

**LAY-CARE PROVIDERS' LIVED EXPERIENCES IN HIV/AIDS MANAGEMENT:
THE CASE OF KAPTEMBWA DIVISION, NAKURU CENTRAL DISTRICT,
KENYA**

BY

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DECLARATION

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

..... DATE: 28/06/2010.....

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This project has been submitted with my approval as a University Supervisor.

..... DATE: 28/6/2010.....

DR. OWUOR OLUNGAH

DEDICATION

To all the invisible heroes who assist in the management of HIV/AIDS.

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This project would not have been completed without the assistance of various persons and institutions. To all of them, I say sincere thanks. However, I wish to express special gratitude to a few of them.

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LIST OF ABBREVIATIONS

AIDS- Acquired Immune Deficiency Syndrome

ART-Anti-Retroviral Therapy

ARV- Antiretroviral (drug)

CBD- Central Business District

CDC- Centers for Disease Control and Prevention

CDN- Catholic Diocese of Nakuru

CG- Care giver

CHW- Community Health Worker

HBC- Home- Based Care

HIV-Human Immunodeficiency Virus

KAIS- Kenya AIDS Indicator Survey

LCP- Lay Care provider

MCN- Municipal Council of Nakuru

NASCOP- National AIDS and STI Control Programme

NGOs- Non- Governmental Organizations

RVPGH- Rift Valley Provincial General Hospital

UN- United Nations

UNAIDS- United Nations Programme for HIV and AIDS

UNDP- United Nations Development Programme

VCT- Voluntary Counseling and Testing

WHO- World Health Organization

ABSTRACT

This study examined the Lay-care providers' lived experiences in HIV/AIDS management. It was designed to describe the types of people who provide lay-care to HIV/AIDS patients. Secondly, to examine the roles that lay-care providers play in HIV/AIDS management and finally, to examine the problems they face in HIV/AIDS management.

The study, which was done in November 2009, enlisted a total of thirty respondents, who were lay-care providers. In order to get the sample, a list of registered HIV/AIDS patients receiving ARV treatment from the Rift Valley Provincial General Hospital was used as the basis of recruitment. It is from this list that those living in Kaptembwa were purposively chosen. Thereafter, through random sampling of the residents of Kaptembwa, thirty HIV/AIDS patients were selected. It is through them that the lay-care providers who were responsible for their care were interviewed.

Data was collected using both secondary and primary data sources. The primary methods included narratives, key informant interviews, in-depth interviews and direct observations. Data was then analyzed using thematic content analysis. The quantitative basic demographic information has been presented using simple frequencies and tables.

The findings indicate that the majority of lay-care providers were relatives and were composed of mostly females. Most of them were poor, earning less than Kshs. 5000 per month and had little or no education and knew they were providing care to HIV/AIDS patient yet they were not professionally trained to do so. Secondly, it is noted that lay-care providers play a crucial role in the management of HIV/AIDS in Kaptembwa division. They provide nursing care, nutritional care, physical therapy, offer advice and promotion of responsible sexual behavior, psycho-social support, spiritual support, material support and counseling. Finally, it is reported that they face numerous challenges in the process of managing HIV/AIDS. These challenges include lack of adequate training in HIV/AIDS management, dealing with difficult patients, poor health services provision, inadequate sources of income, inadequate food, inadequate support from the community, stigmatization, lack of adequate water and sanitation facilities, inadequate care package facilities, inadequate counseling and delay of testing of patients, insecurity and psychological strain.

The study, thus, recommends the need for proper counseling of patients on ARVs administration, need to sensitize the community on HIV/AIDS and its several ways of transmission and the need for timely diagnosis of HIV infection. There is also an urgent need for the Ministry of Health to develop the capacity and skills for Home Based Care management and delivery, there should be a clear policy governing training and minimum standards expected of lay health workers, there should be timely nutritional support by both the government and NGOs to HIV/AIDS patients, there is need to develop strategies and mechanisms of funding care givers to start small and viable income generating projects and finally, there is need to recognize and appreciate the lay-care providers.

CHAPTER ONE

1.0 BACKGROUND TO THE STUDY

1.1 Introduction

The quality of life of those who are infected with or affected by HIV/AIDS is determined in large measure by their access to the care they require. For many, hospital care is neither necessary nor desirable; among the alternatives is home-based care. In Kenya, the growing number of patients, the need for continuity of care, the devastating economic and social impact of AIDS on families and communities, the limitations of hospital care, and limited resources- all combine to severely restrict the availability of health care services. This means that access to appropriate health care is beyond the reach of most ordinary people and delivery of adequate care is beyond the capacity of the health care system. Under the circumstances, many people who are infected with AIDS and AIDS- related illnesses never make it to hospital or other health facilities. Those who have been fortunate enough to receive some hospital care are all too often discharged from a facility where there are trained professionals and sent home while they still need substantial nursing care. Either way, the caregivers at home are usually untrained relatives, neighbours, friends, with no professional backup support. These primary-caregivers are most often than not the women or children with no training in nursing the sick or in how to protect themselves and other household members from infections arising out of handling materials like blood, diarrhoea excreta, and septic wounds, or from other infectious diseases such as tuberculosis. Nor do they know effective practices for helping people living with HIV/AIDS avoid opportunistic infections and live a longer, healthier life (Ministry of Health, 2006: 2).

The study, therefore, explored the experiences of lay-care providers in the management of HIV/AIDS. Specifically, it set out to describe the types of people who provide lay-care to HIV/AIDS patients and also examined the various roles they play in the management of the disease. Further, it examined the problems they face in HIV/AIDS management.

1.2 Problem Statement

HIV/AIDS continues to adversely affect the population in Sub-Saharan Africa. According to NASCOP (2008), HIV/AIDS is still a burden. It is estimated that 1.4 million adults in Kenya are infected with HIV, the virus that causes AIDS. When there is a sick or dying person in the house, someone quite literally has to take care, whether out of love, duty or simply a lack of other options. According to WHO (2000), up to 90% of illness care is provided in the home. Most of this care is provided by lay care providers. This means that infected people are inadequately looked after despite the best efforts of their care-givers and families who face economic, psychological and social difficulties. Most of these care providers only have little knowledge about the disease, therefore, unable to manage it effectively and may also risk being infected with the disease. At the same time, because most families struggle without a formal diagnosis of the disease that is affecting them, they also do not have ready access to even those health sector initiatives that could provide vital support.

The burdens placed upon lay-care providers highlight the scale of the activities they undertake to enhance the patients' quality of life. The contributions of untrained, unremunerated and unsupported family members to the care of people with HIV infection need to be seen as a distinct domain of care provision because the needs, resources and constraints of these providers are different and because the mechanisms required for meeting those needs will be different (Columbia University, 2004: 24). Costing this work is a necessary step to recognizing, valuing and including unpaid HIV/AIDS care work in public health and other policy-making processes. Also, if additional resources are not provided to train care-givers, they will be left feeling unsupported and helpless (UNAIDS: 2000).

The study therefore, set out to find answers to the following research questions:

- (i) Which types of people provide lay-care to HIV/AIDS patients?
- (ii) What roles do lay-care providers play in HIV/AIDS management?
- (iii) What problems do the lay-care providers face in HIV/AIDS management?

1.3 Objectives of the Study

1.3.1 General Objective

To explore the lay-care providers' lived experiences in the management of HIV/AIDS.

1.3.2 Specific Objectives

- (i) To describe the types of people who provide lay-care to HIV/AIDS patients.
- (ii) To examine the roles that lay-care providers play in HIV/AIDS management.
- (iii) To examine the problems the lay-care providers face in HIV/AIDS management.

1.4 Justification of the study

Due largely to the current global political economy, national governments have increasingly coped by 'downloading' the burden of caring for those living with HIV and AIDS onto communities and individual households. As the public sector retreated, 'community-based care' has become the solution to the crisis of care, resulting in increased dependence on NGOs to set up programmes, even in the absence of evidence-based good practices to model them on. Meanwhile, many communities and households in high prevalence areas are themselves increasingly unable to cope with the disease (Steinberg 2002:26). Caring of the sick is mainly left to the lay-care providers, who may be at risk of being infected with the disease as they take care of the sick and also may provide inadequate care to the sick. Also, many intervention programmes are being implemented without finding out from the community what is relevant to them, resulting in failure of some interventions. This research is aimed at finding out from the lay-care providers themselves sustainable interventions in home-based care and how they can prevent themselves from being infected and to highlight the difficulties they face. The results will guide HIV/AIDS interventionists in formulating relevant and sustainable approaches. In the long run, the results are expected to inform the policy formulators in the HIV/AIDS management and care. The results can also be used for advocacy in highlighting the plight of the vulnerable care-givers who are unduly exposed to health risks.

1.5 Scope and Limitations of the study

This study focused on the lay-care providers' lived experiences in HIV/AIDS management. The target of the study was the lay-care providers living in Kaptembwa division of Nakuru District.

A number of limitations were encountered during the research. First, the study was limited to lay-care providers, therefore, any professional care-giver was not included in the study. Secondly, content specific to the culture and environment of Kaptembwa was a bit limiting and therefore, a barrier to the generalization of the findings. Thirdly, there is a possibility of certain unnoticeable biases which may have arisen due to the physical presence of the researcher that may have influenced the respondents and barred them from giving unprejudiced information.

1.6 Definition of Key Terms

Lay Care- providers: consisted of the untrained individuals who look after the sick people.

Roles: referred to what they do in order to mitigate the problems of HIV/AIDS patients.

Problems: referred to obstacles that stand in the way of lay-carers as they provide services to HIV/AIDS patients.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

The following topics were reviewed to highlight the current status of available literature in the area of lay-care provision to HIV/AIDS patients.

- (i) Lay- care providers
- (ii) Roles that lay- care providers play in the management of HIV/AIDS
- (iii) Problems lay-care providers face in the management of HIV/AIDS

2.2 Lay- care providers

According to Roger (2003: 291), the difference between professional and lay care is that professional care is provided by licensed or degreed persons, such as doctors, registered and licensed practical nurses, licensed social workers, psychologists, and the like. Lay care would be that care provided by non-licensed persons, such as sitters, family members, and the like. This does not necessarily mean less quality of care, but it probably means less qualified care. According to Osero (1990: 18), lay referral system consists of non- professionals; which include family members, friends, neighbors, and all those who assist an individual in interpreting his or her symptoms and in recommending a course of action.

According to Luccas Melo de Souza (2006: 340), in his analysis of lay-care providers in the Brazilian scenario, care practice traditionally started in the private home sphere, as the family structure included multiple generations, thus making this practice possible. Relatives were acknowledged as the source of care for dependent persons, and the female figure was chosen to be responsible for this care. In the modern time, in most situations, care providers accompany their relatives for several days in hospital and await hospital discharge; they also provide care even after discharge.

Brown and Stetz (2004:11), highlight three dimensions of care giving beyond the actual task involved. The first phase focuses on adjusting to new role, starting with coming to grips with the diagnosis and the reality, choosing to provide care, developing competency as task performance, and alternating between hope for life and the possibility of death. The second

phase. involves guiding, giving and doing for the ill person to meet his or her needs. This includes managing the illness, struggling with the healthcare system, managing the environment and organizing resources, coming to know one's own strength, handling one's own pain, responding for family issues and preparing for death. In the final phase, the care giver seeks to bring closure to their care giver role and reconnect with their own lives, a process influenced by the length of their involvement in care giving and strength of identification with and internalization of the care giving role. While experiencing relief from intensive care giving, they attempt to tie up the loose ends by completing health care payments, returning medical equipment, notifying insurance agencies, and so on. Dealing with regrets over past situations they wished they had handled differently, building a new life away from care giving as well as adjusting to the absence of the care giver.

Premilla (2004:50), describes several types of care givers:

Parental Care Givers: these are parents caring for an adult child with who they face multiple challenges. Besides the loss of aspirations, the infection represents a life cycle shift for them. At a time when parents may have already completed the task of or may have been in the process of launching their children and considering some of their major life tasks over, the presence of the infection and the care giving it engenders dictate that they may undergo a role reversal. They experience a disruption in the natural order of families, resuming a long discarded role as guardian or decision maker for their child. They also go through pain of having to watch their offspring die and of having to outlive their child.

Child Care Givers: children are the least acknowledged care givers within the home. When one parent dies in a nuclear family, there is usually no one to look after the other parent and siblings, or some of whom may be infected) and in these cases, children assume adult roles. This is a version of skip- generation parenting, which involves parentification of youth. HIV/AIDS is increasingly challenging dominant conceptions of childhood, particularly the notion of children as dependent, passive and non- productive. Children's education and social and recreational life is adversely affected by their care giving responsibilities. Care giving is usually directed in an atmosphere of confusion since the children are not usually informed about the infection, and hence, they are left to grapple with their own conclusions.

Grand Parents Care Givers: when parents are unable or unavailable to provide care to HIV- infected children, it is usually the grandparents who take up the responsibility. While grandparents are the first line of support, where they are unavailable, it is other relatives followed by sibling who take charge. The experiences of grandparents care givers are usually clubbed together with those of other extended family members termed as kinship care. Kinship families often learn of the infected person's diagnosis at the same time when they are requested to provide care. Kinship parent may be an older relative, an aunt or uncle or a grandparent. In cases of grandparents, grappling with great emotional despair on observing truncated life cycles of their offsprings and offspring's families and worrying about their grandchildren is common.

Gay and Lesbian care givers: intimate friends and lovers provide much care for the positive person, based on affiliation and bonding. Since both care giver and care receiver share the same risk factors, there may be greater identification which supports the relationship. Lovers and friends may be providing care with or without any influence from their care receiver's family of origin. This depends on whether the family of origin knows about that family member's family of choice and how they react to it, if they do. Families who respond positively support the care giving dyad, bringing cohesion to the situation. Where there is a tenuous relationship, because of the family of origin's inability to accept the positive person's sexual orientation or choice of partner or HIV status, a strategy of competition may operate, with the family of origin taking over the situation.

Social Support Care Givers: include volunteers, strangers, and friends. They may establish a relationship with the infected person. They may help with the routine household task, but their primary role is to visit the infected person, spend time together in social outing and convey a sense of interested caring. They do not take the place of professional care givers and seldom assume the responsibilities of family care givers, yet their place, as social supports directly for the positive person, assumes prime importance during the long course of illness. They may replace absent, unavailable or rejecting family members. In other families they serve a supportive role, never becoming central to the family role structure.

2.3 Roles that Lay-care providers play in the management of HIV/AIDS

According to Manguyu (1993:53), the quality of the health care provided, is in many cases the reason why health care is not sought even where it is free and accessible. Quality care is not just a greeting, a smile, or saying kind words to patients, but rather the feeling of profound respect and recognition of human being's rights. Quality should be associated with giving sufficient information for the patient to be able to understand the issue at hand. Health care should be more human than technological.

According to UNAIDS (2006), it is estimated that up to 90 percent of illness care is provided in the home by untrained family and associates, and up to 80 percent of AIDS-related deaths occur in the home. During their lifetime, a person infected with HIV will require care, treatment and support so they can deal with their illness and live as comfortably and productively as possible. The diminished capacity of many countries' health sector makes the prospect of having people with HIV treated at home all the more attractive to governments. A potential benefit of being cared for at home is that sick people are continually surrounded by people they love and are familiar with, so they can also receive more flexible and nurturing care.

According to Great Britain's Ministry of Health (1967: 9), the care providers perform five functions:

- (i) Dietary; where they design the diet of the patients to provide a selection of foods from which these needs and tastes can be met. Some patients require only a well-balanced normal diet, but for the majority, modification of the normal pattern is essential. It is therefore, important for the care provider to plan the list of menus so that a selection of dishes is available at each meal from which a range of balanced diets can be provided, and should also ensure that each patient obtains the quantity and type of dish which satisfies his/ her nutritional needs as well as his/ her taste and appetite.
- (ii) Control of food costs; where the care provider ascertains the total amount allowed for provisions. They should keep accurate records of the number of meals actually supplied to patients. A working knowledge should be acquired of the cost per

portion of various dishes, so that, when planning the menu, dearer dishes can be balanced with cheaper items.

- (iii) Preparation, cooking and dispatch of food; they should ensure that methods of preparation and cooking conforms to correct practice to ensure palatability with maximum yield and nutritive value. The cooking of each item on the menu should be timed so that it is ready as near to the time of dispatch from the kitchen and served attractively on the plate.
- (iv) Cleaning and maintenance; the care provider should be responsible for keeping clean their own work tables. Paper tray cloths, beddings should always be fresh and clean.
- (v) Patient's hygiene; since sick people are susceptible to infection, very high standards of cleanliness must therefore be maintained. Care provider must maintain self-cleanliness, that of patients and premises.

According to NASCOP (2005: 46), care for people with HIV/AIDS must be comprehensive and continuous and not simply restricted to treatment. Care focuses on the patient and provides the patient with not only physical but also social, psychological, emotional and spiritual care. Comprehensive care entails:-

- (i) Encouraging the patient to live positively; whereby living positively means an endeavor to live well with HIV infection without being a danger to others or the patient. It also means there is hope and it is important to focus on the quality of life rather than the quantity of life. Stress, anxiety, depression are all common for those living with HIV. Counseling allays myths of HIV/AIDS, provides a new perspective on life, and brings about the desired psychological frame of mind.
- (ii) Provision of proper nutrition: Adequate food security in the household is a requisite for optimum nutrition and survival. HIV/AIDS reduces the households' ability to produce and buy food by taking away the adult labor that would otherwise be engaged in food production or in earning an income. The capacity of an affected household to obtain an adequate amount and variety of food, and to adopt appropriate health and nutritional responses to HIV/AIDS, especially for the already vulnerable ones, is grossly reduced, therefore, it is important for the care provider to ensure that proper nutrition is given to the patient.

- (iii) Preventing and treating opportunistic illness: Because their immune system is weakened, people with HIV infection are at risk of opportunistic infections and cancers, many of which can be treated or even prevented. Opportunistic infections include bacterial skin infections, shingles, thrush: mouth and tongue, severe athlete's foot, diarrhea, tuberculosis, severe pneumonia, meningitis, complex infections and cancers. Care providers can assist in providing safe drinking water, preventing malaria by using bed nets and insecticides, giving the patient cotrimoxazole to prevent diarrhea, pneumonia and malaria, treating and managing opportunistic infections as they occur.
- (iv) Treating HIV infection with antiretroviral drugs: This therapy is expected to reduce mortality and morbidity resulting from HIV/AIDS, maintain a healthy, productive community with reduced stigma towards people living with AIDS, reduce the escalating burden of AIDS orphans, improve quality of life of the infected, reduce HIV/AIDS- related hospital admission by 60%, enhance national prevention effort. They also assist in managing side effects of these drugs which include; skin rash, vomiting, abdominal pain, burning sensation of feet and hands, and diarrhea.
- (v) Providing home-based care: This is the care of persons infected and affected by HIV/AIDS within the home and community, serving as a link between hospital or health facility and the client's home through family participation and community involvement. Quality home based care have four main components; clinical care- makes early diagnosis, prescribes rational treatment and plans for follow- up care of HIV related illness; nursing care- promotes maintaining good health, hygiene and nutrition; counseling and psycho-spiritual care- reduce stress and anxiety, promotes positive living, and helps persons make informed decisions on testing for HIV, changing their behavior, planning for the future and involving sexual partner(s) in such decisions; social support- provides information about support groups and welfare services and refers patients to them, provides legal advice for individual and families, including surviving family members, and where feasible, provides material assistance.

2.4 Problems lay-care providers face in management of HIV/AIDS

According to Olagoke (2004: 24), lay care providers face a lot of challenges ranging from burn-out and impoverishment to injury, increased vulnerability to illness and emotional despair. They also receive no training, no support from formal programmes and no concrete inputs such as gloves or medication. They lack information about the disease they are managing and how it will change over time. Many do not know that the loved one(s) in their care has AIDS. In addition, due to HIV/AIDS-related stigma, caregivers may be closed off from social support at the time they need it most. They may experience hostility and rejection, including outright discrimination. This burden becomes enormous, especially when those providing care are themselves living with HIV/AIDS and are neglected, thus they become exhausted and often run out of options.

Care-giving is very demanding for the family and all those involved. The work leads to physical stress, emotional and psychological stress, social and economic stress. Caregivers experience physical stress related symptoms such as headaches, backaches, and general body weakness and fatigue. Some of the family members also face the risk of infection with tuberculosis because of frequent close contact with patients and also risk of HIV infection because they do not use protective devices when caring for the sick. Emotional and psychological stress manifests in tearfulness, sleeplessness, nightmares, feelings of guilt, helplessness and hopelessness about the imminent and frequent deaths of patients. Caregivers experience social stress as a result of alienation from friends and other social activities and also strains in caregiver-care recipient relationship. The economic burden of caring for the sick sometimes fall on the caregivers who often have to grapple with increased cost of living, decreased income from loss of jobs or job opportunities, transport to health facilities and transport of the dead or funeral costs (Olagoke, 2004: 12).

According to Colombia University (2004: 19), caring for a person with HIV/AIDS requires considerable time and other resources, which is compounded in many developing countries by a lack of basic services such as clean water. About 24 buckets of clean water are required every day to care for a person living with HIV/AIDS, to wash the sick person, to clean soiled sheets, to wash dishes and to prepare food. There is an urgent need for water and sanitation

because related diseases such as diarrhea and various types of skin diseases belong to the most common opportunistic infections. In addition, unventilated houses with inadequate drainage increase the risk for tuberculosis infection and inadequate waste management attracts insects and vermin that carry diseases.

Leake (2009: 27) explains some of these problems as follows:

Caring for someone whose mobility and bodily functions have deteriorated can place great demands on the health of caregivers. Carers may risk their physical health when assisting someone, perhaps heavier than themselves, with the simplest of tasks such as getting out of bed or moving around the home. Some carers suffer physically as a result of caring, with the most common problems being headaches, body aches, back aches and exhaustion. Some elderly women who are physically affected by their care work have existing ailments including arthritis, diabetes and hypertension.

Women are primary caregivers and are often overburdened, with lack of support from other family members. They take on the most physically demanding tasks including bathing patients, helping them go to the toilet, changing soiled nappies, clothing and sheets, and obtaining water, sometimes a long distance away.

Care providers also come to close contact with patients' faeces, vomit, and other bodily fluids. This creates a risk of HIV and tuberculosis infection. This risk is exacerbated in areas where there is poor sanitation and where the carer does not take precautionary measures such as wearing rubber gloves, either through lack of appropriate knowledge or resources.

When a family member falls sick as a result of HIV, not only does that individual's inability to work lessen family income, so too does the fact that carers will spend less time making money. Furthermore, at the time that the earning potential of a household is diminished, the cost of treatment, medicines and other healthcare provisions constitute an added financial burden on carers. Similarly, older people may have to return to work at the time in their lives when they might be expected to cease working and be cared for by their offspring.

Female care providers usually fear sexual abuse and rape, especially when they are caring for male clients who live alone.

According to <http://www.scielo.br/scielo.php>, caregivers face difficulties because the health system does not provide care to companions. Some institutions' rigidity and lack of flexibility is frequently observed in care delivery to companions of hospitalized patients, when the caregiver presents signs of disease or searches for information and referrals. Health professionals, in turn, neither present nor even discuss strategies to facilitate these companions' access to services. On the other hand, it seems difficult to discuss the implementation of companions in health programs if public health policies including them in care planning are not available. This observation often times makes health professionals feel powerless in the face of the reality presented in their daily routine.

2.5 Theoretical Framework

The study adopted socialization theory to study the Lay-care providers' lived experience in HIV/AIDS management. According to Grusec (2006: 13), the term "socialization" refers to processes whereby naïve individuals are taught the skills, behavior patterns, values, and motivations needed for competent functioning in the culture in which the child is growing up. Paramount among these are the social skills, social understanding, and emotional maturing needed for interaction with other individuals to fit in with the functioning of social dyads and larger groups. Socialization is a succession of processes occurring at successive stages of development, with the child's family of origin being the first, and in many cases, the most enduring, socializing institution, joined by peer groups, schools, religious institutions, and, in adulthood, employers and intimate partners as sources of norms of social behavior.

Emile Durkheim is among the founding fathers of sociology. To Durkheim (1950: 95), society is a unity, an organized, more or less definite with permanent system of relationships. He argues that social facts have an independent existence greater and more objective than the actions of the individuals that composed society. Society is seen as a reality above and part from its individual members. The individual is not the self- sustaining and self- directing creature but rather as unalterably dependent upon society and its codes. Society has laws of

development which are based on the articulation of its parts. Society cannot be made or remade. To him, the state is the central nervous system of the body social. It is in the state that the self-conscious collective ideas reside. The state's essential function is to think. The state has the responsibility to see that man fulfils his duty to those whom he owes it. Forms of authority which bind man are religion, family, community and corporative organizations.

The human group is ultimately seen as a system of authority. Everything which disturbs the social order is considered immoral, undisciplined and criminal. All acts considered as criminal evoke punishment from society. To him, culture gives us all our collective ideas, ideals, reasoning power and moral systems. Culture humanizes man in that it transforms him from an under-equipped biological organism into a civilized human being. In order to meet those social imperatives, the members of a society must internalize their collective representations. In this context, he assigns education the task to inculcate in the young moral forces which give society its strength. The aim and end of education is to train the individual in ways of collective thinking and doctrines of morals that are the expression of the group, the group of which man is a part.

According to Spencer (1967: 67), the society exists for the benefit of its members and not its members for the benefit of the society. To him, the society undergoes continuous growth and as it grows, its parts, become unlike and exhibit increase of structure. The unlike parts simultaneously assume activities of unlike kinds. These activities he says are not simply different but their differences are so related as to make one another possible. The reciprocal aid thus given causes mutual dependence of the parts and the mutually dependent parts, living by and for one another, form an aggregate. He believes that nature was endowed with a providential tendency to get rid of the unfit and to make room for the better and that man should not interfere with the natural process going on in society. For nature knows where it goes and prepares a better future for man thus the individual has to act, and in acting, will do the best for himself and society.

2.5.1 Relevance of the theory to the study

According to Mumford (1967:58), the process of conscious and unconscious learning of performance for the various roles one is asked to play is a large part of socialization. All social roles are learned. Even the positions that are given by the fact of birth, for example, sex, become elaborated in any society, so that the individual is pressed in many ways toward certain behavior pattern considered appropriate or desirable in that position. Contemporary concept of sickness includes some notion that the condition entitles one to a temporary privileged position. The person who is defined as ill has the right to be dependent, even though he is an adult. He has the right to expect help even from strangers and the right to believe he should and can be helped. The sick person is excused from his/her normal obligations. The sick person's role is that, (i) he/she is supposed to want to get well, (ii) our concept of sickness is that it happens to the person and therefore, we cannot expect him/her to make himself/herself well by sheer will power, (iii) the person who receives the exemptions of the sick role is expected to seek competent help; s/he is supposed to believe that science and the medical profession can and will help him/her, (iv) the person who demands privileges of sickness is expected by society to cooperate with the technically competent authority s/he has consulted. It is also useful to note that when a sick person fails to live up to this part of the sick role; it can be because s/he comes from a different cultural experience and so s/he has not learned the concepts for patients and for sickness with which the physician and the nurse work.

In as much as AIDS patients rely on the current ART program, some still have faith in traditional medicines. This may be because the current use of generic antiretroviral drugs still faces several challenges including, HIV resistance, toxicity, limited availability, and lack of curative effect, therefore, making HIV/AIDS patients vulnerable in their choice of treatments, such that they can vacillate from conventional ART programmes to traditional healers and vice versa: they want to have the best of both worlds (Kazhila: 2009).

Most chronic patients with severe illness live in their own homes. Most of this care is provided by lay-providers composing of spouses, relatives, friends and neighbors. The family receives the responsibility to take care of its members. Families are required to assess,

monitor, and deliver complex therapeutic interventions such as pain and symptom control, and the administration of complex medical regimens. This task is related to each person's social responsibility towards his/her relatives. Lay-care providers are expected to have acquired sufficient autonomy to take care of themselves and the person they are accompanying. It should be highlighted that the family is not only the care unit, but should also be considered as the unit that needs care. Socialization theory therefore, draws attention to the impact of a patient's disease in the family. Rather than focusing on patients as individuals, it focuses on patients as being part of the society, where persons depend on each other to a large extent. According to this theory, changes in the life of a family member, for example, becoming chronically ill patient, have consequences for other family members, especially for the persons acquiring the role of carer.

2.6 Hypotheses

The following hypotheses guided the study:

- Lay-care to HIV/AIDS patients is mainly provided by family and other closely related persons.
- Lay- care providers play a crucial role in HIV/AIDS management in Kaptebwa Division.
- Lay- care providers face a number of problems in the management of HIV/AIDS.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

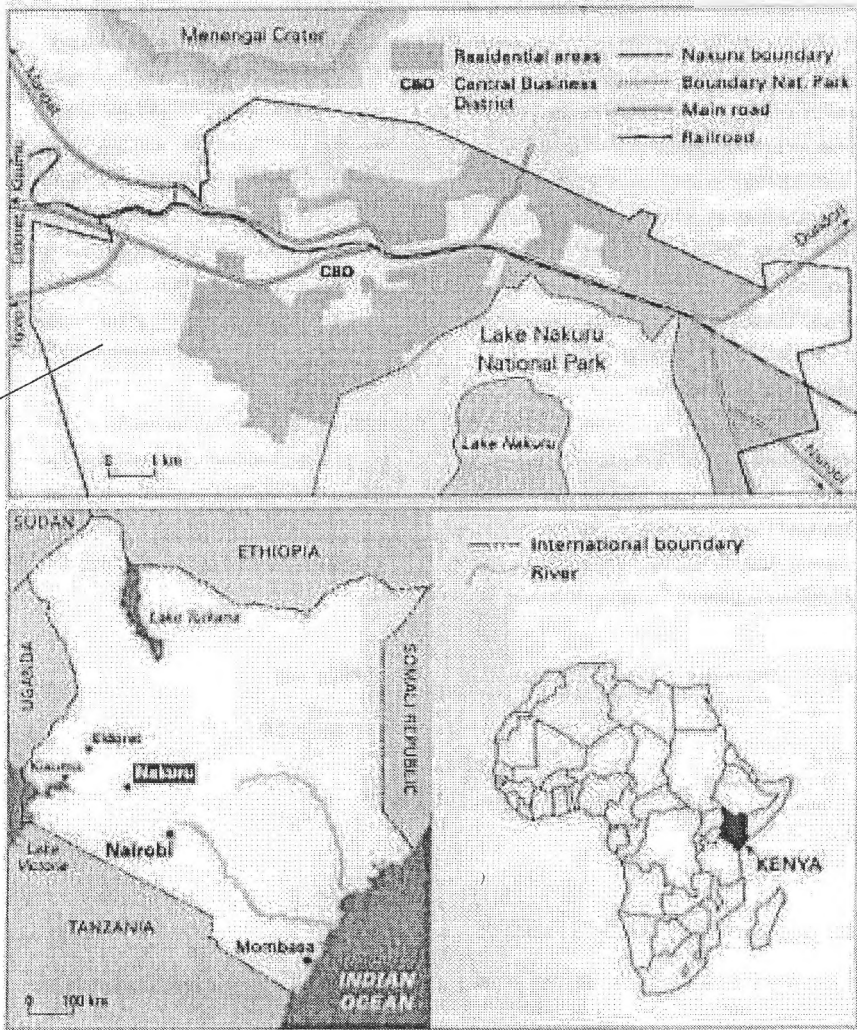
This chapter presents the study area and population, discusses the research design, sampling techniques and data collection methods. Also included are the procedures for data analysis.

3.2 Research Site

The research was conducted in Nakuru town. Nakuru is located in the heart of the Great Rift Valley between latitude 0010' and 0020' South and longitude 360 and 36010' East, at a distance of 160 km north-west of Nairobi. Nakuru is the provincial capital of Kenya's Rift Valley province, with roughly 300,000 inhabitants, and currently the fourth largest urban centre in the country. The town started as a railway station on Kenyan-Uganda railway at the turn of this century. The name 'Nakuru' is derived from *Nakurro*, the Maasai word meaning a 'dusty place'. Nakuru municipality is one of the four local authorities in Nakuru district and is divided into five zones. Zone 1 (Eastern zone) includes Lanet, Kiondo, Free area, Kiratina and KHH. Zone 2 (Western Zone) includes Kipsigis or Tugen farm, Nakuru West, Baruti and Kaptembwa. Zone 3 (Central Zone) comprises the town centre. Zone 4 (Southern zone) comprises of Kanu Street, Mwariki and Racetrack. Finally, zone 5 (Industrial area zone) includes Gilani, Bangladesh, Githima and London (MCN, 1999: 3).

The major economic sectors of the Nakuru urban economy are: commerce, industry, tourism, agriculture and tertiary services. The commercial sector in Nakuru contributes about 19% of the economy of the town. Within the Central Business District (CBD), retail activities occupy 26%; wholesale has 10% and the informal sector enterprises 18% of all the commercial activity space. The most dominant forms of business in the Nakuru economy include: retail in hardware, general wholesale, outlets for agro-industrial machinery, motor vehicle trade, spare parts and servicing, the agro-chemical retail and wholesale outlets. There is a significant network of financial institutions providing banking, insurance and credit services to the business community (MCN, 1999: 5).

The study focused on the Western zone, where Kaptembwa is located. HIV/AIDS prevalence rate in Nakuru is 7.0% (KAIS, 2008). Since 40.5% of its residents are affected by poverty, the burden of HIV/AIDS is enormously felt by the low income neighborhoods. Kaptembwa is an urban slum, with closely located semi-permanent houses. The roads in this division are bad. During dry season, sand piles on the bare road and during rainy season the roads flood, thus becoming impassable. It is also characterized by frequent water shortages and poor drainage patterns. Residents have to buy water from water vendors and also share toilets and bathrooms with others within their neighborhoods. Most residents derive their livelihood from a variety of activities including hawking, offering laundry services, cultivating land, casual employment in construction sites, and some sell goods in the open air market. The health facilities near this division include Kapkures Health Clinic and Langalanga Health Clinic. These health facilities are sparsely dispersed and most of them are low in supplies and most frequently lack medicine. Therefore, patients have to travel long distances to the Rift Valley Provincial General Hospital. This therefore means that most of the patients with HIV/AIDS are found in the homes taken care of by the lay-care providers, who may be family, friends and neighbors.



Map 3.1: Location of Research Site

Source: Wikipedia Map

3.3 Research design

A research design provides a framework for the collection and analysis of data (Bryman, 1998: 27). The study was designed to elicit the impact of lay-care providers on HIV/AIDS management. Case Study design was used in this study. Basic case study entails the detailed and intensive analysis of a single case. As Stake (Bryman, 1998: 49) observes, case study research is concerned with the complexity and particular nature of the case in question. In this study, this method was the most appropriate because it was particularly helpful in describing the types of people who provide lay-care to HIV/AIDS patients and also in examining their roles and problems they faced in HIV/AIDS management.

3.4 Sample and Sampling Procedures

The study used a sample of thirty lay-care providers. The individual was the unit of analysis. The study population included all the lay-care providers residing in Kaptebwa division. To enable the researcher get the population sample, a sampling frame was drawn. A list of registered HIV/AIDS patients receiving ARV treatment from the Rift Valley Provincial General Hospital was checked. From this, those who are residing in Kaptebwa were extracted and through random sampling, thirty HIV/AIDS patients were selected. It is through them that their lay-care providers were reached and later interviewed. Most care providers were found living in the same house with the patients, since they happened to be family members. In instances where the care providers were not living with the patient, the researcher accompanied them to the patient's residence where they provided care. A total of five key informants were selected for interviews outside the study sample. They were purposely sampled and comprised of two medical officers from the Rift Valley General Hospital, Home-Based Care Coordinator from Catholic Diocese of Nakuru and two Community Health Workers. The researcher visited them at their various work stations, so as to get the valuable information they had on the lay-care providers lived experiences in HIV/AIDS management.

3.5 Methods of data collection

Several data collection techniques were used. It entailed using direct observations, narratives, in-depth interviews, key informant interviews and secondary data sources.

3.5.1 Direct observations

In the course of research, the researcher observed the lay-care providers as they provided the care services to the patients. This entailed the use of observation list (Appendix 2). The roles lay-care providers played as well as the problems they faced as they managed HIV/AIDS was observed. Further, the interaction between the patients and the care-givers, the timing of the various activities and the environment in which the activities were accomplished was of interest.

3.5.2 Narratives

Out of the thirty informants, eight showed greater interest in the research and went beyond answering questions in the in-depth questionnaire and were willing to narrate their relevant experiences with regard to managing HIV/AIDS. Narratives were useful in examining their knowledge on caring for an HIV/AIDS patient, their daily encounters with the patient, the various roles that they played and to examine the problems that they faced in HIV/AIDS management. It was also useful in getting their views on how to improve of lay-care service provision in HIV/AIDS management.

3.5.3 In-depth Interviews

This technique involved conducting intensive individual interviews with the informants to explore their perspectives on HIV/AIDS (Appendix 1). Since this type of interview is often unstructured, the respondents were encouraged to talk at length about HIV/AIDS. The basic demographic information of the thirty lay-care providers was collected, which included: age, sex, education, relationship, occupation, income, marital status and religion. It was also

useful in examining the roles that lay-care providers played in HIV/AIDS management and also in examining the problems they faced in HIV/AIDS management.

3.5.4 Key informant interviews

People who are knowledgeable on the situation of lay-care providers were the target of this method (Appendix 3). Their experiences with lay-care providers in HIV/AIDS management were of interest. Information about the organization of home based care system, its strengths and weaknesses as provided by lay-care providers and the areas of difficulties and prospects was of great importance for the study.

3.5.5 Secondary data sources

Documentary materials through library research were a major source of data for this study. Materials that were reviewed included books, journals, newspapers, articles and other literature on HIV/AIDS and management of the disease. These included manuals from National and international organizations that focused on HIV/AIDS, for instance, National Aids Control Council manuals, Center for Disease and Control (CDC) manuals, Family Health International manuals, UNAIDS manuals, records from local health facilities among others. Other sources included the information from the internet.

3.6 Methods of data analysis

Thematic content analysis followed along the main themes of the study and also focusing on the issues and patterns that encompass the data. Data were then coded and grouped according to thematic issues. This was followed by the systemic summary of the data about commonly held opinions, attitudes or beliefs with regard to their experiences in HIV/AIDS management. Verbatim quotes from informants have been used where appropriate to clearly bring out their voices

3.7 Ethical concerns

The respondents were first informed on the research goals and objectives, methods and sponsorship. The researcher sought informed consent from respondents and assured them that the information that they provided was to be treated with confidentiality and the final report would not have any identifying information. The prospective research participants were given as much information as was needed to make an informed decision about whether or not they wished to participate in the study. This also implied that they were fully informed of the research process. They were made aware of their entitlement to withdraw at any stage for whichever reason. The respondents had the right to answer or to refuse to answer certain questions on whatever grounds they felt justified.

The proposal was also presented for review at the Institute of Anthropology, Gender and African Studies board at the University of Nairobi. Actual field work only commenced after the necessary approvals were granted. I also envisage sharing the findings with the informants and the Rift Valley Provincial Hospital and other stakeholders at the local levels who are engaged in HIV/AIDS management.

3.8 Problems encountered in the field and their solutions

Since HIV/AIDS is in itself stigmatizing, the researcher had anticipated to encounter problems in getting the informants to agree to participate in the research. The researcher managed to solve this problem by getting a contact person, who introduced her to the patient, who then introduced her to the lay-care provider. Through this method of rapport creation, acceptance into the community was enhanced. This helped a lot in building confidence and relaxing the nerves of the patients and their care-givers hence success of the exercise.

Some informants thought that they would be paid after participating in the interview. The researcher was able to take care of this problem by emphasizing that the results of the research would not provide any monetary gain to the researcher, but were simply needed for academic purposes and for future interventions in the HIV/AIDS arena. The emphasis on the

researcher being a student made informants less demanding and they therefore, cooperated and gave information without expecting any monetary gain.

CHAPTER FOUR: FINDINGS

4.1 Introduction

This chapter presents the research findings. It is divided into three sections. The first section presents the types of people who provide lay-care to HIV/AIDS patients which include their socio- demographic information detailing the characteristics of the informants. The second section presents the roles that lay-care providers play in HIV/AIDS management and the third section presents the problems that lay-care providers face in HIV/AIDS management.

4.2. The types of people who provide lay-care to HIV/AIDS patients

4.2.1 Sex

A majority of the informants who were lay-care providers were women, which constituted of 80% of the sample while males accounted for 20%.

The CDN coordinator agreed with the above findings as shown by the quote below:

"A high percentage of females take care of the sick. Men see themselves as breadwinners, so they cannot spend most of the time in caring".

4.2.2 Occupation

Most of the informants were engaged in different fields. Only 20% reported that they were not engaged in any incoming generating venture. They stayed in their homes and depended on someone else to provide the basics for them, for instance their partners, siblings and parents. Of those who were working, 6.7% were shop keepers, 3.3% practiced farming, 6.7% operated in saloons, 16.7% offered laundry services, 3.3% cultivated other people's land, 6.7% were casual labourers in construction industry, 6.7% did housekeeping, 3.3% offered repair services of electronics, 16.7% were vegetable vendors and 10% operated food kiosks.

4.2.3 Income

Most informants (90%) earned below Kshs. 5,000, while the other 10% earned above Kshs. 5,000 per month (Table 4.1).

Table 4.1: Income of Lay-care providers

Monthly Income	N	%
No income	6	20.0
1001-2000	1	3.3
2001-3000	4	13.3
3001-4000	9	30.0
4001-5000	7	23.3
5001-6000	2	6.7
6001-7000	0	0.0
7001-8000	1	3.3
Total	30	100.0

4.2.4 Age

Majority of the informants were old people aged between 51- 60 (33.3%), while 20% were aged between 31-40 and 41-50 years respectively. The other 13.3% were aged between 10-20 and above 60 years respectively (Table 4.2).

Table 4.2 Age representation of Lay- care providers

Age in years	N	%
10-20	4	13.3
21-30	0	0.0
31-40	6	20.0
41-50	6	20.0
51-60	10	33.3
60 and above	4	13.3
Total	30	100

4.2.5 Education

53.4% of the informants had no formal education, 26.7% had primary level education, while 13.3% had secondary level education, and only 6.7% had college level of education.

4.2.6 Marital Status

40% of the informants were widows, while 6.7% were widowers. 20% were married women while 6.7% were married males. 13.3% were divorced females. Single male and female informants were equally represented (6.7%).

4.2.7 Nature of Relationship between the lay-care givers and the patients

Majority of the informants (96.7%) were relatives to the patients, while only 1 (3.3%) caregiver was a neighbour. This nature of the relationship that the lay-care providers had towards the patient is represented in table 4.3 below:

Table 4.3: Nature of relationship of Lay- care providers to patients

Relationship	N	%
Mother	11	36.7
Father	1	3.3
Sister	2	6.7
Husband	2	6.7
Wife	3	10.0
Son	2	6.7
Daughter	4	13.3
Grandmother	3	10.0
Grandfather	1	3.3
Female neighbour	1	3.3
Total	30	100.0

Information from the key informants agreed with the data regarding the relationship between the patients and the care-givers. They noted that the family is the first option of care in any environment. Their sentiments were thus expressed as noted below:

“It is the family that understands the history of the patient and since they are the closest kin, it is easy for them to live together than somebody else from outside the family”, (CHW).

“No matter what, the families always take care of the patient, unlike somebody from outside, especially during the final stages of the disease”, (CHW).

"In the family, there is confidentiality since the family is often scared of being stigmatized by the society, they own the patient and rarely reveal the patient's sickness", (Medical Officer).

"There are cases I have seen whereby, patients are not taken care of by relatives, especially when they have been abandoned. Some good samaritans assist them. We also train CIW to assist the patients and care providers at home. We get patients through referrals from the hospital, and with their assistance, we link them to the CIW who provide them with care services". (CDN coordinator).

4.2.8 Care Provision

Majority (73%) of the informants reportedly provided care for HIV/AIDS patients. They knew the status of the patients, could interpret the symptoms or had prior exposure to the disease. As shown by the following sentiments:

"My daughter became very sick; she was so thin and pale. I took her to hospital then she was told she was positive. After that, she came with her children to live with me. She did not stay for long. She died. Now am taking care of her small children who were born positive." (Grandmother to the children).

"It was when my husband became really sick and hospitalized that I came to know of his status." (Wife to the patient).

"The moment I saw this patient, I knew he was positive. I had taken care of others before, so when the neighbours called me to take care of this one, I knew I could manage it," (Neighbour of the patient, who has also been taking care of other patients).

"This is my second wife. The first one died of AIDS. I am also positive and a CIW. It was during one of my many visits to my patients, that I met her while bedridden, I took care of her until she got a bit well then we got married because we apparently understood each other." (Husband is the care giver of the wife. The current wife had also been married but the husband left her soon after their first child died due to complications related to the disease).

Of all the care-givers, 27% said that they were not providing care for an HIV/AIDS patient. Probably, the patient had not informed them of their status and also because they could not interpret the symptoms of the disease as shown by the following sentiments:

"I was given drugs from the hospital and told to give to my mother because she could not understand what the doctor was saying. I don't know what they are treating. The drugs got finished a month ago. I have not gone for others." (A son taking care of a sick mother).

"Whenever my mother becomes very sick, I have to wash her clothes, clean her up, and she tells me to give her the medicine she brought from hospital. I don't know what she is ailing from." (A daughter taking care of her ailing mother).

"When I came to see my daughter, I found her very sick. They usually quarrel with the husband, now she was beaten and has broken her limb, she says she has chest pains and coughs a lot. She usually takes painkillers. When she recovers, I will go back home." (A father taking care of her married daughter whose husband fled after severely beating her).

"My daughter had been married but the husband died. When she became very sick, she came to my place. She has developed bed sores, because she is usually in bed. She told me she has arthritis but has never gone back to hospital after the initial visit." (A mother taking care of her bedridden daughter).

4.3 Roles Lay-care providers play in HIV/AIDS management

The various roles that the lay-care providers play in HIV/AIDS management include the following: (NB. Multiple responses allowed in each case)

4.3.1 Nursing Care

56.7% of the informants bathed their patients, 56.7% nursed their wounds, 53.3% cleaned the house, 70% ensured the patient had taken medicine and 60% shaved the patients' hair and trimmed their nails. The following sentiments run across the different care givers:

"He sometimes develops wounds on his skin, therefore, I dress it using warm water and salt." (Wife taking care of her sick husband).

"When I come back from school, I assist in general house cleaning, cooking and fetching water." (Daughter taking care of her bedridden mother).

"I used to buy water for cleaning his house and I also washed him, when he was severely ill." (Neighbour who is the care giver of the recuperating patient).

"Even when am not around, I find my son has already taken the medicine as I had instructed him." (Mother who is the caregiver of her sick son).

"Sometimes when she is very sick, I have to accompany her to the clinic to get medical attention" (Grandfather to the patient).

4.3.2 Nutritional Care

93.3% of the informants cooked for the patients, 10% ensured that the patient had a balanced diet, 70% fed the patient. The following sentiments run across the different care-givers:

"He has mouth sores, so I have to mash his food like a baby's then I feed him," (Mother taking care of her bedridden son).

"I have to add an extra plate of food when I cook in my house, which I bring to this patient," (Neighbour is the caregiver of the patient).

"The nurse taught me and gave me a book on preparing meals for HIV/AIDS patients, this is what I use for my sister to ensure she has a balanced diet. She has really grown strong. She could not even stand before." (Sister to the patient).

"I usually do the cooking in this house, its part of the routine tasks," (Mother to the patient).

4.3.3 Physical Therapy

56.7% of informants assisted the patients with physical movement and 16.7% massaged the patient. The following sentiments run across the different care givers:

"I carry her outside and place her on the "gunia" to bask, since she says she feels very cold," (Grandfather taking care of her bedridden granddaughter).

"I assist him to go to the toilet when I am available. But when I am not, he uses a plastic container to help himself." (Neighbour is the care giver of the patient).

"She is my sister, I feel bad when she just stays in the house, so I just put her hand on my shoulder and hold her then we go around the estate as we used to." (Younger sister taking care of her elderly sick sister).

"I massage his body since he usually complains of stiffness. It's good for blood circulation." (Wife taking care of her sick husband).

"Since he cannot walk, I stretch his legs every morning and evening, he says he feels better though he is sometimes too tired to do the exercise," (Mother taking care of her sick son).

4.3.4 Advice and promotion of responsible sexual behavior

Only 20% of the informants provided information and education on HIV to the patient. The following sentiments run across the different informants:

"I talked to her and she listened. She left prostitution and now stays at home with me." (Mother taking care of her sick daughter).

"I have told him that we have to protect ourselves by using condoms. I am positive and on ARVs but he is using herbal medicine. He agreed now we are using condoms to avoid increasing the viral load." (Wife taking care of her husband).

"It is difficult to advice the patient on responsible sexual behavior. they think that you are saying that they got the virus from sex, and they will refuse to be cared for by you." (CHW).

4.3.5 Psycho-Social Support

Only 1 (3.3%) informant visited the patient since she happened to be a neighbour, whereas 83.3% eat together with the patients and a further 16.7% linked patients with others in the same condition. The following sentiments by informants capture this role:

"Every evening after I come from work, I ensure that I have visited the patient to see how he is doing, if he requires anything from the hospital or needs any assistance, before I go to my house," (neighbour to the patient).

"We are a family, we share the little food we have. When we eat together, we feel united in this situation and my father feels loved," (Daughter who is caring for her sick father).

"When am not busy, I accompany her to a support group every Friday afternoon, which consists of only positive members, where they share their experiences and try to find solutions to problems they face. Sometimes they are visited by medical officers and CHW and receive some support," (Mother is the care giver of her sick daughter).

4.3.6 Spiritual Support

All informants reported that they pray together with the patients. The following sentiments run across the different care-givers:

"I took him to our pastor, and he made a decision to get saved, now he shares the gospel with those who visit him," (Mother is the care giver of her sick son).

"We pray every day with the patient so that God can see our faith and heal this illness," (Grandmother to the patient).

"Were it not for God, this patient could not have been here. Church members come every Sunday, we pray and sing together. God has been our strength," (Father taking care of her sick daughter).

4.3.7 Material Support

Several informants noted that they provide material support to their patients. Six informants (20%) said that they provide finances to the patients. Other forms of material assistance included the provision of shelter (70%), buying of food (70%) and the provision of clothings (70%) The sentiments below were unanimously echoed by the care givers:

"I use my savings from farming from my "shamba" to pay rent and provide food for my daughter." (Father who is taking care of her married daughter whose husband left her).

"Because my daughter is weak and has three children to take care of, I have to wash people's clothes to get some income to buy food and pay rent," (Mother caring for her sick daughter).

"I provide him with money for transport when he does not have any to go to the hospital when he has an appointment with the doctor," (Neighbour to the patient).

"I am the parent, therefore, I have to buy food, clothes and provide shelter for my son. It is my duty," (Mother to the patient).

"When my daughter fell very sick, she came to live with me in this incomplete house. She could no longer afford house rent and also, there was no one to take care of her where she was," (Mother taking care of her bedridden daughter).

"I have taken my daughter's two children to school. It is hard but I am trying, thank God because of free primary education," (Grandmother taking care of her sick grandchildren).

4.3.8 Counseling

Most (86.7%) of informants listened and talked to the patients. The sentiments below echoes what the informants reportedly do to the patients:

"I counseled her on how to live positively. He was so down, and wanted to commit suicide when he found out that he was positive. He locked himself in the house and never wanted any visitor. I talked to him and told him that he can live a long productive life so long as he takes medication as advised by the doctor,"(Neighbour to the patient).

"I have told her to stop taking "chang'aa" since it will make her die faster as she is on medication." (Sister to the patient).

"I talked to him that having AIDS is not the end of the world, but is just a disease like malaria; he just needs to comply with medication." (Mother to the patient).

"I meet people who haven't accepted their status, I talk to them, and they accept themselves and start to live positively." (Husband to the patient).

4.4. Problems faced by Lay-care providers

4.4.1 Lack of training on HIV/AIDS management

Majority (80%) of the informants had not received any training on HIV/AIDS management and care. Only 10% had received training on HIV/AIDS, through home visits by community based workers, 3.3% through seminars on HIV/AIDS and the other 6.7% in the patients' referral hospitals. This is expressed by the following sentiments:

"It is difficult to know the symptoms of AIDS, until when it reaches its last stages, when the patient is severely ill," (Mother to the patient).

"I just use my natural instincts to attend to my daughter, I have never been taught on how to care of her," (Grandmother to the patient).

"I live in fear everyday when I attend to my son, I fear being infected with the disease. I have not been trained by anyone on how to take care of him," (Mother to the patient).

"The sores I am having are similar to the ones my daughter has, my skin is dry and scaly, maybe am infected. I want to go and get tested because I have never used gloves while cleaning her," (Mother to the patient).

"If I had some training in caring for HIV/AIDS patients, I know I would do my work better," (Husband to the patient).

"We assist families, but because some of us are also positive, we become sick, therefore, cannot be with the patient all the time, so we have to train the family members to take care of them," (CIW).

"When we test people and find they are positive, we link them with community health workers in their region. These CIWs train them and their families on how to take

care of the sick. Not all of them have been trained though. CHWs have not covered the entire Kaptembwa region, because of lack of adequate resources, for instance to finance CHWs." (Medical Officer).

4.4.2 Dealing with difficult Patients

A number (26.7%) of informants said that their patients were difficult to deal with. The following sentiments run across the different care givers:

"You can even smell alcohol; he turned into a drunkard the moment he knew his status and this is not working well with his medication." (Wife to the patient).

"Since this patient found out that he was sick, he decided to spread the virus by having so many affairs with other girls in town, it is now that you see him while bedridden but as soon as he gets well, he is back to the streets." (Mother to the patient).

"When the patient found out his status, he did not want to see anyone or take any medication, he says he is just waiting for his death at home." (Mother to the patient).

"I tell her every time she needs to help herself, she should avoid getting her clothes soiled, she does not listen to me." (Sister to the patient).

"This patient can only take medication when someone is watching over her. She complains that it gives her severe headache and hunger, so she hides or throws it away." (Mother to the patient).

4.4.3 Poor health services provision

Some (33.3%) of the informants said that there is poor health services provision in hospitals and clinics. The following sentiments run across the different care givers:

"It takes time to transfer files to Langalanga health clinic, so the patient prefers Rift Valley Provincial General Hospital where he was first tested,"(Grandmother to the patient).

"RVPGH is more equipped than other local clinics, so I prefer the patient going there even if it is far." (Wife to the patient).

"One time I took the patient to the clinic, we stayed there the whole day, we have never gone back since then, we buy medicines from the chemist, (Mother to the patient)".

"Doctors never visit the patient in the house; you will forever wait for them," (Neighbour to the patient).

4.4.4 Inadequate sources of income

Almost all (93.3%) informants have inadequate sources of income. The sentiments below express the feelings of the informants as regards their sources of finances:

"Am not working, if I had a reliable source of income, I could at least assist my son to buy medicine and food," (Grandfather to the patient).

"I would have loved to take my son to the private clinic since their service is fast and they give a lot of attention to their patients, but now I have to take him to the Kapkures clinic because it's cheaper," (Mother to the patient).

"This particular patient has two children, who left with their mother to Siaya District, because he could no longer provide food and school fees for them. Since there is no one to take care of him, I buy food, painkillers and pay for his transport to the clinic when he cannot work for himself," (Neighbour to the patient).

"We used to sell vegetables in town, but when she became very ill, I took over the business, but it does not bring in much money. I cannot afford house rent. Right now I have got Kshs.800 arrears, the landlord was here yesterday, I don't know where I will get the money; am so weak I cannot work,"(Husband of the patient who is also positive).

"I share this house with another woman who also faces the same problem as me. We sold what we had so as to afford medication for our children," (Mother to the patient).

"Majority of lay- care providers face financial problems. When the patients are on drugs they need adequate food. It is important that Home Based Care starts projects

for the patient or even their families to start income generating activities,” (CDN coordinator).

“Most families are poor and cannot afford basic needs. Patients have special needs and require close attention, when this needs are not attended to fully, there is a gap, especially when the patient is bedridden. Sometimes they lack money for transportation of the patient to the hospital; therefore, the patients stay at home,” (Medical Officer).

4.4.5 Inadequate food

Majority (93.3%) of the informants say that they have no adequate food for themselves and for their patients. The following sentiments run across the different care providers:

“There is no food, my body is weak and I cannot work. We are just surviving by the grace of God. Sometimes I get assistance from good Samaritans, when they pass by and donate us food,” (Mother of the patient).

“He really disturbs me, because he has nothing to eat yet he has to take medication. I tell him to drink warm water at least before he takes medicine if there is no food,” (Mother of the patient).

“My mother came to take my sister who was living with me because I could not afford food for all of us. Yesterday, we slept hungry,” (Sister of the patient).

“The children refused to go to school because of hunger and they are on medication. I gave them Kshs.20 to buy mandazi,” (Grandmother of the patients).

“It is important also that NGOs partner with each other, especially on provision of food to patients,” (CDN coordinator).

4.4.6 Inadequate support from the community

Most (66.6%) of the informants said that they were not being assisted and did all the work on their own. The following sentiments captures some of what were echoed by them:

“I am also positive; no one comes to see us. It’s really hard” (Wife of the patient).

"Her daughters are working in town, they rarely visit nor do they give me any assistance. They said that their mother also abandoned them at their young age and had gone to live with another man, and had struggled to be where they are now," (Mother to the patient).

"This work is a lot and no one assists me, sometimes I experience muscle pains," (Grandmother to the patient).

"I spend a lot of time with my ailing mother; I have no time for myself, since she got bedridden," (Son to the patient).

"My mother told me to leave school to take care of her; it's only my brother who goes to school." (Daughter of the patient).

"Before I go to sell vegetables in the morning, I make sure I have cleaned the house, and cooked for my husband and given him medications, till evening when I come back from work," (Wife of the patient).

"When my husband died, his family took everything from me, and they have never visited me or assisted me to take care of the children, I do it alone," (Mother who is the care giver of her children, she is also positive).

"Taking care of the infected is a lot of work, you have to monitor them day and night, especially when they are bedridden, I have a lot of work to do not just caring, life is hard, you just can't spend your life doing it," (Sister of the patient).

4.4.7 Stigmatization

All the informants (100%) had faced stigma in one way or another. Their sentiments clearly illuminate what they have gone through. The following are some of their confessions:

"I had so many visitors coming to visit me, however, when they learnt that I was taking care of an HIV/AIDS patient, they haven't stepped here," (Grandmother to the patient).

"I fear the CIW visiting me, you know she visits other positive patients in the neighbourhood, if she comes to my place, people will know she's positive." (Husband to the patient).

"My sister prefers going to RVPGH, because she fears news being spread of her status if she attends neighbourhood clinics," (Sister to the patient).

"Family and friends have already run away from me, they don't even come and visit, I feel neglected," (Daughter to the patient).

"My husband knows the kind of work I do, he supports me though sometimes tensions arises especially when I visit this patient because he lives alone and fears I might be raped. I remember there was a time he refused to be intimate with me until I got tested. Several of his family members have told him to prepare for his death since I was working hard to get the disease, some don't even come to visit,"(Neighbour to the patient).

4.4.8 Lack of adequate water and sanitary facilities

Most informants (70%) reported that they were buying water from vendors at 20 shillings per 20 litres jerrican while 13.3% borrowed water from neighbours and only 16.7% had piped water in their homes.

A large proportion of informants (67%) reported that the patient shared toilet and bathroom with others in the neighborhood. 33% reported that they shared both bathroom and toilet with only their family members. The following sentiments were some of the expressions by informants:

"Water is so expensive, I cannot maintain the hygiene of my sister as it is required, washing soiled clothes is so difficult," (Sister to the patient).

"My neighbour pitied me, so she asked me to be fetching a jerrican (20lts) of water from her house," (Daughter to the patient).

"I just wipe my daughter; there is no water to bathe her," (Mother to the patient).

"The municipal council should ensure that we have water running on our taps, to make everything easy," (Father to the patient).

4.4.9 Inadequate care package facilities

Most informants (63.4%) reported that they protect themselves from contracting HIV/AIDS when they attend to the patients. However, 37.6% reported that they did not have the means to adequately protect themselves from infection. The sentiments below captures the divergent situations the care providers find themselves:

"I have bought gloves, spirit, bandage, cotton wool to use as my means of protection," (Husband to the patient).

"I wash her with my bare hands, how can I buy gloves and spirit if I cannot afford food?" (Mother to the patient).

"I wear a plastic bag on my hand when am cleaning the wounds on his back. The wounds are raw and deep," (Mother to the patient).

"If I had gloves and disinfectants, I could clean his wounds properly. All I do is to pour hot salty water," (Grandmother to the patient).

"I separate her clothes from ours, I then soak them in jik especially when they are bloody," (Daughter to the patient).

4.4.1.0 Inadequate Counseling and delay in testing

43.3% of informants said that patients do not receive adequate counseling when they are diagnosed with AIDS. The sentiments below are a clear admission of the lack of counseling that patients have to endure as stated by the care providers:

"My husband refused to take the ARVs he brought from hospital because he thinks he will die faster," (Wife to the patient).

"VCT centers are not adequately counseling patients, they are in a hurry, they should follow up the positive clients and ensure they get the medical attention they need. Not just to test them," (Sister to the patient).

"When you go to hospital, they just give you painkillers, they don't tell me what is ailing my daughter," (Father to the patient).

4.4.1.1 Insecurity resulting from the care environment

80% of the informants said that they were insecure when they provide care for their patients. The insecurity is both in terms of the personal safety of the patients as a result of the insecure environment and the fear of attack by the male patients in the event of isolation. Some of the sentiments expressed by the care givers included the following:

"This neighbourhood is so insecure, you cannot walk past seven in the night, there are cases of mugging and rape. If my sister wants anything from the shop or even medicine from the clinic, I ought to have bought it earlier or to wait until the following day," (Sister to the patient).

"This patient is a man and he lives alone. I cannot risk attending to him alone, I have to come with someone, when no one is available, I don't come," (Neighbour to the patient).

4.4.1.2 Psychological Strain

73.3% of the informants faced psychological strain because of the care they provide to the patients and the fact that a member of the family is positive. Women report intimidation by their in-laws and other relatives and fear losing their property in the event of death. The following sentiments are a testimony to the fear:

"Sometimes I quarrel with my husband; he questions me why I volunteered to take care of the patient, that I will infect him with the disease. He sometimes refuses to be intimate with me until I go for test," (A neighbour taking care of a patient).

"When my husband becomes really sick, I fear death, his family is threatening to take all his property yet they don't even visit," (Wife to the patient).

"I don't know what I will do if these children die, am so used to them. I will be responsible for their death," (Mother to the patient).

"This is my only living brother. I have lost seven family members because of this disease. I don't know what we did to God. I am also positive. I just cannot stand his death," (Sister to the patient)

"I have not received even a cent for doing this work. No one recognizes the work I do. People see it as normal, but it's not " (Grandmother to the patient).

"Today she wants this, tomorrow she doesn't want, I try to figure out what she really wants but I cannot," (Sister to the patient).

CHAPTER FIVE: DISCUSSIONS, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

This chapter discusses and draws conclusions from the study findings and offers recommendations for the best practices in the HIV/AIDS lay care management. It is divided into six sections. In the first three sections each research question is discussed in relation to the findings, whilst in the last section, conclusion, recommendations and areas for further research are suggested.

The purpose of this study, which was carried out in Kaptembwa division in Nakuru District, was to explore the lay-care providers' lived experiences in the management of HIV/AIDS.

5.2 Discussions

5.2.1 Which types of people provide lay-care to HIV/AIDS patients?

According to www.avert.org, it is estimated that upto 90% of care in chronic illness is provided for in the homes by untrained family members and upto 80% of AIDS related deaths occur in the home. Health facilities may not be able to cope and furthermore, fear of stigma and discrimination from doctors and nurses towards people living with HIV/AIDS could deter people from seeking care in a medical setting. So too could the lack of knowledge that effective treatment is available.

In this study, more than half (53.4%) of informants had no formal education. Only 26.7% had primary level education, while 13.3% had secondary level of education, and the other 6.7% had college level of education. In Africa, almost 70% of women are illiterate. They live in a state of ignorance and lack of education. Illiteracy compounds women's problems and their efforts to combat HIV/AIDS (Reardon, 1994:25). It is difficult for an illiterate care-giver to grasp all dimensions of care giving: understanding the patient's disease, advising and promotion of responsible sexual behavior, ensuring the patient has a balanced diet and to protect themselves from contracting the disease. Similar findings were found in case study done in Geneva, Switzerland on Caring for carers, where Illiteracy was found to contribute to low level of care, low productivity and poverty (UNAIDS, 2000).

As the findings indicate, 80% of the lay-care providers were females while 20% were men. Similar findings are reported by Mushonga (1998), in his study of family care givers of HIV/AIDS in rural Zimbabwe, whereby, over population of HIV/AIDS patients in hospitals has resulted in patients' early discharge to their homes for family care. In most cases, women fulfill the role of caregivers for these sick family members because the Zimbabwean culture supports this categorization of care-giving responsibility. This is in addition to their roles as mothers, wives, and in some circumstances, as wage earners.

Gender disparities are among the deepest and most pervasive of inequalities (UNDP, 2005). In daily life, gender relations of power often underpin unequal access to and control over material and non-material resources and unfair divisions of work, leisure and other possibilities of improving one's life. Women have less land, wealth, and property in almost all societies, yet they have higher burdens of work in the "economy of care" ensuring survival, reproduction, and security of people, including young and old. This has implications for women's health, both their occupational health and the consequences of insufficient rest and leisure (UNAIDS, 2008).

Women are more likely than men to serve as the primary care takers of others who are infected and to remain silent about their own health problems when other family members are in need of caring- whether ill or not. In Africa, it is known that the combined physical and emotional burdens of caring for sick family members and also ensuring their food security under harsh economic conditions often takes a toll on women's own health and well being (WHO, 2003).

In this study, most of the care givers began taking care of the patient when they were ill or bedridden; this is what they regarded as an added responsibility. Before that, the roles they performed were regarded as normal. It was the severity of the illness that struck the attention of care givers. This was mainly because the patients had not disclosed their status to the caregivers. In a study conducted on Gender dimensions of HIV/AIDS status disclosure to sexual partners, the most common barriers to disclosure include fear of abandonment, fear of rejection and discrimination, fear of violence and fear of upsetting family members. The length of time since diagnosis and severity of illness were positively associated with disclosure (WHO, 2004).

Most of the care-givers in the study (80%) collaborated with professional carers in caring for the patient. In a research conducted by Caron (2005), on Decision Making at the end of life in dementia: how family care-givers perceive their interactions with health care providers in long term care settings, in Canada, Majority of them expressed a need to meet more often with the care team to provide an understanding of the evolution of the condition. Trust was a key element in the caregiver professional relationship and was facilitated via regular contact and information provision.

A common strategy in AIDS-affected households is to send one or more children away to extended family members to ensure that they are fed and cared for. Such extended family structures have been able to absorb some of the stress of increasing numbers of orphans, particularly in Africa. However, urbanization and migration for labour, often across borders, are destroying those structures. As the number of orphans grows and the number of potential caregivers shrinks, traditional coping mechanisms are stretched to breaking point. Studies in Uganda have shown that following the death of one or both parents, the chance of orphans going to school is halved and those who do go to school spend less time there than they did formerly (UNAIDS, 2000). Similar studies conducted by Nyambedha, (2000) entitled: "Support systems for orphaned children in Nyang'oma sub-location, Bondo District, Western Kenya", found out that one out of three children below 18 years of age had lost at least one biological parent and one out of nine had lost both. In this study, the high number of orphans had overwhelmed the traditional mechanisms for orphan care, which were based on patrilineal kinship ties. Thus, 28% of the orphans were looked after by culturally "inappropriate" categories such as matrilineal kin or strangers. Furthermore, many of the caretakers were themselves not capable due to ill health or old age.

In Africa, older family members have been shown to constitute important health decision makers and therapeutic managers of patients when sick. It has often been assumed that the traditional strength of the African extended family represents an impregnable safety net capable of mitigating any crisis (Ami & Doug: 2005). The rising death toll and the increasing numbers of AIDS orphans worldwide are having far-reaching health, economic and psycho-social impacts on society, particularly in Africa, and particularly on older Africans. HIV/AIDS has changed family structure and social expectations. Older people must wrestle with issues not faced by the young person. Older people have less basic knowledge about

HIV/AIDS and its prevention. They find themselves adjusting to the physical and emotional changes associated with ageing in the setting of a debilitating illness. The health of the older caregiver itself has taken a heavy blow. Older people are suffering under serious physical and emotional stress, and in some cases physical violence, stigma, and abuse resulting from witchcraft accusations. In addition, coping mechanisms among older people are weaker, and they are more prone to depression and less inclined to join support groups (U.N, 2002).

As the findings suggest, 90% of the care givers earn less than Ksh.5, 000 per month. This means that HIV-affected households are trapped in a financial pincer as health costs rise and incomes fall. Costs can amount to more than one- third of household income, crowding out spending in other areas as progress in reducing poverty has been partial. One in five people in the world – more than 1 billion people – still survive on less than \$1 a day, a level of poverty so abject that it threatens survival. Another 1.5 billion people live on \$1 –\$2 a day. More than 40% of the world’s population constitutes, in effect, a global underclass, faced daily with the reality or the threat of extreme poverty. In Namibia and Uganda, studies have found households resorting to distress sales of food and livestock to cover medical costs, hence increasing their vulnerability (UNDP, 2005).

5.2.2 What roles do lay-care providers play in HIV/AIDS management?

According to Pamela & Folkman (2006), in their study entitled: “Are informal caregivers important in AIDS care?”. Caregivers provide practical support such as shopping, housekeeping, and transportation to clinics, as well as more basic assistance such as help with bathing, going to the bathroom, and feeding. As symptoms worsen, caregivers are also likely to take on more clinical roles such as keeping track of medications, giving injections, inserting catheters, and cleaning wounds. Caregivers often provide front-line medical and mental assessment, being the first to note changes in health and to decide when to go for help. In a study done by Ward & Brown (1994), on Labor and Cost in AIDS family care giving, the value of personal care tasks and housework performed by caregivers equaled a per capita value of over \$25,000 a year for caregiving.

According to Kathurima (2009), in the study titled: “Can Lay-care counselors fill the health worker gap?” these roles include provision of psycho-therapy counseling for groups, counseling for trauma and depression, and general provision of home based care. She says

that lay-care providers have served well because they understand the community and relate well to them. According to her, professional health workers are in short supply in Kenya; in the public sector, there are an estimated 3 doctors and 49 nurses per 100,000 people yet the UN and WHO recommends at least 143 nurses per 100,000 people. More problematic is that over half of all health personnel and 80% of doctors are based in the urban areas. This leaves the rural areas very poorly served.

Lay-care providers' play various roles in the management of AIDS- related conditions. They provide nutritional care. The purpose is to ensure proper and balanced diet. It requires that food be well cooked and served in an appetizing way. They also provide nursing care which includes personal and general hygiene. This prevents infections and the spread of diseases. They provide physical therapy, where it involves assisting the patient with physical movement to help blood circulation, improve digestion, ease stiffness of joints and prevent any secondary infection; also helps relieve stress by helping patients to relax. They also advice and promote responsible sexual behavior, which include information and education on sexually transmitted infections and or HIV/AIDS, Information and education on safer sex, provide condoms in order to promote responsible or safer sexual behavior and prevent the spread of HIV/AIDS and other sexually transmitted infections where penetrative sex is practiced, they also provide counseling on pregnancy and HIV/AIDS. In addition, they provide social support, where patients are provided with assurance that they are accepted by other family members. This improves their mental status and brings a sense of belonging. They also provide spiritual support to patients where they are encouraged to trust in God as a source of rest for the mind. Forgiveness and reconciliation replace anger and guilt. Finally, they provide material support which includes shelter, food and clothing; this is due to reduced movement resulting from the physical weakness of the patients (NAS COP, 2006:56).

5.2.3 What problems do Lay-care providers face in HIV/AIDS management?

In a study done by Kangethe (2009), on Kanye community home-based care program in Botswana, the following aspects were found detrimental and affecting the productivity and coping capacities of the primary caregivers: inadequate counseling and debriefings, lack of motivation and incentive, inadequate supervision visits, and lack of support groups to facilitate information sharing and encouraging one another.

Similar problems have been identified by Hansell (2000). in his study titled: “Patterns of problems and solutions experienced by caregivers of children with HIV/AIDS”, the patterns of problems identified for these caregivers clustered as follows: lack of rest, family and child health problems, financial problems, lack of recreation, transportation problems, lack of adequate clothing and food, problems with health care services, unemployment, inconsistency in attending school, poor performance and school drop-out, poor housing, lack of medication and counseling needs. For these caregivers, HIV/AIDS is one of many problems that challenge these families every day of their lives.

The study conducted by UNAIDS, on caring for carers, has highlighted the most common causes of stress. The most commonly-reported causes of stress among carers working with AIDS programmes include: financial hardship, oppressive workloads, secrecy and fear of disclosure among people living with HIV, deep emotional involvement with people living with HIV and their families, personal identification with the suffering of people with HIV, awareness of unmet needs of clients’ children, lack of an effective choice in decisions that affect them and their work, inadequate support, supervision and recognition of their work, inadequate training, skills and preparation for the work, lack of clarity about what the caregiver is expected to do, lack of referral mechanisms, and lack of medication and health care materials (UNAIDS, 2000).

Individuals often confront economic impediments to using antiretroviral drugs in the form of user fees, co-payments or other out-of pocket costs borne by affected households. Most countries have policies providing for free antiretroviral drug. However, many patients that receive free drugs must sometimes cover the considerable costs of diagnostic tests or treatments for opportunistic infections. Limited access to transportation and cost of transport can significantly limit treatment access for HIV positive people. Even when a local clinic is able to provide antiretroviral drugs, HIV-positive rural dwellers must sometimes travel hours to obtain CD4 or viral load tests. In 2008, Indian Railways announced a 50% discount on train fares for HIV-positive individuals travelling to receive HIV treatment (UNAIDS, 2008).

Acute shortages of health-care professionals impede treatment scale-up in many of the countries heavily affected by the epidemic (UNDP, 2007). Numerous factors contribute to the human resource crisis in health-care systems, including the weakness of national medical

education and training programmes, limited implementation of national human resource management policies, and the well-documented “brain drain” of health professionals who migrate from low-paying jobs in their home countries to more remunerative work in high-income or neighbouring countries (UNAIDS, 2008).

According to Femi (1996), in as much as physicians may want to assist in caring, the social environment of abject poverty, scarcity or total absence of basic needs, deprivation and glaring inequality of resources distribution and justice, in which the doctors and the majority of their patients live, caring becomes ineffective and inefficient. Most physicians in Africa usually work in a culture of ‘NA’ which means “not available”- no water, no drug, no electricity, oxygen and they also acquire the culture of not being available both in body and soul and end up not caring.

The poor often live in areas that are sparsely covered by basic health services or covered by facilities that lack drugs and trained staff. Chronic under-financing is part of the problem. Providing basic health coverage in a low-income country costs an estimated \$30-40 per capita. Across much of Africa, spending is less than \$6 per capita. Under these conditions, even where facilities exist, they lack essential medicines. Payments for health care can represent a large share of the income of poor people, leading to reduced demand, uncompleted treatments or increased debt. Removing fees can improve equity. When Uganda did that in 2001, visits to public health facilities rose by 80%, with half of the increase among the poorest 20% of the population (UNDP, 2005).

All the care given in the study report that their patients were referred to public health facilities whether clinics or hospitals. This is in sharp contrast to the study done in India in Rajasthan district, whereby, even where public health is available, they are often not used by poor people. Instead they prefer to use private health providers even when nominally free public services were available. Reason was over half of health centers were closed during periods when they were supposed to be open. When facilities are open, they often lack a trained staff member on site. It has been suggested that developing more accountable health systems can dramatically improve access and health indicators (UNDP, 2005).

Nutritional status is one of the best predictors of HIV-related mortality. As HIV disease progresses, nutritional status often declines. HIV infection increases protein, micronutrient,

and energy requirements in both adults and children. At the same time, HIV-related symptoms such as lack of appetite, mouth sores or nutrient mal-absorption may decrease nutritional intake. Lack of access to adequate food is a particular challenge for people who initiate antiretroviral therapy, and has been shown to inhibit uptake of treatment. HIV exacerbates already severe nutritional deficiencies that are common in many countries that have been heavily affected by the epidemic. Micronutrient deficiencies are one of the most common forms of poor nutrition in low-income countries, and may further compromise the immune systems of people living with HIV, diminishing the body's ability to fight infection (UNAIDS, 2008).

Vulnerability to infectious disease is exacerbated by inadequate access to clean water and sanitation. More than 1 billion people lack access to safe water and 2.6 billion lack access to improved sanitation. Diseases transmitted through water or human waste are the second leading cause of death among children worldwide, after respiratory tract infection. The overall death toll is estimated 3,900 children every day (UNDP, 2005).

5.3 Conclusion

HIV/AIDS is a terminal and incurable disease. It is not a single problem for it comes with many other problems, which need urgent attention and when it strikes an individual, that individual needs a strong social and emotional support to survive. Lay-care providers play a crucial role in home care and commonly undertake complex care tasks. These care providers not only assist in care alongside professional care givers but also provide the bulk of support within the home. The support from families, relatives and friends can reduce stress and may prolong life and enable patients to die with dignity among their own people. Without the input of lay-care providers, the well-being of the majority of individuals with a life-threatening illness would be compromised. However, in some circumstances, the health care system does not acknowledge the centrality of the lay-caregiver's role. Among this group, however, the provision of care falls disproportionately to women and older people. This burden of care assumed by women and the elderly has been recognized at the highest levels. The United Nation's 2006 Political Declaration on HIV/AIDS advocates "providing support and rehabilitation to these children and their families, women and the elderly, particularly in their role as caregivers" (www.avert.org). Both the patient and the lay-care givers should be

recognized as the “unit of care”. Therefore, involving the care providers as well as the patient in delivery of care is recommended. Furthermore, the government on its own cannot deal with these challenges, thus, the community as a whole must respond to the epidemic in its own capacity and capability without waiting for external interventions. It is important therefore, to strengthen Home based care system for an effective continuum of care for the well-being and good health for the people living with HIV/AIDS.

5.4 Recommendations

One of the limitations cited by the informants is the lack of knowledge by the society on HIV/AIDS and its several ways of transmission. In as much as people are aware of HIV/AIDS, the society has not fully grasped the several ways of its transmission. In order to reduce stigmatization, it is important to sensitize communities on HIV/AIDS. This will also assist in decreasing the burden that lay-care providers’ face in providing care as it will increase their participation in the care provision.

Timely diagnosis of HIV infection is critical to effective medical management of HIV infection. Many people living with HIV are diagnosed with the virus only after extensive immune deterioration has occurred (UNAIDS, 2008). Expanding the number of people who conduct VCT services and creating community awareness for an increased demand for testing is essential to expand access to AIDS care and treatment.

The Ministry of health needs to develop the capacity and skills for home based care management and delivery. According to the medical officer, more community health workers should be trained and equipped to reach a larger population of people suffering from HIV/AIDS. The NGOs and other care programs should also be visible in complementing government effort by deploying social workers and other necessary staff to assist in issues of care giving. There should also be specific training made to the care-giver by the ministry of health. Part of the training and supervision should include home-visits by the health workers and also provision of Home Based Care kits to those caring for patients with limited resources.

The government, NGOs, and other care-friendly organizations should put in place a strategy ensuring and forcing caregivers' supervision, counseling, and monitoring of the care

programs. This would improve the coping challenges experienced by the caregivers. Every aspect of care from admission to discharge must be coordinated to ensure that each patient receives the best care available. Professional staff must consider the patient's condition, the care-giving environment, and the amount of social support available for the patient and family. The knowledge, skills, and abilities of the caregivers must then be matched to the needs of the patient. Because on-site supervision in the home setting is limited, professional carers are required to know how to safely delegate patient care tasks and supervise others.

According to Dr. Andrew Suleh (www.aegis.com), Kenya's guidelines allow lay counselors to offer testing and counseling in community settings, refer patients to local health centers for more specialized treatment. However, there is no clear policy governing the training and the minimum standards expected of lay health workers. Most NGO's apply their own standards. These caregivers suffer neglect in that while the government has splendid policies to cover people living with HIV/AIDS, the caregivers' policies have not been well developed let alone operationalized. Immense support system to the caregivers is, therefore, necessary if the level, efficiency, and effectiveness of the care giving in Kenya are to change the face.

The study has revealed that patients default in taking medication, either due to lack of enough food or due to the side effects of ARVs. Timely nutritional support for people living with HIV may help extend the asymptomatic period of relative health for people living with HIV, or, where severe immune deterioration has already occurred, it may reduce the risk of death. Proven strategies for improving the nutritional status of individuals living with HIV include food rations in food-insecure areas, micronutrient supplementation, and therapeutic foods to address the effects of moderate or severe malnutrition. Defaulting in medication has detrimental effects on the patients since it leads to drug resistance. It is important therefore, that patients should be properly counseled at the clinics and VCT centers. This should be reinforced through follow-up counseling.

Poverty of the caregivers has been the biggest challenge besetting the process. Serious poverty mitigation factors need to be put in place to salvage the dwindling work environment of the caregivers and to make coping manageable. Strategies and mechanism of funding the caregivers to start small and viable income-generating projects could possibly address the poverty and meet the food needs of the caregivers and patients as well.

The government, NGOs, and care authorities should create a provision or an environment resulting in caregivers' recognition and appreciation of their tasks. Putting in place a mechanism of rewards, recognition, and incentives would be an important factor that can raise the caregivers' morale.

5.5 Areas for further research

This study is not exhaustive since it has only covered a small section of a division in the whole country. To provide more comprehensive information on Lay-care providers' lived experiences in HIV/AIDS management, similar studies should be undertaken in various parts of the country.

The crucial role that older people play in the care of AIDS orphans is seldom given recognition or support and their health, economic and psycho-social needs are often neglected. Yet they continue to try to cope with the double burden of caring for their dying children and their orphaned grandchildren, often without even the most basic resources to do so. Research should therefore be carried out on the burden of HIV/AIDS on older care givers.

Several Non-Governmental Organizations have and are still growing in the area of HIV/AIDS care and a lot of funds have been allocated to them, yet care-givers for the HIV/AIDS patients are in desperate situations as the findings suggest. It is important therefore, that a research should be carried out on their efficiency and capacity in managing the disease.

As the study has revealed, majority of those taking care of HIV/AIDS patients are women. Therefore, an in-depth study on the feminization of HIV/AIDS should be carried out to clearly map out the burden transfer and the female role in the lay-care provision.

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APPENDIX ONE: IN-DEPTH INTERVIEW GUIDE

UNIVERSITY OF NAIROBI

LAY-CARE PROVIDERS LIVED EXPERIENCE IN HIV/AIDS MANAGEMENT

Confidential

Hallo, my name is Elizabeth Jerop. I am a student in the University of Nairobi pursuing a Master of Arts Degree in Gender and Development Studies. I am doing a research on the experiences of lay- care providers in HIV/AIDS management. Specifically, the research seeks to describe the types of people who provide lay- care to HIV/AIDS patients, to examine the roles that they play and the problems they face in HIV/AIDS management. The study may not be of direct benefit to you but it will be very useful in the contribution towards designing appropriate programs and policies in care provision of HIV/AIDS patients. No payment of any kind will be made. I the researcher will cater for all the costs incurred in the process of research. Your participation in this interview is free and voluntary, in the basis of informed consent. The information provided will be treated with utmost confidentiality. I will highly appreciate your honest answer.

Thank you.

Do you accept to participate in the study

Informant No.....

Interviewer.....

Date.....

Place of interview.....

Time started.....

Time ended.....

Name of the respondent.....

1. Sex of the respondent.....
2. How old are you?.....Years/ When were you born?.....
3. What is your marital status?.....
4. What is your major occupation?.....
5. How much income in a month do you get from the above (Kshs)?.....
6. What level of formal schooling did you attain?.....
7. What is your religious affiliation? (Sect).....
8. Do you have a family?.....
9. Who is the head of your household?.....
10. What is your understanding of HIV/AIDS?.....
11. Do you provide care to HIV/AIDS patient?.....
12. If yes, for how long have you been providing this care to this person?
13. Before this patient, have you ever cared for another patient with similar disease?.....
14. Do you have any training on how to care for HIV/AIDS patient?
15. If yes, what kind of training?.....
16. What is the nature of your relationship to this patient?.....
17. Please explain the kind of care you give to this patient?.....
18. Can you provide care to another patient with this disease?.....
19. Apart from you, is there somebody else who assists you in providing care for the patient?
Please explain.....
20. How do you protect yourself from contacting the disease while providing care?.....
21. Where do you get water to as you attend to the patient?.....
22. Which is the nearest clinic/ hospital from the patient's residence?.....
23. Does the patient share the toilet and bathroom with others?.....
24. Do you provide financial support to the patient?.....
25. If yes how?.....
26. What is the security situation of this area?.....
27. Has your role as the carer affected your personal life in any way?.....
28. Are you satisfied with your performance as a care provider?.....
29. Are you satisfied with the patient as the recipient of care?.....
30. What do you think can be done to make you perform your roles much better?

APPENDIX TWO: OBSERVATION CHECKLIST

Action	Yes/ No	Comments
Does the care provider practice precautionary measures to avoid infection?		
Is the care provider always available when the patient needs care?		
Does the care provider administer medicine to the patient?		
Does the care provider manage the diet of the patient?		
Does the care provider assist the patient with physical movement?		
Does the care provider assist the patient to observe proper hygiene?		
Does the care provider provide counseling to the patient?		
Are there physical signs of exhaustion on the care provider?		
Is water supply adequate?		
Is there proper ventilation?		

Is there proper disposal of waste?		
Is there a health clinic/ hospital near the house of the patient?		
Is the physical environment safe for the care provider?		
Is the care provider assisted in providing care for the patient?		
Does the care provider perform other tasks other than providing care?		
Does the care provider have adequate equipments to avoid infection?		
Others (Specify)		

APPENDIX THREE: KEY INFORMANT INTERVIEW GUIDE

Research questions for Key informants: Community Health Worker, Home Based Care Coordinator and Medical officer.

1. How is Home- Based Care system organized?
2. What is your experience with lay- care providers in HIV/AIDS management?
3. In terms of home- based care provision, who provides most care?
4. In your list, how many lay- care providers are men....? Women...?
5. What is the relationship of the lay- care to the patient?
6. What kind of care does the lay- care provider provide to HIV/AIDS patient?
7. Do you provide any training to lay- care providers?
8. What are the strengths of Home- based care as provided by lay persons?
9. What are the weaknesses of Home- based care as provided by lay persons?
10. Can lay- care be scaled up in HIV/AIDS management? What are the prospects, difficulties, areas for improvement, shortcomings?
11. Any other issue of interest in the lay- care management of HIV/AIDS?