

**FACTORS ASSOCIATED WITH THE UPTAKE OF HOME-BASED
CARE SERVICES AMONG RURAL PEOPLE LIVING WITH HIV
AND AIDS IN NAROK DISTRICT, KENYA**

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DECLARATION

This thesis is my original work and has not been presented for a degree in any other University.

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DEDICATION

I dedicate this thesis to my parents Mr Victor Nyang'aya and late mum Mrs Yuventina Nyakobo and all the members of my family Irene, Jacinta and Bochere for their love, support, and encouragement during this process.

To my wife Nerry and our sweet baby girl Yuventine.

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LIST OF ABBREVIATIONS

AIDS	Acquired immune deficiency syndrome
APHIA	Aids Population and Health Integrated Assistance
ARV	Anti-retroviral
CCC	Comprehensive Care Centre
CBCC	Community-Based Care Centre
CBO	Community-Based Organization
CHWs	Community Health Workers
CORPs	Community Owned Resource Persons
DASCO	District AIDS and STIs Coordinator
DOTS	Directly Observed Therapy
FA	Field Agent
FBO	Faith-Based Organisation
FGDs	Focussed Group Discussions
GHSS	Global Health Sector Strategy for HIV and AIDS
GoK	Government of Kenya
HBC	Home-Based Care
HAART	Highly Active Anti Retroviral Therapy
HIV	Human Immunodeficiency Virus
HTC	HIV Testing and Counselling
IGA	Income Generating Activity
ILO	International Labour Organization

KAIS	Kenya AIDS Indicator Survey
KDHS	Kenya Demographic Health Survey
KEMRI	Kenya Medical Research Institute
KEPH	Kenya Essential Package for Health
KNASP	Kenya National HIV and AIDS Strategic Plan
LIPs	Local Implementing Partners
MGDs	Millennium Development Goals
MoH	Ministry of Health
MTCT	Mother To Child Transmission of HIV
NACC	National AIDS Control Council
NHSSP	National Health Sector Strategic Plan
NASCOP	National AIDS and STI Control Programme
NGO	Non - Governmental Organization
OIs	Opportunistic Infections
OVCs	Orphans and Vulnerable Children
PEP	Post-Exposure Prophylaxis
PITC	Provider-Initiated Testing and Counselling
PLWHA	Person/People Living With HIV and AIDS
PMTCT	Prevention of Mother-To-Child Transmission
RH/FP	Reproductive Health and Family Planning
SDA	Seventh Day Adventist
SILC	Savings and Internal Lending Communities

SSA	Sub Saharan Africa
STI	Sexually Transmitted Infections
TB	Tuberculosis
TOT	Trainer of Trainers
USAID	United States Agency for International Development
UNAIDS	Joint United Nations Programme on HIV and AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

DEFINITION OF OPERATIONAL TERMS

Home-based care: This is the provision of health services by formal and informal care-givers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death.

A **double or total orphan** is a person (typically a child), who has lost both parents, often through death. In context of this study death must have been occasioned by complications related to HIV and AIDS.

Half or partial orphan is a person (typically a child), who has lost a parent, through death caused by HIV and AIDS complications but with one surviving parent.

Neurophysiologic Symptoms are the feelings a person living with HIV and AIDS (PLWHA) has that cannot be seen physically but affect the nervous and normal (physiological) functioning of the body.

ABSTRACT

In 2007, a total of 33.2 million people worldwide were living with HIV and AIDS representing 30.8 million adults and 15.4 million children. In the same period a total of 2.1 million people died of HIV and AIDS related complications. The impact of HIV and AIDS in many developing countries has brought about untold socio-economic and health sufferings. This therefore, has resulted in HIV and AIDS remaining a major public health problem. In Kenya, HIV and AIDS has been declared a national disaster affecting mainly people in the productive and reproductive age group of 15 to 49 years. Home and Community Based Care (HBC) is a critical component in the care, support and mitigation of the effects of HIV and AIDS but whose utilization is still low in Kenya. The aim of this study was to determine the factors associated with HBC uptake among rural PLWHAs in Narok District. A population based cross-sectional survey employing mainly qualitative (FGDs) and quantitative (questionnaire) techniques was conducted in Narok District among adult (>18 years) PLWHAs. Simple random sampling was used to identify the respondents. Data analysis was done using SPSS. The overall prevalence of HBC uptake among rural PLWHAs was 16.4%. Gender distribution was comparable with the ratio of male to female respondents being 1:1, a distribution pattern of 44% to 56% respectively. HBC uptake among female PLWHAs was 23.3% and that of males was 7.5%. HBC uptake among PLWHAs aged <35 years (youth) was 4.4% and 20.3% for those >35 years or more (adults). There was a significant association between marital status and HBC uptake ($P=0.043$) with the single PLWHAs being least likely to uptake

HBC services as compared to the married or divorced. There was a significant association between level of education attained and HBC uptake among PLWHAs ($P=0.035$). HBC uptake among PLWHAs that had attained primary education or none was 20.7% and 8.1% for those with at least secondary education. There was no significant association between religion and HBC uptake among PLWHAs ($P=0.437$). There was no significant association between employment status and HBC uptake ($P=0.087$), suggesting that unemployed PLWHAs were not more likely to embrace HBC services as than employed PLWHAs. Transport to the nearest health facility did not significantly affect HBC uptake. There was no significant association between time taken to reach the nearest health facility and HBC services uptake ($P=0.815$). The study recommends that there is need for scaling up the programs to comprehensively cover the Districts that have established the services and to reach those who have not accessed HBC, strengthening referral systems between HBC and other services including strengthening of linkage between health facilities and community so as to ensure the continuum of care, and strengthening Districts to support monitor and supervise HBC programs.

CHAPTER ONE: INTRODUCTION

1.1 HIV and AIDS globally

The first cases in the world of acquired immunodeficiency syndrome (AIDS) were reported in 1981. Since then, infection rate with human immunodeficiency virus (HIV) has grown to pandemic proportions, resulting in an estimated total of 67 million infections and 25 million deaths by the year 2007 (UNAIDS, 2008; MMWR, 2006). In Kenya, first identified case of HIV in Kenya was recorded between 1983 and 1984 (NASCO, 2008).

During 2007 alone, an estimated 2.0 million persons died from HIV-related causes, 2.7 million were newly infected with HIV and 33 million were living with HIV (UNAIDS, 2008). People aged 15 – 49 years have been shown to have the highest HIV prevalence in the population (JAIDS, 2006). Unfortunately, majority of workers population fall in this age category. According to the International Labour Organization (ILO), at least 26 million people infected with HIV worldwide are workers in this age group, contributing to over 70% of all adults living with HIV (E. Buregyeya *et al.*, 2008).

Effective prevention and treatment of HIV infection with antiretroviral therapy (ART) are now available, even in countries with limited resources (UNAIDS, 2008; MMWR, 2006). Access to ART for advanced HIV infection in low and middle income countries continued to grow throughout 2006, with more than 2 million people living with HIV

and AIDS (PLWHAs) receiving treatment in 2006, a 54% increase over the 1.3 million people on treatment one year earlier in these countries (WHO/UNAIDS/UNICEF, 2006). As of December 2007, nearly 3 million PLWHAs worldwide were receiving ART. This still represents just 31% of the 9.7 million people in need of ART (UNAIDS, 2008).

However, although the availability of ART for individuals infected with HIV is increasing worldwide, many more new infections are occurring for every additional person started on such treatment thus prevention of new infections is the only realistic hope of stemming the HIV pandemic (United States Government, 2005).

Nonetheless, comprehensive programs are needed to reach all persons who require treatment and to prevent transmission of new infections. Globally, sexual transmission is responsible for majority of new infections (UNAIDS, 2008). Behaviour change programs seek to encourage people to adopt safer sexual behaviours that can reduce the risk of acquiring and transmitting HIV. These include: remaining sexually abstinent or delaying initiation of sexual activity, decreasing the number of sexual partners as well as using condoms consistently and correctly if sexually active. A number of studies have documented the effectiveness of behaviour change programs among a broad range of populations at risk of HIV infection (Auerbach, J. D. et al., 2006). Effective behaviour change programs are tailored to the needs and values of the groups they are designed to reach (UNAIDS, 2008).

1.2 HIV and AIDS in Sub-Saharan Africa

Sub-Saharan Africa (SSA), which is home to approximately 10% of the world population, remains the most affected region in the world accounting to 22 million (67%) of all the PLWHAs globally (UNAIDS, 2008). Of the 2.7 million people newly infected with HIV in 2007, 1.9% (70.4%) million were in SSA (UNAIDS, 2008). In 2007, the region accounted for 75% of the total HIV related deaths (UNAIDS, 2008). Since the disease strikes mainly people aged 15 – 49 years, the economically most productive members of society, HIV and AIDS is a problem of critical importance for economic and social development (UNAIDS, 2008). Tragically, the prevalence of the disease is still creasing throughout much of the African continent. In some countries, the rapidity of the pandemic represents a critical element of the disaster that makes efforts to cope with its effects very challenging (UNAIDS, 2008).

Hi and AIDS affects different population segments with different intensities. For instance, studies conducted in SSA have revealed that due to a combination of biological, socio-economic and cultural factors, women become infected at younger ages than men (HIV/AIDS, agriculture and food security, 1999). Consequently, about 2 million more women than men carry HIV in SSA. Children are suffering disproportionately the consequences of the pandemic, with an estimated 13.2 million

children orphaned by HIV and AIDS. This number is expected to more than double by 2010 (HIV/AIDS, agriculture and food security, 1999).

1.3 HIV and AIDS in Kenya

In Kenya, first identified case of HIV in Kenya was recorded between 1983 and 1984 (NASCO, 2008). Kenya has more than one million people estimated to be living with HIV and AIDS. The country's HIV and AIDS prevalence (the percent of PLWHAs) is just about that of the SSA region overall (7.4% compared 7.5%) (KAIS, 2007; KDHS, 2003).

Since the mid 90s to mid 2000s, the HIV and AIDS prevalence declined from 10% to almost 7%. However, this trend has reversed with the prevalence increasing from 6.7% in 2003 to 7.8% in 2007 (KAIS, 2007; KDHS, 2003). Though this may immediately raise fears that the rates of HIV infection in the population are on the rise, the increase in prevalence could also be a result of availability of care and treatment especially with the scaling up of ART and the different methods of estimation used by the two studies.

By 2007, only about a third (35%) of HIV and AIDS infected adults aged 15 – 64 years in need of ART were accessing treatment (KAIS, 2007). An estimated 250,000 infected adults who were eligible for ART were not on treatment in 2007 (KAIS, 2007). In 2007,

90% of HIV infected adults who reported they were HIV positive and were eligible were accessing ART.

In Narok there are no published reports on HIV prevalence, the range, intensity and breadth of HIV prevention and control services available, available policies and their effectiveness, the prevalence of risk factors and drivers of risk factors for HIV infection among rural people living in Narok District.

1.4 Palliative care in HIV and AIDS

There is renewed focus on expanding access to HIV prevention, treatment, care, support and mitigation of its effects by building on the momentum gained from years of activism by groups of PLWHA, the Millennium Development Goals (MDGs), the World Health Organization (WHO) and Joint United Nations Programme on HIV and AIDS (UNAIDS). As a result, millions more people who need treatment for AIDS have accessed it (PEPFAR, 2006).

A key component of palliative care is home-based care, which in many resource-limited settings is the only way to deliver care to the patient. It is estimated that 50 - 60% of people with HIV and AIDS worldwide have no access to professional healthcare workers to address their medical needs. Medical facilities often lack trained personnel and even the most basic medical supplies and medications (Osborne *et al.*, 1997).

Home-based care is the provision of comprehensive services (including health and social services) by formal and informal caregivers in the home, in order to promote, restore and maintain a person's maximal level of comfort, function and health. Usually, these are initiatives from non-governmental organisations (NGOs), community-based organisations (CBOs) or faith-based organisations (FBOs) but they require sufficient support and funding to be sustainable. In resource-limited settings without adequate health care infrastructure, these services are not just needed for end of life care, but throughout the course of illness. They are often the only way to deal with a patient's ongoing and emerging symptoms where diagnostic and treatment resources are limited (NASCOP, 2008).

Home-based care services can be classified into preventive, promotive, therapeutic, rehabilitative, long-term maintenance and palliative care categories (NASCOP, 2008). HBC is an integral part of community-based care. Community-based care is the care that the consumer can access near home, which encourages participation by people, responds to the needs of people, encourages traditional community life and creates responsibilities. Communities are at the foundation of affordable, equitable and effective health care (Pool *et al.*, 2001). The community, in fact, represents level 1 in the Kenya Essential Package for Health (KEPH) proposed in the second National Health Sector Strategic Plan 2005 – 2010 (NHSSP II) with national referral hospitals at the apex of the health care system, provincial hospitals acting as an intermediary between the national central level and the Districts. District hospitals, the network of health centres and

dispensaries are meant to be the system's first line of contact with patients. The overall goal of the community strategy is to enhance community access to health care in order to improve individual productivity and thus reduce poverty, hunger and child and maternal deaths as well as improve education.

1.5 Statement of the problem

The total number of people living with HIV and AIDS in 2007 globally was estimated at 33.2 million [30.6 million - 36.1 million]. It is estimated that more than 25 million people have died of AIDS since 1981 worldwide with deaths attributable to HIV and AIDS amounting to 2.1 million in 2007(UNAIDS, 2007). There were 1.24 million people infected with HIV and AIDS in Kenya (Central Bureau of Statistics Kenya, 2004).

Home-based care has been in operation in Kenya since 2005 following the Kenya Essential Package for Health (KEPH) introduced in the NHSSP for 2005 – 2009 (Ministry of Health, 2006) (c). Over the last six years, joint efforts by the Kenya government and its development partners have resulted in a rapid increase in the number of PLWHA accessing HBC services (FHI, 2007). In Narok HBC services are offered by the Catholic Relief Services since October 2006 as part of the APHIA II project.

Despite this rapid scale-up of HBC services countrywide, coupled with the Subsequent scale-up of resources available for the same, the proportion of PLWHAs above the age

of 18 years who are accessing the HBC services remains very low. Only 14% of PLWHAs have accessed the HBC services in Narok District (FHI, 2006). The factors that influence the uptake of the HBC services among the communities in Narok District were the main problem the research sought to answer.

1.6 Research Questions

- i. What factors influence the uptake of HBC services in Narok District?
- ii. What are the suggested measures to increase the uptake of HBC services?

1.7 Justification of the Study

HBC is the provision of comprehensive services (including health and social sciences) by formal and informal caregivers in the home, in order to promote, restore and maintain a person's maximal level of comfort, function and health. It has been estimated that 50% to 60% of people with HIV and AIDS worldwide have no access to professional healthcare workers to address their medical needs. Medical facilities often lack trained personnel and even the most basic medical supplies and medications. In these settings, palliative care programmes that focus attention on integrated HBC are thus the most efficient and cost-effective approaches to healthcare delivery.

The need for HBC was first established as increasing numbers of people became sick and died from HIV and AIDS. Unfortunately, this problem is escalating, and other relevant issues are gaining importance. Orphan care is an increasing challenge, with

some communities reporting 5–10 children becoming orphaned each month (World Health Organization, 2006). In addition, anti-retroviral (ARV) treatments are becoming more common, especially for preventing mother-to-child transmission. These new challenges require additional research and education in the HBC services provision.

Despite the existence of HBC services as one of the Government strategies of mitigating the effects of HIV and AIDS, little is known and understood by the rural communities about the HBC services (CRS, 2006). Despite being a key component of HIV and AIDS care and prevention, uptake is currently low (FHI, 2007). The low uptake of HBC among the PLWHA in Narok District poses a challenge to the fight against HIV and AIDS. There is limited understanding of the factors associated with the uptake of HBC services. Therefore, as part of the strategy to mitigate the effects of HIV and AIDS, these services must be made accessible to PLWHAs. There is need therefore, to determine the factors associated with the uptake of HBC services (FHI, 2006).

As part of the monitoring and evaluation process of the Catholic Relief Services (CRS) Kenya Program, this study will serve to provide the information required to improve the HBC services provided as part of its AIDS Population and Health Integrated Assistance (APHIA) II program mandate. This formed the basis of this study.

1.8 Objectives

1.8.1 General Objective

To establish the user rate and the factors associated with the uptake of HBC services in Narok District of Kenya.

1.8.2 Specific Objectives

- i. To determine the user rate of HBC services among PLWHAs in Narok District
- ii. To describe the socio-demographic characteristics of rural PLWHAs in Narok District
- iii. To establish the factors associated with uptake of HBC services among PLWHAs in Narok District

CHAPTER TWO: LITERATURE REVIEW

2.1 Transmission of HIV and AIDS

Three main modes are attributed to HIV transmission: sexual, contact with blood and other body fluids and from an infected mother to a child in the womb during pregnancy or through breast feeding. Unprotected sexual intercourse (vaginal, oral and anal) with an infected person is the most common mode of transmission. Transfusion of blood products from an infected person/donor; use of contaminated instruments such as needles, syringes, knives or blades (including instruments used in circumcision, skin piercing, scarification, traditional healing and other traditional practices) is the second most common mode of transmission. However, HIV is not transmitted through casual contact with another. This includes holding hands, hugging, kissing, sharing food or drink or similar contact. HIV cannot be transmitted by mosquitoes or biting insects (MoH, 2005 a).

Mother-to-child transmission (MTCT) of HIV is not inevitable. MTCT is when an HIV positive woman passes HIV to her baby. This can occur during pregnancy, labour and delivery, or breastfeeding. Without treatment, around 15-30% of babies born to HIV positive women will become infected with HIV during pregnancy and delivery. A further 5-20% will become infected through breastfeeding (De Cock *et al.*, 2000).

In 2007, around 370,000 children globally under 15 years became infected with HIV, mainly through mother-to-child transmission. About 90% of these MTCT infections occurred in Africa where AIDS is beginning to reverse decades of steady progress in child survival. In high income countries MTCT has been virtually eliminated thanks to effective voluntary testing and counselling, access to antiretroviral therapy, safe delivery practices, and the widespread availability and safe use of breast-milk substitutes. If these interventions were used worldwide, they could save the lives of thousands of children each year (UNAIDS, 2008).

Without interventions, there is a 20-45% chance that a HIV-positive mother transmits the infection on to her child. If a HIV positive woman is on ARV drugs, though, this risk can be reduced significantly. Before this measures can be taken the mother must be aware of her HIV-positive status, so testing also plays a vital role in the prevention of MTCT. In many developed countries, these steps have helped to virtually eliminate MTCT. Yet Sub-Saharan Africa continues to be severely affected by the problem, due to a lack of drugs, services and information (UNAIDS, 2008).

Kenya's National AIDS and STI Control Programme (NAS COP) estimates that there are 1.2 million babies born each year in Kenya and that as many as 10% of pregnant women in Kenya are living with HIV and AIDS (NAS COP, 2002). At least 50,000 to 60,000 infants in Kenya are thought to become infected with HIV as a result of MTCT each

year. While knowledge that HIV can be passed from mother to child is high in Kenya, 72% of women and 68% of men reported that HIV can be transmitted through breast milk, only one-third of women and 38% of men know that the risk of MTCT can be reduced when the mother takes certain drugs during pregnancy (Central Bureau of Statistics, 2004).

2.2 HIV and AIDS and immunosuppression

2.2.1 Entry and fusion

HIV enters macrophages and CD4⁺ T cells by the adsorption of glycoproteins on its surface to receptors on the target cell followed by fusion of the viral envelope with the cell membrane and the release of the HIV capsid into the cell. Entry to the cell begins through interaction of the trimeric envelope complex (gp160 spike) and both CD4 and a chemokine receptor (generally either CCR5 or CXCR4, but others are known to interact) on the cell surface (Wyatt et. al., 1998). Gp120 binds to integrin $\alpha_4\beta_7$ activating LFA-1 the central integrin involved in the establishment of virological synapses, which facilitate efficient cell-to-cell spreading of HIV-1 (Arthos *et al.*, 2008).

Fusion involves the high-affinity attachment of the CD4 binding domains of gp120 to CD4. Once gp120 is bound with the CD4 protein, the envelope complex undergoes a structural change, exposing the chemokine binding domains of gp120 and allowing them to interact with the target chemokine receptor. This allows for a more stable two-pronged attachment, which allows the N-terminal fusion peptide gp41 to penetrate the

cell membrane (Wyatt *et al.*, 1998). Repeat sequences in gp41, HR1 and HR2 then interact, causing the collapse of the extracellular portion of gp41 into a hairpin. This loop structure brings the virus and cell membranes close together, allowing fusion of the membranes and subsequent entry of the viral capsid (Wyatt *et al.*, 1998).

After HIV has bound to the target cell, the HIV RNA and various enzymes, including reverse transcriptase, integrase, ribonuclease and protease, are injected into the cell. During the microtubule based transport to the nucleus, the viral single strand RNA genome is transcribed into double strand DNA, which is then integrated into a host chromosome (Wyatt *et al.*, 1998).

2.2.2 Replication and transcription

After the viral capsid enters the cell, reverse transcriptase liberates the single-stranded (+) RNA genome from the attached viral proteins and copies it into a complementary DNA molecule (Zheng, 2005). The process of reverse transcription is extremely error-prone, and the resulting mutations may cause drug resistance or allow the virus to evade the body's immune system. The reverse transcriptase also has ribonuclease activity that degrades the viral RNA during the synthesis of cDNA, as well as DNA-dependent DNA polymerase activity that copies the sense cDNA strand into an antisense DNA. Together, the cDNA and its complement form a double-stranded viral DNA that is then transported into the cell nucleus. The integration of the viral DNA into the host cell's genome is carried out by another viral enzyme called integrase (Zheng, 2005).

To actively produce the virus, certain cellular transcription factors need to be present, such as NF- κ B (NF kappa B), which is up-regulated when T-cells become activated (Hiscott, 2001). This means that those cells most likely to be killed by HIV are those currently fighting infection.

During viral replication, the integrated DNA provirus is transcribed into mRNA, which is then spliced into smaller pieces. These small pieces are exported from the nucleus into the cytoplasm, where they are translated into the regulatory proteins Tat (which encourages new virus production) and Rev. As the newly produced Rev protein accumulates in the nucleus, it binds to viral mRNAs and allows unspliced RNAs to leave the nucleus, where they are otherwise retained until spliced (Pollard, 1998). At this stage, the structural proteins Gag and Env are produced from the full-length mRNA. The full-length RNA is actually the virus genome; it binds to the Gag protein and is packaged into new virus particles.

2.2.3 Assembly and release

Assembly of new HIV-1 virions, begins at the plasma membrane of the host cell. The Env polyprotein (gp160) goes through the endoplasmic reticulum and is transported to the Golgi complex where it is cleaved by protease and processed into the two HIV envelope glycoproteins gp41 and gp120. These are transported to the plasma membrane of the host cell where gp41 anchors the gp120 to the membrane of the infected cell. The

Gag (p55) and Gag-Pol (p160) polyproteins also associate with the inner surface of the plasma membrane along with the HIV genomic RNA as the forming virion begins to bud from the host cell. Maturation either occurs in the forming bud or in the immature virion after it buds from the host cell. During maturation, HIV proteases cleave the polyproteins into individual functional HIV proteins and enzymes. The various structural components then assemble to produce a mature HIV virion (Gelderblom, 1997). This cleavage step can be inhibited by protease inhibitors. The mature virus is then able to infect another cell.

2.3 Manifestations of HIV and AIDS

2.3.1 Physical

HIV and AIDS has various common symptoms which may be divided into six different categories based on the various anatomical regions of the body. General symptoms include general malaise, loss of weight, pain, swollen glands and limbs and loss of hair. Skin and hair symptoms include itching, boils, rashes, ulcerations, wounds, infections, thinning of the hair, early greying. There is persistent coughing, chest pain, difficulty in breathing, TB, herpes zoster and meningitis. In the gastrointestinal system diarrhoea, difficulty in swallowing, poor appetite, sour mouth, nausea and vomiting and abdominal pain are the main manifestations. In the central nervous system headaches, memory loss and confusion, tingling and numbness of limbs, convulsions, coma, anxiety and depression are the dominant manifestations (MoH, 2005 b).

2.3.2 Psychological

2.3.2.1 Fear

Fear and shame may prevent PWHIV from confiding in others and gaining support; making them reluctant to seek help from HIV and AIDS organizations and the rehabilitation system. Fear can arise in the infected person from the unpredictable nature of the disease. Fear can aggravate depression symptoms and lead to feelings of hopelessness, frustration and being overwhelmed. Fear can also arise in others, with repercussions for the person with HIV/AIDS. Friends and co-workers may pull away because of irrational fears of contagion or fears of a person's death, therefore leaving the person with HIV with a deep sense of isolation and loss (Mears *et al.*, 2005).

2.3.2.2 Loss

HIV has been called 'a disease of losses'. Sadness is one outcome of experiencing repeated losses. PLWHAs may have to grieve the loss of deceased lovers, children and friends while at the same time mourning the loss of their own future. With many successive losses, it can take the form of "chronic, unrelenting loss". Other losses can include loss of partner, family, friends, co-workers, mobility, strength, weight, appetite, and physical attractiveness, locus of control, social role, income, employment, housing to name a few (Selwyn *et al.*, 2004).

2.3.2.3 Grief

Three stages of grieving can be identified: how did the person die? What caused the death? Was the death sudden, gradual, painful, and easy? What did the person mean to you? Were they a friend, partner, co-worker, parent, child? How will you learn to live without the person? What do you need to do to go on living? Anticipatory grief (i.e., grief about possible future losses) and bereavement often result in anger and depression (Selwyn *et al.*, 2004).

2.3.2.4 Anger

Anger may be directed at several targets simultaneously. The PLWHA may blame themselves for getting infected and the resulting physical and mental loss; their family for not being able to do anything; one's support system for lack of understanding, empathy or compassion; the society for their rejection; and the medical establishment, for failing to find a cure. The fluctuating nature of AIDS disease and the interface with the health care delivery system can cause frustration and anger. The need to stay in control can sometimes produce behaviours such as quarrelling, arguing, complaining, or being demanding (Mears *et al.*, 2005).

2.3.2.5 Depression

Feelings of depression manifest as feelings of discouragement, dejection, or helplessness. Signals that depression is being experienced include disturbance in sleep, appetite changes, withdrawal from all activity, failure to find pleasure in favourite activities, or difficulty in concentration. If depression is unresolved, a maladaptive

coping strategy is substance abuse or attempted suicide. Psychological causes can include the anticipation of dying and death; the loss of friends, lovers, parents, or children; the possibility of becoming disabled; and the discomfort of becoming increasingly dependent on others (Mears *et al.*, 2005).

2.3.2.6 Feelings of dependency

Feelings of dependency can be experienced by PLWHAs with disabilities arising from a loss of functional capacity in both physical and emotional areas. Being dependent on others brings on threats to autonomy, privacy, control, and independence and feelings of helplessness and vulnerability that are often intolerable. This has the effect of being unwilling to ask for accommodation because of change in identity, feelings of shame, not wanting to feel different or pitied (Mears *et al.*, 2005).

2.3.2.7 Hope

Not all emotional responses to HIV and AIDS are negative. For PLWHAs, maintaining hope is not merely a virtue, but a primary task. PLWHAs live longer when they hope for and plan future activities, achievements and relationships. Hope sustains them through the inevitable "bad days" and increases the capacity to appreciate periods of good health. Feelings of hope fluctuate daily, and sources of hope differ from person to person. Hope can be engendered by developing or maintaining spiritual practices such as organized religion, and meditation. Hope is sustained by maintaining employment and relationships with co-workers; becoming involved in activist groups; cultivating social and family ties, and finding meaning in new roles or new experiences. The most

important factor in maintaining hope is active participation in decision-making. Any intervention that enables a PLWHA to feel in greater control of their health care and activities (GIPA) strengthens their feelings of hope (Mears *et al.*, 2005).

2.4 Prevention and control of HIV and AIDS

Abstinence, be faithful, use a condom (ABC strategy) or abstinence-plus sex education (abstinence-based sex education) is a sex education policy based on harm reduction which modifies the approach of abstinence-only sex education by including education about safe sex and birth control methods. The ABC approach was developed in response to the growing epidemic of HIV and AIDS in Africa, and to prevent the spread of other sexually transmitted diseases (Niver *et al.*, 2007).

An abstinence-based approach to sex education focuses on teaching young people that abstaining from sex until marriage is the best means of ensuring that they avoid infection with HIV, other sexually transmitted infections and unintended pregnancy. This means developing skills for practicing abstinence and encouraging participants to adopt social norms that support abstinence (U.S. Department of State, 2009). Abstinence approaches are represented in programmes which aim to teach young people that they should commit to abstain from sex until marriage

Abstinence until marriage does not always ensure safety, because marriage in itself provides no protection from HIV and STI infection. Many people are unsure of the HIV

status of their partners, and those who are faithful cannot be certain that their partner is maintaining the same commitment. Furthermore, abstinence is not a realistic option for the millions of women and girls who are in abusive relationships, or those who have been taught always to obey men. People who do not abstain should do everything possible to reduce risk, including using condoms (U.S. Department of State, 2009).

Condoms play a key role in preventing HIV infection around the world. In Sub-Saharan Africa, most countries have seen an increase in condom use in recent years. Studies show eight out of eleven countries in Sub-Saharan Africa reported an increase in condom use (UNAIDS, 2002) (a). The distribution of condoms to countries in Sub-Saharan Africa has also increased: in 2004 the number of condoms donated to this region was equivalent to 10 for every man (United Nations Population Fund, 2006) compared to 4.6 for every man in 2001 (Shelton *et al.*, 2001).

Relative to the enormity of the HIV and AIDS pandemic in Africa, providing condoms is cheap and cost effective. Even when condoms are available there are still a number of social, cultural and practical factors that may prevent people from using them. In the context of stable partnerships where pregnancy is desired, or where it may be difficult for one partner to suddenly suggest condom use, this option may not be practical (WHO, 2008).

People with HIV and AIDS or other complications requiring HBC are very vulnerable to many kinds of infections which can spread easily to others around them. The patients, their family members and care-givers must be aware of how to control the spread of infections. This includes prevention of the spread of infection from care-giver to patient, patient to caregiver and self infection from one part of the body to another (Mutua, 2004).

The PLWHAs have a lowered immunity as a result of HIV infection and are therefore, prone to infections. If the caregiver is sick with any common infection, it is safe to have another caregiver take care of the client during the period of illness. A caregiver must exercise precautions to avoid direct contact of blood and body fluids of patients with AIDS to avoid contact with HIV or other infectious diseases. The generally accepted infection prevention measures that caregivers should follow include washing hands, using gloves or other protection, handling body fluids carefully, maintaining general and personal hygiene, keeping food and drinking water safe and disposing of waste properly (Lamprey, 1990).

Being HIV-positive does not mean the patient is no longer capable and in need of sexual satisfaction. In the early stages of HIV infection, the patient has minimal or no signs of the disease and is therefore as attractive as before. The infected person still has sexual feelings and thus is capable of passing the infection sexually to any sexual partner(s). This form of infection can be prevented by educating the infected person on the

infection, including mode of transmission and all known preventive measures, stressing total abstinence (primary or secondary) as the primary preventive measure and urging a patient who is not able to abstain to have only one sexual partner with whom they must use condoms to prevent re-infection and spread of the disease (WHO, 2008).

The provision of Voluntary Counselling and Testing (VCT) for HIV is an important part of any national HIV and AIDS prevention program. VCT also provides benefit for those who test negative, in that their behaviour may change as a result of the test. The provision of VCT has become easier, cheaper and more effective as a result of the introduction of rapid HIV testing, which allows individuals to be tested and find out the results on the same day. VCT could and indeed needs to be made more widely available in most Sub-Saharan African countries (Maman *et al.*, 2003).

Around 2 million children in Sub-Saharan Africa were living with HIV at the end of 2007 which represents more than 85% of all children living with HIV worldwide (UNAIDS, 2002 b). The vast majority of these children were infected with HIV during pregnancy or through breastfeeding when they were babies, as a result of their mother being HIV-positive.

Although about half of women and three-fifths of men have heard of Voluntary Counselling and Testing (VCT), only about 15% of them have actually gone for testing.

In 2006, preventive drugs reached only 31% of HIV-infected pregnant women in Eastern and Southern Africa, and only 7% in West and Central Africa (UNAIDS/UNICEF/WHO, 2008). Given the scale of the MTCT crisis in Africa, it is remarkable that very little is being done to prevent the rising numbers of children becoming infected with HIV, and dying from AIDS.

2.5 Impact of HIV and AIDS

2.5.1 Socio-economic

HIV and AIDS has a major economic and social impact on individuals, families, communities and on society as a whole. In Kenya as in other countries in SSA, AIDS threatens personal and national well-being by negatively affecting health, lifespan and productive capacity of the individual and severely constraining the accumulation of human capital and its transfer between generations (Ministry of Health, 2005). Research across many severely affected, low income countries clearly demonstrates that HIV and AIDS is the most serious impediment to economic growth and development in such countries (IMF, 2004).

Poverty reduction, driven by economic growth is the central objective of Kenya's economic recovery strategy (ERS). The impact of HIV and AIDS on economic growth and development, coupled with the direct impact of increased mortality and morbidity on the lives of the poor, makes HIV and AIDS a uniquely corrosive threat to poverty reduction efforts (Hancock, 1996). The impact of AIDS on the gross domestic product

(GDP) of the worst affected countries is a loss of around 1.5% per year; this means that after 25 years the economy would be 31% smaller than it would otherwise have been (Greener, 2004).

With the introduction of Anti-Retroviral Therapy (ART) as part of the comprehensive management of the HIV-positive people, the need of HBC is urgent as people and organisations in the public and private sector strive to improve the quality of life of PLWHA and their families as well as mitigate the effects of HIV and AIDS. Quality of life also encompasses nutritional counselling, including food supplementation for those in great need. Tuberculosis (TB), which has become one of the commonest and most severe opportunistic infections (OIs) for HIV infected people needs diagnosis and prompt management to ensure that patients do not succumb to the dual infection (Ministry of Health, 2006) (a). In all these situations HBC helps achieve the set objectives for quality of life and ensure patients' compliance and adherence to therapy. Home-based care also helps change the attitudes of people towards PLWHA and towards the disease itself.

Communities provide care to their beloved family members, neighbours and colleagues. This increases access to care and ensures that the community becomes involved in prevention activities. HBC generally is not seen as a priority in HIV care and prevention programs. In many parts of the world, and particularly in developing countries, HBC services are not widely available or not available at all (MOHSS/NASCOP, 2008).

Studies in developing and developed countries describe barriers to accessing HBC services as distance, cost for the services, lack of knowledge, self-efficacy expectation and stigma. Studies show that motivation to utilize HBC services is affected by factors such as feeling sick, family factors (for example marriage or new partner) and fear of having to be exposed in society (Wolff *et al.*, 2005).

High-impact HBC strategies are needed to maximize HIV prevention, mitigation of effects and access to care in Africa. Convenience and accessibility appear to have critical roles in the acceptability of HBC services. Previous studies on HBC have indicated that the convenience of receiving care, whether the care is offered, and the attitude of staff providing it are all very important (Corbett *et al.*, 2006). A qualitative study investigating HBC service uptake by pregnant women using focus group discussion in South West Uganda revealed that pregnant women were anxious about taking up HBC services, due to the fear for confidentiality and fear that maternity staff might refuse to assist them when the time comes to deliver if their status was known (Pool *et al.*, 2001).

Some health facilities nurses disclose the HIV status of their clients in the public without informed consent (FHI/IMPACT, 2001). Studies have shown that patients do not accept being counselled by counsellors who are younger than they are which increases the pressure on the availability of counselling services under the HBC service (MOHSS,

2004). Observational studies concur that convenience, direct offer of care and positive attitude of staff have a critical impact on uptake of HBC services, and appear to outweigh individual client-related factors (Cartoux *et al.*, 1998; Gibb *et al.*, 1998; Kassler *et al.*, 1998; Zachariah *et al.*, 2003; 2001; Wolff *et al.*, 2005). It is also proposed that care-givers' attitudes towards HBC in rural areas may be a key factor in uptake (UNAIDS, 2002 b).

2.5.2 Impact on the health sector

In all affected countries the HIV and AIDS pandemic is bringing additional pressure to bear on the health sector. As the pandemic matures, the demand for care for those living with HIV rises, as does the toll of AIDS on health workers. In Sub-Saharan Africa, the direct medical costs of AIDS (excluding antiretroviral therapy) have been estimated at about US\$30 per year for every person infected, at a time when overall public health spending was less than US\$10 per year for most African countries (UNAIDS, 2002 a).

As the HIV prevalence of a country rises, the strain placed on its hospitals is likely to increase. In Sub-Saharan Africa, people with HIV-related diseases occupy more than half of all hospital beds (HRSA, 2003). Government-funded research in South Africa has suggested that, on average, HIV-positive patients stay in hospital four times longer than other patients (Inter Press Service News Agency, 2006). This may be the case in Kenya although specific data is not available.

HIV and AIDS has had a widespread impact on a significant proportion of the African society. In many countries of Sub-Saharan Africa including Kenya, AIDS is eroding decades of progress made in extending life expectancy. Millions of adults are dying from AIDS while young, or in early middle age. Average life expectancy in Sub-Saharan Africa was 47 years, when it could have been 62 without HIV and AIDS (UNAIDS, 2008).

The effect of the HIV and AIDS pandemic on households is very severe. Many families are losing their income earners. In other cases, income earners are forced to stay at home to care for relatives who are ill from AIDS. Many of those dying from AIDS have surviving partners who are themselves infected and in need of care. They leave behind orphans, grieving and struggling to survive without a parental care (Office of the President, Kenya, 2000). In all affected countries, the HIV and AIDS pandemic is putting strain on the health sector. As the pandemic develops, the demand for care for those living with HIV rises, as does the number of health workers affected. Schools are heavily affected by HIV and AIDS. This is a major concern, because schools can play a vital role in reducing the impact of the pandemic, through education and support (UNAIDS, 2002 b).

HIV and AIDS dramatically affect labour, setting back economic activity and social progress. The vast majority of people living with HIV and AIDS in Africa are between the ages of 15 and 49 in the prime of their working lives (Ministry of Health, 2006) (b).

Employers, schools, factories and hospitals have to train other staff to replace those at the workplace that become too ill to work. Through its impacts on the labour force, households and enterprises, HIV and AIDS results in decline in economic growth and development. HIV and AIDS is already having a major effect on Africa's economic development, and in turn, this affects Africa's ability to cope with the pandemic (MoH, 2007).

2.6 Poverty, socio-cultural gender, religion and HBC

With sexuality in the forefront of HIV and AIDS transmission, it confronts religious teachings like no other disease. Religions are important forms of social control, especially in the area of sexuality. Religion has a great influence on people's perceptions and ultimately influences their motivation towards behaviour and setting up of cultural and social environments that have a bearing on health. Even though many religions have ambivalent attitudes toward sexuality they still have abundant teachings which can be explored and adapted in campaigns related to the fight against the spread of the HIV and AIDS. People's behaviour and ways to deal with situations within a society have been governed by their beliefs to a divine being since time immemorial. Based on this belief, rules and regulations on what is good or bad for their life has been formulated and practiced by each member of the society (Maulana, 2004).

As part of the training in HBC and for purposes of reducing dependency on funded programs and ensure sustainability beyond funding, PLWHAs are encouraged and

mobilized to form support and post test clubs in which their capacity in microfinance and income generating activities (IGAs) is build. Such activities generate income which may be re-invested back into care and treatment and other mitigation strategies for the effects of HIV and AIDS. This helps raise the quality of life of PLWHAs, improving their self esteem and therefore demystifying HIV and AIDS and effects of stigma (Franklyn, 2002).

2.7 Stigma, discrimination and exclusion and HBC

AIDS-related stigma refers to the prejudice and discrimination directed at PLWHA and the groups and communities that they are associated with. It can result in PLWHAs being rejected from their community, shunned, discriminated against or even physically hurt. Discrimination refers to treatment taken toward or against a person of a certain group that is taken in consideration based on class or category. Discriminatory behaviours take many forms, but they all involve some form of exclusion or rejection (Wolfe, 2008).

Since the beginning of the HIV and AIDS epidemic over 25 years ago, stigma has been a barrier to HIV prevention and care. The effect of stigma on people's ability to access HIV testing, counselling, diagnosis, care, treatment, and prevention messages varies from setting to setting, but when present, stigma can create an environment where people may avoid HIV-related services (Wolfe, 2008). HIV and AIDS related stigma refers to the prejudice and discrimination directed at PLWHA and the groups and

communities that they are associated with. It can result in PLWHA being rejected by their community, shunned, discriminated against or even physically hurt.

HIV and AIDS stigma and discrimination have been seen all over the world, although they manifest themselves differently between countries, communities, religious groups and individuals. They are often seen alongside other forms of stigma and discrimination, such as racism, homophobia or misogyny and can be associated with behaviours often considered socially unacceptable such as prostitution or drug use (Buve et al., 2001). PLWHAs may impose stigmatizing beliefs and actions on themselves. Self-stigma and fear of a negative community reaction can hinder efforts to address the AIDS epidemic by perpetuating the wall of silence and shame surrounding the epidemic (Stigma Research, 2004)

Stigma directed at PLWHA not only makes it more difficult for people trying to come to terms with and manage their illness on a personal level, but it also interferes with attempts to fight the HIV and AIDS pandemic. On a national level, the stigma associated with HIV can deter governments from taking fast, effective action against the epidemic, while on a personal level it can make individuals reluctant to access HIV testing, treatment and care (Office of the President [Kenya], 2000).

Fear of contagion coupled with negative, value-based assumptions about people who are infected leads to high levels of stigma surrounding HIV and AIDS. Several factors

contribute to HIV and AIDS-related stigma some of which include the belief that HIV and AIDS is a life-threatening disease, HIV infection is associated with behaviours (such as homosexuality, drug addiction, prostitution or promiscuity) that are already stigmatised in many societies (Shisana *et al.*, 2002). Most people become infected with HIV through sex. Sexually transmitted diseases are always highly stigmatised. There is a lot of inaccurate information about how HIV is transmitted and HIV infection is often thought to be the result of personal irresponsibility. Religious or moral beliefs lead some people to believe that being infected with HIV is the result of moral fault (such as promiscuity or 'deviant sex') that deserves to be punished (UNAIDS/WHO, 2000).

The fact that HIV and AIDS is a relatively new disease also contributes to the stigma attached to it. The fear surrounding the emerging epidemic in the 1980's is still fresh in many people's minds. At that time very little was known about the transmissibility of the virus, which made people scared of those infected due to fear of contagion. AIDS-related stigma is dynamic as infection levels, knowledge of the disease and treatment availability vary. Stigma may also vary depending on the dominant transmission routes in the country or region. In Sub-Saharan Africa, heterosexual sex is the main route of infection, means that AIDS-related stigma in this region is mainly focused on promiscuity and sex work (Shisana *et al.*, 2002).

The epidemic of fear, stigmatization and discrimination has undermined the ability of individuals, families and societies to protect themselves and provide support and reassurance to those affected. This hinders efforts at stemming the epidemic. It complicates decisions about testing, disclosure of status, and ability to negotiate prevention behaviours, including use of family planning services. These factors all contribute to the expansion of the epidemic and a higher number of AIDS-related deaths. An unwillingness to take an HIV test means that more people are diagnosed late, when the virus has already progressed to AIDS, making treatment less effective and causing early death (William *et al.*, 2008).

Research by the International Centre for Research on Women (ICRW) found the possible consequences of HIV-related stigma to be loss of income/livelihood, loss of marriage and childbearing options, poor care within the health sector, withdrawal of care giving in the home, loss of hope and feelings of worthlessness and loss of reputation (International Centre for Research on Women, 2005).

2.8 Legal and ethical issues in HIV

Much of the legal and ethical debate around HIV infection focuses on the conflict between society's right to protect itself against the spread of disease and the rights of infected people to confidentiality and civil liberty. In fact, this perceived antagonism is misleading. Measures intended to protect the individual also protect society. The public

health response to the epidemic is compromised by discrimination and the stigma attached to those victimized by the disease (Singer *et al.*, 1996).

HIV is transmitted mainly through sexually though transmission of mother-to-child transmission also another significant contributor. An effective response to the epidemic depends on prevention and on the willingness of individuals to be tested and to cooperate in contact tracing and measures aimed at limiting the spread of the disease. Because so many people are not aware that they are HIV-seropositive, the responsibility for protection ultimately has to rest with everyone, and not just with the person who is infected (American Psychiatric Association, 1993).

A few well-publicized cases of people living with HIV who have deliberately and maliciously infected others have created a strong emotional reaction and demands for coercive measures and specific criminal laws to prevent the spread of infection. These measures would apply to a very small number of people and provide only an illusion of protection. If HIV-seropositivity can result in criminal liability, people will be discouraged from being tested. Testing is a key component of an effective HIV-prevention strategy. In contrast, measures aimed at protecting those who are infected encourage testing and, therefore, the possibility for intervention (Landau-Stanton *et al.*, 1993).

There is little evidence that criminal prosecution and penalty serve any significant rehabilitative function. Counselling and support are widely believed to be more effective means of rehabilitating a person who has engaged in high-risk activities. The small number of people who cannot or will not change their behaviour to prevent the spread of HIV continue to pose a challenge to public health authorities. Many reasons may underlie this behaviour and include denial, anger, ignorance, substance abuse, violence and threat, economic imperatives, disorganization, an experienced inability to change, or a lack of concern for others. Only a concerted approach involving mental health resources, social services, and cultural and community groups can address these complex situations (Canadian HIV-AIDS Policy and Law Newsletter, 1996).

2.9 Care of PLWHAs

2.9.1 Facility based care

Over 95% of PLWHA live in lower-income or developing countries with nearly two-thirds of PLWHA globally live in Sub-Saharan Africa, and Asia is catching up at an alarming pace. As the number of PLWHA increases, the gap continues to widen between the demand for and availability of health care services (UNAIDS/WHO, 2004).

Demand for health services has increased due to the increasing numbers of individuals who have become ill as a result of HIV infection. This has resulted in increased workload and congestion of health facilities. Hospital bed occupancy rates have increased with over 55% of beds occupied by PLWA. Apart from HIV/AIDS, other

chronic diseases such as cancers have made people require long-term care (UNAIDS, 2000).

Facility care ensures specialized medical care and equipment are immediately available for specialized palliative care of its patients while the hospital routine offers structure that the patient and family may need. There may be little privacy and the family may not be able to actively participate in care giving as they would like. The hospital routine may not suit the patient and family's personal routine making the hospital seem as imposing or impersonal. The hospital may not be easily accessible to the family at all times (UNAIDS/WHO, 2004).

Health institutions have limitations such as shortage of health workers, limited hospital beds and a shortage of other material resources. Facility care does not promote family and community awareness of disease prevention and care related to chronic illnesses. It fails empower the clients, the family and the community with the knowledge needed to ensure long-term care and support. Facility care fails to raise the acceptability of PLWHAs by the family/community, hence perpetuating stigma associated with AIDS. Facility care has not streamlined the patient/client referral from the institutions into the community and from the community to appropriate health and social facilities that facilitates quality community care. This type of care does not mobilize the resources necessary for sustainability of services (UNAIDS/WHO, 2004).

2.9.2 Home-based care

HBC is the provision of basic nursing care needs by formal or informal caregivers to people in their own homes. It is an integrated, comprehensive, continuum of care for people infected with HIV as well as those with chronic disabling, the physically or mentally challenged, frail older persons, or those who are terminally ill. The care given is meant to restore and maintain the individual's maximum level of comfort, function and health, including care towards a dignified death (NAS COP, 2008).

HBC is a critical component of the health care system. It affects the socio-economic, psychosocial and medical well being of the patient, the family, the community and the health care system. Home-based care has many advantages to the PLWHAs. These range from the comfort of familiar surroundings to a sense of belonging to the family. A patient who is nursed in a familiar environment usually suffers less stress and anxiety than one who is far from home in a strange hospital or clinic making the illness more bearable (Family Health International/IMPACT, 2001).

The home environment also allows the PLWHAs to continue participating in family matters. This would not be the case if the person were hospitalised in an institution away from home. For a man, it means he can still act as the head of the family and for a woman that she still holds her role. A PLWHA nursed at home is in close contact with the family members, friends and the community as a whole and this promotes a sense of

belonging (Ministry of Health, 2006) (c). Being in constant contact with family members, friends and relatives helps PLWHAs to accept the disease.

2.9.2.1 Rationale for HBC

Demand for health services has increased due to the increasing numbers of individuals who have become ill as a result of HIV infection. This has resulted in increased workload and congestion of health facilities. Hospital bed occupancy rates have increased with over 55% of beds occupied by PLWA. Apart from HIV/AIDS, other chronic diseases such as cancer have made people require long-term care (Kisubi *et al.*, 1997).

PLWHAs and other debilitating illnesses are discharged from health institutions where there are trained professionals and sent home to be cared for by untrained relatives with no professional back up support. The care givers at home often are women with no training in nursing or how to protect themselves from risks related to infections and injuries as a result of the care they give. People with chronic debilitating illnesses, for example HIV/AIDS need continuity of care to prolong their lives and reduce their suffering. Health institutions have many limitations such as shortage of health workers, limited hospital beds and a shortage of other material resources (Kirunga *et al.*, 1997).

2.9.2.2 Merits and demerits of HBC to the client

The patient is cared for in a familiar environment. Such a patient usually suffers less stress and anxiety compared to the one in hospital, clinic or nursing home. When people

are in a familiar environment their illness is more tolerable and they continue to participate in family matters. Those who are heads of their families continue doing so and can be consulted on various family issues. It is quite difficult when one is in hospital or a clinic to make a decision. When one is at home close to family members, friends and relatives, there is a sense of belonging. This is not the case if one is in a hospital setting where the caregivers are strangers who keep changing with every shift. When one is in close contact with familiar people they are likely to accept their conditions and illnesses. The acceptance contributes to quicker recovery or in the case of HIV/AIDS it may assist in better management of the syndrome (Kisubi *et al.*, 1997).

2.9.2.3 Merits and demerits of HBC to the family

Care given in the home is less expensive than that in the hospital. Patients will pay for bed charges, food and other items, which will normally be available and shared at home which makes it easy to provide care and support to the client while attending to other responsibilities. Caring for sick people at home prevents separation and holds family members together. When family members are given education and information on diseases, it helps them to understand diseases better and accept the patients and enables family members to be present at the time of death (Gibb *et al.*, 1998).

2.9.2.4 Merits and demerits of HBC to the community

Training in home-based care helps community members to be aware of the various illnesses affecting members of their communities. HBC therefore, helps the community to understand the nature of the disease and counteract myths, beliefs and misconceptions

especially in relation to HIV and AIDS and other diseases. The costs of visiting a patient in hospital are reduced making it easier and convenient to provide support and maintaining community cohesiveness. This ensures that the community is able to respond to other members' needs (Osborne *et al.*, 1997).

2.9.2.5 Merits and demerits of HBC to the health care system

HBC improves access to quality care: There are areas where a hospital is not accessible to some people but care can be achieved through training of caregivers in HBC. HBC reduces the pressure on the already overcrowded hospital services and hence the health system. Through care at the home, hospitals will have fewer people to attend to and as such they will be able to have more time to provide quality services to those patients who require short-term care and thus reduce the workload of the health care providers. One of the obstacles within the health system in Kenya is limited human resources. HBC helps to overcome this constraint. HBC helps to reduce demand on the health facility under limited resources (Kirunga *et al.*, 1997).

2.10 Home-based care and management of HIV and AIDS

Relying on the strengths of family and community networks, Home-Based Care has emerged as an effective method of providing cost-effective, compassionate care to those infected and affected by HIV and AIDS. HBC is not a replacement for hospital care, but instead is part of a comprehensive continuum of prevention, care, treatment, and support services that include the family, the community, and various levels of health care providers. In addition to providing support to families coping with HIV and AIDS, HBC

also contributes to prevention efforts. By involving community members in prevention, care, and support efforts, HBC brings issues surrounding HIV and AIDS into the open, creating opportunities to clarify myths, reduce stigma, empower those infected and affected by HIV and AIDS, and influence peoples' willingness to know their HIV status and change risky behaviours.

Good basic care can be given successfully at home and it is usually less expensive for families to care for PLWHAs at home than in hospital. For example, there are no hospital bills, transport to and from hospital. Moreover, nursing a PLWHA at home helps to hold family members together and makes it easier to coordinate family activities. Information and education on HIV and AIDS will help family members to understand and accept the PLWHA's condition (Joint Annual Program Review Process, 2004).

Training in HBC helps community members become more aware of HIV and AIDS, helping counteract myths and mistaken beliefs about the disease and encourages people to take steps to prevent infection (MoH, 2006 c). Nursing a PLWHA at home reduces the community's cost of reaching a PLWHA and encourages community participation in the care of PLWHAs. HBC also helps maintain community cohesiveness in responding to community members' needs. The essence of HBC is that it does not require the creation of extra services where none exist. Sometimes hospital care is simply not

possible. HBC helps ease the demand on the health system. Home care can mean that hospitals will be less crowded, so that doctors, nurses and other hospital staff can give better care to those who really need to be in hospital.

Sick people are discharged from hospitals where there are trained professionals and are sent home where they are usually cared for by untrained relatives with no professional back up. These caregivers at home are most often women and children with no training in nursing the sick or in how to protect themselves or other family members from infections arising from handling infected material e.g. body fluids. They do not know how to protect the PLWHA from common infections. PLWHAs need continuity of quality care to prolong their lives and reduce suffering. There are also limitations on hospital care, including limited resources that affect the care that can be given to PLWHAs (William *et al.*, 2001).

All these concerns mean that PLWHAs cannot get the appropriate care they need. HBC is one way to ensure that quality care can be continuously provided for PLWHAs outside the health unit level. The purpose of providing HBC for PLWHAs is first, to prevent problems when possible, secondly to take of existing problems and finally, to enable people to know when to get help (CDC, 2003).

The essential elements of HBC have been developed using research, observations from practice and HBC evaluations in different regions of the world. These essential elements are divided into seven main categories: provision of care; continuum of care; education; supplies and equipment, staffing, financing and sustainability; and monitoring and evaluation. However, in reality, all these elements are integrated. (MoH, 2006 b).

2.11 Components of Home-Based Care

The full range of care and referral services needed for the delivery of optimum care at the community level includes clinical and nursing care, pain relief, counselling and spiritual support (Pool *et al.*, 2001).

2.11.1 Clinical and basic nursing care

Clinical and nursing care in a home set up involves providing basic comfort measures. Such care includes recognizing symptoms, diagnosis, treatment, symptom management, referral and follow-up. In addition, issues related to prevention and protecting the ill person and caregiver through the use of universal precautions are included. Identifying situations in which the basic needs of shelter, food, bedding and clothing and adequate care giving are not being provided may require identifying other resources to enable physical care to be provided at home (FHI/IMPACT, 2001).

Basic nursing care includes positioning and mobility, bathing, wound cleansing, skin care, oral hygiene, adequate ventilation and guidance and support for adequate nutrition. Symptom management depends on the ill person's condition. However, basic symptom

management includes: reducing fever; relieving pain; treating diarrhoea, vomiting and cough; skin, mouth, throat and genital problems; and general tiredness and weakness; and treating neurophysiologic symptoms. These treatments might include pharmaceutical preparations or the use of traditional remedies and herbal treatments (Kassler *et al.*, 1998).

The HBC team have basic home care kits that contain the basic medicines and supplies for home care. For people living with HIV AND AIDS, various treatments may be given for OIs, the most common being TB. Tuberculosis medication is usually administered through a directly observed therapy (DOTS) programme. However, these medicines might be given as part of the HBC programme or through a separate community service (WHO, 2002).

Treatment for preventing OIs as well as ART may be available in some parts. For example, some settings are now providing ARV treatment and alternative breastfeeding options to HIV-infected mothers to ensure PMTCT. In addition, TB medicine is sometimes given as a prevention strategy. These treatments might be provided at a local health facility or, in some circumstances, members of the HBC team may administer these medicines at home. Nurses need to assure themselves and their patients that they are delivering a high standard of quality nursing care. Previously the health care industry was considered above being questioned about the quality of care, but nowadays, health care is a major industry and health workers are accountable to their consumers. The

availability and quality of health care are determined by the values and expectations of the consumers (Doughty and Marsh, 1984).

Consumers of nursing care count on the existence of services when needed. More and more PLWHAs are demanding to be informed partners in decisions regarding their health, and their concerns are now directed at the whole spectrum of their care while in a health care institution. PLWHAs now complain, demand, report, sue and have realized that the quality of nursing care is an important factor in disease outcomes (Doughty and Marsh, 1984).

2.11.2 Palliative care and pain relief

Palliative care is the combination of active and compassionate long-term therapies intended to comfort and support individuals and families living with a life-threatening illness. Such care strives to meet the physical, psychological, social and spiritual needs of ill people and caregivers (FHI/IMPACT, 2001). It requires a team approach including the ill person, family, health and social welfare workers and community volunteers. Palliative care emphasizes living, personal choice, helping people to make the most of each day and maintaining a sense of hope. Terminal care aims to improve the quality of daily life at the end of life by relieving symptoms (especially pain) and enabling people to die in peace, with dignity and in keeping with their wishes (FHI/IMPACT, 2001).

Pain relief is an essential element of palliative care. In resource-limited settings, medicine can be scarce. Aspirin and paracetamol are often available but not given in

adequate doses to relieve pain. This often results from inadequate education on effective pain relief. Trained health workers can administer Class A controlled drugs. Such Class A drugs include morphine injection, tablets, oral mixture and other narcotics (Rajagopal *et al.*, 2003). These drugs must be provided in accordance with the national laws on dangerous drugs and with the national drug policy. People involved in HBC should provide these treatments in accordance with the regulations and lists of essential drugs for their respective settings. Members of the HBC team should be familiar with these policies and guidelines. A physician should prescribe these analgesics, and at least one member of the HBC should be qualified to administer Class A drugs (usually a qualified nurse) (Rajagopal *et al.*, 2003). Herbal remedies and traditional therapies can also be effective in relieving pain.

2.11.3 Psychosocial support and counselling

Caring for a person in the terminal stages of an illness greatly strains everyone involved. Families, children, friends, communities, health and social service workers, community volunteers and other people are all affected (FHI, 2006). Emotional and spiritual support and guidance (where appropriate) should therefore be available for the ill person and family and caregivers. People with HIV and AIDS sometimes suffer from confusion and dementia and often die at a young age (UNAIDS, 2000). Many health and social service workers and community volunteers are either infected themselves (lay treatment workers) or have family members who are. Such experiences put an added strain on care providers. Encouraging community support through HBC and enlisting the help and

support of friends, neighbours and other people can be an important long-term care strategy.

In many communities and cultures, people fear open discussion of illness and death. As a result, adequate preparations for death are not made. Ill people and family members often need help in discussing death and making plans for the future. Such plans might include where to place orphans, memory projects for surviving children, funeral plans and making a will (Lippman *et al.*, 1993).

Dying without a will denies children and other family members (especially women) their right to inheritance. In some countries, cultural practices often deny women and children their right to succession. It is therefore important to help the dying person and family members to adequately prepare for death, including orphan placement and inheritance rights (Ankrah, 1993). Providing support and counselling is very important for the family and members of the HBC team as they provide care to a person who is dying and to the family following death. Bereavement counselling should be continued for as long as necessary. In addition, the bereavement issues of children must be attended to, especially those who are orphaned. The basic elements of effective interpersonal communication can be used to address issues related to death and dying for both individual and group bereavement counselling. The mental health of ill people, family members and members of the HBC team is vitally important. Psychosocial support and counselling is known to improve the quality of life. Emotional support and sometimes

individual or group counselling are therefore important for everyone involved in care within the home. However, provision of emotional support is part of the HBC services, which often minimizes caregiver burnout (Joint Annual Program Review, 2004).

For people with HIV and AIDS and family members, the stigma, fear and discrimination often associated with the illness (or mere suspicion) can create a barrier to effective care. However, there are many examples throughout the world of effective psychosocial support breaking the silence surrounding HIV and AIDS. This can lead to acceptance and caring by family members and the larger community (Wolfe, 2008).

2.11.4 Life skills development

People living with HIV and AIDS are encouraged to adopt positive life styles to strengthen skills that enable them to effectively prevent further infections. Life skills included in the care of PLWHAs are communication and interpersonal skills (interpersonal communication skills - verbal/nonverbal communication, active listening and expressing feelings; giving feedback and receiving feedback; negotiation and conflict management, assertiveness skills and refusal skills; empathy; cooperation and teamwork; advocacy skills), decision-making and critical thinking Skills and coping and self-management skills. Ultimately, the interplay between the life skills is what produces powerful behavioural outcomes, especially where this approach is supported by other strategies such as media, policies and health services (NAS COP, 2008).

2.12 Providers of HBC

The key helpers in the care of AIDS patients in Narok District were the patient providing own care if not very sick, family members, relatives, friends and community members: these needed education and counselling especially in home nursing skills, psycho-social and material support, patient-care-giver interaction and positive communication. Health workers such as community health workers, traditional healers and staff on NGOs and community based organizations played a big role in provision of HBC services (MoH, 2006 a).

Community health workers (CHWs) trained mainly by NGOs funding various projects in Narok District were community's own resources-volunteers from the community itself. These CHWs played a significant role in providing care and support for PLWHA in the home. They operated under the supervision of NGOs, FBOs or CBOs who mobilized them after the community was sensitised about the significant role it could play in supporting Home-based care (Pramualratana, 2005). Community health workers are expected to be mature, responsible and respected members of the community, men or women chosen by the community to provide basic health care. They should be good communicators and leaders who have shown signs of healthy practices as a parent or caregiver in their own household (MoH, 2007).

Community health workers (CHWs) play many roles within the HBC setup, some of which include: Increase level of awareness on HIV disease and available services

through community sensitization activities; Identify and refer HIV and AIDS suspects to health facility for diagnosis and management; Facilitate directly observed treatment (DOTS) of TB; Assist patients adhere to ART and other therapies; Identify defaulters and initiate tracing; Refer HIV and AIDS patients on treatment for follow up CD4 counts; Recording necessary information in relevant community HIV and AIDS tools; Identify HIV and AIDS complications including adverse drug reactions and referring appropriately; Participating in periodic review meetings organised by the HBC site supervisor/CHEW; Submitting monthly summary reports on community HIV and AIDS care to HBC supervisor/CHEW and Ministry of Health, Kenya (Clinical Subcommittee on AIDS, 2003).

2.13 Resources necessary for HBC

To effectively provide Home-based care, there are certain resources that needed. Resource mobilisation entails identifying and using all available resources or goods required to meet the identified needs. It is essential to ensure that set goals at various levels of HBC are achieved (WHO, 2001).

These resources can be broadly classified into four categories or the 4Ms: Money; Manpower or the people needed; Materials or the goods, services and financial support and Moments or minutes: the time required. Money is an important resource in the provision of Home-based care. Diseases like AIDS and cancer are long, expensive and debilitating illnesses. They eventually render the affected and infected incapable of

participating in gainful employment. Yet, they need money to pay for services or to buy goods such as food, clothing, drugs and other materials. They may also need to pay for health, legal and other services (UNAIDS, 2000).

In the HBC system, money can be provided by the family, the community, the government or through Insurance. It is unfortunate that many insurance organizations discriminate against clients with terminal illnesses. However, there is need for sensitizing the community about the needs of the patients and how they can be met (International HIV and AIDS Alliance, 2001).

Manpower is another important resource, which is often overlooked. Health workers at all levels; family members, relatives and friends; community leaders (e.g. Maendeleo Ya Wanawake Organization leaders); spiritual, political, and administrative leaders and community volunteers (individuals who voluntarily spare their time to assist the clients, their families and children for example students from surrounding institutions) are manpower required. In the latter stages of a disease such as AIDS people become too weak to support themselves. This calls for continuous assistance from relatives and friends. A volunteer care provider also needs continuous support from the community, morally and materially (International HIV and AIDS Alliance, 2001).

Many illnesses that require home-based care tend to render the affected persons incapable of meeting even the most basic material needs of everyday life. The material resources required to assist can be in the form of food, cooking fuel, water, or money for

drugs and other purposes. These materials may or may not be readily available. Within communities, the materials can be bought by individuals, communities or families. They can also be donated by organizations. Some non-governmental organization (NGOs) may be willing to donate some of the materials or money to procure them. Some of the materials can also be obtained from the health facilities (UNAIDS, 2000).

Caring for people requiring terminal palliative care is time consuming and emotionally draining. The caregiver may have little time left to tend to other important aspects of everyday life. The constant demands can be very stressful. Yet, time is one of the most essential resources known to man. To be able to accomplish care tasks, we need time. Being present is a major source of psychological and moral support. Friends and relatives should understand the importance of sparing time not only to help out as needed, but also just to be with the client and the family members (WHO, 1997).

2.13.1 HBC kit

Before caring for PLWHAs or teaching their families and the community how to care for them, there are certain materials and supplies that are needed. The caregiver should have a community volunteer kit while the client should have a client primary kit. One level is the material routinely needed by the individual PLWHA; beyond a certain minimum standard of care and hygiene these will contain medications specific to the individual (WHO, 2001).

At the level of the community health worker (CHW), the kit contains necessary nursing supplies such as soap, dressing materials, gloves (latex, non sterile), soap, toilet paper, scissors, razor blades, waste disposal bags, chlorine solution, surgical spirit, plastic sheeting, condoms and basic medication such as paracetamol. It will also contain reference materials and a notebook or diary for record keeping (WHO, 2001).

The health care provider needs to be educated on the importance of replenishing the kit content regularly (patient re-supply kit). Items that are not readily available within the home setting can be improvised with whatever is suitable and affordable, for example, using plastic paper bags for rubber gloves or old newspapers for draw sheets (UNAIDS, 2000).

The initial contents of the home care kit are based on the needs of the PLWHA and are determined at the health facility level when the client is recruited into the HBC program. Replenishing the kits can be a collaborative effort between the community and the health institution where the client goes for the required regular medical checks (WHO, 2001).

2.14 Bio safety and HBC

PLWHAs and their caregivers must be aware of the importance of taking care to control the spread of infection. Infection prevention in home-based care for PLWHAs has four primary aims: prevention of self-infection, prevention of patient-to-caregiver infection,

prevention of caregiver-to-patient infection and prevention of patient-to-sexual partner(s) infection (UNAIDS, 2000).

In Self-Infection the patient gets infection from one part of the body to another, e.g., wounds, faeco–oral infections through improper hand washing after toilet. Patient-to-Caregiver Infection can be a very distressing situation where by the caregiver is infected with either the HIV virus or other infections in the process of caring for the patient. It can occur as a result of not using gloves or other available protective material while handling soiled linen, or blood and other body fluids, attending to an HIV-positive patient while having open uncovered cuts, wounds, or bruises, acquiring chest infections such as tuberculosis (TB) while caring for the patient and splashing blood in the eyes while attending childbirth by an HIV-positive mother (WHO, 2001).

Caregiver-to-patient infection occurs as a PLWHA has a lowered immunity as a result of the HIV infection and is therefore prone to infections. If the caregiver is sick with any common infection, it is safer to have another care provider take care for the patient during the period of the illness. Common infectious diseases include the following Common cold or flu, diarrhoeal diseases, skin conditions such as scabies, typhoid, chest infections like bronchitis, pneumonia, and tuberculosis and fungal infections, especially those affecting the skin (WHO, 2001).

There are a number of general infection prevention measures that the care providers both in hospital and at home should try to adhere to. Washing hands before and after handling the patient or infected material and after removing the gloves because they could have gotten pierced or torn in the process of use. Wearing gloves or other locally available plastic papers when dressing wounds, handling linen soiled with body secretions such as blood, faeces, vomits and pus, and handling soiled instruments and dressing materials. If in a hospital setting, a separate pair of gloves must be used on each patient to avoid cross contamination. Use of disposable gloves is appropriate but where resources are limited, autoclaving of reusable rubber gloves should be emphasized (UNAIDS, 2008).

Gloves or plastic bags must be worn to prevent direct contact with body fluids. Protection of the feet must be done when cleaning body fluids spilled on floors. Cleaning and decontamination of dressing and other materials that will be kept and re-used, such as clothing, bedding, towels, and cloths for bandages is encouraged. Burning, burying, or throwing into a pit latrine any materials that are not re-usable is encouraged. Care must be taken when handling blood or pus, as these pose the greatest danger to the caregiver (UNAIDS, 2008).

Maintaining general and personal hygiene by bathing daily and washing hands frequently, regularly airing patient's linen to ensure a clean and fresh environment, keeping all skin sores or wounds covered with a bandage or clean cloth and ensuring that

things used in the care of the patient are kept away from children must be observed (WHO, 2001).

2.15 Home-Based Care in Narok District

HBC was introduced in Narok District (Figure 3.1) in 2006 as part of the APHIA II project being implemented by a consortium of NGOs through funding of USAID. Home-based care is offered in four Divisions of Narok District: Central, Mullet, Mara and Nairegia Enkare sites. Central and Mara Divisions are urban and semi-urban areas whereas Nairegia Enkare and Mullet Divisions are rural areas. There are 1740 clients enrolled into the HBC program in the District and receiving care from trained Community Health Workers (CHWs). The total number of community health workers trained in the District was 76 (FHI, 2006).

Over and above the personal suffering that accompanies HIV infection, the AIDS pandemic in Sub-Saharan Africa threatens to devastate whole communities, rolling back decades of development progress. Sub-Saharan Africa faces a triple challenge of colossal proportions the first one being provision of health care, support and solidarity to a growing population of people with HIV-related illness, and providing them with treatment (WHO, 2006).

CHAPTER THREE: MATERIALS AND METHODS

3.1 Study Area

The study was carried out in Nairegia Enkare of Mau Division and Mullet Division in Narok District. Narok District covers an area of 15,098km² and lies approximately 1827 metres (5997 feet) above sea level. It has a population of about 474,228 people who are mostly pastoralists, pastoral-agrarian and others. Tanzania borders Narok to the South and Kajiado to the East. To the North it is bordered by Nakuru, to the West by Bomet and Transmara. Administratively, it is divided into 8 Divisions (Central, Loita, Mara, Mau, Mullet, Olokurto, Ololulunga and Osupuko Divisions), 55 Locations and 105 Sub-locations. Narok has 33 Government of Kenya (GoK) health facilities (1 District hospital, 8 health centres and 24 dispensaries) (Pricewaterhouse, 2005).

Narok district has poorly developed physical and industrial infrastructure and is prone to prolonged droughts. The district is home to the world famous Maasai Mara Game Reserve and numerous eco-tourism projects. It enjoys an abundance of wildlife and tourist attraction potential primarily drawing on the rich Maasai cultural heritage (Pricewaterhouse, 2005).

Narok district's topography can broadly be divided into two: the highlands and the lowlands. The highlands have altitude ranging from approximately 3,000 metres above sea level while the lowlands range between 1,000 to 1,400 meters above sea level. Two

thirds of the district is semi-arid. The highlands have rich volcanic soils suitable for intensive agricultural production and potential for growing wheat, barley, maize, beans and potatoes as well as production of wool sheep and dairy farming. Large-scale farmers therefore inhabit the highlands areas, which receives reliable rainfall ranging from 1200mm-1800mm (Pricewaterhouse, 2005).

The lowlands where the altitude ranges from 1400-1800 metres above sea level have high potential for livestock rearing. Nomadic pastoralist and small-scale subsistence cultivators inhabit the lowland areas. The area has poor quality soils and the rains are unreliable. Most of the land falls under trust land and hosts large group ranches mostly owned by the local communities. The rest of the land is individually owned and is mostly under cultivation. Mean temperatures range from 5° C in July to 28° C in December to February (Pricewaterhouse, 2005).

There are 47 health facilities in Narok district in total. There is one GOK District Hospital in Narok Town, 8 GOK Health Centres, 2 Mission Health Centres, 16 Government Dispensaries and 20 Mission Dispensaries and very few Private Nursing Home in an area covering approximately 15,098sq km. Mulot Division has 1 Health Centre and 2 Dispensaries to cater for of over 84,000. Mau Division has 2 health centres and 3 dispensaries serving a population of approximately 78,000 (Pricewaterhouse, 2005).

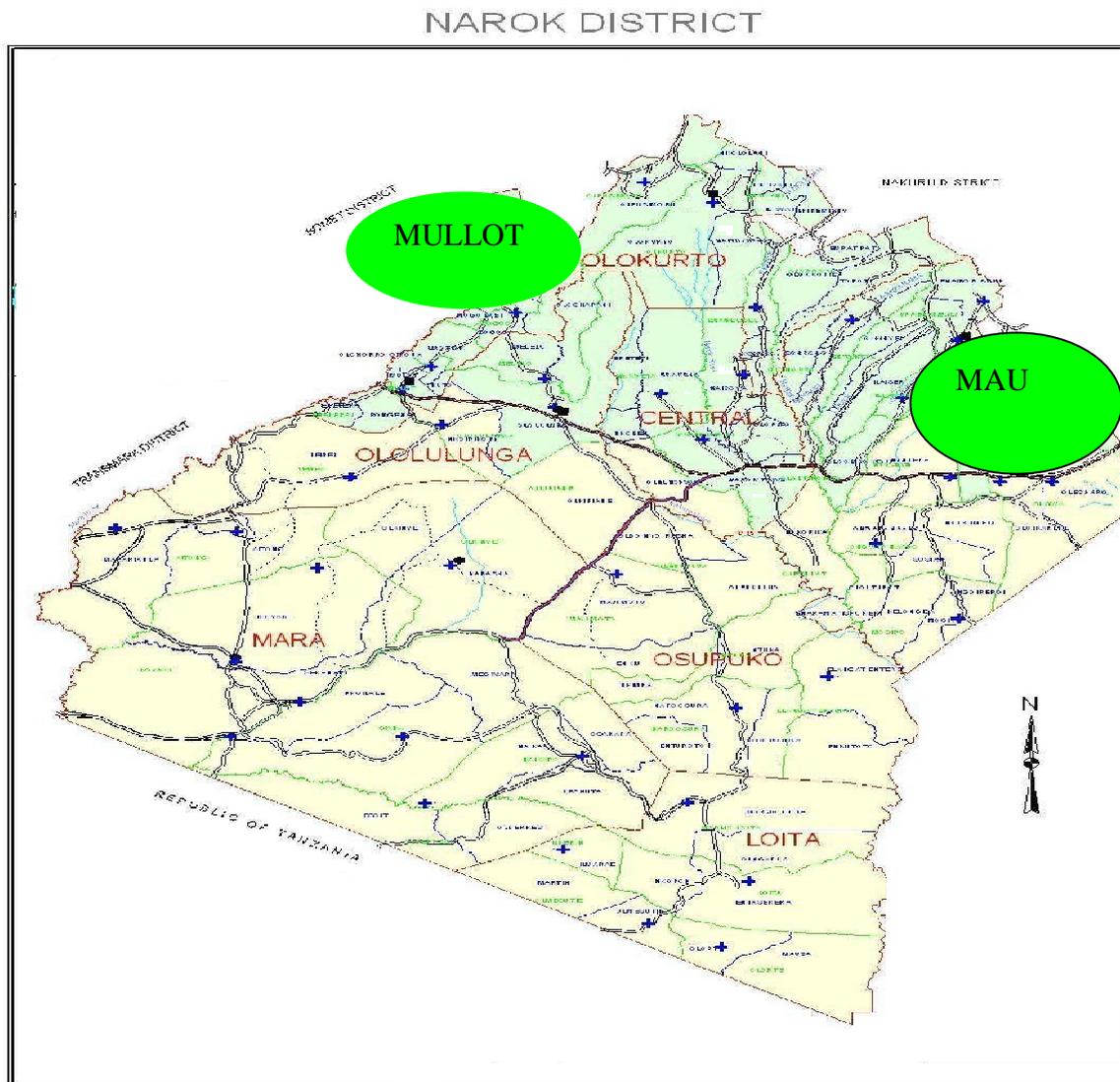


Figure 3.1: Map of Narok Showing Study Areas, adapted from Nidhiwa Agency

3.2 Study Population

The study population comprised of PLWHAs receiving comprehensive care within Narok District. Nurse in-charges of CCCs assisted the researcher to identify the participants by availing the registers at the CCCs from which random numbers were generated before informed consent was sought.

3.2.1 Inclusion Criteria

The study included all adult (above 18 years) PLWHAs who had been residents in Narok for more than 3 months and received care in both CCC sites of Mullet Division and Nairekia Enkare Location of Mau Division Narok District.

3.2.2 Exclusion Criteria

- i. PLWHAs aged below 18 years but had been receiving care and support services
- ii. PLWHAs who had been receiving care and support services outside Narok District
- iii. Very sick PLWHAs who could not participate in the study
- iv. Adult PLWHAs who declined to consent

3.3 Study design

A descriptive cross-sectional study using qualitative and quantitative methods to determine the factors associated with the uptake of HBC services among rural PLWHAs in Mullet and Nairegia Enkare CCC sites of Narok District. Quantitative research relied upon measurement to analyze different variables and used various scales (Fishers et al., 1998). The quantitative research approach was considered to be appropriate for this study because it allowed a formal and systematic approach to collect information on PLWHAs, uptake of HBC services and factors associated with the uptake of these services. It documented descriptions of the fears and factors discouraging PLWHAs from utilizing HBC services.

3.4 Sample Size Determination

The sample size, n, was calculated using Fisher's formula.

$$n = z^2_{1-\alpha/2} P (1 - P)/d^2, \quad (\text{Fisher } et \text{ al.}, 1998).$$

Where - Z= standard normal distribution curve value for 95% CI which is 1.96

P= prevalence of HIV and AIDS (KDHS, 2003) women - 9%; men – 5% mean: 7%

- d= absolute precision (0.05)

$$N = \frac{(1.96)^2(0.07)(0.93)}{(0.05)^2} = 100.04$$

- Allowance for attrition 20% = 20
- Number of PLWHA interviewed was 121

3.5 Sampling Procedure

Convenient sampling of study sites was done to select rural sites for the study. Proportional allocation of men and women according to numbers of PLWHAs receiving services at the rural CCCs was applied in selection of the number of PLWHAs to participate in the study. Simple random sampling was used in selection of the respondents who were interviewed from the existing PLWHAs registers in the District.

3.6 Study Instruments

Quantitative data was collected through individual interviews using a questionnaire (Appendix 3). The main issues in the questionnaire included the socio-demographic,

distance to facility, information on HIV and HBC. The data collection was done by trained research assistants with a minimum education level of a college diploma asking respondents questions and filling them in after consent was sought. They were trained for two days by the principal investigator in using the study questionnaire. Interviews were conducted in the national language (Kiswahili) or English with respondents who were conversant with it. Even explanations, where necessary, were complimented in the local dialect. The questionnaire was pre-tested in Loitoktok District as part of a larger study by catholic relief services (CRS) and the necessary adjustments made before the actual data collection. The questionnaires were administered to all consenting PLWHAs in the two Divisions of Narok District to capture quantitative data visiting the local CCCs for care.

Qualitative data was collected using FGDs (Appendix 4). These involved small groups of PLWHAs (nine to twelve people) moderated by a PLWHA talking freely and spontaneously about themselves and general HIV and AIDS issues pertaining to their community. This was important for the research since participants were selected from target groups whose opinions and ideas were of special interest for the research. In total 4 FGDs were conducted (2 in Mullet and 2 in Nairegia Enkare). During the FGDs, a number of techniques were applied namely: ranking, historical profile and gender analysis. The moderator (principal investigator) was responsible for directing the discussion by asking questions and probing while the field workers who were well

conversant with the local dialect (Maasai) were responsible for recording the discussions. The discussions were held in mainly in Kiswahili language.

3.7 Research Variables

Data on the following socio-demographic variables was collected: age, marital status, parity, education level, occupation, income, access to health facility, gender, type of house and number of household members (Appendix 1).

Level of information on HIV infection was measured by aggregating the responses to questions 10 and 11 and calculating a percentage of the total. A highest score of 8 represented very good information while a score of less than 2 out of 8 was considered very poor information on HIV infection.

3.8 Data management and statistical analysis

Data was entered into a computer using MS Access and analysis done using SPSS version 11.5. Continuous data were compared by Student t-test. P-value ≤ 0.05 was considered significant. Regression analysis was carried out to determine factors predictive of HBC uptake among the quantitative and binomial variables. The Chi-Square test was carried out to determine any relationship between the quantitative variables and uptake of HBC services. Data from the FGDs was transcribed, translated and entered into a computer using MS word 2007. The data was the exported to NVIVO 08 for thematic analysis where all responses from the FGDs were categorised under specific themes and described.

3.9 Ethical considerations

Approval from the Jomo Kenyatta University of Agriculture and Technology as well as the Ethical Review Committee of KEMRI was granted by the KEMRI Scientific Steering Committee and National Ethical Review Committee (Appendix 2). Consent was also sought and obtained from the PLWHAs (Appendix 3) and for all FGDs tape recordings. The data accessibility was limited to the chief researcher only, to ensure confidentiality of the participants' information. The very sick clients who could not participate in the study were referred to the nearest community health worker for care and appropriate referral.

CHAPTER FOUR: RESULTS

4.1 Socio-demographic and economic characteristics of respondents

Fifty six percent of the respondents were male while 44% of the respondents were females. The modal age group was 31 – 39 while the least population set comprised of PLWHA aged 18 – 20 as shown in figure 4.1.

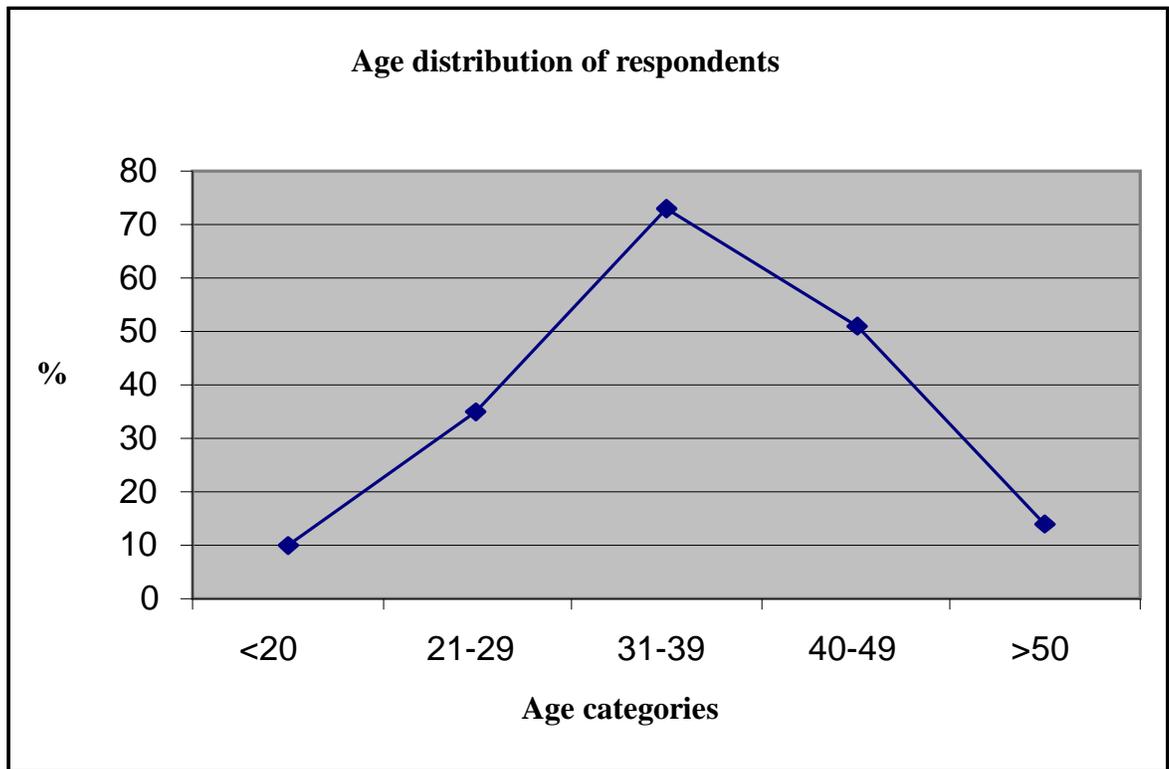


Figure 4.1: Age distribution of the respondents

Majority of the respondents 51.9% had attained a primary level of education, 25.1% had a secondary education while only 8.8% had a university or college education as shown in figure 4.2.

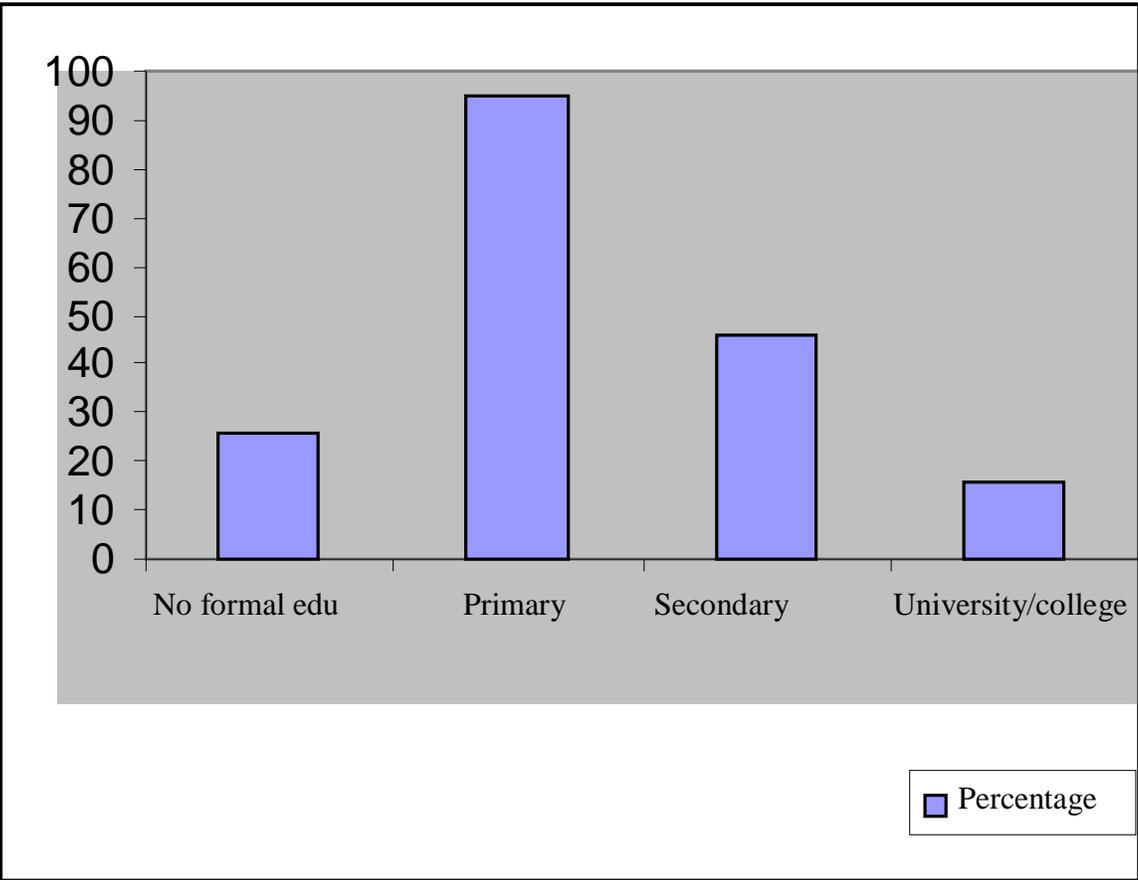


Figure 4.2: Level of education of the respondents

Majority of the respondents were either married (48%) or single and never been married before (23.5%) while 13.7% were separated or divorced and 14.8% were widowed as shown in figure 4.3.

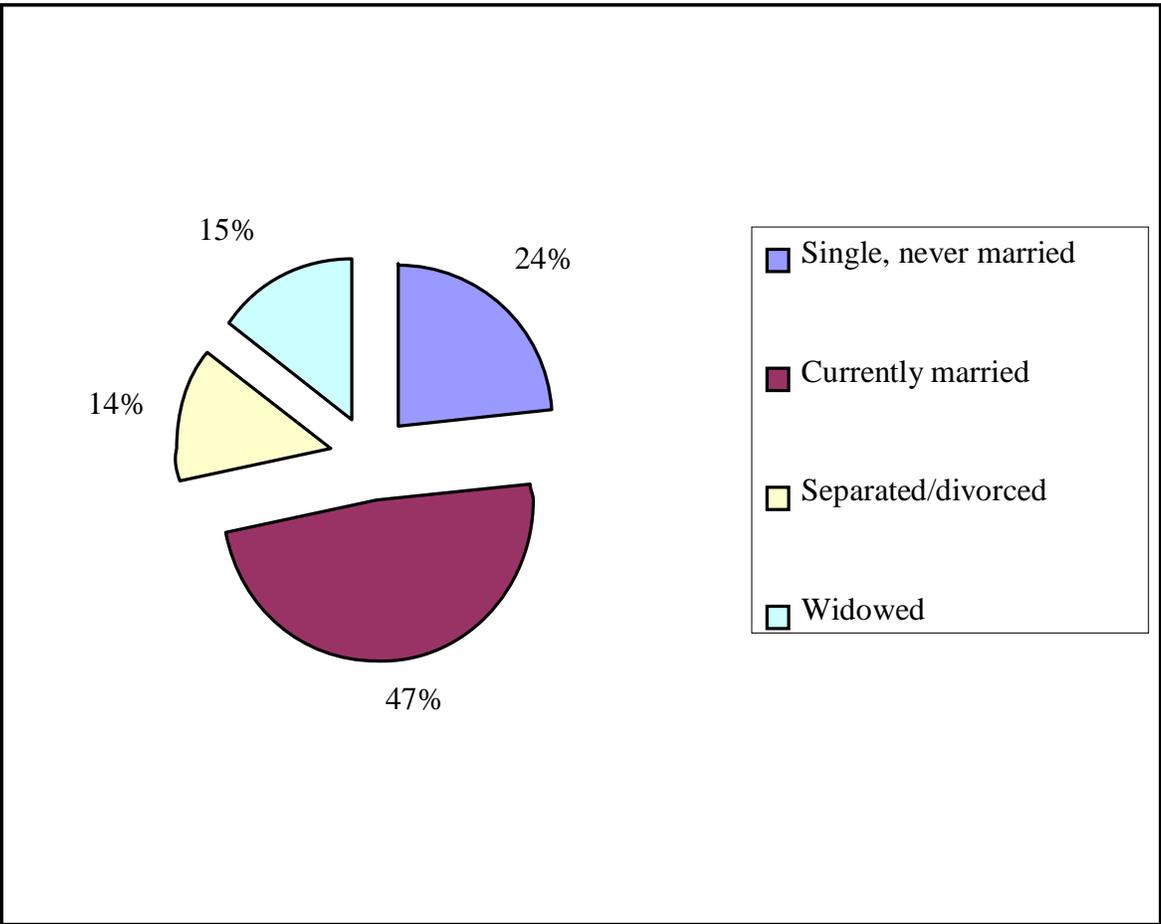


Figure 4.3: Marital status of the respondents

Half of the respondents were self employed while 32.2% were not working and 17.5% were in formal employment as depicted in figure 4.4.

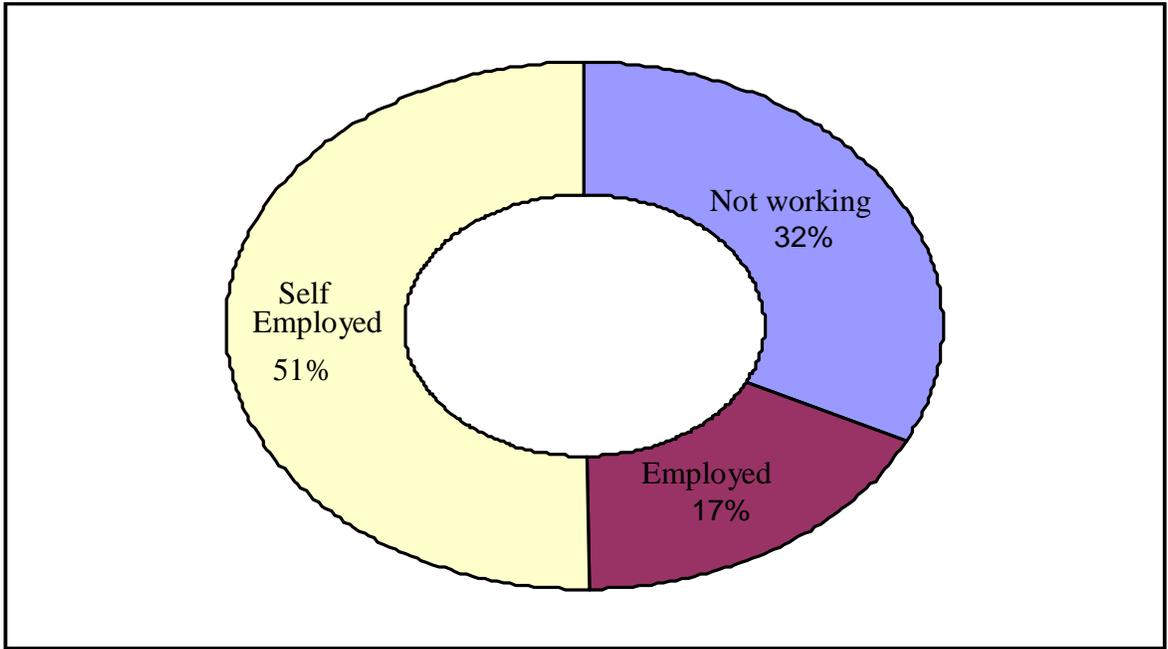


Figure 4.4: Employment status of the respondents

Majority of the respondents were either Protestants (62.3%) or Roman Catholics (32.8) with 3.8% traditional believers and 1.1% Muslims as shown in figure 4.5.

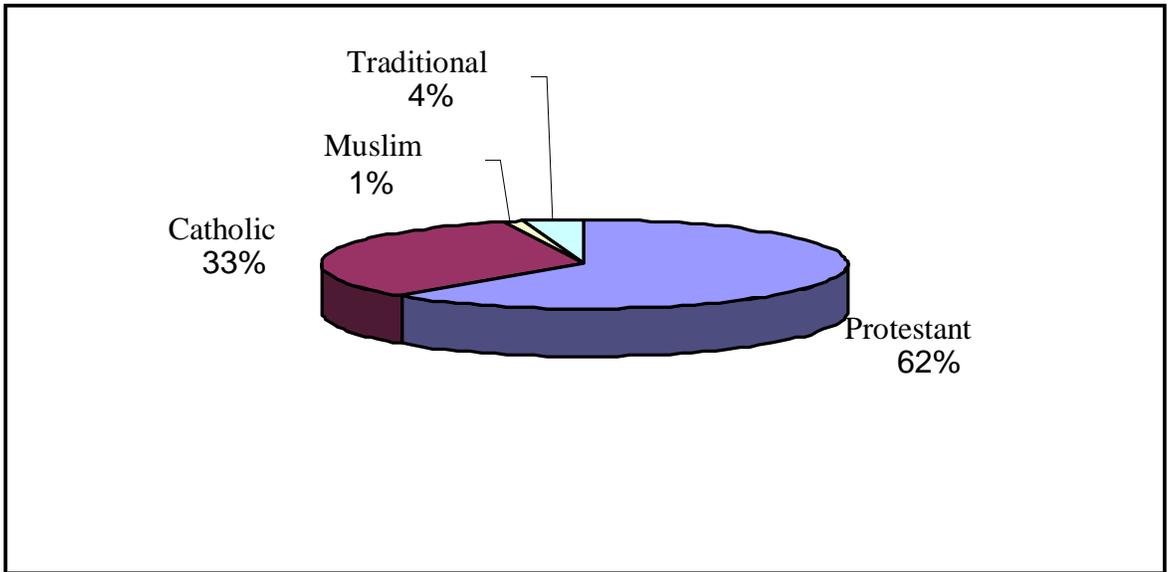


Figure 4.5: Religion of the respondents

4.2 User rate of HBC among rural PLWHAs in Narok

The study targeted a total of 120 participants but 183 respondents consented and filled the questionnaires properly after data cleaning. The overall prevalence of HBC uptake among rural PLWHAs was 16.4%.

4.3 HBC uptake and sex

Female PLWHAs were more likely to uptake HBC services compared to male PLWHAs. The distribution of males and females was 44% and 56%, respectively. HBC uptake among female PLWHAs was 23.3% and 7.5% for males (Figure 4.6). There was a significant association between sex and HBC uptake ($P=0.005$, O.R. 3.7 (1.4 – 9.7)).

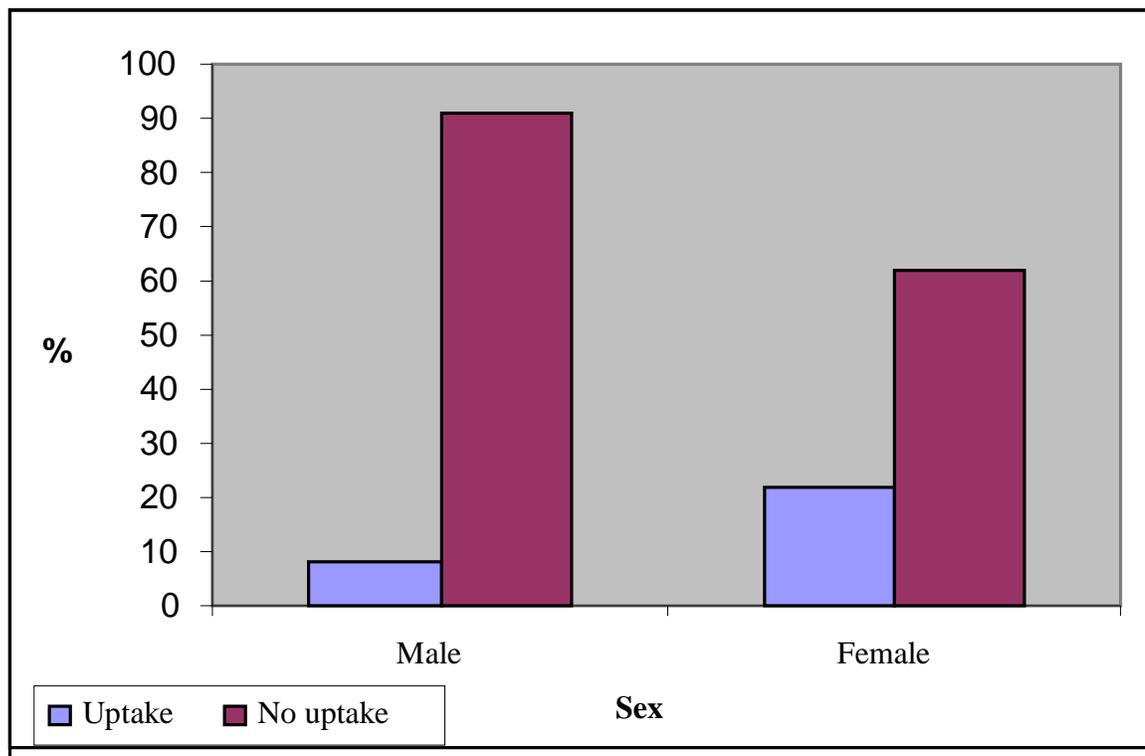


Figure 4.6: Sex of respondents and HBC uptake; N = 30

4.4 Age of respondents and HBC uptake

HBC uptake decreased with age up to age 29 before increasing with age. Respondents were grouped into youths and adults using the WHO classification of youth and adults to compare uptake among the two categories. Adults made up 75.4% of the respondents (≥ 35 years) who were more likely to uptake HBC services (20.3%) compared to the youth (4.4%) as shown in figure 4.7. There was a significant association between age and HBC uptake ($P = 0.011$, Odds ratio 5.5 (1.3– 23.8)). Adult PLWHA were 5.5 times more likely to uptake HBC services compared to youth PLWHAs.

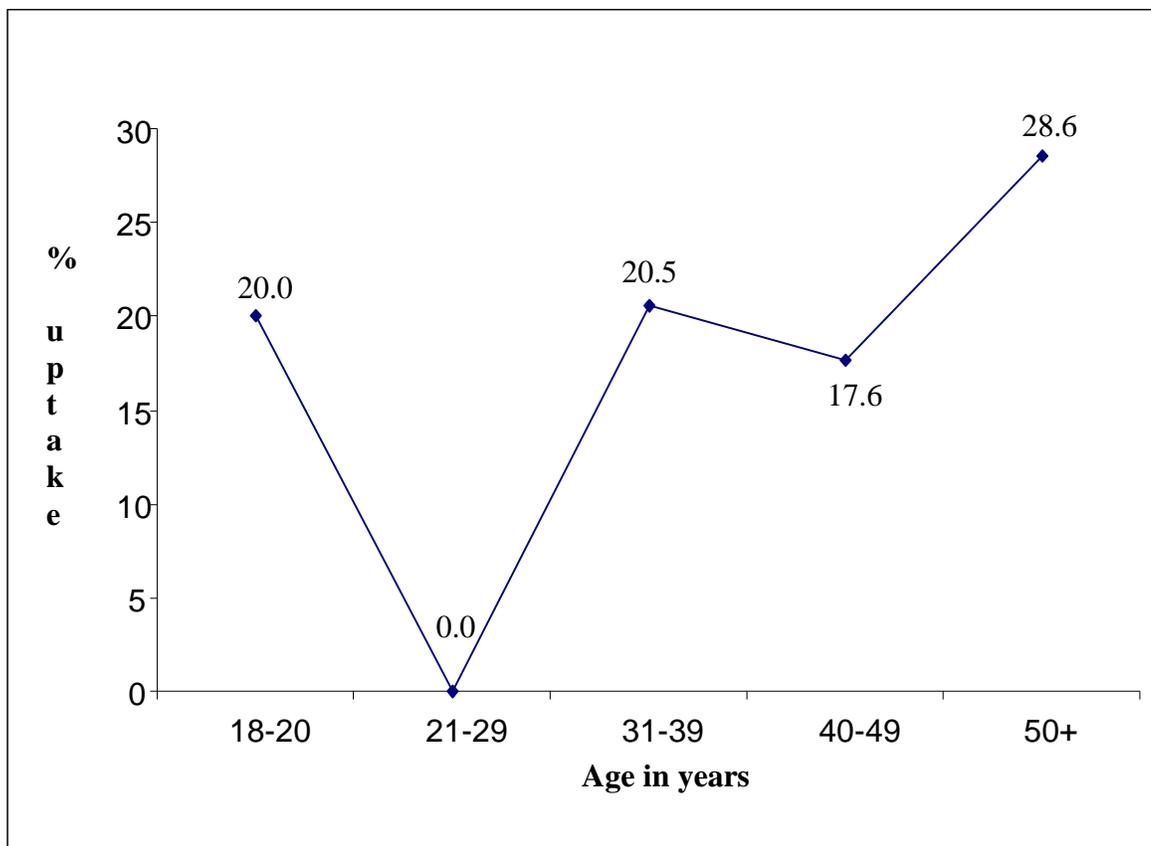


Figure 4.7: Age of respondents and HBC uptake

4.5 HBC uptake and employment status of the respondents

Generally, the unemployed PLWHAs were more likely to embrace HBC services as compared to the PLWHAs that were employed. There was a significant association between employment status and HBC uptake ($P=0.038$, Odds ratio 2.8 (0.9 – 4.7)). Figures 4.4 and 4.8 show the frequency and distribution of employment status and HBC services uptake.

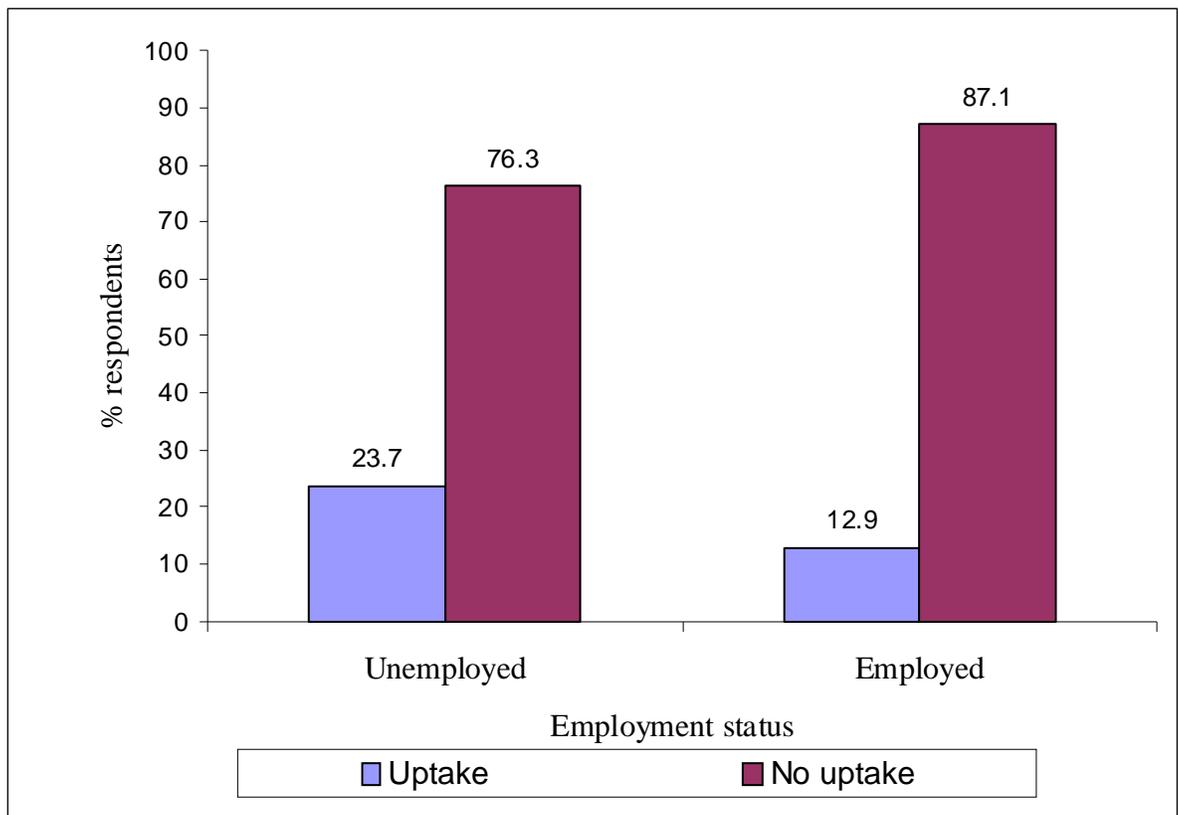


Figure 4.8: Employment status and HBC uptake; n = 30

4.6 Level of education and HBC uptake and

Generally, as the level of education increased, the HBC uptake decreased among rural

PLWHAs in Narok. Twenty five of the respondents (13.7%) had no formal education while 51.4% of the respondents had acquired primary education, 25.7% had a secondary education and 9.2% had attained tertiary level of education (Figure 4.2). There was a significant association between level of education and HBC uptake ($P=0.035$, odds ratio 3.0 (1.1 – 8.2)) as depicted in Figure 4.9. Those that had acquired a basic education or never been to a secondary school (< secondary) were 3 times more likely to uptake HBC services compared to those that had ever acquired a secondary education and above.

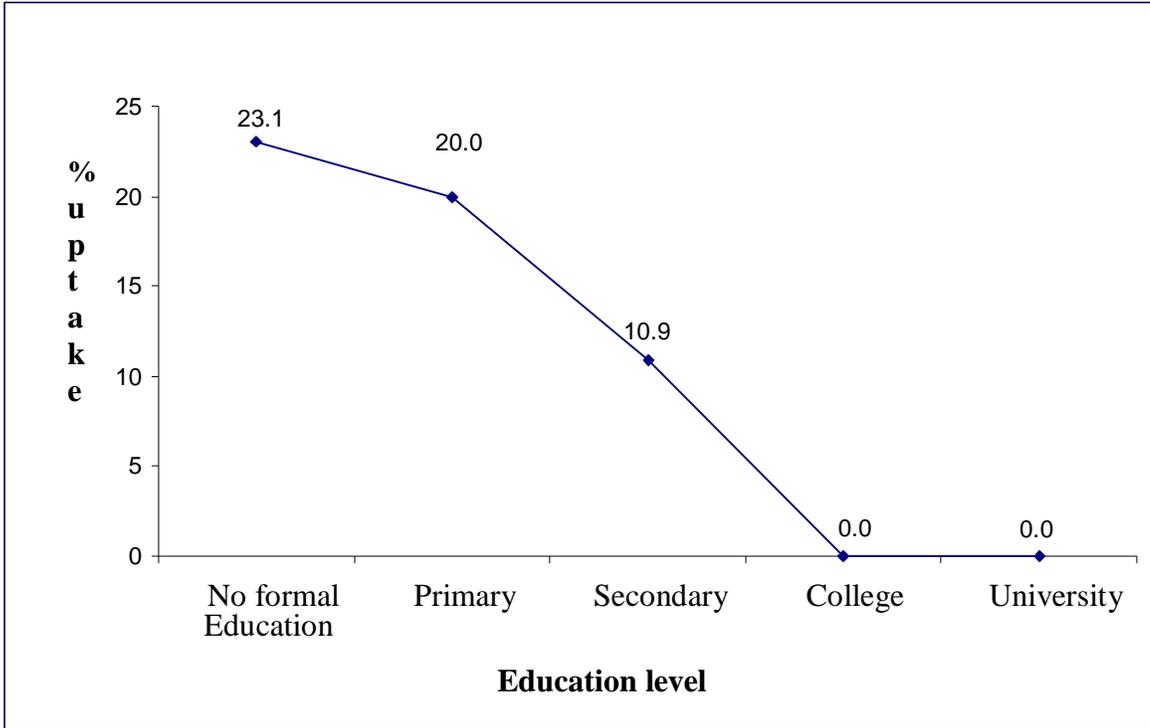


Figure 4.9: Level of education of study participants

4.7 Marital status and HBC uptake

Majority of the respondents (48.0%) were married while 23.5% were had never been married before, 13.7% were separated/divorced and 14.8% widowed (Figures 4.3 and

4.10). There was a significant association between marital status and HBC uptake ($P=0.043$). The single PLWHAs were least likely to embrace HBC services as compared to the married or divorced and widowed PLWHAs. Single PLWHAs had the lowest user rate of HBC (9.3%) compared to married (13.6%), divorced/separated (30.8%) and widowed (23.1%) as shown in figure 11.

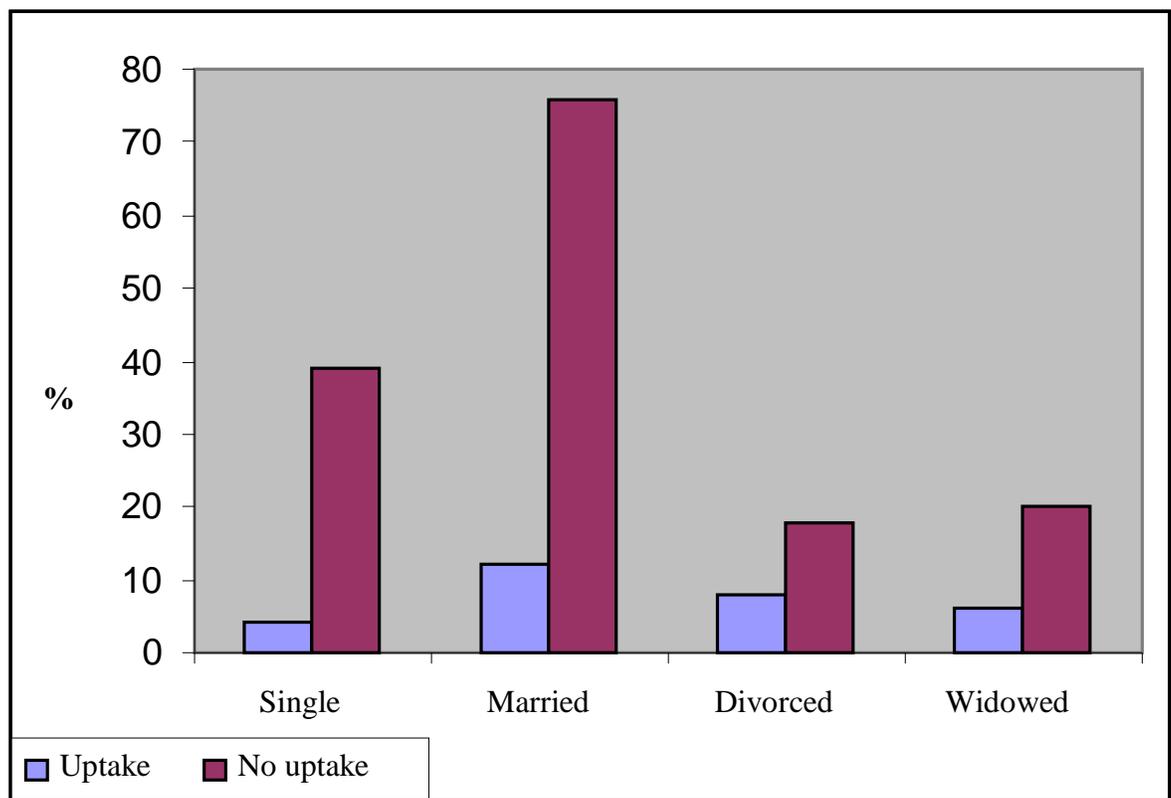


Figure 4.10: Marital status and HBC uptake

4.8 HBC uptake and religion

Majority of the participants were Protestants (58.5%), Catholics (32.8%), SDA (3.8%), traditional (3.8%) and Muslims (5.5%) (Figure 4.5). Religious groups have taken stands on matters of HIV prevention most of which affect the uptake of HBC services. There

was no significant association between religion and HBC uptake among PLWHAs (P=0.437).

4.9 Time and distance to the nearest health facility and HBC uptake

4.9.1 Time and HBC uptake

There was no significant association between time taken to reach the nearest health facility and HBC services uptake (P=0.815, Odds ratio 1.2 (0.5 – 3.1)). HBC uptake among those who spent 1 hour or less to reach the nearest health facility was 14.6% while among PLWHAs who spent approximately more than 1 hour was 16.9% (Table 4.1). The study suggested that majority of those who took approximately more than 1 hour to reach the nearest health facility were not more likely to embrace HBC uptake compared to those who spent 1 hour or less.

Table 4.1: Time taken to the nearest health facility

HBC uptake	≤1 hour		>1 hour		Total	
	n	%	n	%	n	%
Uptake	24	16.9	6	14.6	30	16.4
No uptake	118	83.1	35	85.4	153	83.6
Total	142	100	41	100	183	100

4.9.2 Distance and HBC uptake

HBC uptake for PLWHAs who stayed less than 10Km to the nearest health facility was 9.1% while those staying \geq 10Km was 19.5% (Table 4.2). The distance to the nearest

health facility was an approximate given by the respondent and therefore subjective. This implies that a person staying 10Km or more from the nearest health facility was no more likely to embrace HBC services compared to a person who stayed less than 10Km.

Table 4.2: Relationship between distance to the facility and HBC uptake

HBC uptake	< 10km		≥ 10Km		Total	
	n	%	n	%	n	%
Uptake	5	9.1	25	19.5	30	16.4
No uptake	50	90.9	103	80.5	153	83.6
Total	55	100	128	100	183	100

4.10 Information on HIV infection and HBC uptake

The study found that, information on HIV infection was an important factor influencing HBC uptake among PLWHAs. Majority of PLWHAs who had average or good information on HIV and AIDS, (20.5%) uptake HBC services compared to those with poor information on HIV and AIDS infection (8.2%) (Figure 4.11). Responses to questions 10 and 11 were summed and then calculated as a percentage. Respondents scoring < 40% were classified as having poor information on HIV and AIDS while those scoring ≥ 40% were considered to have average/good information on HIV and AIDS. Pearson's Chi-Square test revealed a significant association between knowledge on HIV infection and HBC uptake (P=0.039, Odds ratio 3.8 (1.1 – 13)).

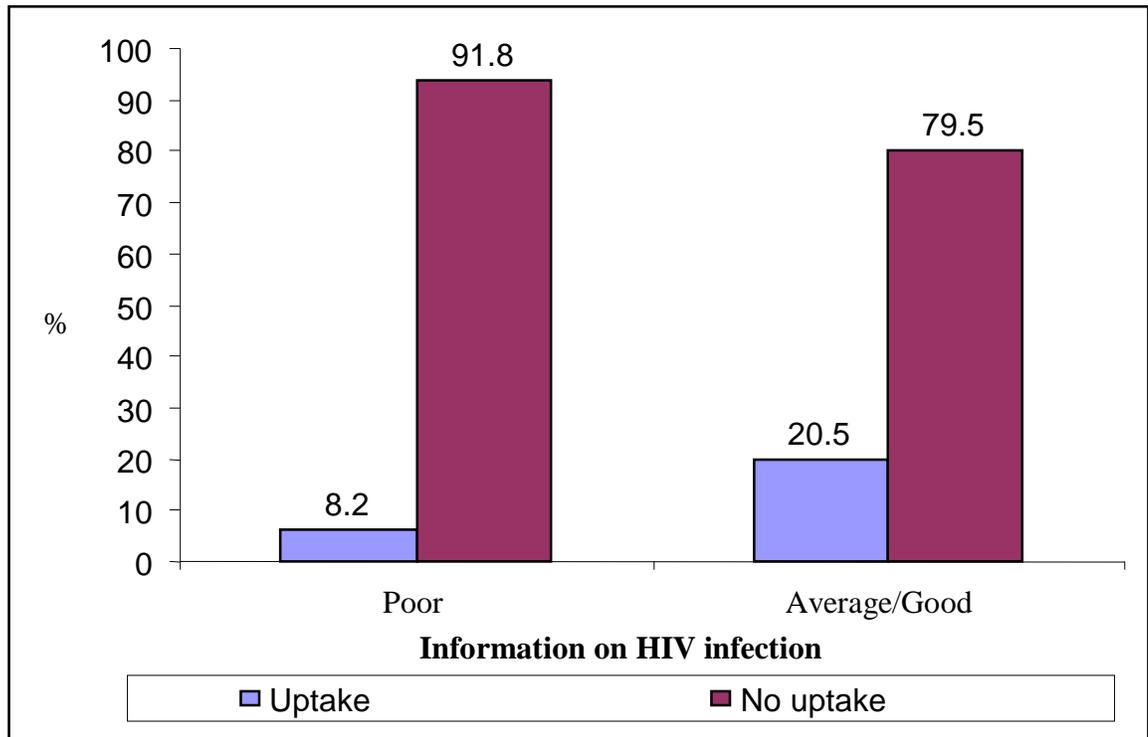


Figure 4.11: Information on HIV infection and HBC uptake

4.11 Sources of information on HIV and HBC uptake

There was a significant association between the number of information sources on HIV and AIDS (hospital, radio, television, newspapers, family members, schools, health magazines and seminars) and HBC uptake ($P=0.036$, Odds ratio 2.9 (1 – 8)). Majority (20.5%) of PLWHAs with multiple sources of information uptake HBC compared to those with none/ few sources of information about HIV (8.2%). The odds ratio revealed that with multiple sources of information on HIV a person was 2.9 times more likely to uptake HBC services compared to one with no or few sources of information.

4.12 HBC uptake and awareness of HBC services

Awareness of HBC services plays an important role in HBC uptake. Majority (22.9%) of those aware of the availability of HBC services uptake HBC services compared to those not aware of HBC (7.7%) (Figure 4.12). There was a significant association between awareness of HBC services among PLWHAs and HBC up taking ($P=0.008$, Odds ratio 3.6 (1.4 – 9.2)). The HBC sensitized PLWHAs are 3.6 times more likely to uptake HBC services compared to those unaware of HBC services being provided.

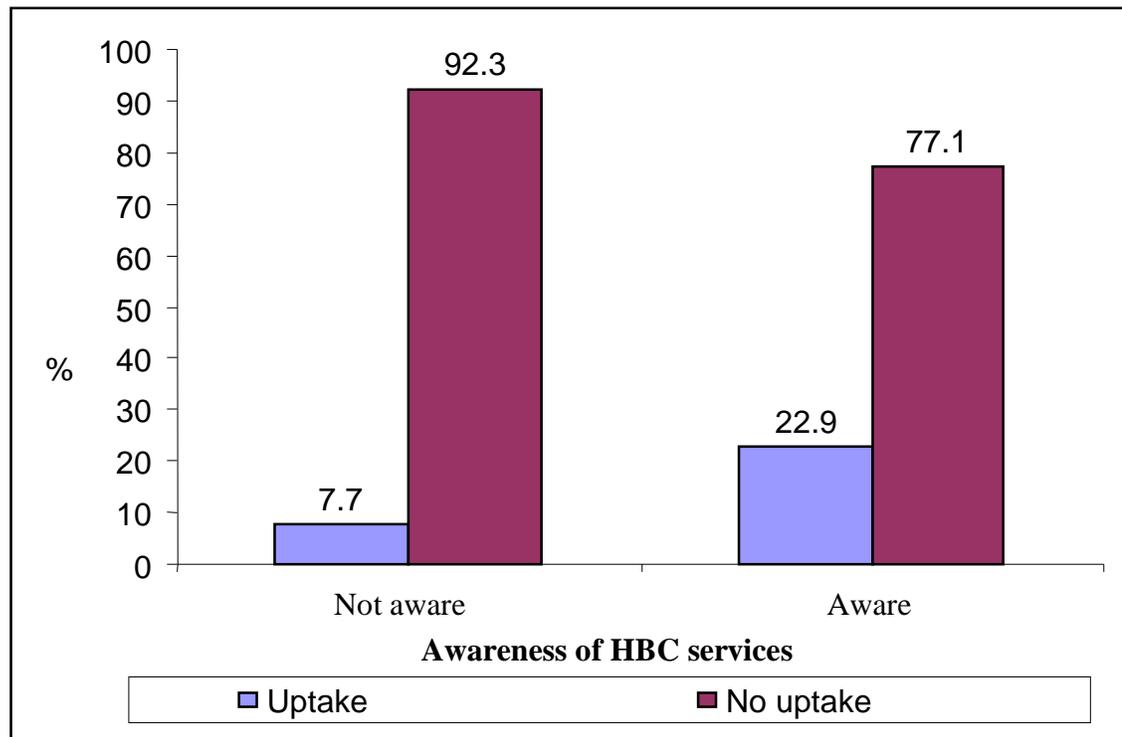


Figure 4.12: Awareness of HBC services and HBC uptake

4.13 HBC uptake and HBC services access

The number of services accessed significantly affected the uptake of HBC services.

21.7% of PLWHAs accessing three or more HBC services uptake HBC services compared to those accessing two or less HBC services (9.1%). This trend is shown in Figure 4.13.

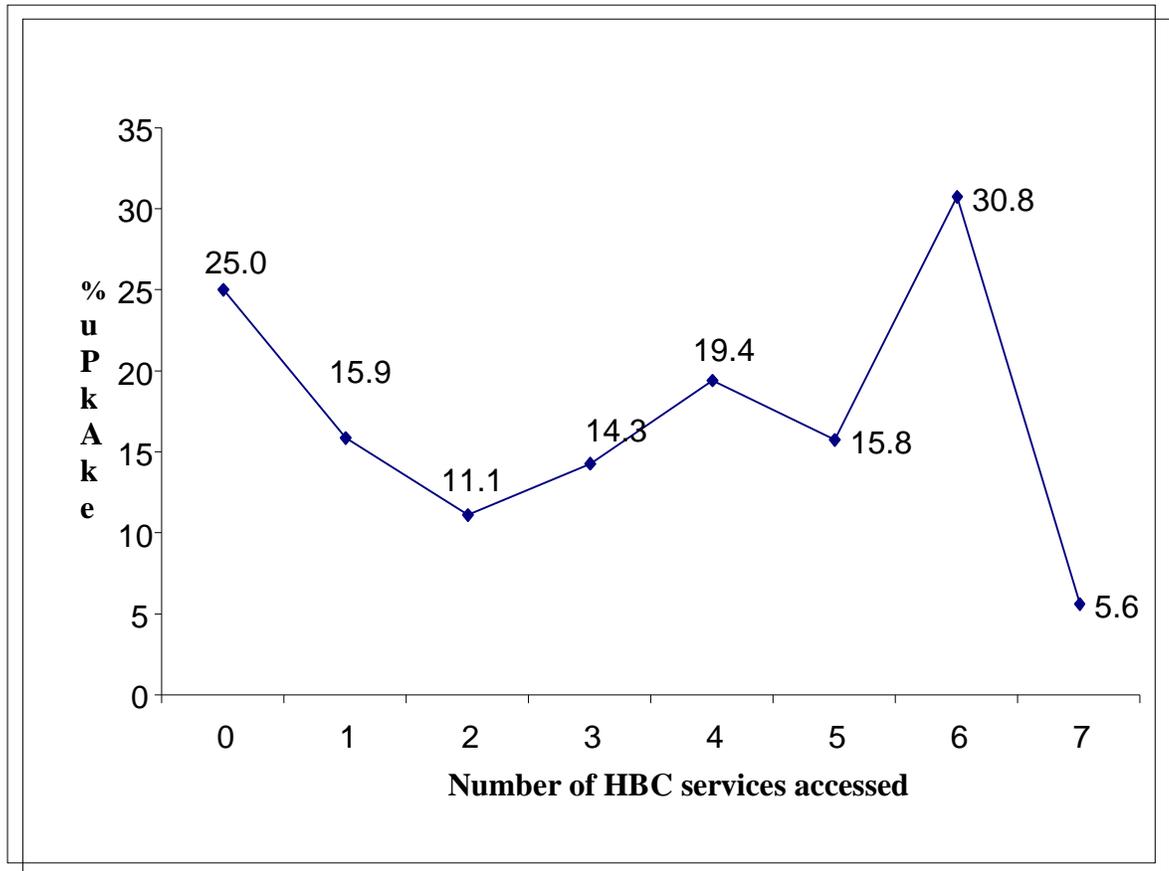


Figure 4.13: Services accessed and HBC uptake

4.14 HBC uptake and knowledge of HIV protection

There was no significant association between knowledge of protection against HIV and AIDS ($p=0.768$, Pearson's Chi-Square value=1.87, DF =1) sources of information on HBC services ($p=0.209$, Pearson's Chi-Square value=1.956, DF =1), main benefits of

HBC ($p=0.768$, Pearson's Chi-Square value=0.087, DF=1) and main fears of HBC ($p=0.222$, Pearson's Chi-Square value=1.707, DF =1) (Table 4.3) and HBC uptake. Though these factors showed no significant association with HBC uptake, they could be affecting HBC uptake if combined. 18.7% of those with average/ good information on protection against HIV uptake HBC services compared to 10.2% with poor or no information.

Table 4.3: Relationship between benefits & fears of HBC and HBC uptake

Factors	HBC uptake status				Odds ratio	95% CI		P value
	Never up took HBC (n=153)		Up took HBC (n=30)			Lower	Upper	
	n	%	n	%				
Main benefits of HBC								
No benefit	29	85.3	5	14.7	1.2	0.4	3.3	0.087
1 or more benefits	124	83.2	25	16.8				
Main fears of HBC								
No fear	57	79.2	15	20.8	0.6	0.3	1.3	0.222
At least 1 fear	96	86.5	15	13.5				

4.15 Multivariate analysis

Independent variables that were significantly associated with HBC uptake among PLWHAs were fitted into a regression model to establish true predictor of HBC uptake.

Table 4.4: Logistic Regression Predicting HBC uptake against Age, Sex, Education, Employment, Distance to the nearest health facility, Knowledge on HIV infection and Awareness of HBC services

Variables	Categories	Odds ratio	95.0% C.I. for Odds ratio		P value
			Lower	Upper	
Age in years	≥ 35	7.1	1.5	34.2	0.015
	0 = 55 1 = 128				
Sex	Female	2.9	1.0	8.1	0.042
	0 = 103 1 = 80				
Education	< Primary	3.6	1.2	11.2	0.026
	0 = 62 1 = 121				
Employment	Unemployed	2.8	1.1	7.5	0.038
	0 = 59 1 = 124				
Distance to the nearest health facility	≥ 10 km	3.1	0.9	10.3	0.062
	0 = 55 1 = 128				
Knowledge on HIV infection	Average/ good	3.4	0.9	13.2	0.081
	0 = 1 =				
Awareness of HBC services	Aware	3.2	1.1	9.8	0.038
	0 = 61 1 = 122				

Ten factors namely age in years, sex, marital status, education level, employment status, distance to the nearest health facility, knowledge on HIV infection, awareness of HBC services, sources of information about HIV and the number of services accessed, were fitted into the model. After four successive iterations three potential predictors were eliminated and the resulting model was as show in Table 4.4.

Binary logistic regression performed on multiple variables to establish true predictors of HBC uptake. Table 4.4 shows odds ratio and P values for each of the factors associated with HBC uptake. A person is 7.1 times more likely to uptake HBC services if he/ she is 30 years or more compared to those below 30 years ($P=0.015$). Sex was significantly associated with HBC services uptake. Females were 2.9 times more likely to uptake HBC services compared to males ($P=0.042$). Level of education is also a significant factor influencing the uptake. An individual with at most primary level of education is 3.6 times more likely to uptake HBC compared to those educated beyond primary level.

Unemployment significantly associated with HBC uptake. The odds of HBC uptake for unemployed persons were 2.8 compared to those employed. Distance to the nearest health facility influenced on uptake of HBC services. A person staying 10 kilometres or more was 3.1 times more likely to uptake HBC compared to one who stayed less than 10 kilometres.

A PLWHA with multiple sources of information on HIV infection was 3.4 times more likely to uptake HBC services compared to those with one or no source of information on HIV infection. In the same token, a person who is aware of the existence of HBC services is 3.2 times more likely to uptake the services compared to those unaware.

4.16 FGD findings

A total of four FGDs were carried out. Each FGD was composed of between 8 and 11 participants. A total of 42 PLWHAs participated (28 females and 12 males).

	Theme	Findings
1.	Role of stigma	<p>Stigma, locally referred to as ‘unyanyapaa’ still remained a huge factor affecting HBC uptake. Majority of the participants expressed fear of having AIDS because of the stigma and exclusion it draws from the community members towards PLWHAs. This has made majority of the PLWHAs not to open up and declare their status in a community that looks down upon PLWHAs. This was evident from conversations such as:</p> <p style="text-align: center;"><i>“Mamaeee! Hi kitu tamaliza sisi kabisa”</i></p> <p style="text-align: center;"><i>This thing (HIV and AIDS) will wipe us out.</i></p> <p>Stigma was a major issue particularly in the remotest parts of the study sites. The Maasai culture according to majority of the participants plays a key role in HIV infection. Wives</p>

		<p>belong to age sets and therefore, have multiple sex partners. Whoever resists such a culture is discriminated upon and more often than not has gender based violence meted against her.</p> <p>Beliefs that HIV was still a curse or punishment from God are still deep rooted and ensured PLWHAs were treated as dirty, adulterous and cursed who should not be treated as a HIV negative person.</p> <p><i>“bwana yangu na watu wake walinifukuza kwangu Ati mimi ni mchafu na nimeleta laana kwao!”</i></p> <p><i>“I was sent away from my matrimonial home, For being dirty and bringing bad omen to them”</i></p>
2.	CHWs training	<p>Though majority of the participants in the FGDs appreciated the great work and services offered by the CHWs to the PLWHAs, a large number still felt that the training they underwent was not comprehensive enough to meet all their needs. The numbers of CHWs trained were also very few considering the demand for HBC in the communities.</p> <p><i>“Hii watu nasaidia sana sana, fundisha hao kabisa kabisa hata nafika huko ndani kabisa”</i></p>

		<p><i>“CHWs help us a lot, train them even more and a lot of them”</i></p> <p>Majority of the participants felt that the community strategy inaugurated recently has led to duplication of efforts by the government of Kenya (GoK) facility trained CHWs and the AIDS Populations and Health Integrated Assistance (APHIA) trained CHWs. This they said not only confused the community but also led to duplication of resources which could be employed else where.</p> <p><i>“sisi nashang’aa sana! Hii vikundi ya CHWs iko ng’api”</i></p> <p><i>“how many groups of CHWs exist?”</i></p>
3.	Role of T.O.Ts and Lay treatment workers	<p>Majority of the participants felt that the services of the trainer of trainers (T.O.Ts) were not felt in the community. Outreaches that should have been planned by them rarely took place and when they did they had little impact due to poor organization and mobilization.</p> <p><i>“Daktari sisi naona mara moja tu mwaka hii, hapana tembelea sisi. Wao nakuja na hakuna kazi nafanya”</i></p> <p><i>“T.O.Ts are rarely seen, only once have we</i></p>

		<p><i>seen them. When they come, they do nothing”</i></p> <p>Majority felt that training of T.O.Ts was a wastage of public resources that would be used to train CHWs. Participants reported that there is need to integrate HBC provision with religious groups and organizations whom they trust and felt will continue supporting them well after the funding is over.</p>
4.	Referral system	<p>Majority of the participants reported that the referrals between facility and community were very weak and there is need to strengthen linkage between the Ministry of Health facilities with the community. Most of the referrals made were never effected and there were hardly any referrals from the facility to the CHWs.</p> <p><i>“Sipitali sisi nakwenda lakini hakuna mtu nashughulikia sisi. Nang’oja siku yote bure”</i></p> <p><i>“we go to hospital but no one helps us out”</i></p>
5.	Sustainability of HBC	<p>Sustainability of HBC services beyond APHIA program emerged as a major doubt among participants who felt that they should have been introduced into microfinance programs to help generate income and therefore, afford HBC services in the future.</p> <p><i>“Sisi tutafanya nini baada ya hii mradi?wataleta</i></p>

		<p><i>ingine”</i></p> <p><i>“what is our future in HBC?is there an extension”</i></p> <p>This made it hard for CHWs to induct people into the HBC program. Poverty and drought were reported by majority of the participants to make it even hard for the communities to accept HBC programmes. This meant that people had to move in search for water, food and greener pastures for their animals.</p> <p><i>“Ero, sisi takaa hapa kungoja huduma na wanyama na watoto nakufa njaa? Mradu hapana pea sisi chakula!”</i></p> <p><i>“will we sit and wait for care while our children and animals die of hunger?”</i></p> <p>Majority of the participants reported the need for increased outreaches to follow the communities as they venture to new areas in search of food and pasture.</p> <p><i>“Kwani sipitali aliwacha mobile kilinik? Hawezi letea sisi dawa?”</i></p> <p><i>“what happened to the mobile clinic? Can’t the hospitals bring us medicines?”</i></p>
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CHAPTER FIVE: DISCUSSION

This study demonstrated that the uptake of HBC among rural PLWHAs in Narok was 16.4%. In 2006, the uptake of HIV and AIDS care (mainly facility based) stood at 14.4% in the Rift Valley province. This was established in a baseline study before HBC services were initiated in the care of HIV and AIDS in the Rift Valley (FHI, 2006). This may be attributed to the high stigma levels that still prevail in the rural areas where myths and culture still lead people to believing that HIV is not real but an act of witchcraft or a curse from God for disobeying His commandments. This was demonstrated in FGDs with support groups of PLWHAs.

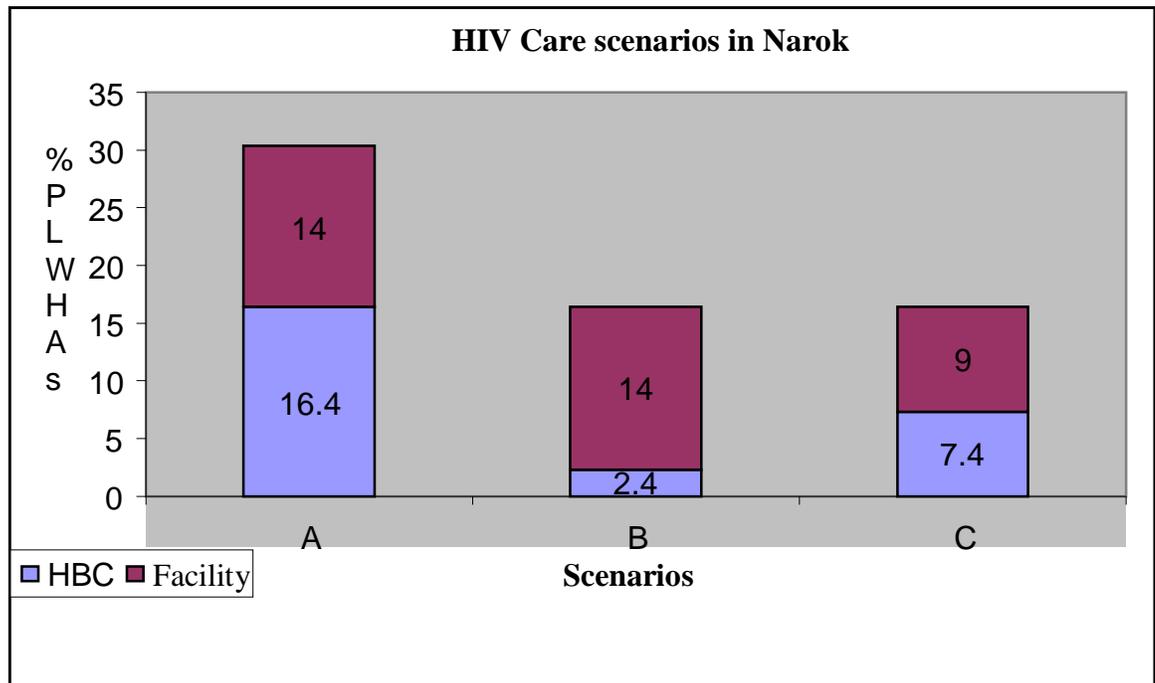


Figure 5.1: Different care scenarios that could be in Narok

Figure 5.1 shows three possible scenarios which could be happening in Narok district in terms of PLWHAs receiving care and support. Scenario A assumes that the 16.4% PLWHAs were new clients testing positive for HIV and therefore, enrolled into care. This would mean that since 2006 the PLWHAs under care have almost doubled. Scenario A is also the best case scenario indicating an increase in care for PLWHAs. Scenario B and C indicate that the care has increased though minimally by a 2.4% margin. However, scenario B shows that all the clients under HBC are all but 2.4% old clients receiving facility care before the initiation of HBC. Scenario C shows a balanced uptake both for HBC and facility but with the marginal 2.4%. Clients could have opted for HBC rather than facility based care due to the expenses involved such as the transport fee, consultation fees, medication fees and time spent at the facility that could otherwise be invested in other productive activities.

The user rate was however, higher among women compared to men with a prevalence of 23.3% and 7.5% for women and men respectively. This could be due to poverty being higher among women with the men controlling family resources (Alemayehu, 2001) and therefore, visiting facilities for care while the poor women turn to the less costly and readily available HBC services. Similar findings of female uptake being greater than among males were documented in a study to ascertain the uptake of HBC services among urban PLWHAs in Venezuela (Coleblunders et al., 2000).

The study showed that age, sex, employment status, marital status, level of education and the level of HBC awareness all influenced the uptake of HBC services. HBC uptake among female PLWHAs was 23.3% and that among males was 7.5%. The significant association between gender and HBC uptake in this study could be explained by the poverty levels among the female PLWHAs and the greater responsibility borne by them to nurture their families limiting the time and other resources available for them to spend visiting health facilities for specialized care (Alemayehu, 2001).

The significant association between age and HBC uptake in this study could be explained by the increased personal responsibility with age as was established in Venezuela (Coleblunders et al., 2000) thus encouraging older PLWHAs to take charge of their lives and those of their dependants. Most PLWHAs age 30 years and above were independent and wanted to engage in IGAs to support their dependents (FHI, 2006). This could be the pulling force for them to uptake HBC as a means of receiving training in microfinance and savings and internal lending communities (SILC). All PLWHAs who come together to form post test clubs or support groups are trained in SILC and deliberate efforts instituted to link such groups to micro-finance institutions (MFIs) for business start up capital.

The study showed a significant association between marital status and HBC up taking among PLWHAs. This finding concurred with earlier finding in Nyanza by the Kenya Red Cross Society where married PLWHAs were four times more likely to uptake HBC compared to the single PLWHAs. This trend can be associated with the tendency of the

married wanting to know the tenets of positive living so as to live longer and maybe bring up their children whereas the single PLWHAs have little responsibility to protect any other community member.

The uptake of HBC services among PLWHAs that had attained primary level of education or none was higher compared to that of PLWHAs who had attained at least secondary education. Many of the PLWHAs with a secondary level of education felt that HBC services were inadequate for their needs. They also had sources of income as majority were either employed or were engaged in some form of income generating activities (IGAs) which provided resources for specialized health care at facility. This finding agreed with the earlier findings in the baseline study in Rift valley province, Kenya by FHI in 2006 on HBC uptake before the implementation of the APHIA II project.

The study showed a significant association between employment status of PLWHAs and HBC uptake. Unemployed PLWHAs are 2 times more likely to embrace HBC services as compared to the employed. Employment is considered a source of extra income and with it improved economic power and a higher purchase power and ability to seek private specialized care. The employed PLWHAs are also considered community leaders by virtue of employment and therefore, are more sensitive to stigma which is attached to HBC. This agrees with findings in Venezuela where the unemployed PLWHAS were twice more likely to uptake HBC compared to the employed (Coleblunders et al., 2000).

Distance and time taken to the nearest health facility are expected to influence HBC uptake for PLWHAs living far away from a health facility and taking much time and using more resources to reach the facility. These are expected to utilize HBC services which are readily available and accessible than trying to seek specialized care in far away facilities. However, distance and time taken to the nearest health facility did not emerge to significantly influence HBC uptake in the study as shown by the observation that there was no significant association between time taken to reach the nearest health facility and HBC uptake. This finding, however, contradicts an earlier baseline survey in Rift Valley, Kenya (FHI, 2006) which had predicted an increase in HBC uptake with reduced distance to health facilities due to enhanced referrals and tracing for all testing positive for HIV. This could be explained by the high stigma levels still prevailing in the rural setups making effective referral and disclosure a big challenge to PLWHAs. The FGDs showed that many PLWHAs were sceptical of disclosing their HIV status to their friends or relatives in their neighbourhoods and this decreased uptake even in areas further away from facilities.

Other factors prior thought to influence HBC uptake included knowledge of protection against HIV, sources of information on HBC, main benefits of HBC and main fears of HBC. However, there was no significant association between these factors and HBC uptake. It was established that the more one knew about HIV prevention the less value they attached to HBC viewing it as inferior to their needs and only meant for those who

knew less. This association may well be negative and can be investigated further to establish the true association that exists. The more knowledge on HIV one had the more sensitive they were to peoples' perceptions of their status. Increased sensitivity therefore, reduces the chances of PLWHAs seeking for care in their neighbourhood and preferring to visit a health facility instead.

Stigma associated with HIV and AIDS was a major factor contributing to non-disclosure of the HIV status especially among those held with high regard in the community including those employed and the male PLWHAs. Men are traditionally held with high regard and hold the mantle of community leadership and therefore, seen as the role models in society. This fact makes them very sensitive to matters of stigma and discrimination associated with HIV and AIDS. Whereas women are socialised to seek treatment and engage in many social groupings that in which they share even the most intimate of their issues, men are not. They are socialized to bear and withstand pain so as to become warriors in the pastoralist communities. This also influences their health seeking behaviour in that they only seek care and treatment when it is too late into the infection.

The FGDs established that the role of the community health workers (CHWs) was much appreciated. Their support, care and counselling very much of assistant to the PLWHAs who previous had given up hope in life. However, there was a general feeling that the CHWs needed to be trained even further in matters of reproductive health and family

planning (RH/FP), TB defaulter tracing, nutrition and HIV, paediatric psychosocial support and linkage. Though different persons had been trained as SILC field agents (FAs), the community felt if the CHWs were trained in SILC and microfinance they could have more impact compared to a few FAs who cannot cover long distances to reach the demand for the services.

Sustainability of any donor funded programme is always a high priority area and HBC services in rural Narok were no exception. The FGDs elicited sharp opinion of what the future had in store for the clients already in the programme now that APHIA II was coming to an end in the next one year. The community needed reassurance and ownership of the program so that even if donors pulled out they could still continue offering the support and services offered in the donor funded program. Sustainability revolves around community involvement in the activities and this can be done by greater involvement of the community members in selection and training of the resource persons to be used. Having the opinion leaders rubber stamp the plans and help in mobilization is quite key in promoting community ownership.

Time and distance to the nearest health facilities were subjectively estimated. Pastoralists' idea of distance and time are normally not the same as other peoples' estimation. Time is measure by the positioning of the sun without a watch while their distance estimation is largely varied and depends on the individual.

CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

This is the first time HBC uptake in Narok district has been established following the government initiation of HBC for the chronically ill persons.

A female PLWHA aged greater than 35 years, with an education not exceeding primary level and who is not employed were the most likely to uptake HBC services in rural Narok. This profile in a nutshell gives the factors affecting uptake as sex, age, education level and employment status.

6.3 Assumptions

Time and distance to the nearest health facilities were subjectively estimated. Pastoralists' idea of distance and time are normally not the same as other peoples' estimation. Time is measure by the positioning of the sun without a watch while their distance estimation is largely varied and depends on the individual.

The study was unable to differentiate if the PLWHAs utilizing HBC were all newly diagnosed people or the 16.4% was inclusive of the initial 14% elicited earlier by FHI in 2006 in a baseline survey before HBC was instituted.

6.3 Recommendations

In view of the above findings and conclusions, this study makes the following recommendations for a comprehensive, efficient and all inclusive HBC program:

1. The fear and prejudice (stigma) that lies at the core of HIV and AIDS discrimination needs to be tackled at community level for the uptake of HBC services to increase in rural Narok. This can be instituted in the NGOs, government institutions and churches.
2. There is need to strengthen perception of referral systems between HBC and other services including strengthening of linkage between clinical and community so as to ensure the continuum of care. This can be done by local implementing partners (LIPs) by proper mobilization.
3. Increase diversity of referral relationships to address social and economic support concerns of clients. Only a few of the CHWs had actively sought and established partnerships with organizations in the community which provide social and economic support and care for orphans and vulnerable children. This targets both the LIPs and health facility T.O.Ts.
4. It is recommended that all HBC volunteers map key services in the community offering assistance with livelihood, food security and supplementation and support PLWHAs.

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APPENDICES

Appendix 1: Consent Form

TITLE OF STUDY:

FACTORS ASSOCIATED WITH THE UPTAKE OF HBC SERVICES AMONG RURAL PLWHA IN NAROK NORTH DISTRICT, RIFT VALLEY PROVINCE, KENYA

KIINI CHA UTAFITI

MASUALA YANAYOHUSIANA NA UTUMIZI WA HUDUMA ZA NYUMBANI MIONGONI MWA WATU WANOISHI NA VIRUSI VYA UKIMWI MASHINANI KATIKA WILAYA YA NAROK, KENYA

PART A

You are invited to participate in a study on factors associated with the uptake of Home-based care among rural people living with HIV AND AIDS in Narok District. The objective of this study is to establish the factors associated with the uptake of HBC services in the Narok area of Kenya in order to help improve its uptake. You have been selected as a possible participant in this study. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

Umealikwa kushiriki kwenye utafiti huu kuhusu *masuala yanayohusiana na utumiza wa huduma za nyumbani miongoni mwa watu wanoishi na virusi vya UKIMWi mashinani*

katika wilaya ya Narok, Kenya. Kiini cha utafiti huu ni kugundua maswala yanayohusiana na utumizi wa huduma ya nyumbani katika eneo la Narok ili kusudi kuimarisha utumizi wa huduma hii ya nyumbani. Umechaguliwa kuwa mmoja wa washirika wa utafiti huu. Twakuomba usome fomu hii na uulize maswali yoyote unayo kabla kukubali kushirikishwa.

This study is being conducted by Omariba Solomon Ogetii from the Institute of Tropical Medicine and Infectious Diseases, Jomo Kenyatta University of Agriculture and Technology.

Utafiti huu unafanywa na Omariba Solomon Ogetii kutoka idara ya utafiti ya madawa na magonjwa ya kuambukiza katika chuo kikuu cha kilimo Na teknolojia cha Jomo Kenyatta.

Purpose of the study

To establish the factors associated with the uptake of HBC services in the Narok area of Kenya,

Mada ya utafiti

Kubaini masuala yanayohusiana na matumizi ya huduma ya nyumbani katika wilaya ya Narok, Kenya

Study Procedures

If you agree to take part in this study:

We shall ask you detailed questions regarding yourself and on your knowledge, attitude, and experiences on the use of Home-based care services, whose answers we shall note on paper. The information that you will provide during the study will be kept confidential. Only the interviewer and the researcher will have access to the questionnaires. The information will be destroyed after the study.

Maagizo ya Utafiti

Ukikubali kuhusishwa katika utafiti huu:

Utaulizwa maswali kwa urefu kukuhusu na kuhusu elimu, mtazamo na ushiriki katika huduma za nyumbani majibu ambayo tutayahifadhi kwa kuandika kwenye karatasi. Habari zote utakazopeana zitabanwa. Ni mhoji na mtafiti tu ambao watakuwa na amri ya kuona karatasi hizo za majibu baada ya utafiti habari zote zitaaribiwa

Risks of Study Participation

This study has no known risks. Although we shall write your details on paper, no other person will be allowed to read this information except the ones directly involved in this study.

Madhara Ya Kushiriki Kwa Utafiti

Utafiti huu hauna madara yanayofahamika. Hata kama kutanakili jina lako kwa karatasi, hakuna mwingine yeyote atakayepata ruhusa kuyaona ila wale wanaohusika kwa utafiti huu.

Benefits

By participating in this study and answering to our questions, you will help to increase our understanding of the needs of the community in terms of Home-based care services. Your participation in this study is voluntary and you have the right to refuse to participate or to answer to any question that you feel uncomfortable with. If you change your mind, you have the right to withdraw at any time. If anything is not clear or if you need further information, we shall provide it to you.

Manufaa

Kwa kushiriki Kwa utafiti huu Na kujibu maswali yetu, utatusaidia kufahamu mahitaji ya jamii kuhusu huduma za kupima virusi vya UKIMWI. Kusahiriki kwako katika utafiti huu ni kwa hiari na una haki ya kukataa kushiriki au kujibu swali lolote. Kama utabadili fikira zako, unaweza, una haki kuacha wakati wowote kama kuna jambo halieleweki au unataka habari zaidi, tutakupa.

Study Costs/ Gharama za Utafiti

Taking part in this study will not involve any payment for those procedures we perform. *Kushiriki katika utafiti huu hakutakugharimu malipo yoyote kwa taratibu zote utakazo fanyiwa.*

Research Related Injury/ Majeraha Kutokana Na Utafiti

There are almost no chances of you getting an injury in the course of our study. *Hakuna uwezekano kuwa utapata majeraha yoyote katika wakati wa utafiti huu.*

Confidentiality

The records of this study will be kept private. The privacy will be enhanced by use of a lockable cabinet. Any publications or presentations arising from this study will not include any information that will make it possible to identify you as a Subject. However, your record for the study may, may be reviewed by officials from the Institute of Tropical Medicine and Infectious Diseases (ITROMID, KEMRI) or Jomo Kenyatta University of Agriculture and Technology. If the records are reviewed, the officials will protect your privacy.

Kubanwa Kwa Utafiti

Majibu yote ya utafiti huu yatawekwa Siri. Sivi itahakikishwa kwa kutumia kifuli na funguo kwa mahali zitawekwa. Vitabu na makala yatakayotokana utafiti huu yatajumuisha habariambayo itafanya mhojiwa ajulikane. Hata hivyo, nambari yako ya usajili, katika utafiti huu inaweza kuajiliwa na maafisa kutoka Idara ya madawa na magonjwa ya kusambaa(ITROMID, KEMRI) au wale kutoka chuo kikuu cha kilimo na teknolojia cha Jomo Kenyatta. Hata hivyo, maafisa hao watahakikisha kuwa jina lako limebanwa.

Voluntary Nature of the Study

Participation in this study is voluntary. Your decision whether or not to participate in this study will not affect your current or future relations with this hospital or the other

institutions involved. If you decide to participate, you are free to withdraw at any time without affecting those relationships.

Utafiti Ni Wa Hiari

Kushiriki katika utafiti huu ni kwa hiari. Uamuzi wako kushiriki au kutoshiriki katika utafiti huu hautaathiri uhusiano wako sasa au katika nyakati zijazo na hospitali hii au vitengo vingine vinavyohusika ikiwa utakubali kushiriki, una haki kuacha kushiriki wakati wowote bila kuhujumu husiano wako.

Contacts and Questions

The researcher conducting this study is OMARIBA SOLOMON OGETII. You may ask any questions you have now, or if you have questions later, you are encouraged to contact him through telephone number: 0722-496 983, E-mail omaribasolomon@yahoo.com

Maswali Na Watakao Yajibu

Mtafiti anayefanya utafiti huu ni OMARIBA SOLOMON OGETII. Unaweza kuuliza maswali yoyote uliyonayo sasa ama ikiwa utakuwa nayo baadaye, unahimizwa umjulisha kwa nambai ya simu: 0722-496 983 au barua pepe omaribasolomon@yahoo.com

If you have any questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you are encouraged to contact the following:

Ikiwa una maswali yoyote kuhusu utafiti huu na ungependa kuuliza swali kwa mtu mwingine isipokuwa mtafiti, unahimizwa ujulishe:

The Director, Institute of tropical medicine and infectious diseases (ITROMID),

Jomo Kenyatta University of Agriculture and Technology,

P. O. Box 62000 00200 Nairobi

Tel. 067 – 52711,

E-mail: itromid@nairobi.mimcom.net

AU

Mkurugenzi (ITROMID)

JOMO KENYATTA UNIVERSITY OF AGRICULTURE AND TECHNOLOGY

S.L.P 62000-00200, NAIROBI

Simu; 067-52711

Barua Pepe: itromid@nairobi.mimcom.net

OR/ AU

The Chairman KEMRI National Ethical Review Committee

P.O. Box 54840 – 00200

NAIROBI, KENYA

Tel: (254) (020) 2722541, 2713349, 0722-205901, and 0733-400003;

E-mail: info@kemri.org

You will be given a copy of this form to keep for your records.

Utapewa nakala ya fomu hii kuweka kama kumbukumbu.

PART B: CONSENT FORM

Please read the information sheet (PART A) or have the information read to you carefully before completing and signing this consent form. If there are any questions you have about the study, please feel free to ask them to the investigator prior to signing your consent form.

Tafadhali soma fomu A ama hakikisha kwamba umesomewa na kuelewa kabla ya kitia sahihi fomu hii ya kupeana ruhusa. Kama una maswali yoyote kuhusu utafiti huu, tafadhali uliza mtafiti maswali hayo kabla ya kutia sahihi fomu hii ya kupeana ruhusa.

Declaration of the volunteer/ Arifa ya mhojiwa wa hiari

I Mr, Miss, Mrs.....here by give consent to Mr. Omariba to include me in the proposed study entitled factors associated with the uptake of HBC services among rural PLWHAs in Narok north District, rift valley province, Kenya. I have read the information sheet concerning this study, I understand the aim of the study and what will be required of me if I take part in the study. The risks and benefits if any have been explained to me. Any questions I have concerning the study have been adequately answered.

I understand that at any time that I may wish to withdraw from this study I can do so without giving any reason and without affecting my access to normal health care and management.

I realize that I will be interviewed once. I consent voluntarily to participate in this study.

*Mimi Bw/Bi.....napeana ruhusa kwa Bw. Omariba anijumuishe kwa utafiti
“Masuala yanayohusiana na utumiza wa huduma za nyumbani miongoni mwa watu
wanoishi na virusi vya UKIMWI mashinani katika wilaya ya Narok, Kenya”.*

*Nimesoma habari zote kuhusu utafiti huu, nimeelewa lengo la utafiti huu na
yanayohitajika kwangu kama nitashiriki katika utafiti huu. Madhara na manufaa ya
utafiti huu yameelezwa kinaga ubaga kwangu. Maswali yote niliokuwa nayo
yamejibiwa vilivyo.*

*Nimeelezwa/nimeelewa kwamba wakati wowote naweza kuacha kushiriki na
sitashinikizwa kutoa sababu yoyote au haitahujumu kupata kwangu kwa matibabu kwa
kawaida.*

*Najua kwamba nitahojiwa mara moja. Ninapeana ruhusa kwa hiari nishiriki katika
utafiti huu.*

Subject’s Name/ Jina la mhojiwa

Signature or left thumb print _____ Date/ Tarehe _____

Sahihi/alama ya kidole gumba (kushoto)

Name of person taking consent.....

Jina la anayepewa ruhusa

Signature/ Sahihi..... Date/ Tarehe

Name of Investigator/ Jina la mtafiti

Signature of Investigator/ Sahihi ya mtafiti _____ Date/ Tarehe _____

Appendix 2: Ethical Clearance



KENYA MEDICAL RESEARCH INSTITUTE

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

KEMRI/RES/7/3/1

SEPTEMBER 22, 2008

FROM: SECRETARY, KEMRI/National Ethical Review Committee

THRO': Dr. Yeri Kombe,
CENTRE DIRECTOR, CPHR,
NAIROBI

TO: Solomon O Ogetii (Principal Investigator)

RE: **SSC No.1443 (Rev):** Factors associated with the uptake of HBC services among rural PLWHA in Narok District, Kenya

Forwarded
[Signature]
22/09/08

Dear Sir,

Make reference to your letter dated 22 September 2008.

We acknowledge receipt of the revised Informed Consent Document in English and the Kiswahili translation. We also note the FGD guide and the revised conceptual framework in the main body of the proposal.

Due consideration has been given to ethical issues and the study is granted approval from today 22nd SEPTEMBER 2008 to 21st SEPTEMBER 2009.

Please note that any changes to the research study must be reported to the Scientific Steering Committee and to the Ethical Review Committee prior to implementation. This includes changes to research design, equipment, personnel, funding or procedures that could introduce new or more than minimum risk to research participants.

Respectfully,

R. C. Kithinji
R. C. Kithinji,
For: Secretary,
KEMRI/NATIONAL ETHICAL REVIEW COMMITTEE

Appendix 3: Questionnaire

**FACTORS ASSOCIATED WITH THE UPTAKE OF HBC SERVICES AMONG
RURAL PLWHA IN NAROK NORTH DISTRICT, RIFT VALLEY PROVINCE,
KENYA**

**MASUALA YANAYOHUSIANA NA UTUMIZA WA HUDUMA ZA NYUMBANI
MIONGONI MWA WATU WANOISHI NA VIRUSI VYA UKIMWI MASHINANI
KATIKA WILAYA YA NAROK, KENYA**

Questionnaire serial number <i>/ Nambari ya questionnaire</i>			
Research assistant's name/ <i>Jina ya msimamizi</i>			
Date of interview/ <i>Tarehe ya mahojiano</i>	Day/ <input type="checkbox"/> <i>Siku</i>	Month/ <input type="checkbox"/> <i>Mwez</i>	
Respondent name (optional)/ <i>Jina la mhojiwa</i>			
Gender of respondent/ <i>Jinsia ya mhojiwa</i>	1 Male/ <i>Mume</i>	2 Female/ <input type="checkbox"/> <i>Mke</i>	

SOCIO-DEMOGRAPHIC DATA/ TAKRIMU YA MHOJIWA

1. How old are you? / *Je una miaka mingapi?*

15- 20 years	21 – 29 years	31 – 39 Years	40- 49 Years	50+
1	2	3	4	5

2. What is your marital status? / *Hali yako ya ndoa ni gani?*

Single/ <i>Hajaoa/Hajaol ewa</i>	Married/ <i>Ameoa/Ameol ewa</i>	Divorced/ <i>Ametalaki</i>	Widowed/ <i>Amefiwa na bwana/mke</i>
1	2	3	4

No formal education/ <i>Haja soma</i>	Primary / <i>Elimu ya msingi</i>	Secondary / <i>Shule ya kati</i>	College/ <i>Chuo cha kadri</i>	University/ <i>Chuo kikuu</i>
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1	2	3	4	5
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3. What is your highest level of completed education? / *Je kiwango cha juu cha elimu ulichokihitimu ni kipi?*

4. What is your religion? / *Dini yako ni gani?*

Muslim/ <i>Muisilamu</i>	Protestant / <i>Protestanti</i>	Catholic/ <i>Katoliki</i>	Traditional religion/ <i>Dini ya kiasili</i>	Other, specify/ <i>Nyingine eleza</i>
1	2	3	4	5

5. What is your employment status? / *Hali ya yako ya ajira ni gani?*

Not working/ <i>Sifanyi kazi</i>	Employed/ <i>Nimeajiriwa</i>	Self employed/ <i>Kazi yangu binafsi</i>	College student/ <i>Mwanafunzi wa chuo</i>	Other Specify/ <i>Nyingine eleza</i>
1	2	3	4	5

DISTANCE BETWEEN FACILITY AND RESPONDENT RESIDENCE/

UMBALI KUTOKA HOSPITALI KWENDA KWA MHOJIWA ANAKOISHI

6. On average how long do you take to get to the nearest health facility? / *Kwa wastani inakuchukua mda gani kufika katika hii hospitali?*

1	Less than 10 minutes/ <i>Chini ya dakika 10</i>
2	10-20 minutes / <i>Dakika 10-20</i>
3	20-30 minutes/ <i>Dakika 20 - 30</i>
4	30 minutes-1 hour / <i>Dakika 30 hadi saa moja</i>
5	More than one hour/ <i>Zaidi ya saa moja</i>

7. What is the distance between where you stay and the nearest health facility? / *Ni umbali gani kutoka unapoishi hadi hapa hospitalini?*

1	Less than 5km / <i>Chini ya kilomita 5</i>
2	5-10 km / <i>Kilomita 5 hadi 10</i>
3	More than 10km/ <i>Zaidi ya kilomita 10</i>
4	Don't know / <i>Sijui</i>

8. What means do you use to get to the nearest health facility? / *Je unatumia njia gani ya usafiri kufika hapa hospitalini?*

1	By foot / <i>Kutembea kwa miguu</i>
2	By bicycle / <i>Baisikeli</i>
3	By motor cycle/ <i>pikipki</i>
4	By matatu / <i>matatu</i>
5	By personal car/ <i>Hutumia gari langu binafsi</i>
6	Other (specify)/ <i>Nyingine(weleza)</i>

9. If response in Q8 =

4, how much do you usually pay for a round trip between home and the nearest health facility?/ *Kama jibu katika Q8 = 4 unalipa pesa ngapi kutoka nyumbani kufika hospitalini na kurudi*

1	Less than Sh20 / <i>Chini ya sh. 20</i>
2	More than Sh20 / <i>Kupita sh. 20</i>
3	Not applicable / <i>Hainihusu/Sihusiku</i>

Information about HIV and Home-based care *Ufahamu kuhusu virusi vinavyosababisha UKIMWI na huduma ya nyumbani*

10. How is a person infected by the HIV virus? (Tick all mentions) **MULTIPLE**

RESPONSES / Mtu huambukizwaje na virusi vya UKIMWI? (Nakili zote zilizotajwa)

MAJIBU MENGI

1	Sexual transmission / <i>Kuambukizwa kupitia ngono</i>
2	Infected mother to child / <i>Mtoto kuambukizwa kupitia mama</i>
3	Transmission through blood

Any other ways?
Please

specify / *Njia zingine zozote? Tafadhali eleza*

11. How can one be protected against getting HIV? (Tick all applicable) **MULTIPLE**

RESPONSES / Mtu anawezaje kujizuia kutokana/ ili asipate virusi vinavyosababisha

UKIMWI? (Nakili yote yanayohusika) **MAJIBU MENGI**

1	Abstinence / <i>Kutoshiriki ngono</i>
2	Be faithful to one uninfected partner/ <i>Kuwa mwaminifu kwa mpezi mmoja ambaye hajaambukizwa</i>
3	Use of Condoms / <i>Kutumia mipira ya kondom</i>

Any other ways? Please specify / *Njia zingine zezote? Tafadhali eleza*

12. In what way can an infected person transmit HIV to another person? (Tick all mentions). **MULTIPLE RESPONSES** / Ni kwa njia gani ndiyo mtu aliyeambukizwa anavyoweza kumwambukiza mtu mwingine viusri vya UKIMWI? (Nakili zote zilizotajwa)

MAJIBU MENGI.

1	Having unprotected sex / <i>Kushiriki ngono bila kutumia kinga</i>
2	During child birth/ <i>Wakati mtoto anapozaliwa</i>
3	Sharing of sharp objects / <i>Kutumia vyombo venya makali Kwa ujumla</i>

Others, Specify/ *Njia zingine zezote? Tafadhali eleza*

13. What are the sources of your information about HIV AND AIDS? Any other ...
 (Tick all mentions) **MULTIPLE RESPONSES ALLOWED/ Njia zako za ufahamu kuhusu virusi vinavyosababisha UKIMWI ni yapi? Zingine Zozote? (Nakili zote zilizotajwa) MAJIBU MENGI yanakubalika**

1	Hospital/ clinic/testing centre/ <i>Hospitali/ kliniki/ kituo cha kupimwa</i>
2	Radio / <i>Redio</i>
3	Television / <i>Runinga</i>
4	Newspapers / <i>Magazeti</i>
5	Family members / <i>Jamaa</i>
6	School/college/university/ <i>Shuleni/ chuoni/ chuo kikuu</i>
7	Health magazines/ <i>Magazeti za kiafya</i>
8	Seminar/ <i>Semina/ mikutano</i>
9	Other (specify)/ <i>Nyingine (eleza)</i>

14. How about your source of information about Home-based care for people living positively. Any other ... (Tick all mentions) **MULTIPLE RESPONSES ALLOWED/ Je,na kuhusu ufahamu wako kuhusu huduma za kupimwa kwa virusi vya UKIMWI. Nyingine yeyote? (Nakili zote zilizotajwa) Majibu mengi yanakubalika.**

1	Hospital/ clinic/testing centre / <i>Hospitali/ kliniki/ kituo cha kupimwa</i>
2	Radio / <i>Redio</i>
3	Television / <i>Runinga</i>
4	Newspapers / <i>Magazeti</i>
5	Family members <i>Jamaa</i>
6	School/college/university/ <i>Shuleni/ chuoni/ chuo kikuu</i>
7	Health magazines/ <i>Magazeti za kiafya</i>
8	Seminar/ <i>Semina/ mikutano</i>
9	Other (specify)/ <i>Nyingine (eleza)</i>

15. What Home Based services are you aware of? (Tick all applicable) **MULTIPLE RESPONSES ALLOWED/Vipengele vipi vya huduma ya nyumbani unavyovifahamu. Majibu mengi yanakubalika**

1	Nursing care /huduma ya uuguzi
2	Nutritional support /usaidizi wa vyakula
3	Pyscho-social support /Usaidizi wa mawazo na utangamano
4	Paralegal support /Usaidizi wa kisheria
5	Economic support/Usaidizi wa kifedha
6	Prevention messages/Ujumbe wa kuzuia
7	Anti-stigma messages/Ujumbe dhidi ya unyanyapaa

Any other services/ *Nyingine (eleza)* _____

16. How many of these services have you accessed? (Tick all applicable) **MULTIPLE RESPONSES ALLOWED**/ *Ni huduma zipi umepokea. Majibu mengi yanakubalika*

1	Nursing care / <i>huduma ya uuguzi</i>
2	Nutritional support / <i>usaidizi wa vyakula</i>
3	Pyscho-social support / <i>Usaidizi wa mawazo na utangamano</i>
4	Paralegal support / <i>Usaidizi wa kisheria</i>
5	Economic support/ <i>Usaidizi wa kifedha</i>
6	Prevention messages/ <i>Ujumbe wa kuzuia</i>
7	Anti-stigma messages/ <i>Ujumbe dhidi ya unyanyapaa</i>

17. How many care-givers attend to you?/ *Una wahudumu wangapi wa nyumbani?*

1	Less than two / <i>Chini ya wawili</i>
2	Between two and five/ <i>Kati ya wiwili na watano</i>
3	More than five / <i>Zaidi ya watano</i>

18. How many times in a month does the community health worker visit you in a month? / *Ni mara ngapi kwa mwezi unatembelewa na mhudumu wa nyumbani?*

1	Less than two times/ <i>Chini ya mara mbili</i>
2	Between two and five times/ <i>Kati ya mara mbili na mara tano</i>
3	More than five times/ <i>Zaidi ya mara tano</i>

Attitude and Practice to Home-based care Services/ *Mtazamo na kushiriki kwa huduma ya nyumbani.*

19. In general, what do you think are main benefits of having Home-based care services available? *Kwa jumla unafikiri ni manufaa gani ndiyo ya muhimu zaidi kwa huduma ya nyumbani*_____

20. In general, what do you think are the main fears of having home-based care services available? / *kwa jumla, unafikirini uoga gani ndiyo ya juu zaidi kuwa kwenye huduma ya nyumbani?*_____

21. Do you think that Home-based care services should be part of routine services for everybody living positively? / *Unafikiri kuwa huduma ya nyumbani inapaswa kuwa huduma ya kawaida kwa kila mtu anayeishi na virusi vya HIV?*

1	Yes/ <i>Ndio</i>
2	No / <i>La</i>
4	Refused/ <i>Amekataa</i>
5	Don't Know/ <i>Sijui</i>

22. What are the benefits of regularly utilizing Home-based care services? / *Ni manufaa yapi yaloyomo katika utumizi wa huduma ya nyumbani wakati wote?*

23. Is it necessary to have partners and other family members as caregivers in Home-based care provision?/ *Je, ni muhimu kuwaalika wapenzi na jamaa wengine katika kupeana huduma ya nyumbani?*

1	Yes/ndio
2	No /la
3	Refused/ <i>Amakataa</i>
4	Don't Know/ <i>Sijui</i>

24. In your opinion do you think Home-based care services are accessible to all people living positively? /*Kwa maoni yako, je, huduma ya nyumbani inafikiwa na wote wanoihitaji?*

1	Yes/ <i>Ndio</i>
2	No / <i>La</i>
3	Refused/ <i>Amakataa</i>
4	Don't Know/ <i>Sijui</i>

25. In your opinion what are the factors affecting the access to Home-based care services? /*Kwa maoni yako ni masuala yapi yanaadhiri upatikanaji wa huduma ya nyumbani?*

26. What is the general attitude of your community towards home-based care services? *Ni upi mtazamo wa jamii kuhusu huduma ya nyumbani?*_____

27. What is the general attitude of your community towards people living with HIV AND AIDS?/ *Mtazamo wa kawaida wa jamii yako kuhusu watu wanaoishi na virusi vya UKIMWI ni upi*

28. When did you have a HIV test? /Ulipimwa lini kujua hali yahoo ya HIV?

29. Where did you have you HIV test done? /Ulipimwa hali yako ya HIV wapi?

1	Hospital/Hospitalini
2	VCT Centre /Kituo cha VCT
3	Other (specify)/Nyingine (eleza)

30. What made you decide to have a HIV test? / *Ni nini kulikufanya uamue kupimwa?*

31. Have you shared the information of your status with someone else? *ulijadili habari ya hali yako na yeyote ?*

1	Yes/ <i>Ndio</i>
2	No/ <i>La</i>
3	Refused/ <i>Amekataa</i>

32. If yes in Q31, who have you share the information of your status with? **MULTIPLE RESPONSES ALLOWED**/ *Kama jibu ni ndio kwenye Q31, ulijadili habari ya hali yako na nani? MAJIBU MENGI YANAKUBALIKA*

1	Spouse/ <i>Mke/Mme</i>
2	Sexual partner/boyfriend/ girlfriend/ <i>Mpenzi wa ngono/ Rafiki wa kiume/ Rafiki wa kike</i>
3	Family member/Jamaa
4	Friend / <i>Rafiki</i>
5	Pastor/priest/religious leader/ <i>Mhubiri/ Katoliki / Mkuuu wa kidini</i>
6	Other (specify)/ <i>Nynginezo Eleza _____</i>

33. Do you know of someone who is on home-based care? / Unajua mtu yeyote ambaye anapokea huduma ya nyumbani?

1	Yes/ <i>Ndio</i>
2	No/ <i>La</i>
3	Refused/ <i>Amekataa</i>

34. How satisfied are you with the home-based care services you receive from the Community Health Workers? (Tick one) (**Ask ONLY those who have taken the HIV test**)/ *Unaridhika kiasi kipi na huduma ya nyumbani unayopokea kutoka kwa wahudumu wa nyumbani? (Nakili moja) (Uliza tu wale wamepimwa virusi vya UKIMWI)*

1	Very satisfied / <i>Nimeridhika kabisa</i>
2	Satisfied / <i>Nimeridhika</i>
3	Neither satisfied nor dissatisfied / <i>Siridhiki wala kuridhika</i>
4	Dissatisfied / <i>Siridhiki</i>
5	Very dissatisfied/ <i>Siridhiki kabisa</i>

35. If you have a choice, whom would you prefer to attend to you as your community health worker? / *Kama unachagua, ungependa kuhudumiwa na nani kam mhudumu wako wa nyumbani?*

1	Female / <i>Mwanamke</i>
2	Male / <i>Mwanmme</i>
3	Somebody younger than you/ <i>Mtu mwenye umri mdogo kukushinda</i>
4	Somebody older than you / <i>Mtu mwenye umri mkubwa kukushinda</i>
5	Somebody of your age / <i>Mtu mwenye umri sawa na yako</i>
6	Anybody/ <i>Mtu yeyote</i>

36. Please tell me to what extent you agree with the following statements. For each statement, state whether you strongly agree, agree, neither agree nor disagree, disagree or strongly disagree./ *Tafadhali niambie ni kiwango kipi unachokubaliana na maelezo yafuatayo. Kwa kila maelezo eleza kama unakubaliana kabisa, unakubaliana, sikubaliani wala kukubaliana, sikubaliani au sikubaliani kabisa*

	Strongly Disagree/ Sikubaliani kabisa	Disagree / Sikubaliani	Neither agree nor disagree/ Sikubaliani wala kukubaliana	Agree/ Nakubaliana	Strongly Agree/ Nakubaliana kabisa
Would prefer being cared for by someone familiar to me/ Ningependa kuhudumiwa na mtu ambaye ninaye mjua	1	2	3	4	5
Would prefer cared for by someone from the community where you come from/ Ningependa kuhudumiwa na mtu kutoka jamii ninayotoka	1	2	3	4	5
Would prefer being cared for within a hospital set-up	1	2	3	4	5
Would prefer being cared for away from where you live/ Ningependa kuhudumiwa katika mazingira ya nyumbani	1	2	3	4	5
HIV AND AIDS poses a great health threat to society/ UKIMWI ni tishio kubwa katika jamii	1	2	3	4	5
Many people you have interacted with are aware of Home-based care/ Watu wengi ambao nimetangamana nao wanafahamu	1	2	3	4	5

kuhusu huduma za nyumbani					
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37. In your view, what are the possible interventions and strategies to succeed in managing HIV AND AIDS in your area? / *Kwa maoni yako, ni mikakati gani yanayoweza kutumika ili kuzuia virusi vya UKIMWI kwenye eneo lako?*

38. How can you support these interventions? / *Unawezaje kuunga mkono mikakati hizi?*

39. As a last question, what are your views with regard to improving Home-based care?/

Je, maoni yako kuhusu huduma ya nyumbani ni yapi?

Thank you for participating in this study.

Ahsante kwa kushiriki katika utafiti huu.

Appendix 4: Focussed Group discussion Guide

1. Who should be trained as a community health worker?
2. Is there need for refresher training for Community Health Workers, how often?
3. Is the role of TOTs and lay treatment workers felt in Home-based care services?
4. Is there adequate support from health facilities in HBC?
5. How can the referral system (community \longleftrightarrow facility) be improved?
6. What role does stigma play in HBC in Narok?
7. Is HBC as practiced comprehensive?
8. How will HBC program be sustained after the end of funding?
9. Is family centred approach the way to go in HBC?