HIV/AIDS AND HOUSEHOLD COPING STRATEGIES IN RESOURCE POOR SETTINGS: A CASE STUDY OF COMMUNITY BASED HOME CARE IN THE EASTLANDS OF NAIROBI

By

Ebel Oyuke Omollo
Institute for Development Studies
University of Nairobi
Kenya

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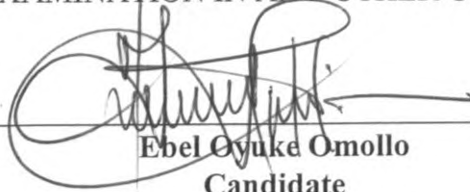
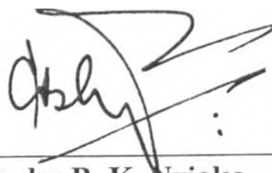


Ebel Oyuke Omollo
Candidate
Institute for Development Studies
University of Nairobi
Kenya

THIS PROJECT PAPER HAS BEEN SUBMITTED WITH OUR APPROVAL AS UNIVERSITY SUPERVISORS

Dr. Mary Omosa
Senior Research Fellow
Institute for Development Studies
University of Nairobi
Kenya



Prof. Charles B. K. Nzioka
Associate Professor
Department of Sociology
University of Nairobi
Kenya

DEDICATION

To my parents particularly my beloved mother Esther Ongondo, my late brother Timothy Orinde and uncles Dalmas Oyake and Elisha Anyango for their ceaseless encouragement even when things seemed virtually uncertain and the future so bleak. Indeed to them I owe everything I am today.

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ACRONYMS

AIDS-------------Acquired Immune Deficiency Syndrome

ARVs-------------Anti Retro Virals

ASO--------------Aids Support Organization

CBO--------------Community Based Organization

CEDPA----------The Center for Development and Population Activities

CPA--------------Certified Public Accountant

DAAC -----------District AIDS Control Committees

DN----------------Daily Nation

DNGO-----------Development Non Governmental Organisation

ECL--------------Ensemble Contre Lesida

FAO--------------Food and Agriculture Organization

FBO--------------Faith Based Organization

FGI---------------Futures Group International

FHI---------------Family Health International

GDP--------------Gross Domestic Product

GIPA-------------Greater Involvement of People with AIDS

GNP--------------Gross National Product

GNP+------------Global Network of People Living with HIV/AIDS

GPA--------------Global Programme on Aids

HBC--------------Home Based Care

HCS--------------Health Care and Support Unit

HIV---------------Human Immune Virus

IARA-------------Islamic African Relief Agency

IDS---------------Institute for Development Studies

IGAs------------Income Generating Activities

IMF--------------International Monetary Fund

KANCO---------Kenya AIDS NGO Consortium

KEMRI----------Kenya Medical Research Institute

KT--------------Kenya Times

NACC----------National AIDS Control Council

NAP+-----------Network of African People Living with HIV/AIDS

NASCOP-------National AIDS and STDs Control Program

NGO------------Non-Governmental Organization

PLWHA--------People Living With HIV and AIDS

PMTCT---------Prevention of Mother to Child Transmission

PNA-------------Participatory Nutrition Approach

RCS--------------Resource Constraint Settings

RoK--------------Republic of Kenya

RTI---------------Research Triangle Institute

SAfAIDS--------Southern Africa AIDS Information and Dissemination Service

SAPs-------------Structural Adjustment Programmes

SCT---------------Social Cognitive Theory

SLT---------------Social Learning Theory

STD--------------Sexually Transmitted Diseases

STI---------------Sexually Transmitted Infections

TASO------------The AIDS Support Organization

ToT--------------Trainer of Trainers

TV---------------Television

UN---------------United Nations

UNAIDS--------United Nations Joint Programme on AIDS

UNDP-----------United Nations Development Programme

US---------------United States

USAID----------United States Agency for International Development

VCT-------------Voluntary Counseling and Testing

WHO------------World Health Organization

WOFAK--------Women Fighting AIDS in Kenya

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ABSTRACT

Institutions and policy makers are rapidly coming to terms with the devastating impacts of HIV and AIDS. Mathematical models have indicated that the impact of Aids cuts across every aspect of the societal fabric with massive socio-economic implications. In Kenya, HIV/AIDS is a declared national disaster, yet many policy makers in the country are just waking up to the reality of what this actually means in terms of national development and human welfare in particular.

This study has explored the various coping strategies adopted by cash strapped households in Nairobi. The study was based on a primary survey of urban poor households in Kayole estate, which has one of the highest reported AIDS cases in Nairobi. In light of additional strains exerted by HIV and AIDS on hospital care, the study also looked into the possibilities of enhancing community based care within the home setting (here referred to as Home Based Care, HBC) as a strategy to reducing the severity of such coping alternatives. This investigation involved the use of both primary and secondary materials on HIV and AIDS particularly those related to the management of the impacts of the epidemic on households. A primary survey was carried out among households that either had experienced or continued to experience the impact of HIV/AIDS during the period of the survey. Data collection for the survey involved the use of structured survey questionnaires. Discussions with key informants formed an integral part of gathering qualitative data for the study. The methods for collecting qualitative data comprised complete observations, open ended in depth interviews, unscheduled open interviews and case studies.

The study found that there were a myriad of strategies adopted by households in the face of HIV and AIDS. The severity of these strategies depended greatly on the amount and nature of resources that were at the disposal of these households. The study found that many households that had assets and savings, resorted to the sale of such assets and de-saving to provide for themselves. However, others simply resorted to borrowing, re-adjustments of household consumption and changes in the behaviour pattern of household members. The study also found that comprehensive care across continuum for People Living with HIV/AIDS (PLWHAs) within the home setting provided the best alternative to hospital care that is already characterized with severe crisis owing to large patient admissions, dilapidated health infrastructure and the general scarcity of resources.

Key Words: *HIV/AIDS, Home Care, Coping Strategies and Resource Poor Settings.*

Finally, the study makes recommendations and suggestions on policy implications. Existing and future government efforts to alleviate poverty should be broadened and strengthened to include households affected by HIV and AIDS particularly the cash strapped ones. Relevant policies that would ensure equitable educational attainment across the societal divide and measures aimed at attaining general HIV/AIDS awareness as well as the institutionalization of prevention and care initiatives, also needs to be effectively put in place. Strategies for improving income distribution and alleviation of other diseases require to be reinforced to help reduce the susceptibility and severity of household coping mechanisms.

In conclusion, the study emphasizes that Home Based Care (HBC) should gain support of the formal health care system besides incorporating community organizations into it. This calls for a continuum of care that extends from home to hospital with a strong referral system and consistent discharge planning.

Key Words: *HIV/AIDS, Home Care, Coping Strategies and Resource Poor Settings.*

CHAPTER ONE

INTRODUCTION

1.1 Background to the Study

Almost all governments are signatories to the International Covenant on economic, social and cultural rights. Indeed, Article 12 of this Covenant states that parties to it recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. In furtherance, the Article states that steps to be taken by signatories to achieve full realization of this right shall include, inter alia the *prevention, treatment and control of epidemic, endemic, occupational and other diseases; and the creation of conditions which would assure to all, medical service and medical attention in the event of sickness* (UN, 1993).

HIV and AIDS have become the world's most devastating epidemic. It is estimated that over 22 million people worldwide have died of Aids, and 36 million are currently infected with the HIV virus. Out of these, 70% live in Sub Saharan Africa (NASCOP, 2001). The disease was first observed in Kenya in the mid 1980s and by 1995; over 63,000 cases had been reported. Presently, it is estimated that 2.2 million Kenyans are infected with HIV/AIDS while 1.5 million have already died of the virus. In any given year, over 200,000 people develop Aids, making a genuine case for care provision that is convincing for investment by policy makers, donors and governments.

Current estimates indicate that out of every eight adults in rural Kenya one is infected with the virus. In the urban areas almost one out of every five adults is infected (NASCOP, 2001). Noting the magnitude of threat posed by the epidemic, the then President of the Republic of Kenya, His Excellency Honorable Daniel arap Moi declared Aids a national disaster, stating that:

AIDS is not just a serious threat to our social and economic development, it is a real threat to our very existence...AIDS has reduced many families to the status of beggars .... no family in Kenya remains untouched by the suffering and death caused by Aids.........the solution remains with each and every one of us (DN 19th November, 1999: 24).

Even more worrying is the fact that data from the sentinel surveillance sites countrywide show continuous spread of the virus. This has largely been attributed to those infected but showing no visible signs of the disease thus increasing infections on a daily basis and consequently the need for care provision shortly after.

In the early years of the epidemic, program managers often lacked information on modes of transmission and interventions necessary to slow spread (NASCOP, 2001). Even though this knowledge has grown greatly of late due to various studies, an information vacuum still persists particularly on care and the necessary interventions for those already infected. Despite this and the high cost of anti-retroviral drugs, the government still puts emphasis mainly on behavior change and promotion of Voluntary Counseling and Testing (VCT) services, early diagnosis and prompt treatment of Sexually Transmitted Diseases (STDs) and tuberculosis; a clear manifestation of little concern for the care of those already infected. In fact, care for People Living with HIV and AIDS (PLWHAs) especially Home Based Care (HBC) is often mentioned only in passing in government policy documents.

The major modes of transmission of HIV in Kenya are mainly heterosexual contact, perinatal transmission and blood transfusion. A larger proportion of infections in Kenya are often through heterosexual contact. Studies have also shown that the probability of transmission in a single act of intercourse may be quite low. However, the risk is often made greater by other factors such as the extent of viral load of the infected partner, the presence of other STDs in either partner, chancroid or herpes causing genital ulcers; lack of male circumcision or trauma during sexual contact (NASCOP, 2001). Transmission risk is also noted to be high particularly amongst men who have sex with other men (NASCOP, 2001).

Perinatal transmission occurs during pregnancy, at birth or through breastfeeding. Approximately 30% to 40% of babies born to infected mothers will themselves be infected (NASCOP, 2001). Blood transfusion on the other hand entails infection through infected blood. This will almost certainly lead to transmission of the HIV virus. This mode, however, is rare in Kenya because of the

near 100% blood screening before any such transfusion can take place. Other modes include injecting drugs and piercing with instruments that are not sterilized (NACC, 2000).

Table 1.1 Estimated HIV infection in adults aged 15 to 49 by Province, June 2000

Province	Number HIV+	Prevalence (%)
Nairobi	175,000	16
Central	240,000	13
Coast	135,000	10
Eastern	380,000	16
North Eastern	15,000	3
Nyanza	480,000	22
Rift Valley	390,000	11
Western	210,000	12
Total	**2, 025,000**	**13.5**

Source: NASCOP, 2001.

The spread of HIV/AIDS in Kenya probably started in the late 1970s or early 1980s with very low prevalence during this period. However, by June 2000 adult prevalence rates had increased to 13.5% (NASCOP, 2001). Whereas urban prevalence is estimated at 17 to 18 percent, rural area prevalence is estimated at 12% to 13% and this is increasing rapidly. It is important to note, however, that although urban prevalence is high the absolute number of infected people remains higher in the rural areas. Eighty percent of the country's population lives in the rural areas, representing an estimated 72% of the infected adult population.

1.2 Statement of the Problem

The HIV/AIDS pandemic has pushed the world even further into a singular movement of history with all aspects of life seeming to have reached a critical turning point. According to Shukla (1999), the world has experienced disappointments at the limitations in the existing therapeutical options as well as the difficulty in sustaining progress in the HIV vaccine development. This elusive development in the clinical context has led to the desperation and vulnerability of millions who become infected with the virus (UNAIDS, 1999).

Whereas some regions of the world remain somewhat untouched, others have seen untold disruption of individuals, families and communities, the companies they work for as well as their nationalities (Bill, 1996). HIV and AIDS have destroyed economic systems and the capacity of communities and households to fend for themselves (World Bank, 1997; Omiti and Omosa, 2002). In many regions and even some countries, AIDS is already the number one killer disease, and still a major cause of death in many others, particularly in the developing world (UNAIDS, 1999).

In Kenya, the epidemic remains the single most important health challenge in the country's post independence history. The government notes that it is the only one known health challenge capable of reversing the gains that the country has achieved in life expectancy, infant mortality and other spheres of development (Kenya, 1998; Omiti and Omosa, 2002). The epidemiological pattern has shown a "scaring" trend and devastating socio-economic impact on all levels of the social context with severe and massive security and political implications.

History, however, shows an interesting dimension of catastrophes. AIDS like many other epidemics has triggered responses of great courage: the capacity to care for others, the desire to show understanding in times of crisis, and the ability to offer support in extreme adversity (UNAIDS, 1999). In a situation characterized with an infection always certainly leading to death and the spread of the epidemic on the increase, care for the victims of HIV/AIDS (both infected and affected) increasingly becomes a fundamental aspect of managing the trail of the ravages of the epidemic. Experts have noted that the two decades of experience with the epidemic reinforce the view that prevention of the HIV transmission, as a measure of containment, will not be achieved without the concomitant efforts to provide care and support to those infected (Kenya Times, June 21st 2001: 7).

However, in Kenya, as the epidemic continues to mark severe development crisis given the main modes of transmission and prevalent rates the government continues to commit extremely limited resources to the health sub sector. The level of desperation of individuals, communities and households either infected or affected by the epidemic is made even more critical by the high poverty levels prevailing in the country.

To many of these individuals and households, the epidemic has pushed them right on to a vertical wall. Among these households, the management of the conditions of those infected is of critical importance. The UN General Assembly's Declaration of Commitment that calls for national, regional and international strategies that strengthen healthcare systems and address factors affecting provision of HIV related drugs also emphasize this position.

Despite this greater need, however, many government policy documents have continued to give emphasis mainly to prevention and advocacy initiatives with little regard for care and support. While the 2000-2005 National AIDS Strategic Plan provides a detailed framework of prevention and advocacy with emphasis on VCT and Prevention of Mother To Child Transmission (PMTCT), care and support is merely mentioned as a function of DAACs and "other" unnamed committees. No resource provisions for these committees are indicated within the 2001-2005 National Development Plan.

The end result of sidestepping issues of resource allocation for care and support has increased the levels of vulnerability and desperation of households and communities that are left with no alternatives but to engage in this vital yet complicated process of health management, more often within their homes. This they do in an empty system devoid of the necessary information and institutional framework. As a result, these households, already ridden with poverty have to resort to extremely severe coping mechanisms.

This study has been undertaken to fill this void; to examine care provision within the home with a view to documenting livelihood experiences and responses of these households in the face of HIV and AIDS, while seeking to generate knowledge to fill information gaps necessary for the execution of programs that ensure the provision of a comprehensive home based care that is effective, high quality and sustainable.

1.3 Study Objectives

Given the fact that families and households bear the greatest burden of AIDS care, the main objective of this research is to examine how such households in resource constrained settings cope within a framework of care provided in the home; and suggest ways to promote comprehensive HBC that reduces severity of coping.

Specific Objectives

i. To identify livelihood responses of resource strapped households to the impact of HIV and AIDS.

ii. To explore forms of care and support in Kayole with a view to suggesting ways of promoting comprehensive HBC.

1.4 Research Questions

Based on the above understanding, this study seeks to provide answers to the following questions.

i. What are the HIV/AIDS household level coping mechanisms in Kayole? This looks into:
   - Forms of livelihood generation by HIV/AIDS households in Kayole;
   - Spending patterns for the competing HIV/AIDS households needs; and
   - Probable patterns of change in behavior (individuals and households) in response to HIV/AIDS impact.

ii. What is the status of Kayole HBC initiative? This looks into the:
   - Forms of care and support provided in Kayole;
   - Needs and necessities of households in Kayole; and
   - Approaches aimed at promoting Home and Community Based Care

An understanding of these aspects is important to provide both the basis for the empowerment of caregivers and a body of information upon which an effective system of home based care provision can be institutionalized in the country. This is of extreme necessity given the pathetically wanting behavioral change and ever-increasing rates of HIV infection.

1.5 Justification for Study

Knowledge on responses of the various levels of social context to the impact of HIV/AIDS is vital as it helps in the identification of the reactions of individuals, families and the affected communities that require reinforcement (UNAIDS, 1999). This does provide a better understanding of the negative consequences of discrimination, stigmatization, and social exclusion as well as individual and household distress. Yet despite the ever-expanding number of studies on the impacts of HIV and Aids on the community and household levels, many always take the form of local descriptions of service provision by CBOs often on certain groups such as women and handling only certain particularistic issues.

Cohen and Trussell (1996) argue that such too singular focus on interventions meant to support responses and mitigate the ill effects tend to obscure the multifaceted nature of community level AIDS related care and support. This offers quite inadequate and less holistic understanding of the local responses to the epidemic. This is one principal reason for this study.

As a nation state, the country should strongly and convincingly demonstrate that families and communities alone cannot bear the burden of care and support. Unlike many public health problems, AIDS can affect all families: fathers, mothers and children being infected thereby disabling the economic viability of the entire family unit in the process. Worth noting are the inherent negative impacts on families and communities of laying the burden of care on households or women in the name of tradition (Chaila, 1994). These are aspects that require in depth exploration so as to enable the families and communities to confidently conceptualize their appropriate roles as care providers.

WHO (1993) does in fact underscore the value of care provision as a strategy of coping with the growing number of victims of HIV/AIDS pandemic. The value of knowing how households, families and communities cope with HIV and AIDS remains critically important if programmes and structures that will serve to reinforce these positive responses and mitigate any further negative reactions are to be put in place. The understanding that is lacking in many studies on the epidemic in Kenya will undoubtedly prove handy both in enhancing the capacity of caregivers as well as act as a tool for the development of effective planning programmes and interventions by the various institutions involved in the management of HIV and AIDS. This information is also expected to save

the various caregivers from the ceaseless strain of massive frustration, information vacuum and limited resources that are at the core of the coping and caring processes. Besides, this study is also meant to ignite research activity on HBC given the few research initiatives on this subject in Kenya. It is on this ground that this study is undertaken.

CHAPTER TWO

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

This literature review consists of two parts. The first section analyses empirical literature on health care, the impact of HIV/AIDS on healthcare systems and home based care. The section also looks at the needs and challenges of households affected by HIV/AIDS. The second section looks at the concept of coping mechanisms and how it relates to the provision of home based care.

2.1 Rationale for HealthCare

HBC as a Growing Problem

It is an indisputable fact that the demand for care for people with AIDS and HIV will continue to grow. Even if it were possible to prevent any new infections as of today, the demand for care will need to expand to meet the needs of at least some of the estimated 2.2 million people already infected and 12,000 new annual cases of HIV who will eventually develop AIDS. The ability of the government and societies to minimise future economic and social impact will be a direct function of the timeliness and comprehensiveness of planning for future demand (Jackson, 1992). It is clear, however, that these problems are not going away and indeed care is needed.

The Right to Care

Access to health care has been accepted by most of the world's governments as a basic human right. Full exercise of this right has been limited by inadequate resource allocation. However, as Aids patients continue to occupy majority of beds in numerous hospitals around the country, it is imperative to note that this right to care is one for which the government can actively plan, or to which it can powerlessly react. The government does not really have the option of whether or not to invest in care. Options available to it (government) in this context are only those of ensuring that within unavoidable resource limitations, the care, which is provided, is the most cost-effective and appropriate. The aim is to maximize the current investment in health infrastructure. According to Goodridge *et al.*, (1994), there are significant costs associated with failing to clearly define the most

appropriate role for the health care system and for not maximizing linkage and referrals to other care and support systems.

Strengthening Prevention

Public health planners will continue to balance resource allocations between care and preventions. It can be demonstrated that care can strengthen prevention. It has been argued, for example, that an exclusive concentration on those who are uninfected reinforces the belief that those who become infected are either careless or immoral. This results in a psychological disassociation with people with AIDS, consequently reinforcing the denial of being or having been at risk (Goodridge *et al.*, 1994). But, when families are helped to care for members with AIDS, people with HIV/AIDS are more likely to be included in community life, stigmatisation is ultimately reduced, and the community is empowered to address the pandemic.

Jackson (1992) notes that when AIDS prevention workers begin to respond to the care needs in their communities, they engender greater solidarity and trust within the community, which can lead to greater influence and credibility. Therefore, failure to respond to care needs undermines this solidarity (Jackson, 1992).

Care and support mitigate the familial and social impact of HIV/AIDS. This reduces vulnerabilities of HIV costs through family break-up. The reality is that some of the best Aids prevention workers are themselves HIV positive (Goodridge, *et al.*, 1994). In this case, the big question is whether we can fail to provide systems for them when they eventually require care or indeed for those who have been the target of our prevention efforts but will have contracted the virus anyway.

Cost-Effective Responses Exist

Cost-effective therapies, which can address opportunistic infections and related illnesses, do exist. Developing systems that provide these therapies in an efficient, and humane manner is a worthy and achievable goal. This can reduce the economic impact of Aids on communities and national development (Jackson, 1992). The continuum of care as articulated by WHO (1993), should be acknowledged as the 'gold standard' of humane and cost-effective care (Goodridge *et al.*, 1994). This model, however, would require adjustments based on the differing resources accessible to

various communities as well as the role of traditional practitioners and village leaders (WHO, 1988). In this regard, defining the therapies, services and strategies for meeting the needs of people with Aids is the responsibility of all stakeholders. This can only be successfully determined by accessing the particular strengths, resources and needs of these very PLWHAs (Seeley *et al*., 1995).

2. 2 HIV/AIDS and HealthCare Systems

Impact of HIV/AIDS on Health Care Systems

In depth and critical information that can provide a thorough assessment of the impact of HIV/AIDS on health care systems yet, this remains largely lacking. This is particularly the case for the developing countries with relatively poor information databases. For example, very little is known about the number of HIV infected people who seek health care, the number of opportunistic infections that they contract in the course of their illnesses, and whether they will indeed seek treatment for every one of these illnesses and at exactly which facilities. In fact, such an assessment can constitute a complete separate study on its own.

In many resource constrained countries, expenditures on health care are approximately US$5.00 or less per capita yet the cost of treating an Aids patient has been estimated to be at least twice the GNP per capital (WHO, 1994). In fact, the actual cost depends on where exactly the health care is delivered and whether or not the recommended treatment can indeed be provided. Typical problems here are such as the unavailability of essential drugs, and the treatment of the various opportunistic infections such as tuberculosis which on its own can cost many times the normal expenditure per capita on health care.

Mathematical models indicate that the estimates of the total economic costs must go further beyond public expenditures into covering the private expenditures associated with the health care for PLWHAs. These range from medical care, drugs, diagnostics, and transportation besides other expenses such as special foods. In certain cultures, funeral expenditures being private expenditures can devastate a household's finances (Woelk *et al*., 1997).

Despite these difficulties in estimates as relates to the unknown parameters of how many people seek care, where, how often, and the kinds of resources used, lifetime estimates of these HIV/AIDS treatment costs are noted to range from hundreds to many thousands of US dollars. In fact, WHO (1994) reckoned that the total cost of HIV/AIDS treatment in the developing world amounted to US$337 million while the cost of those requiring care is estimated at US$ 418 million. These figures were estimated to rise to US$1.1 billion and US$ 1.4 billion, respectively by the year 2000 (UNAIDS, 2002).

Ainsworth *et al*. (1994) have argued that the impact of HIV/AIDS is more like the ripples on a pool surface resulting from a stone thrown into the pool. Its impact is on the family, agriculture, industry, education, etc. According to a study of hospitals in Southern Zambia, the epidemic is having a major impact on health staff, mainly the nurses (Buve, *et al*., 1994). This enlarges the workload coupled with large-scale absenteeism amongst nurses leaving even greater workloads for the remaining staff.

A study in Mama Yeno hospital in Kinshasa showed the result of a random sample of 200 admissions in 1988 had half being sero-positive (Hassig, *et al*., 1990). It is noted that before the epidemic, the hospital was being fully utilized. This means that many patients therefore went untreated. In yet another study at the Kenyatta National Hospital in Nairobi, there was an increase in HIV sero-prevalence doubling in three (3) years. This greatly affected healthcare availability to sero-negative patients. In fact, the increase in workload due to HIV/AIDS meant that 20 percent or fewer sero-negative patients could be admitted. This saw an increase in mortality from 15 to 23 percent (Gilks, *et al*., 1993).

Data are increasingly emerging which show that other morbidities are being crowded out of hospital care. In many regions with over 80 percent medical beds in key cities occupied by HIV related illnesses, it is only logical to assume that patients with other morbidities will almost certainly not access these services unless it is a life threatening condition that requires hospitalization and intensive support care.

In this scenario, the solution to this problem is wanting. Whether additional hospital wards should be built, furnished and staffed particularly in the face of the ever-declining healthcare budgetary

allocations is an issue large and ripe enough for socio-economic and political instabilities. This does indeed call for relevant studies that can provide alternative solutions to this predicament.

Costs of HIV/AIDS Healthcare

Over 2.2 million people are already infected in Kenya. This requires a critical consideration of the kind of care and treatment that is both available and appropriate. The infection increase is causing many problems. This in turn calls for three main aspects of treatment: palliative care, prevention and treatment of opportunistic infections and anti-retroviral therapy (Shepard, 1997). Palliative care refers to the relief of symptoms associated with HIV infection such as skin rash, and these require treatment with relatively inexpensive drugs.

Opportunistic infections are conditions that take advantage of the weakened immune system. They are easily treatable with inexpensive drugs and include tuberculosis and pneumonia. The effective treatment of the infected persons extends life. Other opportunistic infections, mainly at the later stages, however, require more expensive drugs such as those for herpes and simplex virus.

Anti-retroviral drugs on the other hand have proved effective in treating HIV infection. However, the main problem is that these drugs remain quite expensive. They cost approximately US$ 1,200 to US$ 2,000 per year (Shepard, 1997). This translates to approximately Kshs 96,000 to Kshs 160,000 per patient per year exchanged at Kshs 80 per one US Dollar. Still this excludes other related medical costs.

Goodridge *et al.*, (1994) estimated the cost of hospital care for AIDS patients at Kshs 27,200 per patient per year in 1993. Sessional Paper Number 4 of 1997 approximated the direct cost of treating new AIDS patients at Kshs 34,680 per patient per year while indirect costs are estimated at close to Kshs 538,560. This summed to approximately Kshs 573,240 per patient per year (NASCOP, 2001).

According to Nalo and Aoko (1994), the potential cost of treating Aids by the year 2000 equated the entire 1993/1994 recurrent budget of the Ministry of Health. In this same analysis, it was noted that the total cost of Aids to the economy ranged between 2 and 4 percent of the GDP. This was projected to increase to 15 percent by the year 2000 (Nalo and Aoko, 1994). Such patterns of rise in

the cost of Aids, particularly for a developing country like Kenya with a per capita income of US$ 280, is a situation yearning for a solution.

At another level, the demands on the health service paint an even gloomier picture. Even though not all people seek hospital care, a study in 1992 showed that 15 percent of all hospital beds countrywide were occupied by AIDS patients (NASCOP, 2001). Ngugi (1995) argues that bed occupancy for HIV/AIDS patients was 30 percent for urban areas and 10 to 30 percent for the rural areas. There are, however, other exceptional cases such as Kisumu and Busia that recorded close to 70 percent bed occupancy for HIV/AIDS patients. According to NASCOP, about half of all hospital beds were required for Aids patients in the year 2000 (NASCOP, 2001). In this way, it is only reasonable that alternative ways deserve to be looked into such as *home-based care* to help address this critical situation.

Table 2.1 Estimated Costs of HIV/AIDS therapies per patient per year (US $)

Type of treatment		Approximate cost in US$ per patient per year)
Palliative		20
Opportunistic	Inexpensive	30
	Expensive	200-2000

Like in Kenya, Kello (1997) argued that in Ethiopia, the cost of hospital care for an AIDS patient ranges from birr 425 to 3,140 birr, averaging at 1,800 birr. The government projects a rise in total cost estimates from 87 million birr in the year 2000 to 185 million birr in 2014. The study noted further that 42 percent of the country's hospital beds occupied by AIDS patients would rise to 54 percent by 2004. According to Kello, this indeed requires greater search for alternative HIV/AIDS care initiatives (Kello, 1997).

Comprehensive HIV/AIDS Healthcare

HIV related infections and illnesses are opportunistic infections that are caused by native environmental organisms and so are illnesses that anybody within the population can incur. In immune suppressed individuals infected with HIV, however, these illnesses are often more frequent,

severe and prolonged, though they largely remain treatable with the same range of medications typically used in basic health care.

A more critical issue in HIV/AIDS is that very rare morbidities within the general population often occur such as the *cryptococcal meningitis*, aggressive *Kaposi's sarcoma* in young persons, and *oesophageal candiliasis*. In many cases, the medicaments for these conditions are not readily available, or actually not available at all within the public drug supply systems especially in resource constrained settings (RCS). According to Gilks (1993), the full range of pathogens associated with HIV infection particularly in the developing world and even still by regions, remains largely unknown in its entirety (Gilks and Otieno, 1993). An effective care for HIV/AIDS therefore requires a comprehensive health care comprising the components of clinical management, nursing, counselling and social support coordinated in a care continuum.

According to the Health Care and Support (HCS) unit of the WHO Global Programme on AIDS, these programmes are described as thus (WHO, 1993):

i. Clinical management that includes appropriate diagnosis; rational treatment and planning for follow up care of illnesses related to HIV infection (WHO/GPA/HCS, 1991; 1993).
ii. Nursing care includes the provision of medical care, maintenance and promotion of hygiene and nutrition, infection control practices, provision of palliative care, counselling and education of family members on prevention and to provide care for the afflicted family member (WHO/GPA/CNP/TMD, 1993).
iii. Counselling, the provision of psychological support, does include helping individuals make informed decisions on HIV testing, stress management and anxiety reduction, planning for the future, promoting positive living, networking and promoting behavioural changes. In fact, pre and post-test counselling plays a key role in HIV/AIDS prevention.
iv. Social support does include the provision of information, referral to support groups, welfare services and legal advice. This also includes the provision of help in planning care and schooling of surviving family members and where feasible, material assistance can also be provided.

Comprehensive HIV/ AIDS Care across Continuum

The concept of comprehensive care across a continuum refers to the care taking place in an institution, home, or community with services provided by agencies through home visits. The aim is to strengthen and support the patient and family's resources as well as facilitate the caring role of the family. This care can be provided by the patient himself or herself, a friend, a family member, a relative, a volunteer, or the health care personnel. In all these exercises, the main focus is on the individual and the family or household as well as the expansion of the extended community support.

This care should be accessible at several points along this continuum. It is imperative that whatever the entry point, the four components of health care (clinical management, nursing, counseling and social support) are adequately provided (Osborne, 1997). However, such an approach cannot succeed without an appropriate coordination between the points on the continuum. These points, the district level health facilities and community based services, which are largely run by NGOs, private voluntary or religious groups require a well developed awareness of how, where and when such appropriate health care can best be sought or delivered.

A continuum health care for HIV/AIDS patients indeed requires an efficient and effective referral mechanism from hospital/clinic to community based services and vice versa. In all this, the outpatient home based care and community services form the backbone of this care with the mid level (district) health facility only providing support. Many of these community or home based services comprise day care centers, support groups, organization of income generating activities as well as other services enhanced by the assistance of NGOs and voluntary groups. It has widely been acknowledged that the community-based services are capable of making great and significant contribution in the provision of support for families affected by AIDS (Campbell *et al.*, 1990).

At the integral part of the community based services however, is the home-based care. As mentioned earlier, home based care involves the training of family members as care providers, the management of common symptoms, and provision of supervision and guidance by community based workers. It also involves palliative care and moral support for families to sustain hygiene and nutrition, as well as linkages to social welfare systems (WHO, 1994). In fact, according to Mansfield, Simon and Surinder (1993), it is already clear that strictly hospital based service in the care of HIV infected

people is untenable, inappropriate and wasteful. This makes the community an ideal place to meet the numerous needs of those infected. However, to attain success with community-based care, there will be need for effective conditions of tolerance, support and solidarity (UNAIDS 1999). This implies that scenarios characterizing denial, fear, discrimination and stigma indeed require to be dispelled through dialogue on a continuous basis to enhance awareness on the epidemic, including education for prevention.

Benefits of Comprehensive Care across Continuum

The AIDS epidemic has vastly increased pressure both on the formal and informal care systems particularly for the countries of Sub Saharan Africa. Majority of these countries are actually resource strapped and their existing services already eroded by the economic Structural Adjustment Policies (SAPs). The analysis of such a care presumes that given the infection rates, the demands on care services, both health and welfare services, will continue to grow sharply. This growth, however, is against the fact that the state resources attributed to meeting these ever increasing demands are likely to either remain static or decrease in real terms. To therefore look unto the governments for significant increases in support may result into problems (UNAIDS 1999). This is because the pressure on families and communities to cope with AIDS patients will continue to escalate regardless of their capacity to provide adequate care. As a result, other alternative sources of support are required from local, national and international NGOs, through the private sector as well as other potential resource bases (Jackson, 1994).

Care in a continuum thus involves medical, nursing, informational, psychological, social, pastoral/spiritual, material, practical, advocacy, ethical and legal needs (WHO, 1991). It is for the patients, whole family, surrounding community, employees, and their significant ones. The needs for this care arise from illnesses and other related crisis as well as support during the chronic phase or infection through to death and continued support for dependents. Such care may also involve as a consequence, measures of prevention (UNAIDS, 1999). Based on this, it is therefore logical to refer to the comprehensive care as a wide range of needs experienced by a number of people in different ways over an extended period of time.

The value of such care cannot be overemphasized. Well cared for people with adequate emotional support tend to have a positive attitude and are well nourished. This makes them respond better to medication and enhance compliance with drug regimes (Jackson, 1994). This is particularly important for early detection and treatment of opportunistic conditions as well as avoiding complications. This then helps to reduce demands for costly treatment. To the public health system, it is an undertaking that is vital in preventing continued transmission to others.

It is important to note that the benefits of care are achievable at various stages of the HIV infection and disease. Good access to care particularly at the early stages and counseling help the individual's family cope better. This helps delay the progression to AIDS. Palliative care on the other hand, particularly in the late stages and more so for dying patients helps improve the quality of life and the experience of death and bereavement. This often involves relief from pain (Colebunders *et al.*, 1995). Basic care, especially palliative care provided on the basis of humanitarian grounds does ease symptoms, and relieves pain and distress. If provided by the family at home, even the costs remain relatively lower and manageable.

It has largely been noticed that many initiatives have greatly divorced care from prevention efforts. The reality however, is that people who feel cared for are able to cope well with the disease. They are much more likely to understand the value of protecting others and would indeed be motivated to do so. In this context, Jackson argues that PLWHAs must remain key targets for prevention initiatives for "the virus can only be transmitted through them" (Jackson, 1994:2). A safety fundamental in care provision relates to the potential for viral transmission to caregivers from the open sores and body fluids. This puts a solid case for the need for access to information and the means of protection.

Beneficiaries of Comprehensive Care across Continuum

The key beneficiaries of any comprehensive care system remain the individual patients, the family and to an extent community through improved health and welfare enhancement. Though this largely depends on the magnitude of the home based care program, services range from small needs of individuals and families which remain significant in the context of people's experience with illnesses and death; to programs whose impact are felt widely outwards (WHO, 1994).

Communities often benefit from these programs especially when detection and referral networks are improved thereby enhancing better access to health by the people. This calls for direct community involvement. In many cases, this might be viewed as being more burdening to the community, but it also serves to strengthen the degree of control of allocation of resources within the community (World Relief, 2000).

Other beneficiaries are the care staff themselves who benefit through the work undertaken that often involve professionals as well as lay caregivers. This enhances families' capacity to cope and reduce infection levels. In this way, it helps facilitate important links, and improve contacts between various stakeholders such as governments and NGOs. Besides, they remain very necessary aspects in the context of facilitating referrals and reduction of bureaucratic delays in provision of services.

The formal health system cannot be excluded from the list of potential beneficiaries. Their benefit however, requires an in-depth analysis. The need to reduce pressure on hospital bed space, the prioritization of the admissions and treatment for various patients to attain overall optimal benefits is unquestionable. However, this calls for a thorough understanding of the dynamics of hospital-home care relations. This understanding is necessary particularly in the context of discharging patients where HBC schemes are available but without any meaningful follow up to establish the adequacy of such schemes of care. This has often led to great burden on caregivers in the homes leading to home care being lately referred to as home neglect (Nko *et al.*, 2000).

2.3 Home Based Care

Home care remains an integral and potential option in HIV/AIDS care. This, however, requires training of the family care providers to provide back up support of various sorts. These may range from diagnosis, nursing care, drugs, material aid, counseling, and pastoral care among others. The home care component also includes the referral of patients back to hospital, whenever necessary.

The emergence of home care can be placed in various spheres of development. Whereas some originated from within the community and later developed hospital and other links for a sustained care like the TASO of Uganda; others such as the Chikankata hospital initiative developed from hospital outreach programs. Still others begin as collaborative efforts between hospitals and clinics, community groups and NGO agencies like the Kariba AIDS Network in Zimbabwe.

These initiatives often begin with simple medical focus but integrating counseling, pastoral as well as material support and later expand as the need for health related support increases. Of greater concern to home care is the impoverishment of many of these households. The impact of the World Bank and IMF's SAPs has subjected these households to greater economic hardships thus posing an extra burden of coping with the additional financial burdens of AIDS.

According to the results of a baseline survey of AIDS home care service in Zimbabwe, Jackson and Mhambi (1994) note that the most critical problem in home care is poverty. This means that many patients suffer from the inadequacy of food, clothing, blankets, simple nursing aids, and medicines. These patients die in deplorable conditions (Jackson, 1994). In many cases, patients often gain no access to formal health services because of inability to pay. Referral to integrated home care services is often only when the situation is critical. Dew *et al.*, (1994) observe that it is not uncommon for the integrated home care services to only reach 3 percent of those potentially in need of home care (Dew *et al.*, 1994).

Objectives of Home Care

The need for economic growth and development can be viewed in many contexts. Home care is important in improving the quality of low cost care through caring for chronically ill persons within the family context and by reducing congestion in health facilities. Emotional, mental, and moral support that is required to a greater extent by the affected households and particularly the victims are better offered within the environment of the home and community setting. Besides the reduction of social stigma and fears related to HIV/AIDS, home care equally tends to increase the acceptance of PLWHAs within the family and the community (Mansfield *et al.*, 1993).

Home care is also important in supporting the ill persons and their families through solidarity of the community including material support, food, income generating activities (IGAs), and support for children. At another level, home care remains quite necessary particularly in educating PLWHAs, their households and the community members on HIV/AIDS prevention and control. This is more important when the need is felt and the instruction is personalized using credible sources and channels of communication.

Justification for Home Based Care

The increasing number of Aids patients as indicated by the incidence of HIV averaging 12,000 new cases every year in Kenya requires care. Coupled with the observation that HIV/AIDS patients occupied 15 percent of hospital beds spaces in 1992, 30 percent in 1997 and 51 percent in 2000, there is indeed great need to explore other ways of care.

HBC is also needed because good basic care is possible in the home setting given inherent advantages. It has been argued that people who are terminally ill would rather stay at home especially once they accept death (KANCO, 1997). In fact, in the African context, the family remains the greatest strength of the people in the rural areas particularly in Kenya. Sick people have also been noted to derive optimal comfort by being in the environment of their homes and communities with family and friends around them.

Home care is important in reducing overcrowding at hospitals. It is important in improving the quality of care of AIDS and other patients at institutional level. It is also noted to be a realistic and

cost effective approach in the care of PLWHAs since it greatly reduces the costs spent on hospital visits both by the patient and their families. This in turn affords the families some time to attend to other important socio-economic activities in the context of overall development. The home care initiative also enhances continuity of care from hospitals to the home via rural health facilities and the communities' own resource persons. It also leads to the reduction of social stigma and fear associated with HIV/AIDS through participation and involvement in joint activities.

Advantages of Home Based Care

From the foregoing argument, the value of HBC cannot be overemphasized. Home care grants the health care providers the opportunity to assess the patient's social and economic situation as well as patient's requirements. This system of care also helps to break down the sense of isolation often experienced by numerous HIV/AIDS patients just as other chronically ill patients. This enhances acceptance at home and consequently helping to encourage future planning and positive thinking. The system equally does give the health workers an opportunity to get into contact with the family members of the patient. This also enables members of the family to gain access to counseling and consequently support the dieing individual. Home care helps put Aids care providers in actual touch with potential orphans, enabling support services and plans to be developed prior to a crisis.

It is also important to note that this system of care generally creates HIV/AIDS awareness within the community thereby preventing further infections. Its reduction of pressure for the much-needed space on hospital beds is no new knowledge. It helps reduce the cost of care within the health setting, enhances equal sharing of responsibilities amongst family members and giving them the opportunity to participate in the care of their loved ones. In many cases, it enhances occupational therapy: making patients useful by doing some income generating activities such as knitting and kitchen gardening. Besides the promotion of a holistic approach to care including pastoral care, the home care system in utmost helps the PLWHAs spend their remaining days in comfort around loved ones and familiar surroundings. They are able to die with dignity. The system benefits greatly benefits at the household level since family members provide emotional and spiritual support, basic nursing as well as financial and practical support to the sick. The family is also important in enhancing the reallocation of tasks and roles within the household as well as planning for the future welfare of the surviving members of the household.

Needs and Support required by PLWHAS and their Households

The caregivers at the household level, in themselves require great amounts of support to ensure effective provision of care. Such needs include HIV/AIDS education to reduce personal fear and anxiety, the need for skills particularly on basic practical nursing techniques and practices and for maintaining positive outlook. They equally need various other materials, financial as well as practical support. Other needs include effective reallocation of tasks and roles within the family context as well as appropriate planning for the future welfare of the surviving members of the community.

Satisfactory health provision however, should often be based on the needs of PLWHAs as identified by them. These needs differ greatly given the socio-economic context and culture. In many regions of the world, the human rights of PLWHAs have been violated particularly in form of rejection and discrimination (Colebunders *et al.*, 1995). This has greatly affected their chances of receiving adequate care. Indeed, the PLWHAs have made known their needs both in local and international fora. However, the voices from the developed world have apparently been heard more than those from the developing world. This has seen a great variation in their needs as well (Colebunders *et al.*, 1995).

Within the affluent settings that have assured basic requirements such as food, shelter, and treatment for opportunistic infections, the demands by those infected with HIV and AIDS are distinct. These largely include the right to protection in employment, confidentiality, medical care, and access to treatment. They require new drugs, bereavement counseling, emotional support and the consideration of sexual needs. In Resource Constrained Settings (RCS), however, the demands mainly relate to basic needs such as drugs for treating opportunistic infections, financial help to pay for food, support so that they and their surviving children may stay in the family home, and some assurance that their children will be cared for after their death (World Relief, 2000).

Categories of Needs for PLWHAs

The needs assessment of PLWHAs is largely complicated by the fact that their needs often change with the progression of the disease. These needs also change with the different settings whether in formal health centers or home environments. A study in Malawi in 1990, classified the needs of PLWHAs into four main categories.

Food: Cases of repeated episodes of illnesses particularly in the productive adult members of the household often results in a progressive fall in income. Within the last stages of the disease, this may translate into no income at all. Within the food growing and non-purchasing households, such production falls gradually. This may translate into no food at all for the family when the PLWHAs eventually cannot work. In poverty stricken households, the additional disease burden is indeed devastating (WHO, 1994:64).

Clothing: The conditions of PLWHAs require frequent and regular change of clothing both for hygiene and comfort of the patient. The skin lesions and the repeated prolonged episodes of diarrhoea necessitate this (WHO, 1993).

Medicines: The treatment for common ailments and opportunistic infections is necessary for PLWHAs. In resource-constrained settings, however, many health facilities particularly the peripheral centers often lack adequate supplies of essential drugs for such ailments. This indeed, is a classical difference in which the demands of the affluent societies are mainly access to innovative treatment trials (Chaila, 1994).

Support for children: Based on the fact that schooling is largely viewed as the only hope for brighter future (Trostle and Jonathon, 1992), it remains one great aspect of concern, particularly the provision of school fees and uniforms. It is noted that concerns relating to safeguarding confidentiality and even combating discrimination do not feature greatly. This is largely attributed to the families long learned conditions and acceptance of the patients HIV status particularly if cared for at home (Chaila, 1994).

A study in Zimbabwe noted that the most common needs for PLWHAs largely related to the alleviation of emotional stress and the additional economic hardships. According to Jackson and Mhambi (1994) such needs were mainly due to paternal desertion, neglect or conflict over wives and children, inheritance of property, or lack of acceptance by the extended family (Jackson and Mhambi, 1994).

An evaluation study of PLWHAs' needs in Uganda indicated that medical treatment, counseling and material assistance as the most common (Barnett *et al.*, 1992). This study, like in the case of Zimbabwe showed a larger percent of PLWHAs feeling accepted not only by the families or households but also by the community (TASO, 1994). From this evaluation, stress was noted to be most acute. This was particularly at the times of diagnosis, when regular or occasional cash income is lost, or when need emerged for specific additional expenditures, say for funerals, or transportation to hospital. Stress was also experienced especially when matters of inheritance arose, when wife or mother became ill or died and, when the extended family's capacity or willingness to assist broke down (Jackson *et al.*, 1994).

It is worth noting that the perception of the community as regards the acceptance of the disease has been noted to be mixed yet these remain very fundamental to HBC efforts. A study in Zambia reported that many women felt that even if the relatives of PLWHAs are also themselves infected by Aids, they still remained, together with friends, in the best position to provide care to own infected kin(s). A significant number of the women perceived the role of care provision as the task of the government while a small group of them felt that PLWHAs deserved no care at all.

Nnko *et al.*, (2000) carried out a study on care providers in families with chronically ill AIDS sufferers in Igoma, Mwanza in Tanzania. The study focussed on the needs of the AIDS victims and their carers. Such needs were noted to range from palliative care to technical needs. They also noted that the success of such care largely depended on the economic support system that the country enjoyed. In addition, they analysed the coping strategies and the concepts' relevance to understanding the survival alternatives available to HIV/AIDS affected households. Their conclusion confirmed that the burden of caring for Aids patients remained with the family itself, and

with outside support mainly from friends and neighbours. Economic needs ranked highest given the poverty levels in many of those households.

Machipisa (2001), reporting on UNIFEM's community based study in Zimbabwe noted high levels of discrimination especially for women and their double burden as the primary care givers to HIV positive relatives and orphaned children. The study noted that the authorities (hospitals) resorted to discharging patients and encouraging home-based care (HBC) due to the cost of hospital based care. The report noted that the home carers were mainly women yet many of them were of childbearing ages with little or no prior experience in caring for Aids patients. They faced practical nursing problems due to *inadequate information on HBC*. It concluded with a call for the need for multicultural programmes and strategies to empower women and girls who were the main carers. This outcome provides an important insight for this study particularly on information vacuum and challenges faced by the home based carers.

However, the above study is more focused on gender relations and falls short of understanding the coping mechanisms of the caregivers. One key recommendation of the study is that there is need for more information particularly on HBC as what was available was simply awareness.

Kusimba *et al*., (1996) outlined in their result of a study on women's responses and needs that the critical kind of support to the families, particularly to the women, were psychological, social, economic, health, education and information. They noted great need for counselling particularly at the provision of test results. Noted as critically important was also counselling of the caregivers and other immediate family members for effective guidance in supporting the affected family members. The result also noted the potential role that could be played by government and NGOs together with other interest groups in support provision.

The above study is important and relevant. It touches albeit superficially, on the various support systems and the possible roles of various institutions. However, the study is largely limited to the requirements of women thereby denoting a gender bias in the context of recommendations. It equally fails to move in depth into understanding the means by which such institutions could practically meet the needs of the people.

The World Bank has noted that the effects of HIV and AIDS on the household are aggravated by the extent and depth of poverty (World Bank, 1997). It argues that in this context, households might, as a coping mechanism, attempt to compensate for the loss of economically active adults through "working longer hours, selling assets, and withholding children from school" (UNAIDS, 1999; World Bank, 1997). It is also noted that the extent to which these households can cope with these impacts vary dramatically. The World Bank argued further that economic impacts tend to be larger on poor households thereby affecting food consumption, child nutrition, and school attendance besides other factors (World Bank, 1997). This World Bank study though relevant, fails to move in depth into understanding the various coping strategies that are at the core of my research.

Ankrah (1996) argued in his study on the impact of SAPs in aggravating the situation of the disease that the programmes were characterised by increased migration and urbanisation. This was coupled with reduced spending on health and other social services. Consequently, this resulted into massive out migration by men leaving the female as household heads with little or no option than being occasionally or regularly involved in sex trade as a strategy to obtain income.

Role of Institutions in HIV/AIDS Comprehensive Care

Care and support provision particularly at the community level can be viewed in three interlocking respects. The formal healthcare system, the voluntary care system including support provision through Community Based Organizations (CBOs) and non-governmental organizations (NGOs), and the informal care system constituted by support from friends, families and other relatives (UNAIDS, 1999). The formal health services constitute the primary healthcare (health posts, dispensaries, traditional healers and orphan care), secondary healthcare (district hospitals, HIV clinics, social/legal support, hospices etc) and tertiary healthcare (specialists and specialized care facilities). The voluntary based Community care system includes services by churches, CBOs and NGOs, youth groups, volunteers etc. The informal home care system on the other hand constitutes palliative, emotional and spiritual support as well as self-care (occupational therapy) often provided by friends, families, relatives and the patient himself/herself if still strong and capable. This should be complemented by VCT services as an entry point. This is the continuum of care and support.

This arrangement denotes responsibilities for various institutions such as the government, NGOs, CBOs, churches, communities and the other levels of the social context in providing care and support within the health care delivery system. In Kenya, these efforts aimed at delivering health care and support particularly as relates to HIV/AIDS have often lagged behind in priority compared to prevention. According to Ankrah (1996), this is apparently the case everywhere particularly in the developing regions (Ankrah, 1996). These daunting tasks of care have in turn been left to the community members, mainly the women who are often unpaid for services rendered. Breaking this burden indeed requires a deliberate institutional intervention. According to Shrestha (1996), a few CBOs are beginning to provide such interventions by giving specific responses to the burdened families. These CBOs, however, operate on the principles of self-help. Their successes and initiatives are therefore likely to conceal the gaps in the more formal health care provision, thereby making the formal health authorities to abdicate their responsibility in health care provision to these organizations.

Whereas the value of CBOs, NGOs and other voluntary institutions in provision of care is significant, Leonard and Khan (1994) have however, argued that a number of factors especially limited resources could limit the effectiveness of these organizations. Mannemplaven (1992) notes however, that even in some well-funded organizations, resources are often put to waste because of poor management. In this context, options for care and support become limited. This is particularly so when the national government slips off its obligatory role of taking the center stage in shouldering the responsibility of coordination and activation of the international donors, NGOs and other stakeholders towards this initiative. Cohen and Trussell (1996) argued that because of this, there is indeed a fundamental need for AIDS specific NGOs that would then enhance care provision and assist in mitigating the impact of the epidemic.

The various other institutions also engaged in HIV/AIDS care activities besides the NGOs and CBOs are in themselves equally important. Together they promote networking and sharing amongs the various individuals, groups, and organizations. They have a key role in undertaking researcl particularly to identify community needs, attitudes, behaviour, as well as practices. Thei responsibilities involve training the Trainer of Trainers (ToTs), educators, counselors, and car providers. They train self-help groups and provide support in cash, kind and the expertise t

ommunity based groups as well as the provision of linkages with the donor community. These nstitutions are also quite important in promoting forward planning especially in member agencies vith particular attention to the impact of Aids on individuals, families, communities and organizations. They equally promote positive policy development at national, local and organizational levels as well as advocate for the rights of PLWHAs and their families. The nstitutions are also renowned in mobilizing communities into taking responsibilities for prevention nd mitigation against the impacts of STIs and HIV/AIDS on the family and orphans.

.4 Theoretical Rationale and Conceptual Framework

Theoretical models greatly facilitate understanding of health behaviour and equally aid the levelopment of appropriate assessments and interventions. Such initiatives are themselves very mportant in helping people initiate and maintain health behaviours and lifestyle changes that are esponsive to their conditions. The following three behavioural science models have been employed n this study. The aim is to answer the following research questions:

What are the HIV/AIDS household level coping mechanisms in Kayole? This looks at the forms of livelihood generation by these households, the spending patterns for the competing household needs and the probable patterns of change in behavior (individuals and households) in response to HIV/AIDS impact.

What is the status of Kayole HBC initiative? This looks at the forms of care and support provided in Kayole, needs and necessities of households in Kayole and the approaches aimed at promoting Home and Community Based Care.

1) Social Cognitive Theory

The Social Cognitive Theory (SCT) is one of the most influential models of human behaviour. The theory stemmed from the Social Learning Theory (SLT), which has a rich historical background dating back to the late 1800's. Albert Bandura, the originator of this theory began his work on Social Learning Theory (SLT) in the early 1960's, culminating into the launch of SCT with the publication of his book titled "*Social Foundations of Thought and Action: A Social Cognitive Theory*" in 1986. The SCT has its origins in the discipline of psychology, intended to explain why people and animals behave the way that they do. Bandura (1986) notes that the theory focuses on how children and adults operate cognitively on their social experiences and how these cognitions then influence behavior, responses and related development. In 1986, Bandura renamed his SLT, Social Cognitive Theory (SCT). His work has been extremely fruitful in developing techniques for promoting behavior change and more recently has been redirected from developmental psychology to the field of health psychology. Rotter (1954) also focused on the application of SLT to clinical psychology arguing that health outcomes could be improved by the development of a sense of personal control over one's life.

According to this theory behaviour. cognition and other personal factors as well as the environment are all seen as influencing one another. The relative influence of each of these is seen as varying from one activity to another and from one person to another, but each component is considered in developing behaviour change interventions. The model also focuses on how people learn thereby making lifestyle changes. In fact the process of making lifestyle changes in itself represents a process of learning. This complex process may include adopting new behaviours and/or discarding old ones and making simple and graduated changes. The model also gives emphasis to the importance of self-efficiency or judgements of capabilities to engage in specific behaviours required for various tasks. Self-efficiency in this respect is considered as a strong and consistent prediction of health behaviour change, across multiple types of behavioural and health conditions. The theory also emphasises the value of learning by observing others and following the behaviour of role models.

Aggleton and Warwick (1999) employed this theory in investigating community responses to AIDS in India, Dominican Republic, Mexico, Thailand and Tanzania. The model was also employed by WHO (1993) stating that: "...human beings, either as individual or collective bodies, act in response

to events and crises that challenge their structured patterns of existence and survival and, in the process, their lives move on and societies evolve" (WHO, 1993). Therefore, people naturally develop coping mechanisms when they have been traumatized.

In this context, the experience of HIV/AIDS as a challenge to individuals, households and communities provides a learning process that translates into the development of behavior change interventions. These responses, whether undertaken as individuals or collectively emanate from a learning process that entails behavior, cognition or psychology, personal factors (socio-economic) as well as the environment and how these influence one another.

The behavior change interventions may involve adopting new behaviors, discarding old ones and/or making simple and graduated changes to enhance survival and continuity. These behavior change interventions are herein referred to as the coping strategies. The main limitation of the theory is its comprehensiveness and complexity that makes it difficult to operationalize. Many of its applications also focus largely on either one or two of its numerous constructs, such as self-efficacy, while ignoring the others.

The model also fails to give a clear understanding of the principal factors of accessibility, affordability and other socio-cultural factors and their impacts on the health care seeking patterns of individuals and communities. These are factors that remain extremely important in determining health care outcomes and are better explained by approaches of health care seeking behaviour.

2) Health Care Seeking Behavior Approach

The health care consumption patterns of individuals, households and communities depend greatly on the accessibility, affordability as well as other socio-cultural factors held by these various levels of the social context. According to McKinlay (1972), these factors that determine an individual's healthcare seeking behavior include economic dimensions particularly the financial barriers that tend to inhibit healthcare service consumption due to inability to afford such services by individuals. The socio-demographic factors that influence utilization of health services include age, parity, gender, and education while geographic factors mainly relate to the issues of proximity to health care services. Psychological dimensions take into account the individual motivations while socio-

cultural factors relate to norms, values, beliefs and lifestyles: all of which influence how an individual seeks healthcare. The effect of the health care organizations is also important to the health seeking behavior of individuals.

According to Kroeger (1983) however, the socioeconomic and demographic factors together with exposure to modern health care services are crucial in determining the decision to seek care. In this context, age, education as well as places of residence greatly influence the decision to seek care services. Other principal factors that influence decisions to seek care include expected benefits from treatment and belief considerations on the quality of care as well as the cost and availability of healthcare facilities.

This approach is particularly important for this study as it explains the factors that influence the decision making process of individuals in seeking for care. Many individuals (PLWHAs) cared for at home constantly face these decisions and have to make choices based on their financial abilities, age, gender, education, psychological as well as cultural considerations. These in turn have a great bearing on the comprehensiveness of health care provision particularly within the home settings.

The SCT has been applied to understand how people learn from their everyday experiences thereby making lifestyle changes particularly in the face of HIV/AIDS. The health care seeking behavior on the other hand has been applied to understand the health consumption patterns of individuals, households and communities and their resultant outcomes. These models however, do not effectively explain the coping strategies adopted by the individuals and households in response to the strains resulting from the impact of HIV/AIDS. This explanation is captured by the coping strategies approach.

3) Coping Strategies

The coping strategies approach adopted in this study aims to help understand how individuals and households respond to the impacts of HIV and AIDS. The analysis of the impact of HIV/AIDS on livelihoods has often been undertaken under the rubric of coping strategies. The use of this framework in explaining household responses to disasters gained prominence largely in the 1970s and 1980s when famine threatened larger magnitudes of human lives mainly in the NorthEast Africa and the Sahel region. Since this period, various scholars have used the model to analyze household responses (Topouzis, 1999; UNAIDS, 1999). Whereas the concept has had vast use in social science literature, its use in medical literature has been limited mainly to cases of mental health (McCubbin, 1979). The emergence of HIV/AIDS has, however, given the framework a new lease of life particularly in analyzing the impact of the disease on the households (De Waal, 1989; Rahmato, 1991; Devereux, 1993).

The framework is traceable to the resurrection of the neo-liberal free market ideology in the 1970s. This worldview holds that households are as economic agents that will cope with adversity based on the specific knowledge that they have of their environment. In this context, the assumption is that households do exist in an institutional framework where the market is the prime mover (Rugalema, 2000). Consequently, the market's role is to facilitate the involvement of the household in economic activities where the household would then secure the resources necessary for coping.

The framework assumes that when the household is confronted with difficulty, the economic units or agents such as individuals, households and firms do make rational decisions to overcome such a situation. It also assumes that the market helps in the facilitation of the process of coping. Thus a household that lacks money to purchase food or other household requirements during the lean period or periods of inadequacy, probably due to reduced incomes resulting from the death of household members will resort to the sale of livestock or other assets or simply exchange the same for food (Rugalema, 2000). This means that the households can cope by drawing from their own resources rather than through reliance on state provision.

According to Devereux (1993), households therefore engage with the market and make rational choices about which assets to dispose of and which ones to retain. This involves the juggling with

portfolio of activities to attain a balance between the needs and resources while the market reacts to the supply and demand signals thereby enhancing a fair deal for both the buyers and sellers.

The present form of this conceptual framework owes largely to the works of Michael Watts (1983) on famine survival strategies in northern Nigeria. According to Curtis (1995):

Famine coping strategies are a set of activities taken by a household in a particular sequence in response to external shocks that lead to the declining availability of basic needs. The long-term objective of these strategies is for the household to maintain its economic and social viability after the crisis has passed (Curtis, 1995:58)

Whereas the framework has widely been used to explain household responses to famines (Corbett, 1988; De Waal, 1989; Rahmato, 1991; Devereux, 1993), it has also been considerably employed to explain the impact of HIV/AIDS on households (UNAIDS, 1999). Adopting this framework in their investigations, numerous scholars have increasingly pointed out that HIV/AIDS epidemic has significantly impacted on household and families (Kwaramba, 1998). Barnett and Blaikie (1992) and Rugalema (2000) noted that HIV/AIDS induced illness and death of adults pose significant implications for the household composition, labour and income. Rugalema (2000) has argued that these adversely affect the "ability to produce food, schooling of children, cropping patterns, livestock production, labour allocation, access to productive assets and consumption of goods and services essential for household maintenance and reproduction"(Rugalema, 2000:538). Complex patterns of change have consequently resulted amongst these households. This has in turn reshaped how these households do their daily business as well as react to the society.

Rugalema (2000) however, cautions on the use of this framework on the basis of its variability for explaining the effects of the HIV/AIDS epidemic particularly as relates to policy decisions and resource allocations between government and the communities. Focusing on rural livelihoods, he noted that coping concerns the analysis of success and not failure. Consequently, its use in describing households implies that they are managing well or at least persevering. This however, may not necessarily be true especially when an adult's death is involved resulting into household dissolution. He emphasized the dangers inherent in utilizing the framework to shape policy since the

concept assumes that 'things are fine' or that the 'situation is under control'. This he argues may make policy makers visualize little or no rationale for intervention. As a result, communities may increasingly be forced to bear more in programme responsibilities yet issues relating to resource allocation between government and communities are sidestepped.

Therefore whereas the concept is relevant for analyzing other disasters such as famine, Rugalema argues that it may have little relevance especially where the socio-economic and ecological transformations are involved with long-term implications for recovery, as is the case for HIV/AIDS. To him, the case of AIDS is not a coping strategy. Instead, it is a struggle and one that is being lost given the nature of household transformations and related implications for recovery.

Rugalema's study gives a critical analysis of the conceptual framework within which this study was based. It draws attention to the limitations of the concept of coping strategies in understanding the impact of HIV/AIDS on livelihoods particularly under circumstances where adult mortality results in household dissolution. In these instances, survivors often leave the household and join (an)other household(s) mainly due to economic and social insecurities resulting from the loss of such a key household member.

This study, however, focused on existing households that were experiencing the impact of HIV/AIDS and not those that had undergone dissolution. This therefore makes the framework applicable. In addition, the framework explains the factors that govern these coping strategies and the relevant choices made by individuals and households. These choices and strategies have implications on the people's health seeking behavior and what is within their knowledge. The choices and strategies enable them to make rational decisions while transacting within the market.

The combined application of three models in this study has served to ameliorate model specific weaknesses. This strategy provides a powerful explanation to the research questions on HIV/AIDS household coping mechanisms and how these relate to the status of HBC at the study location.

2.5 Study Assumptions

From the literature review, the central argument is that the nature and type of coping mechanisms at the household level depends largely on the socio-economic and cultural conditions of the household. This is also patterned by the extent of variation between household income and expenditure patterns especially in the light of HIV/AIDS and its impact. This research has therefore employed the following assumptions:

i. Poverty reinforces households inability to care and support PLWHAs;
ii. Impact of the HIV/AIDS on the household leads to changes in patterns of behavioral amongst household members;
iii. Incidence of HIV/AIDS within the household triggers a sense of union/togetherness towards caring for others; and
iv. Comprehensive HBC promotes prevention while reducing the severity of household coping.

2.6 Definition of Concepts and Variables

This study made use of terminologies that require clarification:

Affected: Refers to a non-natural condition. It is used in this study to refer to the individuals, friends, and other relations whose natural lives and conditions have been changed variously by the infection of a friend, relative or other relation. This has been used to include those staying with the patient within the same household as well as those not living within the household.

Care providers: This refers to the persons who look after the sick and old persons. It is used here to refer to individuals caring for HIV/AIDS patients in various ways including those providing material support and other components of comprehensive care.

Comprehensive home based care: Refers to care in the home setting that meets the needs of the PLWHAs. In this study, this is also meant to meet the conditional requirements of the HCS unit of the WHO Global Programme on AIDS.

Community: Refers to the geographical, ideological or behavioral commonality. In this study community is used to denote a set of households within a given area or location living together.

External assistance to the household: This refers to any manner of help, whether cash or kind to a household and coming from outside the entity of that particular household. This could be help from NGOs, religious groups, volunteers, government, as well as community networks.

Households: Refers to the relationships between people staying together. It can also be just one person living alone.

Individuals: Refers to the persons with respect to their biological nature, emotional, and social characteristics, and their cognitive capabilities as well as/or spiritual qualities. This is used in the study to refer to a single person as in the case of one living with HIV/AIDS.

Infected: This term refers to the persons who are HIV positive including those who have already developed the AIDS condition.

Patterns of change amongst household members: This refers to alterations by the household members, whether noticeable or otherwise, in the manner in which they conduct themselves and carry out their day-to-day activities. This study focuses on such changes that are attributable to the incidence of the epidemic within the household.

Scope of coping strategies: Coping strategies refer to the plans set out to successfully deal with a difficult condition. In this study, this is used to refer to the ways and means that households resort to so as to regain, maintain or even surpass if possible, the initial livelihood conditions prior to the incidence of the epidemic. The scope of coping strategies thus refers to the variety of these 'plans' that constitute the responses by households to the epidemic, whether behavioral or otherwise.

Severity of coping pressures: This refers to the intense need to successfully deal with the difficult and anxious conditions created by the impact of the epidemic on the household.

State of home based care: This refers to the nature and condition of care given within the home. This could be satisfactory or not depending on the circumstances that inform the care provision.

Vulnerability of the household: This refers to the inability of the household to provide for itself or satisfactorily realize its livelihood requirements due to the impact of the epidemic.

CHAPTER THREE

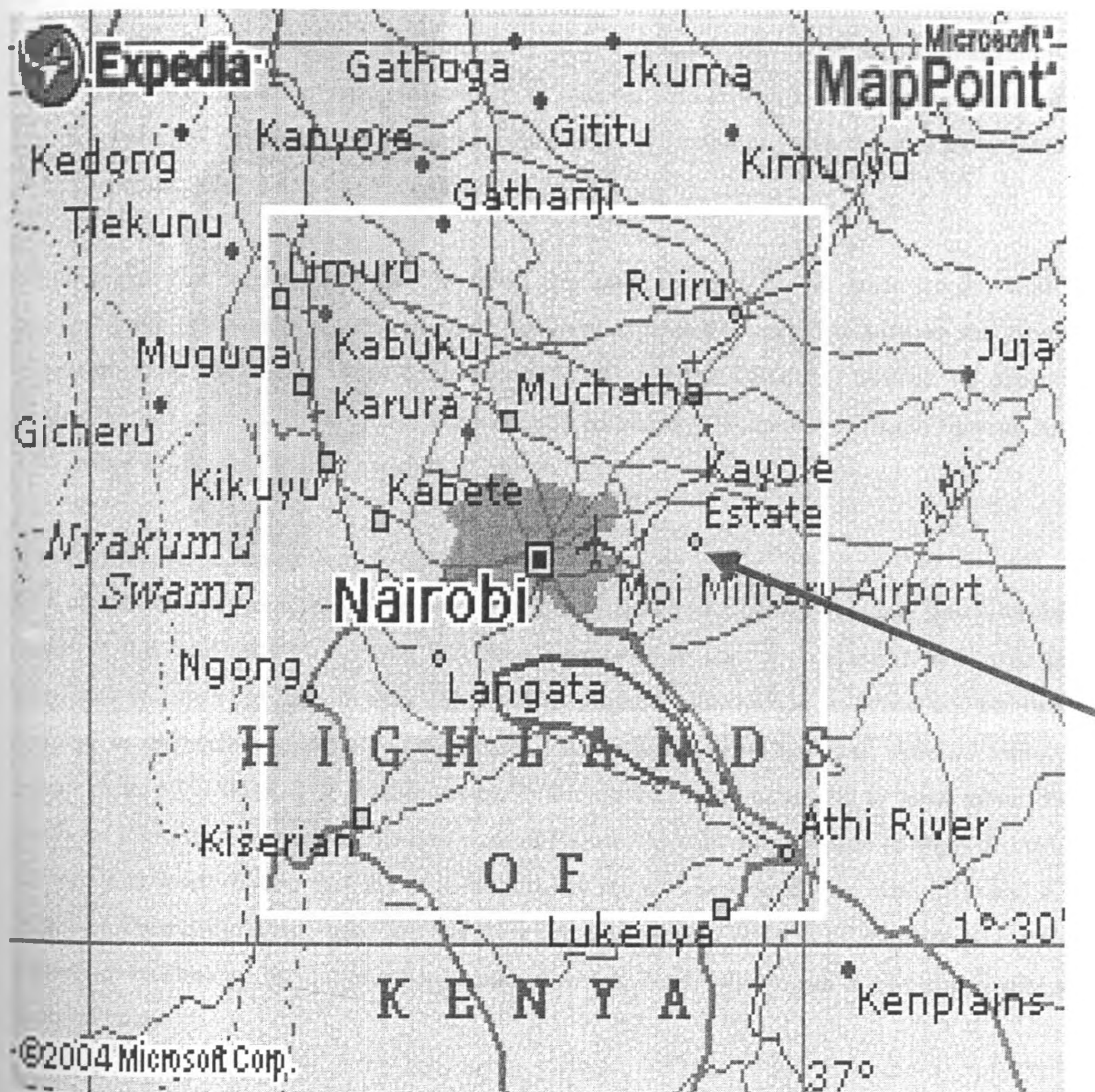
METHODOLOGY

3.1 Study Site

This study was carried out in Kayole, a low cost residential estate in Nairobi, the capital city of Kenya. The choice of study area in Nairobi was influenced by the convenience it accorded the researcher in terms of time and cost given the limitations in financial resources. Kayole is a residential estate located in the eastern part of Nairobi (see map on page 53). It is situated within the administrative Division of Embakasi and boarders Umoja and Komarock estates to the west and north directions respectively. The estate covers an area of 1.9 square kilometres with a population of 76,015 people (39,518 females and 36,497 males) giving a population density of 40,008 people per square kilometre (Kenya, 2000). The estate also has 24,630 households (Kenya, 2000). Being a residential estate, many of the inhabitants work within the city of Nairobi and the nearby industrial are. A number of people also engage in small scale trading within the residential estate while a few others carry out urban farming (raising crops and livestock) particularly along the streams passing through the estate.

The decision to carry out research in Kayole was two thronged. First, it is because the study focussed on poor households in urban Nairobi. More importantly however, is that out of these pockets of poverty, it is in Kayole that Women Fighting Aids in Kenya—WOFAK ran a well established home based care initiative. WOFAK was helpful as an entry point, particularly in tackling issues of access to potential respondents given the stigma, fear and suspicion associated with HIV/AIDS. The researcher obtained a published list of organisations involved in home based care projects all over the country and zeroed down on Nairobi. The list was obtained from the resource centre of Kenya National NGOs Consortium (KANCO); a network of HIV/AIDS organisations in Kenya. Various organisations that ran HBC projects within resource poor estates in Nairobi were identified and visited by the researcher to establish the possibility of carrying out the stuqy. Various organisations attached different conditions to carrying out such a study. The biggest hindrance was membership access fee. Due to the financial constraints, the researcher settled on WOFAK, which charged a fee he could afford at the time. The organisation also granted the researcher an attachment to the organisation while carrying out the study.

Map showing the location of Kayole in Nairobi



Topographical map showing Nairobi and its environs

The location of research area (Kayole) is shown by arrow

Women Fighting AIDS in Kenya (WOFAK)

WOFAK is a non-governmental AIDS support organization, established to support and empow affected and infected women to live positively with HIV and AIDS. The support group was found in August 1993 by a group of women, majority of who were HIV-positive. They came together give support to one another because they were experiencing rejection, stigmatization ar discrimination as a result of being affected by or infected with HIV/AIDS. In addition, many of the spouses had died and they were faced with the burden of supporting their families alone (WOFA News, August, 2002; www.wofak.or.ke)

Upon registration in January 1994, WOFAK continued to reach out to other women who we facing similar problems. Its outreach effort has since expanded to include education and awarene programmes across Kenya, with a recent emphasis on HBC. WOFAK through its education outreaches has reached various parts of the country particularly Homa Bay in South Nyanza. Nairo City centre and Kayole in the Eastlands of Nairobi.

The Kayole Home Based Care Project

The educational outreach in Kayole owes much to pioneer programmes in Homa Bay. The lessor learnt in the rural setting of Homa Bay have been used to start a programme in Kayole in th Eastlands of urban Nairobi. In July 1997, twenty women were trained in education, followed b training in counselling and home-based care. These women provided these skills to families c people with HIV/AIDS. The drop-in centre in Kayole has been expanded to meet more clinica needs for those members within the Eastlands of Nairobi through the provision of drugs and medica advice. It is worth noting that the organisation has since incorporated men with HIV and AIDS However, these still remain quite few and therefore none were covered as principal respondent(s) o household head(s) by the survey. Some men however, were interviewed during the unscheduled open interviews.

3.2 Sampling

The unit of analysis for this study was the household with the household head(s) being the survey respondents. The target population was the households that were providing care to PLWHAs at home during the period of the survey. The sampling frame of potential respondents constituted a list of these target households that were registered members of WOFAK. This list was availed to the researcher by WOFAK. The survey involved sampling in two stages: multi stage stratified random sampling. The first level involved the division of the study area on the basis of residential locations. This was meant to ensure an adequate representation since some locations within the study area exhibited greater levels of deprivation. This was noted from the observation results noted during the pilot assessment. There were five clusters: Kayole 1, Kayole 2, Kayole 3, Kayole 4 and "Other areas". The cluster of "Other areas" comprised respondents who lived within the estates neighboring Kayole but was members of WOFAK and utilized WOFAK services. This group also acted as a control to facilitate comparisons.

The second level involved random sampling, which was used to draw respondents from each cluster. The method was employed because it is more rigorous, ensures equal probability of selection and therefore suitable for generalization of the entire population. A sample of nine (9) household units was drawn from each of the four clusters in Kayole and four (4) from "Other areas". This gave a sample size of forty (40) household units and the drawing was determined by the size of the sampling frames. The sampling process for obtaining qualitative data was a purposeful selection of informants and materials with specific regard to obtaining the best answers to the research questions. The key informants comprised five (5) specialist home based caregivers (experts), three (3) HBC project managers and/or representatives and a religious official.

3.3 Data Collection

Scholars like Creswell (1994) have advocated pragmatic reasons for the use of a single paradigm- either qualitative or quantitative for research study. Over the years however, there has been a growing need for combining qualitative and quantitative approaches. This is necessary to neutralise the bias inherent in particular data sources, investigations and methods. This multiplicity was adopted in this research both in data collection and analysis and drawing particularly from the "between methods". This was meant to reduce bias as well as seek convergence of results with a

view to devising common practical and implementable recommendations (Greene *et al.*, 1989). This pragmatists approach was also favoured as a way of making the most efficient use of both paradigms.

The use of qualitative research was influenced particularly by its concern with "process" rather than product; the former being the essence of coping and care provision. According to Merriam (1988), the approach also provides keen interest in meaning particularly on how individuals make sense of their lives and experiences. This is at the core of understanding how individuals, households and communities respond to the impact of HIV/AIDS. The use of quantitative methods on the other hand was especially important because of its ability to identify attributes of population from smaller samples.

Qualitative Data

Qualitative data collection methods employed included complete observation while the researcher took observation notes. This was mainly during the group therapies. Such notes were also made on the general observations of respondents and their households during the household visits by the researcher. This method was particularly useful in capturing issues or topics that informants found uncomfortable to discuss. Open-ended in-depth interviews based on earlier prepared interview guides (see appendices II and III) were carried out with specialised home based caregivers (experts) and the HBC project managers/representatives. The researcher took notes on these interviews. The researcher also conducted unscheduled open interviews with informants during group therapies and the household visits. These informants comprised those identified by the researcher as having "potential information", either resulting from their group therapy speeches or their keenness and/or eagerness to contribute information during the administration of household surveys to the respective household heads. Case studies were also used to collect data. The information target was on key issues relating to coping with HIV/AIDS by households and the inherent constraints to care provision at home.

Quantitative Data

Quantitative data for the study was collected using structured survey questionnaires with open and closed ended questions. These tools were administered to household heads on a face-to-face format by the researcher himself. The questionnaires were administered in the presence of a home-based caregiver attached to WOFAK who acted as the "gate opener" for the interviews. During the survey, the researcher noted households that either had experienced very severe impact of the epidemic and/or those whose household head(s) showed unease due to the presence of the WOFAK caregiver. The researcher revisited these households particularly for probing purposes. This was done in the absence of the said caregiver.

Secondary Data

Secondary data was used to provide background information to the study focusing on HIV/AIDS coping and care. This was derived mainly from library books and documents, journals, maps, magazines, newspapers and the Internet. Most of this information was also used to augment primary data as well as enrich the study findings and recommendations.

3.4 Data Analysis

The survey data was analysed using SPSS for windows. The statistical technique used was descriptive statistics—mainly frequency tables, graphs and charts. This is because these present the most elementary way of summarising and displaying data as well as being the most effective. Qualitative data was analysed as an activity simultaneous with data collection and interpretation. The data from open-ended in-depth interviews, unscheduled open interviews and case studies were analysed thematically (developing categories, making comparisons and contrasts) in relation to study objectives and research questions. This analysis involved examining the coping responses at the household level, status of HBC, the interrelationships between these, and the socio-economic and cultural determinants that influence these variables. This exploration was meant to bring out the relationship between what members of the households said and the expert opinions vis-à-vis the actual situation on the ground. The overall aim here was the identification of specific issues of relevance to planning for future program interventions. Case study as a procedure of analysis was employed to build plausible explanations for the suggested interventional programs.

CHAPTER FOUR

POVERTY AND HIV/AIDS IN KAYOLE

4.1 Overview

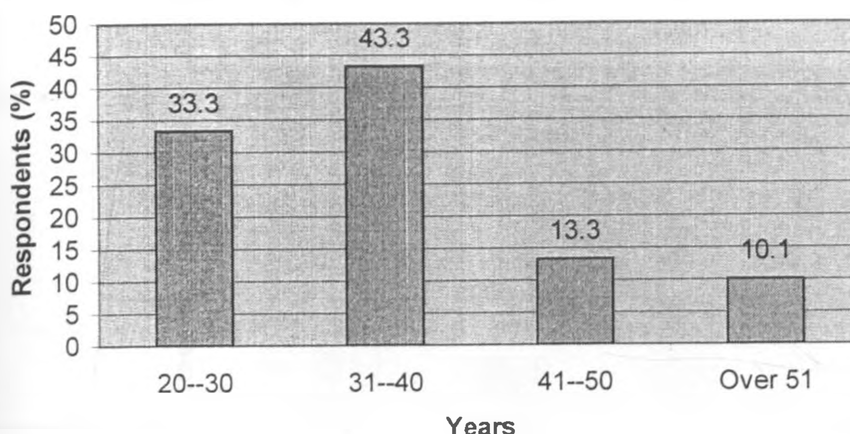
This chapter comprises of two sections. The first section analyses the socio-economic and demographic characteristics of households interviewed in Kayole. It presents the pattern and distribution of ages, residential locations, districts of origin and ethnic and religious composition of respondents. Also presented are the marital status of respondents, education and training particularly HBC training and employment. The second section discusses poverty and HIV/AIDS situation in Kayole. This section highlights the problems of dependency, education, healthcare, water and sanitation, unemployment and asset ownership.

4.2 Household Socio-Economic Characteristics

The surveyed households in Kayole provided forty (40) respondents to whom the household questionnaire was administered. Demographically, all the household heads to whom the survey questionnaires were administered were females.

From Figure 4.1, majority of the respondents had their ages distributed between 20 and 40 years. Those between the age group of 20 and 30 years accounted for slightly over 33%, those between 31 and 40 years accounted for slightly over 43% and those between 41 and 50 age group accounted for slightly over 13 percent. The rest of the respondents were above 51 years of age accounting for 10 percent. These were mainly elderly persons within the households. They were in many cases grandparents who were caring either for their sick children or supporting orphaned children.

Figure 4.1: Respondents' Age Distribution



WOFAK membership within Nairobi draws from beyond Kayole. A number of responden interviewed particularly during group therapies came from outside Kayole, but were affiliated to th Kayole drop-in center. Kayole as a region is very large and this necessitated its division into fou sub regions: Kayole 1, Kayole 2, Kayole 3 and Kayole 4 (Figure 4.2). Those who came from outsic the region were classified under "Others".

Of these regions, over 17 percent of the respondents were from Kayole 1, about14 percent from eac of Kayole 2 and Kayole 4, and about 21 percent from Kayole 3. Those from outside Kayo accounted for about 35 percent. These other residential areas included Kibera, Dandora. Onga Rongai, Shauri Moyo, Huruma, Gomongo, Soweto, and Riambai. Nearly all of which are resour strapped areas of Nairobi.

Figure 4.2: Respondents' Areas of Residence

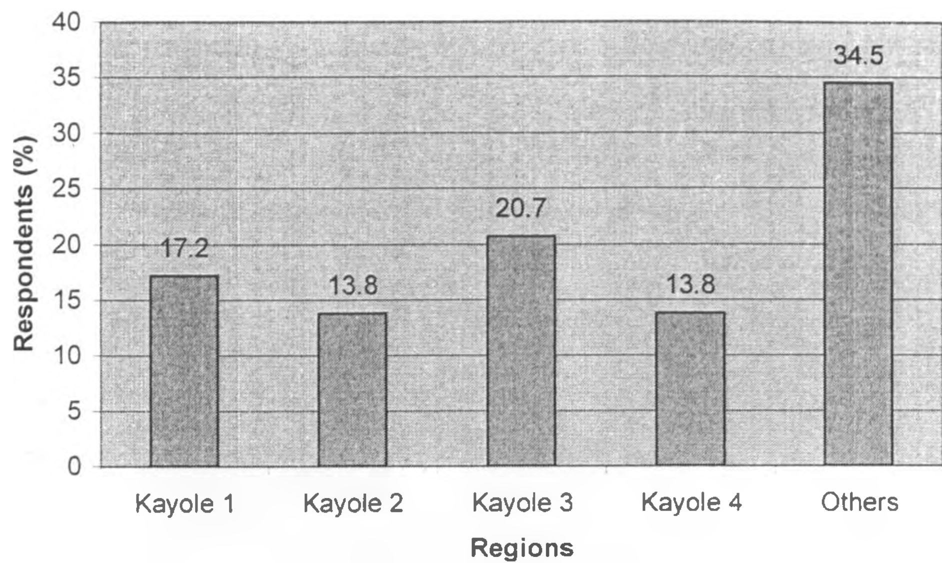
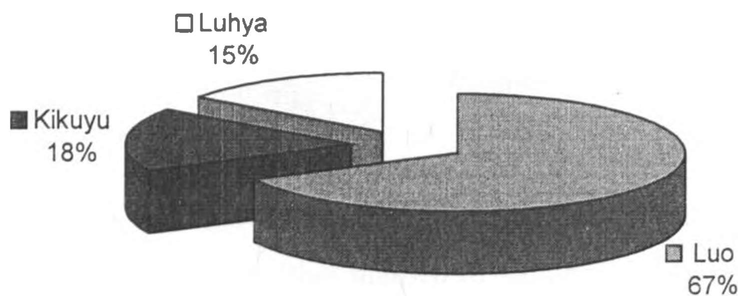


Table 4.1: Respondents' Home Districts

Provinces	Home District	Number of Respondents	Percent
Nyanza	Siaya	7	17.5
	Kisumu	1	2.5
	Homa Bay	3	7.5
	Migori	7	17.5
	Rachuonyo	4	10
	Bondo	5	12.5
Central	Kiambu	3	7.5
	Muranga	1	2.5
	Thika	3	7.5
Western	Busia	5	12.5
	Lugari	1	2.5
	Total	**40**	**100**

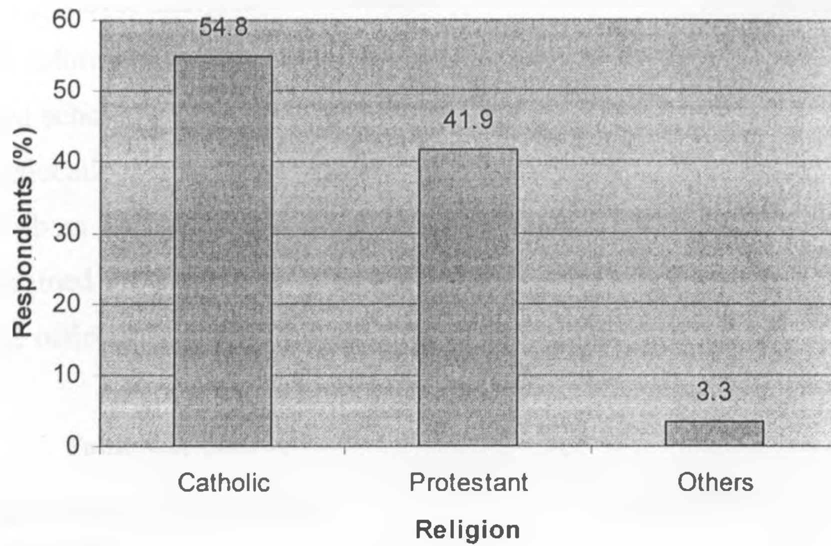
The districts from which the respondents hailed were quite diverse. Many of these respondents were from Western, Nyanza and Central provinces. Nyanza province accounted for most of the respondents at 27 accounting for approximately 68%. Central provinces had 7 respondents accounting for about 18% while Western province had 6 respondents accounting for 15% (Table 4.1)

Figure 4.3: Respondents' Community of Origin



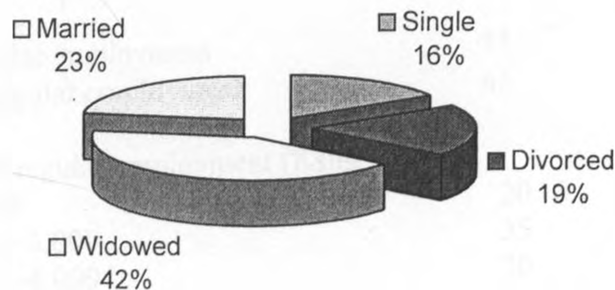
The ethnic composition of the respondents was mainly from three communities. The Luo constituted the largest number of respondents at over 67 percent. The other respondents were Kikuyu at 18% and Luhya at 15% (Figure 4.3). Of all the respondents interviewed in the survey, over 54 percent were Catholic; over 41 percent were Protestants and only 3 percent professed other faiths such as Islam (Figure 4.4).

Figure 4.4: Religion of Respondents



Majority of the respondents were widowed accounting for about 42% while over 19% were either divorced or separated. Those who were either married or simply living with a man accounted for over 23 percent. The rest were singles who never married out of own volition accounting for over 16% (Figure 4.5)

Figure 4.5: Respondents' Marital Status



As illustrated in Table 4.2 above, many of the households were relatively well educated. However, they mainly engaged in informal economic activities giving them generally low incomes. All the respondents had attended school, with over 48% attaining secondary school level of education and 29% attaining primary education. It is worth noting that this group also characterized cases of high educational levels with about 23 percent having post secondary education. Within this group were University graduates trained in education and other social sciences. Others were trained as accountants and clinical officers. Many of these were intensive training programs that lasted well over two years.

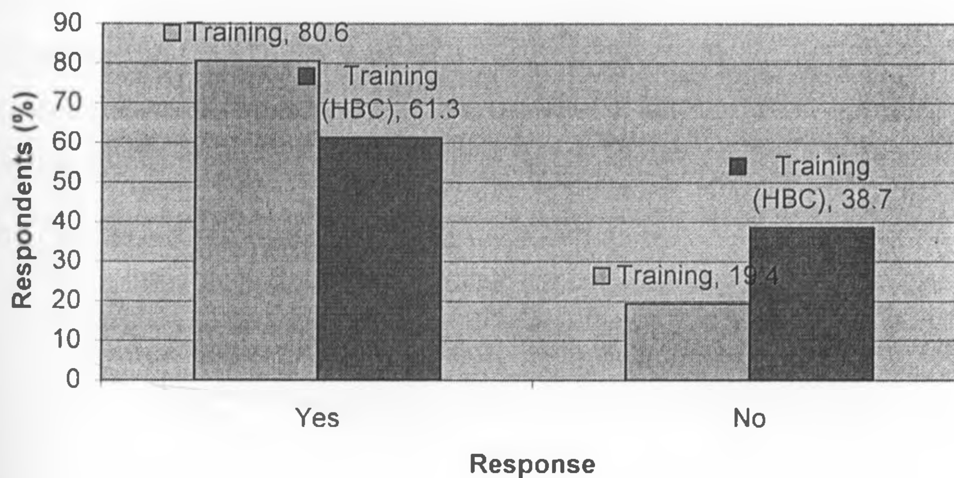
Table 4.2: Characteristics of Household Respondents

Characteristic of Household Respondents Respondents	Percentage of (%)
Schooling	
Primary	29
Secondary	48
Post Secondary	23
Any form of Training obtained	
Trained	81
Not trained	19
Length of training	
Less than 6 months	45
7 months to 2 years	31
Over 2 years	24
Employment	
In regular employment	55
Non-regular employment	45
Earnings: non-regular employment (Kshs/Month)	
< 1,000	20
1,001—3,000	35
3,001—4,000	20
4,001—5,000	15
Above 5,000	10
If current work matches training	
Yes	41
No	59

Of all those interviewed in the survey, about 81% had at least undergone some training while 19% had not (Table 4.2; Figure 4.6). Accountancy training accounted for over 9% including CPA and diploma level holders. Those trained in dressmaking, hairdressing and tailoring accounted for over 32%. Specialized training in teaching, medical and other forms of graduate training accounted for over 39% of the respondents while others trained in short business courses such as secretarial accounted for 19%. The time period for which these courses lasted was varied. Those that took less than six (6) months accounted for about 45%; those that lasted between seven (7) months to two (2) years accounted for over 31% while those that took over two years accounted for over 24% (Table 4.2).

From amongst the interviewed respondents, over 61% had actually undergone training in HBC (Figure 4.6). This prepared them well for providing care at home. They noted that these trainings often focused on palliative care, proper use of condoms and treating opportunistic infections. They also dwelt on how to facilitate at HBC forums and awareness creation. Topics relating to stress management, counseling, behavioral change as well as nutritional requirements and psychosocial support were also covered.

Figure 4.6: Training Acquired by Respondents



Whereas about 55% of the respondents were working, about 35% of this working group carried out public education on HIV/AIDS, counseling, home based care as well as other voluntary work especially with WOFAK as their primary occupation. Over 34% were involved in trade, while close

to 30% engaged in white-collar jobs and other forms of service delivery. About 1% of respondents comprised of students (Table 4.3). Many of these jobs fetched very low returns in terms of wages. As a result of these low wages, respondents indicated that they engaged in other forms of activities just to make ends meet. These activities were varied. While some engaged in other very small scale trading accounting for 60%, others carried out WOFAK outreach services (28%) and yet others carried out agricultural farming along the river streams (5%) to beef up their domestic food supplies. About 8% also noted that they carried out "other things" (Table 4.3).

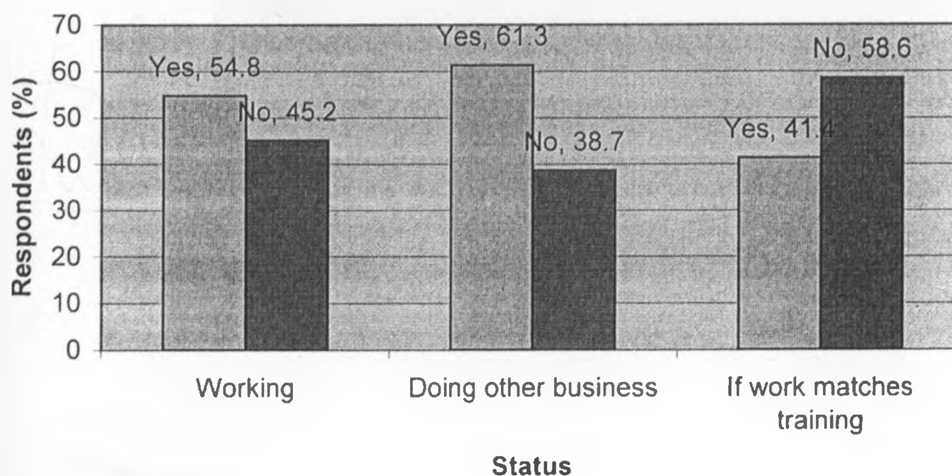
It is worth noting that this group, which carried out "other things", did not freely explain these "other things" that they carried out to subsidize their incomes. Upon closer investigations and much probing of some respondents especially in the absence of WOFAK caregivers, it clearly emerged that these "other activities" included working as servants for other relatively better off families. This involved doing household duties such as dusting floors, cleaning utensils and household clothing for a paltry fee of Kshs 70 a day. Other activities carried out by members of these households included prostitution and sale of drugs especially bhang, among others. Asked how often they carried out these tasks, about 45% noted that they always carried out these tasks as long as they felt well. Over 40 percent noted that they carried out the tasks once in a while, and the rest indicated that they did this only when such work was available.

These activities according to the respondents were largely carried out for some organizations or other people not related to the household. This accounted for over 52% while self-employment accounted for over 33%. Carrying out these activities for other family members accounted for over 14%.

Table 4.3: Respondents' Occupations and Activities

Nature of Occupation	Specific Activities	Number of Respondents	Percent
Primary Occupation	Public awareness educator	14	35
	Trader	13	32.5
	White collar jobs/Services provision	11	27.5
	Student	2	5
	Total	**40**	**100**
Other businesses Carried out	Small scale business	24	60
	Outreach /public awareness	11	27.5
	Agricultural/farming	2	5
	Others	3	7.5
	Total	**40**	**100**

Figure 4.7: Respondent's Economic Engagement



The form of compensation given for these chores undertaken by members of the household were either in form of cash, kind or at times both. Cash payments accounted for over 24%. Payment in kind accounted for over 21% while compensation involving both cash and in kind accounted for over 53%. In many of these cases, payment in kind was in the form of food and clothing besides

other items. In all these instances, over 41% of all respondents noted that their work or activities carried out matched the training they had undergone.

The greatest concern of this group was the availability of jobs and discrimination for those at work. The average annual income of these households was Kshs 18,000 (US$ 231), a level already considered low by national standards. Assessing these figures against the World Bank's 1988 poverty line of US$ 275, it clearly indicates that over 75% of the surveyed households live below the poverty line. These households exhibited a great deal of impoverishment even in terms of household asset ownership. Their only significant asset belongings were simple and basic household necessities. They hardly had any assets that would be referred to as luxurious (Table: 4.4).

Figure 4.8: Approximate Household Cash Income per Month

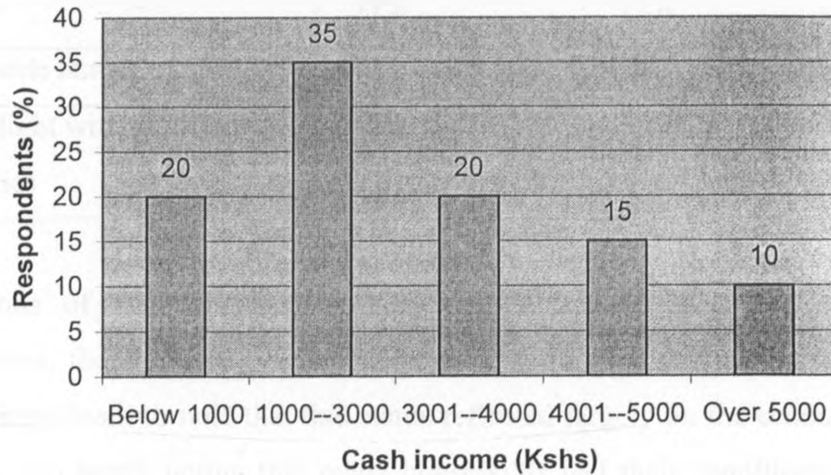


Table 4.4: Assets owned by Households

Items owned	Yes (%)	No (%)
Television	54.8	45.2
Fridge	9.7	90.3
Paraffin cooker	64.5	35.5
Gas/electric cooker	35.5	64.5
Telephone	26.7	73.3
Sofa set	67.7	32.3
Bicycle	16.1	83.9
Vehicle	9.7	90.3
Radio	71.0	29
Motorcycle	19.4	80.6
Table	77.4	22.6
Kerosene lamp	71.0	29
Flashlight with working batteries	44.8	55.2

The dwelling conditions of many households surveyed further depicted a state of severe impoverishment. However, there were a few isolated cases of households that lived in relatively better conditions. It is significant to note that this status reflected largely on the economic strength of the household. It is also worth noting that many households had their conditions, in terms of economic and financial well being decline gradually. This meant that the households had to constantly keep changing their places of dwelling to reflect their levels of affordability. From the interviews, there were quite a number of households that initially lived within relatively up market estates but with time had to settle in various slums within the city.

The misery of these households was evident in the status of houses that they occupied. Majority of houses had walls made from mud; iron sheets, plastics sheets and timber or wood. Others were made from cement, stone block and bricks. The floors were mainly made of mud, dung and sand. Some houses had floors made of cement and vinyl. Majority of the houses had the roofs made of iron

sheets with some old and rusted while some were made from tins joined together. A few roofs however were made of tiles and this accounted for only 6%. Majority of the houses however, had electricity supply accounting for about 74%. This is attributable to the proximity of the area to the main power supply grid connected to the nearby industrial area and other adjacent middle class residential estates (Table 4.6).

Table 4.5: Materials used in making Dwelling Walls and Floors

Material used	Percentage of Households	
	Walls	Floors
Mud/dung/sand	9.7	16.1
Iron sheets/Mabati	16	
Plastic sheets	6.5	
Timber/Wood	9.7	12.9
Cement	22.6	71.0
Stone block	32.3	
Brick	3.2	

Table 4.6: Features of Household Structures

Structure Features	Percentage of Households
Number of sleeping rooms	
Single	61
One bedroom	26
Two bedrooms	13
Roof material	
Iron sheets	94
Tiles	6
Electricity supply	
With electricity	74
Without electricity	26
Types of Toilets	
Septic tanks	50
Pit latrines	36
Open fields	14

In many of the cases, the dwelling structures had the roofs largely made from iron sheets or "Mabati" accounting for over 93 percent while those made of tiles slightly over 6 percent (Table 4.6). The walls were made of various materials including mud, iron sheets, plastic sheets, timber or wood, cement, stones and bricks (Table 4.5). Floors of these structures were largely made of mud or dung, cement and wood, tiles or vinyl (Table 4.5). Amongst all the households interviewed, over 74 percent had electricity while about 26 percent did not have power supply (Table 4.6). This is probably so because despite being an impoverished area, its proximity to power supply system within the city might have seen the landlords take advantage of the power supply even to characteristically low-income houses. Majority of the households lived in single rooms accounting for 61% of the households, 26% had one sleeping room and the rest (13%) had two sleeping rooms. This congestion posed greater risks of infection especially during disease outbreaks.

4.3 Poverty and HIV/AIDS

The poor have been defined as members of society who are unable to afford minimum basic human needs comprising of food and non-food items (UNDP, 2002). In urban Kenya, this group lived on less than Kshs 2,648 per month in 1997. These are the absolute poor largely found within the informal settlements of these urban areas. Poverty in Kenya's urban areas increased from 29% in 1992 and 1994 to 50% in 1997 (Kenya, 2000) showing that poverty is indeed a major problem of urban centres. The report noted that Nairobi experienced the greatest increase in poverty thereby worsening welfare by affecting health, education, social welfare and employment. This was aggravated by HIV/AIDS.

As a consequence, HIV/AIDS has been difficult to combat thereby severely affecting the lives of these poor people. Many of the affected households are in turn forced to reshape their lives in terms of consumption, expenditure and behaviour in an effort to cope. This has only served to fuel the level of impoverishment. Clearly, this shows that the relationship that exists between poverty and HIV/AIDS is such a complex one. They exhibit two bi-causal relationships that call for a thorough understanding by those engaged in policy and programme development. One is the relationship between poverty and Aids that involves the spatial and socio-economic distribution of HIV infection among the population such as those within Kayole and equally considering the poverty related factors that affect these households and the community coping capacities. Second is the relationship

between HIV/AIDS and poverty that involves understanding the processes through which the experience of HIV and AIDS by households and communities leads to an intensification of poverty.

Understanding the impact of these relationships require the conceptualization of poverty as a multi-dimensional process. Such an analysis must appreciate the gender dimensions of poverty among the poor households since many of these households are female headed. The analysis must also appreciate ways in which HIV and AIDS alters the complex relationships between the poor and the wealthy in terms of changes in income and asset distributions for households and how the process of social exclusion serves to intensify those changes and alterations. Such an analysis however, could constitute a completely different study. The following are discernable dimensions of poverty in Kayole.

1. Problem of Dependency

Results from Kayole survey indicate that the process of poverty has manifested itself amongst the households in quite a number of ways. The region is characterized by larger household sizes with those having between one and three of own children accounting for 83%, those with between four and five children accounting for 13% while those with over five children accounting for 4% (Table 4.7). Of these children 45% were female and 55% male. Very few of these children were working accounting for only 10%.

Table 4.7: Characteristics of Household Children

Number of children	Percentage
1-3	83
4-5	13
Above 5	4
Sex of children	
Male	55
Female	45
Schooling children	
Currently in school	83
Currently out of school	17
School expenses met by	
Parents	60
Relatives	10
Other sponsors	30
If children working	
Yes	10
No	90

Besides own children, a number of the households (76%) said that they lived with "other" people within their households who were not their children. Out of these "other" household members, those who were below twelve years of age accounted for 37%, thirteen to eighteen years accounted for 30% while those over eighteen accounted for 33%. They included parents (4%), siblings (47%) and other relatives accounting for 49%. Only 37% of this group was working (Table 4.8)

Table 4.8: Characteristics of Other Members of the Household∞

Characteristics	Percentage
Ages	
0—12	37
13—18	30
Above 18	33
Sex	
Male	57
Female	43
Working	
Yes	37
No	63
Constitution	
Parents	4
Siblings	47
Other relatives	49

∞ This includes people staying within the same household other than the respondents and their children

Tables 4.7 and 4.8 depict massive economic strain on households already ridden by poverty. There are larger household sizes consisting of bigger numbers of own household children and other members staying within these households who are under 15 years of age. This lot together with those above 15 years but not working pose greater problems of dependency that serve to aggravate the poverty situation in these households. Even many of the household children and "other" household members in employment were engaged as simple labourers with dismal earnings within the nearby industrial area. Majority of other relatives who stayed with the households were largely orphans, many of whom were integrated into these households due to their poverty and HIV/AIDS related situations.

Besides those living within these households, there were as many as 64% of the respondents who noted that they also support other people who live elsewhere (not within their households). Many of these are parents, siblings, friends and relatives. The households offer them purely cash assistance ranging between Kshs 1,000 to Kshs 2,000 per month, accounting for 20%, and assistance in kind

accounting for 16% mainly in form of household supplies such as food, groceries and toiletries, medical treatment, clothing and school related provisions. Majority however, are assisted in both cash and in kind accounting for over 64% (Table 4.9)

Table 4.9: Household Support to Non-household Members

Support by households	Percentage
Nature of support	
Cash	20
In Kind	16
Both (cash/kind)	64
Amounts given (Kshs/Month)	
< 1,000	53
1,000—2,000	42
Above 2,000	5

This dependency from outside the households is attributable to the kinship network of many African societies and greatly erodes the resilience of many households. Consequently, this further aggravates the poverty condition of such households. Out of all the households interviewed, 10% acknowledged that indeed they had people who needed their support but were unable to provide this support due to the difficult circumstances they were facing. Many of those seeking assistance were friends and relatives, as well as parents and siblings. This study also observed that a significant number of households could not even support their own children.

2. Problem of Educational Opportunities

Limited accessibility to basic social amenities is the hallmark of poverty in many societies. Obudho noted that accessibility to education, healthcare, safe water and sanitation, and the nature of toilets and houses characteristically symbolize urban poverty Obudho (1992), (Box 4.1).

Box 4.1: Evidence of Urban Poverty

Urban areas have a considerable share of households with traditional pit latrines and mud/sand/dung houses. These are mainly in the slum and squatter settlements, which are the major urban poverty pockets. Slum settlements represent urban misery and virtually all the dwellers have low incomes, making it difficult for them to access education and health care. Urban poverty is also illustrated by the fact that the proportion of urban dwellers using flush toilets connected to the main sewer lines or septic tanks is quite small. This poverty is also seen in urban water, with most of it being contaminated and of poor quality due to its constant contact with raw sewerage from burst sewer lines. In some urban areas, excreta wastes from slum locations, where there is poor sanitation, contaminate river water. In other cases, which affect nearly all-urban residents, there is laxity or sheer inefficiency in water treatment and management by the local authorities.

Source: Obudho (ed.) 1992.

Poverty is evidenced in many households as the inability of such households to meet the costs of education and healthcare facilities. In Kayole, poverty is also evidenced from the proportion of children who are of school going age but are out of school. These accounted for 17% and were mainly out of school because of inability to meet school fees and levies, to care for sick family members and to help boost family income by engaging in trade and other income generating activities. A few cases were attributed to pregnancies and general apathy with families not seeing any economic benefit to their children attending school. About 83% of children who were in school however, had their school related expenses met by other persons rather than members of their own households. These included grandparents, siblings, aunts/uncles, friends and relatives, other well-wishers and institutions such as NGOs and religious organizations (Table 4.7).

Education is a critical factor in the fight against poverty and HIV/AIDS. The inability to guarantee education does not only denote human poverty but also a denial of a basic human right. It is due to poverty that though a significant number of children are unable to attend school, although people and institutions outside the household still play key roles in sponsoring them. The inability to provide education to children due to poverty, HIV/AIDS and other related conditions adversely compromises the potential of these very children to be adequate income earners and responsible

members of the society in future. As a consequence, the vicious circle of poverty is perpetuated and sustained while prospects and potential for development are dispensed with.

3. HealthCare Problems

Healthcare is a basic human right and its availability, accessibility and affordability within any healthcare delivery system is critical in combating poverty and HIV/AIDS. Many households interviewed acknowledged the availability of health service delivery stations within Kayole and around it. They also noted that a significant number of these delivery points were privately owned, expensive and therefore out of the reach of many patients. About 70% of patients acknowledged that at one time or another, they had felt sick but did not seek treatment. A greater number of this group (52%) said it was because they could not afford treatment costs, 20% said they were shy since they didn't want other people to know their conditions, 17% said they knew what to do (self medication) while 11% did not know where to seek treatment (Table 4.10).

Table 4.10: Health Seeking Patterns

Health Seeking Behavior	Number of Respondents (%)
Felt sick and sought treatment	30
Felt sick but did not seek treatment	70
Reasons for not seeking treatment	
Could not afford	52
Stigma (did not want condition known)	20
Administered self medication	17
Did not know where to go	11
Meeting Healthcare Costs	
Free hospital treatment	10
Own funds	50
Assistance from relatives	10
Assistance from institutions*	30
Referrals	
Patients ever referred	83
Have not been referred	17
Frequency of referral	
Monthly	42
Weekly	13
Anytime	45

*Institutions include NGOs, ASOs, religious institutions etc

The problem of affordability was at times eased by free hospital treatment but this was extremely rare, accounting for only 10% of the respondents. A number of patients also mentioned having been detained in hospitals for failure to pay for healthcare services rendered, and referring to it as a "very common thing". Almost all patients wholesomely met their healthcare costs from own funds accounting for 50%. Assistance from friends and relatives accounted for 10% while that from NGOs and support groups accounted for 30% (Table 4.10). Those households who mainly met the healthcare costs from their own funds normally sourced such funds from own household savings, sale of assets, borrowing and other sources which included donations by religious organizations, friends and relatives, well wishers and sympathizers.

The NGOs and support groups that assisted residents of Kayole included WOFAK, TAPWAK, NAP+, SWAK, MSF Belgium, KEMRI, and the Nairobi Hospice. The services offered by these organizations include counseling, orphan support, treatment including free medication for opportunistic infections and herbal care, capacity building as well as empowerment initiatives.

Accessibility to healthcare by these households was from various sources. While majority visited public sector related healthcare providers such as government, hospitals, health centers and government dispensaries, a relatively smaller number visited private healthcare centers particularly private doctors because of the costs involved. Other private centers visited include mission hospitals and pharmacies. Healthcare providers who were widely visited by patients included community-based distributors, traditional healers, spiritual healers as well as shopkeepers/kiosk owners, support groups, NGOs, friends and relatives.

Respondents noted that some of these healthcare providers especially the pharmacists, private doctors and dispensaries often referred the patients to hospitals for further medical examination and treatment. About 83% acknowledged having been referred to hospitals. The frequency of these referrals depended on the health situation of the patients. Many respondents however, said that they often did not take up these referrals because they did not have money either for transport or to pay at the hospital. About 42% said they were referred on monthly basis, 13% on weekly basis while the rest (45%) said they were often referred anytime within the week or month. The 17% who said they had not been referred to hospital explained that it was either because they tried very much to remain

healthy, they had not been falling sick very often or they often visited their support groups when they felt sick.

It is important to note that patterns of accessibility and levels of affordability of healthcare are greatly determined by socio-cultural and economic factors of the households. While poverty levels will determine which healthcare packages a household would afford, factors relating to the households health seeking behavior would determine the sources of healthcare. Indeed, this is explained by the fact that besides visiting public and private healthcare providers, a larger number of respondents also visited traditional and spiritual healers as well as community distributors, shops and kiosks for various healthcare services.

4. Water and Sanitation Problems

Urban poverty in many societies today is mirrored on urban water, which is largely contaminated and of poor quality. Residents of Kayole obtain their water supplies from a number of sources all of which are prone to contamination. Residents surveyed said that they obtained their supplies from pipes, wells, rivers, rainfall, and water vendors that comprised hawkers, public taps and tanks. Rainwater was tapped from old rusted and dirty iron sheets while water from wells and streams was contaminated by excreta waste due to the slum's poor sanitation. The piped water was contaminated due to its frequent contact with raw sewerage from broken sewer lines. The poor quality of this water was also as a result of general laxity and inefficiency in water treatment and management by the local authority that is the Nairobi City Council.

The sanitation situation in this neighborhood was aggravated further by the use of traditional pit latrines that accounted for 36% of the households surveyed. Flush toilets connected to the main sewer lines or septic tanks accounted for 50%, many of which were shared. The rest of the households used open fields nearby and quarry caves accounting for 14% of the sample. These wastes always found their way into the streams and wells used by the residents thereby spreading diseases further.

5. Under-employment and Low Incomes

Low incomes are a principal factor that denies households the ability to access welfare requirements. About 55% of the respondents interviewed were in regular employment. This group however, was quick to add that the compensation from their employment was inadequate forcing them to engage in other businesses mainly small scale trading. The other 45% without regular employment were engaged either in HIV/AIDS related public education and awareness creation, counseling, feeding programmes and other volunteer services from which they received allowances both in cash and in kind. Many individuals from this group also worked as domestic servants besides engaging in small scale trading. There were also a few households that engaged in agricultural farming along streams to boost their food supplies. As earlier noted, a significant number of respondents noted that besides these engagements, there were some "other" activities they carried out for livelihood reasons. They were however, reluctant and unwilling to delve more into what these activities were. On probing, later in the absence of the research guide, some respondents said they engaged in commercial sex, sale of drugs such as bang amongst others.

Respondents emphasized that they were "conditioned" to engage in these activities by their poverty situations against their wishes. The frequency of these transactions varied but also depended on the availability of the activities and services. The compensation for engaging in these "other" transactions was either in cash or in kind, just like compensation for those in non-regular employment. Cash compensations for "other" transactions accounted for 74% while the rest (16%) was in kind often in form of food and clothing. Cash earnings from these "other transactions" varied greatly. Those earning less than Kshs 3,000 per month (in summations) accounted for 45%, those earning between Kshs 3,000 and Kshs 5,000 accounted for 40% and those earning above Kshs 5,000 accounted for 15%. This is closely similar to earnings of those in regular as well as non-regular employment whose average monthly income was Kshs 5,000 per month. This is by far below Kenya's 1997 figure of Kshs 1,229 per month; the absolute poverty line for urban residents (UNDP, 2004), if considered within the context of the number of household members that depend on this income.

Household incomes are known to usually depict positive correlations with educational levels. This means that education generally enhances earning ability. Households characterized with high

education levels are generally believed to have more resources to turn to in times of need. Even though all respondents interviewed attended school, those with post secondary education accounted for 23%, secondary education accounted for 48% while primary education accounted for 29%. This means that only a few of these households were able to access good employment opportunities and adequate income. A larger number of the households (81%) underwent at least some form of training however, many of these obtained training in courses that did not fetch them adequate income.

The courses pursued included dressmaking and hair design as well as short business and government courses such as secretarial. A few individuals undertook training in accountancy, medical, teaching and other graduate programmes. This group consisted mainly of those who were in regular employment and with relatively adequate incomes. Many of the courses lasted far less than six months and this accounted for 45%, those that took between seven months to two years accounted for 31% while those that lasted above two years accounted for 24%. It is instructive to emphasize that among those household members who were both trained and working, a significant number (59%) said that their work did not fit the training they had obtained. Overall, relatively low educational levels coupled with limited training characterized majority of these households in Kayole. The limited skills thus deprived them of opportunities for good employment and better incomes. In many respects, this serves to perpetuate the poverty situation of these households.

7. Nature of Household Assets

Limited household incomes normally imply limited household expenditures. As a consequence, households would only be able to access limited assets and other household necessities. Many households interviewed acknowledged that they had not made any significant purchases of household assets from the time illness began mainly because of increased demand for medical expenses. Instead, the increase in expenditure requirements of these households meant that they had to sell off some of the assets they previously had.

Table 4.4 shows a wide range of assets that households possessed at the time of this research. Clearly the table indicates that almost all the households had simple basic household assets such as radios, tables and kerosene lamps. Extremely fewer households had items that would constitute a

luxurious category such as motor vehicles, fridges etc. This shows the impact of both poverty and HIV/AIDS on these households. The expenditure on non-asset related items included transport, rent, school fees, clothing, food and medical requirements. Food and medical expenses accounted for a larger portion of the expenses.

The dual problems of poverty and HIV/AIDS have adversely affected households in Kayole. Their consumption patterns changed forcing over 67% of the households to cut down on their average consumption due to low and declining incomes coupled with increased expenses on medical requirements. As a result, 57% of households acknowledged decline in their overall welfare becoming worse off compared to periods before the illness began. In response, the households engaged various strategies to enable them cope with the difficult situations. These strategies form the basis of our next discussion.

CHAPTER FIVE

HOUSEHOLD COPING STRATEGIES IN KAYOLE

5.1 Overview

This chapter discusses coping strategies adopted by households experiencing the impact of HIV/AIDS in Kayole. The analysis of household coping strategies I have adopted is based on a model of household economic decision-making. It is a simple model in which households or families are particularly concerned with their welfare along various distinct dimensions. These include health status, education, consumption, the number of children as well as the welfare of other members of the household both related and unrelated to the social unit.

Experiences with HIV/AIDS in households generally create suffering to the infected individual as well as the affected members. In addition, members of these households are themselves affected by an immediate reduction in their resources and welfare. In cases where such an individual is an income earner, the illness gradually reduces the infected individual's earning capacity until the household finally loses that individual. It is important to note that these households however, do not react passively. Instead, they act to minimize the impact on their overall welfare. In many instances when individuals first become ill, they tend to work less while probably seeking medical care. The implication of this is that there is indeed, lost income from the reduced time spent working as well as the increased medical expenses. This finally translates into even much fewer resources available for the rest of the household to meet their needs. Consequently, other members of the household may see the need to reorganize their time to minimize the income loss and even cut down on consumption.

One such reallocation of time and which remains extremely costly to the household is pulling children permanently out of school. This greatly lowers their future earning capacity. In some households, decisions are often made to sell assets to pay for medical care as well as smoothen out consumption. This too has the potential of compromising the future earning capacity of such households. The affected households often feel the extent of the impact of the disease heavily and directly. However, other related households such as the extended families may also experience readjustments. In many cases, these are in the form of resources transfer to the acutely hit

households, involvement in orphan support initiatives or simply the elderly parents going back to work. These households may also go out seeking assistance from other households with adult children.

By and large, the principal response to cushion such adverse effects of increased medical costs for the sick, declining income from lost earnings, lost labour supply for household production as well as the strains and stresses of social discrimination is that the households often opt to use various strategies to cope. The success of these strategies and their impact on the households' current and future welfare largely anchors on the socio-economic characteristics of these households. This implies that those households with greater economic resources would experience relatively smaller adverse impact than households with fewer resources. The nature and extent of social networks of these households, and the value that these networks provide are also important in this context. The following analysis is an examination of coping strategies adopted by households in Kayole vis-à-vis their ability to cope in relation to their inherent socio-economic characteristics.

In Kayole, many households already with experiences of HIV/AIDS are punctuated with suffering and hardships arising out of the impact of the disease. In these regions, almost every household has invariably lost a family member, a close relative, or even a valuable friend to the epidemic. Majority of those interviewed acknowledged that indeed they have lost to the disease, either persons close to them or some other persons they knew. Virtually no individual or family remained untouched by the consequences of the epidemic.

To any household living in acute destitution and imminent danger as in the Kayole case study, coping considerations often become of great priority. As a consequence, these households within Kayole have learned the various techniques of coping as part of their every day experience. The techniques they adopt could be crude or indigenous depending on the extent and magnitude of the impact of the disease on them as well as their perceptions. These techniques also depend on the stock of accumulated knowledge by these households as relates to their production and coping, their natural and social resources as well as the social relations and communal values in existence.

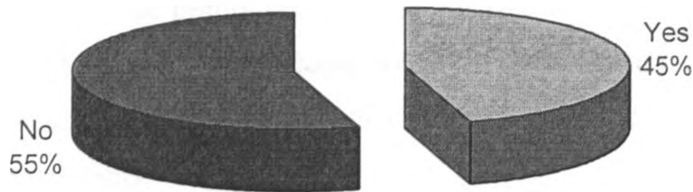
In times of crisis, notes UNAIDS (1999), ingenuity, strength of character, effective use of natural resources and communalism enables populations to live through large-scale impacts. This candidly confirms the situation that is in Kayole. The indigenous coping strategies adopted by the households include emergency induced resource management measures, effective use of household resources, and disinvestments of savings, disposal of assets as well as greater and more efficient use of the market system. In many ways than one, this outcome reinforces the works of Cutler and Stephenson (1984) which state that reactions would first involve going into debt followed by selling off less important assets.

Various households surveyed had own resources to which they pursued their welfare. These resources included the human capital relating to the number of family members, their educational needs, and earning capacity. These resources were also in form of physical capital such as savings, productive assets, land and other durable goods. The resources, whether human or physical, were used by the households to generate income for use in making purchases subject to the environmental constraints. These constraints included prices, quality of goods and services available in form of food, housing, medical care, or schooling. In all these, the decisions that the households undertook resulted in welfare outcomes such as consumption, health status and schooling of children.

5.2 Borrowing

Borrowing is one of the fundamental ways, which households resort to during moments of hardship. The success of this strategy however, depends largely on the social capital that such a household has. Many households, despite adjustment and use of existing resources to cope with the situation, still turned to borrowing. The cost of borrowing in terms of interest charged however, added to the households' burdens. This outcome reinforces the findings of Sumalee *et al.* (2000) in Chiangmai, Thailand. From the analysis, 55 percent of the households surveyed borrowed money or other items during times of hardship (Figure 4.9). Most of these households borrowed from informal credit sources such as support groups particularly WOFAK, relatives and other moneylenders. Probe outcomes indicate that the interest charged by these lenders was quite high. A number of households turned to local revolving funds where interests rates were relatively low. Exceptionally few households borrowed from formal credit institutions such as banks.

Figure 5.1: Loans Borrowed by Households



The amounts of money borrowed ranged between Kshs 3,000 and Kshs 10,000 and this averaged Kshs 5,000 (US$ 64.1). Even though support groups were the most common source of funds, the amount involved was relatively small. Borrowing was also in form of non-financial items such as taking food items from shopkeepers on credit. It is important to note that majority of the respondents however, noted how difficult it was to get a willing lender. This was largely because of the general feeling that the borrowers were likely to die before paying back the borrowed items whether financial or otherwise. This was the key item of insecurity that hindered this strategy. A significant number of those who engaged in borrowing said that they used the borrowed amounts mainly for medical expenses and other household uses. These were mainly from informal credit sources. The few who borrowed relatively larger sums did so mainly from formal credit institutions and largely used the money to do business and pay school fees.

Many households acknowledged the importance of money lending during the time of illness. However, they noted that money lending did dry up given the risks that were associated with it. This risk was considered to be very high especially given the perceived inability to pay back and the likely death of the borrower. An interesting outcome amongst the borrowers particularly those who still had a larger loan portfolio to repay indicate that the borrowers did not expect to repay the remaining loan balances in full. This was because they found it difficult to juggle between meeting the household requirements and repaying the loans. However, a good repayment track was evident amongst those who borrowed from support groups, as this was necessary for further loan advances.

5.3 Austerity and Reduced Consumption

This is where many of the poor households in Kayole had their resource management systems put to their severest tests as the needs of the family required careful balancing. Food resources had to be used frugally to make them last as long as possible. Resource management involved sharp alteration of the mix of food items, medical requirements and other items normally consumed in the household as well as reduced variety and quality.

In many of these households, particularly where the couples were still married and staying together, there was distinct division of labour where the women were entrusted with the management of all immediately consumable food resources while the men were responsible for entering into reciprocal arrangements with other households for purposes of mutual support and exchange.

The most important components of food management in the resource strapped Kayole slum involved skipping meals. In those households, many of which were female headed, the women and their household members would cut down on meals, often preferring to go without lunch. This was a great challenge particularly to households that had younger children.

As crisis deepened with the household food stocks dwindling, the food management in general and allocation in particular became increasingly difficult. I noticed from the study, particularly emerging from the female-headed households, that this became an additional burden to the women as they became solely responsible both for the preparation and allocation of the little available food resources to the entire household membership.

This condition was however, made just a little easier by the intervention of WOFAK to patch up in order to reduce the severity of these situations. Deep crisis stages were noted when the household heads, many of whom were women became bed ridden and virtually incapable of any alternative. At this point, WOFAK through INTERSOS (Italian Humanitarian Organization), Ensemble Contre Lesida from France, Islamic African Relief Agency (IARA) and Nyumbani Children's Home often intervened under the umbrella of orphan support program to provide for these households. The

households would pick packets of flour and other necessities mainly beans and cooking oil to prepare food for members of their households.

This initiative also included feeding children from other hard hit households together with other orphans who lost either one or both of their parents. They were integrated by WOFAK into an orphan support program in which the children were fed lunch three times a week, depending largely on the level of stocks held by WOFAK at any given time.

An assessment of this initiative found very great potential as it offers the orphans some levels of security and safety. It reduced the likelihood of children taking on adult responsibilities such as the girl child offering sex in exchange for favours at a very tender age. What comes out very clearly however, is that with the increasing number of orphans to feed, counsel, provide medical care and to an extent school fees, the support granted by INTERSOS, Ensemble Contre Lesida, IARA and Nyumbani Children's Home though very valuable, largely remains inadequate.

It is instructive to note that many of these services were to an extent restricted to registered WOFAK members only. This economic bias, which continued even in very distressed conditions, served to exclude some very genuinely deserving households but who were not capable of meeting the requisite conditions. One example was a cancer patient who was in a critical condition, vulnerable and unable to fend for herself and her young daughter. She cried out to this researcher how she wished she could also have AIDS that she would access these services.

The composition of the households in Kayole changed greatly during the phases of crisis survival. It was indeed, not uncommon for household members particularly the children to move into their relatives' households. In many cases this movement was into the grandparents' households (for those whose grandparents were still alive). Mama Wambui is one such grandmother who had lost two daughters to AIDS and was still nursing another in her house. She only had one son who was a casual laborer at the nearby industrial area but who also had a wife and two children to care for. The old lady who was not on any regular employment had nine grandchildren to care for in her house besides the ailing daughter.

As indicated earlier, households in which the man was the household head would enter into deals and arrangements that guaranteed mutual benefit for the household. In other extreme cases, the household head traveled to distant households perceived to be able, to borrow food or money from a relative, friend or someone with whom such an arrangement could be made. Such offers were expected to be paid back in form of exchanges or other service repayments when conditions improved, as was often anticipated.

It is worth noting that survival responses from the study indicate that there were marked changes in the normal diet of poor households. Beyond this, there was indeed a noticeable change in the variety of foodstuffs consumed and the frequency of meals served. With the increases in overall expenditures particularly medical expenses, coupled with reduction in income levels, the position of income for food expenditures shrank, the households were then treated to monotonous diet of simple and poorly processed and/or prepared food items. These included boiled maize (not mixed with beans as always the case), bone soup and vegetables, which was served only once a day. At this level, this regimen indicated that the households had indeed exhausted all their material resources, and all sources of support had actually dried up.

This issue came up as a serious matter of concern during one of the group therapies. Whereas nutritional lessons demanded the implementation or actualization of the "good food-good medicine" phrase amongst the PLWHAs, many households wondered allowed, about the nutritional implications of such dietary requirements against a background of massive starvation. In many cases, these conditions called for readjustments in food consumption. Such adjustments were indeed inevitable even though they greatly added to the loss of weight by PLWHAs. Basic nutritional requirement demands the consumption of organic nutritional foods, drinking boiled water and more of natural soups, tea, other warm beverages and more importantly, eating after every three to four hours. Reconciling these two certainly required some meal-oriented intervention.

5.4 Disinvestments and Asset Disposal

Rahmato (1991) argued that average peasants would often monitor the markets in their locality to determine the movements of prices of marketed products. In difficult circumstances like the HIV/AIDS scenarios in Kayole, poor households largely accord the market even much greater attention thereby making much better use of it with relatively expanded market horizon.

Whereas the system of disinvestments adopted by these poorer households varied amongst these very households, a common thread noted was that the process was selective and graduated. The outstanding argument here is that the households tended to dispose of their commodities perceived to be less important first! This system was clearly evident in a number of households in Kayole and other related areas. Even though it might be too simplistic to consider a neat well-cut and logical formula in this, majority of the households indeed employed this system. It is also important to point out that a number of households preferred to consider anything sold out as important. This could however, be attributed to the nature and level of asset ownership by these households. The households in fact, highly valued many of the assets, which would otherwise be considered as standard or ordinary.

Based on the responses from those interviewed, it emerged that the disinvestments plans adopted by the households were significantly influenced by a number of things.

a) The extent of wealth of assets at the disposal of the household. This meant that households with greater variety of disposable assets often had wider choices in comparison to the particularly poorer households who were then conditioned to sell their limited asset possessions much easier and at insignificant prices.

b) The specific needs of the family. This consideration was greatly influenced by the number of household members. Results indicate that the households with larger numbers of household members mainly non-working dependents put much pressure on the demand for food. Other households that had more than one infected individual or those households within which patients suffered other diseases (such as cancer) besides HIV/AIDS indicated much preference for drugs.

c) The connection with other households, kinship, religious or other institutional arrangements. This was particularly important where these structures were willing to lend a hand. These were coupled with other forms of assistance the households received or expected to receive from other sources. In many cases, these were donations either in cash or simply in form of food, clothes, loans or others such as sanitary services at home.

Literature says that an asset is any item of possession or any resource that may be sold in the market or exchanged for food through barter. All that households like those in Kayole own, including members' personal effects are in fact, marketable and/or marketed. Whereas researchers have documented notable exceptions to the sale of assets during distress conditions particularly land, the results from Kayole did not give a clear indication to this. This was because even though very few of the households indicated having sold land, majority of these households did not even own land in the first place.

Table 5.1: Selected Household Coping Strategies

Coping Strategy adopted	Yes	No
Borrowed Loans		
Sold household Assets		
Sex trade		
Other household known to engage in it	80	20
Households' own daughters/sisters engaged in it	30	70
If respondent ever engaged in it	54.8	45.2
Street Begging		
Other household children known to do it	70	30
Households' own children doing it	26.7	63.3

A few of the households however, sold their houses particularly those who experienced the critical impact of the pandemic. This was noted largely to be a measure of last resort. The households however, acknowledged that these did in fact, fetch better prices.

The sale of personal effects was very common. All the respondents to the survey and some of the respondents to the unscheduled open interviews said they had sold *all* or nearly all of their personal belongings including jewellery and clothing. Even though no man admitted having sold their personal effects during the unscheduled open interviews, some women said they had sold their spouses' clothes and even those belonging to their children to get some money to buy food and drugs. Other household assets sold included, televisions, gas cookers, fridges, radios, bicycles, and sofa sets (furniture). Others included iron boxes, electric kettles, utensils, mattresses, and livestock (goats and chicken).

5.5 Livestock Flows

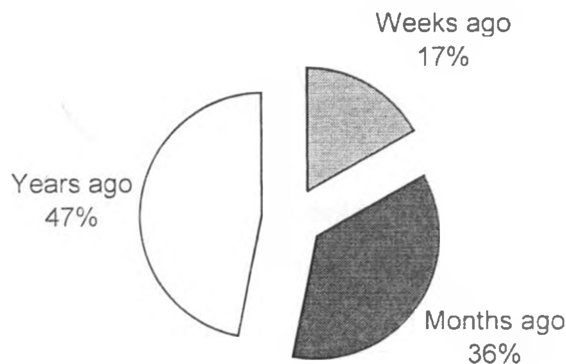
Livestock flows during periods of distress have been associated largely with episodes of famine. Different traders often purchase them in different ways (Ramato, 1991). Of these methods, only one case applied to the sale of livestock amongst the poor households in Kayole. This was an isolated case of a household that kept livestock (goats) and farmed along a stream. This household practiced urban farming. Owing to the conditions of distress due to the impact of HIV/AIDS on the household unit, the respondent indicated that they had to sell their animals mainly to the urban businessmen and speculators whose main interests were to acquire the goats for local consumption. They also disposed of chicken that were sold largely to customers within the neighborhood. Much of these returns went to meeting household food requirements and the purchase of medicine.

5.6 Normal and Abnormal Behaviour

This is a sensitive subject. The subject received more often than not, a relatively less serious and less objective treatment thereby creating many fascinating views. Reasoned analysis in this context would first; as a matter of priority obtains the definitions of what is 'normal' and 'abnormal' without going into the social and psychological in-depths of the concepts. It is worth noting that many writers have indicated sets of abnormal behaviour largely carried out during conditions of distress: child abuse, abandonment of children; inhuman treatment of the weaker members of the household by stronger members: entering or selling of oneself or others in slavery, murder by negligence or through selfish acts; high incidence of criminal behaviour such as robbery and murder; and cannibalism especially child cannibalism by mothers (Cutter and Stephenson, 1984).

It is a principal component of coping that emerged from amongst the households in Kayole. Prostitution and slave labour were steadily practiced. Over 80% of the respondents interviewed said that at least they were aware of households where members engaged in sex trade. About 23% of the respondents acknowledged that their own daughters or sisters did engage in prostitution (Table 5.1). Even though many women would not disclose this during their joint discussions or the famous "group therapies", many explicitly agreed in a one-to-one interview with the researcher that they indeed practiced prostitution. Over 55% of the respondents acknowledged having engaged in commercial sex. About 17% of these respondents said they had engaged in prostitution within the last few weeks, over 36% said in the last few months while over 47% said a few years ago (Figure 5.2).

Figure 5.2: Last Time Respondent engaged in Commercial Sex



What emerged however was that many of those who practiced prostitution were very much aware of the risks involved, not only to their partners but also to themselves given the differences in levels viral load. Said one respondent:

"...But you see, I have no choice... I'm fine and I've not developed Aids. I look fine. I do it but personally I would not want to if I can get a way out".

There was out-rightly no evidence of household members being sold, neither were there cases of murder, criminal behavior or acts of cannibalism generally associated with famines. However, slavery in the context of domestic servants was quite a common feature. What was striking here was that these women would not disclose their conditions to their employers. One respondent said:

"...You see I do not have good education. Even if I had like (name of fellow PLWHA withheld), they will still send me away like they did to her. But because I am still strong I just wash for them (masters) their things".

On probing if her masters knew of her condition, she said:

"...You can only tell them if you are a fool. They will just send you away".

According to households with members who practiced prostitution, the main reasons for which they engaged in this act were varied. While some attributed this to poverty (47%) and marital or family problems (30%), many others talked of peer pressure (13%) and other factors including mistreatment by parents, and death or separation from spouses which accounted for 10%.

Many household members including some household caregivers always approached other neighboring households (not necessarily affected) to have their clothes washed or cleaned for them at a fee. This compensation fee could be either in cash or in kind, the later often being in form of food and clothing.

A unique practice that would largely be treated as child abuse was noted in Kayole. "Child contracting" is a system in which due to adversity in shortages, households would "contract" or "lend out" their children to work for other well-to-do households while living within their own households. The parents were then also paid either in cash or kind, often in form of food items.

The subject of child abandonment was observed in Kayole albeit on a smaller scale. The term "abandonment" here requires careful treatment. The abandoning of children in this context was not necessarily out of sheer 'neglect,' but was a survival measure of the very last resort. This researcher

was told of cases where parents had willingly let go their children as young as 5 years to beg on the streets in the hope that they would bring something home for the family when darkness finally sets in. One such case turned tragic when a young small girl was raped so badly while out on the street. The young girl was later taken up by one children's home (Endebbes) for treatment, counseling and subsequent care and education.

Other cases of child abandonment were noted by the researcher in which children who dropped out of school because of lack of school fees were pushed further by parents into picking up old dirty metals and paper for sale in a bid to get something to feed on. Many of these children ended up on streets either fending for themselves or on behalf of their families. Of those interviewed, 70% acknowledged being aware of some households where children went out on to streets to beg. However, only 18% acknowledged that their own children indeed went to streets to beg (Table 5.1). Majority of these households also attributed the breakaway of children to beg in streets on poverty (41%), family problems (27%) and bad company/peer pressure (26%). One household also reported a case in which this was attributed to mental disorder. This together with other reasons accounted for 6%.

5.7 Adjustments of Household Resources

The most ordinary and immediate reaction of many households that had accumulated savings was to utilize this available resource. Even though the use of this resource did not largely affect the welfare of other household members then, it did compromise future household investments. In fact, even the opportunity cost in terms of lost interest associated with de-saving was in itself an indirect cost of illness on the household.

About 60 percent of the households interviewed had savings to finance increased health costs. It is noted that many of the households largely did not have much savings or simply had none at all. This was largely attributed to the resource strapped conditions of many of these households. The few households that had some savings indicated that much of these were used mainly in meeting increased medical expenses (52 percent). This was followed by food (30 percent); rent (10 percent) and other expenses (8 percent) such as transport, school fees, and assistance for people back at home (Table 5.1). Due to this inadequacy, these households were conditioned to finance the rest of the

healthcare expenses and other non-health expenditures from other sources. This was the case too for those households that had completely no saving. Due to this, over 75 percent of the respondents indicated that their financial positions became even worse off compared to periods before the illness.

Table 5.2: Approximate Household Expenses

Household expenses	Number of Households	Percent
Medical expenses	21	52.5
Food items	12	30
Rent	4	10
Others	3	7.5
Total	**40**	**100**

Another important strategy adopted by the households was selling of household assets. These households resorted to this means to cushion themselves from rising expenses and the falling incomes. Whereas some assets of low quality owned by poor households might not have necessarily had greater impact on the households' welfare when sold, many others particularly the productive assets such as land, livestock, motorcycles and housing however, were expected to result in greater negative impacts on family production both then and in the future.

From the survey, 79 percent of the households did opt for this strategy. The assets most often sold included radio, TV, household electrical appliances such as electric kettle, iron boxes as well as clothes and household furniture. Whereas there were certain households that resorted to the sale of their parcels of land and motor vehicles, these were extremely rare given the cash strapped condition of the households. Such households were particularly wealthier but had since experienced drastic decline in wealth ownership especially due to the impact of HIV/AIDS.

It is also observed that of the households surveyed, almost all of them (87 percent) had not purchased any new assets for their households from the beginning of the illness. Instead, a number had sold many of the assets they had. In terms of asset ownership, the researcher noted that this

variable mainly depended on the level of support accorded by other households and particular individuals. Households with relatively large amount of resources and with support from other household units or individuals often owned assets such as TV, radio, sofa sets, fridges etc. Cash strapped households however, had no meaningful asset ownership. Many merely owned a bed and no table or chairs. Certain households did not even have basic bedding requirements. They lay down old "kangas" on the mud-covered floors where they spent the night together with their young children covered in old tattered bed sheets.

It is important to note that much of the money raised through the sales largely went into meeting the increased health care costs. Some of it, however, was used partly to maintain household consumption. Particular households that had fewer reserves or simply none at all to fall back on saw reductions in their household expenditures on consumption as the next available alternative. If by whatever means this reduction in consumption was significantly large enough, then it did adversely affect the nutritional and health status of the household members as well as their ability to work. From the survey, 46 percent of the households adopted this strategy. Of these, one half actually experienced serious effects on their welfare.

Information obtained from respondents through probing served to reinforce this result. One infected respondent, a young woman aged 24 with three children all aged between 9 and 15 said:
"My name is Mariamu. I stay in Kibera (slum in Nairobi) and I am a member of WOFAK. I was living together with my husband and children when I was informed at the hospital that I have Aids (HIV). When my husband knew about my condition, he decided to go away and leave me with the children. He was a matatu driver and the only source of our income. I have no job and cannot feed my children. In a week we normally go without food for three days. We only get food from WOFAK and it is not even enough. I am really suffering with the children".

Mariamu's case is one amongst many other similar households in Kayole. In depth interviews revealed severe suffering amongst these households. Many of them indeed acknowledged that their economic status had changed greatly compared to periods prior to the illness. They largely attributed this to the inability to get jobs, death of partners, and persistent sickness amongst other reasons.

The survey also revealed that many of the households coped through the reallocation of the time that members spent on various activities. I need to stress here that this reallocation was only possible for household members and individuals who were living with the virus but were yet to develop clinical Aids. These were individuals still capable of carrying out activities and provision of services. The reallocation was often in form of adjustments in the amount of time that members spent on various activities. The reallocation also involved other members of the household taking on more work than was the case previously. This was meant to make up for lost income. They helped with family businesses through the substitution for lost labour and reduced time spent at their places of work to help the family.

Other methods of readjustment included finding supplementary work, or simply quitting a job to help with family chores or take care of the sick individual. Literature reinforces this outcome indicating that a greater proportion of members that adopted this coping strategy were the elderly parents, particularly if the patient was incapacitated. Under these circumstances, other children of school-going age who were also members of these very households were normally withdrawn from school to start work and to help with family production.

In one of the unscheduled open interviews in one household, a male high school student who had dropped out of school in form two against his wish narrated how he had to look for work to assist his family members. With no training at all, the first-born boy ended up as a free-lance tout with the "matatus" (public transport vehicles) plying Kayole-City centre route so as to get money to assist his household members. Said the young man:

"...You see my brother (researcher); us guys were staying in our house in Koma (Komarock, a middle class estate in Nairobi). But my dad decided to sell the house without us knowing and left for the States (USA). So we were chucked out of the house and we came here with our mum (main respondent). My mum does not have a steady job, just this WOFAK thing (public educator). My sisters are going to school yes but me...........(deep silence). .... Bro (brother) even you, you understand, mum could not pay my school fees, instead of just sitting, I look for money because she is also sick and we have to feed".

Clearly and without question, while this withdrawal of children from school to start work did to some extent assist the families restore their income and production levels; it did greatly affect the earning ability of these very children in the days that lay ahead.

It is important to add that amongst the households interviewed; principally there was hardly a case of hired labour to replace the ill persons in the family businesses as a study in Thailand by Sumalee *et al.* (2000) showed. The Thai study noted that with rising household expenses and falling incomes, additional expenditures on increasing substitute labour could result in shortage of production capital for the household production in the future. The case of Kayole was markedly different. This was attributable largely to the smaller size of trading activities that formed the bulk of responsibilities for households. This did not warrant substitute labour. But even more relevant was lack of substantial capital to start up business and the expertise to manage such business, leave alone funds for hiring labor.

The level of deprivation in Kayole has greatly served to intensify the severity of coping by households. One of the most important end results of these processes among these households is the nature and quality of care provided to PLWHAs at home. In many respects, the quality of care provision is compromised because of the various limitations facing these families. The basis of our next discussion is to examine this in a bit of detail.

CHAPTER SIX

HOME BASED CARE AND SUPPORT IN KAYOLE

6.1 Overview

The recognition of treatment and care that includes access to ARVs by the UN General Assembly special Session on HIV and AIDS was in itself a milestone in the fight against Aids particularly the component of care provision. Core to comprehensive HIV/Aids care strategy is the integration of preventive and treatment planning and interventions.

Traditionally, care provision for the sick and elderly members of the family has been the primary undertaking of women. The Aids epidemic has only recently added to this burden. As a result, this additional burden has stretched the women's meager household resources to the breaking point, greatly adding to their workload. Given their general lack of resources in the face of increasing workload, many women, supported by their communities and other institutions from the civil society have opted to care for their patients within their homes. Over the years, comprehensive HBC has increasingly been the only practical form of care in many societies such as Africa especially given the inadequacy of extensive hospital based or alternative care services.

In recognition of the essential role that HBC plays in realizing a comprehensive HIV/AIDS care across continuum, WHO developed guidelines on HBC that categorizes issues of care provision into various elements. These elements were assessed during this research to establish their extents of applicability. All respondents interviewed acknowledged belonging to at least some HIV/AIDS related support organization that dealt with issues of care for PLWHAs. These support organizations provided various forms of care and support to their members. The nature of these support services is analyzed with respect to WHO guidelines and Kenya's NACC home care guidelines.

6.2 Care and Support in Kayole

1. Clinical Care

The fundamental aim of clinical care is to reduce suffering by providing treatment and preventing opportunistic infections. This is the responsibility of healthcare workers who either prescribe or distribute medicines and giving instructions of how such drugs are to be taken. Clinical care within a home based care delivery system therefore implies that the patient either has to visit a health care system on referral whenever need be. However, the health care providers can also visit patients at their homes to prescribe drugs. This is what takes place amongst the patients who are members of WOFAK.

During the therapy sessions organised by WOFAK, a doctor is invited who carries out clinical examination of the patients and prescribes drugs for them. Many of the patients would complain of pain, fatigue, insomnia, and shortness of breathes. They would also complain of diarrhea, skin problems, fever as well as weight loss and depression. The quality of clinical care provided by WOFAK is however, compromised by lack of personnel and basic supplies such as drugs for opportunistic infections, gloves, antiseptics etc. The situation is particularly worse with patients who also suffer from TB, diarrhea and skin rashes. At any one group therapy session, there would only be one doctor attending to over a hundred patients in less than six hours!

A number of these patients also visited hospitals within the city (mainly public hospitals) where they were treated and drugs prescribed for them. Many women complained of gynecological and cancer infections as well as inability to afford many of the prescribed drugs.

2. Nursing Care

Nursing care refers to the management of symptoms by attending to the personal needs and maintaining dignity of the patient, preventing transmission of infections and administering prescribed medication to ensure patients' compliance (NACC, 2000). Nursing care also takes into account the patients' comfort, nutritional needs and a safer environment. The care is provided both at hospital and home environments more often by family members trained in basic nursing care skills. Nursing care provided by WOFAK was comprehensive albeit shrouded in severe limitations.

The success of this care was mainly attributable to the skilled home caregivers who were trained in nursing skills by WOFAK.

It is worth noting that there was however, very limited number of family members who were well trained in nursing skills. Nonetheless patients were kept physically comfortable with good nursing care while helping them prepare for their deaths. In certain circumstances, though not greatly noticed, the support group went further to plan for the dependants. This care also included bereavement counseling for the affected households, their relatives and friends to enable them cope with grief. This care remains one of the critical pathways to promoting comprehensive care at home.

Nurses however, often complained of too much workload due to the number of patients they had to attend to, lack of basic nursing facilities and the general lack of skills amongst their colleagues. This outcome reinforces the observation in Uganda by Kaleeba *et al.* (2000), where many of the problems that afflicted home care largely related to the inexperience of many health workers in dealing with HIV and AIDS as well as the limited human and physical resources.

Another fundamental problem experienced by patients as a hindrance to the success of care provision in the home was meeting nutritional obligations. Good nutrition is extremely important for PLWHAs since a well balanced diet enhances longer periods of healthy stay through the provision of nutrients needed by the body. Skills required relate to food preparation, serving and identification of the right foods. The big challenge to many households in Kayole is the limited resources to purchase the essential food requirements.

3. Psychosocial Support

The role of psychosocial support in the provision of care and curbing the spread of HIV and Aids cannot be overemphasized. It ranges from counselling, spiritual support and medication adherence to end of life, bereavement support and practical economic assistance. The main underlying reason that informs the provision of this support largely remains the attempts to mitigate the devastating impact of Aids on the lives of people, their social interactions and incomes as well as ensure success of medical treatment.

The counselling component involves the confidential interaction between the client and the counsellor. This is aimed at reducing psychological stress and providing PLWHAs with necessary information to make informed decisions. This is equally important for the prevention of further spread of HIV and positive living for those infected.

Spiritual support entails the involvement of religious persons to help PLWHAs effectively cope with concerns of death. Social support involves improving the ability of PLWHAs and their families to cope, participate in activities and be accepted by their fellow communities (NACC, 2000). This component enhances the profile and visibility of PLWHAs thereby reducing stigma. It involves legal support, orphan support, support to PLWHAs and their families in form of materials, identification of resources for care, information, educational and networking as well as discharge and referral services.

In Kayole this care involved individual counseling, meeting with other people infected with HIV in support groups and receiving support from community and household members that assisted people to accept their situations. It also involved talking about diagnosis and coping with both anxiety and depression. Majority of the respondents interviewed indicated that indeed this was the greatest benefit they obtained from WOFAK. Many patients, who initially sat hopelessly outside their houses lonely and desperate, now only attended the group therapies either once or twice and were freely talking about their conditions. The support helped embrace openness.

It was further enhanced by community education carried out by WOFAK and greatly served to counteract the stigma associated with the epidemic. From this initiative, many members of WOFAK

were already serving as role models for PLWHAs and public educators on issues of HIV and Aids. To many HBC experts, this was one fundamental way of enhancing openness as a strategy to promoting care amongst those who suffered in silence. This is portrayed in Box 6.1.

Box 6.1: Value of Community Education in 'Open' Living

"...Enhancing care and support at the community level requires changes in public attitudes with idols and key personalities going "open" a bout their status. In this way, such people living openly with HIV/Aids at community level would make significant contributions to care and prevention. They can perform plays, dances, music, and give personal testimonies".

Openness encourages positive living which is extremely important in overcoming challenges related to stigma and discrimination and more importantly, restoring hope. According to one representative of a home-based care project in Kariobangi North (slum in Nairobi), there is urgent need to put in place a process that entrenches hope amongst the PLWHAs. He argued that this could only be realized through an appropriate care strategy for PLWHAs as away of enhancing prevention against further spread (Box 6.2).

Box 6.2: Hope and Care: A Necessary Linkage

"...Unless we express care for PLWHAs, we will have little hope of preventing and controlling the disease. Unless communities with which we work sense some hope, which usually comes through knowing someone who cares, they will not be motivated to work towards preventing the spread of HIV infection. Stress needs to be put on the importance list for caring for PLWHAs and communities to prevent further spread of the disease".

Emphasizing the need to confront stigma and discrimination as a strategy to enhancing home care, Christine, one of WOFAK's home based care providers added:

Box 6.3: Open Living: Tool against Stigma and Discrimination

"...Those living openly really make unique contribution in fighting denial and discrimination. They speak about living with Aids at various platforms. They meet with groups of PLWHAs giving them advice and information, encouraging them and providing hope for the future. In this way, they are confronting denial, stigma and discrimination in a big way. They are helping extend the boundaries of openness about the reality of HIV and Aids. Even for us this makes our work very easy".

Supporting Christine's views on positive living as a strategy to fighting stigma, discrimination and consequently promoting home care, Ms Otaye, one of WOFAK's volunteer home care providers had this to say:

Box 6.4: Positive Living

"...It doesn't matter how I feel, whether I have any health problem or not, I just go to WOFAK every Saturday afternoon. Even if I lack the fare, I just walk to the drop in center. It is not very far. At the center I get a lot of encouragement from counseling. I see the counselors and meet other people with similar problems to mine. We share our experiences, talk about our problems and how to deal with them.

I am also a member of SWAK and also carry out public awareness and prevention work with WOFAK. I talk to relatives and neighbors about the importance of HIV testing. I also advice them to go for testing. This is because if you remain ignorant, it helps nobody. You live in fear and uncertainty and whenever you fall sick you go and waste money on witchcraft. It is best to know your status. If you are negative you can make precautions to remain so, and if you are positive, you can get support from other people or organizations such as WOFAK.

I would like to appeal to people to show love to one another, not to stigmatize those who are infected, to share information with one another, and to counsel one another.

I have no regrets about being open on my status. I have instead benefited from WOFAK's group therapies and also get sympathy from friends and relatives when I am sick. My sister in law particularly helps by giving children second-hand clothes. Once or twice a week, I also get food from WOFAK. It is not much but it helps us quite a lot. Even the counsellors from WOFAK often come and check on me here, and give me information and comfort".

Many respondents indeed acknowledged having benefited from this support especially those who attended HBC trainings. It was always one of the major topics of discussion during these trainings. It was also notably true particularly among those who had been trained and were now involved in HIV and Aids public education awareness and campaigns. For many, this formed their primary occupation. Asked about the nature of involvement by various institutions in the fight against Aids, majority of respondents (over 68 percent) said that the NGOs, the churches, other community organizations together with the government ought to, as a matter of priority, engage in the provision of this support.

According to one religious official, care and prevention are intertwined. He emphasized that psychosocial support embraces both prevention and care for PLWHAs. He noted that this makes it an ideal HIV and Aids management strategy particularly within the community level. He also pointed out however; that in many other cases this care strategy has been viewed simply as an extra burden to these very communities. This is illustrated in Box 6.5 below.

Box 6.5: Care and Prevention are intertwined

"…Care is often portrayed simply as a burden on communities. Even some religious leaders and some health professionals too, have said that care for PLWHAs is a waste of resources because these people are going to die anyway. But we strongly believe that care is a very important component of prevention. When people show that they appreciate you, that they trust you and value your contribution to society, you also feel the responsibility to protect others from HIV infection. Better care, treatment and support will encourage more people to come for HIV counseling and testing, and if they are HIV-positive, to be open about their status. As things stand now, many people with HIV feel that the disadvantages of being tested and going public outweigh the advantages. They risk facing stigma and rejection, but with no tangible benefits. If there were some clear benefit, like access to better medical treatment, many more people with HIV would be willing to come out. This would be good for both care and prevention efforts".

4. Caring for Caregivers

This is one of the cornerstones to any comprehensive care provision at home. In many cases, these caregivers whether family members, community volunteers, or health workers are assumed to be able to cope. It is important to note that many of these caregivers are also themselves infected. As a result, they more often experienced stress, depression and burn out.

In one case study, Dorine a home based care provider with WOFAK emphasized that the greatest challenges they faced as caregivers were the massive expectations from fellow PLWHAs, exhaustion and burn out. Dorine like many other care providers was emphatic that caregivers also need to be cared for if the gains made from their work were to be sustained (Box 6.6).

Box 6.6: Case Study showing the Need to Care for Caregivers

"…My name is Dorine. I am a graduate of Kenyatta University. I used to work but when they (employers) realized that I was HIV positive, they sacked me on very flimsy grounds. We also separated with my husband after he knew my status. He is a lawyer. But I had accepted my status and I'm not bothered much now. In fact, I'm a counseling aide with WOFAK. I have attended counseling courses and other home care trainings sponsored by WOFAK. I meet most of the clients at the group therapy but also visit them at their homes particularly those who miss a therapy session. I also visit Mbagathi hospital and Kenyatta National Hospital (KNH) to attend to some of our admitted members.

The Greatest challenge we face is that many of the patients get so close to you that they forget you are also infected. They always expect a lot from you, almost wanting you to solve all their problems. The distance is also very tiring especially when you have to make visits on foot. It leads to burn out. If we could afford a better means of transport, the home care program would really work wonders.

I do this work, not because I get any payment, but because I want to encourage others within the community to make the best out of their lives. I was well counseled when I knew my status and it has kept me going. I want others also to benefit from my skills. I feel satisfied when I see that someone has accepted my advice. It really makes me feel good".

The above case study shows that the caregivers too need emotional support and stress management to prevent depression and burn out. Even though this component appeared to be taken care of within WOFAK, an in-depth examination revealed that many counselors and more particularly those on home based care programs largely experienced much depression, stress and burn out.

Burn out is not only a problem of caregivers within the households. Community based health workers also experience burnout especially when isolated from their supervisors and peers while also faced with heavy workload of care provision. This situation is worsened when many of the health worker's clients keep dying, many of whom are friends and relatives. A home care expert suggested that supervisors in charge of community health workers should advise them to confide in trusted counsellors and take breaks from work as often as possible. They were also encouraged to organize themselves into peer support groups that in turn can provide a forum where health workers meet, share out experiences and support each other.

Almost all caregivers interviewed in Kayole also acknowledged in one way or the other how difficult it is to care for terminally ill patients. They noted that the work of giving care becomes more painful especially if the infected individual is a family member, a friend or any other loved person. Many of the caregivers lamented the stigma attached to AIDS and noted that this made the work very trying.

Caregivers underscored the fact that even the strongest care providers often reach levels at which they get tempted to quit the responsibility. It is against this background that home care experts emphasized the need for such care providers to talk to other persons such as priests, counselors, imams, friends as well as other trusted confidants. They also advised that such caregivers or their families should also join other caregivers or families of PLWHAs with a view to either sharing out their experiences or support groups.

Many families interviewed acknowledged the value of sharing and support groups, noting that they indeed obtained great encouragement from the periodic group therapies organized by WOFAK. Home care experts also emphasized the need to organize care provision at home amongst family

members in a way that everyone within the family gets a break from time to time. In this way, the burden of care provision is greatly reduced.

Many of the caregivers with WOFAK also lamented on problems related to transportation. The PLWHAs and their households are spread all over the vast Kayole program area. The caregivers often move from one household to another on foot becoming exhausted long before they begin providing their services. It is because of this reason that nearly every caregiver decried the problem of vehicles to facilitate their movement (Box 6.6).

5. Occupational Therapy

Occupational therapy refers to the component of care continuum that enables PLWHAs to practice self-care and economic self-reliance. It involves the creation of IGAs and other moneymaking opportunities for PLWHAs to broaden their economic base. Such economic independence enhances the ability of PLWHAs and their households to meet their needs such as food, treatment, rent, school fees and other physical needs.

In Kayole, WOFAK initiated this component as early as 1997 in response to the striking deficiencies in meeting the basic needs amongst its members. Many of the households are condemned to high levels of poverty besides being affected by HIV/AIDS since a larger number of members are single and have to care for their households. One particular IGA initiated was a cereals selling business that the support organization started because of its inability to formulate a budget line for household assistance for rent, food, transport etc. The project however, did not see great success due to the organization's "poor conceptualization" of the income generating idea. It reflected the organization's lack of expertise and capacity to promote IGAs for its members. This led the organization to seek the services of Improve Your Business–Kenya; an organization that specializes in small enterprises sector development to enable WOFAK to develop successful initiatives for income generation.

6. Complementary Therapies

Respondents in Kayole reported the use of traditional and complementary therapies. The treatments were used to help exert control over healthcare by offering hope to the PLWHAs. Many of the PLWHAs sought treatment from community-based distribution points mainly run by NGOs, CBOs and support groups. Government health facilities were equally utilized especially upon referrals.

Whereas such a dismal number of PLWHAs ever visited private doctors mainly because of the non-availability of money, it is interesting to note that many often visited the pharmacists when they "felt bad" or when symptoms of opportunistic infections first appeared. A number of PLWHAs equally did not seek treatment from the formal health care systems for they did not want others to know their conditions. To others, they simply had no strength to move to the health service providers.

Key to note from the outcome of this research is the significant utilization of services offered by traditional healers. Almost all the individuals interviewed had visited traditional healers. This was true even at the time that they were utilizing the formal health services. This outcome confirms a UN report, which showed that in Africa; about 80 percent of the people rely on traditional medicine for healthcare needs both in rural and urban settings (UNAIDS, 2002). A very notable outcome here is that while majority of the respondents knew that traditional and other related complimentary therapies did not cure AIDS, they still kept seeking these services as they were seen to be able to alleviate certain symptoms.

6.3 Household Needs and Necessities

A comprehensive HBC that fits satisfactorily into the overall continuum of care requires many materials and facilities for use by the PLWHAs themselves, their households and the surrounding community. These needs may vary greatly depending on the socio-economic and cultural backgrounds of these entities. Understanding these needs must therefore involve a critical assessment of the nature and extent of these needs as well as the various entities whose needs are to be addressed. More importantly, such an assessment must take into account the time when such needs are addressed particularly because of the problems associated with the various stages of the epidemic.

Box 6.7: Needs and Concerns of PLWHAs

Needs

- Food
- Drugs (for Opportunistic Infections and ARVs)
- Clothing and Beddings
- Shelter/Rent
- Love and Acceptance
- Training and Employment opportunities
- HBC Kitty (Gloves etc)
- Loans
- Water

Concerns

- Children Education
- Information Awareness
- Counseling
- Laws to Guarantee Rights
- Transparency in management of HIV/AIDS funds
- Stigma and Discrimination

Many of these needs are more basic and at times in critical shortage in resource strapped settings. All the respondents ranked food and drugs as the most important necessities for PLWHAs. Many households noted that they were unable to get adequate food as was always recommended by the doctors. A number of respondents also complained that they were unable to get on regular basis the drugs that were prescribed for opportunistic infections. A very small number (20%) of the respondents were on ARVs at the time of study.

Respondents also spoke of greater need for clothing including beddings in order to ensure hygiene and comfort as well as prevent spread of infection and boost morale. A number of respondents also said they experienced significant problems in meeting shelter and rental obligations as much of the household budget leaned towards meeting medical and food requirements. As a result, many households constantly changed their residential houses after staying in them for very short time periods. Majority of the households stayed for an average of five months before relocating to other house(s). The main reasons for relocation were inability to meet rental obligations, which they saic

were quite high. The rent averaged Kshs 2,000 per month. Others however, attributed their relocations (previous) to insecurity or "just for a change". On probing, a number of respondents said they were "chased" out of the houses by landlords. One fundamental outcome of probing is that majority of those households that moved often relocated to houses that had fewer facilities thereby attracting lesser rental charges as compared to those houses that they were moving from. This implies that the households were only prepared to spend a little less on shelter.

Other general concerns of PLWHAs and their households included discrimination, occupational therapy, psychosocial support and general information availability on living with HIV and AIDS. They emphasized the need to fight stigma and discrimination to enhance general acceptance in all spheres of human life. They noted the need to train PLWHAs and avail jobs to those who are still capable of working as well as their caregivers. The households also emphasized the need to avail information to PLWHAs, their households and the community as away of fighting stigma and discrimination. Many households also talked of the need for counselling, spiritual support as well as general assurances that their children would be cared for and supported when they finally die. Home based care providers and experts particularly decried the lack of HBC kitty that exposed them to greater risks, problems of transportation, general burn out and massive expectations by PLWHAs.

Given the problem of poverty and HIV/AIDS, many households did not access all these needs. Individuals and institutions however, provided assistance on a number of needs. Support was sourced from friends and relatives, NGOs and CBOs, religious institutions as well as volunteers and well-wishers. The common provisions included clothes and drugs. Others like food were provided in a very limited scope. Information from key informants was emphatic that this was actually deliberate to avoid creating a syndrome of dependency. This was also applicable to giving cash money to PLWHAs, which WOFAK highly discouraged. The health department of the government through NASCOP and NACC in partnership with NGOs, CBOs and religious organizations tried to meet the general concerns relating to counselling, spiritual support, advocacy and awareness creation as well as empowerment campaigns. Respondents however, said that a lot still needed to be done concerning ARVs, orphan education, and occupational therapy.

6.4 Institutional Roles and Responses

Institutions play significant roles in development and the case for HIV and AIDS is no exception. The fight against the epidemic in Kenya, like the rest of the World has benefited greatly from the efforts of these very institutions. Policy and programme recommendations arrived at in a number of forums often require the interventions of these institutions. This fundamental role in the fight against HIV/AIDS particularly in enhancing care provision in particular emerged very clearly from this research. Respondents were also very categorical in bringing out the margin of limitation by which the responses of these institutions have fallen short of their actual capabilities.

Many households noted that the government has the responsibility of mobilizing resources to freely train PLWHAs, their households, communities and healthcare workers as a way of promoting healthcare delivery. These trainings could be on HBC, IGAs, fundraising, orphan support etc. They noted that the government deserves to undertake public awareness creation on the potentials of HBC, establish adequate VCT centers as well as mobilize other actors in enhancing HBC initiatives. It also has an obligation in availing cheap and affordable drugs including ARVs, fighting stigma and discrimination, strengthening anti-poverty policies as well as effective management of HIV/AIDS related funding. They noted that the government deserves to put in place effective interventions aimed at changing behaviors to avoid further infection.

Many respondents lamented that these important responsibilities were not being carried out except for establishment of VCTs and some limited public awareness campaigns mounted by NASCOP. Many patients, they said, still lack essential drugs and yet money meant to help PLWHAs were grossly being mismanaged. They singled out HBC as having received no attention from the government except for the national guidelines produced by NASCOP, but which still has failed to either promote or ensure standards within the limited HBC initiatives being carried out by support organizations in very ad hoc manner.

The private sector in Kenya was criticized by many respondents on grounds of discrimination and lack of active policies that respect human rights as contained in the UN's International Guidelines on HIV/AIDS and Human Rights. They noted that many PLWHAs had been sacked from their jobs upon being diagnosed with HIV virus. A few respondents however, noted that some companies had

started prevention programs; but they (respondents) were quick to add that none had initiated HBC activities. They noted that the corporate sector can achieve a lot in mobilizing resources, capacity building, and financial interventions for care and support provision as well as entering into partnerships with other institutions in developing policies aimed at combating HIV and AIDS.

Currently there is a severe lack of sessions exploring the role of faith-based organizations in HIV/AIDS prevention, treatment, care and support. They can however, respond effectively by designing programs on advocacy, prevention, care and support due to their enormous influence over the cultural norms that guide individuals and community behaviour which in turn influences how information about HIV and AIDS is interpreted. This potential has indeed been noted the world over as regards the use of condoms, teaching faithfulness and abstinence, acceptance of PLWHAs as well as sexual education.

The respondents noted that Faith Based Organizations (FBOs) can also go further into offering drugs besides prayers or spiritual support, avoid discrimination as well as initiate and finance HBC and orphan support services. Despite this potential, they regretted that many of these organizations only offered general prayers in mosques and churches with quite a few giving food, drugs and clothing. They noted that there still exist greater levels of discrimination and stigmatisation and very low levels of acceptance of PLWHAs amongst the faithful. Very few of them had programs on the ground that supported home-based care.

Communities and households including PLWHAs themselves have a critical and valuable role in fighting HIV/AIDS and particularly enhancing prevention, treatment, care and support. In many developing countries, unpaid household and community members provide care and support usually women. PLWHAs have formed own support organizations that play a critical role in response to the epidemic by providing psychological, social and material support to help reduce isolation and avoid stigma. This fact is reinforced by the views of respondents interviewed in Kayole. They noted that their communities greatly appreciate HBC and often welcome and work together with HBC teams. A few however, noted that not all members of the community understood HBC and consequently still believe that PLWHAs should be cared for in hospitals. This tended to perpetuate stigma and discrimination. A number of PLWHAs also noted that many individuals still lived in denial

preferring living in secrecy to candour. Many also still do not know their status thereby excluding themselves from the care continuum.

CHAPTER SEVEN

PROMOTING COMPREHENSIVE HOME CARE AND SUPPORT

7.1 Overcoming Barriers to Care and Support

The stigma and discrimination associated with HIV/Aids has seen many individuals infected with HIV and AIDS often reluctant to seek care. This is the typical scenario in Kenya particularly amongst those who have not embraced the element of openness. As a consequence, this has been a big set back in accessing and promoting care in the country. Promoting and enhancing appropriate care therefore requires that PLWHAs themselves must be ready to overcome the inherent socio-cultural and economic barriers to them accessing care and support that they need. This brings into focus the need to put in place structures that encourage PLWHAs to overcome these barriers

Significant barriers also emerge from the government's non-commitment. The government has indeed been slow in taking the lead in action to enhancing care probably due to the long latent period before the development of clinical AIDS. This has been reinforced by a steady transmission that has largely been attributed to the stigmatised groups. It is important to note that even in areas like Uganda within which there existed both the political and social will to confront the epidemic and specifically provide care, the scale of the epidemic largely overwhelmed resources given the small per capita health expenditures and a generally weak health infrastructure (Kaleeba, *et al.* (2000). It is advisable that the government show active commitment by increasing resource allocations to combat the epidemic and more generally at improving the health infrastructure.

Departures to seek greener pastures, low morale due to pay packages and working conditions, stress and to a limited extent, the HIV/AIDS related deaths amongst the health care personnel have greatly reduced the scope of health care available to PLWHAs in Kenya. With the economy at an all time low, an effective mix of prevention and care initiatives meant to improve the quality of life for PLWHAs is very critical. Such interventions will obviously require resources. However, given proper planning, such a mix can indeed be obtained at much more cost effective ways. This puts an even heavier burden on policy makers to decide on difficult alternatives such as between HIV/AIDS and other public concerns and even balancing between prevention and treatment programs.

It is in this chapter, that I make suggestions and recommendations for implementation to help improve and promote home based care for PLWHAs. In this way, the stress amongst PLWHAs and their household and health worker caregivers will be reduced and as a consequence, there shall be a reduction in the severity with which PLWHAs and their households have to cope.

1. Promoting Clinical Care

The realization of a comprehensive HBC in any system requires thorough integration of drug therapy that caters for all manifestations into the primary health care sector. Such an effective integration will allow better access to treatment including ARVs as well as early diagnosis of infections.

The increased level of vulnerability amongst women due to gynecological and cancer related problems as noticed in Kayole call for more vigilance in reproductive healthcare to address the additional risks. Particular attention also requires to be given to the treatment of TB, as it is the leading cause of morbidity and mortality among PLWHAs especially in developing countries (Bill, 1996). This is because it accelerates the progression of HIV/AIDS, increase viral load and make people more vulnerable to other opportunistic infections (UNAIDS, 1997). Effective provision of ARVs at affordable rates must also be enhanced to reduce the amount of viral load, delay the development of AIDS, reverse its effects on the immune system and prolong survival (WHO, 2000)

Given the wide range in resource requirements to enhance clinical care, policy makers must thus balance the prevalence and suffering associated with opportunistic diseases against the cost of diagnosis, treatment and prevention. According to UNAIDS, looking beyond AIDS epidemic and prioritization of health needs shared by the general population is fundamental. It is also important to note that good nutrition, maintaining hygiene and other behaviors greatly reduce the risk of opportunistic infections.

2. Promoting Nursing Care

Nursing care is extremely critical to attaining comprehensive care in the home. The government in collaboration with stakeholders in the fight against HIV/AIDS must invest adequately in providing nursing care to enhance hygiene that safeguards the patients' environment as well as prevent further transmission. These stakeholders could be community groups such as churches, women groups, support organizations etc. The investments must also be in form of personnel (nurses) and facilities necessary for supporting activities of feeding, prevention and relief of discomfort, pain and other forms of complications.

A proper nutrition is also essential particularly amongst the resource strapped households to which the need for food remains an overwhelming priority. This is particularly of great concern as nutrition and Aids operate in tandem. Whereas nutritional deficits make PLWHAs more susceptible to various diseases and infections, malnutrition in itself remains one key clinical manifestation of HIV infection. According to UNAIDS (2002), HIV/AIDS and food security are closely linked in that HIV affected households increasingly risk food insecurity and malnutrition through reduced work, income and time available to care for younger children as well as increased expenses for health care. Food insecurity in turn increases both the risk of being exposed to HIV and household's vulnerability to the impacts of the disease as it progresses. This tight linkage is also noticeable between nutrition and treatment especially ARVs and clean water supplies.

It is critical to note that nursing care providers must be very cautious not only on language, but also non-verbal communication or behavior to which many PLWHAs are constantly vigilant. One home care provider at WOFAK noted that negative behaviors often left patients more disturbed thereby increasing social stigma and discrimination. Healthcare workers (nurses) must also undertake universal precautions to reduce cross infections. This is necessary even if the patient infected with HIV is symptom-less. They must be careful with blood and other body fluids. Precautionary measures include the use of gloves and other barriers and protective material. They must also be cautious against contracting other infectious organisms such as hepatitis B

3. Promoting Psychosocial Support

In light of the fundamental values inherent within psychosocial support as an ingredient of comprehensive care within the home setting, it is instructive that institutions such as churches and counseling groups dealing with matters relating to psychosocial support should initiate care and support programs that are critical to the provision of psychosocial care and to which greater involvement of PLWHAs is integral.

Evidence from TASO and WOFAK itself indicate that such peer support programs hold great potential of success with extremely low costs to healthcare systems. The support groups that give psychosocial therapies are equally useful in the provision of and/or advocating for social and economic support programs such as IGAs and vocational trainings. It is also necessary that a policy on counseling be defined and applied to ensure thorough training of counselors and a proper pre and post test counseling process that guarantees confidentiality. Of great necessity is also the need to strengthen the psychosocial component particularly at the health centers and other health service outlets often used by PLWHAs.

The spiritual component was significantly lacking from WOFAK program in Kayole and surprisingly this is the case all over the country mainly due to the judgmental attitude of some religious leaders (NACC, 2000). Religious organizations need to critically look into ways of changing this attitudinal apathy. An effective and efficient referral system also needs to be put in place with active engagements of health facilities or agencies, support groups and/or family caregivers. This demands an effective discharge referral planning that focuses on discharge points for PLWHAs as well as focus person(s) who specifically deal with discharge planning and prepares PLWHAs and their families for further episodes of HIV/AIDS related illnesses. Social support was mainly provided by CBOs and NGOs. According to the respondents, strengthening this component requires an effective information provision service on HIV/AIDS and related programs, the development of an ample referral and networking system to support groups, welfare services and legal services. It should also have structures that enable PLWHAs and their households acquire and access material assistance, provide for orphaned children as well as engage in community mobilization services.

4. Promoting Caring for Caregivers

Supporting families and households burdened with care is an important and necessary undertaking to enable caregivers in these families to perform other critical tasks other than just care provision. This is because these other tasks are important sources of livelihood that is critical to the welfare of those infected and their households in general. From a background of resource limitation and overstretched health infrastructure, governments require to develop support programs that feed effectively into already existing social security nets. Many countries however, have extremely fewer social safety nets beyond those provided by family resources. The situation is worsened particularly within urban settings that are characterized by loose familial relations.

In turn, many institutions beyond the family yet outside the government have increasingly emerged to offer hope, support, strength and nourishment to many caregivers who are themselves overwhelmed by the day-to-day demands relating both to care provision and general living. A number of these institutions such as NGOs and CBOs have the potential of educating, counseling as well as caring for caregivers. They can provide support in cash, kind and expertise to caregivers and their communities besides linking them to various organizations. These are important provisions that can also be rendered even by FBOs to ease the task of care provision within the home.

Many of these caregivers also require general HIV/AIDS education to reduce personal fear and anxiety, enhance skills on basic practical nursing techniques and practices as well as maintaining positive outlook. As already noted, the value of material provision, financial and practical support to these caregivers cannot be overemphasized. Tasks and roles must equally be constantly reallocated amongst the caregivers as well as proper planning for the future welfare of those members of the family who are still alive. These are difficult and involving tasks that must not be left only to caregivers.

In certain regions of the world, the role of government has been to source for funding in collaboration with the private sector and channel such funds to communities to help caregivers and the patients to whom they render care services. This implies the decentralization of responsibility to community level, an approach that has often been associated with delays in implementations due to

administrative bureaucracies. In Kenya, this can be overcome by taking advantage of the district and constituency Aids Committees within the regions of the country.

Other than support to caregivers, greater support must also be given to the NGOs, CBOs and ASOs engaged in community-based care in order to attain a truly significant part of the continuum of care. Such support should involve interventions in form of capacity building and the improvement of fundraising and administrative abilities. It is only in this way that such support groups can satisfactorily render adequate help to PLWHAs and their caregivers within the home setting.

Experiences from the rest of the World indicate that HIV/AIDS responses cannot often be reached to the necessary scale while maintaining quality as well as providing sufficient flexibility by acting solely through centrally operated programs (UNAIDS, 2002). In light of this, the government must then work in partnership with NGOs and CBOs to permit as many people as possible, especially those in remote areas to access services that they might shun or could simply be unaware of.

5. Promoting Complementary Therapy

The health seeking behavior of PLWHAs particularly those receiving care within the home is particularly important in designing an effective discharge-referral planner for healthcare delivery at the community level. The outcome of this research has demonstrated the increasing need for the government to expand the utilization of health facilities within the communities while making it even more integrated.

The unique health seeking behavior demonstrated in Kayole; in addition to the nature of geographical spread of pharmacies place the very pharmacists at a central focus in the provision of care particularly within the communities. It is advisable that the government in collaboration with the pharmacists' society and other NGOs put in place a process that teaches pharmacists more about STIs including HIV/AIDS and their identification, counseling and dispensing of drugs appropriately. Individuals can then be referred easily by pharmacists to other formal healthcare facilities at given places and time if need arises. This is the essence of an effective referral system.

The outcome also asserts the need to recognize and effectively integrate alternative health care into the continuum of care. This is because traditional healers are potentially the largest available community resource for providing PLWHAs with much information on the care and support they need. Such collaboration would certainly help dispel the myths on causes of HIV/AIDS, as well as counter the spurious claims of "miracle AIDS cures". According to UNAIDS (2002), one aspect of nurturing such an initiative is to train a core group of traditional healers who can then be supported to educate communities as well as train their peers.

7.2 Opportunities for Institutional Interventions

Governments have fundamental obligations of providing healthcare to their populations. This responsibility has however, attracted institutions outside the government because of concerns relating both to inadequacy of government provisions as well as an effort to enhance equity while fighting poverty within societies. It is important to realize that the nature of response by a government can be "inspirational and passionate" or "ignorant and discriminatory" (Grunseit and Kippax, 1992). This has fundamental implications as it can affect the quality and efficacy of care interventions by other institutions other than the government. It is on the basis of such responses that collaborations have emerged between governments and development agencies (NGOs, CBOs, ASOs etc) to sharpen the skills of program design and implementation as well as resource mobilization necessary to facilitate such implementation. This partnership has also been extended to religious organizations and communities. It helps ensure that efforts aimed at mitigating the impact of HIV/AIDS are successful such that there is reduction in the level of adverse coping mechanisms that the households have to adopt.

Given this background, the government and its various departments actively need to develop workplace HIV/AIDS policy and programs. This would enable the appointment of HIV/AIDS focal point persons that take the responsibility of coordinating department specific programs aimed at managing the epidemic. For departments that already have this in existence, implementation should be a top priority. The interventions should relate to aspects of voluntary disclosure and the establishments of home based care programs in line with national guidelines. In this way, the socioeconomic determinants and their impacts on the households, prevention programs and wellness management programs together with monitoring and evaluation strategies that reflect the

environment, issues and realties of managing the disease at the home setting will be institutionalized. This would greatly reduce the burden on the households of such employees.

The corporate sector in Kenya, as a key multi-sectoral partner holds great potential in developing responses against the epidemic by enhancing increased understanding in terms of the roles of different entities in the prevention and care of the epidemic. This calls for the inclusion in their strategic plans, activities aimed at mitigating the impacts of the epidemic. Such initiatives should touch on the prevention, care and support, involvement of PLWHAs as well as impact mitigation initiatives. It is also important to recognize that indeed there exists great potential in awakening the advocacy potential of the corporate sector to rally the necessary means and resources to enhance home care. This might include building capacity of other businesses to come up with a collective corporate advocacy strategy that would help effect changes within the HIV/AIDS environment in Kenya. The sector would indeed become real agents of social change. This would not only be limited to care initiatives but to overall management of the epidemic.

The Developmental Non-Governmental Organizations (DNGOs) and their direct links with developmental initiatives within communities strategically provide them with roles that make them equal partners in the fight against HIV/AIDS. These institutions are positioned to deliver to the households at the community level where the greatest burden of the disease is felt. Care at home can indeed be improved by these organizations. It could be facilitated by delivery in terms of Income Generating Activities (IGAs), agriculture based initiatives such as vegetable gardens to provide food for affected households and literacy programs to increase the responsiveness to HIV/AIDS messages in general and home based care in particular. DNGOs in Kenya have the capacity to effectively utilize existing networks within the various communities in which they operate to confront the structural and cultural rigidities that work against full attainment of effective home based care activities.

The DNGOs can achieve this by emphasizing on the internal capacities of grassroots organizations that still do not have HIV/AIDS care programs as part of their core areas of work to ensure the integration of the same. This calls for DNGOs to develop and establish a natural link between HIV/AIDS and development, engage in plotting and thorough planning, programming and implementation of HIV/AIDS and care activities as well as advocate, mobilize and network for

resource flows to facilitate broader community participation in issues that directly affect their (community) lives. This can also help increase awareness and advocacy on human rights as well as sharing on "best practice strategies" to provide support and prevent further infection.

Faith based organizations play an important role in responding to HIV/AIDS. A strengthened faith based sector response holds great potential in reaping fundamental results in terms of providing care, reducing the prevailing stigma and imparting the much needed hope to carry on. FBOs have a firm and direct linkage to both the infected and the affected individuals and communities. This puts them in a stronger position to tackle the issues around HIV and AIDS in general and home based care in particular. This is because the faith based sector commands a powerful influence on the priorities of the society and the policies of national leadership. Particularly important is their role in strengthening care and support strategies of infected and affected communities and individuals for which the sector can easily respond within the dictates of their faith without necessarily having to shift their roles.

According to Steinitz (2002), the church reaches into the population further than any other institution in Africa and fills a critical partnership role with the government, a role both groups recognize. Faith based organizations are also very important in providing spiritual nourishment and their structures are sustainable for long-term community outreach, education and support. They won't just go out of business any sooner! This makes them have greater potential for sustaining long-term change. Religious institutions also provide leadership and posses a reservoir of volunteers and youth activists who are important in promoting prevention, care and support.

The key responses which the faith based organizations can put in place include establishing their own place on the continuum of care. This involves confronting issues of stigma and discrimination within the infected and affected communities. By conveying appropriate messages and incorporating HIV/AIDS component in their work, spiritual leaders can develop an enriching and supportive environment for affected individuals and households. Their position right at the heart of the communities grants them the opportunity to fill the gaps that exist with regard to community care and support. Indeed, linking their care activities with existing home and community based care structures will certainly mobilize a collective mass of care response.

The religious sector can also develop faith-based structures that focus on the epidemic. This could be in form of established faith based forums and networks that seek to build a committed and coordinated sectoral response to the epidemic. These structures could thus address key developmental issues that reinforce individual and community vulnerabilities to the epidemic. As one member of the clergy put it (Box 7.1), such issues could range from gender, poverty, unemployment, social stigma and denial, substance abuse, social disruption and cultural practices.

The strengthening of already existing networks within the faith-based framework is at the core of integrating individuals and communities in confronting the HIV/AIDS situation. As noted in Box 7.1, existing structures within the sector such as women groups, care networks and even youth groups need to steadily incorporate HIV/AIDS specific programs particularly those relating to the home care component. As a special focus, such networks should emphasize the reduction of fear, discrimination and inertia surrounding the epidemic. These were the most emergent elements of concern amongst households and PLWHAs in Kayole.

Box 7.1: Value of Religious Institutions in Care and Support

"…Religion is inextricably woven into every aspect of human life. Religious beliefs have continued to play a significant role in the people's sense of personal identity, thought patterns, moral judgments and their perceptions of disease. In fact, religious leaders command great influence and respect, and authority amongst community members. As such they play a pivotal role in determining how individuals, families and communities respond to the unique challenges of HIV and Aids. We need to exploit this for the sake of our people.

The roles played by these churches (religious organizations) include medical care, counseling and social support to PLWHAs. Also here are reproductive health, nutrition and immunization, hygiene and sanitation and HIV preventions and Aids care. For us here, (clergy's church in Kariobangi) we make use of structures within the church such as Sunday schools and primary schools, young people, posttest clubs for those who have undergone tests and the parents through the positive parenting program".

The media is a principal institutional player in facilitating change processes. Such changes could be on the economic and/or political arena. The social component of this change, however, might comprise structures, norms, values etc. It is in this realm that the media is viewed to have a fundamental responsibility in the battle against HIV and AIDS. A report by Futures Group International, Research Triangle Institute (RTI) and The Center for Development and Population Activities (CEDPA) noted that

"It is an undisputed fact that the international scale of the epidemic shapes the environment the media reflects. The media, by and large, have not approached their response to HIV with a clear proactive strategy. And this "business as usual" approach results in ever increasing feelings of fear, mistrust, and confusion. Rather than add fuel to fire, the media should ensure that their reporting—while accurately reporting the AIDS debates, mishaps, and issues of the day—dispel myths, spreads hope, and increase public ownership and understanding of the complexities of HIV/AIDS."

It is undeniable that the media has always carried stories on the epidemic right from its onset. The big concern is the sensationalism, ranging from graphic pictorials of people dieing of AIDS and insensitive language, to reports of personal "cures". Given the political nature of the epidemic and consequently its potential for headline grabbing and the related heartfelt stories, the media requires to demonstrate a higher level of responsibility, sensitivity, and accuracy for an efficient and ethical reporting on HIV and AIDS. This indeed, is a necessary prerequisite for effective care and support initiatives within the home environment. It would only be possible if such reporting was developmental and as comprehensive, focusing on successes rather than "gloom and doom'. This would certainly reduce stigma and spread hope that is at the center of care provision particularly within the home setting.

The principle of Greater Involvement of People Living with HIV/AIDS (GIPA) together with their households and communities remains a cornerstone to any multi-sectoral response. According to UNAIDS (2002), PLWHAs are probably the greatest resource in the global response to the epidemic. Given resources, these networks and their communities are capable of building on their experiences, mutual support, providing services as well as actively participating in national and international HIV/AIDS policy formulations. With technical assistance, these networks can create multi level working partnerships that provide advice and consultations as well as developing training materials. They can train fellow PLWHAs, health workers, executives, staff, volunteers and

other community based groups on issues of advocacy, fund raising, networking, communication, management, leadership etc. thereby enhancing care provision within home setting.

Thorough understanding of the roles of institutions in combating HIV/AIDS is important in developing planning designs and implementation programming to ensure effective responses in enhancing prevention, care and support. The more actors from government, private sector, civil society and communities are engaged in policy dialogue, planning and evaluation, the greater the chances for effective responses to prevention care and support. This remains the greatest challenge in promoting HBC.

7.3 Summary

Visionary interventions meant to curb the impact of the epidemic must be designed to take care of long-term and short-term periods. Short-term interventions in form of relief provisions to households in critical conditions must be combined with investment-oriented strategies to ensure that when funds are finished, projects are able to continue. In this way, long-term strategies should therefore be able to continue addressing the underlying problems that make poor households vulnerable to the impact of HIV and AIDS. The main focus should be on enabling households and communities to avoid irreversible coping strategies particularly those that reduce future income-earning potential. They should also focus on those strategies that destroy the productive capacity of households such as de-saving and withdrawing children from schools as was observed in Kayole.

Such efforts in form of programs and activities should also be initiated to particularly target the mitigation of vulnerability of these households. It should increase access to credit through self-help groups for income-generating activities, micro-projects and micro-credit especially for women and teenage-headed households. Mitigation also requires the promotion, improvement and application of dietary management (nutrition). This is important as a mitigation factor for people with HIV. It involves developing nutrition guidelines for PLWHAs and implementing training programmes on local, regional and national level.

Equally important is the provision of information to PLWHAs and members of the affected households about appropriate nutrition and diets such as the Participatory Nutrition Approach (PNA) adopted by (FAO). This should be coupled with the promotion of continuous transfer of

technical knowledge and skills from PLWHAs to household members and the community at large. Achieving this equally calls for the need to foster active participation of the community including PLWHAs and their caretakers. This would also involve the identification of actions meant to strengthen community-based home care and support as well as reinforce the "constructive measures" of coping. Mitigation efforts need to come up with appropriate communication programs aimed at preventing stigmatization and marginalisation of affected households/people as well as provide necessary information to and for PLWHAs, their caretakers and the community as a whole

Specific programmes and activities that target prevention and/or containment of further spread of the disease must be put in place. This is because as noted earlier, prevention and care are both intertwined and their programmes reinforce each other. Such policies and programmes should serve to strengthen and/or support response capacity development at national and local government, private sector and civil society levels with emphasis to the household level. They should promote the effectiveness of poverty alleviation programs and activities aimed at vulnerability reduction in order to cater for the specific needs of the affected households and communities. This requires the development of proper information, education and communication approaches aimed at triggering behaviour change.

7.4 Policy Implications

This study demonstrates a number of important coping mechanisms by households experiencing the double burden of HIV/AIDS and poverty in Kayole estate within the Eastlands of Nairobi. It is indeed, a reflection of many other pockets of urban poor in Kenya and the World over. The findings confirm earlier work by Bloom and Glied (1993) and Thant (1993). Thant noted that HIV/AIDS spreads on a non-random pattern and that the poor are more at risk than those who are economically better off. This means that the costs of the epidemic fall disproportionately on the poor, consequently intensifying the severity of household coping mechanisms particularly for poor households. In Thailand, Bloom and Glein noted that HIV/AIDS disproportionately affected low-income households. They observed that increases in medical costs due to HIV/AIDS serve to enlarge the inequality gap of economic well-being. As a result, this leads to further immiserization of the poor and the intensification of household coping strategies.

This study shows that a link exists between AIDS and low income, lack of education and poverty. This was notable in the households' different levels of susceptibility to the impact of the epidemic and consequently the nature and extent of coping mechanisms. It means that poor households with little education experience greater economic shock compared to those with relatively higher income levels and better education. This implies that the poor are least able to cope because they have fewer household resources.

The Kenyan government has since viewed poverty alleviation, improved income distribution and alleviation of diseases as urgent and most important issues to address in the interest of national growth and development. The economic impact of AIDS and related mitigation efforts so far undertaken by the government deserve special attention. Recently, the government showed firm commitment to putting appropriate interventions to help curb the spread, but even more importantly, to assist those individuals, households and communities both affected and infected by the epidemic. It is therefore imperative that the government effectively puts in place intervention programs in specific areas that still lack such programs and also move to strengthen those that already exist.

One principal area that deserves speedy attention is the care provision including the provision of ARVs. The impact of HIV/AIDS on the health infrastructure coupled with the ever-declining health budgets have resulted in many PLWHAs being cared for at home. Proper policy issues and intervention programs therefore must target this area as a matter of priority.

This task requires a joint effort of not only the government and its departments but also incorporating non-governmental organizations, the corporate sector and other philanthropic organizations. The following are some of the strategic intervention approaches that can be put in place to reduce the impact of the epidemic on households and consequently reduce the severity of household's coping strategies. The ultimate goal is indeed to promote and improve the status of home-based care provision in Kenya.

7.5 Mitigation and Support: Strategic Approaches

In low prevalence areas, the emphasis for mitigation and support should be on developing long-term strategies that address the underlying problems, which make households vulnerable to the impact of HIV/AIDS. Such should be sustainable strategies aimed at eliminating socio-cultural and economic structures that hinder the free interplay of households to realize their livelihoods. These should include enhancing equitable access to credit by the poor, market facilities as well as alleviating and/or reducing vulnerability effects of poverty particularly on women.

Equally, more emphasis is required for strengthening the households as well as the communities' response capacities to include the installation of early warning systems, training in community based mutual aid and training in community mobilization and empowerment strategies for women. A necessary prerequisite to this is an elaborate research that ensures appropriate familiarization particularly with local or area specific coping strategies. This is more important especially as relates to the orphan and widow headed households. It is also necessary to ensure identification of specific needs and consequently develop appropriate technologies and interventions.

In high prevalence areas however, the high rates of infection require more urgent measures. It requires a strategy that moves beyond prevention to seeking ways that serve to mitigate the impact of the epidemic. In this context, two approaches appear: that which is intended at building the economic resources of households and that, which support and strengthen community safety nets and support groups. These should be deliberate efforts to foster the involvement of affected households and communities as well as PLWHAs.

Some of the various activities and interventions that would go a long way in mitigating the impact of the epidemic in the country are suggested below. These must be executed as a matter of priority with active participation of PLWHAs with the hope that it reduces the overwhelming burden of care provision.

1. Women and Credit

There is a strong need to increase women's access to credit in Kenya. This is particularly necessary within resource strapped regions like in Kayole. The necessity of this requirement is reinforced even further by the nature of households, majority of which are women headed. The strategy here is to encourage the formation of women groups and offer incentives to them for IGAs. One possibility is to engage in income-generating activities where widows, or adolescent girls/boys, get together to work on a micro-project. These groups should be flexible in membership so that if one person cannot show up one day, somebody else can replace them. IGAs then must be relevant to the communities' or groups' skills and resources, relevant to the community's socio-cultural norms and values, and more importantly sensitive to the existing gendered division of tasks.

Micro-credit services along with income-generating activities hold great potential as effective tools for strengthening the economic resources of poor households. In Kayole, micro-credit programs were run only by WOFAK itself. But even this was run under various conditions pegged to membership and with limits on amounts loaned. These conditions largely excluded many deserving cases. Overcoming this thus calls for expansion of the scheme to cater for many individuals excluded largely by the formal banking system.

2. Strengthening the Household

This is a fundamental way to realizing mitigation efforts. In order to strengthen households in Kenya, it is necessary to improve access to resources particularly for women, children, orphans and widows. The main goal of such an initiative is to reorient the whole process to facilitate the realization and/or restoration of the levels of household income. These would then involve promoting the diversification of income sources such as small-scale manufacturing, trade and other small-scale urban-based businesses. Other home-based sources of income/IGAs also add significantly to this list of intervention programs.

3. Nutrition Projects and Education

A nutrition project requires an approach specific to it: *nutrition project participatory approach* is particularly applicable to mitigation efforts in the context of HIV and AIDS. Such Participatory

Nutrition project approaches consist of joint development of local household food and nutrition strategies by the different stakeholders. It also helps identify the affected households and clarify local dynamics between HIV/AIDS, food insecurity and malnutrition. Results from this research showed that this project remains virtually unexplored by WOFAK.

Awareness creation and information flows are also very fundamental in efforts aimed at mitigating the impact of HIV and Aids on households in Kenya. Nutrition education provides specific information and training on nutritional care and support for PLWHAs and members of affected households. It needs to be provided at different levels: addressing the public as well as service providers. It also involves capacity building at various levels, but particularly important is at the local level. It is essential that information be prepared and provided in a manner that strongly considers local conditions. At the moment, this facility is only at its preliminary stages at WOFAK. It does need to be encouraged at WOFAK and other regions that require such services.

4. Emergency Food Aid

Early diagnosis with access to food and care for PLWHAs prolongs life and keeps a person healthy and productive for a longer period of time. It also helps those members of families indirectly affected by HIV/Aids, especially infants, children, pregnant women and the elderly by guaranteeing regular quality food-intake. This helps reduce the need to adopt short-term irreversible coping mechanisms by cushioning households against the loss of assets and allowing for income to be invested in education and IGAs. To a larger extent, this strategy remained unexploited because of limited resources by WOFAK. It was only the INTERSOS and Nyumbani Children's Home that provided periodic support under WOFAK's orphan support project. Even this was actually limited in scope as it remained focused largely on orphans and households that were in extremely critical conditions.

5. Capacity Building

One of the main scopes of capacity building in the context of HIV/Aids involves activities that facilitate and/or strengthen the autonomous Aids responses of households. It entails reinforcing the management and mobilization skills of NGOs, CBOs, ASOs, and government institutions at local level. It also includes training of these institutions in project design, participatory research,

participatory and bottom-up planning, management, monitoring and evaluation. Establishment of forums to facilitate communication and information sharing between NGOs, CBOs and other support organizations is also an integral part of this initiative. Such forums include the Internet that is used to allow for the exchange of information about best practices and/or training in mitigation and prevention of HIV/AIDS.

Capacity building also entails encouraging the creation of community run safety enterprises as well as supporting trainers at risk working with affected and infected people. This means that the initiative requires creating support for community nets through the establishment of community-run enterprises and building linkages with civil society organizations, NGOs, and government institutions. The HIV/AIDS institutions in Kenya, in collaboration with the government have indeed covered much ground in this respect. Many of WOFAK members had indeed undergone various forms of capacity building especially the HBC providers and many of the counselors. Due to the increasing number of PLWHAs and the swelling WOFAK membership however, much actually needs to be done to expand this noble strategy to mitigating the impact of the disease.

6. Children and Youth

Many households severely affected by the epidemic have often seen children and the youth take the responsibility of fending for themselves and their siblings. In Kenya, majority of these cases are more common within the rural areas. From this study, many of these children and youth were largely assisted by WOFAK through the orphan support program. From a practical standpoint, greater support needs to be given to orphaned children and adolescents. This support could be in form of life skills training, transfer of technical knowledge related to food security, nutrition and trade. Besides, it should also be supplemented by household income through the introduction of income-generating activities/projects or provision of small-scale credit.

Special attention needs to be given to girls who are taken out of school to work and care for their families. They must be targeted specifically through education, training and special assistance programs. These interventions require initial assessments, of the problems and constraints faced by these adolescent girls from HIV/AIDS affected households and their corresponding training needs.

Equally important is the need to identify and mobilize the local institutions that are or could be involved in training and assisting these adolescent girls.

Recovery efforts in Kenya and Kayole in particular have not seen much of these interventional options. To a larger extent, this explains in many cases the increasing number of adolescent girl infections as they struggle to cater for their families. They are conditioned by circumstances to engage in episodes of sex trade. Reinforcing mitigation efforts therefore calls for the need by the Kenyan government to embark seriously on skills training for the youth to prepare them well for such livelihood challenges.

7. Community Mobilisation

Returning to the issue of community mobilization, I strongly suggest the need for a further in depth research that provides a better familiarity with local coping strategies, especially those of orphan and widow-headed households as was mainly the case in Kayole. This would help identify the specific needs and consequently develop technologies and plan interventions accordingly.

According to UNAIDS (1999), the various principles of community mobilization projects that need to be considered often include upholding the rights and dignity of the people infected as well as those affected by HIV/Aids. This includes the active participation by a group of household members with as broad representation as possible. Community mobilization also provides for equal partnerships and mutual respect between community and external facilitators. It involves building capacity and ensuring sustainability, building on the realities of living with HIV and AIDS and also maintaining hope based on community collective action. These principles maximize the use of community resources while identifying and using additional external resources as needed.

The implication of this strategy is that greater emphasis deserves to be placed on techniques that help households and communities formulate their own responses. This requires that members of the community and the respective households genuinely consider it in their own best interests to take primary responsibility for solving these problems. This is because the key to community mobilization rests in participation..

As a result, NGOs, CBOs and ASOs must be strengthened in order to enhance and develop autonomous responses as well as building the capacity of communities to undertake own responses. These capacities could be built in numerous ways: provision of training and technical assistance, reinforcement of management skills of CBOs, training in project design, planning, and management as well as establishing forums for NGOs, CBOs, community members and PLWHAs to exchange views and experiences.

The activities proposed herewith are intended to serve as a menu of options and can be used according to the people's needs, concerns and specific circumstances. They are also by no means complete and definite. This means that specific circumstances might render these options open to discussion and possible change to reflect and enhance conformity of the program initiatives especially in light of the various conditions in Kayole and other regions in general.

CHAPTER EIGHT

SUMMARY AND CONCLUSIONS

8.1 Summary

The ever-increasing number of people developing AIDS has continued to strain the already burdened healthcare system in Kenya. In response, partnerships have emerged amongst family members, healthcare workers, local CBOs and NGOs that provide care and support to those infected and affected by HIV/AIDS. Home Based Care programs have gained prominence as an alternative to hospital based care. It is a collaborative effort between the hospital, the patient's family and the community. It is a holistic and comprehensive care across a continuum from the health facility through community and the home and entails physical, medical or clinical care, nursing care, psychosocial support and occupational therapy as well as caring for caregivers. It also entails strong and efficient referral system and discharge planning.

In many resource strapped settings however, the condition of HBC has been deplorable. Poverty has added to the burden of care. Lack of food, clothing and shelter, rejection and isolation, uncertain fate of orphaned children as well as problems of money for transport incase of referrals are just but a few of the problems that affect the condition of home care.

In response, households have opted to pursue their welfare along various different dimensions. The coping strategies adopted in this context largely depend on the socioeconomic characteristics of these households as well as their networking levels within the community. These include borrowing, austerity and reduced consumption, dis-investments and asset disposals, livestock flows, change in behavior as well as adjustments of household resources.

Indeed the value of HBC rooted in the community cannot be overemphasized. Success stories have been told in Nigeria, Thailand, South Africa, Uganda, Zambia, Zimbabwe and many other regions. The challenge thus is to initiate better-resourced HBC programs as well as strengthen and promote those already in existence. Achieving these concerns must involve reducing the severity of coping strategies by strengthening the households through provision of credit particularly women and teen headed households, assist households in the establishment of IGAs, nutritional projects and

educational initiatives and provision of emergency food aid. Building the capacity of NGOs, CBOs and ASOs, to which households are affiliated, is equally important. The provision of life training skills and transfer of technical knowledge related to food security, nutrition and trade amongst children and youth as well as enabling the households to effectively network and engage in community mobilization are all integral to promoting and improving the condition of HBC.

8.2 Conclusions

In Africa and Kenya in particular the battle against the HIV/AIDS epidemic could be said to be just picking up given the monumental task that lies ahead. This task cannot be achieved only by one entity. It does require joint efforts coupled with various multiple strategies aimed at combating the various components of the epidemic. As this paper has pointed out, the government of Kenya has in the past concentrated much of its efforts on curbing further spread of the disease by embarking more on awareness creation, attitude change and other preventive measures. While these remain important, the impact of the epidemic upon various levels of the societal fabric has not seen the necessary attention that it seriously deserves. More particularly is the bare minimal attention that home based care has received in Kenya. This urgently needs to change.

The policy suggestions that I have outlined as arising from the results of this study are meant to provide policy makers with guidelines. These are guidelines on dealing with the socio-economic miseries at the household level resulting from the impact of HIV and AIDS. They are also meant to assist policy makers decisively address the extreme adversities experienced by poor households as they strive to cope with the epidemic. My intention has been to equally explore the areas under which various institutions both within and without the government could, in togetherness or in their different ways initiate programmes and/or project interventions meant to reduce the level of suffering of households affected by HIV and AIDS as well as strengthen and improve the condition of HBC in Kenya.

8.3 Relevant Areas for Further Research

I consider this research a pioneering one. Indeed, a broad research agenda of care on HIV/Aids would involve many dimensions. Such research would be economic research looking into the financial impact on families providing care and even the caregivers themselves, the cost of not giving that care and many more. Social science research would look into the needs of these families, caregivers and even the impact of increased care requirements on women, and possibly how they could be reduced.

Policy research on care requires convincing policy makers on the positive impact of home care and related efforts of prevention meant to curb further spread. This merits a further study. It is also important to carry out further research to convince these very policy makers that care and prevention are complementary. This is necessary to convince them that care facilitates prevention and that the credibility of such prevention messages does decline when we ignore the fundamental needs of PLWHAs and their caregivers. This brings me to the need for further study on how to develop effective advocacy that renders effective care for PLWHAs in their home environments and how they can partner up with the government, NGOs, private sector and other donors to effectively achieve these objectives.

Much more detailed analysis of successful models of care is needed to establish how to attain sustainability, replicability and suitability for coping with the increased demands by the individuals, households, communities and the national economy at large. This is necessary to help improve programme planning and resource allocations. Even though my study did touch on barriers to care, I do acknowledge the need for a more detailed analysis of the same besides assessing other alternative forms of care.

While my study looked into the coping strategies for households faced with care at home and how their lot can be improved, more specific information and understanding is required on how care programs and systems can be improved. This would provide planners and implementers with insights on how to enhance efficiency, effectiveness and quality of care as well as the availability, accessibility and acceptability of care.

Particularly, researchers need to move with urgent speed to conduct qualitative and quantitative research on the impact of HIV/AIDS with special emphasis to gender and poverty. Such a study should take into account the needs of different user groups like widows/widowers, orphans, and the elderly to which many of the respondents at Kayole are, and largely to the wider republic of Kenya. Researchers deserve to place more emphasis on innovations that address special recovery needs of people and households affected by the HIV/AIDS pandemic. They also require assessing the impact of development policies, programs and activities on vulnerability to HIV/AIDS. This is particularly important within the urban poor settings. Critically important in this context is the need for a study that looks into the gender differentials, its impacts and necessities amongst the various households.

In depth research into economic and other socio cultural coping mechanisms and strategies as well as identifying international and national firms to mobilize the private sector in Kenya to join efforts to intensify action are necessary. The approach of engaging sectors not entirely specific to HIV/AIDS as noted earlier in this study is not at all new. However, until now such broadened responses have received neither adequate attention nor resources in Kenya. The problem is that it has more often amounted to the haphazard dispersion of HIV/AIDS activities within health and other social related programs.

These research initiatives require to be complemented by promoting the involvement of sectors not specific to HIV/AIDS and, to avoid dispersion, provide a common framework of action that outlines the activities, programs and initiatives. It should provide guidelines to coordinate combined efforts and action as well as involve staff from the private sector in training and/or capacity building for both prevention and mitigation.

This study is certainly not without flaws and limitations. Besides the budgetary and time constraints that adversely limited the scope of my work; the fact that Aids is still a sensitive and controversia topic made it hard to discuss openly with household members. This made my interviews extremel difficult. To enhance access and alleviate confidentiality problem, I used WOFAK home base carers. The respondents (PLWHAs) and their households knew these caregivers as they ofte attended to them as members of WOFAK. Because of this, I was introduced and quite well receive by the households and interviewees.

I must add that I developed a survey tool that had lengthy questions. This asked for many details about the households' economic conditions that would be useful for analysis. These turned out to be too complicated for the interviewees. Consequently, it resulted in many questions going unanswered. Time constraints also hindered me from crosschecking and correcting answers to finer details. It is my desire that these deficiencies are checked in future household surveys and analyses targeting HIV and AIDS affected households.

Finally, I strongly suggest that future research should target comparative studies of rural poor households to ascertain rural-urban differences. Such a study in future should also make the time dimension flexible for time series study on the same.

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APENDICES

Appendix I: Survey Questionnaire

1. Birth Date
Month---

Year---

2. Home district ---

3. Area Code/Name
Kayole 1
Kayole 2
Kayole 3
Kayole 4
Others---

4. Ethnic group/tribe? --

5. Have you attended school?
Yes-------------------1 No------------------2

6. If yes, what is the highest level of formal education you attained?
None--------------------1 Primary -----------------2
Secondary---------------3 Post secondary----------4

7. What is the highest standard/form/ yearn reached at that level?

8. Have you had any training?
Yes--------------------1 No -------------------2

9.a) If yes, please explain---
----

b) How long was the training--

10. Have you had any training in home based care?
Yes -------------------1 No------------------2

11. If yes please explain what you were trained about---
----

12. Sex
Male-------------------1 Female--------------2

13. What is your religion? ---

14) Marital status
Single never married-------1 Divorced, separated---------2
Widowed ------------------3 Married/living with a man--4

15) Does your partner have any other spouse beside yourself?
Yes----------------1 No---------------2

16. If married, what is your spouse's highest level of education?
None-------------1 Primary----------2
Secondary--------3 Post secondary---4

17. What was the highest standard form /year s/he completed? ----------------

18. What does your spouse do currently to earn a living? ----------------------------

19. Approximately how much does your spouse earn per month?
Less than 3000---------1 3,001-----5,000----------2
5,001-----7,000--------3 7,001-----9,000----------4
Over 9,000---------5

Children

20. Have you ever given birth?
Yes--------------1 No-------------2

If yes:

21a) How many children did you give birth to?

21b) How many of them were boys---

21c) How many of them were girls--

Please fill this table for children

22a)	22d)	22e)	22f)	22g)	22h)
Sex Male-----1 Female--2	Living with Me-------------1 Grandparent--2 Own self-----3 Other--------4	In school now Yes--1 No--2	Present level in school Nursery---------1 Primary---------2 Secondary-----3 Post secondary-4 Not applicable-5	Working Yes-------1 No--------2	Occupation-- (Specify) Not applicable--2

23a) Are there children who are of school going age but are out of school?
Yes-----------------1 No---------------2

23b) If yes, please explain why?

	Yes	No
01 got pregnant--	1	2
02 got married---	1	2
03 to care for younger children---------------------------	1	2
04 to care for sick family member-----------------------	1	2
05 families needed help on farm or business------------	1	2
06 needed money-------------------------------------	1	2
07 completed /had enough school-----------------------	1	2
08 could not pay school fees ----------------------------	1	2

09 school not accessible /too far————————1 2
10 family sees no economic benefit————————1 2
96 other ————————————————1 2

24. For those in school who helps to contribute to the children's school related expenses
Father/mother————————————————1
Brother/Sister————————————————2
Uncle/Aunt————————————————3
Grandparent————————————————4
Other Relatives————————————————5
Friends————————————————6
School/NGOs/ Religious Group————————7

25. Sometimes, children go to the street to get money for themselves or their family due to difficult circumstances. Do you know of any household affected by HIV/Aids where children have done this?
Yes————1 No————2

26a) Have your children been involved in this kind of activity?
Yes————1 No————2

27. What is the main cause for your children going to beg in the streets?
Poverty————————1
Family/marital problems————2
Peer pressure/bad Company————3
Lack of self-discipline————4

28. Sometimes, some girls have sex in order to get money for their family or for themselves. Do you know of some HIV/AIDS affected households where girls have done this?
Yes————1 No————2

29. Have any of your daughters /sisters ever been involved in this type of activity?
Yes————1 No————2

30. How many of your daughters /sisters are doing this?
Number of girls————————

31. What is the main cause for your daughter(s)/sisters?
Poverty————————1
Family/marital problems————2
Peer pressure/bad Company————3
Lack of self-discipline————4

32. Are there other people living with you in your household?
Yes————1 No————2

If yes, please fill in the following table

33a) Household member	33b) Age 0–12 yrs—1 13-18 yrs—2 Over 18 yrs—3	33c) Sex Male——1 Female——2	33d) Working Yes————1 No ————2	33e) Relationship to respondent Parent————————1 Child————————2 Brother/Sister————3 other relative————4 other, non relative----5
1				
2				
3				
4				
5				

Work/Employment Data

34. Do you work?

Yes-----------------1   No------------------2

35.If yes, what is your primary occupation?————————————————————————

36a) A part from formal employment or even if you don't work, do you do any other work like small business or family farming?

Yes——————1   No——————2

36b) If you do, please name the activities——————————————————————————

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37. For whom do you do this?

Family member ————1   For someone else————2

Self employed—————3   NGO--------------------4

38. How often do you do this?

Once in a while——————————1

Always————————————————2

When the work is available—————3

39. In what form are you paid for this?

Cash——————1   Kind——————2

40a) If cash, how much per month?

Less than 1,000—————1   1,000——3,000—————2

3,001——4,000—————3   4,001——5,000—————4

5,001—10,000—————5   More than 10,000—————6

40b) If in kind, what are you given? ____

41. Do you think the work you are doing fits your training skills?
Yes-----------1 No-----------2

42. Sometimes a woman may have sex with a man (not her husband) because circumstances force her to do so or simply because she likes the man. Have you ever had sex with any one because of this?
Yes-----------1 No-----------2

43. When was the last time you had this sexual intercourse?
Days ago---------1 Weeks ago---------2
Months ago---------3 Years ago---------4

Other Household Members and Care Provision
44. Do any of your household members assist with care?
Yes-----------1 No-----------2

45a) Do you employ anyone in your household to assist with the care?
Yes-----------1 No-----------2

Expenditure and Wealth
Which of the following expenses do you pay regularly from your own resources?

46a) *Item*	*46b)* *Pay*	*46c)* *If yes, how much (indicate if per month, term or year)*	46d) In your opinion, is what you spend adequate for your needs in each of these areas? Yes-----1 No-----2
1. Own transport	1 [ ] Yes 2 [ ] No		
2. Rent/Housing	1 [ ] Yes 2 [ ] No		
3. School fees	1 [ ] Yes 2 [ ] No		
4. Other school expenses i.e. uniforms, books, stationery, transport etc	1 [ ] Yes 2 [ ] No		
5. Own clothing and personal expenses	1 [ ] Yes 2 [ ] No		
6. Clothing and personal expenses over other household members	1 [ ] Yes 2 [ ] No		
Food	1 [ ] Yes 2 [ ] No		
Health/Medical	1 [ ] Yes 2 [ ] No		

Have you purchased any of the following since the beginning of the illness?

47a) Item	47b) Purchased? Yes------1 No-------2	47c) Approximate cost	47d) Any comment/ Further explanation
1. Land			
2. House			
3. Jiko			
4. Cooker			
5. TV			
6. Fridge			
7. Radio			
8. Bicycle			
9. Furniture			
10. Other-----------			

48a) Have you sold any assets since the beginning of the illness?
Yes-----------------1 No-----------------2

48b) If yes, which ones?
[ ] Land ---------------1 [ ] house----------------2
[ ] vehicle -------------3 [ ] TV------------------4
[ ] gas /electric cooker---5 [ ] Fridge-----------------6
[ ] radio-----------------7 [ ] bicycle----------------8
[ ] clothes----------------9 [ ] other furniture--------10
[ ] table------------------11 [ ] sofa set---------------12
[ ] paraffin cooker-------13 [ ] motorcycle-----------14
[ ] other-----------------15 (specify)

49. Do you support anyone else not living within your household?
Yes-------------1 No --------------2

50. What is your relationship with the persons you support?
My children-----------1 My nieces/nephews----2
Parents-----------------3 Brothers/sisters--------4

Other relatives---------5 Friends ----------------6
Other ------------------7

51. In what form do you support them?
Cash ---------------------------------------1
Kind ---------------------------------------2
Both (cash/kind)------------------------3

52. If in cash, approximately how much do you give per month?
Less than 1,000-----------1 1,000----2,000------------2
2,001----3,000------------3 3,001----4,000-----------4
4,001----5,000------------5

53. If support is in kind, what do you give (explain)--

54a) Sometimes you may have people to support but may not be able to because of the difficult circumstances. Do you have any people like this?
Yes -----------1 No-----------2

54b) If yes, how are they related to you?
My children---------------1 My nieces/nephews------2
My Parents----------------3 My Brothers/sisters------4
Other relatives------------5 Friends --------------------6
Other --------------------7

55. What kind of support do they need from you? Please explain--

Residential House/Structure
56a) What are the walls made of?
[ ] Mud------------------------1 [ ] Iron sheets/Mabati----------2
[ ] Plastic sheets /cartons------3 [ ] Timber/wood -------------4
[ ] Cement ------------------5 [ ] Stone block --------------6
[ ] Brick etc-------------------7 [ ] others---------------------8

56b) What is the floor of this house/structure made of?
[ ] Mud/dung/sand----------1 [ ] Cement----------------------2
[ ] wood /tiles/vinyl-----------3 [ ] Other----------------------4

56c) What is the roof of this house made of?
Tiles--------------------------------1 Iron Sheets/Mabati-------2
Plastic Sheets/Cardboard Sheets----3 Grass Thatched-----------4
Metal Sheets/Tins-----------------5 Wood/Timber-------------6

57. What is the main source of drinking water for this household?
Piped water into
Residence-------11 Public------------12
Well water
Residence ------21 Public- ----------22
Surface water
River/stream----31 Pond /lake------33
Rainwater------------41

Buying water
Taps ----------01 Tanks----------02
Hawkers -----03 Others--------------------------------

58. Does this house have electricity?
Yes-------------1 No------------2

59. Of the following items, which ones do you own in your house (in Nairobi)?

Television	1[ ] Yes 2 [ ] No
Fridge	1[ ] Yes 2 [ ] No
Paraffin Cooker	1[ ] Yes 2 [ ] No
Gas/ Electric Cooker	1[ ] Yes 2 [ ] No
Telephone	1[ ] Yes 2 [ ] No
Sofa Set	1[ ] Yes 2 [ ] No
Bicycle	1[ ] Yes 2 [ ] No
Vehicle	1[ ] Yes 2 [ ] No
Radio	1[ ] Yes 2 [ ] No
Motorcycle	1[ ] Yes 2 [ ] No
Table	1[ ] Yes 2 [ ] No
Kerosene lamp with glass/lantern	1[ ] Yes 2 [ ] No
Flashlight with working batteries	1[ ] Yes 2 [ ] No

60. How many years have you been occupying this same house/structure continuously?
Months------------------------------------1
Years ------------------------------------2

61. Just before you moved into this house/structure, where did you live?
Within the same slum--------------------------1
Another slum in Nairobi--------------------2 (specify)
Part of non-slum Nairobi-------------------3 (specify)
Another town---------------------------------4 (specify)
Upcountry /rural village--------------------5 (specify)
Other (specify)------------------------------

62. How long did you live at last residence?
Months------------------------------------1
Years--------------------------------------2

63. When you moved here, did you move to
Join a household-------------------------------1
With others to start a household-------------2
A lone to start a household-------------------3
Others -------------------------------------

64. Why did you move a way from your last residence?

	Yes	No
01 Rent too high	1	2
02 Divorced/separated/widowed	1	2
03 Got married	1	2
04 Slum insecure	1	2
05 Got a job	1	2
06 For a change	1	2
07 Other	1	2

65. Of the above reasons, which was the most important?

06 Pharmacy---1 2
07 Private Doctor------------------------------------ 1 2
08 Community based distributor --------------------------------1 2
09 Traditional healers --1 2
10 Spiritual healers --1 2
11 Shop---1 2

92. Have you ever felt bad (sick) and not sought for treatment?
Yes------------------1 No-------------------2

93. Why did you not seek treatment?
Had no money---1
Did not know where to go----------------------------2
Was shy since did not want anyone to know-------3
Knew what to do/self medication---------------------4
Other---

94a) Do you belong to any support organizations?
Yes------------------1 No-------------------2

94b) If yes which ones? (Please list them)---

94c) If yes, explain what the organization does---

Training and Home Based Care

95a) Do you think one requires training to care well for PLWHAs at home?
Yes-----------------1 No-----------------2

95b) If yes, what should such training involve---

96. From where do you think this training can be obtained?---

97a) Would you prefer some basic education for home-based caregivers?
Yes ---------------1 No----------------2

97b) If yes, what level?
Primary----------------1 Secondary-------------2
Post secondary--------3

98. How do you go about meeting the extra income?--

99a) Has any member of the household migrated out in search of work to supplement the family income?
Yes -------------1 No-------------2

100a) Has the household gone in debt?
Yes--------------------1 No--------------------2

100b) If yes, please explain---

101a) Have you sold any of the household items?
Yes------------------1 No------------------2

101b) If yes would you consider them the less important or more important items of the household?
More important---------1 Less important-------------2

102a) What would you say about money lending during the time of sicknesses-----------------------------------

102b) Why do you say so--

103a) Are people willing to lend money?
Yes--------------1 No---------------2

103b) If no why?---

Consumption

104. Would you say the illness has affected your household's consumption level?
Yes----------------1 No ---------------2

105. Where do you get money to pay for hospital treatment expenses?
Free hospital treatment---------------------1 Subsidies from health card------2
Subsidies from employers and insurance-3 Own funds and relatives---------4
Churches-------------------------------------5

106. Where does the household get the money income to meet the health care expenses?
Using own savings--------1 Selling assets-----------------2

Borrowing------------------3 Others ----------------------4

Extent of acceptability
107a) Where would you prefer to be cared for?
Home--------------------1 Hospital-----------------2

107bi) Please explain your choice of (107a) above *(care at home)*---

107biii) Please explain your choice of (107a) above *(care at the hospital)*--

108a) Who decided that the patient be cared for at home?
Own self ------------------1 Family member(s)--------2
Friends---------------------3 Hospital authorities ------4
Others---

108bi) What reasons were given for this decision (*patient to be cared for at home*)--------------------------------
----

108bii) List of reasons given by respondents that contributed to the patient being cared for at the hospital------
----

109a) Are you satisfied with your care at home?
Yes ------------------1 No -------------------2

109b) If yes how would you rate it?
Very Satisfied--------------- 1 Satisfied-----------------------2
Neutral------------------------3 Dissatisfied------------------4
Very Dissatisfied-----------5

110a) Do you often get referred to the hospital?
Yes----------------1 No-----------------2
110b) If yes, how often?
Any time -----------------1 Weekly-----------------2
Monthly ------------------3

110c) If no, please explain why---

Appendix II: Key Informants (Caregivers Check List)
1. What do you think should be *involved in training home-based caregivers*?
2. From your experience with the affected households, *what are the kinds of activities that households carry out just to get extra income*
3. What would you say these households *complain most about* in their efforts to meet the daily requirements?
4. As members of a support organization, *what assistance or help* do you or other related organizations give to the affected households?
5. A part from your organization, *which other institutions* give this kind of assistance to the affected households?
6. Do you think these are the *kinds of assistance that you would wish to be provided?*
7. Suppose you had additional/extra resources, *are there other aspects of assistance* that you would provide

8. As a home based caregiver, what would you consider as the *most necessary requirements* for care provision?
9. What can you say about *our society's general acceptance* of care provision at home
10. In your personal assessment, *which relatives are commonly engaged* in care provision particularly at home?
11. Have you ever *received any counseling* on how to *care/interact* with the sick while providing care
12. What in your opinion do you think the *community should /can do to improve* and encourage home based care?
13. In your opinion, *what should NGOS and CBOs* doing for PLWHAs in order to improve and encourage home based care
14. What would you say are the *problems that you face as caregivers*?
15. In your opinion what can you *say the government has done to improve* /encourage home-based care?
16. Do you think there is *anything extra that it can do*?
17. What about *religious organizations?*
18. What other thing can you say these institutions and *other organizations not mentioned* above can do to assist PLWHAs to improve home based care?
19. From amongst your clients, what *form social discrimination* would you say they complain more often about: social pressure to live a job, loss of former customers, lack of new customers, employees quitting household business or any other
20. From where do the *patients seek treatment* more often?
21. Please can you explain briefly *what your support organization does*?

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22. As a home based caregiver, do you think *one requires training to care* well for PLWHAs at home?
23. What in your opinion should such *training involve*?
24. From where do you think this *training can be obtained*?
25. As a home based caregiver, would you prefer some *basic education* for home-based caregivers?
26. From where would you say many *households get the money to meet their health care expenses?*
27. Please kindly comment on the *behavior pattern of the members of the households due to the incidence of the disease*
28. What do these households *do to keep going* when the income is reduced and expenses increasing because of sickness? *(coping strategies)*
29. How in your opinion do you think HBC can be *improved and encouraged*?
30. Please kindly describe *how vulnerable these households* are? *(obtain vulnerability indicators)*
31. What *advice would you give* to these families and other caregivers?
32. What can you say are *the patients special needs*
33. Do the households often *request for assistance or you simply give it out*?
34. Which type of *drugs* do you give to the patients
35. Where do you *obtain these drugs* from
36. Are there any *special foods* that you recommend for the patients
37. As a caregiver, would you say you *are satisfied with the nature of home care* that you are giving as at now?
38. What is the *nature of care /support* that you provide?
39. How do you think *these needs can be met?*
40. What can you say a re the *advantages of home based* care?
41. What are they *problems/your anxieties about HBC*
42. In what expenses would you say *much of the household's income go to?*
43. For *how long* have you been giving care?
44. Since you started caring at home, have you changed your attitude towards PLWHAs?
45. Can you explain above answer?
46. What ca n you say is the most important thing that has occurred to you since you started caring for PLWHAs at home?
47. Amongst the households you care for are there households where

√ Children have to find jobs to fend for the family?
√ Area there children who have left school for work?

Appendix III: Key Informant's Checklist (HBC Project Managers)

1. In your opinion Sir/Madam, do you think there is any rationale for care provision to the sick?
2. Do you think terminally ill people such as PLWHAs actually need care?
3. What would you say is the nature of care that these people require?
4. How would you say the HIV/AIDS has impacted on the health care system?
5. What is comprehensive care across a continuum?
6. What can you say is the role-played by the following in responding to the impact of the disease on the household?
   Ingenuity,
   Strength of character,
   Effective use of natural resources and
   Communism
7. What do households do in response to the impact?
8. What do you think these households should do?
9. Do we really need HBC?
10. What can we then say are the objectives of HBC?
11. How can we justify HBC in the context of its potentials and advantages?
12. What would you say are the problems affecting HBC particularly in Kenya?
13. What are your anxieties about HBC?
14. How then do you think we can improve HBC in Kenya?
15. What can you say is the role of households in HBC?
16. Would you kindly identify and if possible rate the fundamental requirements for HBC?
17. What would you say are the costs of HBC to the households?
18. Kindly give any comment on the relationship between the HBC and poverty especially amongst the cash strapped households
19. Please give any possible gender implications of HBC
20. Kindly mention the role of institutions (religious, government, NGOs media private sector etc in promoting HBC.

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