents who are ill; hence the children become the primary care givers for their parents, young siblings and other dependants. It is estimated that many more persons living with HIV/AIDS stay at home, are unable to access health care and are overstretching the households' ability to cope. The demographics behind HIV/AIDS are as diverse as the world in which we live and work, calling for a range of responses from the social work profession (Shebi,2006). The eradication of HIV/AIDS represents one of humanity's greatest challenges, one that requires cooperation and comprehensive collaboration between scientific disciplines, governments, social institutions, the media, the social work and health care professions, and the general public (Sterinberg,2011). The mounting morbidity and mortality of the epidemic has placed increasing pressure on most African countries' public health sectors (Tshililo and Maselesele, 2009). The care of HIV/AIDS patients has created demand for healthcare beyond the capacity of hospitals and clinics, forcing states to look for alternatives. In response, several southern African countries have initiated Community Home Based Care programs (CHBC), a strategy viewed as more affordable and attainable than hospital care.

Community Home Based Care programs have the potential to bring about important health and social benefits for the patients, families, and communities involved, a strategy that transfers some of the responsibilities of care from the health facilities to families and the communities in which patients live. CHBC programs have the potential to bring about an attempt to provide a quick and easy solution to relieving overburdened hospitals and clinics, without a real commitment to strengthening the services provided to those deeply affected by HIV/AIDS. Home-care programmes were started in North America and Europe when it was found that families had difficulty coping on their own with the demands of caring for people living with HIV/AIDS (PLWHA) (Molefe, 2009). During the late 1980s and early 1990s this type of service was introduced in a number of African countries (Sardiwalla, 2004).

In South Africa, hospices and community-based care organizations have been designed to take care of those that are homecare workers, and the expansion of home care technology has increased the care giving responsibilities of families (Steinberg, 2011). Family caregivers are being asked to shoulder greater burdens for longer periods of time. In addition to more complex care, conflicting demands of jobs and family, increasing economic pressure, and the physical and emotional demands of long-term care giving can result in major health impacts on caregivers

(Shebi, 2006). Home based caregivers who experience the greatest emotional stress tend to be female. They are at risk for high levels of stress, frustration, anxiety, exhaustion and anger, depression, increased use of alcohol or other substances, reduced immune response, poor physical health and more chronic conditions, neglecting their own care and have higher mortality rates compared to non-caregivers (Tarimo.etal, 2009). Home-based care has emerged as an effective method of providing cost-effective and compassionate care to people infected with HIV and AIDS. Many governments have acknowledged the need and value of caring for people living with HIV and AIDS in their homes. In South Africa, this was recognized by the government in 2004 as being an effective care measure when the government called for the establishment of 600 home-based care programmes by 2005 (Ehlers, 2006). In 2002, the World Health Organization published a framework for establishing community and home-based care programmes in poorer nations in response to the growing realization of their valuable role in dealing with the epidemic (WHO, 2002).

National guidelines have been established by various countries including Kenya, Tanzania and Malawi (WHO, 2002). However these guidelines could not be made operational due to lack of funds. Despite this lack of coordination in Community Based Home Care (CHBC) there have been sporadic government based home care initiatives in Kenya. For example in 1999 to 2000, 50 people were trained in the districts of Nyando, Kisumu, Rachuoyo and Kuria. In addition 24 people received a diploma in home based care in Nairobi and central provinces. These training programmes were conducted by personnel from mild international in collaboration with the University of Nairobi, and Kenya Voluntary Women’s Rehabilitation Center (KVOWRC). Although this training programmes were helpful in sensitizing health care personnel to the care and support needs of people at home, due to lack of government funds, this training has not been maintained (Onyango, 2009). However, despite the recognition of the vital care work that goes on in the home, many caregivers and home-based care organizations are not sufficiently supported.

Globally, up to 90% of such care is provided in the home by women and girls (WHO, 2002). But as HIV and AIDS take its toll, it is becoming apparent that women alone cannot shoulder the responsibility of HBC work. The inability of health systems to care for all people living with HIV and are in need of services has led many governments to rely on home-based care to fill the gap. In order to provide appropriate care and support for people with HIV and AIDS, especially in less developed countries with minimal resources and health budgets, a comprehensive integrated approach that addresses the medical, psychosocial, spiritual and emotional needs, is necessary.In Kenya a formal system of community based care (CHBC) has not yet be implemented by ministry of health (UNAIDS, 2007). However, there are a number of NGOs, religious organizations and donor agencies engaged in the provision of home based care throughout Kenya. The HIV pandemic is overwhelming public hospital capacities. In Njoro Sub-county due to the cosmopolitan in nature and establishment of various agri-business industries for example flower farms, processing industries and institution of higher learning, the prevalence of HIV and AIDS in the Sub-county has increased among the community living.

In Njoro Sub-County District Hospital due to high prevalence of HIV/AIDS the pandemic places enormous burden on healthcare services, as a result patients are forced to be discharged prematurely due to low bed capacity in the hospital. This has led to HIV/AIDS patients to seek care at their homes which includes physical, psychosocial, palliative and spiritual interventions. In Njoro Sub-county home based care is done at homes for a number of reasons, including, limited health infrastructure and human resources, and the preference of patients. A serious consequence of this being that other patients care is compromised due to premature discharges from hospitals. The increased demands placed on medical budgets, combined with the prolonging of patients’ lives through antiretroviral therapy treatment, has led to vast majority of care costs and burdens are borne, therefore, by households and individuals.

Home-based care entails the provision of necessary health care by a volunteer caregiver to a patient or family at home, often with the support of a Home Based. In Njoro Sub-County these support services are offered by Home Based Caregivers, Community-Based Organizations and include home visits, where assistance is given with physical, medical, and emotional care. This, however, can only be done for a limited number of hours per week due to the number of patients allocated to a volunteer worker in a specific area and nature of work of the caregiver. Although the services of community-based caregivers are available, it is the informal caregivers who provide most of the care for the PLWHA. Thus they experience a lot of emotional, financial, physical and social difficulty. Despite the fact that there may be no significant financial impact on home based caregiver offering caring for people living with HIV/ AIDs at home, there can be significant impact on the emotional and physical health of the caregiver. Because of the strain and burnout often associated with caregiving, caregivers require counselling support services to cope with burnouts, stigma and discrimination (Jackson, 2002). These people are typically the lovers, spouses, children, friends or family of someone diagnosed with HIV/AIDS. The aim of this research was to explore the operational gaps and challenges in the care giving process that make coping of the caregivers a daunting task.

1.2 Statement of the Problem

AIDS scourge has put to test the capacity of Kenya's health delivery system to meet the ever-increasing number and needs of AIDS related illnesses and complications for equitable and humane treatment. Home-based care has emerged as an effective method of providing cost-effective and compassionate care to those infected with HIV/AIDS. In Kenya, there has been a gradual shift from hospital-based care of people living with HIV/AIDS to home-based care. People living with HIV/AIDS often constitute a large proportion, if not majority of people seeking medical treatment at hospitals. Many hospitals do not have adequate resources to care for HIV patients. In response, hospitals and departments of health have implemented policies to promote home-based care of patients. However, HIV/AIDS pandemic places enormous burden on healthcare services in Njoro Sub-County District Hospital, as a result patients are forced to be discharged prematurely due to low bed capacity in the hospital. This has led to HIV/AIDS patients to seek care at their homes which includes physical, psychosocial, palliative and spiritual interventions. Hence there was need for a study to establish socio-economic challenges that are faced by home based care givers and their coping mechanisms when taking care of People Living with HIV/ AIDS.

1.3 Purpose of the Study

The purpose of the study was to investigate the socio-economic challenges and coping mechanisms of home based caregivers in Njoro Sub-county.

1.4 Objectives of the Study

The following objectives guided the study:

i) To examine the types of support provided by home based caregivers for people living with HIV/AIDS in Njoro Sub-county.
ii) To determine the social challenges faced by home based caregivers for people living with HIV/AIDS in Njoro Sub-county.
iii) To analyse the economic challenges faced by home based caregivers for people living with HIV/AIDS in Njoro Sub-county.
iv) To explore the coping mechanisms used by home based caregivers for people living with HIV/ AIDS in Njoro Sub-county.

1.4.1 Research Questions

i) Which types of support are provided by home based caregivers for people living with HIV/ AIDS in Njoro Sub-county?
ii) What are the social challenges faced by home based caregivers for people living with HIV/ AIDS in Njoro Sub-county?
iii) Which economic challenges are faced by home based caregivers for people living with HIV/AIDS in Njoro Sub-county?
iv) What are the coping mechanisms used by home based caregivers for people living with HIV/AIDS in Njoro Sub-county?

1.5 Significance of the Study

The findings of this study will be used indicate the extent to which coping mechanism impact on the welfare of home based caregivers for PLWHA. The information generated will be essential to counselors who will appreciate the role of counseling in assisting the caregivers for PLWHA to confront the multiple challenges they face. The study results will also be of great value to the society at large to understand and address the issue of stigmatization on caregivers for PLWHIV and the psychological trauma they experience. Researchers and academicians will get an insight on the current knowledge and on areas for further research.

Secondly, the study results will help educate families, communities and home based caregivers to cope with challenges of care giving when providing care to people living with HIV. This will strengthen families to provide for the full range of their needs hence reducing the challenge of stigmatization when providing care.

Thirdly, this study will provide information on home based care support available which may be essential in formulating a comprehensive programming for policy makers. The information obtained will also assist people living with HIV to obtain extra support for dealing with their HIV status, managing and adhering to treatment, disclosure, coping with illness in their family and caring for relatives through the voluntary counseling services available.

1.6 Scope of the Study

The study investigated the socio-economic challenges and coping mechanism of home based caregivers in Njoro Sub-county. It focused on individual home based caregivers who were at that time providing care and were registered with the local administration for relief of people living with HIV/AIDS in Njoro Sub-county. Key elements that were dealt with were socio-economic challenges faced and the coping mechanisms of home based caregivers.

1.7 Limitations of the Study

The participants in this research were mostly siblings of the PLWHA and parents of PLWHA some of whom (2.9%) were illiterate; this made the researcher to engage interpreters who could interpret the questions to the respondents. The other limitations were that the level of openness expressed by the participants varied in their responses to questions asked as the issue was very sensitive and traumatizing hence it was handled with utmost confidentiality and assurance to the victims. The respondents had assumed that the research was aimed at funding. This was addressed by assuring the respondents to be transparent and accountable.

1.8 Assumptions of the Study

The study was based on the assumption that;

i) The selected subjects were a representative of the whole population of the study as the sample was obtained through purposive sampling.

ii) The responses were honestly given in relation to the items in the questionnaire, and both men and women had an equal chance of being in the population sampled since simple random sampling was used.

iii) The population sampled genuinely provided home based care to HIV/AIDS patients.

1.9 Definition of Terms

Care Giving According to the Macmillan Dictionary, it referred volunteer activities in the community that keep the social fabric in good order. According to this study, it refers to voluntary work undertaken within the home, which ensures the physical, social and psychological maintenance and development of family members.

Challenges According to the Macmillan Dictionary, it refers to obstacles that are faced when executing a given task. According to this study, it refers to difficulties faced by the home-based caregivers when providing physical and palliative care when offering care to people living with HIV/AIDS.

Coping According to Lazarus and Folkman (1980), referred to a process that is characterized by functions of continuous appraisal and reappraisals of the shifting person environment relationship. According to this study, it refers cognitive and behavioural efforts made to master, tolerate or reduce external and internal demands and conflicts.

Counselling According to WHO (2012), it refers to a process that is directed towards defining the problem, generating alternative solutions, weighing costs and benefits, and then an individual choose and acting on a solution. According to this study, it refers to the skilled and principled use of relationship to facilitate self knowledge, emotional acceptance and growth and the optimal development of personal resources. The overall aim is to provide an opportunity to work towards living more satisfying and resourcefully.

Debriefing According to WHO (2012), it refers to finding positive meaning as they involve the activation of beliefs, values, or goals that help define the positive significance of events. According to this study, it refers to provide HBCGs with a platform to explore their emotions and frustrations in order to cope with the challenges that they face in their daily duties as they care for PALHIV.

Guidance According to the Macmillan Dictionary, it refers to Positive reappraisal, goal directed, problem focused, and the infusion of ordinary events with positive meaning. .

According to this study, it refers to advice offered from an official organization on how to deal with particular situation.

Home based caregiver According to the Macmillan Dictionary, it refers to helpful functions performed by significant others such as family members, friends, co-workers and neighbours and thereby enhances the individual's physical and psychological well-being. According to this study, it refers to a person who regularly looked after somebody who is unable to look after himself/herself because of illness at home.

Palliative care According to WHO (2012), it refers to tasks performed by Careers like personal and household chores, giving advice about health and welfare, providing psychological reassurance. According to this study, it refers to a combination of active and compassionate long-term therapies intended to comfort and support individuals and families living with a life threatening illness.

People living with HIV/AIDS According to WHO (2012), it refers individuals diagnosed with the virus that cause HIV/AIDS. According to this study, it refers to a person infected with HIV/AIDS.

Psychosocial needs Refers to inability to deal with psychiatric conditions and symptoms by person infected with HIV/AIDS (Zimba and McInerney, 2001). According to this study, it refers to social, mental and spiritual requirements of home based caregiver for PLWHA in order to live quality life and contribute to development of the society.

Social support According to WHO (2012), it refers to the positive, potentially health-promoting or stress-buffering aspects of relationship. According to this study, it refers to helpful functions or supportive resources that are provided for primary caregivers of PLWHA to enhance their physical and psychological well-being.

Socio-economic challenges refer to those factors that had a negative influence on the individual's economic activity (WHO, 2002). According to this study, it refers to difficulties experienced by caregivers that have to do with patients' comfort and financial constrains especially when patients are acutely ill.

Spirituality refers to believing in God and prayer in order to cope with the challenges that HBCGs face in their daily duties as they care for PALHIV (UNAIDS, 2007). According to this study, it refers to requesting divine intervention from Supreme Being through of prayers for healing and comfort especially when patients are acutely ill or cognitively impaired.

Stigma referred to the act of identifying, labeling, or attributing undesirable qualities targeted towards those who are perceived as being shamefully different and deviant from the social idea (UNAIDS, 2012). According to this study, it refers to a stressful event that occurs when an individual’s feels he/she is isolated, hidden and fearful.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

The literature review discussed current research on the impact of HIV/AIDS on Kenya’s health delivery system**,** socio-economic challenges experienced by home based caregivers and the coping mechanism of home based caregivers. Also theoretical and conceptual frameworks were discussed.

2.2 HIV/AIDS Situation in Africa and Kenya

The global AIDS epidemic has caused vast suffering throughout Sub-Saharan Africa. This region has the highest HIV prevalence rates in the world, accounting for 32% of all HIV infections (UNAIDS, 2012). The number of people living with HIV in the world was estimated at 33.3 million in 2009, out of which 2.6 million were newly infected. In the same year, 1.8 million people died of AIDS. The Sub-Saharan region, although it contains little more than ten per cent of the world’s population, remains most severely affected by HIV. It accounts for over two-thirds of all HIV cases, and some of 75 per cent of deaths. The virus disproportionally affects women and prime-age adults who are at their productive and reproductive peak (UNAIDS, 2009).

Four southern African countries Botswana, Lesotho, Swaziland, and Zimbabwe had national adult HIV prevalence rates exceeding 20% (UNAIDS, 2012). The mounting morbidity and mortality of the epidemic has placed increasing pressure on these countries’ public health sectors. The care of HIV/AIDS patients has created demand for healthcare beyond the capacity of hospitals and clinics, forcing states to look for alternatives. In response, several Sub-Saharan African countries have initiated CHBC programs, a strategy viewed as more affordable and attainable than hospital care. CHBC programs have the potential to bring about important health and social benefits for the patients, families, and communities involved, but many studies have questioned their effectiveness (World Health Organization, 2012).

As of December 2011, 1.6 million people in Kenya were living with HIV (UNAIDS, 2012). Kenya projects that the number of people living with HIV will continue to grow, placing continuing demands on health and social service systems. A comprehensive update of the HIV/AIDS epidemic in Kenya summarizes progress achieved over the last decade as; the rate of new HIV infections has fallen by 40%, 69% of HIV-positive pregnant women received drug prophylaxis to prevent transmission to their infants in 2011, and antiretroviral therapy reached 83% of all adults who were medically eligible (NASCOP, 2012).

Kenya has a severe, generalized HIV epidemic, but in recent years, the country has experienced a notable decline in HIV prevalence, attributed in part to significant behavioral change and increased access to ART. National adult HIV prevalence is estimated to have fallen from 10 percent in the late 1990s to about 6.1 percent in 2011(National AIDS and STD Control Programme, 2012). Women face considerably higher risk of HIV infection than men, and also experience a shorter life expectancy due to HIV and AIDS. Populations in Kenya especially at risk include injecting drug users and people in prostitution, whose prevalence rates are estimated at 53 percent and 27 percent, respectively. (NASCOP, 2011a).

2.3 The Concept of Home Based Care

Home based care programmes started in North America and Europe when it became clear that hospital care was too expensive, and that family and other caregivers found it difficult to cope on their own with the demanding nature of caring for people living with HIV/AIDS (PLWA) (Spier and Edwards, 1990). In the USA, the Committee on a National Strategy for AIDS (1986:101) concluded that: “If the care of these patients is to be both comprehensive and cost effective, it must be conducted as much as possible in the community, with hospitalization only when necessary. The various requirements for the care of patients with asymptomatic HIV infection, ARC or AIDS (i.e. community-based care, outpatient care, and hospitalization) should be carefully coordinated (Mabude, 2008).

In most African countries, there are now well developed home based care programmes and systems, although access to these programmes is still not universal (Uys and Cameron, 2013). The impact of this on health services, families and communities is placing an overwhelming burden on society at large. In an attempt to deal with this impact, it is common practice for health care facilities to rationalise services to people with HIV, and shift the bulk of the burden of care onto the shoulders of home based caregjvers' households and communities. No wonder that in South Africa, home based care has become a national policy priority (Steinberg, 2011).

According to Mabude, (2008) any discussion on the care and support of HIV/AIDS patients inevitably turns to the consideration of how to enlist community participation, both in minimising the impact on the formal health sector and in meeting the needs of the patients. Community mobilization becomes a key factor to sustaining the success of home based care and support programmes. Community mobilization uses deliberate, participatory processes to involve local institutions, local leaders, community groups, and members of the community to organize for collective action towards a common purpose (Ogden, 2006). Community mobilization is characterized by respect for the community and its needs. Historically, health and welfare services adopted a top-down approach where little recognition and consideration were given to the reality that communities had an inner knowledge and capabilities to develop their own resources (Opiyo, 2008). The AIDS pandemic has forced communities to rally together and address the challenges of the disease. Therefore, conventional methods of care and support require to be revisited in the light of the devastation of the disease.

Today, AIDS is no longer a certain death sentence in sub-Saharan Africa and other parts of the developing world. In 2011, over eight million men, women and children were on treatment in developing countries, with the vast majority of them in Africa. This is up from 6.6 million in 2010 an impressive increase of more than 20 percent and therefore increased demand for preventive and curative services to respond to the epidemiological and clinical impacts of the pandemic (UNAIDS, 2012). These effects include increased burden of disease, increased service needs associated with caring for these illnesses and for HIV/AIDS itself, and the inadequate and diminishing capacity to respond to these needs, central to which is the limited human resource capacity. Its effects on Kenya's health delivery systems is devastating and has led to unprecedented pressure on the health delivery system as cases of AIDS illnesses are increasing on a daily basis (Onyango, 2009).

Home-based care programs have been muted in an endeavor to prop up the health delivery system whose inadequacies have been severely exposed by the AIDS scourge (Makoae et al., 2008). The care of terminally ill AIDS patients has also morally and financially burdened family caregivers as a result of an increase in family members who are falling victim to the life-limiting disease. It is on this contention therefore that voluntary euthanasia can be morally justified in an attempt to lessen the burden on both the health delivery system and the home-based caregivers. The concept of home-based care, itself, promotes discrimination and segregation against terminally ill AIDS patients. It shows that the medical profession has resigned the life of AIDS patients to fate. When hospital staff tells a terminally ill AIDS patient to go home and be cared there, obviously, he will feel discriminated against. He will feel that he has been treated like an inferior being and this is emotionally and psychologically disturbing on the part of the patient (Held and Brann, 2007).

AIDS patients normally occupy hospital beds for long periods of time and have, therefore, proved to be a burden on the health delivery system that has to offer services to patients with other health conditions (Hlabyago and Ogunbanjo, 2009). The pressure exerted by HIV/AIDS patients on the health delivery system that is already struggling to provide efficient services to the nation is immense. As a result, the idea of home-based care was muted to fill in the gap left by the inability of the health delivery sector to cope with the increasing number of chronically and terminally ill AIDS patients. Hence this study explored the role of home based caregivers in Njoro sub-county as a result of the inability of the health delivery sector to cope with the increasing number of people living with HIV/AIDS.

2.4 Home Based Care Support Provided by HBCGs

The establishment of home based care programmes for people with chronic diseases such as tuberculosis and HIV/AIDS was found to be more attractive by many African governments because it was found to be a relief on the overcrowded hospitals (Uys, 2002). In its National guidelines the South African government has identified the increased demands on health care services due to HIV/AIDS epidemic. In South Africa it was noted that public hospitals were unable to cope with the increasing number of patients because hospitals are overcrowded with inadequate number of medical, nursing and allied health professionals (Department of Health, 2002). In response to these challenges, South Africa became one of the countries that signed a Declaration of Commitment of the United Nations General Assembly Special Session on Children (UNGASS) that was held in 2002 (Department of Social Development, 2005). One of the declaration was to: build and strengthen governmental, family and community capacities to provide supportive environments for orphans infected and affected with HIV and AIDS, including the provision of all basic needs as well as the protection of Children`s rights (Department of Social Development, 2005). The South African government in its National guidelines on home-based care stressed the importance of community participation in caring for the sick in their home environment (Department of Health, 2001). Civil society responded to the need for community-based care services through non-governmental organizations (NGOs), community based organizations (CBOs) and faith based organizations (FBO), which collectively are known as Home and Community Based Care (HCBC) (Department of Social Development, 2006). In South Africa, the African National Congress (ANC) (1994) in its Reconstruction and Development Programme (RDP) policy framework stressed the importance of community development through active involvement and empowerment of the people. In South Africa, Home-Based Care (HBC) organizations together with the government are responsible for training community members who volunteer to provide care to the sick in their homes, these people are known as volunteer caregivers (Akintola, 2008b)

Home-based care (HBC) programmes for People Living with HIV (PLHIV) in Sub-Saharan Africa have evolved over the past two decades in response to the roll-out of antiretroviral therapy (ART). HBC programmes developed through the early 1990s, providing nursing and palliative care, as well as general support for households affected by HIV. As ART has become more widely available, many PLHIV have regained their physical health and strength, and resumed ‘normal’ levels of social and productive activity. Home-based care has become more medicalised as a result of the drive to initiate and sustain patients on ART. Home-based caregivers’ roles and tasks are changing in important ways as they are drawn on to support the public sector ART roll-out in Southern Africa. However, they remain a vast and highly diversied group of lay workers whose contributions to HIV care have low visibility, an little or no formal recognition and compensation.

There is a major shortage of health care workers in Southern Africa. In this context, comprehensive HBC programmes are a popular strategy for ensuring a continuum of care and support to PLHIV outside of the health facility environment. HBC services can help to reduce the burden on health facilities by shifting certain tasks to patients' homes. They may prove more effective than providing alternative clinic-based services using formally trained healthcare workers. Providing care within the household can overcome some of the barriers to accessing HIV care, including those that relate to the economic and opportunity costs incurred by patients if they have to travel to attend health facilities. HBC also has the potential to reduce the pervasive stigma that surrounds the illness, thus improving uptake of HIV testing, and access to care and support for those diagnosed with HIV. Caregivers continue to provide physical nursing care, psycho-social support, as well as help with household work but are additionally involved in supporting the formal health system: they identify and refer clients for testing and for treatment of co-infections; they accompany clients to the clinics, and they provide support for PLHIV on ART. HBC caregivers intervene at crucial steps of the care-seeking trajectory. They are often the first to recognise thresholds of ill health and distress and to encourage clients to test for HIV, to seek formal care.

A number of challenges face home-based caregivers in the current landscape of HIV care. The lack of training, remuneration, and recognition of their support contribute to staff demotivation and poor retention. Training for home-based caregivers has not always evolved adequately to equip home-based caregivers with the skills required to support clients initiation and follow-up on ART, as well as other medical tasks, partly because of the lack of available funds or restrictions on their use. In addition, training of caregivers still remain adhoc and irregular. Inadequate training, lack of on-the-job mentorship, and inadequate supportive-supervision have constantly been cited by caregivers as key de-motivating factors that need to be addressed.

Caregivers feel that their increased responsibilities and accountability to the health system are not formally recognized. They express dissatisfaction that the acquisition of skills to support ART roll-out is not matched by a formal change in status (Box 2). Additionally, caregivers receive little or no compensation for the work they do; many consider themselves volunteers although some receive small incentives (e.g. travel money, training per diems, T-shirts) that are often dependent on the donor organisations funding the programmes. The uneven distribution of incentives contributes to demotivation and tension among caregivers.

Most caregivers come from low-income backgrounds and are not engaged in formal employment. In addition, they are often caring for someone living with HIV within their families. Some are also living with HIV themselves. They report high levels emotional stress, usually arising from the increased burden of care, feelings of helplessness towards their clients, emotional attachment to their clients, and the lack of requisite logistical and supervisory support. The psychological burden on HBC volunteers is particularly high in programmes focusing on providing end-of-life care.

Home based caregivers see the reality of HIV/AIDS in their area of work and yet strive to ensure that infected and affected people can live with hope and dignity to face the challenge of living with the epidemic, from the time of infection to their eventual death. This is done through provision of medical, emotional and physical support to PALHIV and their families, including sustainable relations in the community (Opiyo, 2008). They also provide psycho-social support to the families of PALHIV (France, 2008).

In Africa there has been a gradual shift from hospital-based care of people living with HIV to home based care, since people living with HIV constitute a large majority of people seeking medical attention at hospitals, and hospitals do not have adequate capacity to take care of them. People living with HIV admitted in hospitals are usually discharged after a short period of admission or are not admitted at all due to shortage of beds (Akintola, 2004). The benefits of home-based care compared to hospital care include that sick people can spend their final moments at home, surrounded by people they love and are familiar with, who will provide flexible and nurturing care, therefore reducing stress, time spent on hospital visits and transport costs for the family.

The government of Kenya recognized the catastrophic impact of the AIDS pandemic on its citizens and has declared HIV/AIDS a national disaster that requires the state’s assistance in the welfare of people who are living with HIV/AIDS (National AIDS Control Council, 2010). It has, therefore, established a council that is meant to assist in the delivery of care for people infected and affected by HIV/AIDS. The Kenya National AIDS Council (NAC), which is under the Ministry of Health, distributes the funds obtained from the National government to various AIDS groups throughout the country and also channels part of the funds to the ministry of Health so that it buys antiretroviral drugs for the government’s ARV scheme (National AIDS Council, 2005). However, the Ministry of Health is failing to fully meet the demands for ARVs for people living with HIV/AIDS. This has prompted the caregivers to take the role of collecting ARVS of the ailing HIV victims.

According to estimates, there are more than 1.6 million people who are HIV/AIDS positive in Kenya and, out of these, about 540,000 are in dire need of ARVs, but only about 120,000 are accessing the drugs in both the private and public sectors because of foreign funding (National AIDS and STD Control Programme, 2011a). In addition, most family caregivers are financially incapacitated to afford the life prolonging ARVs, other medications for opportunistic infections, and special dietary requirements of the AIDS patient (Lever, 2006b). This has made the life of AIDS patients miserable and filled with episodes of pain and suffering as their health further deteriorates**.**

Home-based care is an aspect of community-based care that focuses primarily on physical/medical and palliative care of the patient at home, with the support of family and the immediate community. Home-based care, while politically correct, expedient, and culturally relevant, embodies the germ of exacerbated human suffering for patients and caregivers alike, unless rigorously controlled and generously supported through appropriate allocation of material and psycho-social resources (Jacques, 2004). This study focused on the current status of these programs in Njoro sub-county, with particular attention to the challenges and potential obstacles they face, and with the intent also to address this underlying question about suffering. It is on this base that this study sought to investigate the type of care provided by home based caregivers in Njoro Sub-county in order to advise on developing interventions and support structures for home based care in the Sub-county.

2.4.1 Physical Care

People living with HIV/AIDS need access to a broad continuum of care throughout the course of the illness. The burden of everyday care falls on family members (Steinberg, 2011). In the later stages of HIV/AIDS, family caregivers face a long list of tasks, including helping feed, toilet, and wash the patient; cleaning and dressing sores and ulcers; administering medications; and providing comfort and company. Community-based care programs can give them the training and psychological support they need to do these jobs well, including a thorough grounding in infection prevention (Opiyo, 2008). Home based caregiver provide basic nursing care and comfort measures such as symptom recognition, diagnosis, treatment, symptom management, referral and follow up (Opiyo, 2008). Basic nursing care include positioning and mobility, bathing, wound cleaning, skin care, oral hygiene, adequate ventilation, and guidance and support for adequate nutrition. Based on this role of physical care this study examined whether home based caregivers in Njoro Sub-county offered physical care further more identify situations where adequate caregiving such as basic needs of shelter, food, bedding and clothes were provided.

2.4.2 Palliative Care

HBCGs also provide palliative care, which involves a combination of active and compassionate long-term therapies intended to comfort and support individuals and families living with a life threatening illness. The home based caregiver strive to meet the physical, psychological, social and spiritual needs of people living with HIV, a task that requires a team approach and that includes the patient, family, health and social welfare workers as well as the home based caregiver (WHO, 2002). Early counseling, as soon as people receive a diagnosis of HIV, can help them cope with the diagnosis and advise them on behavioral changes that will reduce future health problems and limit transmission of the disease (Lever, 2006b). Community-based care should be supported by the formal health care system. People living with HIV/AIDS need comprehensive care delivered across a continuum that extends from the home to the hospital and includes community organizations as well as the formal health care system. Above all, a strong referral system and consistent discharge-planning will link services together so that people living with HIV/AIDS can seek care at the most appropriate level and move freely between levels of care (Akintola 2004).

In Njoro Sub-county compassionate International assist registered people living with HIV with recreational services, companionship, transportation, in-patient services, clerical work, conference participation, public speaking, and counselling among other duties, to lighten the burden of the disease on the client and family. They also accompany the patient to the hospital to obtain medical treatment and negotiate for what they perceive as appropriate treatment based on their experience (Opiyo, 2008).

In a survey of home-based care patients in Malawi, about 15% of people living with HIV were healthy and not showing visible signs of HIV. More than one third needed help bathing and walking, and about 28% needed help going to the toilet (Leake, 2009). In another study in South Africa about 16-17% of people living with HIV could not control their bladder or bowels, and needed help getting on and off the toilet (Gumbi, 2001). A similar proportion required help in bathing themselves. Given the debilitating effect of HIV/AIDS, a certain percentage of people living with HIV may need assistance performing the simple tasks that most of us take for granted, and they are often assisted by home based caregivers. It is on this ground that this study examined the type of palliative care offered in Njoro Sub-county since HIV/AIDS offers special challenges to palliative care because the course of the disease and its possible complications are unpredictable and highly variable.

In a South African survey it was found that less than half of the households had a tap-water and only 20% of rural homes had access to a flush toilet, with a quarter having no access to any form of toilet or latrine (Leake, 2009), which does not make roles and responsibilities any easier. All these factors make it difficult for the HBCGs to optimally fulfill their roles and responsibilities. According to Jackson (2002), the role of caring for PALHIV is very difficult, even to the point where a caregiver may end up feeling a sense of failure, inadequacy, resentment and anger. The care role is made more difficult by the fact that PALHIV may get sick, recover, and become ill with something else, gain recover, and so on. This could be an endless, confusing circle which can be emotionally exhausting to both the caregiver and the patient (Leake, 2009). Due to this special challenge of offering palliative care and because the course of the disease and its possible complications are unpredictable and highly variable there was need to fill this gap.

2.5 Social Challenges Faced by Home Based Caregivers

HBCGs are faced by many challenges emanating from caring for PALHIV. Caring for PALHIV is associated with high levels of stress, burnout, anxiety, and financial burden, and can be very draining–physically, emotionally and psychologically as well as socially (Homan et al., 2005). Both caregivers and PALHIV are faced with challenges such as continuous physical and psychological deterioration, their own mortality and the fear of contagion and death. This can challenge a caregiver‘s ability to cope. If they do not learn how to care for themselves, they will not survive the on slaughter of the HIV pandemic (Akintola, 2004; Van Dyk, 2001).Despite this challenges, the CHBC programs in Kenya, as currently being implemented, have faced several challenges therefore there was need to evaluate whether in Njoro Sub-county HBCs faced the same challenges.

Family members, including those with HIV, are involved in many different roles, from parent to child to caregiver. As an international public health issue, HIV/AIDS is proving severely disruptive to families, entire communities, and social structures worldwide. AIDS affects the entire household, with family members losing their most productive years, resulting in permanent poverty as the illness reduces the ability to work, and increases medical costs, as well as funeral expenses (UNAIDS (2012). Young people continue to be at the growing center of the pandemic. For example, in Africa, nearly one million African students are deprived of a teacher annually because of the impact of HIV/AIDS (Grindel, 1999). Worldwide, there is insufficient programming and support services for family members/caregivers and orphans. Children orphaned due to AIDS-related deaths of parents or caregivers face an unpredictable future that is often compounded by the same stigma, discrimination, and social isolation faced by their parents/caregivers (Greene, 2008).

Children infected and affected by AIDS will face similar problems to other children in difficult circumstances. It was estimated that by the year 2010 in sub-Saharan Africa alone, more than 18 million children more than all the children in the United Kingdom will have lost at least one parent to AIDS (Ehlers, 2006). The loss of parents can have profound emotional, economic, and developmental consequences for any child, especially in poor households. In Africa, AIDS has produced the phenomenon of child-headed households, where the older children have to care for their siblings in the absence of adults (France, 2008). This situation will be worse in cases where some of the children may also have HIV/AIDS and are in need of medical care. Child caregivers and other orphans in poor households may have to earn a living off the streets or in poorly paid work where they are even further at risk from hunger, disease, or sexual exploitation and consequent risk of HIV infection (Homan et al., 2005).

2.5.1 Stress and Burnout

According to VanDyk (2001), burnout can be defined as a syndrome of physical and emotional exhaustion involving the development of a negative self-concept, negative job attitudes, and loss of concern and feeling for clients. According to Gueritault et al., (2000), occupational burnout may occur where work demands especially those of an interpersonal nature lead to chronic emotional exhaustion, depersonalization and a reduced sense of personal accomplishment, such as may happen when caring for PALHIV.

HBCGs work very closely with PALHIV who are dying and this can leave them emotionally and physically drained. According to Ross, Greenfield and Bennet (1999), emotional overload brings unhappiness, over-involvement, exposure to others' grief, death of a client and a feeling of helplessness on the part of the caregiver. When HBCGs feel emotionally stressed they therefore face work-related stress, which leaves them very susceptible to symptoms of burnout such as loss of interest in and commitment to work, a lack of job satisfaction, not being punctual and neglecting duties, a loss of sensitivity in dealing with clients or patients, referring to clients in a dehumanized or purely impersonal way, avoidance of clients to limit the time spent with them and frequently but unnecessarily referring clients to other health care professionals, deteriorating relationships with colleagues and friends, tension and distress in their personal life as well as difficulties in getting on with people. These symptoms can lead to a high level of turnover, absenteeism, and reduced productivity, which impact on the general running of the organization (Jackson 2002; Pendukeni 2004; WHO 2002).

When HBCGs begin to feel that they are not supported, it often leads to burnout. If burnout is not controlled it may lead to depression, which will make them feel despondent and will affect the caregiver‘s ability to provide optimal care to PALHIV. Depression in the context of HIV is caused by many factors including a feeling of a lack of control over one‘s fate, changes in a person‘s self-image, and exposure to stigma (Simpson 2006; Uys & Cameron 2003; WHO, 2002). A study by Demmer (2004) provided evidence that younger caregivers for PALHIV are more likely to experience burnout than older workers. This may be due to lack of experience as well as to being over-involved in the job. There is no significant difference in burnout based on marital status and sexual orientation in HIV caregiving or a person‘s occupational role.

The following has been found in different African countries: a study in Zambia reported that, despite the fact that health workers were still relatively motivated, emotional exhaustion occurred among 62% of the respondents who took part in the study (Dieleman et al., 2007). In one Namibian study, mentioned in Pendukeni (2004), it was found that nurses were not prepared to deal with PALHIV, and as a result looked for reasons to stay away from work – clearly confirming that stress leads to absenteeism. Workload also contributes to burnout. According to the study conducted by Dieleman *et al.* (2007) in Zambia, HIV/AIDS has had a negative impact on the workload of caregivers and has considerably changed or added tasks to an already overburdened health sector.

According to Gueritault-Chalvin et al., (2000) research reported that the perceived workload was positively correlated to burnout, and even significantly predicted burnout. Stress leads to frustration as a result of HBCGs‛ lack of knowledge and skills in dealing with patients, work demand, lack of competence, and as a result also of their hiding their true feelings, emotions and fear. According to Primo (2007), caregiver stress can be divided into primary and secondary stress. Primary stress comes from the everyday duties of a caregiver such as assisting a patient with bathing, toileting and managing the patient‛s difficult behavior as well as the planning of daily care. Secondary stress emanates from the caregiver‛s conflict with other family members (own family or the family of the patient). Hence need to fill the gap whether home based caregivers in Njoro Sub-county experienced a negative impact of stress and burnout when providing care to PALHIV.

2.5.2 Physical Effects

According to Primo (2007), caregiving is burdensome and may compromise a caregiver’s health. Symptoms of poor physical health are markedly present among AIDS caregivers and are associated with care-related demands and stressors. The level of depression among caregivers strongly correlates with different physical ailments. The multiple tasks they perform often result in neglecting their own self-care, such as nutrition, exercise, socializing and sleep. They develop detrimental health behavior such as over eating, smoking, not exercising and disturbed sleep.

Consequent to detrimental health behaviour, certain caregivers, especially women, gain weight, their immune system weakens and the healing of their wounds are often affected .One study mentioned by Leake (2009) found that most caregivers suffered physically as a result of caring and experience headaches, body aches, backaches and exhaustion as common problems.

Consequently, there was need to fill the gap by identifying whether caregivers in Njoro Sub-county suffered physically as a result of caring.

2.5.3 Stigma and Discrimination

Home based caregivers who experience the greatest emotional stress tend to be female. They are at risk for high levels of stress, frustration, anxiety, exhaustion and anger, depression, increased use of alcohol or other substances, reduced immune response, poor physical health and more chronic conditions, neglecting their own care and have higher mortality rates compared to non-caregivers. According to Van Dyk (2001), and Friedland, Renwick and McColl (1996), both infected and uninfected HBCGs working in the HIV/AIDS are stigmatized. According to WHO (2002), for PALHIV and their family members, the stigma, fear and discrimination often associated with the illness can create barriers to effective care. This was reported in a study mentioned in a WHO report, which revealed isolation, fear and discrimination as common themes that were related to HIV/AIDS. The study also acknowledged that teaching health and social service personnel about universal precautions is not sufficient to reduce stigma behaviour (WHO 2002).

In a study carried out by Pendukeni, (2004), it was noted that the caregiver actively dealt with associative stigma by challenging the negative behaviours and discriminative remarks uttered by family members and other societal members directly and indirectly to PLWHA by correcting and confronting those that stigmatised the infected people. Stigma encompasses a perception of negative characteristics and a global devaluation of the possessor of the characteristic. Issues of isolation and rejection, and subsequent prejudice and discrimination, stem from the fact that people often try to avoid interaction with individuals whose bodily and psychological characteristics deviate from the norms of family members and society.

HBCGs on the other hand are at times avoided or ostracized because they work with PALHIV, and therefore they are deprived of much needed support. The caregivers and the sufferers are vulnerable to the effects of stigma such as isolation, emotional turmoil and shame. This could possibly lead to poor coping strategies as a result of poor social support because caregivers are resistant to disclosing what they are really dealing with. Hence this research focused on whether stigma in most cases leads to isolation from usual support networks in Njoro Sub-county with the intent also to address this underlying question about stigma and discrimination.

2.5.4 Risk of Contracting the Disease

Many studies, such as Primo (2007), Pendukeni (2004) and Dieleman et al. (2007), have identified contagion as one of the serious concerns among HBGC. One major stress producing concern shared by many AIDS workers is anxiety over safety practices and fear of occupational contagion, rooted in occupational exposures to HIV. According to a study conducted by Pendukeni (2004), the nurses in her study expressed fear of contagion not only from the PALHIV but also from their colleagues. This fear is exacerbated by the difficulties experienced in maintaining consistent and appropriate infection control precautions. HBCGs may also harbor irrational fears of contagion taking place through casual contact, or touching utensils used by a PALHIV, despite their knowledge of the facts about HIV/AIDS. This fear can consequently cause physical or empathetic withdrawal from persons with HIV/AIDS, resulting in deprivation of physical and emotional contact with the PALHIV, which is the most valuable intervention.

In another study of caregivers in Zambia, more than75% of the respondents expressed fear of infection in the workplace, despite the fact that there are protective measures in place (Dieleman *etal.,* 2007:1). According to Leake (2009), close contact with patients ‘faeces, vomit and other bodily fluids create the risk of HIV and tuberculosis infection for the caregiver. The risk is exacerbated by not taking precautionary measures such as wearing rubber gloves. However, even though there are anecdotal reports of caregivers becoming infected with HIV in this manner, there is little documented evidence of this (Gueritault-Chalvin *et al*. 2000; Pendukeni 2004; Primo 2007). Consequently in this research the study focused on burnout among the HBCGs who experienced fear of contagion as well as those feeling discomfort in dealing with PALHIV.

2.5.5 Confidentiality and Autonomy

Confidentiality is one of the challenges faced by HBCGs. According to Makoae and Jubber (2008), confidentiality has mainly been considered from the perspective of protection of PALHIV from stigmatization, however, this contradicts the fundamental values of shared responsibility in informing other sexual partner/s so that they can practice safe sex (WHO,2002). According to WHO (2002) some PALHIV do not want their families, including their spouses or sexual partners, to know their diagnosis and the HBCGs should agree to this as the human rights of the patients. This is evident in the study by Primo (2007), which reported that HBCGs are often designated as the keepers of secrets.

The keeping of secrets not only depletes emotional energy and causes inner conflict and isolation, but also affects the ability to provide a professional relationship. Some patients cared for by HBCGs present obvious symptoms of opportunistic infections but refuse to test for HIV, and the HBCGs cannot force them. All these ethical dilemmas, together with a lack of appropriate community resources and facilities, can make a HBCG in the field of HIV/AIDS experience a sense of inadequacy and exacerbate their difficulty in coping with their work (Primo,2007). Little research has been conducted on confidentiality of caregivers when caring for PLWHA. This is particularly needed with regard to primary caregivers since these people spend most of the time with the HIV sufferers. Consequently the study focused on whether confidentiality helped in dealing with disclosure and the effect of HIV/AIDS among the caregivers in Njoro Sub-county.

2.6 Economic Challenges of HBCGs

The global estimated value of unremunerated work by women is 11 trillion dollars (Bharat & Mahendra, 2007). At the societal level, economic growth in many nations is lagging because so many skilled and experienced workers have died of AIDS. High unemployment and high rates of infection among skilled workers bode ill for countries’ ability to keep social supports intact (Center for Disease Control, 2004).

2.6 .1 Financial Aspects

Long term caregiving has significant financial consequences for caregivers, particularly for women. Caregivers face the loss of income of the care recipient, loss of their own income if they reduce their work hours or leave their jobs, shrinking of savings to pay caregiving costs (Wringe *et al.,* 2010). In a study by Jackson (2007), finance was one of the challenges experienced by HBCGs as their stipend included transport to see a doctor, and transporting patients to hospital, for example. Some therefore leave caregiving after having received training, as they often do not receive any stipend or it is not sufficient to cover their needs and those of their patients. This challenge can be categorized as secondary stressors (economic hardships), which may include loss of employment and income (Aldwin, 2007). When it comes to the financial costs, caregiving may negatively impact working daughters more than sons, both in terms of their ability to work and the hours they log at work. More than one-third of caregivers end up leaving the workforce or reducing their work hours, and women are more likely to leave their jobs once they begin caring for a parent than to reduce the hours they work (Demmer ,2004). This study focused on establishing whether HBCGs in Njoro Sub county experienced the challenge of lack of finances when dealing with PALHIV.

2.6.2 Poor Nutrition

Women face particular financial burdens in care giving, particularly in diverting their time from other productive chores (Makoae& Jubber, 2008). Women produce between 60-80 percent 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 macroeconomic modeling (Leake, 2009).Studies have shown that the extra responsibilities of AIDS related care can divert their labour from productive agricultural work creating further household food insecurity (Mohammad & Gikonyo, 2005). There was therefore a need to establish whether HBCGs in Njoro Sub county had a challenge of nutrition when dealing with PALHIV.

2.6.3 Unemployment and Reduced Time for Skill Building

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 care giving 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 care giving time (Bharat and Mahendra, 2007). 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 caregivers in the home. One study found that one in five Kenyan health workers were caring for an immediate family member living with HIV (Mohammad and Gikonyo, 2005).

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 (Horman *et al.*, 2005). 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.

Studies of teachers and health care workers, for example, indicate that many in those professions have been infected with HIV (Dageid, Sedumedi, & Duckert, 2007). Society faces the challenges of having many of its productive members sick or dying, leaving few people to care for children and the elderly. In many countries, the number of people affected by HIV/AIDS is overburdening health care and social support resources. This study intended to establish whether unemployment affected the home based caregivers in Njoro Sub-county.

2.6.4 Poverty and Rising Number of Orphans

Family members, including those with HIV, are involved in many different roles, from parent to child to caregiver. As an international public health issue, HIV/AIDS is proving severely disruptive to families, entire communities, and social structures worldwide (World Health Organization, 2012). AIDS affects the entire household, with family members losing their most productive years, resulting in permanent poverty as the illness reduces the ability to work, and increases medical costs, as well as funeral expenses. Young people continue to be at the growing center of the pandemic. For example, in Africa, nearly one million African students are deprived of a teacher annually because of the impact of HIV/AIDS (UNAIDS, 2012). Worldwide, there is insufficient programming and support services for family members/caregivers and orphans. Children orphaned due to AIDS-related deaths of parents or caregivers face an unpredictable future that is often compounded by the same stigma, discrimination, and social isolation faced by their parents/caregivers (UNAIDS, 2012).

In Africa, AIDS has produced the phenomenon of child-headed households, where the older children have to care for their siblings in the absence of adults. This situation will be worse in cases where some of the children may also have HIV/AIDS and are in need of medical care. Child caregivers and other orphans in poor households may have to earn a living off the streets or in poorly paid work where they are even further at risk from hunger, disease, or sexual exploitation and consequent risk of HIV infection (UNAIDS, 2012). Hence need to fill the gap on whether home based caregivers in Njoro Sub-county experienced poverty when providing care to PALHIV.

2.7 Coping process

Coping is a process that is characterized by functions of continuous appraisal and reappraisals of the shifting person-environment relationship. According to Aldwin (2007), how a person copes with a problem is largely dependent upon his or her own appraisal of the situation. Appraisal is considered to be a conscious evaluation of whether a situation is benign, threatening, involves harm or loss, or constitutes a challenge. Lazarus and Folkman (1984) see coping as a process which consists of four steps. The first step involves determining the meaning of an event or situation and its implication for one‘s well being. The second step is assessing one‘s coping resources and the likelihood of the effectiveness of various coping strategies. Selecting a coping strategy concludes this step. The third step involves carrying out the selected coping strategy. Finally, the fourth step involves evaluating one‘s coping efforts with regard to the effectiveness in eliminating or reducing the stressors or managing one‘s response to the stressful event.

When working with people living with HIV it is inevitable to deal with death and grief and it will therefore be interesting to note how home based caregivers follow the above mentioned steps in order to cope with their own grief and that of their patients therefore having to adopt some or all of these steps. This study focused on how home based caregivers coped with their patients and the grief their families undergo after loss of a loved one.

2.7.1 Coping strategies

There are two widely accepted models of coping strategies, which are seen by Lazarus and Folkman (1984) as major categories of coping responses, namely emotion-focused and problem-focused forms of coping: Emotion-focused forms of coping are more likely to occur when there has been an appraisal that nothing can be done to modify harmful, threatening or challenging environmental conditions. It consists of cognitive processes directed at lessening emotional distress and includes strategies such as avoidance, minimization, distancing, selective attention and positive comparisons from negative events. However, there are also cognitive strategies that increase emotional distress, such as self-blame which comes in a form of self-punishment.

Problem-focused forms of coping are more probable when such conditions are appraised as amenable to change. Its strategies are similar to those used for problem-solving, and are directed at defining the problem, generating alternative solutions, weighing alternatives in terms of their cost and benefits, choosing amongst them, and then acting. Problem-focused coping also include strategies directed at the environment and those directed at the self (Lazarus and Folkman 1984).These coping responses are interconnected and necessary for effective coping. They emphasise managing responses to various problems and incorporate a reactive perspective to the situation; they are not mutually exclusive and may even occur simultaneously.

Women are seen to be more comfortable with emotion-focused strategies (Hood and Carruthers 2002). Lazarus and Folkman (1984:119) identified various coping strategies, which are referred to as coping devices, and which include self-control, humour, crying, swearing, weeping, boasting, talking it out, thinking it through, and working off energy .They are regarded as normal or, at worst, distinctive characteristics. According to Grindel (1999), holster experiencing lower levels of loneliness and depression and higher levels of self-esteem. If these characteristics are used inappropriately or to an extreme, for example, when a person talks too much, laughs too easily, loses his or her temper frequently or seems erratic, they lose their status as coping devices and becomes symptoms which indicate a degree of dysfunction and threatened disequilibrium.

2.8 Theoretical Framework

The study used Coping theory and Behavioral theory which are relevant to this study. Coping theory provides understanding in the way home based caregivers reflect on what is happening and their own emotional reactions to situations in relation to coping, and how it affects the physical and societal environment. These two theories allow the researcher to explore how people experience, describe and interpret a phenomenon: In this case, living with and caring for PLWHA. By exploring their experiences as well as their coping strategies, a description of the experiences by these participants was given in order to discover the common meanings underlying the phenomena.

The study departed from Lazarus and Folkman`s (1984) theory of stress and coping. According to Lazarus and Folkman`s theory there is a relationship between the person and the environment. Psychological stress results when individuals appraise their environment as demanding or exceeding their resources and endangering their well being (Lazarus and Folkman, 1984).Primary appraisal is a process in which a person perceives risks related to an encounter, thus resulting in stress. In primary appraisal a person may perceive a stressful situation as a benefit, challenge, threat and harm or loss (Lazarus and Folkman, 1984). A stressful situation is appraised as challenging if it results in physical and psychological activity involvement. The theory describe secondary appraisals as the individual`s available coping options for dealing with stress. In the process of dealing with stress the individual evaluates his/her competence, social support, material support and other resources in order to readapt to the circumstances and to reestablish equilibrium between the person and the environment.

According to Lazarus and Folkman (1984) coping is related to cognitive appraisal and to stress relevant person environment transactions. Various studies revealed that home-based care giving results in physical, emotional and psychological stress on the voluntary home-based caregiver (Akintola, 2008a; Jack, Kirton, Birakurataki and Merriman, 2011). Voluntary home-based caregivers are in an interactional relationship with persons and the environment, and therefore the study sought to explore how they describe the challenges that they experience while providing care to people in their homes.

It further highlights the strategies that the home based caregivers implement to solve problems. The theory deem to be relevant to this study as it tries to explore the problems experienced by home based caregivers for people living with HIV in order to provide quality care and to be productive in the society to people living with HIV/AIDS. Behavioral theory is also integrated as it tries to apply principles of human learning to facilitate the replacement of maladaptive behavior with more adaptive ones.

2.8.1 Coping theory

Under normal and natural phenomenon, coping constitutes the actions taken by individuals and animals when faced with stressful events in order to lessen the threat to them. Stress is a state of tension felt in the presence of an object or a task that is perceived as presenting a challenge to one's safety or self-esteem (Gottlieb, 1997). Stress emanates when there is a perceived discrepancy between environmental demands and one's ability to meet those demands. Stress has both psychological and physiological causes and effects. For an individual to continue functioning in an adaptive way, he/she must learn to cope with stress. There are many ways to cope, varying from avoiding stress or denial of stress at one extreme to seeking and confronting the source of stress.

According to Friedland, Renwick and McColl (1996) coping attempts either to reduce the demand, to reduce its effects, or to help one change the way one thinks about the demand. It also attempts to eliminate or moderate the initial source of the stress reaction (stimulus-directed coping), reduce the magnitude of the stress response (response-directed coping), or change the way the stressor is perceived (cognitive coping). For individuals such as caregivers in the HIV/AIDS field, both the internal factors (such as knowledge) and external (such as money or friends) are necessary to help one cope with a stressful event. Social support or resources provided by other people to enhance one's self-esteem, psychosocial support, and assistance are critical in helping the coping process. According to Friedland, Renwick and McColl (1996) coping responses are classified as either problem-focused or emotion-focused. Problem focused coping, known as confrontive coping, is that strategy used by the individual to identify causative factors for an occurrence, and then devising means and ways of dealing with that in an effective manner (Rose and Clark-Alexander, 1999). This form of coping is goal-directed as it is directed at defining the problem, generating alternative solutions, weighing costs and benefits, and then choosing and acting on a solution. Examples of confrontive coping include bargaining, focusing on the positive, social support, and concentration of efforts (Gottlieb, 1997).

Emotion-focused coping, also known as passive and emotive coping, is the avoidance of a problem which can be used to maintain hope and optimism; but it can also be used to deny both the facts and implications of the facts, and to act as if what has happened does not matter that is, the impact and consequences do not have to be addressed Gottlieb, 1997). It is generally used when individuals believe they are unable to change a stressful situation. Emotion-focused responses include cognitive escape-avoidance, behavioural escape-avoidance and distancing as a result of poor outcomes, such as high levels of depression (Gottlieb, 1997). Research linking caregiving and stress has been taking place for many years. Several reasons explain this striking growth of interest. According to Friedland, Renwick and McColl (1996), one of these reasons concerns the changing demographic landscape of contemporary societies: People live longer, and therefore are more at risk of chronic ailments that impair their ability to care for themselves. As a result of medical advances, they survive for longer periods of time despite their health problems, consequently needing those that can care for them.

Today, people are infected with HIV/AIDS, which leads to debilitation as the disease progresses irrespective of age at infection thus needing someone to care for them. Stressors are experiences, conditions and activities that are problematic to people, threatening them, and thwarting their efforts, resulting in their dreams ultimately being defeated by fatigue. Coping and social support are the two principal mediators used by researchers to measure whether people exposed to seemingly similar stressors are affected by them in dissimilar ways. The context, in which a stressful event occurs, as well as the demographic variables of age and gender, influences the kinds of coping used by individuals to cope with stress. This research focused on whether home based caregivers faced a stressful situation and whether social support or resources provided by other people to enhance one's self-esteem, psychosocial support, and assistance are critical in helping the coping process.

2.8.2 Behavioral theory

This theory postulated that behavior whether adaptive or maladaptive is learnt, shaped and maintained through reinforcement. The approach of operant conditioning to learning development by B.F Skinner (1904-1990) examines how environmental influence affects or shapes the behavior of individuals. Basically operant conditioning is a type of learning in which behavior is altered by systematically changing consequences. The general goal is to create new conditions for learning to apply principles of human learning to facilitate the replacement of maladaptive behaviors with more adaptive ones. The assumption is that learning can ameliorate problem behaviors.

The Counselors task is to apply principles of human learning to facilitate the replacement of maladaptive behaviors with more adaptive ones. At each developmental stage in life important social skills must be mastered. Children need to learn how to interact with the opposite sex peers and administrators. Persons who lack social skills frequently experience interpersonal difficulties at home, school and during leisure time. Behavior methods have been designed to teach such individuals ways of interacting successfully. Many persons have difficulty in feeling that it is appropriate or right to assert.

Assertion training can be useful for the following persons: those who cannot express anger or irritation, those who have difficulty in saying no, those who are over polite and allow others to take advantage of them and those who find it difficult to express affection .All these behaviors can be observed and noted among the home based caregivers. Since 1970 behavior therapy has been applied to a great number of areas such as child rearing, improving athletic performance, and enhancing the lives of people in nursing homes, psychiatric hospitals (Mishne, 1994). Furthermore behavior therapy has been better understood as a process in which patient and therapist (counselor), in many cases, collaborate together for improvement in psychological functioning. In behavioral therapy the relationship with the client is valued as the client is supposed to find solution to his/her problems through guidance and counselling process.

2.9 Conceptual Frame Work

From the study topic the dependent variable is home based care which is conceived as a means of alleviating the strain on overburdened and under-resourced hospitals whilst providing better and more holistic care to chronically ill HIV/AIDS patients. The independent variable is the socio-economic challenges faced by home based caregivers who provide palliative care, spiritual care and social support for persons living with HIV and AIDS. Home based caregivers face challenges such as stigma and discrimination. Home based care is meant to be a support mechanism for the hospital system and the PLWAs and their families; a way to empower communities to respond to the impact of HIV/AIDS themselves by supporting them. When there is a sick or dying person in the house, someone quite literally has to care, whether out of love, duty, or simply a lack of options. The intervening variables are the characteristics of caregivers (gender, age, socio-economic status and level of education). Quite often, the burden of care is borne by women and female children. The care work done by women and girls in the household, which includes the services associated with physical, social and psychological development of family members, as well as volunteer activities in the community that keep the social fabric in good order.

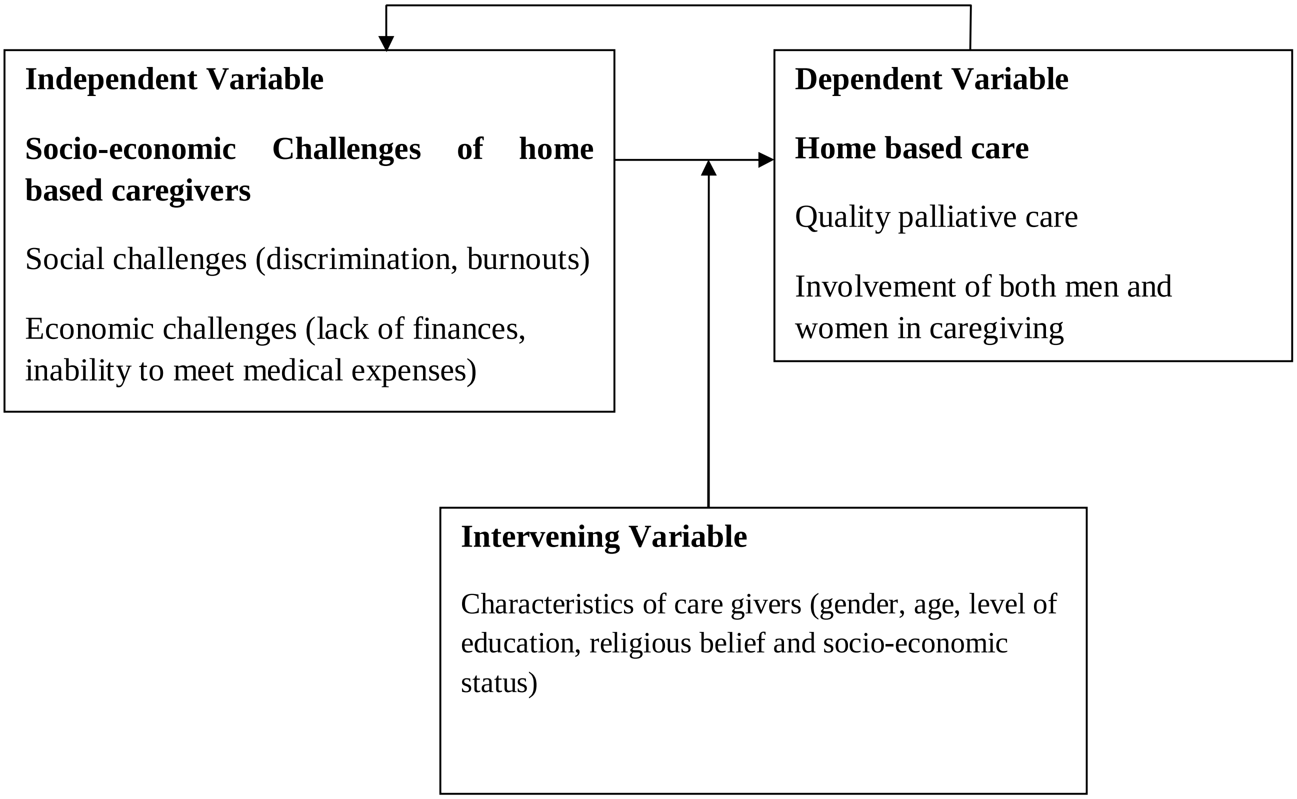

Figure 2.1: Interaction between Independent Variables and Dependent Variables

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

This chapter describes the method used to carry out the study. It discusses the research design employed, study area, population of the study, sampling procedure, instrumentation, data collection procedures and data analysis.

3.2 Research Design

The study used descriptive survey design which sought to obtain information that describes existing phenomena by asking individuals about their perceptions, attitudes, behavior or values. Surveys, according to Kathuri and Pals (1993) are important in research and have been found useful in describing the characteristics of a population under study. This research design assisted to explain the situation on the ground on the socio-economic challenges and coping mechanism of home based caregivers for people living with HIV/AIDS in Njoro Sub-county.

3.3 Location of the Study

The study was carried out in Njoro Sub-county in Nakuru County. The Sub-county was selected because HIV/AIDS pandemic places enormous burden on healthcare services in Njoro Sub-County District Hospital, as a result patients are forced to be discharged prematurely due to low bed capacity in the hospital. This has led to HIV/AIDS patients to seek care at their homes which includes physical, psychosocial, palliative and spiritual interventions. This has led to home based caregivers to suffer from psychological, social and economic challenges when caring for people living with HIV/AIDS. NGOs such as Compassionate International through AIC church and APHIA II USAID project have initiated projects aimed at caring for people living with HIV/AIDS through families and the community. This had initiated interest to carry out the study in the area. The area is known for various agri-business industries for example flower farms, processing industries and institution of higher learning dealing with agricultural research. The Sub-county has a population of 110803 people (MOPND, 2009a) and receives an annual rainfall of about 900-1200 mm. The Sub-county is served by several AIC churches where projects aimed at caring for the people living with HIV/AIDS have been implemented. A hundred and three individual home based caregivers caring for the people living with HIV/AIDS were selected from a study population of 420 home based caregivers who were registered in the local administration for relief in Njoro Sub-county.

3.4 Population of the Study

The study population was derived from the four locations of Njoro Sub-county as stipulated in Table 3.1.The population of this study was 420 individual home based caregivers who were registered in the local administration for relief of people living with HIV/AIDS in Njoro Sub-county.

Table 3.1

Distribution of Population per Location

Locations	Population	Households	No. of registered home based caregivers
Njokerio	27727	5546	180
Mukungugu	24356	4871	110
Njoro town	43746	8749	90
Ng’ondu	14974	2995	40
Total	**110803**	**22161**	**420**

Njoro Sub-County Hospital Field Survey: 2012

3.5 Sampling Procedures and Sample size

From a population of 110,803 purposive sampling was used to obtain a study population of 420 home based caregivers who had ever provided care or were at that time providing care and were registered with the local administration for relief of people living with HIV/AIDS in Njoro Sub-county. The sample was derived using the formula developed by Walter and Meredith (2006).

$$n = \frac{Z^2P(1-P)}{E^2}$$

$$n = \frac{1.96^2x0.928(1-0.928)}{0.05^2}$$

Where;

n- Sample size

E -The standard error in this study, set at 5%

P-proportion of practice of Home Based Care among home based caregivers for PLWHA in the target population is estimated to be 92.8% (Walter& Meredith, 2006).

Z- The standard normal deviation, set at 1.96

Substituting;

$$n = \frac{\underline{1.96^2 x 0.928(1-0.928)}}{0.05^2} = 103$$

Therefore, the sample size used was 103 which was generated from the formula. To pick the 103 respondents from 420 random numbers were assigned and individuals picked randomly from the 420 registered caregivers with the local administration for relief of people living with HIV/AIDS in Njoro Sub-county.

3.6 Instrumentation

The study used questionnaires which were administered to the home based caregivers. According to Kathuri and Pals (1993), a questionnaire is a self-report instrument used for collecting information needed for the survey. The questionnaire was designed into different sections: section A captured socio-demographic data of the respondents such as gender and age of caregivers, Section B captured information about home based care support provided such as basic nursing, Section C captured information about the Socio-economic challenges faced by home based caregivers and section D captured information about coping mechanism of home based caregivers. The questionnaires assured high response rate, accurate sampling, providing necessary explanations and giving the benefit of personal contact. Another advantage of the questionnaires is that data processing and analysis was cheaper. Also, self-completed questionnaires which respondents filled were very efficient in terms of researchers time and more accurate.

3.7 Validity and Reliability

To determine the reliability of the instrument, the questionnaire was piloted on a small sample of 10 subjects selected in Elbergon sub-county that was not to form part of the main study sample. Respondents were presented with the questionnaire on two different occasions with a time frame of 10 days apart. A Pearson correlation coefficient between the two sets of questionnaires was determined. The correlation coefficient arrived at was 0.7547 that suggested the instruments employed during data collection had a high reliability. According to Mugenda and Mugenda (2003) a reliability coefficient of 0.7 and above is recommended as it implies high degree of reliability.

To determine validity of the instrument the researcher sought the expertise of the supervisor and piloted regarding the test items included in the tools of data collection. This was to determine if the instrument measured adequately the research objectives. According to Kathuri and Pals (1993), internal validity is concerned with the extent to which a study establishes a factor or variable that actually caused the effect. It is the extent to which extraneous variables have been controlled. External validity of the instrument indicated the appropriateness and applicability of inferences to the target population.

3.8 Data Collection Procedures

The data for the study was collected by conducting household survey whereby individual members of registered home based caregiver were located after which questionnaires were administered to them by the researcher. Local leaders and social workers were used in assisting the researcher to locate the home based caregivers who were registered. This enabled the researcher to easily access the households in the study areas. Appointments for visits were made to the home based caregivers in advance. According to Fraenkel and Wallen (1995), questionnaires were used as they had room to explore participant responses and provided the respondent freedom in answering the questions in the questionnaire. When the home based caregivers were busy they were left with the questionnaire to fill at their own free time and were collected later.

3.9 Data Analysis

After fields visits the responses were checked for completeness .The filled questionnaires were coded and data entry was done in the computer for analysis .The data was then analyzed using Statistical Package for the Social Science (SPSS) software (Version 22). The data that was generated from the study was analyzed by descriptive statistics .Data presentation was done using frequency tables, bar graphs and pie charts. This offered a systematic and quantitative description of the objectives of the study.

CHAPTER FOUR

RESULTS AND DISCUSSIONS

4.1 Introduction

This chapter presents the results of the study and a discussion of the study findings. The purpose of the study was to investigate socio-economic challenges experienced by home based caregivers for people living with HIV/AIDS and their coping mechanisms in Njoro Sub-County. The findings of the study are presented based on the following research questions:-

i) What types of support are provided by home based caregivers for people living with HIV/AIDS in Njoro Sub-county?
ii) What are the social challenges faced by home based caregivers for people living with HIV/AIDS in Njoro Sub-county?
iii) What are the economic challenges faced by home based caregivers for people living with HIV/AIDS in Njoro Sub-county?
iv) What are the coping mechanisms used by home based caregivers for people living with HIV/AIDS in Njoro Sub-county?

Data for the study was collected from 103 individual home based caregivers who were registered in the local administration for relief of people living with HIV/AIDS in Njoro Sub-county, Nakuru County. The responses to the questions were presented using frequency tables and charts which were then discussed on the basis of research objectives and the reviewed literature.

4.2 Socio-demographic Data

This section dealt with socio-demographic data of respondents. This data included information on respondents' ages, gender, marital status, educational level, employment status and their estimated monthly incomes. This section also reports on the duration of awareness of HIV status of their clients and the training of home based caregivers.

4.2.1 Gender of the Caregivers

Out of 103 caregivers, 76 (73.8%) were females and the rest were males. This implies that majority of the home based care givers were females hence gender disparity on care-giving as few men are providing care. Worldwide, it is well known that the majority of home based caregivers are women (UNAIDS, 2003).

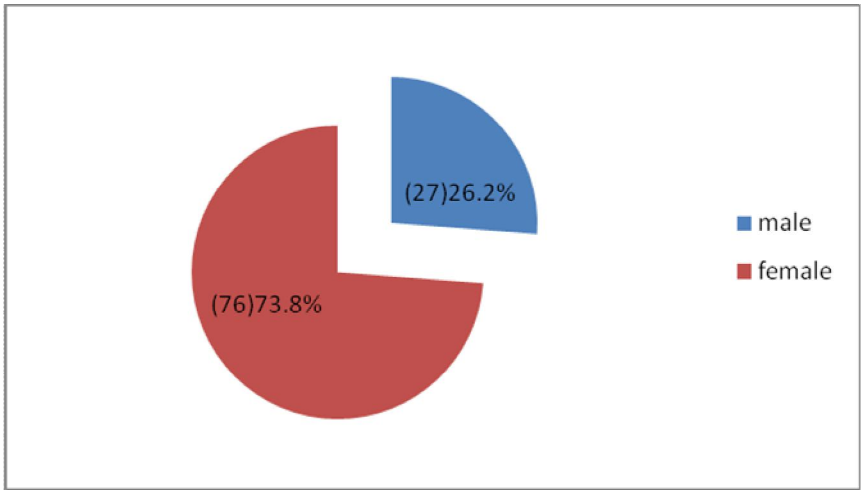

Figure 4.1: Gender of Home Based Caregivers

From the study results the home based caregivers consisted of both men and women; their care recipients were also men and women. The reason for having both male and female caregivers is that though in the past caregiving was associated with women, ever since the recognition of HIV/AIDS it was found that men do also become caregivers (Shebi, 2006). It was also noted that, in the past, women were perceived to be more emotional in comparison to men, and consequently were perceived to be unable to cope with certain challenges. But the most salient finding that emerged is that majority of the caregivers consisted of women, with only very few men being caregivers. A conclusion drawn on this fact is that care-giving seems to attract more women than men a view that authors such as Leake (2009), Homan et al. (2005), as well as Bharat and Mahendra (2007) support in their studies. This scenario could be because of the fact that more women than men work in or around homesteads. For this reasons, it becomes natural for women to take care of the affected. Men on the other hand, are more mobile as they go out to look for jobs, especially in urban areas, often away from their homes. The men in most cases send whatever they are able to get to their families. For this reason the most visible caregiver in the homes is mostly the woman.

4.2.2 Age of the Caregivers

The age of caregivers was categorized from those who were younger than 25 years to the older than 45 years. This is shown in Figure 4.3. From the results 14 (13.6%) caregivers were at most 25 years which happened to be the category with the least percentage of caregivers. The category with the highest percentage of caregivers was 36-45 years (35%). The other categories were as shown below.

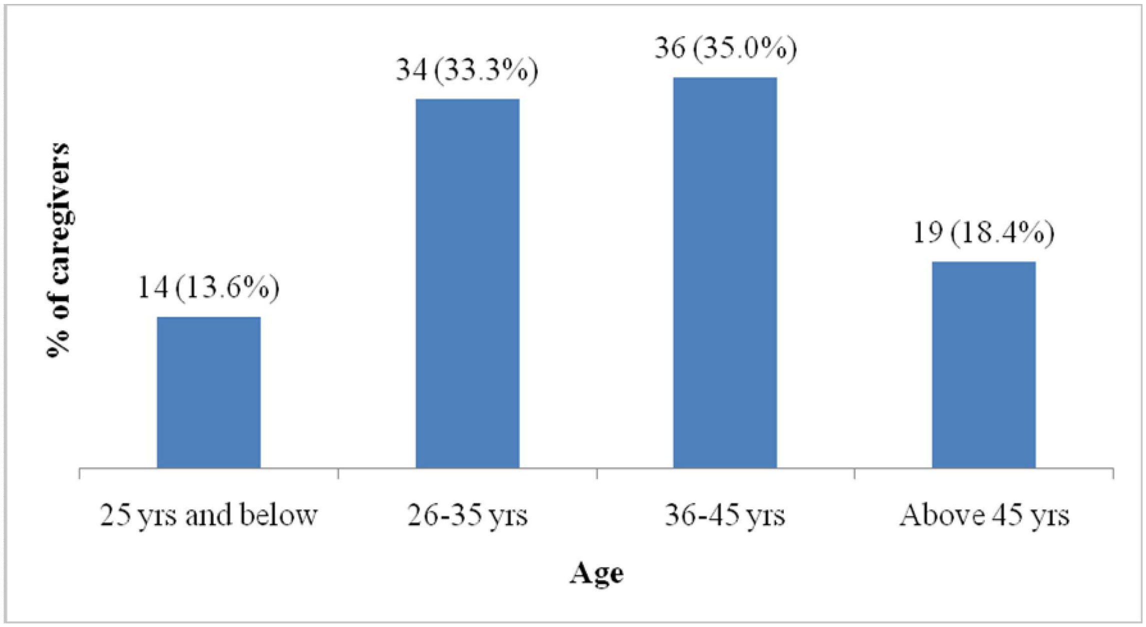

Figure 4.3: Age of Home Based Caregivers

From the results there was a clear indication that home based caregivers were of varied ages as young as below 25years and as old as above 45years. Most of the caregivers were between 25years and 45years. These are the ages during which most people are economically active, married, or are involved in stable relationships, have children to raise and are expected to be socially and sexually active. The age of the home based caregiver may also have had an influence on the interaction and coping mechanism on the challenges as it could influence emotional and psychological support being offered to the people living with HIV. According to a study by Bharat and Mahendra (2007) young adult caregivers of below 40 years suffer from the costs of lost opportunities as these individuals are striving to establish careers and economic security, developing stable relationships and entering the political and social life of the community. This concurs with this study which noted that care-giving imposes disruptions in task development, which might have detrimental long-term economic and psychosocial consequence.

4.2.3 Level of Education of Caregivers

In reference to figure 4.4, respondents' educational levels ranged from non attendance of school to university education. Of all the respondents, only a small percentage had not attended school (2.9%) while all the others had at least primary level of education. Of total respondents, the level with the majority of respondents was secondary where 57.3% reported to have this level of education. The other levels reported are summarized in the figure below.

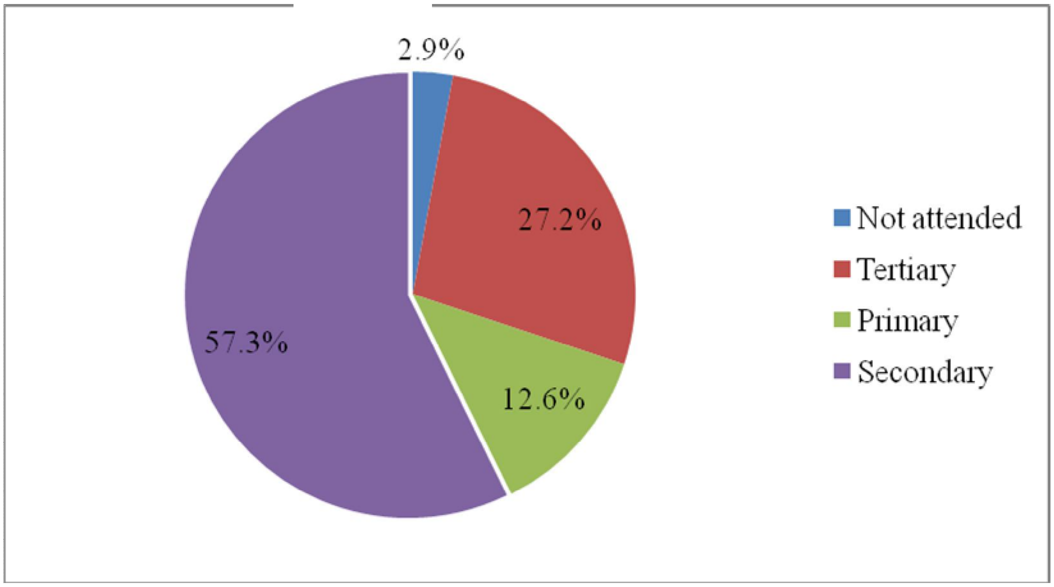

Figure 4.4: Education Level of Home Based Caregivers

The level of education is important as it may affect training on home based care, the interaction with the patient and also how they deal with challenges of caregiving. In this manner the level of education could influence the quality of care offered. Majority of the caregivers (57.3%) were educated up to the level of secondary education. The lowest level of education was primary. Since a majority of the caregivers had education level beyond primary education (57.3% secondary and 27.2% tertiary), this implied that the ability of the majority to deal with various aspects of their work, including compassion, personal accomplishment of skills and experience was adequate.

4.2.4 Employment Status of Caregivers

Study findings showed that out of 103 respondents, 50.5% (n=52) were self employed, 19.4% (n=20) were housewives, 17.5% (n=18) were government employees while 9.7% (n=10) were students and 2.9% (n=3) were unemployed. There was a relatively high level of unemployment (including housewife) amongst home based caregivers (32%) in the study. This is shown in figure 4.5

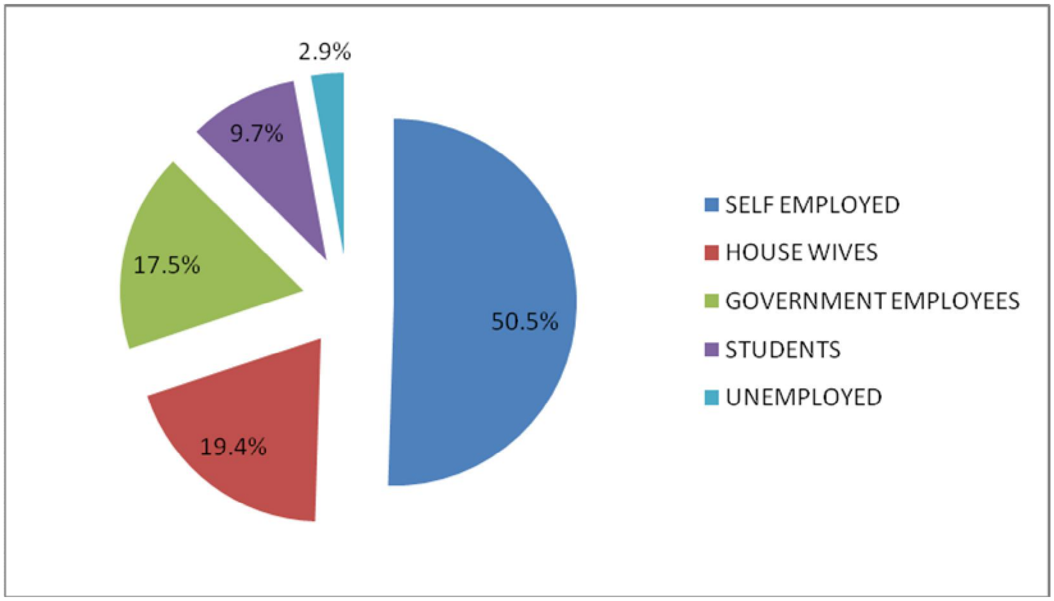

Figure 4.5: Employment Status of Home Based Caregivers

From the results majority of caregivers (50.5%) were self employed and this could have some effects on their productivity on their work, as more time was used in provision of care than on productive work. Employment of caregiver influenced availability of resources necessary for provision of care for people living with HIV. The income obtained could also be used to provide quality palliative and physical care. Some of the caregivers were not working since some were housewife's, others students and they depended on pension funds/social grants, causing an adverse financial impact. Caring for a terminally ill individual can be financially demanding due to medical costs and a need to feed the ill-person healthy food. Some of the caregivers were burdened by financial constraints, leading to stress and frustration. This concurs with the study by Mohammad and Gikonyo (2005), who observed that financial constraints increased feelings of helplessness, as the individual could not meet the medical requirements of the care recipient. According to studies by Demmer (2004) extra responsibilities of AIDS related care divert labour from productive agricultural work creating further household food insecurity. 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 (Aldwin, 2007). 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.

According to Lever (2006a), poverty increases the worries of caregivers, as they might not have enough money for a balanced diet and regular medical check-ups especially when the person is bedridden, as there is a need for transportation to medical facilities. In the present study, it is noted that most of the caregivers and care recipients are unemployed, thus are dependent on social grants. This concurs with the study by Uys and Cameron (2003), who noted that home based caregivers reported economic constraints as a challenge to their work.

4.2.5The Duration of Knowledge of HIV-status of the Client

From 103 respondents, the largest percentage of the respondents (34%) indicated knowing the HIV status of their clients for less than 5 years. An almost similar percentage (33%) of the respondents indicated knowing the HIV status of their clients for a period of 5-10 years. On the other hand only 2.9% of the respondents reported knowledge of their client's HIV status for more than 20 years. The other periods reported by the rest of the respondents is shown in Figure 4.5 below.

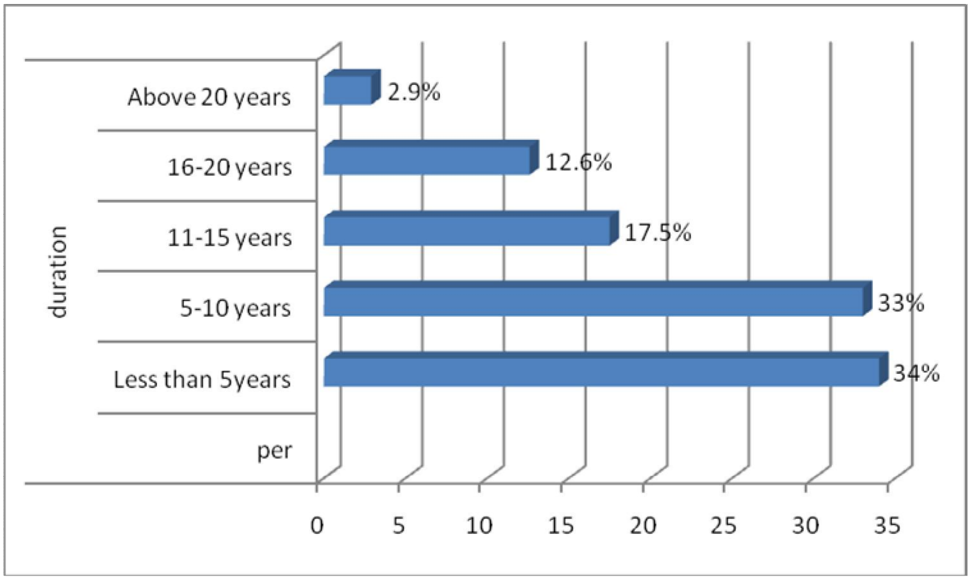

Figure 4.6: The Length of Time Participants had Known the HIV- status of their Client

From the results majority (67%) of home based caregivers had known the status of their clients for a period of up to 10 years of whom slightly more than 50% had known the status for less than 5 years. One of the reason most of the caregivers knew the status of their client for short durations could be as a result of people living with HIV facing a challenge of disclosing their status, even to the home based caregivers who are caring for them, as it is often conceived as a taboo to be HIV-positive in certain communities and one runs a risk of being stigmatized.

The stigma in most cases leads to isolation from usual support networks. This results in fear to disclose the illness to other family members, friends and neighbours. It is common for the affected as well as the infected to rather speak about opportunistic illnesses, explanations or attributions, like meningitis or pneumonia, to avoid rejection and humiliation because of the stigma associated with this illness (Gwyther, 2008). According to Held and Brann (2007), the caregiver and the PLHIV are vulnerable to the effects of stigma such as "isolation, emotional turmoil and shame". This could possibly lead to poor coping strategies as a result of poor social support because caregivers are resistant to disclosing what they are really dealing with. It is found that caregivers tend to keep this a secret and deal with it alone.

4.2.6Training on Home Based Caregivers

From the respondents 72(69.9%) of home based caregivers were not trained while 31(30.1%) were trained. This shows that most of the caregivers were informal caregivers, they did not have any formal training and this makes them to lack the skills required in dealing with PLWH, this is in accordance to Mohammad and Gikonyo (2005).

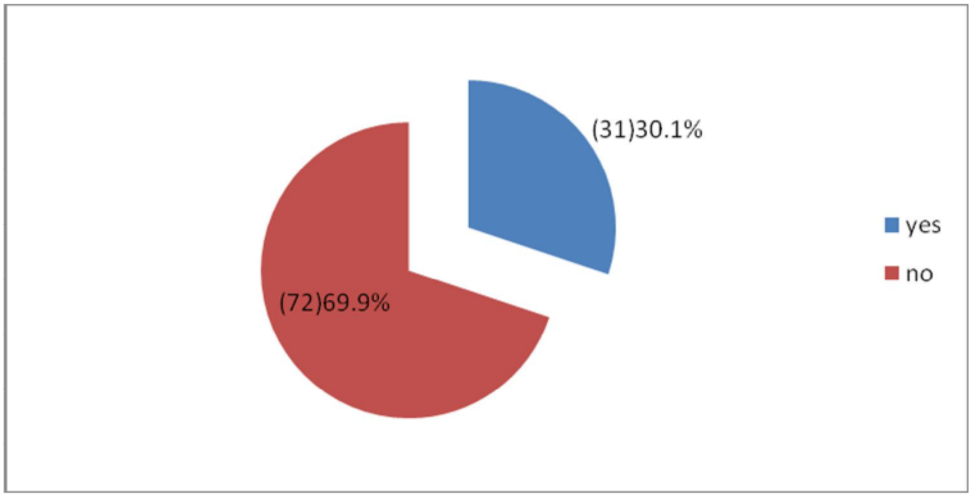

Figure 4.7: Training on Home Based Care

Majority of caregivers expressed lack of knowledge and information as well as inexperience in dealing with the ill people; they indicated that this led to feelings of helplessness. Some also indicated that the duty of home based caregivers was to help the PLHIV; hence, they did not have to worry about them. This concur with previous study by Mohammad and Gikonyo (2005), who observed that with time, caregivers accept the illness as part of their daily living and to completely resort to assisting the PLHIV to deal effectively with the diagnosis. Caregivers also indicated that encouraging and supporting the PLHIV to correctly and regularly take their medication was fulfilling for them.

4.2.7Area of Training on Home Based Care

Figure 4.8 indicate areas of training of home based caregivers. From the findings 31 (30.1%) of the trained respondents 24 (77.4%) were trained on handling HIV/AIDS patients, 22(71%) were trained on nutrition while 26(83.9%) were trained on financial management, while (29) 93.5% were trained on dealing with denial and 23 (74.2%) were trained on farming methods.

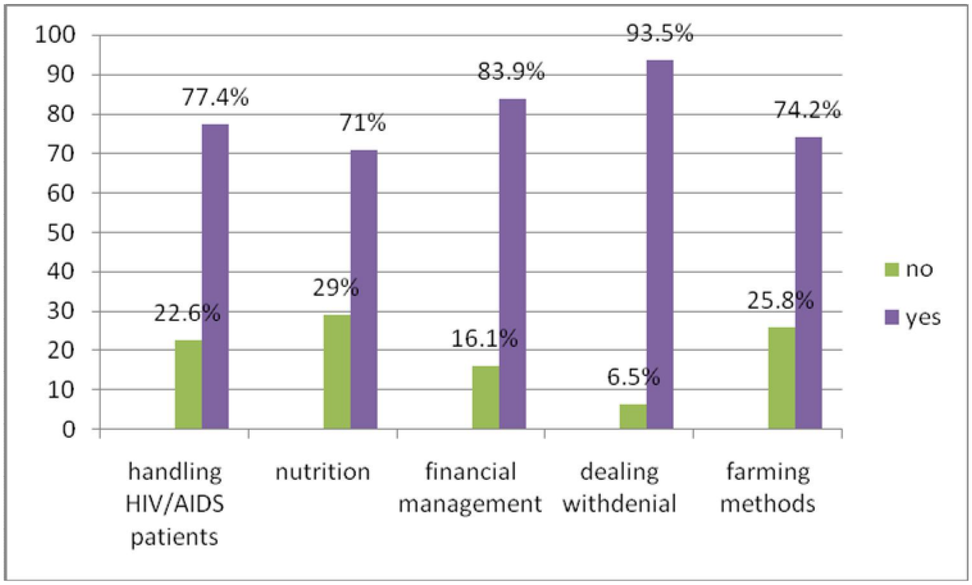

Figure 4.8: Areas of Training on Home Based Care

From the results, formal training in caring for the PLHIV is minimal. This training is given by home-based caregivers who are themselves trained at a minimal level. For this reason, training usually focuses only on assistance with practical care. According to Ogden (2009), caregivers experience a lot of difficulties that have to do with patients' comfort; especially when patients are acutely ill or cognitively impaired. From the current study it has been noted that continuous capacity building is vital for home based caregivers to refresh their current skills and be equipped with new skills so that they can be able to provide the necessary quality care to their patients. If they are not equipped with the knowledge and skills they need, they will not be able to function too well (UNAIDS, 2003).

4.3 Home Based Care Support Provided by Caregivers

The first research objective was on support provided by home based caregivers for people living with HIV/AIDS in Njoro Sub-county. This research objective was answered by the results presented below. Various forms of support were provided to people living with HIV/AIDS by Home Based Caregivers**.** The possible home based care supports offered to people living with HIV are indicated on Table 4.1. The itemized list of home based care initiatives was presented to the respondents to indicate their ranking in terms of most highly provided, highly provided, moderately provided, lowly provided and not provided. From the responses basic nursing was most highly provided with 86% followed by spiritual support with 72% and counseling support at 66%.

Table 4.1:

Home Based Care Support Initiative

Care provided	Most highly provided %	Highly provided %	Moderate provided %	Lowly provided %	Not provided %	Total
Basic nursing	81	10	8	1	0	100
Counseling support	66	14	6	6	8	100
Nutritional support	54	20	7	9	10	100
Financial support	47	30	6	10	7	100
Spiritual support	72	12	8	2	6	100

Field Survey, 2013

From the above results caregivers acknowledged that PLHIV need their support and they can make a difference in the lives of their clients. The home based caregivers have various roles and responsibilities that they have to fulfill as they provide service to their patients. This concur with previous studies by Wringe etal., (2010) who observed that most frequently mentioned perceived palliative care needs for people living with HIV were financial assistance, basic nursing, nutrition/food, counseling and access to ARVs. The emotional stress on caregivers of all ages and gender can be significant. According to UNAIDS (2012), children without adult supervision and 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 (Uys and Cameron, 2003). Some adults care for their partners and loved ones and, for those that don't 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 caregivers often find 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. The demanding nature of caring for both sick adults and for children means those caregivers can face social isolation (Tshililo and Maselesele, 2009).

Home based caregivers provided information regarding HIV/AIDS and care, as well as sought economic, physical, and psychosocial support from family, friends, health care workers and community members. This concur with previous studies by (Tarimo and Blystad, 2009; Greene,2008; Gwyther, 2008) who observed that some of the caregivers disclosed to family, friends and community members so that they could be assisted when in dire need. Some patients needed practical help that involved cleaning, washing, bathing and cooking; requesting their friends and neighbours to assist them minimize the burden (Gwyther, 2008). Some of the caregivers joined the home-based care organisation by requesting referrals from the clinic staff so that they could be assisted with care, transport and food parcels for the sufferer and the families. The studies further sheds light on the minimal support structures available to caregivers, resulting in poor coping mechanisms, which can lead to increased stress and can result in physical and emotional burnout. In the case of the home based caregivers in Njoro the respondents in this study highlighted the following:

4.3.1 Provision of Nutritional Support

Nutrition/food provision was perceived as most highly provided (54%) by the respondents. Nutrition or food provision support is a palliative care need. Other studies in Kenya have supported these findings (National Aids Control Council, 2003). The reason for the need for food assistance to people living with HIV is the fact that drugs such as ARVs weaken the bodies of people living with HIV and there is no use continuing the treatment without food. Studies have shown that micronutrient deficiencies are common with people living with HIV and may accelerate the progression of HIV infection, which in turns leads to a worsening nutritional status (Dieleman, Biemba, Mphuka, Sichinga-Sichali, Sissolak, Vander, Kwaak, & Van der Wilt, 2007). From the study results the respondents highlighted nutrition as the most provided support which meets the basic daily needs (nutritious diet). Nutritional care is extremely important for a HIV positive person. A person may be HIV positive, but if appropriate nutritional and other care is provided, he or she will remain productive and survive for many years. Poverty increases the worries of caregivers, as they might not have enough money for a balanced diet (France, 2008). In addition, estimates from food relief groups in Kenya suggest that approximately 50% of PLWHA require some form of food assistance. However, only 20% of people living with HIV had their need met with food assistance (Lever, 2006a). Food support/assistance is paramount, boosting the immune system of people living with HIV, which in turn will decelerate the progression of AIDS. This concurs with the study by Greene (2008) which highlighted that nutritional support enhances the quality of life of PLWHs.

4.3.2 Basic Nursing Care

Of all the respondents, 81% of the home based caregivers reported their provision level of medical care as “most highly provided”. According to the national policy on anti-retroviral therapy (ART) only patients with HIV/AIDS who had a low CD4 cell account below 200/mm3 could have access to ARVs free of charge (UNAIDS, 2011a), Asian Community AIDS Services (2003) report that, there is no medical support for PLWHs whose CD4 cell count is above 200/mm3 despite their illness. The results of their study show that there is a gap in the provision of basic nursing care since not all who are HIV positive are provided with the anti-retroviral therapy. Of all the respondents, 19% were in this category of those not provided with ART.

4.3.3 Financial Support

Only 47% of the respondents reported provision of financial support as “most highly provided” financial support to their clients. 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. Other studies have highlighted the need for financial support for example in Uganda the caregivers are offered a stipend by National AIDS Control Council to enhance their support in caregiving services (Naidu, 2005). In Kenya majority of the Kenyan population live below the poverty line. This was confirmed by the coordinator of the HIV/AIDS unit at the centre for treatment and AIDS research at the national level (UNAIDS, 2003).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. Lower income caregivers were more burdened in comparison to higher income caregivers as they had more caregiving demand. Promoting the provision of care in the home may be a cost-effective strategy for governments and the private sector, but gives little consideration to the physical, emotional and economic costs to households and the caregivers themselves who take on the additional burdens, many of whom are often poor and themselves living with HIV (Homan etal., 2005).

4.3.4 Counseling and Spiritual Support to Family Members

Seventy two per cent of the respondents reported spiritual support as “most highly provided”. Home based caregivers prepare families for the eventual death of their loved ones, and advise them on steps they could take once that happens. After the death of the patient, the home based caregivers visits the bereaved family to give them counseling on how to deal with the death of a loved one (Asian Community AIDS Services, 2003).The roles and responsibilities of home based caregiver vary from one caregiver to another. Similar cases were reported by Akintola (2004), who found that most care organizations do not have resources to take on some services and that few care organizations in South Africa have taken into account the need to accommodate the changing needs and demands of their services over time, often because of lack of financial resources.

4.4 Social Challenges Experienced by Home Based Caregivers

With regard to identifying challenges faced mainly by caregivers due to their caregiving services, respondents indicated their ranking of the listed challenges in terms of major challenge, minor challenge, not a challenge or do not know (cannot tell). The major challenges of home based caregivers in the area were stigma and discrimination at 87 % while stress and burnout when dealing with people living with HIV was suggested by 76% of the respondents. The financial effect was suggested by 69% of the respondents. Risk of contracting the disease was suggested by 63% while physical effects were suggested by 61% of the respondents.

Table 4.2:

Social Challenges Faced by Home Based Caregivers

Challenge	Severe challenge %	Minor challenge %	Not a challenge %	Do not know %	Total %
Stress and burnout	76	17	7	0	100
Physical effects	61	31	6	2	100
Financial effect	69	21	9	1	100
Stigma and discrimination	87	10	3	0	100
Risk of contracting the disease	63	24	10	3	100
Confidentiality and autonomy	54	21	11	14	100

Field Survey, 2013

From the results on the Table 4.2 on the issue of the major challenges of caregivers in the study area, it can be stated that the four major challenges in the area were reported by the respondents in order of highest percentage as “major cause” were stigma and discrimination (87%), stress and burnout (76%), financial effect (69%), risk of contracting the disease (63%) and physical effect (61%)**.** In all relationships personal or professional discrimination counteracts trust, as mentioned by Molefe (2009). Stigmatization is still a major challenge since it prevents open statements about HIV status. Universal tolerance of HIV/AIDS needs to be advocated for, through awareness programmes in an attempt to reduce stigmatization and discrimination. caregivers also experience feelings of poor self-esteem, stress, low morale, fatigue, anxiety and hopelessness about the future. Past psychiatric status, personality, social support networks, and the relationship of the caregiver and recipient, together with the nature of the illness and the degree of impairment, all are factors that aggravate the emotional experiences of caregivers (Ehlers, 2006). According to Bharat and Mahendra (2007) caregivers experience feelings of helplessness, denial and despair, and that this happens more often when the sufferer does not want to eat or respond to the services being rendered to him/her. These conditions might bring feelings of uncertainty that in turn will exacerbate feelings of stress and low self-esteem among the caregivers. It is also noted that poverty increases the worries of caregivers, as they might not have enough money for a balanced diet and regular medical check-ups, especially when the person is bedridden as there is a need for transportation to medical facilities (Dieleman et al.2007).

4.4.1 Fear of contagion

A clear majority of the HBCGs (63%) expressed fear of contagion. Fear of contagion is one of the major concerns among HBCGs working in the field of HIV/AIDS. This is confirmed by studies such as Primo‘s (2007:56), where some of the home based caregivers feared that wearing gloves may not provide sufficient protection to prevent infection by HIV/AIDS. Despite the knowledge that HBCGs may have about HIV transmission, they still have fear of contagion which can compromise the quality of care that PALHIV might need, and which explains why a HBCG can think of using disinfectant when taking a bath after caring for a PALHIV. This is confirmed by a study of Akintola (2004), that the fear of contracting the disease has been noted as a concern among HBCGs and many regard working in the field of HIV/AIDS as a high risk occupation. This fear is further exacerbated by difficulties experienced in maintaining consistent and appropriate infection control precautions. Despite the well-documented fact that the AIDS virus can only be transmitted through bodily fluids, there are still health care workers who harbour irrational fears of contagion taking place through casual contact, or touching the patient’s clothes, bedding, eating utensils or bathing facilities (Demmer, 2004). This fear may result in physical or empathetic withdrawal from persons with HIV/AIDS, resulting in clients being deprived of physical and emotional contact, a most valued intervention, which could make them feel unclean and contaminated. These factors can cause considerable stress, anxiety and discomfort for the client as well as the person working with the AIDS patient.

4.4.2 Economic Challenges Faced by Caregivers

The third research objective focused on economic challenges faced by home based care givers. The economic challenges experienced by the caregivers when taking care of HIV/AIDS victims were listed by the respondents as in the Table 4.3 below:

Table 4.3:

Economic Challenges Faced by Caregivers

Socio-economic challenge	**Frequency**	**Percentage**
Lack of finances	94	91.3
Poor nutrition	86	83.5
Reduced time for skill building and time for engaging in leisure activities	81	78.6
Unemployment	77	74.8
Rising number of orphans and vulnerable children	69	67.0
Poverty	63	61.2
Shortage of basic necessities such as gloves, soap, disinfectants	55	53.4
More people requiring care	41	39.8
Lack of skills	37	35.9

Field Survey, 2013

As indicated in Table 4.3, 91.3% of the caregivers reported that lack of finances was one of the major challenges faced when taking care of HIV/AIDS victims. This is because majority of caregivers were not in a position of securing job or even engaging in activities that were income generating. Poor nutritional status was the other challenge among the infected and affected person’s which deteriorated their health status as reported by 83.5% of the respondents. Moreover, 78.6% of the caregivers stated that they have limited time for skill building and engaging in leisure activities. This makes them feel isolated in social groups and hence develop a negative attitude of self denial. Other economic challenges experienced included; unemployment, poverty, rising number of orphans and vulnerable children. Income generation by HBCG was hindered due to the fact that they had to provide care before operating their business. This implies that economic challenges pose great challenges to the caregivers. In line with the findings, Lever *et al.,* (2002) asserted that strengthening the family structure is important because of the tremendous stress that HIV puts on family systems. Besides caring for ill relatives and for orphans, families are often beset by economic and social problems as well as the grief that accompanies the loss of family and friends. Furthermore, Tarimo *et al,* (2009) argued that the increased financial costs related to caring for the sick ranges from costs incurred to provide immediate care such as gloves to financial outlays for medicines and user fees for accessing health care services, transportation costs involved with attending clinics, rising food costs and others.

4.4.3 Lack of Finances and Poverty of Caregivers

Lack of finances was reported as a major challenge by 91.3% of the respondents as well as poverty by 61.2% and unemployment by 74.8%. Coupled with limited time to work due to the demand of caregiving, poor finances become a big limitation in giving good care. Income generating activities would go a long well in improving the financial status of the caregivers. There are also companies that come and sponsor the income generating activities like home gardens, e.g. Compassionate International gave patients, milk goats, seeds and farming training to enhance food security and reduce malnutrition cases. Financial support, whether formal or informal, is an important buffer for the caregivers. This concur with studies by Ntsuntswana (2006), that poverty remains one of the main challenges faced by HBCGs when they provide care to PALHIV and unless it is reduced there will be little progress in achieving more in caring for PALHIV as the quality of the care given to PALHIV will be compromised for they would not be able to afford basic essentials including food, which they need to be able to take their medication.

4.4.4 Lack of Skills

Lack of skills was cited as a challenge by 35.5% of the respondents. This makes it hard for them to give full quality care to the patient. As seen earlier on training of home based care givers 72(69.9%) of home based caregivers were not trained while 31(30.1%) were trained. Therefore, many lacked the skills required in providing the services to PLWHA. More intensive training about the clinical aspects of caregiving can equip them better to provide a better service and auxiliary nursing can assist in dealing with some of the clinical challenges they encounter( ).

4.5 Coping Mechanism of Home Based Caregivers

The fourth research objective focused on coping strategies of home based caregivers for PLWHA. Table 4.4 below shows how home based caregivers cope with the challenges they face when they are offering their services. They mentioned spirituality and sharing in informal support groups as the most used coping strategies with 80.6% and 78.6% of the respondents mentioning them respectively. Debriefing was another coping strategy with 73.8% while consultation of medical practitioners by caregivers and emotional understanding were mentioned with 59.2% and 52.4% respectively.

Table 4.4:

Coping Mechanism of Home Based Caregivers

Coping mechanism	Frequency	Percentage
Debriefing by trained counselor	76	73.8
Consultation of medical practitioner by caregivers	61	59.2
Emotional understanding	54	52.4
Informal support groups	81	78.6
Spirituality	83	80.6

Field Survey, 2013

From the results majority 80.6% of home based caregivers resorted in believing in God and prayer to cope with their work. Others resorted to debriefing sessions which were provided by trained counsellor with an aim to explore their emotions and frustrations in order to cope with the challenges that they face in their daily duties as they care for People living with HIV. Most home based caregivers indicated that they resorted to sharing their fears, anxieties and most work-related challenges with fellow home based caregivers. Some of the home based caregivers resorted to emotional self- reliance as they were able to depend on themselves to deal with their emotions in a positive manner. They expressed their coping mechanisms as follows:

4.5.1 Debriefing by Trained Counsellors

Most HBCGs (73.8%) explained their coping mechanisms in relation to caring for their patients and none of them mentioned their own status and how that affects their work. Emotionally coping at work was difficult and the debriefing helps, but more long-term intervention is necessary. The choice of coping strategies used appeared to be influenced by factors such as self-esteem, whether stress experienced involved family members, and the degree of control an individual felt they had over the stressful situation. Self-control, confrontative coping, accepting responsibility, escape avoidance and a reduction in seeking social support are used when a person feels that their self esteem is threatened (Lazarus and Folkman, 1989). In a related study conducted by Driedger and Cox (1991 in Melnick, 2002) it was noted that inexperience was significantly related to the level of emotional exhaustion reported by the nurses. This has possible implications in South Africa where caregivers are increasingly younger and the siblings to the sufferers.

The results revealed that feelings of pain, difficulty performing the work due to discrimination and stigmatization by society, poverty and inaccessibility of hospital and professional medical supports were the major concerns. Feelings of helplessness were expressed, especially with dying patients. Coping mechanisms employed were faith, trying to control feelings, and asking for support from colleagues and families (Melnick, 2002).The purpose of the debriefing sessions is to provide HBCGs with a plat form to explore their emotions and frustrations in order to cope with the challenges that they face in their daily duties as they care for PALHIV (UNAIDS, 2011a). Emotional difficulty associated with knowing that your loved one is living with the virus was observed not to be experienced by the caregivers only. Participants in the study reported different emotional experiences of the family and the community when they knew about the patient’s diagnosis. Homan et al. (2005) also found that families may respond to the news of the diagnosis with disbelief, shock and confusion. The present result also supports the notion that these feelings impact not only on the caregivers, but also on the entire family structures. Difficulties associated with whether to disclose or not to disclose when dealing with HIV/AIDS have been observed by several researchers (Primo, 2007). Participants in the study reported experiencing rejection, prejudice, and discrimination, mostly directed at the care recipients by their families following the disclosure (Orner, 2006). Other participants in the study resorted to blaming the opportunistic infections as the causes of illness in order to avoid humiliation and rejection (Primo, 2007). Although caregivers used opportunistic infection explanations as a way of minimising negative responses, participants in the study observed the family and community responses as positive. The families and the communities offered support to the caregivers as well as the patients. The results correlate to Owens’ (2003) findings, which reported that families of

HIV positive women gave emotional and concrete support. The present study found that support was mostly offered to the care recipients, and not so much to the caregivers. A study by McCann and Wadsworth (1992) also found that support from care team members was mostly directed towards patients, and less so to caregivers. The current study elicited the coping strategies employed by caregivers in the arena of HIV/AIDS. Participants in the study reported controlling their emotions as a way of coping with their knowledge of the disease and the caring demands. Self-control as a coping mechanism was also supported by Lazarus and Folkman (1989) and Melnick (2002). As a buffer, this improved caregivers' self-esteem, which in turn boosted the care recipients' courage and hope for the future. Other coping mechanisms employed by caregivers included integrating HIV/AIDS into their lives, spirituality, having feelings of hope, as well as gathering support. These coping mechanisms entail what is termed as "problem-focused coping mechanisms" (Folkman and Lazarus, 1989; Folkman, 1997; Melnick, 2002). Poor coping mechanisms used by caregivers in the study included denial and inappropriate humour.

4.5.2 Consultation with Medical Practitioners

Most HBCGs (59.2%) when faced with problems which they could not resolve on their own for example, they consulted on issues such as symptoms of opportunistic infections like tuberculosis, pneumonia, herpes, fungal and parasitic infections throughout the body, infections in the brain and infections being carried around the body by the blood. These experiences might also be noted with caregivers who are uninformed about the development of the disease. Due to a lack of information, caregivers might think that the sufferer is dying when the sufferers develop extensive pressure sores as a result of being bedridden, or become incontinent, confused or forgetful, or experience persistent nausea and vomiting this leads to caregivers consulting with medical practitioners. The ability to solve problems through consultation and referral is associated with positive experiences on the part of the HBCG (Makoae and Jubber 2008:42). According to Shebi (2006), caregivers experience a lot of difficulties that have to do with patients' comfort; especially when patients are acutely ill or cognitively impaired and home based caregivers have to sort advice from medical practitioner.

4.5.3 Informal Support Groups

Most home based caregivers (78.6%) resort to sharing their fears, anxieties and most work-related challenges with fellow HBGCs. Sharing their experiences provides some comfort, due to similar experiences. There is no formal time set aside for such sharing of experiences; it happens informally and spontaneously (Leake, 2009). It is noted that not only the patient goes through emotional difficulties, but family members of people infected with HIV/AIDS also experience those difficulties. According to Bor et al., (1993), stress is seen in families who may respond to the news of the diagnoses with disbelief, shock and confusion. These feelings impact not only on the caregivers but also on the entire family structure. A study by leake (2009), found that caregivers experienced courtesy stigma or associative stigma, resulting in individuals being isolated, hidden, fearful and stressed. Being uncertain about those around them, caregivers resorted to secrecy and defensiveness. In order to minimise attribution of stigma, some of the caregivers resorted to the use of opportunistic infections as a way to keep the diagnosis a secret to defend themselves and the patients. Use of opportunistic infection to keep the diagnosis a secret was supported by several research findings in the field of HIV/AIDS and caregiving. They also expressed feelings of helplessness caused by not knowing how the disease is acquired and not being able to deal with it. This signifies lack of knowledge and information.

4.5.4 Emotional Understanding

Home based caregivers had positive coping mechanisms that keep them optimistic as they provide care to PALHIV. More than half of the respondents reported depending on emotional self- reliance (54%) as a coping mechanism as they were able to depend on themselves to deal with their emotions in a positive manner. This should be encouraged as it reduces the emotional burden that comes with a caring profession. Lazarus and Folkman (1984:119) view self-control, humour, crying, weeping, and boasting as coping devices which are normal. . It was noted that while all the participants experienced good emotional and concrete sources of support, the majority experienced little or no cognitive/informational support. Emotional support was experienced in a form of affective support (i.e. love, care, reassurances and sincere attempts encouragement), and family commitment, as well as acceptance, concern and empathy. Concrete or tangible support included accommodating the sufferer (offering a place to stay), assisting with parental responsibilities, activities of daily living, and providing transportation. According to Owens (2003), the lack of cognitive support was due to the families' lack of awareness or denial of HIV/AIDS and its implications. There was insufficient emotional support as well as insufficient practical support for the caregivers. Families as well as society avoid associating themselves with the infected and the affected as a way of protecting themselves from being stigmatised. This is due to lack of information regarding the manner in which an individual acquires the disease. Katz (1981) argues that stigma encompasses a perception of negative characteristics and a global devaluation of the possessor of the characteristic. Issues of isolation and rejection, and subsequent prejudice and discrimination, stem from the fact that people often try to avoid interaction with individuals whose bodily and psychological characteristics deviate from the norms of family members and society

4.5.5 Spirituality of Caregivers

The majority of the home based caregivers (80.6%) believe in God and prayer to cope with their work. They believe that through God anything is possible. Being spiritual and close to God help research participants deal with their emotions better and soothe their pain. According to Makoae et al. (2008: 144), deriving comfort through religion is one of the most common coping strategies. Religion plays an important role in the HIV/AIDS arena. . In this study spirituality emerged as a coping strategy that most caregivers used to deal with their challenges. Spirituality also provides practical, supportive resources that assist with psychological adaptation such as ritual, prayer, an outlet to express affect, and community. However, although there is overlap between the concept of spiritual support and social support long shown empirically to benefit psychological adaptation the support provided by spiritual beliefs is distinctive because it describes ones relationship with a higher power and the unique rituals and community that surround those beliefs. Spirituality may help individuals conserve meaning and transform their sense of significance through integration of the stressor into existing definitions of self. The caregivers expressed spiritual beliefs and practices either negatively or positively. In a positive way, it was expressed in the form of praying as an individual or with members of the church and/or community, and going to church for spiritual support and giving praises that God has heard their prayer. In a negative way, it was noted that caregivers felt that for their loved ones being diagnosed with HIV was God’s way of testing their faith. Coping processes, identified spiritual beliefs and practices, which intensified after the partner has passed on. In the present study, spirituality was observed either positively, in the sense that the caregivers were praying for their care recipients’ well being, or negatively, by having thoughts of their faith being tested or it being a punishment from God. According to Melnick (2002), voluntary caregivers, also identified faith as one of the coping mechanisms employed in the arena of HIV/AIDS caregiving. Catalan et al. (1996), in their study to determine coping mechanisms used by AIDS and oncology nurses and doctors, identified religion as a coping mechanism.

CHAPTER FIVE

SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

This chapter presents a summary of the study, conclusions, recommendations as well as the suggestions for further research.

5.2 Summary of the Major Findings

From the study results the respondents highlighted nutrition as the most provided support which meets the basic daily needs (nutritious diet). Nutritional care was extremely important for a HIV positive person. A person may be HIV positive, but if appropriate nutritional and other care is provided, he or she will remain productive and survive for many years. Another support provided by home based caregivers was financial support. This was most seek due to increased financial costs related to caring for the sick which 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.

The caring experience was found to be an emotionally ambivalent situation, where participants experienced feelings of shock, stigma, confusion, sadness and helplessness. Participants further expressed experiencing financial challenges as a result of caring demands, because they were not employed, thus depending on grants. As a result of the strains experienced by caregivers, some of the participants expressed experiencing emotional strain due to caring demands. With regard to family and societal responses, caregivers also observed that families and society experienced emotional turmoil when first hearing about the diagnosis. Although these feelings were apparent, some of the caregivers had found it difficult to disclose what they were dealing with as a result of being ashamed of what the responses could be towards them and especially towards the PLWHA. Some of the participants expressed using opportunistic infections that the PLWHA was suffering from, like TB, Meningitis, pneumonia, and strokes as the causes of illness. Those caregivers that disclosed to their families experienced rejection and hostility from family members, which was mostly directed towards the PLWHA. This resulted in feelings of discrimination and isolation for both the PLWHA and the caregiver. Furthermore, participants told of being offered support by family members and society in the form of "instrumental support" i.e. bathing, feeding and supplying transport for the PLWHA, together with emotional support, which was mostly directed towards the PLWHA.

Caregivers further expressed integrating the disease into their daily lives by accepting the PLWHA condition as being real and existing, and by creating joyful meaning for the PLWHA and other family members, and by fulfilling their commitments to the PLWHA. Use of spirituality, in either a negative or positive way, was also experienced. Some of the caregivers expressed going to church, and praying with other family members and the community for the well being of the PLWHA. Participants also expressed having feelings of hope, especially with the introduction of anti-retroviral therapy as part of the disease management for their loved ones. They hoped for better results from the treatment for the sake of the PLWHA, as well as for the benefit of the PLWHA children. Caregivers further expressed gathering support from other family members and health care workers to be able to deal with the disease's demands actively.

The findings of this research are relevant as they supplement previous research on social-economic needs and demands of home based caregivers for people living with HIV/AIDS, providing the experiences and coping strategies. It shows that caring within the HIV/AIDS arena can be emotionally challenging, and that caregivers within this context still experience HIV related stigma, leading to nondisclosure. And where the disease is disclosed, careivers and PLWHA experience discrimination, resulting in isolation, which later results in the use of poor coping mechanisms. The results further suggest that although there was emotional and cognitive support, it was mostly directed towards the PLWHA, with minimal support for the caregivers. In summary, the participants' experiences and coping strategies were found to support and supplement the findings from previous research on HIV/AIDS primary caregivers' subjective and objective experience, thereby adding new insight.

5.3 Conclusions

Based on the findings of the study, the following conclusions were made:-

i). It can be noted that financial constrain and poverty increases the worries of caregivers, as they had no enough money for a balanced diet and regular medical check-ups, especially when the person is bedridden as there is a need for transportation to medical facilities.

ii). The results suggest that caring for an HIV positive individual can be emotionally and physically draining, but later can be fit into one's daily lifestyle. It can lead to prejudice and stigma from those that could potentially offer support to the PLWHA as well as the caregiver, causing strain.

iii). The study further reveals that participants experienced little emotive and financial support from family, society, and the community health workers who were visiting PLWHA at home. This led them to feel more helpless, leading to the use of poor coping mechanisms.

iv). Regarding the participants' way of managing their own experiences and feelings, as well as the way society and families responded to them, some of the caregivers spoke of controlling their emotions, especially when in company of the care recipient, in order to protect the PLWHA and cope better with the disease.

5.4 Recommendations of the Study

Based on the findings of the study, the following recommendations were made:-

i). Training of home-based caregivers should be emphasized to enable them assess stress-related symptoms among themselves and people living with HIV/AIDS hence refer them accordingly.

ii). Policies on home based caregivers should be developed to accommodate the challenges faced by this group which provide alternative health care at home that ease pressure on health care facilities.

iii). The social workers in collaboration with home based caregivers to work together in identifying difficulties and the resources that impact in the individual experiences of caregiving, both in the families themselves as well as in the larger socio-economic context iv). The government and other organizations to provide counseling interventions and grant support that supplement what home based caregivers provide to people living with HIV/AIDS so as to reduce emotional strain and stigma that drain the caregivers leading them to develop negative coping mechanism.

5.5 Suggestions for Further Research

i). This study shows that caring for an HIV/AIDS individual can be emotionally, physically, socially and economically demanding. It is therefore recommended that future research explore these caring demands to provide additional insight and understanding of the primary caregivers of HIV/AIDS, specifically among young adults.

ii). Further research should be carried out to identifying difficulties and the resources that impact on the individual experiences of care giving, both in the families and society level.

iii). Studies should be carried out to explore the experiences and coping strategies of partners who are caring for their infected partners, so as to compare men and female roles in care giving.

iv). Another study should be carried out with an aim of suggesting ways of implementing support systems for home based caregivers of people living with HIV / AIDS.

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APPENDICES

APPENDIX A: QUESTIONNAIRE FOR HOME BASED CAREGIVERS

Instructions

Do not write your name anywhere on this paper

Your response will be treated with utmost confidentiality

Respond to all questionnaire items by either putting a tick (✓) in the brackets provided or by writing on the space provided.

Thank you for your cooperation

SECTION A: Demographic profile

1. Gender[ ] Male [ ] Female
2. Age in years…………………………………………
3. Name of Location…………………………………..
4. Level of education
   Primary [ ]
   Secondary [ ]
   College/University [ ]
   Never went to School[ ]
5. Employment status

Not employed [ ] self employed [ ] government employee [ ] casual employment [ ]

6.Monthly income in Kenya shillings

0-5000 [ ] 5001-10000[ ] 10001-15000 [ ] 15001-20000 [ ] 20001-25000 [ ]25001-30000[ ]
30001 and Above [ ]

7. For how long have you been offering care to people living with HIV?

Less than 5years [ ] 5-10 years [ ] 11-15years [ ] 16- 20 years [ ] 20 years and Above [ ]

8. For how long have you known the HIV status of your client?

Less than 5years [ ] 5-10 years [ ] 11-15years [ ] 16- 20 years [ ] 20 years and Above [ ]

9. Have you been trained on home based care giving?

Yes [ ] No [ ]

10. What is your relationship with the person living with HIV/AIDS
    Parent ( ) sibling ( ) partner ( ) Friend ( ) Relative ( ) others ( )

11.If Yes which areas of training have you been trained?

Area of training	Yes	No
Handling HIV/AIDS patients		
Dealing with denial		
Financial management		
Farming methods		
Nutrition		

Section B : Type of Home Based Care Support given

11. What do you think are the possible support services offered to people living with HIV? Tick as appropriate in the columns under: most highly provided, highly provided, moderate provided, lowly provided and not provided in the table below.

Care provided	Most highly provided %	Highly provided %	Moderate provided %	Lowly provided %	Not provided %
Basic nursing					
Counseling support					
Nutritional support					
Financial support					
Spiritual support					

Section C: Social Challenges of offering Home Based Care

12. What will you say about the following challenges when offering home based care? Tick as appropriate in the columns under: Severe challenge, Minor challenge, Not a challenge and Do not know in the table below.

Challenge	Severe challenge	Minor challenge	Not a challenge	Do not know
	%	%	%	%
Stress and burnout				
Physical effects				
Financial effect				
Stigma and discrimination				
Risk of contracting the disease				
Confidentiality and autonomy				

13. Tick appropriately on the economic problems encountered when offering home based care?

Economic problems	**Frequency**
Lack of finances	
Poor nutrition	
Reduced time for skill building and time for engaging in leisure activities	
Unemployment	
Rising number of orphans and vulnerable children	

Poverty	
Shortage of basic necessities such as gloves, soap, disinfectants	
More people requiring care	
Lack of skills	

14. Are the medical facilities accessible?

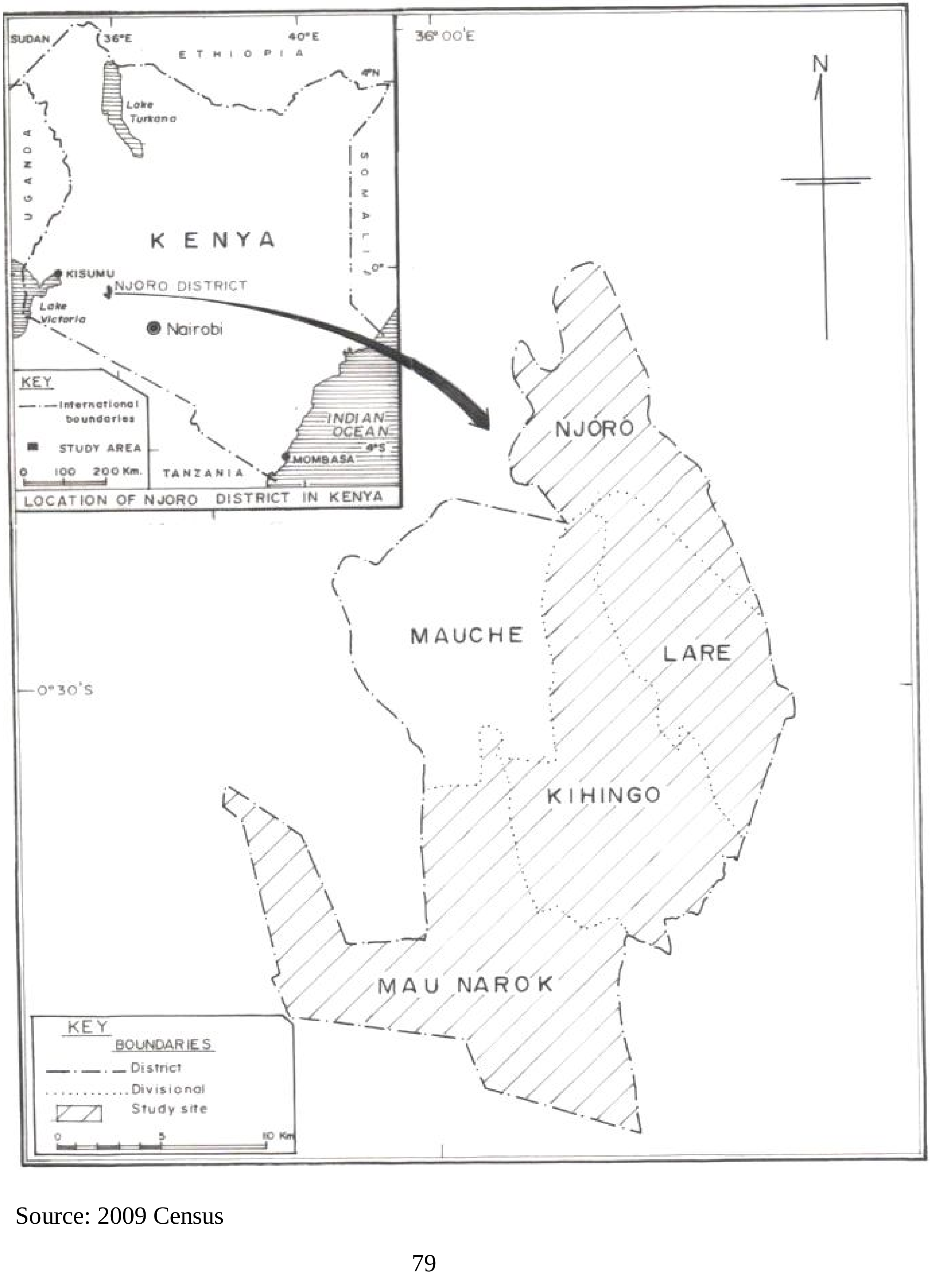
Very easily to accessible [ ] Easily accessible [ ] Difficult to access [ ] very difficult [ ]

Section D: Coping Mechanisms of Home Based Caregivers

15. From the list tick the most appropriate coping mechanism you use

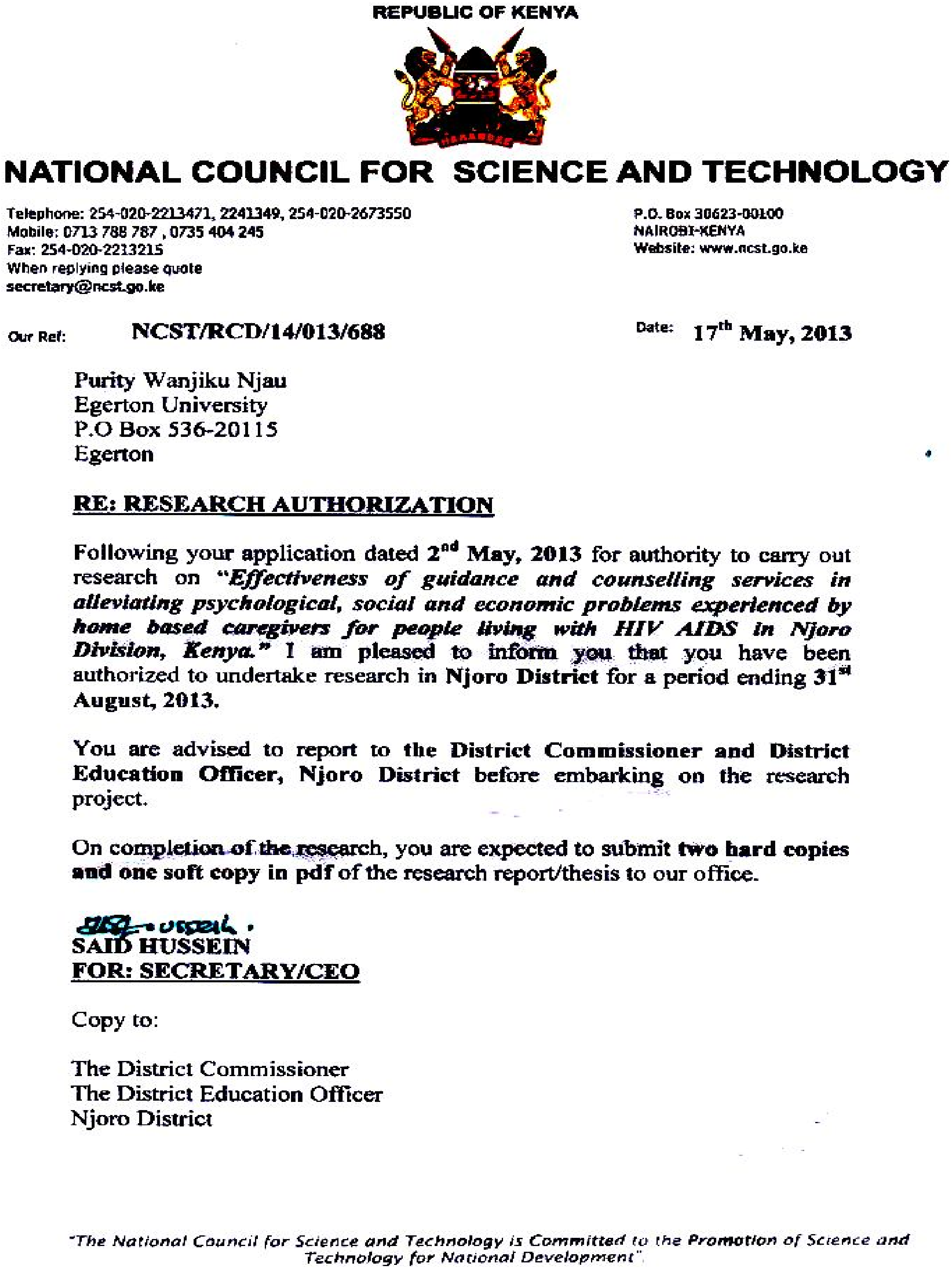
Coping mechanism	Frequency
Debriefing	
Consultation with medical practitioner	
Emotional understanding	
Informal support groups	
Spirituality	
Others	

APPENDIX B: MAP OF NJORO SUB-COUNTY



Source: 2009 Census

APPENDIX C: LETTER OF RESEARCH AUTHORISATION



REPUBLIC OF KENYA

NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

Telephone: 254-020-2213471, 2241349, 254-020-2673550
Mobile: 0713 788 787 , 0735 404 245
Fax: 254-020-2213215
When replying please quote
secretary@ncst.go.ke

P.O. Box 30623-00100
NAIROBI-KENYA
Website: www.ncst.go.ke

Our Ref: **NCST/RCD/14/013/688**

Date: **17th May, 2013**

Purity Wanjiku Njau
Egerton University
P.O Box 536-20115
Egerton

RE: RESEARCH AUTHORIZATION

Following your application dated **2nd May, 2013** for authority to carry out research on ***"Effectiveness of guidance and counselling services in alleviating psychological, social and economic problems experienced by home based caregivers for people living with HIV AIDS in Njoro Division, Kenya."*** I am pleased to inform you that you have been authorized to undertake research in **Njoro District** for a period ending **31st August, 2013.**

You are advised to report to **the District Commissioner and District Education Officer, Njoro District** before embarking on the research project.

On completion of the research, you are expected to submit **two hard copies and one soft copy in pdf** of the research report/thesis to our office.

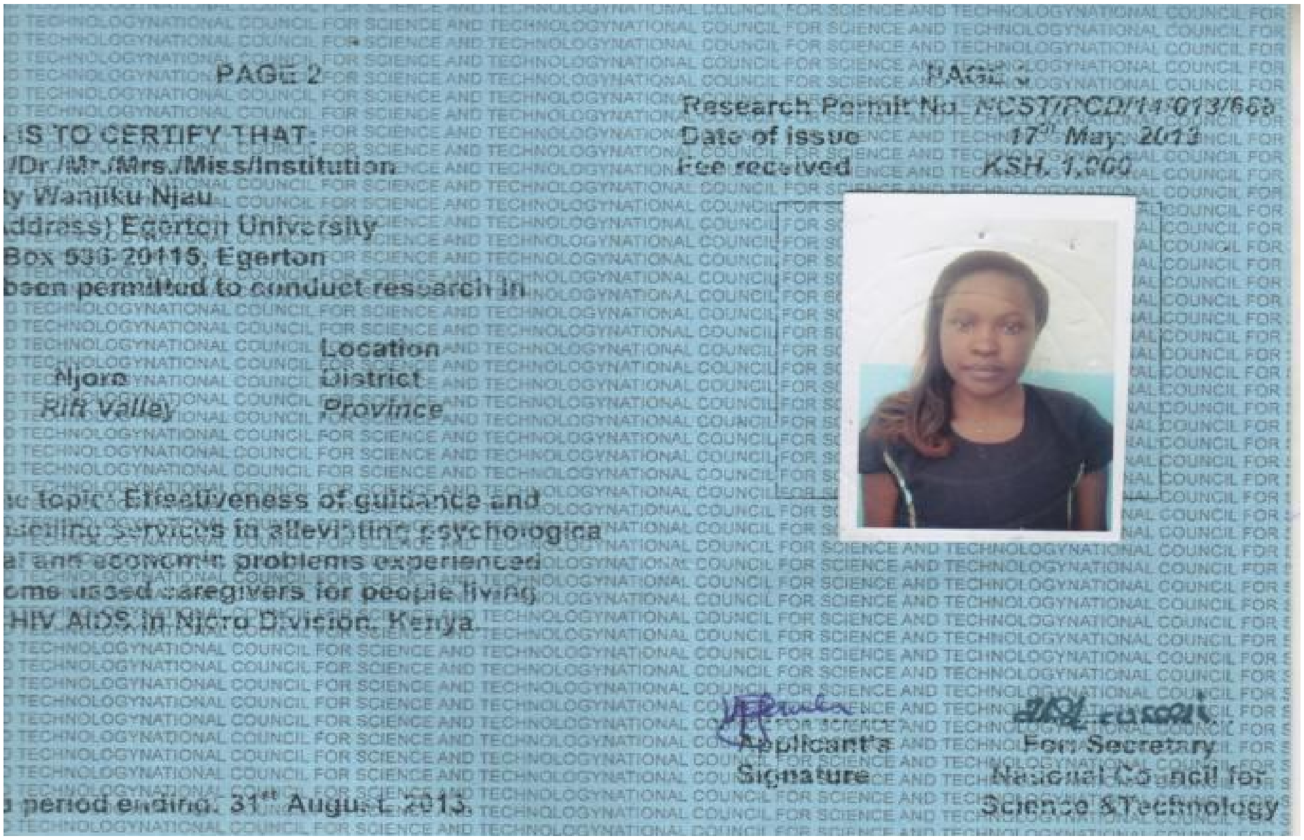
SAID HUSSEIN
FOR: SECRETARY/CEO

Copy to:

The District Commissioner
The District Education Officer
Njoro District

"The National Council for Science and Technology is Committed to the Promotion of Science and Technology for National Development".

APPENDIX D: RESEARCH PERMIT



PAGE 2

IS TO CERTIFY THAT:
/Dr./Mr./Mrs./Miss/Institution
ty Wanjiku Njau
ddress) Egerton University
Box 536-20115, Egerton
been permitted to conduct research in

Location
Njoro District
Rift Valley Province

e topic: Effectiveness of guidance and
selling services in alleviating psychologica
al and economic problems experienced
ome based caregivers for people living
HIV AIDS in Njoro Division, Kenya.

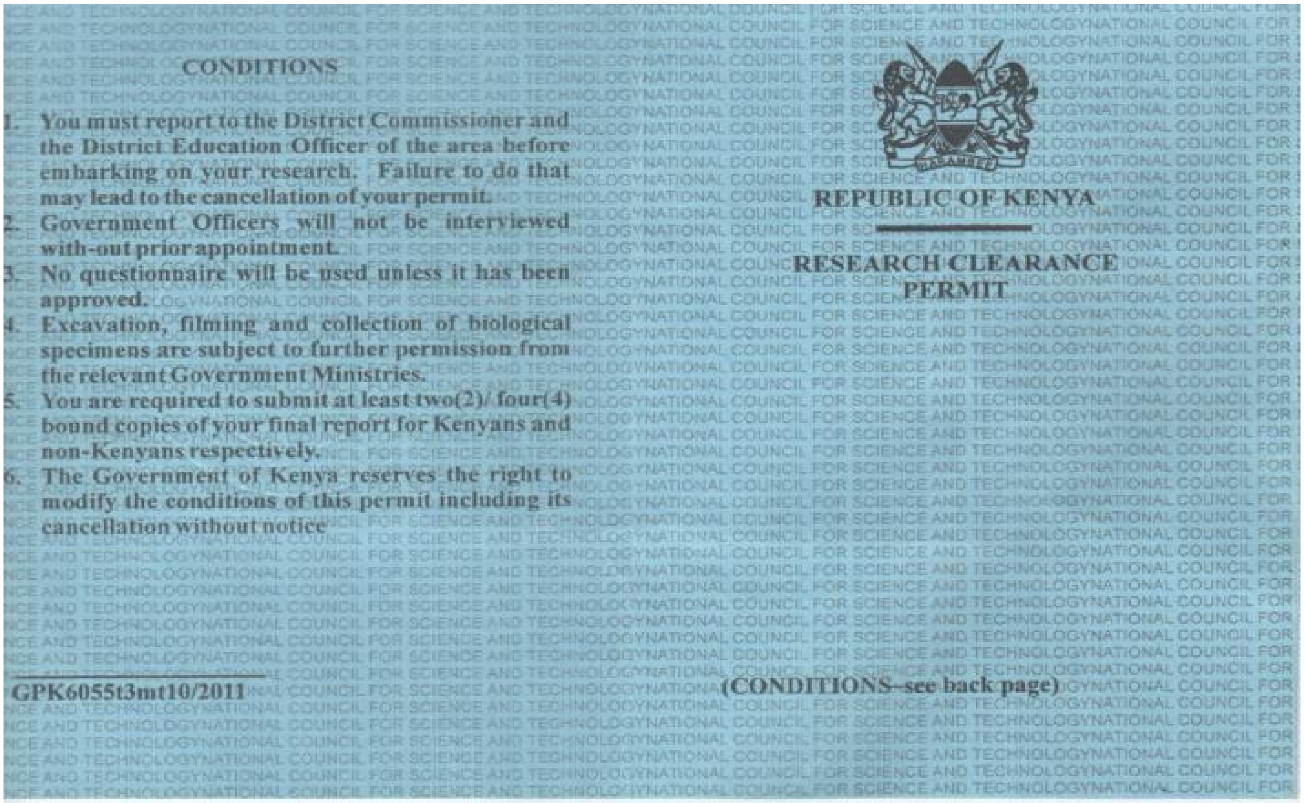
period ending: 31st August 2013.

PAGE 3

Research Permit No. NCST/RCD/14/013/668
Date of issue 17th May, 2013
Fee received KSH. 1,000

Applicant's
Signature

For Secretary
National Council for
Science &Technology



CONDITIONS

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

GPK6055t3mt10/2011

REPUBLIC OF KENYA

RESEARCH CLEARANCE
PERMIT

(CONDITIONS–see back page)