EVALUATION OF HOME-BASED CARE AND INSTITUTIONAL-BASED CARE NEEDS OF PEOPLE LIVING WITH AIDS IN NAIROBI KENYA

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DECLARATION

I, Dr. Lucy Muhia-Ndahi declare that this thesis is my original work and has not been presented to any other University or Institution for the purpose of obtaining a degree.

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DEDICATION

To my husband Dr. Mwaniki and children Elizabeth, Esther, Alfred and Ivy who tolerated my frequent absence and provided support. To my parents Esther and George thanks for the education and continuous encouragement.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immuno-deficiency Syndrome
BI	Bamako Initiative
CBDs	Community Based Distributor
CHW	Community Health Workers
CME	Continuous Medical Education
DHMT	District Health Management Team
FCG'S	Family care givers
FGD	Focus Group Discussions
HBC	Home Based Care
HC	Health Centre
HIV	Human Immuno-deficiency Virus
HWs	Health Workers
IGA	Income Generating Activities
KAP	Knowledge, Attitude and Practices
KNH	Kenyatta National Hospital
MDH	Mbagathi District Hospital
MOH	Ministry of Health
NACC	National AIDS Control Council
NASCOP	National AIDS/ STDs Control Programme
NGO's	Non Governmental Organisations
PLWA	People Living With Aids
PSC	Patient Support Centre
PTB	Pulmonary Tuberculosis

SES	Social Economic Status
STD’s	Sexually Transmitted Diseases
WHO	World Health Organisation

SUMMARY

The main objective of this study was to evaluate Home-Based Care (HBC) and institutional-based care needs of people living with AIDS (PLWA) in Nairobi. Based on the findings of this study, the understanding of the care needs as well as contribution towards design of the most appropriate continuum of care of PLWA would be enhanced.

Care of patients with HIV/AIDS is costly, both to individual citizens and to Kenya's health care system and this has severely affected the country's ability to provide and sustain good services. The existing health care system lacks the resources to provide equitable services and follow-up of the thousands of patients afflicted by HIV/AIDS. However, as the number of those infected continue to increase, home care for PLWA seems to be an inevitable option.

The choice of where the care would be provided may be influenced by a number of factors including, accessibility, affordability and availability of facilities. Attitudes of providers and their knowledge of care are also important. At patient level, acceptability and satisfaction with care provided are equally important. It is against this background that this study was carried out.

Specifically the study sought to determine socio-demographic characteristics, knowledge, attitude and practices of the caregivers and to establish how these factors influence provision of care. It also sought the views of PLWA regarding the care they receive to determine their preference of home-care versus institutional-care and the reasons for the preference. This was investigated through a cross-sectional descriptive study using both quantitative and qualitative methods of data collection.

The study centre was Mbagathi district hospital where PLWA are referred from various health centres within Nairobi. The study population included nursing cadre of health workers (HWs), family care givers (FCGs) and PLWA. Only those PLWA who were confirmed and informed about their HIV status were interviewed. Similarly only those FCG's who knew about the status of their patients were interviewed. A total of 384 PLWA were recruited, comprising of 192 PLWA cared for at home and 192 PLWA cared for in the hospital at the time of interview. FCGs were also 192 and HWs were 192. The PLWA cared for at home and FCGs were drawn from informal settlements within Nairobi. Those areas which were covered included, Kibera, Korogocho, Dandora and Mugumoini.

The results showed that most (77.4%) PLWA preferred home-based care to institutional-based care. Similarly, despite various constraints which were encountered by FCGs as they provided care to their patients, majority (92.7%) felt home was the best place where PLWA should receive care.

PLWA were found to have three major pressing needs of psycho-social and medical dimensions. Psycho-socially the two main needs were support for their dependants in the form of food and understanding from everybody in order to cope with the stigma. Medical needs included providing medical care and medicaments which are affordable and accessible.

Practically all FCGs were willing to provide care to their patients and majority of PLWA expressed satisfaction with the quality of home-based care. However, FCGs thought that further training would improve their knowledge and skills to provide better services. They reported that they received little support and supervision from health institutions.

Many HWs had not received any additional training and preparation to care for PLWA. Majority (67.2%) of HWs were worried of getting HIV/AIDS while providing care to PLWA. However, their knowledge on modes of transmission and prevention of HIV/AIDS was excellent.

Satisfaction with quality of care at home was higher than for hospital-based care (P=0.03) implying that PLWA were generally satisfied with care provided but place of care was statistically related to satisfaction of care.

Poverty was the implied impediment of satisfactory care of PLWA both in hospitals and at home. Therefore, programmes of income-generating activities to alleviate poverty in families are and should be a priority of all stakeholders including the family, government, NGOs, churches and development partners.

CHAPTER ONE

1.1 INTRODUCTION AND BACKGROUND INFORMATION

World wide, Human Immunodeficiency Virus (HIV) infection and Acquired Immuno Deficiency Syndrome (AIDS) has increased the cost of health care. Millions of people have become infected with HIV world-wide making AIDS the worlds' most serious public health problem, more so in developing countries.

Poverty creates the conditions and environment which help spread of HIV and consequently AIDS causes further poverty. Preventive, promotive, as well as health care measures need to take into account the socio-economic, cultural factors and religious beliefs that may promote the spread of HIV. For instance, poor socio-economic status (SES) is more likely to compromise the quality of care to PLWA and encourages involvement in risky sexual behaviour.

In Sub-Saharan Africa, heterosexual route is the principal mode of transmission of HIV infection (WHO, 1997). No proven cure exists for HIV infection to date. The burden of the disease goes far beyond the suffering and eventual death of the individual. Stigmatisation of the family, loss of a healthy work force and therefore revenue, loss of main breadwinner amongst others, occur as a result of AIDS. Governments particularly those of developing countries cannot afford the huge costs involved in taking care of AIDS patients, while both families and communities have been impoverished by the high costs involved in caring for those with AIDS.

Existing medications which ameliorate the disease are expensive, and by and large, beyond the reach of those who need them in Africa. While numerous control programmes and campaigns have been launched in different countries with diverse results, HIV continues to spread rapidly throughout Sub-Sahara Africa, accounting for about 67% of all HIV/AIDS cases estimated at 30.6 million world-wide as of December 1997. The cumulative total of orphans in Sub-Sahara Africa is estimated to be over 7.8 million (WHO, 1997). The figures could very well be an underestimation of the true position as it is virtually impossible to test all the people infected by the HIV virus. It was estimated that by June 2000 over 2.2 million Kenyans were living with HIV/AIDS (Baltazar et al, 1999).

Although East Africa was one of the first countries to experience regional epidemic on a massive scale, South Africa is now considered to be the most affected country in Sub-Saharan Africa (WHO, 1997). Experience from Uganda indicates that concerted and open efforts to control HIV infection and care of PLWA can lead to consistent changes in knowledge, attitude and practices especially among youth and care-givers (Konde et al, 1997).

In Kenya between 1993 and 1998 the number of persons reported to be infected with HIV doubled from 725,000 to 1.4 million. The National AIDS/STD'S Control Programme of Kenya reported that there were more than 80,000 cases of AIDS at the end of July 1998 and estimated the actual number of case could be 3-5 times higher than reported cases (Baltazar, et al, 1998).

At Kenyatta National Hospital (KNH) a study done in 1994 found there was a doubling of bed occupancy by patients, however, staff size and space have not increased (Republic of Kenya 1994). Factors increasing bed occupancy included the following reasons:

Patients refusal to go home because of stigma of having AIDS, lack of money to pay hospital bills and relatives refusing to pick up patients.

In general, most of the health care facilities in the country can only be described as partially equipped to cope up with the HIV/AIDS challenge given the rapid spread of the epidemic. For PLWA, psychological and social support cares are as important as the medical management and ought to be provided as a package.

Many HIV/AIDS patients are discharged from health facilities as soon as the HIV test results are known. At times without informing the patients and their relatives. Other times relatives prefer to provide home care in order to avoid the unaffordable health facility-based care and to conserve their scarce resources for other basic needs.

However, for caregivers to provide good care they need to be trained on some basic practical and emotional support to allow them give care appropriately, for example:

- How to make sick person comfortable
- Basic nursing techniques
- Nutritional advice
- Bereavement counselling
- Coping with chronic illness
- Recognition of opportunistic infections.

Perception of the PLWA about the care they receive is an essential aspect of the process of improving care needs.

However, it must be noted that since Kenya is faced with the problem of rising population of PLWA in already crowded health care facilities, alternative practical ways of caring for these clients ought to be explored. The search for this alternative form of care resulted in an evaluation of home-based and institutional-based care needs of PLWA in order to help in understanding their care needs and also establish the roles and constraints of care-givers both in the hospital and at home.

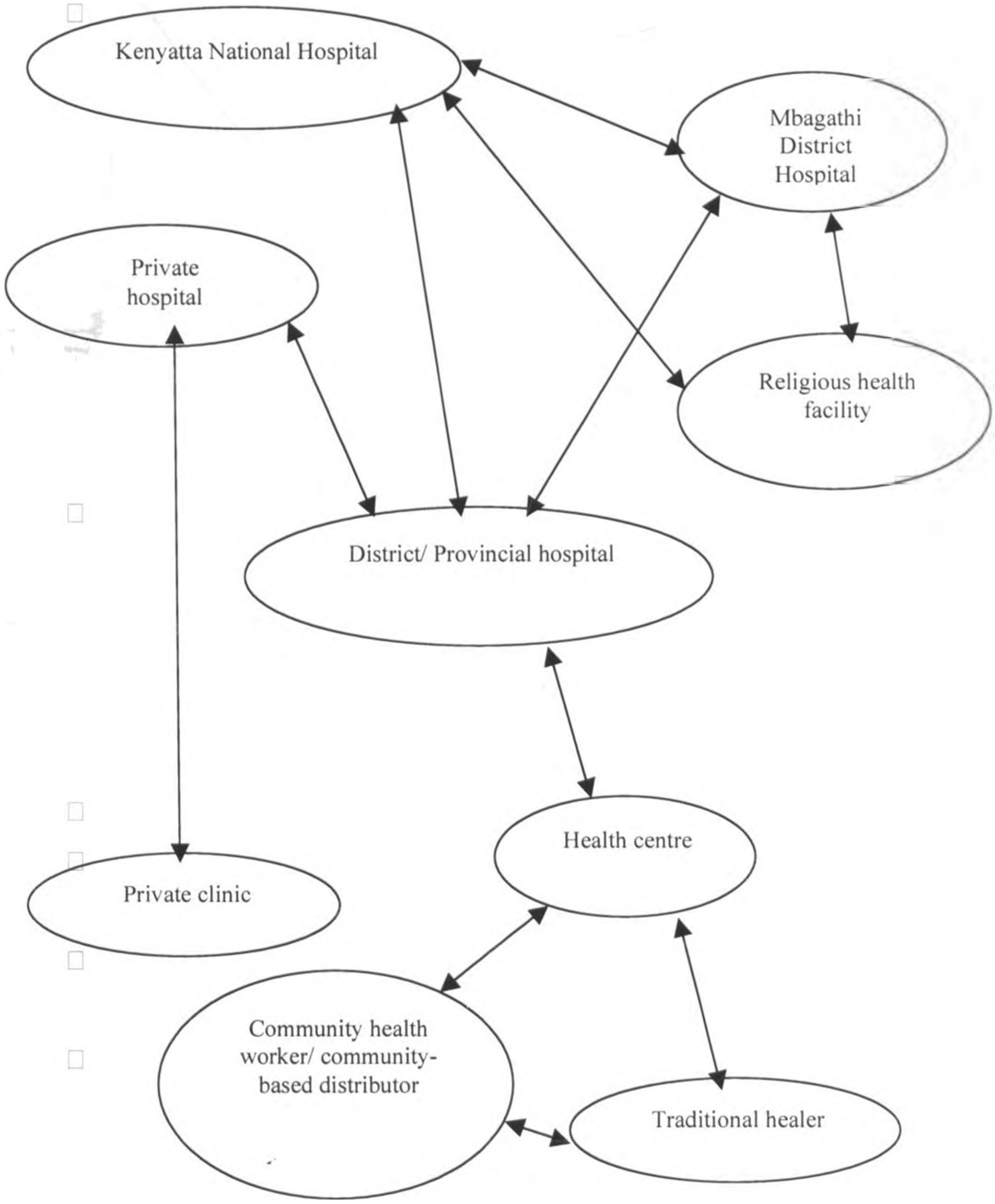
1.2 Utilisation of Health Services in Kenya

Health care delivery system in Kenya is made up of both public and private sectors. Within the public sector there is a referral system whereby patients are seen and referred to other health facilities starting from dispensary, then health centre , then district hospital, then provincial hospital and Kenyatta National Hospital (KNH). This system attempts to ensure that patients are given optimal care and management required in each level of care. However, due to the inadequate resources available, the government institutions, are experiencing a shortage of trained manpower and equipment. In addition to the shortage there is an imbalance in the distribution of trained health personnel. Majority of the trained health personnel are working in the urban areas which have 20%of the total population. This imbalance in terms of where health personnel are working could also affect the quality of health care in rural areas. The private sector on the other hand, which is made up of individual private practitioners, NGOs and mission hospitals has the capacity to provide comprehensive health services but this is often very expensive and can only be utilised by relatively few high-income groups.

The bed occupancy by PLWA in various stages of the disease has increased tremendously (Baltazar et al; 1999). At the same time government expenditure on health care has reduced dramatically when the funds are needed most. The consequence is overcrowding in the hospitals, drug shortages and dissatisfaction with health care. In addition the trained personnel are leaving government service to provide health services in the private sector, while others are leaving the country to work elsewhere, where the terms of services are better.

All these factors affect provision of good care to the clients. However, utilisation of health services is said to be a function of their availability, accessibility and acceptability. Acceptability of services in Kenya is related to factors such as quality of care in relation to amount of money spent, time and the results achieved (Mwabu, 1986). All these factors influence the choice of place where care is sought.
The common referral system in Kenya is as shown in the diagram in the following page. (Ngugi et al 1995). However, the referral system is similarly related to other factors such as affordability, accessibility and availability. For instance a PLWA may seek health services from private sector clinics in the initial stages, but when the funds are depleted will seek treatment in government hospitals where the costs are minimal.

Diagram I: Common referrals within the health system in and out of Nairobi



Ref: Ngugi et al, 1995

1.3 Home-Based Care Services in Kenya

In many developing countries care of HIV/AIDS patients is inadequate. In Kenya the public health system has already reached full capacity with many hospitals overcrowded and beds frequently shared. Because the MOH budget has not kept pace with population growth or renovation needs, the capacity of the health system is already strained. Home-based care (HBC) for PLWA has been identified as an alternative strategy for providing health care especially in resource poor countries like Kenya (WHO, 1997).

Unfortunately, very few African countries such as Zimbabwe and Zambia have experimented on non-hospitalised strategies. In Kenya, for example the government has recognised the need for home-based care in its district-level strategy for curbing the impact of HIV/AIDS, but to date, no significant efforts have been made to implement it country wide. As a result, Kenya lacks a formalised system of home-based care to cope with AIDS.

HBC provided in Kenya relies on the family members and the community. Most Home-based care programmes in Nairobi have been implemented by NGOs in collaboration with Ministry of Health. Others by community-based organisations (CBO). Most of them are implemented in the slum areas where the prevalence of the HIV/AIDS is high and population is economically disadvantaged. In 1999 a patient support center (PSC) was established in Mbagathi District Hospital in an attempt to encourage family members to participate and acquire skills in providing care to PLWA. This was expected to culminate in reduced overcrowding that was being experienced at the district hospital. The PSC tasks included;

Pre and post-test counselling of PLWA, training of FCGs before discharge of their patients, counselling of FCGs to reduce stigma and fear of taking care of PLWA, follow-up of PLWA at home where there are no established HBC programmes and collaborating with various HBC programmes for follow-up of PLWA.

The readiness of family members to give care to patients with AIDS at home is important. Thus it is important for the care to be provided in a non-stigmatising way, affordable and acceptable to the needs of the patients. It is also important for the carers to be provided with necessary knowledge and skills through health education and formal training.

Home-based care provides guidance to patients and their families on palliative care. Studies have shown that if families were taught basic nursing care skills, personal hygiene, pain control and maintenance of hydration and nutrition, families with the help of CHWs would improve the quality of life of the sick and people with AIDS even without access to the modern medicine (Gill; 1998) and (Berhane; 1995).

The main objectives of HBC programmes are;

To provide good holistic care within the home environment over an extended period, to facilitate and enhance family involvement in the support and care for their patients, to increase AIDS awareness within the family and community, educate them on prevention and to alleviate pressures on hospital beds and reduce the cost of patients care.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

AIDS is a social, behavioural as well as a medical problem. According to official data, majority of the people in Kenya have heard of AIDS. Knowledge of AIDS and the key transmission mechanism is widespread (90-95%) among the population and almost everyone knows that the disease is transmitted through sexual intercourse (Ministry of Health, 1997).

As the problem of AIDS affects more and more countries and greater number of people, provision of information, education and communication has become a major weapon against the disease. High-risk sexual behaviour with frequent STD's places persons at greater risk of acquiring HIV/AIDS. Many people perceive HIV as a very dangerous, infectious and incurable disease. This perception has many social consequences of stigmatisation and social isolation of HIV patients and their families. Due to fear, patients often deny diagnosis and reject medical treatment. As a result there is need for a concerted health education campaign to convince the general population that HIV is preventable and all health care providers should act as destigmatizers.

Since people have awareness and knowledge about the disease, the trends of those infected indicate that these two factors are not sufficient to modify their behaviour. Other factors in our society which prevent the process of awareness and knowledge to be translated into sustained behaviour changes need to be explored. For instance poverty, cultural/religious beliefs and un-supportive government structures. In general, the health education goal is to ensure that morbidity and mortality trends in the population is/are reduced through disseminating relevant information for promoting health, prevention of diseases and seeking prompt treatment for illness as well as rehabilitation of disabilities.

Thus the strategy of health education in this case would be, to improve the health environment for AIDS patients, their families, neighbours and eventually the whole community.

According to Kleinman. A health system includes patterns of belief about the causes of illness, norms governing choice and evaluation of treatment, socially legitimated statuses, roles, power relationships, interrelation settings and institutions'.

Medical pluralism increases the range of therapeutic choices and thus complicates health-seeking behaviour. Views of HIVAIDS at community level varies among different societies and it is viewed as a curse, consequence of wrongdoing and associated with witchcraft among others. PLWA are highly stigmatised and have been neglected particularly early in the epidemic and even health workers have shown reluctance to care for them.(Alonzo et al, 1995).

The risk of becoming infected with HIV is a major concern to everybody especially those taking care of PLWA. Although the risk is very low for caretakers, fear of infection persists. The need for love and acceptance from care-givers is deemed necessary in their endevour to serve PLWA. The patients may despair because of the absence of a cure, be anxious about partners and family or feel grief and fear of death.

Studies have shown that institutional based care is costly (Republic of Kenya, 1994). Kenya National AIDS & STD control programme in 1996 estimated that maintaining an AIDS patient in the hospital during the course of illness would be approximately Kshs.600, 000 per person per year (Republic of Kenya, 1994). Studies on HBC on the other hand indicate that home care is less expensive for families but the home based programmes have experienced a lot of difficulties due to various factors such as poor social economic status (SES) among families, inadequate knowledge about the HIV infection, negative attitudes of the care-givers, lack of drugs and/or protective equipment and fear of occupational exposure. A study done in Kiambu revealed that training in the care of AIDS patients is crucial yet lacking at the family and community level (Olenja, 1999).

2.2 Care for PLWA by Health Care Workers.

Carer-givers need practical and emotional support because if they themselves are tired or distressed, they cannot give sick people the care they need. Counselling can help care-givers to deal with the fears, feeling of isolation, helplessness, depression and/or anxiety during the person's illness and after their death.

Carer-givers need information and training about;

How HIV is and is not spread to reduce fears about looking after someone with HIV/AIDS and to reduce the risk of transmission, symptoms control such as pain, how to care for sick person's physical, emotional and spiritual needs and care of someone who is dying.

Health care workers are concerned from being stigmatised as a result of caring for PLWA (Alonzo et al, 1995). A study that was done comparing nursing students in the U.S.A and Zimbabwe indicated that 30% of U.S.A participants were worried that people would think that they were homosexuals if they got HIV/AIDS, whereas 74% of Zimbabwean participants were worried that people would think that they were prostitutes (Alonzo et al, 1995). These findings underlines the significance of shared cultural understanding of HIV/AIDS in different environments/communities and the importance of challenging specific local fears in educational interventions.

Another study done in KNH on hospital-based management of HIV/AIDS found that routine care of HIV/AIDS patients was complicated by unavailability of facilities, the lack of understanding and acceptance of the problem and also the negative attitude of health care providers (Bhatt, 1993).

2.2.1 Health Care Workers Knowledge

Health care workers knowledge of HIV/AIDS care is variable and may be inadequate in some areas and insufficient for them to be able to adequately counsel and care for PLWA. Continuous health education has been found useful to fill the gaps in knowledge and correct the inaccurate information from media which is a major source of information for the lower cadres health worker. (McCann et al, 1998). Health care workers fears may be resolved through constant dissemination of up-to-date knowledge of transmission and ensuring that equipment's/instruments are readily available to allow staff take necessary precautions. HWs are expected to in turn educate the community members accordingly.

Knowledge and attitudes affect the practice of health workers. For instance in 1986, the American Nurse's Association released the results of a survey of state nurses associations: 14 states reported instances in which registered nurses refused to care for AIDS patients and in other 9 states employees were permitted to request reassignment to avoid caring for persons with AIDS (Gill et al, 1998).
They feared being isolated by friends and family members.

2.2.2. Health Care Workers Attitudes

Negative attitudes to AIDS patients and to groups of people among which AIDS is particularly prevalent such as prostitutes may be a barrier to care. It's important to recognise that carers attitude and beliefs have developed in the context of their social experience both in their immediate relationship and the wide culture, that is care-givers attitudes and beliefs should be considered in the context of socio-cultural beliefs and not just at the level of the individual (Humbley, 1995). Fear of occupational exposure may affect the practices of health care workers.

A KAP study on doctors and clinical officers in respect to HIV/AIDS in Nakuru District in Kenya found out that they had a high level of awareness on transmission and clinical presentation (Kariuki et al, 1993). However, there were fears of contracting HIV infection while managing patients among some of the doctors and clinical officers.

2.2.3 Practices of Health Care Workers in AIDS Care

In view of fears and reluctance to care for PLWA among health care workers and the community at large, it is necessary to investigate the care that PLWA and HIV positive people receive. Some studies suggest that care of PLWA may be of a poorer standard than that given to patients with other illness. In hospitals, patients with AIDS receive inferior care compared to patients with other illnesses (Horsman et al, 1995).

There are potential difficulties in providing optimal care for PLWA due to lack of knowledge of some aspects of HIV/AIDS-related illnesses, negative attitudes towards PLWA, persistent fear of acquiring HIV infection while taking care of the patient and reluctance to treat PLWA. The other major obstacle encountered by PLWA and their families is the problem of obtaining treatment and drugs due to poverty, especially in developing countries (Baltazar et al, 1999). PLWA may also be unwilling to go to health clinics because they are frightened to reveal their HIV status and/or may not realise that their illness can be treated.

Considering the increasing number of people living with AIDS, it is apparent that existing hospitals cannot cope with all patients. However, effective community based programmes have been shown to increase people's understanding of HIV/AIDS and to reduce the stigma (Flaskerid et al, 1989). For PLWA staying at home implies continuing to live a normal life as possible without being separated from their families. This makes the concept of home-based care a viable alternative to care for PLWA. Indeed the care of PLWA may be a source of stress among health care workers and family members. Consequently it is important to identify factors which increase the stress and attempt to identify ways of minimising stress in family both from the point of view of family well-being and quality of care delivery. Provision of comfort and support in alleviation of suffering are the main satisfaction in caring for PLWA (Baltazar et al, 1999).

2.3 Care for PLWA at Home

Studies have shown that home-based care and community-based care for AIDS patients results in lower expenditures (Anderson et al, 1997 and Hansen et al, 1998). With increasing number of people infected with HIV, home-based care has become an important, attractive and cost-effective alternative to communities for the care of PLWA.

A study done in Jamaica 1997 revealed that training of lay persons and CHWs to assist with home-based care of PLWA achieved the required standards of attendance and proficiency and most patients preferred to be managed at home (Bain, 1998). However, certificates were valid for two years and refresher courses were recommended by this study.

The urgent needs to establish HBC programmes in Kenya arose from the following reasons;

> a drastic increase in chronically ill patients with HIV/AIDS related illnesses, to ease congestion at the limited health facilities to accommodate other medical needs and to provide comprehensive personalised care at home.

HIV/AIDS is a stigmatised disease among many communities and those infected requires empathy from the care-givers. Stigma is a social constriction, which dramatically affects the life experiences of the individuals infected with HIV. Although stigma associated with HIV/AIDS is overpowering, individuals with this illness do not necessarily experience the same degree of stigma. Stigma experience can be explained to a large extent by variations. Some population groups are more likely to be regarded by the society as innocent victims of HIV/AIDS, for instance recipients of blood transfusion, infants of HIV positive mothers and thus treated less harshly (NASCOP, 1996).

At the community level, provision of home-based care is primarily given by family members, friends and neighbours with or without the help of CHWs. The patients face many social and economic problems and since females and children are usually economically dependent on their husbands/parents they need their co-operation to get treatment.

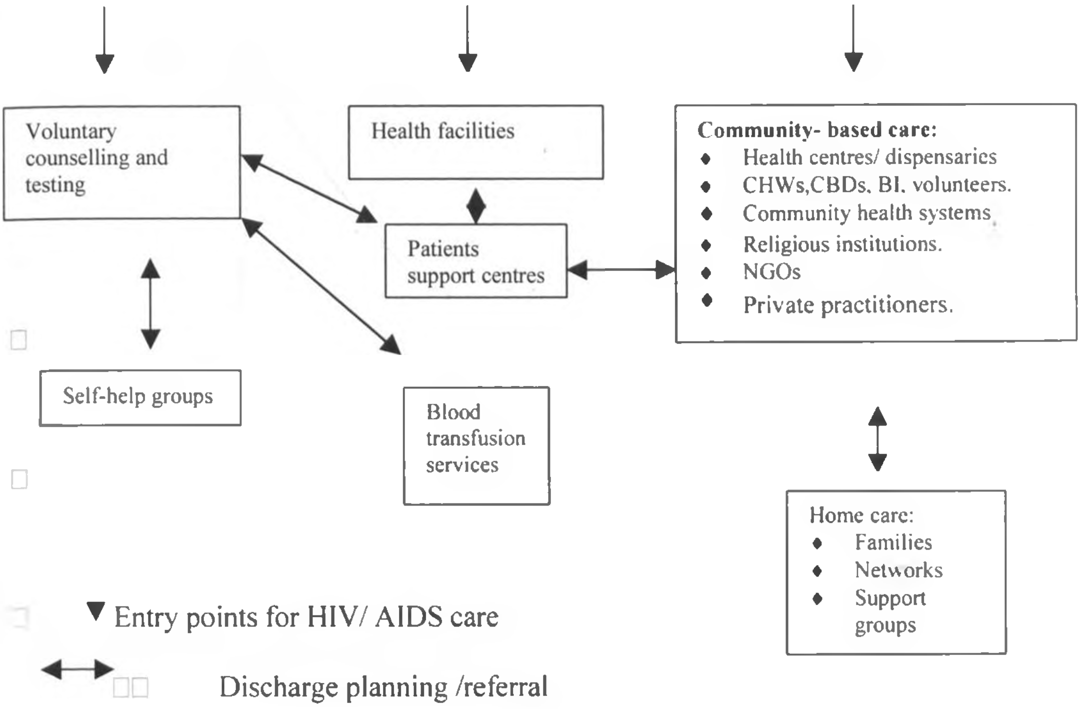
Community Health Workers form the first level of contact between health care system and community members. They emphasise on simple low cost activities such as first aid, treatment of common illnesses e.g. oral rehydration for diarrhoea diseases, fansidar for malaria, distribution of contraceptives, nutrition and environmental improvement. They have formal education and are trained by DHMT's or NGOs. Community Health Workers are volunteers or receive community compensation in return for the services rendered. The role of CHW in HBC programme is to provide both preventive and basic curative care to PLWA in the community in conjunction with family members (Gill et al, 1998).

The CHW's are trained by DHMT's or NGO's to teach family members the principles of hygiene for protection against HIV transmission at home. In terms of their roles as health care workers they are expected to teach family members about caring for PLWA, so that fears due to inadequate knowledge about the disease transmission and attitudes based on socio-cultural understanding could be minimised. (Kaimenyi et al 1994). It is therefore important for both the community and health care workers to come to terms with the epidemic and treat AIDS patients in a non-stigmatising way. A person with AIDS needs both psychological support and physical care.

While home based-care is being promoted by some policy makers, the existing health care systems in Kenya lacks the resources to provide training and follow -up of the thousands of families trying to care for their ill family members at home (Baltazar et al, 1999).

The link between HBC and hospital-based care in Kenya is as shown in diagram 2 next page (Ngugi et al, 1995). The diagnosis is usually made at the health facilities or at voluntary counselling centres. After diagnosis, the patients are discharged or referred to various places. The discharge and or referral are governed by various factors. The factors include, affordability, availability, accessibility and acceptability of health services offered.

Diagram 2: Continuum of HIV/AIDS care in Kenya.



(Ref: Ngugi et al, 1995)

3. CHAPTER 3: THE RESEARCH PROBLEM

3.1 Problem Statement

Between 1993 and 1998 when Kenya held two National AIDS Conferences, the number of persons reported to be infected with HIV had doubled from 725,000 to 1.4million with the number of infected children trebling from 30,000 to 90,000 (Baltazar, et al 1998). The knowledge levels was 80% of general population who had heard of AIDS and knew how it's transmitted. It was estimated that by June 2000 over 2.2 million Kenyans were living with HIV/AIDS (Baltazar, et al 1999).

With 700 deaths and 500 new infections occurring daily due to HIV/AIDS, Kenya faces the biggest catastrophe ever in its history. Already the killer scourge has claimed the lives of more than 2.5 million people while currently an estimated 2.2 million others have been infected by the deadly virus (Daily Nation 1st December 2001). Considering the increasing number of people living with AIDS its apparent the existing hospitals cannot cope with all these patients.

Palliative care for someone who is terminally ill is related to medical, Psycho-social and emotional support, and the quality of care given will depend on whether those taking care of the patient are in a position to provide all these. Medically, the main requirement is availability and accessibility of affordable medical care. Psycho-social support requires understanding and empathy to cope with the disease. It also involves support of the patients and family members to meet their basic needs, for instance nutrition to maintain good health.

It is against this background the study was carried out to establish the extent to which the care-givers are able to provide the necessary care and evaluate what factors enhance and/or hinder the provision of quality care to PLWA.

Research Questions

1. Are the caregivers adequately trained to care for PLWA?
2. Are the caregivers able to recognise and make appropriate preliminary diagnosis of opportunistic infections at community level?
3. Are there necessary protective equipments at community and institutional levels?
4. What is the patient's assessment and views on the care they receive?
5. What strategy of care can improve the services that PLWA receive?

3.2 Justification

The health institutions are already heavily overburdened by an increasing demand for curative services. Currently, reports indicate that patients with HIV/AIDS occupy more than half of health institutions' beds. Based on this fact, home-based care programmes were introduced as one strategy to decrease the pressure on hospitals, while improving support to PLWA and their families. Most programmes were started with donor support although some were implemented in the hospital with local resources.

Given the varying environments within which the PLWA received care, their views about care provided were sought.

The study also evaluated the experience, successes and difficulties reported by care-givers, and it is hoped that the findings will be useful in improvement of care needs for PLWA.

Based on evaluation of care needs the findings will facilitate the establishment of a strategy for continuum of care for PLWA at various levels to attempt to achieve equity of health care and to improve quality of care to PLWA.

3.3 Objectives

3.3.1 General Objectives

To evaluate the quality of care given to patients with AIDS at home and at health institutions in order to facilitate understanding of care needs as well as making contribution towards design of a more appropriate continuum of care.

3.3.2 Specific Objectives

1. To determine the socio-demographic characteristics of PLWA and the caregivers and establish how these characteristics influence the quality of care provided to PLWA.
2. To assess the knowledge, attitudes and practices of both community and institutional care-givers regarding care of people living with AIDS and establish how they influence provision of care.
3. To assess the main constraints experienced in providing care for people living with AIDS.
4. To determine the views of PLWA regarding the care they receive and determine the preference of home care versus institution care and reasons for the preference.

3.4 Hypotheses

1. Quality of care given to PLWA is not influenced by:
    - Level of education of caregivers.
    - Place where the care is provided (home or hospital)
    - Previous training of family care-givers

2. Previous training to caregivers equip them with skills to offer quality care to PLWA.

- socio-economic status

3. The SES of people living with AIDS (and the caregivers) influence the quality of care provided.

Measurements of SES

1. Education:
    - Primary/none
    - Secondary
    - Middle college/University

2. Occupation:
    - Employed on permanent basis
    - Self employed/casuals
    - None

3. Living quarters:

    - Permanent house (stone/brick houses)
    - Semi permanent house (timber & iron sheet houses)
    - Temporary house (mud & carton houses)

High SES – Middle/college/University education, employed permanently and living in permanent house.

Middle SES – Secondary education self employed/casual labourers and living in semi permanent house.

Low SES – Primary or no education at all, no source of income and living in temporary house.

CHAPTER 4: METHODOLOGY

4.1 Study Design:

This was a cross-sectional descriptive study using both quantitative and qualitative methods of data collection to evaluate the care given to PLWA at home and at hospital. The provision of care was determined in relation to SES and KAP of care-givers. Factors affecting provision of quality care to PLWA were also sought.

PLWA views about the care they received were also determined.

4.2 Study Area:

The study was conducted in the city of Nairobi; which is also the main commercial and Industrial centre of Kenya. Nairobi province extends over an area of approximately 690 square kilometres with an estimated population of 2143, 253 according to the 1999 population and housing census results. Administratively, Nairobi province is divided into nine divisions namely; Dagoretti, Embakasi, Industrial area, Kahawa, Kasarani, Langata, Makadara, Pumwani and Westlands. All these divisions have informal settlements or slum areas. The study centre was Mbagathi District Hospital where PLWA from various health centres within Nairobi are referred. PLWA cared for at home were from the informal settlements (slums). For the purposes of this study, the informal settlements were grouped according to the nine divisions based on the familiar names of the slums. Sub-divisions (areas/ villages) in these slums were covered, specifically those which have active collaboration between various NGOs and MOH on home-based care of PLWA.

Those areas which were covered included, Kibera, Korogocho, Dandora and Mugumoini.

These areas had existing HBC projects and were recognised by Mbagathi district hospital and patients were discharged under the respective HBC projects. Proportion of the total population in the informal settlements is 55% of total population in Nairobi, while densities range from 23,000 – 82,000 persons per square kilometre. The population in these settlements is heterogeneous in all aspects including ethnicity and religion. The predominant religion of slum dwellers consists of Christianity and Islam. The majority of the residents in the informal settlements are of low socio-economic status. The majority are migrants from the rural areas but a few were born in Nairobi. Most of the slum residents work as semi-skilled or unskilled labourers, often on temporary basis, but there is also a large group of slum residents engaged in small scale enterprises for self-employment.

4.3 Study Population:

The study population comprised three groups:

1. **People Living with AIDS (PLWA)**

   Only those clients who were counselled and informed about their status were selected. They were interviewed at the hospital or at home while under certain home based care programme.

2. **Family Care Givers (FCGs)**

   FCGs were identified through various NGOs providing or implementing HBC programmes and were known to the group leaders.

3. **Health Care Workers (HCWs)**

   They were drawn from Mbagathi district hospital and various health centres within Nairobi selected by a stratified random sampling procedure. They were providing nursing care to PLWAs either on in-patient or out-patient basis.

4.3.1 The Inclusion Criteria

1. PLWA were included if they had been informed about their diagnosis by a health worker.
2. Family members were included as FCG if
   - (a) One was aware and had been informed that the patient, being cared for is infected with HIV/AIDS with proven diagnosis in the health facility.
   - (b) One had been caring for the patient personally for the last 3 or more months. This ensured a good recall of the events in relation to the care of the patients.
3. Nurses were included if they were providing in-patient/out-patient care and had participated in provision of care to AIDS patients for more than 3 months in their respective places.

4.3.2 Exclusion Criteria

The following criteria were used to exclude study subjects.

1. Newly qualified nurses were excluded (< 3 months working experience).
2. FCGs were excluded if they were not aware of the diagnosis of the patient they were caring for.
3. PLWA-Based on WHO (World Health Organisation) classification those in stage 1 and 2 were excluded (Gilks et al, 1998).

WHO staging system clinical stage	**Patient performance scale**	**Disease level for care and support needs**
1 Asymptomatic	Normal activity (Asymptomatic)	None
2 Mild disease	Normal Activity (mild symptoms) eg. Weight loss, minor skin or oral problems, recurrent sinusitis herpes zoster etc	Standard care
3 Moderate disease	Bedridden <50% of time (symptomatic) eg. Chronic diarrhoes, weight loss unexplained fevers	Many patients need hospital admissions several visits to health facilities and private physicians for follow up.
4 Severe disease	Bedridden >50% of time symptomatic with profound immuno suppression characterised by multi diseases and clinical problems due to optimistic infections	Terminal care

4.5 Sampling

4.5.1 Sampling unit

The sampling unit was the PLWA diagnosed to be infected with HIV and were either being cared for at home or hospital at the time of interview.

4.5.2 Sample Selection Procedure

The study centre was Mbagathi District Hospital (MDH) which is the only district hospital in Nairobi province. The study sites at the informal settlements was on the basis of information from patient support centre (PSC) at Mbagathi district hospital. Based on this information PLWA and FCGs under different HBC programmes were interviewed using structured questionnaires. No sampling of PLWA and FCGs was done due to the following reasons; during the pre-test it was found out that some clients were unable to answer the questions because they were too sick, some clients complained that they are always interviewed but never assisted in any way and most FCGs were busy with other chores during the day. Therefore most of PLWA and FCGs were included on their willingness and consent to participate.

Therefore the research assistants visited the clients on a door-to-door basis and administered the questionnaire if the PLWA and FCGs consented and fulfilled the inclusion criteria. For health workers, the sample size was drawn from MDH and several health centres within Nairobi, selected randomly.

For FGDs, PLWA and FCGs were selected randomly on the days they usually have their weekly meetings at specific points and those who had not been interviewed using questionnaires. For health workers who participated in FGDs, they were randomly selected from those who were on leave or off duty during the administration of questionnaires and therefore had not filled them.

4.5.3 Sample Size

Over 87,000 cases of AIDS have been reported to the MOH since the first case was described in Kenya in 1984 through June 1999. Reported AIDS cases represent only the visible part of the epidemic. However, there is much more to the epidemic than the number of reported cases. Not all AIDS cases are reported. This happens for several reasons, some people with HIV/AIDS never seek hospital care, some doctors may not want to record a diagnosis of AIDS because of the stigma attached to AIDS, especially for insurance purposes, some people with HIV infection may die of other diseases before they ever manifest with features of having AIDS and some rural health care facilities may not have capability to test for HIV infection so diagnosis may be missed.

The true number of AIDS cases in Kenya is not known. However it is estimated that over 700,000 adults and children had developed AIDS by the end of 1998. In urban areas prevalence of HIV is estimated to be 17-18%. HIV prevalence in rural areas is between 12-13%. Although prevalence is higher in urban areas, the absolute or total number of people infected is larger in rural areas since 80% of the population lives in rural areas (NASCOP 1999).

During the year 1999, there were 3654 total admission of adult patients aged 15-49 years at Mbagathi District Hospital. From the records obtained at the hospital among these patients, 238 had chronic diarrhoea, 19 had kaposis sarcoma, 57 had meningitis, 21 had pneumocystis carinii pneumonia, 519 had pulmonary tuberculosis (PTB) and 184 had immunosuppression syndrome.

Assuming that 25% of PTB patients have AIDS and all the others in this group have AIDS it means approximately 908 patients had AIDS which converts to approximately 25% of all the admissions. Studies done have shown that PLWAs are willing to be cared for at home but proportion of those willing to be cared for at home have not been established (Mwabu, 1986 and Humbley, 1995). On the other hand a study done in Kiambu revealed that PLWA families preferred hospital care. They felt there was better care and qualified personnel as HIV/AIDS is a disease that is so demanding in care that unskilled people with little resources find it difficult to cope with the condition (Olenja, 1999).

According to NASCOP, PLWA currently occupy more than half of the health institutions beds (Baltazar et al, 1999).

For the purpose of this study it was assumed that 50% of the PLWA will prefer home based care and 50% hospital care.

Calculation of the required minimal sample size for PLWA was based on the formula

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

Where P = 0.5 (Assumed that 50% of PLWA prefer home base care)

Z = 1.96 (percent point of the normal distribution to the significant level = 0.05)

D =0.05 (maximum standard error at 95% level of confidence)

n=384

Substituting for the equation, the sample size was 384

Half of this i.e 192 were PLWA managed by health care workers in hospital and 192 managed by family caregivers at home. For each patient one health worker or family care-giver were interviewed.

4.6 Variables

The variables considered in evaluation of the objectives and testing the hypotheses are discussed below.

4.6.1 Independent Variables

A. Socio-demographic characteristic of PLWA and care-givers

1. Age
2. Sex
3. Religion
4. Occupation
5. Educational background
6. Marital status
7. Socio-economic status

B. AIDS - Related Knowledge of care-givers.

1. Knowledge of the modes of spreads of HIV/AIDS
2. Previous contact with PLWA
3. Modes of prevention of HIV/AIDS

C. Prior training of family caregivers on home care before discharge of patients.

4.6.2 Dependent Variables

1. Ability and/or willingness to provide care to PLWA
2. Perceived personal risk of getting HIV/AIDS while caring for PLWA
3. Attitudes towards care of PLWA at home versus hospital care

4.7 Data Collection (methods and tools)

The instruments of data collection for the quantitative data were structured questionnaires, which were administered to health workers, family caregivers and PLWA consenting into the study. Qualitative data was collected through focus group discussions using a prepared guide (Appendices).

4.7.1 Questionnaires

Structured questionnaires were administered to determine :

1. Socio-demographic characteristics of the carers and their general knowledge on HIV/AIDS care. This included pertinent questions on cause, mode of spread, risk of becoming infected while providing care and prevention.
2. Attitudes of care-givers towards care of PLWA

   The questions included whether the carers are comfortable taking care of PLWA, and reasons for not wanting to participate in provision of care and/or difficulties they encounter.
3. Practice of care-givers while providing care to PLWA

   The main questions included carer's experience and time spent caring for PLWA

4.7.2 Focus Group Discussion

A prepared guideline for FGDs was used to determine carer's perceptions and attitudes towards care of PLWA. FGD is a research method used to obtain in-depth qualitative information on concepts and perceptions of a study group. Discussions are based on the study objectives. Participants are encouraged to discuss the subject freely in an informal manner. The ideal number of participants is between 8 - 12 to ensure that all of them participate. In this study the FGDs information was used to clarify and supplement information gathered quantitatively.

4.8 Data Management and Analysis

The data was edited before analysis. Descriptive and statistical analysis were carried out in relation to the study objectives and hypothesis.

4.8.1 Quantitative Data

The data collected using the questionnaires was validated and analysed by computer using statistical package for the social science (SPSS) programme. For family care givers (FCGs) an index on knowledge on getting AIDS and on prevention was computed by giving a score of 1 to each correct response, summing up the scores and categorising them. The same was done for health workers on knowledge about HIV/ADS. To test for differences between PLWA managed at home and those in hospital, chi-square or Fisher's exact test where applicable was used for categorical variables. Mann-Whitney U test was used for continuous and discrete variables. A 5% level of significance was used. This helped to determine the relationships between various variables and presentations made in form of frequency tables, pie charts or graphs.

4.8.2 Qualitative Data

The qualitative data was analysed manually. The information collected through FGDs was first transcribed before being synthesised and categorised into relevant themes of study objectives.

4.9 Ethical Considerations

A number of ethical considerations were taken into account.

1. Confidentiality of participants was kept at all levels of activities to avoid any social disruption and discrimination at place of work and at community level.
2. Minor ailments of PLWA visited were treated. Otherwise those found to have more serious medical problems which could not be treated at home were referred to the nearest health centre for management.

CHAPTER FIVE

5.0 RESULTS

A total of 384 PLWA were interviewed comprising of 192 PLWA cared for at homes and 192 PLWA cared for in hospitals at the time of the interview. The care-givers were 384, of which, 192 were health workers and 192 were family care-givers.

5.1 Health workers

5.1.1 Socio-demographic characteristics

Out of 192 health workers interviewed, 47 (24.5%) were males and 145 (75.5%) were females. Those from Mbagathi District Hospital were 72 (37.5%) and 145 (75.5%) were from health centres. The health workers interviewed were composed of Kenya Registered Nurses 48 (25%), Enrolled community nurses 114 (59.4%), Public health nurses 10 (52%), Community health workers 13 (6.8%), and 7 (3.6%) of the health workers did not specify their training background, out of these seven, one stated that she was a nutritionist and two said they were midwives). At the time of the interview, 110 (57.3%) were working in out-patient departments, 54 (28.1%) in in-patient department and 28 (14.6%) in counseling unit. Their working experience in their fields of specialization ranged from 1 to 14 years with a mean of 7.5 (SD = 3.2) and a median of 7.5 years.

5.1.2 Health Workers Knowledge Classification

A knowledge index was computed from the scores given to correct responses on recognition of relationship between having STD and HIV/AIDS, difference between HIV infection AIDS and various ways a person can get HIV/AIDS.

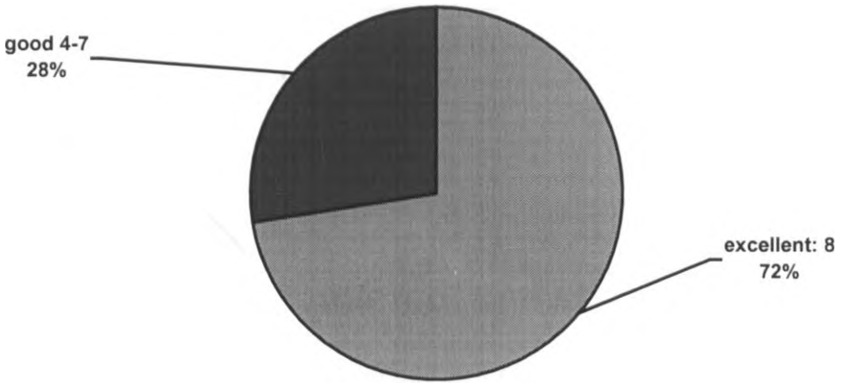
The maximum expected score was 8 and the index was graded as excellent score of 8, good knowledge score of 4-7 and poor knowledge score of 0-3 as shown below.

The knowledge of health workers was categorized using the above criteria and 139 (72%) of the health workers had excellent knowledge as shown in the Figure 1 below.

Table 1: Health Workers Knowledge Index

n=192	**Correct**	**Some idea**	**No idea**
Difference between HIV & AIDS	2 points	1 point	0 point
	(167)	(15)	(10)
n=192	**Yes**	**No**	**No idea**
Any relationship between having STD & HIV/AIDS	2 points	1 point	0 point
	(184)	(8)	(0)
n=192	**3 correct responses**	**2 correct responses**	**1 correct responses**
Various ways a person can get HIV/AIDS	3 points	2 points	1 point
	(182)	(8)	(2)
How can you tell someone has HIV/AIDS n=192	**Correct response**	**Wrong response**	**No response**
	1 point	0 point	0 point
	(168)	(18)	(6)

Fig 1: Distribution of knowledge score



5.1.3 Perceived Personal Risk of Getting HIV/AIDS while caring for PLWA.

On occupational hazards, 30 (15.6%) thought there were high chances that they might get AIDS while caring for PLWA while only 6 (3.1%) thought there were no chances as shown in table 2 in the following page.

Table 2: Distribution of perceived chances of getting HIV/AIDS while caring for PLWA

Perceived chances	**Frequency**	**%**
High	30	15.6
Some	58	30.2
Low	98	51.0
None	6	3.1
Total	**192**	**100**

The possibility of getting AIDS while caring for PLWA was cited by 129 (67.2%) health workers as their concern. They indicated that they were likely to get HIV/AIDS through coughs (34.6%), accidental pricks (60.8%), handling of patients (3.1%) and handling of dead bodies (1.5%). To reduce chances of getting AIDS while caring for PLWA all health workers said they used available protective equipment and took extra care while handling them.

5.1.4 Practices towards people living with AIDS

With regards to the practices of health workers towards PLWA, 112 (58.3%) of the health workers perceived they were in a position to provide good care to PLWA because; they were trained 56 (50%), have been doing it for sometime and were confident 52 (46.4%). A small proportion 4 (3.6%) had other reasons which included feeling that provision of care was part of nursing and all patients required similar services from nurses. The kinds of care given to PLWA are as shown in table 3 below.

Table 3: Type of care given to PLWA by health workers (n=192)

Care	Frequency	%
General nursing	160	83.3
Feeding	88	45.8
Counselling	104	54.2
Directly observed treatment	104	54.2

NB: Some patients had received more than one type of care and therefore, the percentages exceeded 100%.

Among those interviewed, (38.3%) felt they had enough knowledge to take care of PLWA, 83% said they would like to know more about care of PLWA, while (89.4%) felt there is need for continuous medical education in order to improve the attitude/practice about the care of PLWA.

5.1.5 Constraints encountered by health workers while providing care to PLWA.

The health workers cited various factors which impended provision of quality care to PLWA.

Table 4: Constraints encountered by health workers.

Constraints	**Frequency**	**%**
Inadequate protective equipment	140	74.5
Inadequate drugs	136	72.3
Unco-operative relatives	88	46.8
Unco-operative patients	84	44.7
Work overload	128	68.1
Inadequate up-to-date information	108	51.4

NB: Percentage exceeded 100% because more than one response was allowed.

Among the constraints encountered by the health workers were inadequate drugs and/or protective equipment which accounted for more than 70% and work overload constituted 68.1%

To improve care for PLWA, the health workers (n=188) indicated the following suggestions.

Table 5: Suggested modification to the constraints encountered by the health workers

Modification	Frequency	%
Refresher courses	164	87.2
Rotational duty allocation	64	34.0
Availability of necessary drugs	140	74.5
Reduce workload by increasing number of nursing staff	116	61.7
Improve availability of protective equipment	168	89.4

NB: There were multiple responses and therefore the percentage exceeded 100%. A total of 160 (83.3%) of the health workers cited home as the best place to give care to PLWA, 28 (14.6%) mentioned hospital and 4 (21%) indicated both. The reasons they gave in favour of home care were regular meals, company of the family, cheap and affordable, overcrowding in hospital, limiting hospital acquired infection, good nursing care was possible because a relative was involved in the care, home care was less stressful because one was able to see the family members and make decisions on family issues.

5.2 Family Care Givers (FCG's)

A total of 192 FCG's were interviewed. Majority 174 (90.6%) were trained and had no problems with their roles and were willing to provide care.

5.2.1 Socio-demographic characteristics

Most of FCG's (72.9%) were females and (27.1%) males. The age distribution and education level was as shown in tables 6 and 7 below:

Table 6: Age group distribution of FCGs

Age group in years	Frequency	%
<20	46	20.8
20-29	106	55.2
30-39	36	18.8
>40	10	5.2
Total	**192**	**100**

Table 7: FCGs level of education

Level of education	Frequency	%
None	12	6.3
Primary	103	53.6
Secondary	44	22.9
College (middle college)	27	14.1
University	6	3.1
Total	**192**	**100**

Slightly over half 103 (53.6%) had primary education, 12 (6.3%) had no education and the rest 40.1% had secondary education and above.

With respect to religious affiliations, it was found out that protestants were the majority 107 (56.3%) followed by Catholics 75 (39.1%), Muslims 5 (2.6%) and other denominations 3 (1.6%). Two FCGs did not state their religious affiliations.
Only 34 (17.7%) of the FCGs were married while 75 (39.1%) were unmarried, 66 (34.4%) were separated, 9 (4.7%) were divorced and 8 (4.2%) were widowed. The combined proportion of FCGs who were single for one reason or another i.e unmarried/separated/divorced or widowed accounted for 82.3% of the total population of FCG's. This is reflected in the relationship of FCGs to PLWA where by 123 (64.1%) of FCGs were caring for their brothers/sisters or daughter/sons.

The relationship of FCGs to PLWA is as shown in table 8 below.

Table 8: The relationship of FCGs to index PLWA

Relationship	**Frequency**	**%**
Parent	30	15.6
Spouse	18	9.4
Friend	19	9.9
Brother/sister	81	42.2
Daughter/son	42	21.9
Grandchild	1	0.5
Others	1	0.5
Total	**192**	**100**

90% of PLWA had a member of the family unit involved in the care, implying the family unit plays an important role in HIV/AIDS care at home. Involvement of friends and others e.g employers, NGOs and Church Organizations is an option to research on as alternative source of care.

Only 56 (29.2%) of the FCGs stayed in their own houses. The rest stayed in rented houses where they paid, monthly rent ranging from Kshs 100 to Kshs 2,000 with a median of Kshs 500. The type of housing and number of rooms is shown in table 9 in the following page.

Table 9: Type of living quarters of FCGs and number of rooms.

Type of quarters	One room		Two rooms		Three rooms		Total	
	N	%	N	%	N	%	N	%
Permanent	13	6.8	10	5.2	1	0.5	24	12.5
Semi-permanent	36	18.8	16	8.3	9	4.7	61	31.8
Temporary	75	39	23	12	9	4.7	107	55.7
Total	**124**	**64.6**	**49**	**25.5**	**19**	**9.9**	**192**	**100**

The type of housing betrays the poverty of the majority of the study population with 124 (64.6%) living in one-roomed house of which 107 (55.7%) were temporary structures.

The occupation of the FCGs was mainly self-employment 116 (60.4%) followed by farming 22 (11.5%), students 20 (10.4%), casual labourers 11 (5.7%) and others 19 (9.9%) which included, retirees, orphans and teenagers abandoned by their parents. FCG's with formal employment were only 2 (1%) as shown in table 10 below.

Table 10: Employment status of FCGs

Employment	Frequency	%
Formal employment	2	1
Farmer	22	11.5
Casual labourer	11	5.7
Self employed	116	60.4
Student	20	10.4
None	2	1
Others	19	9.9
Total	**192**	**100**

The high proportion of un-employment can be explained by the fact that more than half of FCG's had primary level of education (53.6%) and therefore it was hard to secure formal employment. Their monthly income ranged from Kshs 800 (USD 10) to Kshs6,000 (USD 75) with a median of Kshs 2,000 (USD 25) for the 26 FCGs who indicated their earnings as shown in table 11 below.

Table 11: Monthly income of FCGs

Earning in Kshs	Frequency	%
800	2	7.7
100	3	11.5
1,200	2	7.7
1,500	3	11.5
1,800	1	3.8
2,000	6	23.1
3,000	3	11.5
3,500	4	15.4
4,000	1	3.8
6,000	1	3.8
Total	**26**	**100**

***NB*: 1US Dollar= Kshs 78-80**

5.2.2 Knowledge of FCGs on HIV/AIDS

Scores were given for each correct answer on knowledge of FCG's towards HIV/AIDS modes of transmission (1 score for each correct answer). A maximum score of 11 was expected and these scores were categorised as excellent knowledge $\geq$10, good 7-9 and fair 1-6. Based on this categorization, 145 (75.5%) of the FCG's had excellent knowledge, 27 (19.3%) had good knowledge and 10 (5.1%) had fair knowledge.

Similar scoring system was done for knowledge of HIV/AIDS prevention where a maximum score of 3 was expected with those who scored 3 being classified as having excellent knowledge, score of 2 good knowledge and score of 1 fair knowledge on HIV/AIDS prevention. Using this scoring system 119 (62%) had excellent knowledge, 64 (33.3%) had good knowledge and 9 (4.7%) fair knowledge of HIV/AIDS prevention.

5.2.3 Distribution of topics of training in PLWA care

A total of 174 (90.6%) FCGs had received training in various disciplines about care of PLWA as shown in table 12 in the following page.

Table 12: Topics of training in PLWA care offered to FCGs

Areas of training	Frequency	%
Nursing care	162	93.1
Nutritional advice	167	95.9
Infection control	174	100
Environmental cleanliness	167	95.9
Others	2	1.1

Despite the fact that majority of FCGs were trained in various disciplines, they still felt that they needed further training to enable them provide the necessary care. Only 4 (2.1%) FCGs felt they knew enough and 190 (99%) indicated they would like to know more about care of PLWA and would also like health workers to visit them and their patients regularly. Refresher courses would improve their knowledge and skills to provide better care to PLWA.

The health workers who made home visits comprised of 120 (62.5%) CHWs, 164 (85.4%) nurses and 4 (2.1%) doctors (there were multiple responses).

The role of these health workers during their home visits included the following activities shown in table 13 below:

Table 13: Activities of health workers during their home visits (n=192)

Activity	Frequency	%
Nutritional advice	189	98.4
Nursing care	162	84.4
Counselling	167	87.0
Treatment advice	172	89.6
Others	26	15.5

NB: There were multiple responses while other activities included organising transport to hospital whenever necessary, spiritual nourishment (prayers) and feeding.

5.2.4 Constraints encountered by FCGs while providing care

The following constraints were cited by FCGs while providing care to PLWA.

Table 14: Constraints encountered by FCGs while providing care to PLWA

Constraint	Frequency	%
Drugs expensive (cannot afford)	56	29.2
Inadequate time to care	38	19.8
Unable to provide the necessary care due to poverty	180	93.8
Inadequate knowledge of care needs	45	23.4
Lack of follow up by health workers to give guidance	45	23.4
Fear of getting HIV/AIDS while caring for patients.	39	20.3

Other constraints reported included lack of protective equipments like gloves, antiseptics, dressing materials and inadequate support from close relatives because they feared touching or sharing with the patients.

Among the FCGs interviewed, 178 (92.7%) indicated home as the best place to give care to PLWA due to privacy, availability of time, accessibility, affordability, ability to do other work, shared responsibility, and good care. However, they mentioned that severe and complicated cases required specialist care mainly at the health facilities.

5.3 People Living With AIDS

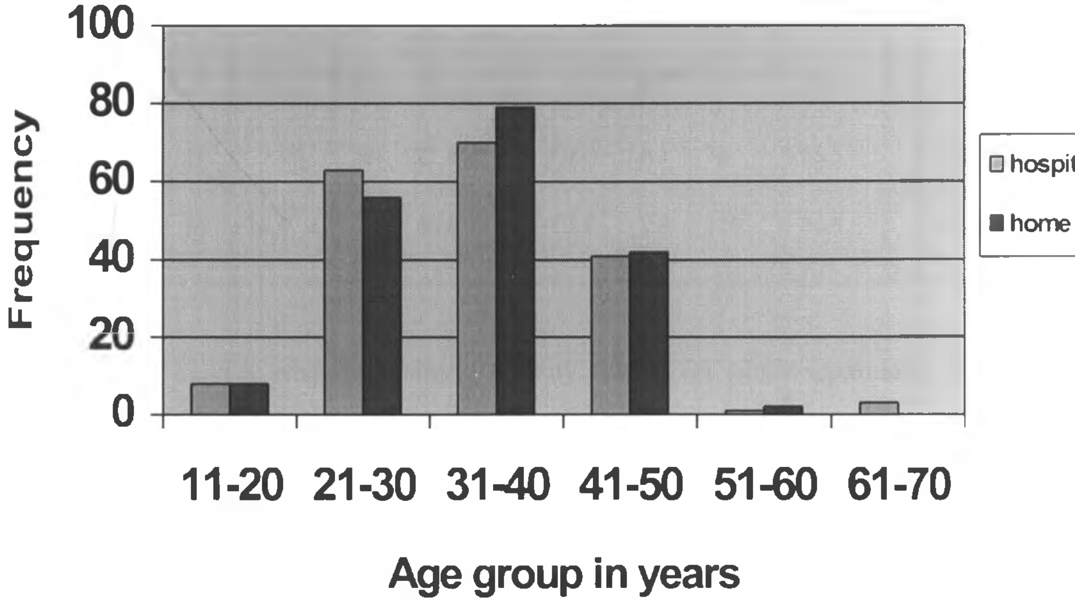
A total of 384 PLWA were interviewed with 192 receiving care at home and 192 being cared for in hospital at the time of interview. All of them had received both hospital and home-based care at different times earlier.

5.3.1 Socio-demographic characteristics of the PLWA

All the respondents cared for at home were from the informal settlements (low income areas) in Nairobi. Females were nearly three times more than males and there was no significant difference in sex distribution between PLWA in hospital and PLWA cared for at home (25% vs 29.2% males; p=0.36).

The respondents age ranged from 13 to 69 years and among those cared for at hospital the mean age was 34.6 ±8.9 and a median of 35 years and for those cared for at home their mean age was 34.4 ± 8.2 and a median of 34 years. There was no significant difference in age distribution between those cared for at hospital and home (p=0.93). The ten-year interval was used because of the wide range of age of PLWA. This distribution corresponds to the national pattern where majority of PLWA are aged 20-40 years.

Fig 2: Age distribution of PLWA



Only 56 (14.6%) of the PLWA were married and staying with spouses, 94 (24.5%) were single, 103 (26.8%) separated, 117 (30.5%) widowed or widower and 14 (3.6%) were divorced (table 15). There was significant difference in distribution of marital status between the two groups ($p < 0.001$) where 23.4% of PLWA in the hospital group were married compared to 5.7% of the PLWA cared for at home who were married.

Table 15: Marital status of PLWA

	Single		Married		Separated		Divorced		Widow/widower		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
Hospital	48	25	45	23.4	50	26	6	3.1	43	22.4	192	50
Home	46	24	11	5.7	53	27.6	8	4.2	74	38.5	192	50
Total	94	24.5	56	14.6	103	26.8	14	3.6	117	30.5	384	100

The total proportion of PLWA who were single for any reason (s) single/separated/ divorced/ attrition due to death) was 85.4%.

Most of the PLWA had received some formal education with 146 (38%) having primary education, 139 (36.2%) secondary, 47 (12.2%) college level, and only 3 (0.8%) had gone up to University level, while 49 (12.8%) had no formal education. No significant difference in education level between the two groups was found (p=0.38).

Table 16: Level of education of PLWA

	No education	Primary	Secondary	College	University	Total
Hospital	21 (10.9%)	82 (42.7%)	65 (33.9%)	23 (12%)	1 (0.5%)	192 (50%)
Home	28 (14.6%)	64 (33.3%)	74 (38.5%)	24 (12.5%)	2 (1%)	192 (50%)
Total	49 (12.8%)	146 (38.0%)	139 (36.2)	47 (12.2%)	3 (0.8%)	384 (100%)

About half of PLWA 200 (52.1%) were self-employed, dealing to a large extent with small-scale businesses, 18 (4.7%) were formally employed and 131 (34.1%) were not employed.

Table 17: Employment status of PLWA

	Employed	Self employed	None	Others	Total
Hospital	10 (5.2%)	94 (49.0%)	60 (31.3%)	28 (14.6%)	192 (50%)
Home	8 (4.2%)	106 (55.2%)	71 (37.0%)	7 (3.6%)	192 (50%)
Total	18 (4.7%)	200 (52.1%)	131 (34.1%)	35 (9.1%)	384 (100%)

Among those who reported other alternative sources of income, 35 (28 hospital and 7 home care), some of them were commercial sex workers, volunteers for various NGOs & churches, house helps (maids) and casual workers.

All the PLWA recruited into the study had received care either at home or hospital at one time. The relationship between the PLWA and the main care giver was as shown in table 18 below (as reported by PLWA).

Table 18: Relationship between PLWA and the FCGs

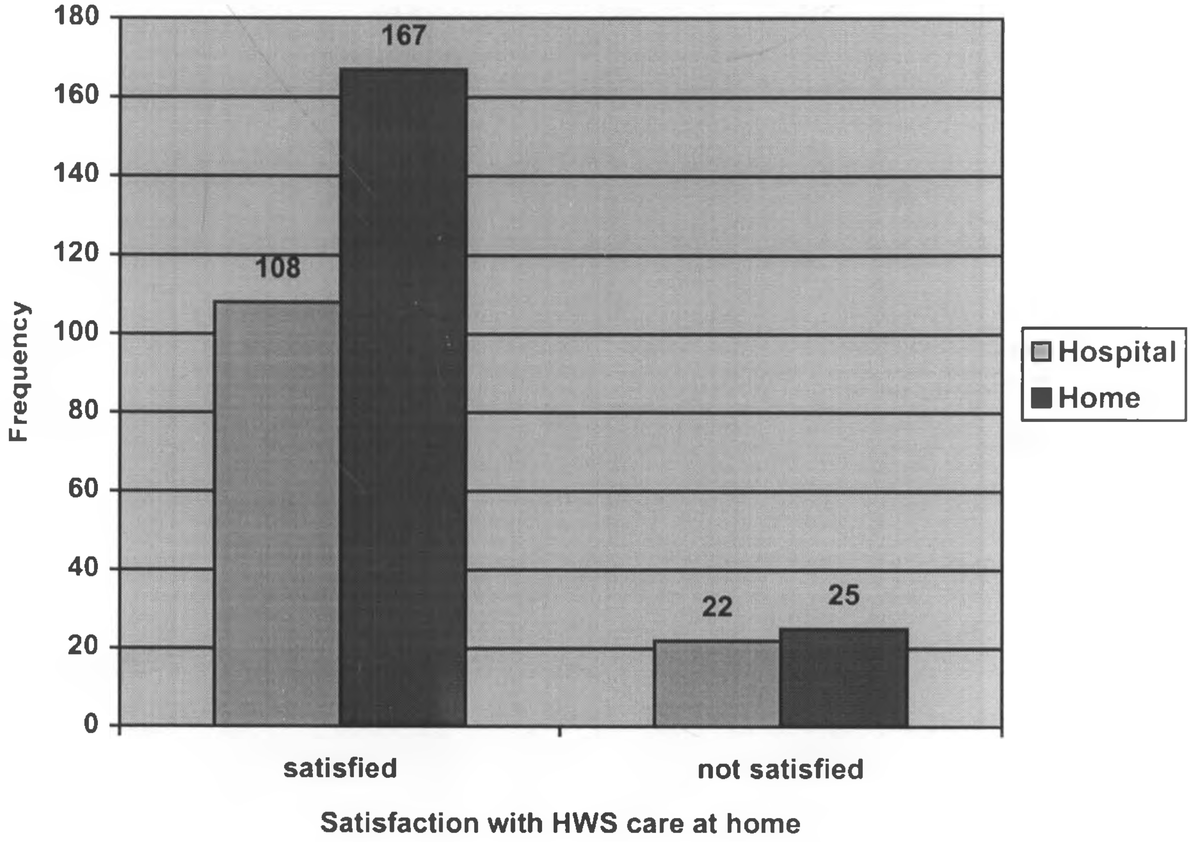
	Parent	Spouse	Son/ daughter	Brother/ sister	Grandparent	Friends	Others
Hospital	45 (23.4%)	23 (12.0%)	45 (23.4%)	42 (21.9%)	4 (2.1%)	23 (12.0%)	10 (5.2%)
Home	44 (22.9%)	5 (2.6%)	57 (29.7%)	65 (33.9%)	8 (4.2%)	10 (5.2%)	3 (1.6%)
Total	89 (23.2%)	28 (7.3%)	102 (26.6%)	107 (27.9%)	12 (3.1%)	33 (8.6%)	13 (3.4%)

Most PLWA were cared for by relatives. Only 33 (8.6%) were cared for by friends, 13 (3.4%) were cared for by others which included various church groups and NGO's. There were significant differences in distribution of relationship of FCG between the two PLWA groups ($p < 0.001$). A higher proportion of PLWA cared for at home were paying for their medical expenses compared to PLWA in hospital (45% vs 37.5%; $p=0.02$). The explanation of this was revealed during FGDs whereby it was reported that when one was admitted in the hospital friends and relatives gathered and contributed to buy drugs. But when one was discharged he/she was left on his/her own irrespective of the employment status and may only receive assistance with food.

5.3.2 Views of care received by PLWA

All the PLWA interviewed had received both hospital and home-based care at difference times in the course of illness. Majority 275 (85.4%) were satisfied with the care provided by health workers at home but 47 (14.6%) were not satisfied, with 4 (1.2%) PLWA citing irregular visits, 6 (1.9%) lack of drugs and 37 (11.5%) other reasons. These other reasons included:- hurried visits by the few health workers who also had to visit other different people in a day, inability to provide transport when they recommended a patient to be taken to the health centre, some HWs were not willing to touch the patients even when they found out the FCGs were not there. This information was mainly gathered from FGDs.

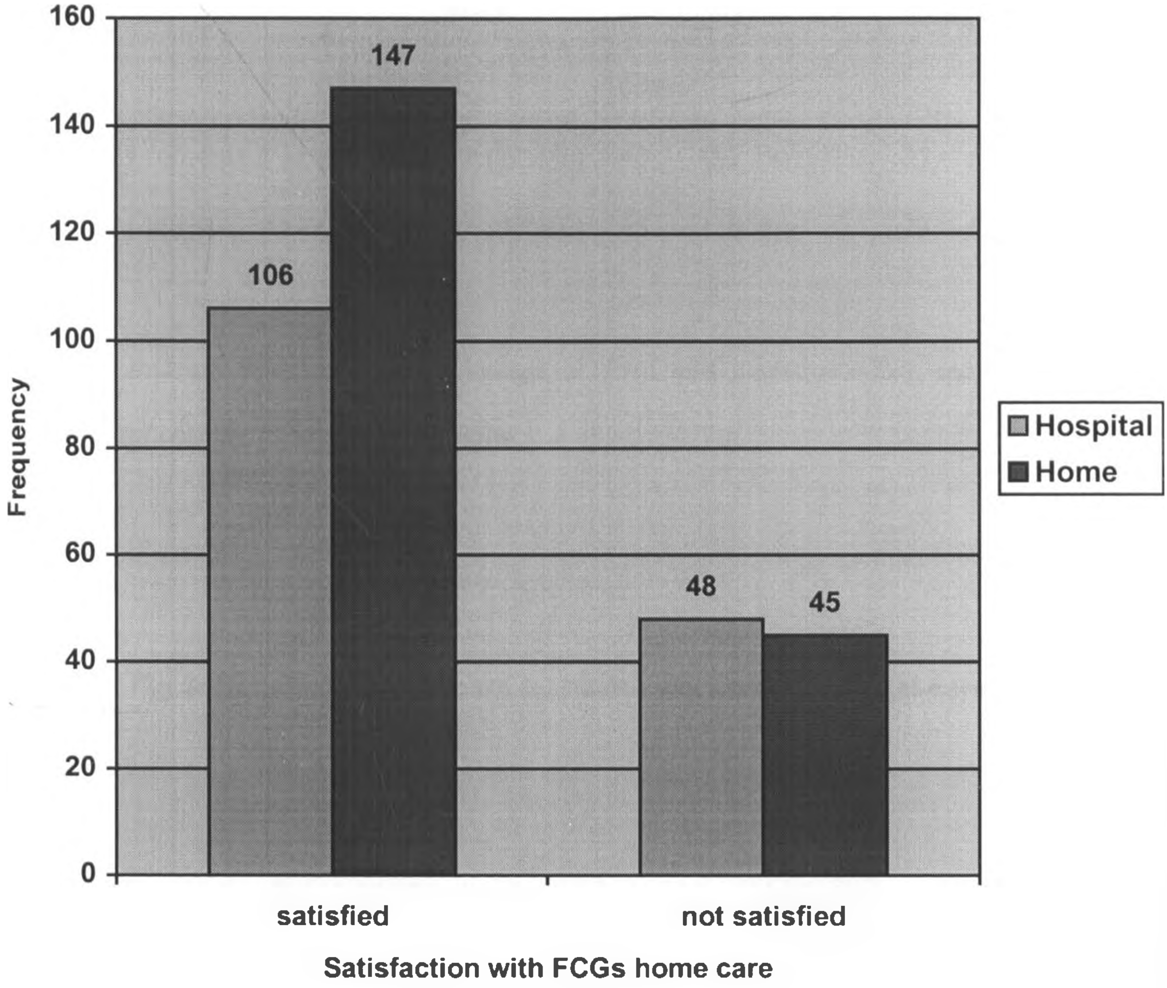
Fig 3: Satisfaction of PLWA with care by health workers care at home



***NB*:** responses of PLWA from hospital do not add to 192 as some were not visited by health workers.

The results showed that 253 (73.1%) were satisfied with care provided by FCGs at home while 93 (26.9%) were not. The reasons for not being satisfied were as earlier mentioned.

Fig 4: Satisfaction of PLWA with care by FCGs care at home



***NB*:** The responses for PLWA from hospital do not add to 192. Some were non-committal while others said they could not remember.

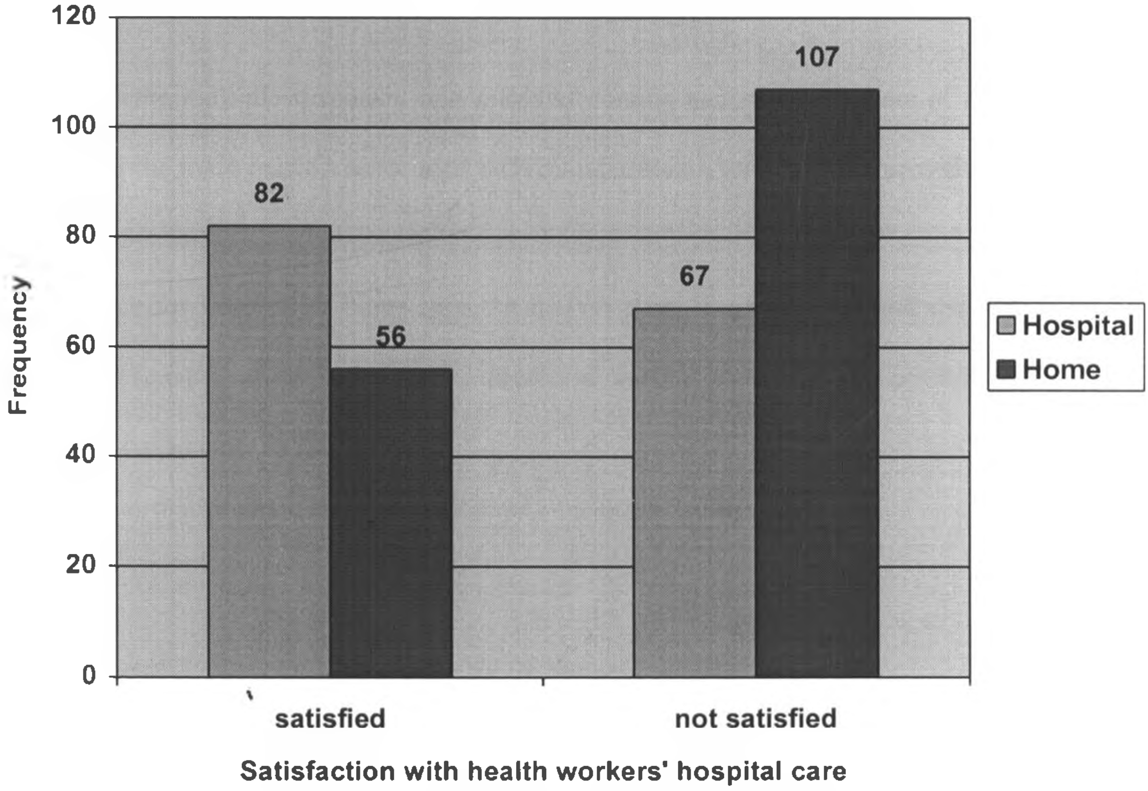
The reasons given by those who were not satisfied with care provided by FCGs at home (hospital 48 and home 45) are as shown in table 19 in the following page.

Table 19: Reasons for lack of satisfaction with FCGs care at home

	Neglected	Isolated	Shortage of food	Inadequate and/or lack money to buy drugs	Nobody to care during the day
Hospital	29 (60.4%)	11 (22.9%)	39 (81.3%)	40 (83.3%)	37 (77.1%)
Home	31 (68.9%)	14 (31.1%)	44 (97.8%)	45 (100%)	33 (73.3%)

There were multiple responses with shortage of food and inadequate/lack money being the main reasons for the dissatisfaction.

Fig 5: Satisfaction with care by health workers in hospital care



The total in each group was not 192 as some PLWA were non-committal on the care provided by health workers at hospital. However, most of those interviewed at home 107 (65.6%) were not satisfied with care provided during their last admission, while 82 (55%) of those interviewed in the hospital were satisfied.

Among those who were not satisfied with health care workers (hospital 67 and home 107) the following reasons were cited as shown in table 20 below.

Table 20: Reasons for lack of satisfaction with health care at hospital

	Neglected	Isolated	Minimal nursing	Shortage of drugs	Shortage of food	Rude members of staff
Hospital	9 (13.4%)	8 (11.9%)	46 (68.7%)	28 (41.8%)	17 (25.4%)	41 (61.2%)
Home	8 (7.5%)	15 (14%)	73 (68.2%)	38 (35.5%)	24 (22.4%)	72 (67.3%)

NB: There were multiple responses and minimal nursing and rude members of staff were cited as the main reasons associated with dissatisfaction with the care provided.

On preference for hospital or home care, 13 PLWA were non-commital and did not give any preference while 287 (77.4%) preferred home-based care as opposed to institutional-based care 76 (20.5%).

Table 21: PLWA place of preference for care

	Prefered place of care at time of interview			
Place of care at interview	**Hospital**	**Home**	**Both**	**Total**
Hospital	48 (26.1%)	128 (69.6%)	8 (4.3%)	184 (49.6 %)
Home	28 (15%)	159 (85%)	0	187 (50.4%)
Total	**76 (20.5%)**	**287 (77.4%)**	**8 (2.2%)**	**371 (100%)**

The reasons for these preferences included regular meals, company of the family, friendly environment, presence of entertainment, cheap & affordable, good nursing care, drugs and choice of good food as reported by most patients in both places of care at the time of interview.

5.3.3 Relationship between quality of care and selected characteristics of the study.

Quality of care was measured using response of satisfaction from the recipient (PLWA). An assumption was made that good quality care equals satisfaction with care at whatever stage of the disease since those interviewed were either in stage 3 or 4 according to WHO classification.

Table 22: Relationship between FCGs level of education and satisfaction with quality of care.

	No Education	Primary	Secondary	College/ University	Total
Satisfied					
Yes	8 (5.4%)	78 (53.1%)	36 (24.5%)	25 (17%)	147 (76.6%)
No	4 (8.9%)	25 (55.6%)	8 (17.8%)	8 17.8%)	45 (23.4%)
Total	12 (6.3%)	103 (53.6%)	44 (22.9%)	33 (17.2%)	192 (100%)

Chi-square = 1.38

Df = 3

P = 0.71, not significant

Table 23: Relationship between place of care and satisfaction with quality of care offered

Place	Satisfactory	Un satisfactory	Total
Hospital	80 (59.7%)	54 (40.3%)	134 (41.1%)
Home	137 (71.4%)	55 (28.6%)	192 (58.9%)
Total	217 (66.6%)	109 (33.4%)	326 (100%)

Chi-square = 4.8

Df = 1

P = 0.03, significant

Most patients in both places of care at the time of interview were satisfied with the care provided. However, the patients cared for at home were relatively more satisfied with care than PLWA in hospital. Satisfaction with quality of care at home was 71.4% versus 59.7% for hospital (p = 0.03).

Table 24: Relationship between previous training and satisfaction with quality of care

	Trained FCG	**Not trained FCG**	**Total**
Satisfied			
Yes	129 (88.4%)	17 (11.6%)	146 (76.4%)
No	45 (100%)	-	45 (23.6%)
Total	**91.1%**	**17 (8.9%)**	**191 (100%)**

F test = 0.013

DF = 1

P = 0.02, significant

Previous training was found to have a statistically significant association with quality of care to PLWA. However, almost all (91.1%) of FCGs reported that they had been trained. It was therefore not possible to generalize the influence of training on quality of care.

Relationship between SES and satisfaction with quality of care.

A large proportion of FCGs and PLWA were not willing to state their income and this impeded statistical analyses of the effects of SES on quality of care. However, based on observation regarding the type of living quarters and ownership of the house the statistical analysis was as shown in tables 25 & 26 below.

Table 25: Relationship between type of living quarters and satisfaction with quality of care.

	Temporary	**Semi-permanent**	**Permanent**	**Total**
Satisfied				
Yes	84 (57.1%)	46 (31.3%)	17 (11.6 %)	147 (76.6%)
No	23 (51.1%)	15 (33.3%)	7 (15.6%)	45 (23.4%)
Total	**107 (55.7%)**	**61 (31.8%)**	**24 (12.5%)**	**192 (100%)**

Chi-square = 0.7

DF = 2

P = 0.70, not significant

They type of residential housing did not influence the individual PLWA's satisfaction with care provided.

Table 26: Relationship between house ownership and satisfaction with quality of care.

	OWN	**RENTED**	**TOTAL**
Satisfied			
Yes	47 (32.4%)	98 (67.6%)	145 (76.3%)
No	9 (20.0%)	36 (80%)	45 (23.7%)
Total	**56 (29.5%)**	**134 (70.5%)**	**190 (100%)**

Chi-square = 2.5

DF = 1

P = 0.11, not significant

5.4 Results of Focus Group Discussions

A total of six FGDs were carried out: Two sessions were held with health workers of which one was held at the study centre, Mbagathi District Hospital and the other one at Langata health centre; Two sessions with FCGs were held at Korogocho and Dandora respectively. Similarly two FGDs were carried out with PLWAs, at the hospital (Mbagathi) and the other at KENWA (Kenya Network of Women with Aids) offices at Korogocho.

From the FGDs it emerged clearly that HIV/AIDS was a national problem and required urgent measures from everybody to control it. The main problem which impides provision of quality care was poverty. Most participants of FGDs thought that poverty alleviation measures were of paramount importance in control of spreading HIV/AIDS and provision of care to those infected.

Majority of PLWA said they preferred home-based care to institutional care and gave various reasons for this. These included personalised, nursing care, they could make a choice of meals, get entertainment and enjoy company of the family. Though, majority of the respondents said home-based care was good there were disadvantages of the same which were elaborated during the FGDs. These included the following reasons:

Isolation by the family members. One PLWA said "some do not even want to touch the patient or share with them utensils and such things make somebody feel distressed".

When relying on neighbours (friends) as the FCGs, a patient misses some dosages of their medication and this affects their recovery. One PLWA stated "on several occasions he missed his anti-TB drugs because there was no one to prepare food for him and had been instructed to take his medication after meals".

Another PLWA stated that "due to many responsibilities, she used to forget to take her medication as instructed. As a result she never improved and she infected two of her siblings with pulmonary tuberculosis (PTB)".

However, some PLWA who were women said they were victims of circumstances because they got the disease unknowingly, either from their spouses or as commercial sex workers because circumstances had forced them to engage in such acts in order to survive. When asked to give their personal experiences, one PLWA narrated how she learnt that she was HIV positive during her 5th pregnancy. When she confronted her husband about the issue he started mistreating her and beating her on and off on flimsy grounds. Later on, he started forcing his daughter to have sex with him. When the wife learnt about it she called the in-laws/clan members so that the matter could be sorted out, but they did not believe her. Later on the husband was forcing his son to have sex with his daughters. This particular "PLWA" ended up by saying that all of them are HIV positive with the husband currently in terminal stage but she was not sure because they had separated. She has gone through counselling and learnt to live positively with the disease and she is a trained FCG and she is trying to assist as many people as she can to come to terms with their status.

When asked to make comments at the end of the sessions, most of them were asking if it was possible for the government/NGOs to give them credit to improve their economic status since that was their biggest problem.

Most FCGs felt that the training they had acquired was very important. The training had improved their skills in provision of care to their patients and were willing to provide care not only to their relatives but to others in their neighbourhood.

The difficulties they encounter included:

Unrealistic patients were demanding what the family was unable to afford e.g meat and soft drinks alleging that these were doctors' recommendation. Some PLWA refused to be handled with gloves or nylon papers even when they had wounds which could infect their care-givers. There was lack of antiseptic solutions, drugs and dressing materials which had been recommended at the health facility and were an impidement to care provision. Burden of two families especially when one was taking care of his/her family and that of a relative who had lost a spouse while the children were still very young and could not even cook for themselves. Some FCGs said that some of the siblings especially girls were forced by circumstances to engage in prostitution to cater for the family needs when the parents are terminally ill.

It was reported that some PLWA gave instructions that they do not want to be visited by people who are "empty handed" even if it were a health worker because they were distressed by the fact they were unable even to feed their children.

When asked about what assistance they would like to be given, FCGs gave the following examples.

PLWA should be educated more about their status so that if they saw somebody using protective materials they should not feel humiliated. This would enable them to understand that this is for hygiene purposes rather than discriminated care.

The Ministry of health could provide FCGs with gloves to remove stigma of using nylon papers and provide beddings to change patients if possible.

Financial assistance from government, NGO's and well wishers for children of people living with AIDS e.g school fees waiver, free medical services and provision of food if possible; Ministry of health could provide ambulance facilities to transport those who are very sick from their houses to hospitals. Other organizations with ambulance services e.g St. Johns, Nairobi City Council and Nursing homes should also assist. In addition PLWA & FCGs needed credit facilities to start their own Income Generating Activities (IGA) to cater for their basic needs. Health workers should also continue training FCGs so that they can improve their care skills. On drug supply, the concern was to reduce prices of anti-retrovirals so that they are more affordable;

Service providers should disclose the HIV status to the patient and FCGs once diagnosis is confirmed to prevent spreading of the disease unknowingly.

Health workers reported that there was congestion at the hospitals and therefore they were unable to cope with the patient's demands. More over, when the patients were critically ill and required feeding and bedside bathing. They also cited inadequate resources as another drawback, for instance inadequate protective equipments and dressing material yet they were expected to carry on with their duties. Most of them said they were willing and were in a position to provide quality care. However, their terms of services and working condition needed to be improved. The government, through ministry of health should appreciate their good work by giving them better remunerations and this would motivate them to render quality services to all patients in general.

Some comments from health workers included:

- "I just go to work because I have no alternative" (ATTITUDE).
- "I cannot clean a patient when I don't have gloves" (SHORTAGES).
- "I only do what I can because there is no extra money" (RENUMERATION VERSUS MOTIVATION)

CHAPTER SIX

DISCUSSION, CONCLUSION AND RECOMMENDATION

6.1 Discussion

The care needs of individuals with HIV/AIDS change as the disease progresses. The disease has early, late and terminal phases. Care and support needs vary and relate directly to the disease phase. The study sought to investigate the care and support needs of those in stage 3 and 4 according to WHO classification. At these stages PLWA require both curative and supportive care services such as; pain relief, management of distressing physical symptoms, spiritual and emotional support and nutritional and physical support. These services are provided at different locations.

The decision of where these services should be provided is determined by various factors. Many people with late stage disease will first be seen at a health facility. The health facility visited, either private or public, will depend on several considerations that include proximity, affordability, acceptability, quality of care and ability to diagnose and provide care.

It was estimated that by June 2000 over 2.2 million Kenyans were living with HIV/AIDS (Baltazar, et al, 1999). Since 1984, one million Kenyans have lived with AIDS or have died as a results of AIDS (Baltazar, et al, 1999). The Government of Kenya recognises the problems associated with the HIV/AIDS pandemic. Two years ago, indeed the government declared HIV/AIDS a National disaster.

With the problem of increasing proportion of PLWA who occupy about 50% of all beds in hospitals, people are searching for alternative ways of alleviating this problem. Bed occupancy for AIDS victim in Kenya is considered to be worrisome (Republic of Kenya, 1994). It was estimated that by year 2000, half of all hospitals would be required for AIDS patients (Baltazar et al, 1999). This leaves an insufficient number of beds for patients with other illnesses.

In recognition of the fact that hospital based management of AIDS is expensive (Republic of Kenya 1994) and (Gilks et al 1998), other alternative methods of care have been identified and adopted in some countries. More specifically, home-based care has been suggested, especially for the poor countries like Kenya (WHO, 1997). However, very few African countries eg. Zambia, Zimbabwe, have experimented on non-hospital based strategies.

In Kenya for example, although the Government has identified home-based care at the district level, for curbing the impact of HIV/AIDS, to date no significant efforts have been made to implement this strategy. As a result, Kenya lacks a formalised system of home-based care to cope with the AIDS.

The main objective of the study was to evaluate the hospital-based care and home-based care needs of PLWA in order to facilitate the understanding of their care needs as well as contributing to the most appropriate continuum of care.

6.1.1 Hospital-based care

The health workers knowledge on HIV/AIDS was good as reflected in the results of computed scores of correct responses on various questions about HIV/AIDS. However, 67.2% of the health workers in the study were worried that they were likely to get AIDS while providing care to PLWA. For this reason they all indicated that they usually use available protective equipment and take extra care while handling PLWA. This is similar to the findings of other studies done elsewhere where nursing staff have either resigned or requested for departmental transfers to avoid nursing PLWA (Flaskerid et al, 1989).

Another study in Australia indicated that most participants were more willing to work with colleagues and PLWA following educational intervention. However, majority said they would continue to take additional precautions for fear of contracting HIV in the work place especially when more invasive procedures are being carried out (McCann et al 1998).

On the other hand many health workers, 58.3%, thought they were in a position to provide good care to PLWA, 50% felt that they have been trained while 46.4% felt that they have been doing it and were now confident. This means that the regular training programmes do not equip health workers with adequate knowledge and skills on HIV/AIDS care. Most health workers reported that they have not received any additional training and preparation to care for the terminally ill PLWA.

Majority of health workers (89.4%) felt that continuous medical education would improve their capability in care of PLWA and change their attitudes towards them. The health workers views concurs with those of a study done in Australia which revealed that educational intervention improved knowledge, attitudes and willingness to care for HIV/AIDS (McCann et al, 1998).

Health workers cited some constraints they encountered while providing care: 74.5% reported inadequate protective equipments, 72.3% inadequate drugs, 54.4% inadequate up-date information about HIV/AIDS, and 68.1% work overload. During the FGDs some health workers again reported that they were not provided with necessary protective equipment, yet they were expected to perform their duties. They also reported that some relatives were uncooperative as they took their patients and did not go for them at discharge later. Other relatives abandon their patients as soon as they knew the HIV status and did not want to take the patient home. These findings implies that interventional programmes should focus on variables and concerns expressed by health workers.

Most health workers, 83.3% indicated home as the best place for the PLWA to receive care.

Although a large proportion of health workers were doing a good job, low morale was evident amongst some of the staff and few were already feeling the strain. During the FGDs, some health workers expressed their disappointment with poor remuneration despite being overworked and often exposed to risk of infection during the course of their work. Some said they should be insured in case one got the virus from their place of work. The health institutions were found to be coping under very difficult circumstances. More than 50% of the beds were occupied by patients with HIV/AIDS related illnesses. This being a chronic illness there is no doubt the services are overstretched as most of them required longer duration of in-patient management. The result was that there was sharing of beds and therefore most of the staff were overworked. Since most of them had not received any additional training and preparation to care for the terminally ill they were working under very difficult and stressful conditions.

Finally as the number of those infected with HIV infection continue to increase there is need for establishment of a continuum of care of PLWA. This would help to decongest the wards and enable PLWA benefit from home care services since hospital assistance is not beneficial throughout the terminal stages.

Home care programmes have been found to be successful in provision of services such as counselling, social support, medical and nursing care for opportunistic infection. For instance, the AIDS support organisation (TASO) an NGO of HIV infected and affected people in Uganda had demonstrated that individuals and their families are able to live positively with HIV/AIDS through counselling, medical care and material support to the clients and their families. TASO had effected change in people's attitudes, knowledge and lifestyles (Kaleeba, et al, 1997). Such programmes ought to be implement in Kenya.

6.1.2 Home-based care

Majority of the FCGs 72.9% were females and this finding concurs with those of other studies done elsewhere where majority of caregivers are females (Ngugi et al, 1995). Most of these FCGs (74%) were between 20-40 years of age and slightly over half (53.6%) had primary level of education with only 6.3% having no education at all, while the rest had secondary school and above. As opposed to findings of a study done in 1998 in Kisumu where 84.8% of FCGs were not trained, most FCGs (90.6%) had received training from hospital based health workers on how to care for their patients (Okumu, 1999). They had received training in various areas including simple nursing procedures such as dressing wounds, turning patients regularly, nutritional advice, environmental cleanliness and infection control measures such as use of antiseptics, gloves or nylon papers. This could have been a contributing factor to why majority of PLWA were opting for HBC as opposed to hospital care. Training is therefore an essential part of successful HBC programme.

The perception of the FCGs to home-based care was supportive and majority of them had no problems with their roles. They were willing to provide the care as per the training they had received. However, inability to meet the medical, nutrition and social support were major constraints. From the interviews, it emerged that the supervision and support from the health institutions was inadequate if not totally lacking. However, the assistance they received from the local NGO's and church organisations was appreciated but it did not contribute to meeting their daily needs. The study found out that 99% of FCGs indicated they would like to know more about care of PLWA and would like the health workers to make regular home visits for further guidance.

Based on a scoring system, which was adopted, 75.5% of FCGs had excellent knowledge on modes of transmission and 62% had excellent knowledge on modes of prevention. As hypothesised in the study, previous training among the FCGs was found to have an influence on quality of care to PLWA (P value =0.02). This result suggests that training of FCGs was essential to make the HBC programmes fully operational without stigma.

Reports of a study done in Australia in 1998 indicated that there was a improvement in knowledge following an educational intervention (McCann, T.V et al 1998). Therefore there is need for further improvement in the knowledge levels of the care-givers (McCann, T.V. et al).

The occupation of the FCGs was mainly self employment with a monthly income ranging from Kshs 800 (USD 10) to Kshs 6,000 (USD 75) for the 26 FCGs who indicated their earnings. Most of them were not willing to indicate their earnings for fear of missing any potential financial assistance that would be forthcoming. This fear was stressed during the FGDs. Due to the small number of those who gave their monthly income it was difficult to find out whether there was significant relationship between SES in terms of their income and care needs. Only 29.2% of the FCGs stayed in their own houses, with majority of the houses being temporary. The rest stayed in rented houses. Based on the type of living quarters, whether permanent, semi-permanent or temporary, the study found out that there was no significant difference between satisfaction of care and type of housing occupied (P value = 0.070). This suggest that type of quarters had no influence on satisfaction of care.

During the third International Conference on home and community-based care in HIV infection/AID, held in Amsterdam in May 1997, it was reported that there is a difference between the rich West (developed) and developing countries in regard to numbers of patients and availability and accessibility of care. Inferior socio-economic position of women and children in developing countries, substantially impairs effective care programmes. Drugs against HIV and against opportunistic infections, and means of palliative care are not available and not affordable in these countries (Wigersma, 1997).

Despite the economic hardships and constraints encountered while providing care to PLWA, 92.7% of FCGs indicated home as the best place to give care to PLWA. This is in contrast to findings of another study done in Kiambu where most FCGs opted for hospital based care for their patients and they cited inadequate knowledge and skills of HIV/AIDS care as the main reason for this (Olenja, 1999).

The reasons for preference of HBC among FCGs in this study included:- shared responsibility among family members, good care, privacy , FCG able to do other work, affordability, accessible to those who cannot afford fare to hospital, and enough time to visit patient when free

By and large the quality of HBC was viewed as good and adequate. There was significant difference between satisfaction with care at home and hospital (P value = 0.03). This means place of care was found to be statistically related to satisfaction with quality of care. The most important factor in this case was the FCGs support to the PLWA.

Since majority of FCGs in this study were trained, this could have been a contributing factor to their willingness to provide care. A programme aimed at training lay persons and practical nurses to assist with home care of PLWA in Jamaica identified the need to provide special training to persons who would be responsible for caring the AIDS patients at homes where most patients preferred to be managed (Barin, 1998). Similarly such programmes ought to be started in our set up to provide cost effective support for family members caring for a people living with HIV/AIDS.

However, the study found there was no significant difference in satisfaction of care in relation to FCGs level of education (P value = 0.71). This suggest that HBC can be more successful if supported from all sectors. A study done in Britain on care of the terminally ill revealed that FCGs dedicated an enormous proportion of their lives to caring for their ill family members. They experienced their own form of suffering as they watch their loved ones die (Sletz et al, 1997). The implication from these findings is the need for a partnership between health care professionals and the families providing care to PLWA and continuous support and guidance.

From the results of the study it emerged that 90% of PLWA had a member of the family unit involved in the care. Therefore, the family unit plays an important role in HIV/AIDS care. Involvement of friends and others e.g employers, NGOs and church organisation is an option to research on as alternative source of care.

6.1.3 PLWA views of hospital and home-based care

A total of 384 PLWA mainly from low income areas were interviewed. The largest proportion of the respondents, being females. This can be attributed to the fact that more women are willing to accept their HIV status than men. An article in East Africa Standard newspaper on 5th December 2001 quoted the findings of United Nation Development fund for women which indicates that 55% of AIDS cases in Africa are women while 22% of girls in the 14-18 age bracket have contracted HIV and about 60% of all new infection are women. The characteristics of the study population with respect to age, is that of a young population where majority of the respondents were aged between 21-40 years making up 69.8%. The total proportion of PLWA who were single for any one reason(s) either, unmarried/separated/divorced/attrition due to deaths was 64% of the total sample population.

The peak age of 21-40 years was consistent with findings from other studies which have shown 25-39 years to be the peak age of HIV/AIDS especially in African countries where transmission is mainly through heterosexual contact (Gilks, et al 1998).

The respondent's educational level also fits the profile related to their social, cultural and economic status. Most of them, 38% had attained primary education, 36.2%, secondary and only 15.2% had attended colleges/university for professional courses. Their level of education may in turn be related to their employment status where only 4.7% had formal employment and majority, 52.1% were self-employed while 34.1% reported they had no employment and depended on relatives or churches/NGOs for financial assistance. Among those who said they were involved in other activities, several of them volunteered to mention that they were commercial sex workers. They justified why they engaged themselves into such activities during the FGDs saying:-, “when your children go without food for two days, circumstances force you”. Others said that they were introduced into the practice by their mothers in search of money for the upkeep of their younger brothers/sisters.

Majority, 73.1% PLWA said they were satisfied with care provided by FCGs at home. However, due to poverty, FCGs were unable to meet their expected needs e.g well-balanced diet, purchase of drugs or transport of patient to hospital when necessary.

In general the quality of HBC was satisfactory to majority of PLWA. The role of FCGs was also seen as good irrespective of their levels of education. Satisfaction with quality of care at home was 71.4% versus 59.7% for hospital (p value = 0.03). This means the quality of care received was satisfactory to both groups. However, PLWA cared for at home had more satisfactory response at the time of interview

The leading advantage of HBC in the study was the perceived better quality of care given to PLWA and affordability. The main reasons for dissatisfaction with the public health institutions were cost and neglect or mistreatment by hospital workers. During FGDs some PLWA reported that one of the determining factors in decision to seek hospital care was the severity of the illness. However, it must be noted that it would be unrealistic to expect the staff of the public health institutions to provide personalised attention to PLWA compared to FCGs. After all FCGs deal with only one client at a time whereas the nurse has a whole ward to attend to. This aspect emerged more prominently when hospital health workers cited heavy workload as a major constraint of care.

Majority of the PLWA who had experienced a hospital admission complained not so much about absence of a nurse or doctor next to them, but noted that nobody was taking even a moment to explain anything to them about their illness. Communication was therefore lacking. Hospital staff should therefore be sensitised to the need for a more humane approach towards PLWA rather than a strictly clinical approach. It does not take much time or any structural adjustment to give a kind word of assurance or encouragement or even an empathising gesture. All it requires is a change of attitude and recognition that in the unfamiliar hospital environment, the health service provider is the only person a patient with AIDS can turn to.

Most PLWA, 77.4% preferred home-based care as opposed to institutional based care. These findings are similar to those of a study done in Britain which found that 50-70-% of patients with advanced HIV/AIDS indicated a preference to remain at home for as long as possible until death (Koffman et al, 1996).

The reasons for this preference included:- regular meals, choice of food, friendly environment, entertainment (from TV, Radios etc), good nursing care from FCGs, family company, cheap/affordable care and oral drugs administered by members of the family. These finding reflected a significant need for interventions designed to provide direct and effective support for members of the family caring for a loved one with HIV/AIDS.

6.2 Limitations of the study

1. Inability to sample the PLWA or the FCGs due to the fact it was difficult to find the PLWA and FCG at the same time or at times the patient living with AIDS were too sick to be interviewed the same day with FCG. Other occasions the interviewers found patient with AIDS alone.

2. Due to financial constraints the collection of data took longer than anticipated, four months instead of two. This could have given time to PLWA/FCGs interviewed to interact and discuss with those not interviewed and therefore a likelihood to bias the answering of some clients.

3. Only a small proportion of FCG were willing to state their monthly income. The small sample size reduce the generalisability of the results of care needs in relation to their SES.

6.3 Conclusion

The study was able to attain its objectives. The main objective of this study was to evaluate the quality of care given to PLWA at home and at health institutions in order to facilitate understanding of their care needs. From the findings it became apparent that PLWA preferred HBC as opposed to institutional-based care. HBC was preferred for various advantages including affordability, good nursing care and because of the general hope that everything will be done perfectly well by the FCGs.

With more than half of Nairobi's population in the low SES bracket, the type of care utilized was determined primarily by its affordability, followed by perceived quality of care. PLWA were seeking services that are respectful, personalized and which make them feel at ease in the environment of provision of care. HBC was found to provide acceptable, affordable and convenient care.

PLWA saw survival and provision of basic needs for themselves as their priorities for assistance both at hospital and home level. Their needs can be grouped into 3 categories:.

- **Medical needs:** The main medical requirement was accessibility and affordability of medical care and drugs.

- **Socio-economic needs:** Nutritional support to maintain good health, financial assistance to support IGAs and care for the widows/widowers and orphans.

- **Psychological needs:** They require support, understanding and empathy to cope with the stigma. Cases of PLWA being despised, ignored and avoided were mentioned during FGDs.

Majority of health workers had excellent knowledge about modes of transmission and prevention of HIV/AIDS. However, most of them had perceived personal risks of getting HIV/AIDS while taking care of PLWA. This means basic training does not equip them with adequate knowledge and skills about HIV/AIDS care.

Most FCGs were willing to provide care to their patients. Their knowledge about modes of transmission and prevention was good. Almost all of them had no problem with their role but poverty was a major constraint in provision of care. Majority said they would like to know more about how to care for their patients.

Although most health workers and family care givers have been trained, further training is necessary as this would help to improve their knowledge and thereby influence their attitude and practices towards PLWA. Despite the fact that majority of health workers reported that they were willing to provide care to PLWA, majority of patients were not satisfied with the quality of care provided.

Challenges

How households and families respond to HIV/AIDS care is of functional importance when designing programmes and interventions to provide support and care for PLWA. When developing the care programmes, the stakeholders should focus on issues that may be present in the house settings for instance expressed wishes, fears and concerns that are not always routinely addressed in health like measures to alleviate poverty. There is also need to assess the prevalence of needs and unmet needs for supportive services and the impact of these variables among PLWA.

6.4 Recommendations

A. At National Level

- Improve accessibility of existing public health institutions to provide comprehensive care and support for HBC. For instance provision of ambulances to enhance referral system. Transportation of health workers to supervise CHWs and FCGs. Avail affordable basic drugs at the health facilities.
- All possible encouragement and support should be given to advocacy by HIV positive/AIDS patients. This must include positive and unequivocal backing by political leaders and opinion leaders in the community.
- Collaboration of government and home-based care implementers on poverty alleviation measures. There should be united fronting strategies on HIV infection control from government, NGO's, churches and other interested sectors to avoid conflicting statements.

B. At Institutional/Community Level

- Continuous medical education is necessary to improve the basic training knowledge of health workers. These should be organised in the hospitals and at community level. This would help to improve the competence of care-givers and change their attitude/practices towards care of PLWA.
- Since almost all PLWA will require HBC at some point of their illness and this being a chronic illness, FCGs should be trained prior

to patients discharge from hospital. However, for HBC programme to be successful, poverty alleviation measures needs to be considered. For instance, provision of credit facilities to start IGAs or improve their existing small scale businesses is a priority.

- Establishment of strategies for continuous care of PLWA would improve the quality of care given to PLWA. Coordination of nursing care is very important. Those attending to patients in wards should discuss with FCGs before patients are discharged and those attending to them at outpatient clinic should discuss regularly with FCGs about their care needs.
- Motivation of CHWs by giving them volunteer allowance is recommended. This would improve their commitment because they form the first link between community and health services and thus improvement in quality of care of PLWA. Majority of CHWs are already doing a good job and they need further encouragement. A scheme to remunerate them should be considered and implemented.

C. **Individual Level:** It is recommended that credit facilities from government, NGO's, church organisation and community-based organisations be initiated in order to start IGAs or improve existing small scale businesses for self/and or family sustainance.

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Appendix I

HEALTH WO RKER QUESTIONNAIRE

Respondent number ____

Nature of Health facility

1. District Hospital ☐
2. Health Centre ☐

Personal data of the health worker

1. Title of the respondent

    1. Kenya Registered Nurse ☐
    2. Enrolled Community Nurse ☐
    3. Public Health Nurse ☐
    4. CHW ☐

2. Station attached

    1. Out-Patient ☐
    2. In-Patient ☐
    3. Counseling unit ☐
    4. Field ☐

3. Sex

    1. Male ☐
    2. Female ☐

4. How long have you worked as a Nurse/CHW?(in years) ☐

Knowledge about AIDS

5. What is the difference between HIV infection and AIDS?

____

____

6. Is there any relation between having an STD and getting AIDS?

1. Yes ☐
2. No ☐
3. No idea ☐

7. If yes to No.6 tick the most appropriate

a. Both sexually transmitted ☐

b. STD enhance HIV transmission ☐

c. All of the above ☐

d. Others ☐

8. List various ways a person can get AIDS

1. ______________________________

2. ______________________________

3. ______________________________

9. How can you tell someone has HIV?

____

10. The responsibility for preventing/reducing the spread of HIV/AIDS rests largely with (Tick the most appropriate)

1. Men ☐
2. Women ☐
3. Both men & women ☐
4. Health workers ☐
5. School/institutions health education ☐
6. All of the above ☐

7. Others ☐

8. Don't know ☐

Perceived personal risk of getting HIV/AIDS while caring for People Living With AIDS

11.What do you think are the chances that you yourself might catch (get) AIDS while caring for people living with AIDS?

a. High chance ☐

b. Some chance ☐

c. Low chance ☐

d. None ☐

e. Don't know ☐

12. Does the possibility of getting HIV/AIDS while giving care to your patients worry you?

1. Yes ☐

2. No ☐

13. If Yes, when are you likely to get it?

1. Through coughs ☐

2. Accidental/Pricks ☐

3. Handling of patients soiled clothes ☐

4. handling of dead bodies ☐

14. What do you do to reduce your chances of getting HIV/AIDS while caring for People Living With AIDS?

1. Use of available protective equipments and take extra care while handling them ☐

2.Nothing ☐

3. Don't know ☐

4. Others ☐

Practices of the health workers towards People Living With AIDS

15. Do you think that you are in a position to provide good care to people living with AIDS (PLWA)?

1. Yes ☐

2. No ☐

16. If answer to no.15 is No, the reasons are

1. Inadequate knowledge ☐

2. Space too small/congestion ☐

3. Time too short ☐

4. Too many patients to care for ☐

5. Inadequate protective equipment e.g. gloves , dressing materials ☐

6. I have not been adequately taught ☐

17. If the answer to No. 15 is yes the reasons are

i. Have been trained ☐

ii. Have been doing it for sometime and now I am confident ☐

iii. Others ☐

18. Are modifications required on the following to improve your care for people living with aids?

	Yes	No
1. Your post-basic training programme in order to be taught more(refresher courses)	☐	☐
2. Your working schedule (rotational duty allocation)	☐	☐
3. Availability of the necessary drugs to treat-opportunistic infections	☐	☐
4. Employment of more staff to reduce the work load	☐	☐
5. Availability of the necessary protective equipment e.g. gloves, dressing materials etc	☐	☐

19. Considering care of people living with AIDS do you feel	Yes	No
1. That you have enough knowledge to take care of HIV/AIDS patients	☐	☐

2. You would like to know more about care of patient with aids ☐ ☐
3. Continuous medical education would improve the attitude/practice about care of patient with aids ☐ ☐

20. What constrains do you encounter while providing care to people living with AIDS: (Tick)

1. Inadequate protective equipments ☐
2. Inadequate drugs to treat opportunistic infections ☐
3. Uncooperative relatives ☐
4. Patients are uncooperative ☐
5. Work overload (too many patients to care for) ☐
6. Inadequate up-date information about the disease ☐
7. None ☐

21. What do you do for people living with AIDS (tick)

1. General nursing ☐
2. Feeding ☐
3. Counselling ☐
4. Directly observed treatment ☐

5. Others ____________________

____

22. Do you deal with relatives?

1. Yes ☐

2. No ☐

23. If yes, what do you tell them about the people living with AIDS?

1. Nutritional advice ☐

2. Teach them simple nursing procedures ☐

3. Teach them the general symptoms
to observe at home ☐

4. Counseling ☐

5. Others ________________________

24. Which is the best place to give care to people living with AIDS?

1. Hospital ☐
2. Home ☐
3. Others ☐

25. What are your reasons for the answer to no. 24?

____

____

____

____

____

Appendix II

Family caregivers questionnaire

Name of Interviewer

Socio –Demographic Data

Household Number ______________________________

Sub-Location ______________________________

Location ______________________________

Division ______________________________

1. Name of the respondent ______________________________

2. How old are you? ____________ years

3. Sex of the respondent

    1. Male ☐
    2. Female ☐

4. What is your religion?

1. Catholic ☐
2. Protestant ☐
3. Muslim ☐
4. Others (specify) ______________

5. Marital status

1. Single ☐
2. Married ☐
3. Separated ☐
4. Divorced ☐
5. Widowed ☐

6. What is your relationship to the patient?

1. Parent ☐
2. Spouse ☐
3. Friend ☐
4. Brother/sister ☐
5. Son/daughter ☐
6. Grandchild ☐
7. Other (specify) ______________________

7. (a) Have you ever attended any formal education?

Yes ☐

No ☐

(b) If yes, up to what level?

1. Primary ☐
2. Secondary ☐

3. Middle College ☐

4. University ☐

7. Type of living quarters

1. Temporary house ☐
2. Semi-permanent house ☐
3. Permanent house ☐

8. How many rooms does the house have?

1. One room ☐
2. Two rooms ☐
3. Three or more rooms ☐

10. Is the house your own or rented?

1. Own ☐

2. Rented ☐

11. If rented, what is the monthly payment? KShs…………………

12. What is your main source of income?

1. Own earnings ☐
2. Husband/wife/earnings ☐
3. Others (specify) ____________________

13. What is your usual occupation?

1. Permanent employee ☐

2. Farmer ☐

3. Casual labourer ☐

4. Self-employed (business) ☐

5. Student ☐

6. None ☐

7. Others (specify) ______________________________

14. Approximately how much money do you earn per month KShs.?...........

15. General Understanding about AIDS

15.1 **Knowledge on getting the HIV/AIDS virus**

One can get HIV/AIDS by/through

	True	False
1. By shaking a victims hands	☐	☐
2. By having sex with an infected person	☐	☐
3. Through mosquito bites	☐	☐
4. Through transfusion with infected blood	☐	☐
5. Through sharing needles and syringes that are contaminated with infected blood	☐	☐

6. By having sex with multiple sexual partners ☐ ☐

7. By wearing clothes used by PLWA ☐ ☐

8. Sharing utensils with PLWA ☐ ☐

9. Living in the neighbourhood of PLWA ☐ ☐

10. Coughing and sneezing ☐ ☐

11. Using public toilets ☐ ☐

15.2 Knowledge on HIV/AIDS prevention

One can prevent himself /herself from getting HIV/AIDS by doing the following

		True	False
1.	Restrict sex to single partner relationships	☐	☐
2.	Abstain from all risky behaviour (multiple sexual partners, alcoholism etc)	☐	☐
3.	Use a condom	☐	☐

4. Others (specify) ____________________

16. Have you been trained to care for your patients?

1. Yes ☐
2. No ☐

17. Which areas among the following were you trained on (tick appropriate)?

1. Nursing care ☐
2. Nutritional advice ☐
3. Infection control ☐
4. Environmental cleanliness ☐
5. Others ______________________________

____

____

18. Considering care of patients do you feel

	Yes	No
1. That you know enough about how to take care of your patients	☐	☐
2. You would like to know more about care of PWA	☐	☐

3. You would like health workers to visit home and give guidance regularly ☐ ☐

19. Where would you prefer to be taught about care of patients with AIDS ?

1. Government hospital ☐

2. Group meetings ☐

3. Chiefs barazas ☐

4. Others (specify) ______________________________

20. Do the health workers come to visit you/your patient?

1. Yes ☐
2. No ☐

21. If yes who?
1. CHW ☐

2. Nurses ☐

3. Doctors ☐

22. What do they do when they come?

1. Nutritional Advice ☐
2. Nursing care ☐
3. Counselling ☐
4. Treatment advice ☐
5. Others (specify) ____________________

23. What constraints do you encounter while providing care?

1. Cannot afford it (too expensive to buy drugs) ☐
2. No time to care ☐
3. Inability to provide the needed care due to poverty ☐
4. Inadequate knowledge to give appropriate care ☐
5. Lack of follow up by health personnel at home to give guidance ☐

6. Afraid to get the disease while caring for the patient ☐

7. Others ______________________________

____

24. Which is the best place to give care to your patients?

1. Hospital ☐

☐

2. Home

3. Others (specify) ______________________________

25. What are your reasons for the answer to no 24?

____

____

____

____

____

Appendix III

PEOPLE LIVIVING WITH AIDS QUESTIONNAIRE

Name of interviewer ______________________________

Patient Number ____________________

Personal data of PEOPLE LIVING WITH AIDS

1. How old are you? _____ years

2. Sex

   1. Male ☐

   2. Female ☐

3. What is your religion?

   1. Catholic ☐

   2. Protestant ☐

   3. Muslim ☐

   4. Others (specify) _____________

4. Marital status

1. Single ☐

2. Married ☐

3. Separated ☐

4. Divorced ☐

5. Widowed ☐

5. (a) Have you ever attended any formal education?

Yes ☐

No ☐

(b) If yes, up to what level?

1. Primary ☐

3. Secondary ☐

4. Middle College ☐

5. University ☐

6. What is your source of income?

1. Employed ☐

2. Self employed ☐

3. None ☐

4. Others (specify) ______________________________

7. Approximately how much do you earn per month KShs?………………..

8. Who pays your medical bills?

1. Employer ☐

2. Self ☐

3. Insurance ☐

4. Relatives ☐

5. Spouse ☐

5. Others(specify)______________________________

Care at home

9. Who is your main care giver at home?

1. Parents ☐
2. Spouse ☐
3. Son/daughter ☐
4. Brother/sister ☐
5. Grandparent ☐
6. Friends ☐
7. Others (specify)____

10. What does she/he help you with? (type of assistance provided)

1. Assists in feeding ☐
2. Preparing food ☐
3. Bathing/cleaning of beddings ☐

4. Financial support ☐

5. Provides company when other members are away ☐

6. Advises on use of drugs and accompanies to hospital ☐

7. Others (specify) ____________________________________

11. Do any health workers visit you at home?

Yes ☐

No ☐

12. If yes, how often?

1. Once a week ☐

2. Once a month ☐

3. Once every two weeks ☐

4. Twice a week ☐

5. Others (specify)____________________________________

13. What do they do during their visits?

1. Health education ☐

2. Advice on use of medicines ☐

3. Counselling ☐

4. Assists in feeding/washing ☐

5. Other (specify) ____________________

14. Do you pay for the services provided by these health workers?

1. Yes ☐

2. No ☐

15. If yes how much per visit? ____________________

16. Are you satisfied with the type of care provided by the health workers?

1. Yes ☐

2. No ☐

17. If No why?

1. The visit are not regular ☐

2. They don't have drugs with them for treatment and instead refer you to a hospital ☐

3. Others (specify____________________________________

____

18. What assistance do you think the health care workers can be given to enable them provide better care ?

1. Increase their numbers so that they are able to provide regular visits ☐

2. Provide them with drugs for treatment of minor illnesses ☐

3. Train the family care givers how to provide the necessary care. ☐

4. Others (specify)_______________________________

19. Are you satisfied with the care provided at home

1. Yes ☐

2. No ☐

20. If No why?

1. I am neglected ☐

2. I am isolated ☐

3. Shortage of food ☐

4. No money to purchase drugs ☐

5. Nobody to take care of me during the day ☐

6. Others (specify)______________________________

Care at health institution

21. Have you been admitted to a hospital in the last one year?

1. Yes ☐

2. No ☐

22. If yes how many times?

1. 1 ☐

2. 2 ☐

3. 3 ☐

4. >3 ☐

23. For how long?

1. Less than a week ☐

2. Two to four weeks ☐

3. One to two months ☐

4. More than two months ☐

24. Where were you admitted (specify the nature of health facility)

1. Health centre ☐

2. District hospital ☐

3. Provincial hospital ☐

4. Private hospital ☐

5. Mission hospital ☐

6. Others (specify)________________________________

25. Were you satisfied with the care provided at the health facility?

1. Yes ☐

2. No ☐

26. If No to Q 25, why?

1. I was neglected ☐

2. I was isolated ☐

3. Minimal nursing care ☐

4. Shortage of drugs ☐

5. Shortage of food/poor diet ☐

6. Rude members of staff ☐

7. Others (specify) ______________________________

27. Where are you most comfortable while receiving care?

1. Hospital ☐

2. Home ☐

3. Others (specify) ______________________________

28. What are your reasons for the answer to Q27?

____

____

____

____

APPENDIX IV

FOCUS GROUP DISCUSSION GUIDELINES FOR HEALTH WORKERS

Morning everyone!

My name is Dr. Lucy Ndahi, currently undertaking a post graduate course (Masters in Public Health) at the University of Nairobi, department of community health. I would like to welcome all of you to this discussion and thank you for coming.

Our topic of discussion is care for PEOPLE LIVING WITH AIDS. You are free to give your views and all the information will be valuable and may help in improving our understanding of care needs as well as contributing towards design of the most appropriate source of care.

With me are: 1. ______________________________

2. ______________________________

3. ______________________________

Who will help me to record the proceedings.

We also have a radio cassette recorder to record the discussion so that we do not miss any of your views during the analysis and writing of the report. All the information you provide will be held in strict confidence.

Date of FGD ______________________ Time FGD started ______________

Venue ______________________ Time FGD ended ______________

No. recruited for FGD _______________

- What are your views about taking care of someone who has HIV/AIDS?
    - Are you comfortable providing care?
    - Are you willing ?
    - Is it difficult?

- Do you think you are capable of providing the necessary care to PEOPLE LIVING WITH AIDS?
- What constrains do you encounter
- Patient loads
- Working hours
- Availability of drugs

3. What in you views are the main issues which need to be addressed to help in improvement of care provided to PEOPLE LIVING WITH AIDS

Capability - Continuous medical education &
- Refresher courses

Capacity - Increase the number of staff
- Finances - Availability of drugs

4. Do you feel that there are chances that yourself might get infected with HIV/AIDS as you provide care?

5. Are there any other comments that anyone of you would like to make about taking care of someone who has HIV/AIDS? Or ask any questions?

Once again let me thank you for you participation and I am very grateful for your contribution.

THANK YOU ALL.

APPENDIX V

FOCUS GROUP DISCUSSION GUIDELINES FOR FAMILY CAREGIVERS

Morning everyone!

My name is Dr. Lucy Ndahi, currently undertaking a post graduate course (Masters in Public Health) at the University of Nairobi, department of community health. I would like to welcome all of you to this discussion and thank you for coming.

Our topic of discussion is care for people living with AIDS. You are free to give your views and all the information will be valuable and may help in improving our understanding of care needs as well as contributing towards design of the most appropriate source of care.

With me are: 1. ______________________________

2. ______________________________

3. ______________________________

Who will help me to record the proceedings.

We also have a radio cassette recorder to record the discussion so that we do not miss any of your views during the analysis and writing of the report. All the information you provide will be held in strict confidence.

Date of FGD: ________________ Time FGD started: __________

Venue: ______________________ Time FGD ended: ___________

No. recruited for FGD: ____________________________

1. What are your views about taking care of someone who has HIV/AIDS?

Are you comfortable providing care?

Are you willing ?

Is it difficult?

2. Sometimes it is necessary to help a sick person with daily activities. What do you do to for your patients?

- Help in
    - Feeding/bathing
    - washing clothes
    - Financial assistance

3.What constrains do you encounter as you provide care to your patients?

Inadequate of food

Inadequate of drugs

Lack of time

It is expensive

Poor communication with health workers

4. Do you think you need more information about how to care for someone who has HIV/AIDS?

Regular visits by health workers.
Availability of drugs

5. What are the advantages of taking care of a sick person at home

Disadvantages?

6. Are you worried of getting infected with HIV/AIDS as you provide care?

7. Are there any other comments that any of you would like to make about taking care of someone who has HIV/AIDS? Or ask any questions?

Once again let me thank you for you participation and I am very grateful for your contribution.

THANK YOU ALL.

APPENDIX VI

FOCUS GROUP DISCUSSION GUIDELINES FOR PEOPLE LIVING WITH AIDS

Morning everyone!

My name is Dr. Lucy Ndahi, currently undertaking a post graduate course (Masters in Public Health) at the University of Nairobi, department of community health. I would like to welcome all of you to this discussion and thank you for coming.

Our topic of discussion is care for people living with AIDS. You are free to give your views and all the information will be valuable and may help in improving our understanding of care needs as well as contributing towards design of the most appropriate source of care.

With me are: 1. ______________________________

2. ______________________________

3. ______________________________

Who will help me to record the proceedings.

We also have a radio cassette recorder to record the discussion so that we do not miss any of your views during the analysis and writing of the report. All the information you provide will be held in strict confidence.

Date of FGD: ________________ Time FGD started: ________________

Venue: ______________________ Time FGD ended: __________________

No. recruited for FGD: __________________________

1. What are your views regarding care you receive?

Inadequate ____________

Minimal ____________

Adequate _______________

Enough _______________

Neglected _________________

2. What are the advantages of receiving care at home

Disadvantages?

- Good foods
- More attention from family members

3. Are you satisfied with the type of care provided by the health workers at the health institutions?

- Neglected
- Isolated
- Minimal nursing
- Shortage of drugs/poor diet

4. Do you ever worry about transmitting HIV/AIDS?

5. What are the consequences HIV/of AIDS?

6. Do you think HIV/AIDS is as serious as it is made out to be?

7. Since onset of illness, how has your family managed financially?

Well

Poorly

Others

9. Are there any other comments that anyone of you would like to make or ask any questions?

Once again let me thank you for you participation and I am very grateful for your contribution.

THANK YOU ALL.