

**AN ETHNOGRAPHIC STUDY OF HOME-BASED CARE FOR
PEOPLE LIVING WITH HIV/AIDS IN NYANG'OMA DIVISION,
HONDO DISTRICT, WESTERN KENYA**

BY

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DECLARATION

This thesis is my original work and has not been presented for a degree award
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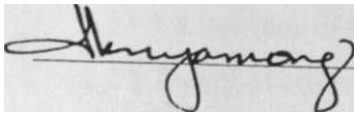
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ABSTRACT

This study investigated the dynamics of home-based care for people living with HIV/AIDS in Nyang'oma Division in Bondo District of western Kenya. Specifically, the study sought to investigate the healthcare support available for people living with HIV/AIDS in the study area and examined the influence of socio-economic and cultural factors on the care of HIV-infected persons at home. The study subjects were mainly people living with HIV/AIDS and their caretakers as well as community health workers. Health care institutions and NGOs involved in the care of HIV infected persons and the elderly persons considered to have good knowledge of the community in terms of cultural practices and experiences of care giving in the traditional past were also included in this study.

The study design was longitudinal and adopted qualitative and quantitative methods of data collection. Specifically qualitative data were gathered through focus group discussions, narratives, key informant interviews and in-depth interviews. Quantitative data were collected using semi-structured interviews. Qualitative data were analyzed using non-computerized methods while quantitative data was analyzed using the SPSS software.

The findings show that there is inadequate health care support for people living with HIV/AIDS in the area. Bondo District hospital as the main referral facility is inaccessible due to long distance and high transport costs. Other equipment like the CD4 machine was not available in Bondo District during the better part of research period until CDC finally installed the facility in November 2006, when the study was almost winding up. However, many HIV/AIDS patients still go for treatment in far places and do not link with any NGO for support for fear of stigma

The partnership approach of incorporating the community into the care programme has led to a situation where patients are cared for by a constellation of people here referred to as the *care management groups (CMG)*. The groups include CHWs, the patients themselves and the family members as well as friends. However, the groups keep on

changing as care demand increases and in the long run leaving only close blood relatives to care for the HIV infected persons. Women living with HIV/AIDS are mainly cared for by their own children. The study also shows that shortage of food leads to poor drug adherence as the HIV/AIDS patients complain that they cannot take drugs on an empty stomach. Poor drug adherence is also partly as a result of the fact that a majority of the patients keep their HIV status secret and no one can remind or encourage them to take drugs when time is due.

The supporting NGOs generally face shortage of medicines, finances and other logistics, which make many HIV/AIDS patients transfer to other new in-coming NGOs considered to have adequate resources. The study also indicates that integration of CHWs into the home-based care programme is unreliable as those aged 40 years and below pull out while others move to new NGOs that can afford to provide some incentives. The transfers generate tensions among the NGOs.

Cultural beliefs in witchcraft, *chira*, and spirit possession not only delay going for VCT but also influence those who have tested HIV positive to ignore ARVs and use traditional concoctions instead. Cultural practice of wife inheritance engenders poor housing conditions for widows living with HIV/AIDS, who do not have men to inherit them. In addition, the rule of contact and spatial avoidance among in-laws, parents and their adult children also inhibit proper nursing care among these close relative, which then pushes care into the hands of young children and unreliable distant people.

LIST OF ABBREVIATIONS

AIDS	-	Acquired Immuno Deficiency Syndrome
ART	-	Anti-retroviral Therapy
ARVs	-	Antiretroviral
CBOs	-	Community-Based Organizations
CD4	-	Cluster designation 4 (disease fighting cells)
CHWs	-	Community Health workers
CMG	-	Care Management Group
DBL	-	Danish Bilharziasis Laboratory
FBOs	-	Faith-Based Organizations FGDs
FGDs	-	Focus Group Discussions
HIV	-	Human Immunodeficiency Virus
MOH	-	Ministry of Health
NACC	-	National AIDS Control Council
NASCOP	-	National AIDS/STDs Control Programme
NGOs	-	Non-governmental Organizations
PLWHA	-	People living with HIV/AIDS
STD	-	Sexually Transmitted Diseases
TOTs	-	Trainers of trainers
UNDP	-	United Nations Development Programme
VCT	-	Voluntary Counselling and Testing
WHO	-	World Health Organization

CHAPTER ONE

INTRODUCTION

1.1 Background to the study

Home-based care is defined as the care of persons infected and affected by HIV/AIDS that is extended from the hospital or health facility to the patient's home through family participation and community involvement within available resources and in collaboration with health care workers (NAS COP 2002). It is an area that is currently generating attention, especially in developing countries. This is because of high prevalence rates of HIV/AIDS and the infected persons are otherwise released to go home to be under the care of family members (Hauserman and Basrister at law1998). According to UNAIDS (2002), there are approximately 42 million people living with HIV/AIDS, of whom over 90% live in developing countries. Kenya is not exceptional. Recent reports estimate that 2.5 million people are living with HIV/AIDS (NAS COP 2005).

It was realized in mid-1990s that as the number of patients continues to grow, facilities in the hospitals, even if expanded, would soon be insufficient and some patients would have to be turned away (Cabrera *el al.* 1996). Home-based care was thus introduced to extend the continuum of care at home to those living with HIV/AIDS. With the increasing access to ARVs there is an increasing array of hope for the infected and affected families.

Based on a network of referral system, the programme draws on an array of actors ranging from well-trained health care professionals to community health workers (CHWs) in conjunction with family members to provide clinical care, nursing, counselling and psychological comfort as well as social and material support for PLWHA. The MOH and NGOs as well as FBO adopted use of CHWs on a voluntary basis to offer palliative care to people living with HIV/AIDS (NAS COP 2002).

The original intention of this study was to explore the use of social networks and implications of gender on home based care. But the scope soon broadened as many of the informants placed the debate about the programme in the context of accessibility to the

health services, stigma, nutrition and relatedness as well as beliefs in bewitchment and *chira*, a culture bound syndrome that results from violation of traditional rules. It thus became inevitable to direct my attention to the availability of health care support as well as the influence of relatedness and cultural factors on the programme.

This study was carried out among the Luo of Nyang'oma division in Bondo District. The Luo community, like many other African ethnic groups, is characterized by patrilineal kinship structures. Traditionally, the community valued extended family systems, which consisted of both patrilineal and maternal kin as well as affines. The relationships extended even beyond clans and were traced in the context of their ancestry (Whisson 1964). Whisson further says the extended family system acted as a safety net during crisis like war, sickness or death.

The community was traditionally characterized by an egalitarian social system, which rested on the mutual social responsibility under which any support including food was readily available for needy persons. However, these support systems have tremendously declined due to drastic social change and economic hardships as Nyambedha (2000) notes in his study of orphans and vulnerable children in the same community. And this problem is probably more serious in the face of HIV/AIDS, where the infected persons are stigmatized. Many people fear sharing utensils and food among other things with HIV/AIDS patients (Pathfinder International 2000).

As Cabrera *et al.* (1996) concluded that mainly close family members care for people with HIV/AIDS, there is concern that HIV/AIDS patients without close relatives, like widows and orphans do not get proper care even at this time when ARVs are becoming more accessible. And since few people are willing to help, the demand for nursing care and other necessities probably is beyond the management of CHWs who have been incorporated into home-based care just as volunteers. Children probably bear the brunt of caring for their ailing parents, which condition them to drop out of school (UNICEF 2002) and so become vulnerable to abuse by other people who may take advantage of their social and economic situations (Nyambedha 2000).

1.2 Problem statement

There are many PLWHA who need health care and social support. But they face serious problem of accessibility in their various local settings due to uneven distribution of such services (NCAPD and ORC Macro 2005). Stigma that is attached to HIV/AIDS (Cabrera *et al.* 1996) perhaps hinder patients from seeking related medical care in the local health facilities, while others opt to seek similar services from far hospitals, which is not sustainable due to limited financial capacity.

Some PLWHA also may refuse to link with CHWs in their respective villages for fear of lack of confidentiality and hence fail to benefit from the expanded network of home-based care programme. The voluntary basis of community health workers is also brought into question given that HIV/AIDS is resource demanding in terms of time and material as well as social inputs (Cabrera *et al.* 1996). In a resource-constrained setting where people live on hand-to-mouth activities there is doubt whether the CHWs could be committed to the task at hand.

There is another concern that many PLWHA will die of malnutrition even if drugs are issued for free (Ogotu 2002). This is with respect to the fact that the ability of the affected families to earn income is reduced as the caregivers take much time to care for the infected person when they are too ill (NASCOP 2002). The problem also becomes more serious because very little support is anticipated to come from other extended family members (Cabrera *et al.* 1996).

Cultural beliefs and practices may also have implications on the care provision at home. For example, Mboya (1965) talks of contact avoidance among the Luo community whereby in-laws avoid each other as parents and adult children are also prohibited from going into each other's living quarters. This certainly means that the care of a patient straight away goes to children with no skills and experience and hence poor management of the HIV infected persons. It also denies the children chance of going to school as was predicted during the second national HIV/AIDS/STD conference organized in Nairobi in 1998 (NASCOP 1998)

This study therefore sought to answer the following questions:

1. What health care support is available to HIV/AIDS patients from health facilities and organizations in the study area?
2. How does relatedness influence home-based care for HIV/AIDS patients in the study area?
3. What cultural beliefs and practices influence care for patients at home?

1.3 Objectives

1.3.1 General Objective

To explore the dynamics of home-based care for AIDS patients in Nyang'oma division, with special interest in healthcare support available for people living with HIV/AIDS, as well as the influence of relatedness and cultural factors on care at home.

1.3.1 Specific objectives

1. To investigate healthcare support available to HIV/AIDS patients from organizations and health facilities in the study area.
2. To examine the influence of relatedness on home based care for HIV/AIDS patients.
3. To investigate and describe cultural beliefs and practices that influence care for HIV/AIDS patients at home.

1.4 Justification of the study

Even though the government has intensified commitment to fight HIV/AIDS, specifically by declaring free access to anti-retroviral therapy in all public health facilities besides awareness campaigns (NACC 2006), there is need to further define problems of accessibility that PLWHAs face, especially in rural settings.

As home-based care programme relies heavily on volunteer CHWs and family caretakers (NAS COP 2002), it is necessary to examine factors that may compromise their commitment in order to ensure that PLWHA get proper care as envisioned. It will be useless and expensive for the government and NGOs to invest heavily in training CHWs who would otherwise drop out and not extend services in their various communities.

Therefore, apart from knowledge contribution, the findings of this study should help the government, NGOs and donors to formulate strategies that will alleviate the problems of HIV/AIDS patients and fair to the caretakers as well as culture friendly.

1.5 Limitations of the study

Due to nature of the topic and the main data collection method adopted in this study as well as the type of study subjects, specifically HIV/AIDS patients, only a small number of participants were included in the study, which of course limits generalization of the results.

Because HIV/AIDS is still a stigmatized health issue, many infected persons were not free to discuss about it. Other PLWHA did not allow any interviews with their caretakers because they had not disclosed their HIV status to them. Only 44 PLWHA permitted interviews their caretakers. That means information regarding some caretakers were just obtained from the PLWHA and not the caretakers themselves.

Gathering of detailed information was also hindered by the fact that some patients were too sick to talk, while others died after the first visit. It was also not possible to do follow-up studies on a fortnight basis as was earlier planned. This was because the informants did not allow any field assistant from the community to help in the research process. As the principal investigator I had to walk to all participants myself. It therefore became impossible to capture all slight changes or problems that occurred in between before I had another visit, which sometimes could go beyond one month. This in itself had a strong bearing on the accuracy of the information gathered.

CHAPTER TWO

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1 Literature review

2.1.1 HIV/AIDS situation in the Luo community

The Luo community, like other ethnic groups in Kenya, is affected by the HIV/AIDS pandemic. The community falls under high prevalence zones as grouped by NASCOP (1998). For example, in Nyanza Province people whose ages fall between 15 and 49 years have HIV prevalence rates of 30-39%. Even the Kenya Demographic and Health Surveys (KDHS) conducted in 2003 indicate declining trends, Nyanza Province still leads with prevalence rates of 15%, whereas Kenya's average is 6.7% (Central Bureau of Statistics (CBS) of Kenya. Ministry of Health (MOI I) Kenya and ORC Macro. 2004).

In terms of ethnic groups, the Luo have the highest prevalence rate of 17.5% for men and 25.8% for women who are HIV- positive as reported in the KDHS of 2003. In Usigu, a division neighbouring the study area, Prince (2004) summed up common expressions among people, both old and young in Uhero village that *"the land is dying" (piny tho)*. *"The land"*, refers to people and the community as well as the land itself in terms of economic production. In the study division, Nyambedha and Aagaard-Hansen (2003) also described the effect of HIV/AIDS as shown in fresh graves and deserted houses in homes inhabited only by old grandmothers and young grandchildren as well as the weekly funerals that the people of Sakwa attend in the villages and elsewhere.

Prince also added that the roads are busy during the weekends transporting bodies of those who have died in towns to be buried at home, which has become like a Luo tradition (Cohen and Atieno-Odhiambo 1989). Today, several business premises dealing specifically in selling ready-made coffins exist in the small town of Bondo as a reminiscent of the high death rate, which most probably resulted from HIV/AIDS in the recent past. It could have been the high demand that triggered the specialized business of coffins in the small town.

In the Luo community, high prevalence rates of HIV/AIDS have been associated with cultural practices. The practice of widow inheritance, locally known as *tero*, has been singled out as the main contributor to the transmission of the virus causing AIDS. Prince (2004) noted in her introduction on *tero*, a practice in which a male relative of the deceased husband undertakes to look after his widow, as a subject of heated debate and conflict in the face of HIV/AIDS and Christianity:

The crisis is not *terruok* (fornication) or *chode* (adultery) but *golo chola* (ritual cleansing) and *rit* (family guardianship). Here there is no wealth, no education, no foreign or non-Luo origin, and no westernization. Marriage has been sealed by bride wealth and ritually consummated on the nuptial night; and now, a husband is lost, wife and children are left behind, ritual cleansing is the answer. Any unorthodox alternative *ok kony* (will not do) (Prince 2004:180).

Upon the death of a man both the home and widow are considered unclean (Nyambedha 2000). The practice of *tero* is part of a ritual process of freeing the widow and the home from the bonds of death, a process of regeneration centred on the home and the house, referred to as "completing the taboos of death" (*tieko kwer mar tho*). Like other practices of rules concerned with ordering the flows of life, bodily intercourse between man and woman is central to the transformative process (Prince 2004). The government of Kenya has now outlawed the practice, but only to the extent that a widow should not be forced by her in-laws to get a man to remarry her.

Another contributing factor to the spread of the HIV virus is life on the beaches along Lake Victoria, which is basically surrounded by the Luo community on the Kenyan side. Hard economic conditions have pushed many people, especially widows to the beaches to do fish mongering. Because of high demand for the commodity, the women must know somebody to connect them with the fishermen in order to get fish. The practice demands a kickback, which is now popularly known as "sex for fish" (Nyambedha 2006). The problem not only faces women, but also young men who want to do fishing. Widows who then keep them as sexual partners hook them up. Commercial sex workers also hang around because of floating money from the sale of fish. But as Guest (2001) also noted, poor people often have little choice but to undertake dangerous jobs like prostitution in order to survive. This background therefore indicates the gravity of the HIV/AIDS

problem in the study area even if the latest report says that the rate of infection has gone down in Kenya. According to NACC (2005) HIV prevalence has declined from the high of 14% four years ago to 5.9% in 2005. And this is attributed to the increased uptake of condoms in the recent past as well as expanded HIV information campaigns and VCT programmes.

2.1.2 Home-based care and availability of Antiretroviral Therapy

Home-based care for HIV/AIDS patients intends to reduce overcrowding in hospitals and high expenditures on medical services and other hospital facilities. According to Tuju (1996), taking care of patients at home, at least when they are not in acute danger, helps the community to put the limited health resources to a more efficient use for the benefit of all. That is, as the occupation of beds by AIDS patients is reduced, people suffering from other ailments find spaces. Meanwhile, patients discharged from hospitals get sufficient care from family and other community members. Some studies further show that many people living with HIV/AIDS prefer to die in their homes rather than in a hospital upon knowing that there is no cure for their (Cabrera *et al.* 1996; Hauserman and Basrister at law (1998).

Whereas, a person is enrolled into home-based care only after doing the HIV test, very few people are willing to go for voluntary counselling and testing. The battle is further rendered difficult because families and even hospitals discuss the sickness merely in terms of the opportunistic diseases rather than as manifestations of AIDS (Cabrera *et al.* 1996).

Prince (2004) also noted in her study that many Luo know both facts of HIV transmission and related deaths but it is impolite talking about AIDS in particular. Some people also attribute the sickness to "*chira*", the illness that arises from confusion in social relations when people forget to follow or explicitly reject the relational practices or rules (*chike*) that structure kinship and social life. And as (Whisson 1964) notes, belief in witchcraft and magical powers is a well-developed feature of Luo life; some people associate their illness with such powers. More so, witchcraft accusations are common at times of social

change, uncertainty, social conflict and ill health (Helman 2001). So, instead of going to hospital, the patient goes to consult traditional healers. Others who also believe in illness being caused by supernatural powers like gods, spirits and ancestral shades also go for faith healing by confessing or acknowledging the sin committed.

All these social practices and the associated stigma adversely affect the quest for HIV/AIDS related therapy, where in most cases a sick person goes for health care support when he or she is totally wasted and weak. HIV attacks the body's defense mechanism and progressively weakens and damages the immune system, which makes the infected person susceptible to opportunistic infections. Many of these diseases are serious and fatal if not treated in good time, for example, tuberculosis, herpes zoster and cancer. Moreover, some of these diseases like tuberculosis recur even after a full treatment is given, as long as the body immunity system is weak. Opportunistic infections are the main cause of sickness and death among HIV-infected people (NAS COP 2002).

However, many of the opportunistic infections can be prevented with appropriate medications. Thus, provision of anti-retroviral drugs and other prophylaxis is an important part care for the infected persons. But some of these HIV-related conditions require certain infrastructures, which range from simple microscopes to advanced equipment necessary to diagnose the conditions and monitor the treatment. This makes the study to question the spread of such service in Kenya and more specifically in Bondo district.

According to National Coordinating Agency for Population and Development (NACPD) and ORC Macro. (2005) health care services related to HIV/AIDS are unevenly distributed throughout Kenya. The proportion of these facilities that offer HIV- related services varies by province. For instance, anti-retroviral therapy (ART) is most available in Nairobi, whereas other regions with high prevalence of HIV infection, particularly Nyanza, offer fewer HIV- related services. In Nyanza only 19% of health facilities in the province offer VCT services, while Nairobi has a total of 77%. Similarly, health care facilities offering anti-retroviral therapy in Nairobi and Nyanza are 19% and 5%,

respectively. The same variance applies to trained providers on site. In Nairobi, just over 60% of the facilities offering health care service and support have a trained provider on staff compared with 40% in Nyanza.

Although ART is becoming more accessible in Kenya, most of it is available at private and NGO managed facilities. Just about 20% of government facilities have CD4 cell test facilities compared with over 80% of facilities managed by NGOs, FBOs and private-for-profit agencies. Cabrera *et al.* (1996) highlights the significant role the NGOs and other FBOs have played in the awareness campaigns about HIV/AIDS. Like in Uganda the efforts of NGOs in home-based care is great, without which the national governments and local population would have suffered even more from the impact of the epidemic.

Like in other countries, MOH and the NGOs as well as FBOs support the infected and affected families through CHWs in their various villages (NASCO 2002). The CHWs belong to different CBOs, which are basically welfare oriented. The idea of mobilizing local support to help PLWHA is in congruence with the traditional system (communal system) where it was the responsibility of family members and the community in general to care for their members, including the sick (Mboya 1965; Whisson 1964).

But many of the CBOs are predominantly formed by women and they do experience constraints related to financial and technical resources as well as lack of supervision (Cabrera *et al.* 1996; Ouko 1998), which probably prevent them from fully utilizing their potential. The support from the NGOs is sporadic and without commitment for further aid. Some NGOs come with programmes that last 2 to 5 years and instead of scaling up they pull out or move to other regions. Such glaring deficiencies are likely to prevent local groups from fully committing time for effective participation in the care for HIV/AIDS infected persons.

The CHWs are also likely not to offer extensive training to caregivers especially on safety measures and further awareness creation due to lack of time and secrecy that still surrounds HIV/AIDS. But these are very important components of home-based care that

cannot be ignored. For example, Cabrera *et al.* (1996) noted that sensitization guards against stigmatization among AIDS and their families. Many people have been reported to fear sharing utensils and food among other things, with AIDS patients (Pathfinder International 2000).

At the same time, many families in the local villages still need a lot of knowledge concerning the necessity of keeping the living environment clean, safe drinking water and proper nutrition. Nyambedha (2000) observed that many families in Nyang'oma division do not have access to good drinking water, which may make the infected persons become so prone to water-borne infections. Such sanitary measures would also reduce the burden of treating opportunistic infections.

Unless supported in their roles by their family members, the CHWs may otherwise pull out of the programme. As was mentioned in the introduction that HIV/AIDS is a resource demanding (Cabrera *et al.* 1996), the families of the CHWs may resent the time they spend away and extra work that others have to do when they are absent, especially when there are many patients to be visited. These circumstances make it necessary to look at what studies show about gender involvement in caring roles, and the needs of HIV/AIDS patients against the available human and economic resources in the next section.

2.1.3 Caring for a patient with HIV/AIDS

Most people living with HIV/AIDS normally provide their own care when still strong enough (NAS COP 2002). Because there are times when patients are too ill, they require some external support either from among the household members or some relatives living around. Family members have been noted to play a pivotal role in caring for HIV/AIDS patients while at home. It is upon the strength of families that the home-based care programme was considered most sustainable.

However, family care implies that all members of the family are involved in the caring, but Loustaunau and Sobo (1997) say that the burden of caring for HIV/AIDS patients falls most heavily on women. This is perhaps because of role allocation by gender as

dictated by culture. Women's roles are regarded as being in the private domain in which care giving is part and parcel (Brettel *et al.* 1993). Akintola (2004) from his study in Uganda and South Africa also observed that when men do assist, for example, by bathing patients, cleaning and treating pressure sores, female patients often feel uncomfortable as opposed to when men do hospital visits and arrange for transport for the sick.

Low levels of literacy among women may have a negative influence on their performance in home-based care. Gender inequality traditionally dominated access to education, for most African societies preferred taking boys than girls for higher learning (Achola *et al.* 1978). Girl-child dropout at secondary level is still alarming. According to the Republic of Kenya (2002), the percentage of girls compared to boys is 38.1% and 61.9% respectively at secondary level. This means many girls do not receive secondary education. With the advent of home-based care, where female CHWs are to be taught health issues, most of which have English terminologies, they must have a lot of keen interest, if not some appropriate level of education in order to cope with the programme.

On the other hand, the caretaker's limited financial power, most probably makes home-based care very difficult. According to UNDP (1998), so many families live on incomes of less than a dollar a day, and the situation is more severe in Sub-Saharan Africa. They cannot afford enough food for their families as most of them rely on small-scale farming which most of the time is affected by adverse environmental conditions. The situation is further aggravated by the fact that when the sick is too ill, caretakers are forced to stay home to attend to his or her needs (Cabrera *et al.* 1996). Home-based care thus means a lot of sacrifice to the family (Loustaunau and Sobo 1997).

Whereas the principal caretakers live in abject poverty, HIV/AIDS patients need a balanced diet to replace worn out tissues, energy to walk as well as strong immunity system to fight infections. Food insecurity worsens the fight to prolong the life of people suffering from HIV/AIDS. Studies have shown that HIV-infected people who are malnourished are likely to get sick more often, and have lower survival rates as compared to those who get adequate and well balanced diets (Mombe 2004).

In the next section I want to move beyond the household level and look at the general economic and social situation of the Luo. This is because both economic and social aspects interact closely when taking care of the sick, more so, HIV/AIDS patients.

2.1.4 Declining economy and social change among the Luo

According to Republic of Kenya (2002) many districts in Nyanza province including Bondo district mainly occupied by the Luo community, are known for food insecurity. This is supported by a lot of literature specifically touching on this community. The history of economic decline is traced from the time of colonial period in the 1920s when young and energetic men from the Luo community entered the labour market in town centres. Mainly women and old men were left behind to do farming activities in the rural areas (Hay and Stitcher 1984).

Although, to some extent, wages from the external labour sustained rural households and provided hope for development, marginalization of the Luo as a result of the post-independence politics has also in part played key role in economic underdevelopment of the region (Cohen and Atieno-Odhiambo 1989). This problem has also been aggravated by massive unemployment and "down-sizing" of number of employees due to the policy of structural adjustment programmes, which saw many families lose their jobs as the government privatized enterprises it previously owned and operated.

This area along the Lake Victoria basin has suffered adverse environmental conditions, such as increasing unreliability of rainfall, which discourage people from cultivating land. Onyango-Ouma (2000) quotes a remark by one opinion leader who says, "*People work so hard and it only dries up, so you do not want to expend a lot of energy in a large piece of land but only something to try luck with*". The opinion leader adds that the landscape has been changing from the 1980s and has made people in the area live under constant threat of famine. Onyango-Ouma (2000) and Prince (2004) observed that the elderly informants remember with nostalgia a landscape once full of plenty of rain, abundant food, gold and fish in the lake. Now, the lake is choked by the water hyacinth

and so very little fishing takes place. HIV/AIDS has worsened the situation by draining family resources in terms of time, wealth and the productive young people who die from the disease leaving behind several orphans under the care of old grandparents.

Similarly, as early as 1938, a mission-educated Luo, Paul Mboya, in his book "*Luo Kitgi gi Timbegi*" (Luo characters and customs), expressed fear that Luo ways of life were being lost and forgotten as people embraced Christianity and became labour migrants and city dwellers (Prince 2004). Kilbride and Kilbride (1993) also noted that the extended family is on the verge of extinction. The breakdown of this cultural institution is associated with the penetration of modern life and its economic implications. It is dying slowly and giving way to paid labour.

The Luo like many other African communities used to be rich in social networks, especially the extended family institution. Kilbride and Kilbride (1993) assert that this kind of family was widespread and efficient and it ensured that everyone was cared for. They expressed their mutual solidarity during such times of crisis through physical and material support. Everybody contributed to the growing of food crops they consumed (Kayongo-Male and Onyango 1984) through communal labour exchange locally known as "*saga*" (Whisson 1964). The composition of the group could go beyond family relations to include neighbours and friends from far places. Mboya (1965) said that the Luo liked helping one another. One who did not help others was disliked and got no help when in need of it. People did not have to wait to be invited to render help but responded whenever they noticed there need. Such people were referred to as *asjochuny* (people with a good heart).

Social network are very crucial at this time of HIV/AIDS where t terminal nature makes the affected families to deplete their material and financial. However, based on the background of social change and economic hardships, many PLWHAs have small social networks to rely on. For instance, studies in Uganda and Nigeria have shown that mainly close blood relatives stand up to the strain and do not run away from AIDS sufferers (Cabrera *el al.* 1996). This suggests that infected person whose close relatives have died

like widows and orphans are adversely affected with regard to support provided. Given the practice of exogamy, women who are married far away from their blood relatives are likely to be left alone to be cared for by their own children.

Church and informal groups like local revolving-fund groups become very useful as forms of social networks mobilized to respond to the needs of HIV/AIDS patients (Ouko 1998). But the burden of care may also force them to withdraw as the level of patients' dependency increases. Caring for an HIV/AIDS patient demands a lot of time as well as material resources (NAS COP 2002).

2.2 Theoretical framework

This study was guided by two theoretical approaches. These are Bourdieu's theoretical concepts of habitus, field and capital, and theory of relatedness. The study combined these two theoretical approaches to enable exhaustive explanation of all factors that influence supporting and taking care of HIV/AIDS patients and the actions of the patients themselves in relation to their health situation.

2.2.1 Habitus, capital and field

Habitus refers to durable, transposable dispositions, structured structures predisposed to function as principles of the generation and structuring of practices and representations that can be objectively orchestrated without being the product of the orchestrating action of a conductor (Bourdieu 1977). In other words, habitus refers to the systems of durable dispositions people acquire through socialization and experience in a social setting, which predispose them to act in a certain way. That is, all acquired forms of behaviour plus life experiences become inculcated in people's schemes of thought (mental structures) and unconsciously influence practices.

Although human beings are thinking agents and can improvise strategies to face social conditions, Bourdieu emphasizes, but habitus still remains the source of strategies. People's actions are guided by perceptions they have of the social conditions.

Bourdieu and Wacquant (1992) continue to say that in a society there is a plurality of social fields, which in this case refer to social activities that people participate in as social actors. And in all the activities it is not just the habitus, but also the capital endowment that determines how effective people perform them. There are three forms of capital namely economic, cultural and social. Economic capital in this sense includes money, food, cattle and other forms of wealth.

Cultural capital, on the other hand, exists in the form of beliefs, norms and other embodied traditions as well as academic qualifications. Finally, social capital refers to the network of connections that actors have. That is, the volume of social capital possessed by a given agent depends on the size of the networks of connections that he/she can effectively mobilize (Bourdieu 1986, quoted in Siisiainen 2003). These networks include voluntary associations, women's groups, unions, political parties, and work groups.

2.2.1.1 Relevance of Bourdieu concepts to the study

Based on the idea that habitus is a past in the present, the framework allows interpretation of the cultural beliefs and practices as well as patterns of responses to home-based care for HIV/AIDS patients. It facilitates explanations for gender representation in the programme, reactions like stigma and means of approaching and caring for the sick.

The three forms of capital (economic, social, and cultural) as espoused by Bourdieu and Wacquant (1992) are core to the success of the home-based care programme. Taking care of HIV/AIDS patients requires money, food and materials like medicine, lack of which renders the home-based care ineffective. Above all, it is now well known that management of HIV/AIDS involves a multifaceted approach, which goes beyond individual stakeholders. Emphasis is put on collaboration of the local community, family members, NGOs and health providers in an attempt to help the infected persons (NAS COP 2002). The framework provides an explanation and helps predict the outcomes of such networks mobilized.

However, Bourdieu's concept of social capital only shows how individual actors rely on network of connections to improve their social positions but fails to explain how such networks are formed and maintained. HIV/AIDS being a stigmatized illness many sufferers cut links with some kin members, while on the other side, create new relationships, especially with CHWs and colleagues suffering from the same affliction. Theory of relatedness is thus incorporated to further explain such gaps.

2.2.2 Theory of Relatedness

The theory of relatedness focuses on the connections between persons, which include those given by biology and those relations produced via social interactions in a given cultural setting (Carsten, 2000). The concept of relatedness is based on the current theoretical shifts in kinship studies from structure to practice. Early anthropological studies had put a lot of emphasis on kinship relations over other forms of ties between persons, which equally carry particular weight - socially, materially as well as affectively. But these connections are grounded not only in genealogy, but also made through other social practices, like adoption, substance sharing, mundane acts of eating together, sharing of conversation and space, among others, that make a person part of each other (Prince, 2004).

Theory of relatedness goes beyond kinship relations. It looks at exchange relations people have in the daily situations. For instance, it looks at why people invest in certain relation (Nyambedha 2006). But social situations that make individuals to move through different states of relatedness are sense of belonging, reciprocity and mutuality (Carsten, 2000). Hutchinson (1996) shows the way the Nuer of southern Sudan construct relatedness to overcome tension, power struggles and controversies in their livelihood practices in a war-torn environment.

2.2.2.1 Relevance of relatedness to the study

In adopting this approach of relatedness, I do not want to describe Luo cultures of relatedness, but basically look at the influence of such relations on the provision of support and care for people living with HIV/AIDS in this study area. My concerns are

threefold. First, at the programme level I examine how CHWs go about recruiting and maintaining contacts with clients in their villages.

Secondly, I explore the basis for the *care management group* and the dynamics in the care process for the infected and affected persons at home. Being that the study is situated in an area facing a lot of social change due to external economic systems and hardships of life (Nyambedha 2000; Nyambedha and Aargaard-Hansen 2003; Whisson 1964), people have become more individualized than previously. Not all family members have the moral obligation to render support to the needy. I am interested in bringing into the picture all persons who take care of HIV/AIDS patients.

Thirdly, I am interested in the emerging social club referred to as *patient support groups*, which PLWHA form based on their health affliction. The *patient support groups* act as a coping mechanism for moral and economic support.

Next page is a conceptual model tying together theory of relatedness and Bourdieu's concepts of habitus, field and capital.

From the conceptual model, figure 2.1, habitus being the inculcated dispositions (cultural orientations, and experiences) of all those involved in home based care including PLWHA determines who links with whom. The whole process is voluntary. The PLWHA, CHWs and kin members join hands based on how they perceive each other. Non-kin CHWs approach and maintain links with PLWHA through sharing of materials like food, financial support and painkillers (economic capital) and thus enlarges number of connections (social capital) for the PLWHA. Therefore the whole process is a cycle of interrelated factors that depend on each other for effective management of PLWHA at home.

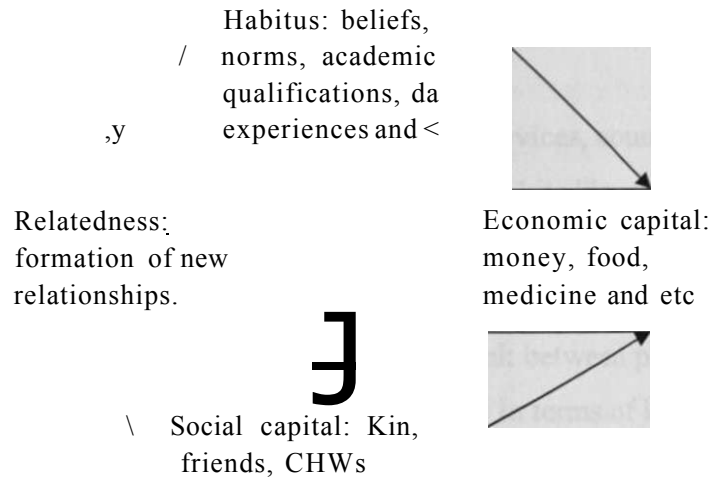


Figure 2.1. Conceptual model

2.3 Assumptions

1. There is inadequate healthcare support for HIV/AIDS patients in the study area.
2. Relatedness determines flow of support for HIV/AIDS patients at home.
3. Cultural beliefs and practices compromise provision of home-based care for PLWHA.

2.4 Definition of key terms

Beliefs -refer to perceptions people hold regarding cause of ill health such as *chira*, spirit possession and witchcraft.

Care management groups - includes patients themselves and all caretakers who either lived with the patients in the same household or nearby as well as those who supported from far by sending food or remitting money.

Habitus -refers to the systems of durable dispositions people acquire through socialization and experience in a society, which predispose them to act in a certain way.

Health care support - includes provision of treatment services, counseling, nutritional supplements and trainings on safety kits like gloves and condoms among other home care kits.

Reiatedncss - refers to the connectedness or link between patients and their caretakers as well as CHWs either in terms of kinship, friendship or group membership.

CHAPTER THREE

METHODOLOGY

This chapter situates the context within which the study was conducted. It gives a description of the research site, both physical and social setting, which briefly touches on people's everyday life. Also included is the study design, units of analysis, sampling strategy and sample size. The chapter finally looks at the methods of data collection.

3.1 Research site

3.1.1 The physical setting of the study site

This study was conducted within the administrative division of Nyang'oma in Bondo district of Nyanza province in western Kenya. Bondo district is bordered by Siaya district to the north, Kisumu to the east and Homa-Bay district across the Winam Gulf to the south. The district has four other divisions, of which the rest include Usigu, Boro, Rarieda and Bondo. The division lies along the shore of Lake Victoria (Nyambedha 2000).

Nyang'oma division like other parts of Bondo district receives erratic rainfall and in most cases experiences long drought (Republic of Kenya 2002). Despite the unreliability of rainfall, subsistence farming remains the chief economic source. People grow drought resistant crops like sorghum and finger millet, though maize is also grown. Fishing is another source of income for some many families (Nyambedha 1998). Basically, men do fishing as women trade in fish by retailing at the local shopping centers. Mining is done in small scale.

The road network in the division is in a poor state (Nyambedha 1998; Onyango-Ouma 2000). Hence the main means of transport in the division is bicycle taxi locally known as *boda boda*. But these *boda boda* are reliable only during dry seasons. Immediately the rains begin, it not only becomes difficult to use but also very expensive as the *boda boda* operators hike up traveling charges.

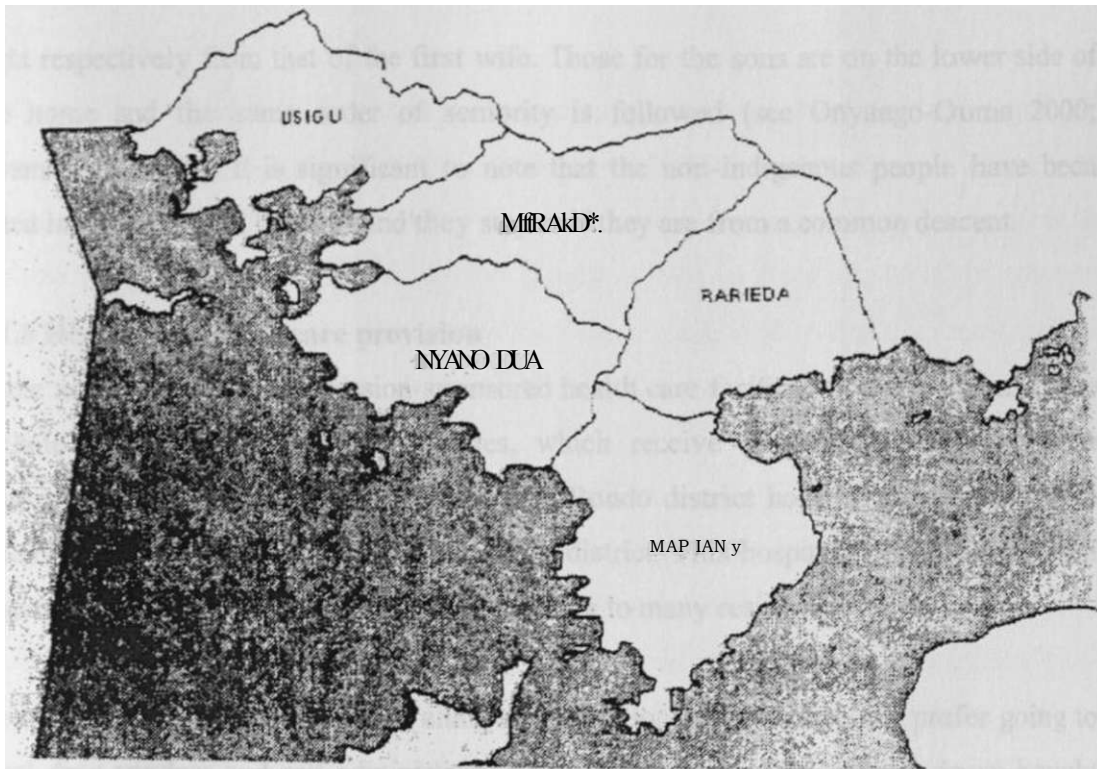


Figure 3.1 Map of Hondo District (adapted from Siaya district surveys office)

3.1.2 The social setting and everyday life in the villages

The majority of the inhabitants of the study area are the Luo of Sakwa clan locally known as *JoSakwa*. According to Republic of Kenya (2002), Nyang'oma division is estimated to have a population of 34,790. There were projections that the population would shoot higher due to high population growth and in-migration of people along the beaches to take part in fishing activities and trade.

The Luo have collective living arrangement, which in relation to home-based care makes it easy for families to support their sick members. They live within the same homestead (*dala*) or adjacent to their agnatic kin. The Luo *dala* comprises of a senior man, his wife (wives), sons and their wives as well as their children and sometimes relatives from outside the nuclear family (Onyango-Ouma 2000). The arrangement of the houses in a *dala* is according to seniority, with the first wife's house (*od mikayi*) is at the center, while the second wife (*nyachira*) and third wife (*reru*) have their houses on the left and

right respectively from that of the first wife. Those for the sons are on the lower side of the home and the same order of seniority is followed (see Onyango-Ouma 2000; Nyambedha 2006). It is significant to note that the non-indigenous people have been fitted into the original lineages and they stay as if they are from a common descent.

3.1.3 Health and health care provision

There are government and mission-sponsored health care facilities in the division. These include Uyawi and Nyayo dispensaries, which receive government support, while Nyang'oma is a catholic mission dispensary. Bondo district hospital remains the main referral facility for all the divisions in Bondo district. This hospital is over 10 km from Nyang'oma division, and is therefore inaccessible to many residents.

Because of transport problems and charges at these local facilities people prefer going to local drug vendors and self-administration where they use on-the-counter drugs bought from chemist shops (Onyango-Ouma 2000). Furthermore, the government-run health care centres often lack facilities and drugs.

3.2 Study design

From the onset I knew I was entering into a research topic that is very sensitive and touching the lives of the affected and infected families. I had thus anticipated that it would require a strong heart and time in order to slowly build rapport with the study subjects.

Since my interest was to capture the experiences of HIV/AIDS patients and caretakers, I realized I needed an ethnographic approach in order to grasp the informants' point of view (Bernard, 1995). Inspired by anthropological concepts of relatedness (Carsten 2000) as well as Bourdieu's concepts of habitus, field and capital (Bourdieu and Wacquant 1992), I saw the ethnographic approach suitable for observing the social and cultural implications of caring for people living with HIV/AIDS. The study combined both qualitative and quantitative data collection methods. Triangulation was also involved in the study to check the validity of the information collected (Ritchie and Lewis 2003).

When I began fieldwork. I realized the informants were so reserved. I strived very hard to be friendly and close through frequent visits and informal conversations in order to let them open up. During the visits, I observed some dynamics in the care process, where some patients transferred to other places as well as from one NGO to another. These factors prompted me to initiate follow-up studies with patients, caretakers and CHWs.

In total, I spent eleven months in the field, which began from January up to the end of November 2006. Follow-up visits were made on a monthly basis, though the original plan was to conduct it fortnightly. The fortnight basis could not be met because I had to walk to all of the informants myself because they did not allow me to send my field assistants as was mentioned in the section on limitations.

The follow-up study was done through a checklist, which spelt out what to observe and areas for further in-depth interviews. The aim of the follow-up study was to find out any changes in the caregiving or any transfers to a new location or from one NGO to another and any changes in relation to access of drugs. It also looked at the support received and from whom as well as the relationship with the person who offered it. The follow-up also included patient support groups.

3.2.1 Study population and units of analysis

The study population included various players in the home-based care programme in Nyang'oma division. These were people living with HIV/AIDS, the family members taking care of the patients, health providers and community health workers, selected elderly people in the community, local administrative leaders, and religious officials. The unit of analysis was the care management group.

3.2.2 Sample strategy and sample size

Because of the nature of study and the target population, purposive and snowball sampling methods were employed. Purposive sampling was adopted in order to reach

health workers and people from organizations that dealt with the home-based care programme in the community. Health providers as well as NGOs operating in the study area helped to locate individual CHWs (*Nyamrerwa*) attached to them as volunteers in charge of their respective villages.

Snowball sampling strategy, was used to identify PLWHA and their colleagues with whom they share support groups. Snowball sampling is a strategy for hard to find cases (Bernard 1995). The stigma that still surrounds HIV/AIDS makes it difficult for those suffering from the pandemic to come out openly.

A total of 70 PLWHA and 68 caretakers were interviewed. The number of caretakers interviewed is small because some PLWHA did not permit interviews with their caretakers because they had not disclosed to them their HIV status. The caretakers interviewed were mainly for 44 PLWHA. But the number of caretakers around each patient was recorded according to how they were regularly mentioned by the patients anytime they gave support. Thirty CHWs and six elderly key informants as well as two church officials were interviewed.

3.2.3 Data collection methods

In-depth interviews, focus group discussions, direct observation, narratives and key informant interviews were used to collect qualitative data. On other hand, a short questionnaire was administered to patients to collect quantitative data. Details are as provided below.

3.2.3.1 In-depth interviews

In-depth interview was the main data collection method in this study. The in-depth interview guide contained open-ended questions that provided room for thorough probing and detailed information. Bernard (1995) says that it is appropriate for sensitive topics. For instance, HIV/AIDS is a life threatening illness and the infected and affected must be handled with a lot of care. In addition, probing helped to unearth specific support patients received, relationship with caretakers, problems the patients and caretakers faced and

reasons for the dynamics observed in the care process. Other areas also included cultural beliefs and practices taboos. However, probing is time consuming and thus limited the sample size.

3.2.3.2 Key informant interviews

Key informants are a people believed to be knowledgeable on the topic under investigation (Nkwi *et al.* 2001; Fetterman 1989; Bernard 1995). Six elderly people between the ages 65 and 75 years and thirty CHWs were interviewed. Also interviewed were six NGO personnel, five health care providers in the local health facilities and one from Bondo district hospital. An interview guide was used in order to obtain standardized data.

3.2.3.3 Focus group discussions

Three focus group discussions were conducted with CHWs only. The informants were selected before hand after consultations with NGOs and health providers as advised by Krueger (1994) quoted in Nkwi *et al.* 2001). This was to help avoid domineering candidates that would lead to a skewed data, representing the views of a small number of the study population. In the first session there were seven CHWs in attendance. Only one CHW out of eight invited failed to turn up. During the last two sessions all the eight CHWs invited attended. I chose eight for focus group discussion because it is manageable number.

In each session there were only women who basically dominated the programme. The discussions centered on areas like approaches they use to gain entry into the affected families, problems patients face, challenges the CHWs meet and reasons for their drop out. The discussions were put in notebooks and also tape-recorded for transcription.

3.2.3.4 Narratives

In using this method, five PLWHA were requested to recite their experiences before and after knowing their HIV status. Basically these few informants were selected for

convenience but criteria were based on their availability and free will to talk. Their stories predominantly covered problems regarding access to ART as well as nutrition. They also included feelings of people around them, especially the partners and other support providers. Three principal caretakers below twenty years and other three adults were also given notebooks and asked to write their experiences of taking care of their sick relatives.

3.2.3.5 Direct observations

This technique involved making direct observations on visible areas related to the topic. It basically entailed looking at housing conditions, cleanliness, performance of duties with respect to the care around the sick person and other related visible features. It was very useful in noting the people who were frequently around the patients, which helped in judging their closeness and concern for the sick.

3.2.3.6 Questionnaire

A short questionnaire was administered towards the end of research period. All the 70 PLWHA were interviewed in order to get quantitative data. However, since the number of informant was small, they were all considered for interview. Though the small number has a limitation in making generalization (Mugenda and Mugenda 1999).

3.2.4 Data analysis

Qualitative and quantitative data were analyzed separately. Qualitative data obtained from in-depth interviews, narratives, direct observations and focus group discussions were analyzed thematically. For each of these data, separate code sheets were created in an attempt to establish and interpret the patterns and relationships.

It also involved a descriptive approach where direct quotations and selected comments from the informants were used to explain exhaustively the trends. Basically all these depended on the content of the texts. All tape-recorded work was transcribed and translated into English. Terms that were mentioned in English during interviews were directly picked and used as they were. Some Dholuo terms were also used and they are

italicized in the analysis. Secondly, meaning of certain terms as used by informants were also sought and analyzed. Quantitative data were coded and analyzed using software package known as SPSS.

3.3 Problems encountered

In the beginning the informants were so reserved about their issues relating to their illness and people surrounding them. I had to make more than one trip trying to explain to them the importance of this research and more so their participation. With time the informants began to open up. At this time almost each informant was very specific to tell me, *"Now, I want to tell you the truth"*, which of course, hinted to me that a lot of information had been hidden during the previous interviews. But the statement also raised my hope that I was getting to the very bottom of my research interest. It strengthened my confidence that the patients had developed trust in me.

I realized that I had to visit the families for an extended period of time to get true data. It also meant that I had to go an extra mile to maintain the relationship that was already created. For example, I had to respond quickly whenever they sent message that they wanted to see me. I had become like a family friend such that any time there was a slight health complication they sent somebody to inform me. When some of the informants visited me, I could fix some tea or lunch and we ate together.

However, I could see some patients come to me so frequently without any reason, but just to see me. Partly, it was an advantage since we could have healthy informal talks but it was inconveniencing especially when I had appointments with other informants. It put me in a fix because telling them that I was busy could not only tear apart the relationship that took me time to nurture but also risking future contacts. But I had to stop cooking for myself and get meals from a restaurant at a nearby centre. With my experience as a Luo I gave an explanation that I was finding it too difficult to cook and wash utensils all the time. This was taken kindly because among the Luo men are known to be lazy in kitchen duties.

There were high incidences of opportunistic infections among the respondents that affected the smooth running of data collection. Some informants got seriously sick and died after the first visit. In that respect, I recruited more *clients* for replacement though it was tiresome and time consuming. In certain situations I found the informants too sick, which forced me to postpone planned interview to a later date. But it was very hard to predict when exactly the sick would get some relief and get ready for next interview.

Fear of confidentiality among PLWHA forced me to do away with my field assistant. When I began to visit the PLWHA I realized that many of them were not free to talk about their health issues in the presence of people they know. My field assistant hailed from the same community. It was too difficult to manage everything alone. For example I had to conduct even focus group discussions alone because during sessions names of the patients could be mentioned

3.4 Ethical dilemmas

The consent of informants was sought through CHWs and health providers to gain their acceptance. Because some of these PLWHA did not want me to go to their homes, they made arrangements that we meet at the CHWs' homes. This was to avoid suspicion about their health status (Hardon *et al.* 1995) because people from the community frequently saw me at the local health facilities. As a result, they mistakenly called me "doctor" whenever they met me in the field. The local health facilities were loci of many activities during the research process. First, I met new *clients* here through health providers. Secondly, here I met with some *clients* whom I could not visit at home for various reasons. I also observed the turn up of HIV/AIDS patients for continuous clinical services as well as other dynamics related to the health care service provision.

However, when conducting research with HIV/AIDS patients, a number of ethical problems have to be faced that are associated with stigma and the concomitant psychological and emotional problems (Hadorn *et al.* 1995). Some patients more often broke in tears during the interviews, especially when I asked about the problems they face. At first, I experienced great shock though I tried not to show any reaction. But when

I attempted to seek permission to stop the interview, these same emotionally laden informants encouraged me to continue. I thus learnt a trick, simply giving them time to express their feelings and give consolation thereafter. In the process they explained to me that they were full of grief, which they had to let out in order to gain strength and talk about their health situations. Although reasons for the grief did not come out clearly, I could not dare revisiting the issue. I had to learn some tactic of counseling to manage all these painful experiences, though I never went to a college to obtain the basics skills. However, this success does not undermine the fact of my personal experience of emotional pain and anxiety when these patients cried. I have to acknowledge the fact that dealing with an emotionally charged topic is really not easy.

The informants and their families had high expectations, in terms of financial and other material support. They always doubted reasons I put forward that bound me from giving direct benefits. The whole situation was complicated, in part by the fact that I belonged to the same community although from a different district. In the Luo community it is morally believed that the sick cannot be visited empty handed. And so, my reasons were not binding. I thus got the experience of ethical dilemmas researchers doing fieldwork in their own societies face. Onyango-Ouma (2003) noted that researchers at home are always torn between the obligation to the discipline and the people they study, with whom they also share the same background, especially the moral demands. The study concurs with Onyango-Ouma where he added that research is as well taken as a form of employment. Moreover, research was taken as an equivalent of an NGO. The affected families believed that only NGOs reach out to the sick.

In certain situations I found the informants too sick to walk to a health facility when time for clinic was due and nobody was around to help. While I grappled with a feeling that I was being too inhuman to ignore such people, on the other side, I knew it would be against professional ethics to give money. Along the way I not only got carried by humanitarian sympathy to chip in but also influenced by a correlated agreement reached at by the Council for International Organization of Medical Services (2002) that says research subjects might receive free medical services for participating in a study. Those

who received no direct benefit from the research may be compensated for any inconvenience or time spent. But before I took the steps I asked myself why anthropologists could not reciprocate in the same manner.

All the same, I helped CHWs to carry some HIV/AIDS patients up to the nearest health facility using my bicycle. Other patients I gave cash in the range of Ksh 100 and Ksh 200, which could only reach them to the nearest health facility by *boda boda*. This payment was directly given to the *boda boda* operators. However, it was a tricky arrangement because I could not extend the same to all informants. I had to remain extremely cautious. The cash payment was purely circumstantial and based on "moral negotiations" (see Onyango-Ouma 2003). Pels (1999) as quoted in Onyango-Ouma (2003), calls this is kind of negotiation an "emergent ethics", defined as "a set of moral arrangements composed contingently perhaps inconsistent, but at least appropriate for the situation at hand".

Another dilemma was related to the research methodology. Researchers doing participant observation are always encouraged to strive to situate themselves in the physical and social proximity of their informants in order to be able to observe their daily lives and practices (Ritchie and Lewis 2004). I found it extremely difficult to maintain the researcher's role as an independent questioner. The affected families called and expected me to see them anytime they had a problem or disappointed in any way. They expected me to intervene when they missed drugs from health facility. I could only do the listening and give hope that the problem would be dealt with soon.

Sometimes the CHWs referred me to people who they feared approaching directly but had not gone for VCT, hence dragging me into the work of counselling. The CHWs took advantage of my being new in the area and neutral in terms of village affiliation, which they believed would impact positively on the ailing persons to open up. They (CHWs) just told the sick that some "visitor" would come to talk with them without giving them full details of what I was out to. I could only realize the problem during interview sessions when the person states that he or she had not gone for HIV test. But it was

impossible pulling out in front of a person very eager to hear from me. I just digressed into sharing about the importance of going for VCT and early entry into home-based care should serology test suggest so. Luckily, 9 out of 10 people I talked with and volunteered to go for test were diagnosed as HIV positive. So, the point here is that it is not only sharing in the emotional pain and suffering as well as anxiety that a participant observer is more likely to experience but also so tempting to veer off the researcher role when it comes to applied health research (Hardon *et al.* 1995).

Nonetheless, the study adhered to code of ethics to ensure that the research did not harm the informants in any way. Names of the respondents were kept anonymous through the use pseudonyms (Bernard 1995). In the analysis, the pseudonyms are italicized.

CHAPTER FOUR
HEALTH CARE SUPPORT FOR HIV/AIDS PATIENTS

This chapter presents demographic information about the patients and community health workers interviewed and findings regarding availability, accessibility and adequacy of health care support from health care institutions and non-governmental as well as faith-based organizations in the study area.

4.1 Demographic and socio-economic characteristics of study population

4.1.1 Demographic characteristics of the patients

As contained in Table 4.1 below, out of all recruited HIV/AIDS patients 50 (71%) were females and 20 (29%) were males.

Table 4.1 Sex of the patients

Sex	Frequency	Percent
Male	20	28.6
Female	50	71.4
Total	70	100.0

The ages of the patients ranged from 8 to 66 years old. But the majority of the patients were between the ages 21 and 50 years old as contained in Table 4.2 below.

Table 4.2 Age of the patients

Age range	Frequency	Percent
1-10	2	2.9
11-20	2	2.9
21-30	21	30.0
31-40	18	25.7
41-50	17	24.3
>51	10	14.3
Total	70	100.0

A total of 28 (40.0%) patients were married, out of which 14 individuals were in a discordant relationship. Ten patients were concordant HIV positive, where both spouses were infected with HIV. Four patients were single. These included three unmarried girls, with ages 8, 16 and 21 years old. The remaining unmarried client was a young boy, 8

years old. There were also 5 male patients who were deserted by their wives after undergoing the HIV test together while others ran away on suspicion that the partners were infected with the deadly virus. Lastly, there were a total of 33 (47.1%) widowed patients. These were composed of 31 widows and two men who had lost their wives. Table 4.3 below gives a summary of marital status of all the patients who participated in the study.

Table 4.3 Marital status of the patients

Marital status	Frequency	Percent
Single	4	5.7
Married	28	40.0
Separated/divorced	5	7.1
Widowed	33	47.1
Total	70	100.0

4.1.2 Socio-economic and demographic characteristics of community health workers

Table 4.4 below shows that thirteen (43.3%) CHWs had primary level of education, while six (20%) others reached secondary level but dropped out of school in form one and two. Three other CHWs had up to eleven years of schooling. Whereas five (16.7%) CHWs had form four certificate, only three (10%) CHWs went beyond secondary school. In terms of occupation, only 8 (27%) CHWs had formal employment as the rest 22 (73%) relied on informal income generating activities like farming and small-scale businesses.

Table 4.4 Education level attained by community health workers

Education levels	Frequency	
	Men	Women
Illiterate (No formal educ.)	0	0
Lower primary (up to class 3)	0	0
Upper primary (class 4 to 8)	2	11
Lower sec. (form 1 & 2)	0	6
Upper sec. (form 3 & 4)	2	6
Post sec. (beyond secondary)	0	3
Total	30	

As contained in table 4.5 below, 17 (56.66%) CHWs interviewed were married, whereas 11 (36.66%) others were widowed and the remaining two (6.66%) were single.

Table 4.5 Marital status and gender of community health workers

Marital status	Males	Females	Total
Married	4	13	17
Single	0	2	2
Widowed	0	11	11
Separated	0	0	0
Grand total	4	26	30

In addition, a majority of the CHWs in various home-based care groups were women. In each group, there were hardly any male CHWs. As a result, only 4 (13%) male CHWs participated in the study. The remaining 26 (87%) CHWs were females as contained in the Table 4.5 above.

Focus group discussions have shown that a majority of men who were recruited into the programme pulled out for lack of payment. It was revealed that a man being *de facto* breadwinner "*needs money to provide for his family. So, it becomes difficult for him to provide free service. But if home-based care were remunerative then men would be predominating programme* ".

But some informants maintained that men lack instincts for tender care as well as perseverance that a sick person requires. Their participation becomes even more difficult in situations where a bedridden patient requires somebody to help with washing of cloths or beddings and bathe them. In particular, male CHWs fear handling female patients in such a state. The few male CHWs interviewed maintained that *it is awesome to see a woman nude*. Even the HIV infected women themselves do not feel free to let men help them. Moreover, washing and cooking are always women's duties, which of course, these

men cannot adapt so easily just because the programme requires so. Hence in serious health conditions men tend to shy away. Such a terrible health situation "*requires a person with a big heart*", that is, tolerance, a quality that both male and female CHWs affirmed that only women possess.

4.2 Health care support from the government and NGOs

Data collected through in-depth interviews with health providers, NGOs and patients as well as caretakers show that there is healthcare support for persons living with HIV/AIDS at home in the study area, although very inadequate. The inadequacy ranged from small number of voluntary counselling and testing sites, limited supply of antiretroviral drugs and those for opportunistic infections and shortage of health providers as well as limited health centres in the study area.

The home-based care started in the late 1990s when Bondo district was selected as one of the pilot areas. The programme is provided through a combined effort of NGOs and the government. There are a number of non-governmental and faith-based organizations in the division, namely. Center for Disease Control and Prevention (CDC), International Community for Relief of Sickness and Starvation (ICROSS), Comprehensive Course of Franciscan Mission Charism (CCFMC), which later changed its name as St. Francis Community Development Project (FRACODEP) and Mildmay International.

The NGOs adopted two different models. In the first model, the NGOs, for example CDC, only supported local health centers with the necessary kits, which include test apparatus and medicine as well as clinical personnel. The second model is where the concerned NGOs give support directly to patients through the CHWs in their respective villages. ICROSS, CCFMC and Mildmay International applied this approach as will be discussed later.

VCT service as the determining point of entry into home-based care was for along time far from the reach of many people of Nyangoma division. Apart from Bondo district hospital, there were only two other VCT sites throughout the district. These sites were

Lwak and Got Agulu health centres located in the neighbouring divisions. The NGOs dealing with home-based care relied very much on mobile VCT programmes in order to reach people on the ground.

VCT and DTC services were initiated at Uyawi health center and Nyang'oma dispensaries in the years 2005 and early 2006 respectively. Health providers noted that many people accepted HIV test only when they were too sick. In particular, only persons with illnesses considered as opportunistic infections like Tuberculosis were tested for the HIV virus through a programme known as diagnostic testing and counseling (DTC). Whereas HIV/AIDS patients who began ART when strong regained faster, the health providers also observed that patients who delayed exhibited slow recovery process.

Home-based care in this area is conducted through a network of referral system, such that once a person is found to be HIV positive at any VCT centre or transferred from a far hospital having the same health problem, the patient is linked to CHWs, through whom he or she gets support from the NGOs as will be seen later.

It was until mid April 2006 when Nyang'oma and Uyawi dispensaries started to provide HIV/AIDS related health care services with support from CDC. The collaboration between CDC and these local health facilities began when this study was in its advanced stages. CDC stepped in upon persistent requests from Nyang'oma dispensary that many patients could not manage to seek for HIV/AIDS related treatment farther than the study area. The organization thus began to provide ART and other related services at the dispensary. CDC clinical officer visited Uyawi and Nyang'oma dispensaries on Wednesdays and Thursdays, respectively on a weekly basis to administer services to patients. But Uyawi dispensary hitherto dispenses only prophylactic drugs and treats some opportunistic infections and refers patients to Bondo district hospital for ARVs and any other complications.

Since the introduction of the programme at Nyang'oma dispensary up to the end of November 2006, a total of 270 HIV/AIDS patients got registered for treatment. Twenty-

five out of all registered clients were put on ARVs. On the other hand, at Uyawu health center a total of 135 patients were registered for similar services, except ARVs.

However, there is a steady increase in the number of patients eligible to start ARVs, which then causes concern to Nyang'oma dispensary because CDC volunteered to support only around 20 patients on ARVs. Apart from the already registered *clients*, so many patients already on ARVs are coming from other far hospitals requesting for registration at Nyang'oma dispensary. They want to transfer closer home due to transport problems.

Besides, there is a serious shortage of health providers. The health providers in this dispensary have no capacity to administer ARVs or change drug regimen in case of any complications. They have to wait for the specialist from CDC to come, which then forces patients to wait for a whole week or more days especially during rainy seasons when the roads become impassable. Furthermore, a one-day service is never enough as the health provider from CDC comes and finds a very long queue of patients and takes a very short time with each patient in order to attend to all of them. Thus several patients complain that they are not being given enough time to express their problems.

In spite of free treatment for HIV/AIDS related conditions in this mission-sponsored dispensary, any treatment for opportunistic infections is given at some fees to ensure sustainability. For instance, CDC does not supply drugs apart from ARVs. Mildmay International also just supplied the dispensary with HIV/AIDS kits just once throughout 2006. Likewise, MOH does not support this dispensary with any drugs. This makes the treatment for opportunistic infections expensive for many HIV/AIDS patients, hence discouraging their health care seeking.

On the other hand, the programme also proves burdensome to health providers. Some health providers sympathize and go into their pockets to buy medicines for patients, especially those drugs that are lacking. Four patients, among whom one suffered from

genital warts, confirmed the receipt of such support from the health providers. Medicines for such opportunistic infections are very much lacking.

Uyawi health center suffered a big set back when CDC withdrew support because the MOH had taken over to supply the centre with the needed drugs. The last supply the government sent was in September 2006. Since then up to the end of November 2006 the facility did not receive any additional supplies and the health providers got worried about what to do with the patients already registered. The problem is not only experienced in the two local health facilities, but also at Bondo district hospital. Patients recommended from within the hospital as eligible for ARVs as well as those who get transfers from other districts take time before they are included into the programme simply due to shortage of medicine. In-migrating patients are always advised to come with drugs that would take them for at least two months.

Children living with HIV/AIDS in the division still have to get their medicines from Bondo district hospital despite the long distance. At the local health facilities there are no medicines and a pediatrician to serve them. Apart from the two children who participated in the study there are several others whose parents are also infected and participated in this study. It is too cumbersome and expensive for the caretakers to travel to Bondo every month to take the children for medication.

The other serious challenge is lack of pertinent laboratory facilities. Before CDC installed the facility for CD4 count test at Bondo district hospital in November 2006, all HIV/AIDS patients in the whole of Bondo district were forced to go either to Siaya district hospital or Kisumu, which of course was hindered by transport cost. In order to help these *clients*, Nyang'oma dispensary arranged to take blood samples and rushed them to Siaya via Bondo Hospital that routinely sent blood samples for test every Thursday. Each patient was required to pay Ksh 100 to facilitate transport of the samples. At the same time, the samples had to be taken as early as 6.00 a.m. for them to reach Bondo by 8.00 a.m. Patients who lived far away had to look for accommodation around Nyang'oma centre in order to comply with that arrangement. But the facility in Siaya was

fond of breaking down, thereby discouraging many patients as well as the health officers. In addition, the personnel in Siaya always put conditions on the number of samples to take for CD4 cell test. For instance, there was a time a notice from Siaya was put in the corridors of Bondo district hospital, which strictly specified that only 30 samples would be accepted from the whole of Bondo district each week. This restriction was not only for Nyang'oma division, but also applied to other facilities in other divisions like Usigu, Rarieda, and Bondo divisions.

It was thus, a big relief when CDC responded to the need and installed the facility at Bondo district Hospital, though it found when the study was winding up. The installation was an indicator of some improvement and commitment towards service delivery. At least a good number of patients can access Bondo either on bicycle or still make arrangements with Nyang'oma dispensary to help them and save some cost and time. Nyang'oma dispensary still charges Ksh 100 as was earlier highlighted, while fare to and from Bondo town is slightly over Ksh 300 specifically for those patients who live at the far ends of Nyang'oma division like Wichlum, Nyanguda, Sirongo and Uyawi beaches.

Fear for breach of confidentiality and stigma is yet a big challenge to the activities of home-based care in the study area. Though some patients began treatment in those far areas, in-depth interviews show that approximately 46% of *clients* preferred going to far places for treatment for fear that their status would be disclosed when they go to the local dispensaries. Some patients went to Bondo district hospital as others traveled to Kisumu and Chulaimbo hospital located near Maseno. Others went to Nairobi for similar services.

However, the issue of not keeping secrets and approach among volunteers seems a major concern to HIV/AIDS patients. *Clients* complain about lack of privacy on their health matters. There was a claim that implicated both a CHW and health personnel at a centre, which also happened to be the focal point from where I operated. A follow-up interview with the involved *client* was as follows:

Ja-PB: You see I was tested by the health personnel in-charge, but I was surprised to hear some "woman" calling me at the market that "*Ja-PB*" (pseudo name) tomorrow you are needed at 8 a. m. you will be taken to

Siaya for "CD4 tests". I was so shocked and I asked her, "do I have AIDS that you call me so loudly at the market like that"? She replied, "That it is your own problem if you don't want to go". I was seriously astonished and wondered how she got to know this but the counsellor did the test when we were only the two of us.

Interviewer: *Who was this "woman" you are referring to?*

Ja-PB: She is some woman in the hospital as a *nyamrerwa* (community health worker).

Interviewer: *Did you go for the services as she told you?*

Ja-PB: No.

(Ja-PB, a widow aged 45 yrs).

Such rumours spread throughout the community and several people opted for services far away from the division as others decided to forfeit health care seeking saying *they would not be the first persons to die*. The depth of concern about confidentiality was further observed during a training organized for *clients* by some CBO under the auspices of Mildmay International that I happened to attend. The victims petitioned similar cases so bitterly to the area Divisional Officer and one assistant chief, who were also in attendance. The victims threatened to take the case to court if the implicated individuals did not stop the habit.

Nevertheless, transport expense is a big set back to these *clients* who go to far health facilities. They complain of spending much money travelling each month. It is difficult because almost all the patients rely on financial donations from friends and relatives, except one patient who is employed. As a result these patients often fail to return to collect medicine on appointment date for lack of fare. And this always sparks off quarrels with health providers who on the contrary feel that the patients are not serious about their treatment process. Below is an example;

My parents just burn charcoal to accumulate enough money for fare to take me to Bondo hospital. But sometimes the charcoal fails to be ready in time, so I postpone going till another day. When I finally go there the health providers quarrel me just like a child and threaten to stop treating me because I'm not serious with my life. And since the problem of money is persistent I feel so discouraged. And when my brother rides me on a bicycle to Bondo, my legs swell and become very painful. (*Ste-Uya, a 25-year-old man*)

The excerpt above points out another health challenge, which HIV/AIDS patients who resort to bicycle transport experience. Apart from being too cumbersome, when the patients sit on bicycles for a long time their legs get swollen and become very painful. Consequently, the patients refuse totally to go for treatment because of recurrent pains caused by the means of transport.

I want to look at the second approach where NGOs dealt directly with patients in the villages through CHWs. At this point we shall see the services given and approach the CHWs applied to gain entry into the families affected by the pandemic to enroll patients into the home-based care.

This second model adopted by NGOs like ICROSS, CCFMC and Mildmay International as was mentioned earlier was the first intervention in relation to home-based care in the study area. For instance, ICROSS began its operations in the Bondo district in late 1999, while CCFMC came into the area in 2001. They started when HIV/AIDS related medicines were not yet available in public hospitals, though private hospitals had the drugs and sold them very expensively. These NGOs do not give ARVs, but only limited to prophylaxis, painkillers and multivitamins. Prophylaxis here means drugs meant to prevent bacterial infections. The NGOs also supply simple drugs to manage other opportunistic infections. Furthermore, the NGOs issue food supplements, which one NGO referred to as *moducare*. The supplements are meant to boost the patients' immunity system. They are in the form of flour packaged in sizable packets.

In terms of accessibility, these NGOs applied village pharmacy approach, where they trained CHWs, referred to as "village pharmacists" to stock and prescribe medicine to *clients* in their respective villages. This idea is meant to bring services closer to the homes for people with HIV/AIDS because so many *clients* lived far from health care centres. However, in as much as the drugs are brought closer home, not all patients access them. For instance, ICROSS considered only 10 clients per CBO for support. And in the whole of Nyang'oma division the organization took just five CBOs, which in total are 50

PLWHA. It is such a big discouragement to the CHWs because they mobilize many *clients* but lack what to give or where to direct them for assistance.

CCFMC, on the other hand, supported a maximum of 30 patients throughout the two divisions it covered, that is, Nyang'oma and Maranda divisions. It was only these thirty PLWHA who received free drug supply, while the rest of the sick bought medicine from the organization's "village pharmacists". According to the CCFMC, selling of the drugs is to ensure continuity of the programme.

This business approach generated tension between the CHWs and the *clients*. First, data from CHWs and patients show that when the organization came in the area it promised free medicine for the infected persons. But later the support was given only to a small number of patients the NGO called "support group members". Apart from being HIV positive, the ability to declare HIV status in public is an important qualification, which an individual had to meet in order to be considered in the organization's support group as a beneficiary of the medicines provided. This means the greater involvement in the support group translates into health care and other material benefits. But many infected persons keep away for fear of stigma.

The second contradiction results from the fact that other NGOs like ICROSS and Mildmay International have been providing free drugs, which then creates a feeling that health care support for HIV/AIDS patients ought to be free everywhere. This was even long before President Kibaki declared free treatment for HIV/AIDS related ailments in all health facilities on first of June 2006. The patients, thus, blame the CHWs for linking them to an organization, which charges fees for its services. The patients feel this NGO takes advantage of their HIV status as "gold mine" to enrich itself. The CHWs also recount experiences of heartlessness exhibited by some NGO staffs that after coming to attend to a seriously ill patient demand payment, without which they withhold treatment. Some *clients* were thus given half dosages for failure to get the required fees. In spite of such contentions, the reality is that so many *clients* were not able to buy the drugs because of lack of money.

The *village pharmacy* approach is faced with several other challenges. So many trained village pharmacists pulled out of the voluntary service and opened individual chemist businesses, while others operated their businesses parallel to the programme. The NGOs lament that the *village pharmacists* are only geared towards personal benefits, even though the organization awards 10% commission after total sales. At times the drugs supplied are not sold at all. And more often than not medicines expire in their stores. Other *village pharmacists* also sold the drugs and disappeared with all the money. But the organization never had any written agreement signed at the time of supplies to guarantee some security. Instead, the organizations relied on the goodwill of the "village pharmacists" and believed that their sponsoring CBO could offer some control for such irresponsible behaviours.

4.3 Dropout of community health workers

The team of CHWs is composed of three distinct groups. That is, trainers of trainers (TOTs), "village pharmacists" and general CHWs. These CHWs were selected based on membership in the local welfare groups and willingness to support HIV/AIDS patients voluntarily. The CHWs were either affiliated to church or revolving fund groups. In areas that were not well represented, the CHWs were selected through village meetings organized by assistant chiefs or village elders locally referred to as *barazas*.

In this study, there were no CHWs sampled as TOTs, but information regarding them was found from retrospective interviews with the NGOs. The TOTs had at least secondary level of education. They were in turn expected to train other CHWs in their various groups and villages. The team of TOTs was composed of both unemployed and employed, especially teachers and subordinate staff who work in local institutions like schools. But the approach did not work effectively because a majority of TOTs were employed and had job commitments and thus pulled out of the programme. The few TOTs who remained merged with the other general CHWs.

The ages of all CHWs interviewed ranged from 25 to 68 years old. But the majority of were 30- 39 followed by 40-49 years of age as shown in Table 4.6 below.

Table 4.6 Drop out for community health workers by age range

Age range	No. initially recruited (Feb 2006)	No. at end of follow-up (Nov 2006)	No. of drop-outs
20-29	4	1	3
30-39	10	5	5
40- 49	8	7	1
50-59	5	4	1
60 plus	3	3	0
Total	30	20	10

However, follow-up studies show that there is high drop out and shifting among the CHWs, especially those whose ages bracket 30- 39 followed by 20- 29. The dropout was not only witnessed in NGOs but also at the local health facilities. In the beginning of the study a total of 30 CHWs were recruited, but at the end of the study 10 of them had dropped out completely. Even among the remaining 20 CHWs, five of them were not active as before. Among the same five inactive CHWs, four had transferred to new NGOs where still they were not active.

The NGOs affirmed the shift and dropout as a problem over the past years. For example, CCFMC began its services in the area in 2001, where a total of 80 CHWs (15 men and 65 women) were recruited. By 2004 only 22 CHWs were active, as 50 of the original figure had withdrawn and 8 had died. The same applies to village health committees appointed in 2002, consisting of 19 men and 6 women. By the end of 2004 only 16 were active, whereas 7 of them had dropped out and 2 had died. In 2005 the same NGO recruited more CHWs and did refresher training for original members and had a total of 47 CHWs. By November 2006 the NGO was left only with 19 active CHWs as some had migrated to other NGOs, while the rest completely dropped out of the programme.

On the other hand, ICROSS began operating in 1999. but there were no clear records concerning individual CHWs because it only dealt with contact persons from CBOs. However, its record shows that by November 2006 only two CBOs out of the original five recruited consistently brought their reports. A follow up on the CBOs shows that some of the CBOs had split and formed new CBOs, which also sought partnerships with new NGOs instead. Nyang'oma dispensary and Uyawi began with 15 and 20 CHWs respectively, but by November 2006 only 12 CHWs in both facilities were active. The remaining 23 had disappeared. However, focus group discussions show that many CHWs who dropped out of home-based care but remained committed only as TB ambassadors under CDC, instead.

Some CHWs dropped out due to job commitment, especially those employed as was in the case of TOTs. While some young CHWs also left to seek for employment in towns, the married female CHWs were conditioned by their husbands to stop because they were *wasting time*. In this sense, "waste of time" meant lack of payment.

The drop out was also partly prompted by high expectations the affected and infected families had from the same CHWs. For example, when the CHWs visited them more than once without any material like food, soap or medicine, the affected families behaved strangely to show their disapproval. Some patients covered themselves tightly in bed while others became very aggressive. On the other hand, *village pharmacists* got discouraged because the NGOs forced them to pay all bad debts that accumulated when patients took drugs on credit and could not afford to pay or died before paying. Other CHWs blamed the dropout on poor leadership in the NGOs. For instance, some NGO officials treat the CHWs with high-handedness and sometimes quarrelled those opposing their ideas and approaches.

However, many CHWs moved from one NGO to another because of the perceived benefits, specifically those new in the area. For example, they considered very much the allowances offered during the trainings they attended. Venues for the trainings were more often in hotels in Bondo town. The participants were either accommodated in hotels or

sometimes returned home after each day's session. Transport and lunch allowances were sometimes provided at the end of each day's session. But the allowances varied from one organization to another. An NGO could give KSh 300 or KSh 500 depending on the transport cost participants incurred. However, not all the NGOs provided such allowances in the form of cash, and instead they provided food for instance CCFMC. But the CHWs preferred the former approach where cash is offered. The CHWs say, "*You know, when you are given food, you eat the whole of it yourself while back at home your children have nothing to feed on*".

In addition, since almost half of the CHWs are widows who also are household heads, it becomes too difficult to continue with the voluntary work. "*So, if any organization can offer allowances, then that's where we go,*" they stated. In fact, the allowance could accumulate to some reasonable figures, which on average, if the training period took five working days, it accrued to around Ksh. 2000. So, some CHWs put up with relatives around the training venues and go home happily with that money when the session ends. In reality, the issue of allowances is a major concern for these CHWs, because they were told that perhaps the government would consider giving them some token one time. Thus, as years passed by and nothing comes forth, the allowance given during training periods is the only benefit the CHWs scrambled for. The same CHWs linked with several NGOs, which some do not even deal with home-based care, but the intension is to increase chances for trainings and allowances.

The CBO officials has underground operation concerning attendance of seminars whereby they circulated information about dates and venues only to a clique of friends, whose faces appeared in trainings more often and are mistakenly considered as very active. However, back in the villages they do not visit *clients* at all. The patients say some CHWs take even two months before visiting them. Follow-up studies over time show that out of the 48 linked HIV/AIDS patients 20 (41.7%) were visited consistently, 16 (33.3%) were not visited consistently while 12 (25%) were abandoned by the CHWs. This suggests that a majority of the patients are not regularly visited.

CHWs aged 40 years and above proved stable by maintaining their affiliation to the original NGOs. According to them, they maintained loyalty to original NGOs for one main reason. *"It is embarrassing to be seen still craving for "little things" (allowances) at this our age"*. These CHWs hold that a good name in a group and village is the most important thing. *"The community recognizes our contribution and we are now known all over. So, it is good for us "*. But another common factor among CHWs in this age bracket is that many of them have limited family responsibilities. For example, they live with other young people in their households, who they assign household duties like fetching water, firewood and looking after children. Some of them get support from other sources like remittances from employed sons and daughters, while others rely on the wealth they had accumulated in the past. This means they have very little to worry about family needs and thus able to spare time for visiting patients in the village. Meanwhile, the CHWs trained as "village pharmacists" took advantage to promote their personal business of selling simple drugs in the villages. In reality it is this business that keeps these CHWs in home-based care as volunteers.

Nevertheless, it is still an up hill task for the few persevering CHWs. There are so many *clients* under their care. For example, among all the thirty CHWs interviewed, one of them had up to ten *clients* to look after. But on average a majority of the CHWs had at least five patients in their coverage area. And this raises concern because the number of *clients* increases day by day. And due to age factor, these CHWs can only visit *clients* who live close to their homes. The NGOs also provided only a few bicycles, which the CHWs share among group members. But some CHWs have personalized the use of these bicycles and do not want to share with others.

4.3 Relatedness and patient enrolment

The CHWs also had the duty of walking through the villages looking for and encouraging people to go for VCT, besides visiting and helping already identified *clients*. Specifically, the CHWs put more efforts to get people who have been sick but have not gone for VCT, a process that some CHWs referred to as "village inspection" as contained in the excerpt below:

When a new day breaks, we hang out, doing "village inspection". We greet and ask people how the "village has woken up". In the process we get to know who and who are sick. Then we start approaching them by paying regular visits until they open up to discuss their health problems. That's when we talk about the need for VCT. But it is not just a day's work; we persistently push until the sick goes for HIV test. Sometimes we give some material support like food, soap and medicine to bring them close. The process is difficult even with relatives, unless you were used to each other before he or she became sick. You have to know "ones heart" for you to start a topic related to this disease (HIV/AIDS).
(*Jo-Ma*, a 62-year-old male CHW)

The above case indicates that, gaining access to the sick depends on how close the CHW and the sick had been with each other in the past. CHWs find it easy to advise and recruit patients directly under their responsibility, like belonging to same household or having close blood relations. The scene changes immediately a CHW moves beyond his or her house. The CHW and the patient must have had some history of friendly relations, which both patients and the CHWs often expressed as *being used to or free with each other and knowing ones heart*. They shared conversations, food and confided to each personal problem. In the absence of such relatedness, CHWs feared tension that could build for associating the sick with HIV/AIDS. The affected families always feel disregarded when they are particularly advised about VCT. HIV/AIDS is still known in the community as a disease of sexually promiscuous people.

On the other hand, some CHWs borrowed experiences from the neighbourhood and were scared that the burden of care would be left on them once they intervene to provide support in order to win the sick. Instead, a CHW negotiates with another colleague who lives far to come and talk to the sick person. This distant CHW bridges the social gap by frequently visiting the affected family and offering some material support to show concern but with an intension to gain acceptance. They gave items like medicine, food and soap. Nevertheless, the tactic is too expensive for CHWs as the supply of such items from the NGOs is too sporadic and insufficient. The CHWs are thus forced to take their own materials and give out in order maintain close relationship with these patients. When the CHWs visit the patients empty handed two consecutive times, the patients become

repulsive. The situation is further complicated by a perception that the CHWs are paid money for being in home-based care.

In certain cases patients and caregivers secretly approach CHWs for networking and are basically influenced by the perceived benefits from the NGOs, especially when they see PLWHA who were once down regained fully after joining the programme.

The reputation of a CHW in the village, specifically *being known to keep secrets and generous*, determined a sick person's acceptance either to go for VCT or disclose the health status if already tested. This is because so many clients are so concerned about their confidentiality and subsequent stigma and rejection. The sick do not trust some CHWs whom they perceive to lack the quality of *a deep heart*, that is, not able to keep secrets. And in most cases the sick generalized and said "*villagers are always full of loose talks. You tell them your status today and tomorrow the whole community knows about it*". Other patients thus, prefer distant CHWs whom they feel would not have time to discuss them with other community members.

However, because of these negative attitudes, a total of 22 (31.4%) patients remained unlinked to CHWs. These patients solely relied on health providers at the local health centres. But it is a problem in a situation when such a patient is seriously sick and fails to go for medicine and there is nobody to give any report on his or her whereabouts. The CHWs who lived far a part from clients cannot visit the sick regularly due to long distance. Hence when such a patient develops complications there is nobody to help.

4.4 Patient migration and generated tension between NGOs

Follow-up studies indicate that 12 (25%) out of the 48 HIV/AIDS patients initially identified stopped links with all the NGOs, while 16 (33.3%) changed to other NGOs. The remaining 20 (41.7%) patients maintained their membership in their original NGOs. Apart from inadequate supply of medicines, lack of moral support by the NGOs triggered patients' migration. This happened, especially when a patient was very sick and sent out a

message that a CHW or staff from the NGO to come and see him or her and nobody responded. Here is a case:

I was with CCFMC, but it shocked me. Now it is three weeks when I'm sick and I haven't seen any staff come to visit me. I have sent a word to my "caregiver" (the CHW) and I haven't seen her up to now. It troubles me because it looks like they have disowned me. Not even their "nurse" whom I sent message to has come. I have decided that if I get strong again I will join another strong NGO.
{To-Ko, a male HIV/AIDS patient, aged 35}

Some CHWs also complain that the NGOs favoured certain areas while ignoring others. Since the patients sometimes want to see NGO staff visit them too, the CHWs could promise and make an attempt to invite the staff, but they fail to turn up. The NGOs, on the contrary, maintained that the failures are as a result of understaffing. That is, they are few to effectively pay regular visits to all clients whenever they are called upon. This illustrates that the work is overwhelming to the few field officers.

In addition, these NGOs initially began with a broad spectrum of support objectives and promised to help orphans, and build houses for widows who lived in pathetic housing conditions as part of the home-based care. The NGOs found these activities too expensive. The NGOs came at a time when so many people were dying of AIDS and several orphans were being left behind. It was a sigh of relief for the families living with HIV/AIDS as there was some sense of bright future for their children when the NGOs promised orphan support. The organizations took records of such children as well as their photographs. Consequently, several families came out requesting for school fees and other related support for the orphaned children. The number became unmanageably big and lots of promises went unfulfilled.

The NGOs, on their part, complain of insufficient funding from Global Health Funds and are forced to cut down their support. Conversely, there is contradicting data from the *clients* and CHWs who mention corruption among the field officers as the main problem surrounding support provision. It is alleged that the officers channelled the funds into their personal activities. For example, six CHWs confided to me one case where they accompanied an officer from one NGO to a home of a *client* who lived in a poor housing

condition. They took photographs of the home, children and the *client*. The organization promised to help her establish a good house. The cost of construction was made and the budget was drawn. But they were surprised when the support came and the officer ignored the widow's situation and used the funds on his personal business. The house eventually collapsed and the poor widow then migrated to her maternal home, where she ailed and passed on.

On the side of orphans, the same NGO vested power of selecting orphans for education support in the department of "widows and orphans", which is not in any way linked to the department of home based care for people living with HIV/AIDS. This means that the field officers who visit the affected families and have first-hand knowledge of orphaned children have to put requests through another independent department, which also has its own way of identifying the beneficiaries. The department of widows and orphans consider orphans not necessarily from the HIV/AIDS *clients* but from among welfare members in the various catholic parishes in the district. Coupled with the allegations of embezzlement of funds and unfair distribution of resources *clients* got discouraged. As a result many patients decided to cut links as others opted for other NGOs still perceived as good. During a focus group discussion, the CHWs said:

We had so many clients but we've lost them. You see, we recorded names of the orphans, together with death forms and took them to the office for approval. Since then no response has been received yet. Actually orphans whose parents were under home-based care programme haven't got any significant support. What is annoying is that there are some orphans we know who were taken recently after the ones we forwarded and have now been taken for vocational trainings. The community complains a lot about such irregularities. The clients also feel short-changed. So, we lose clients who now think we use their names for our own benefits. Some clients have now migrated to other NGOs (Focus Group Discussion).

However, this act of migration had dire consequences not only on the patients themselves but also on the CHWs and NGOs in general. It generated tension among CHWs, with the former blaming the new CHW for providing a link to the new NGO. "*You go to my client as who and with whose permission?*" was one the questions, which characterized the struggles over possession of *clients*. The scene culminated in a situation where the CHWs

do not share ideas or help one another whenever a patient is in need of assistance. The NGOs also issue warnings to the remaining patients and CHWs not to be seen with or visiting the "rival groups" lest they be thrown out of the support programme and group. The CHWs lamented during a focus group discussion that this conflict over patient possession even interferes with their freedom and public relations back in the villages. Patients who tried their luck in two or more NGOs had nowhere to accommodate themselves once they were identified. The latter NGO simply told them to go back to avoid problems and the former also distanced itself asking why they come back and yet they had joined another NGO. The patients are then left wondering about such mistreatment whereas what they need is support, which if they are offered they cannot reject. Some of the patients ended being neglected completely without anywhere to go.

4.5 Patient support groups

People living with HIV/AIDS in Nyang'oma division formed social clubs called *patient support groups*. The groups are basically on the basis of their HIV status. And since the groups are numerous they are named depending on their localities, though they all bear the name *support group* as an identity. The groups include *Nyang'oma Discordant Patient Support Group*, *Abimbo Home-based Care Support Group*, *Nyang'oma Dispensary patient Support Group* and *Nyang'oma CCFMC Patient Support Group*. The groups have already registered with the Department of Social Service and have certificates of operation.

The groups owe their origins to the meetings that were organized by the NGOs and the local health facilities. The meetings were regularly arranged for continuous provision of counselling services and training of patients on how to overcome stigma, what the organizations called *psychosocial therapy*. During such *group therapy* meetings the infected persons shared their daily experiences. And this was found very effective as many shy *clients* began to open up. The patients then saw the need to strengthen the groups further to help them achieve certain goals, specifically on things that commonly touched on their lives as the infected. There were three dominant objectives that cut across all these support groups. First, the groups aim to provide each other with

psychosocial support. The patients meet at regular intervals to share feelings, experiences and encourage one another. They also visit each other while in the villages. *Onya-Wa*, a client says, "I have found new brothers and sisters after all my relatives neglected me because I tested HIV positive".

In the meetings I attended I observed the members put a lot of emphasis on the strong sense of brotherhood. That is, the members always urged each other to enhance feelings of affection and kindness a person would expect from a brother. When one of them died they visited the bereaved families and consoled them. For discordant couples, the task is to see that the families remain intact. They broker peace when one family has strife related to the fact that one partner has the deadly virus. At the meetings, the couples are encouraged to sit next to each other to *enhance bonding between partners*. That is, strengthening the relationships between these married discordant partners. The discordant partners also urge each other to participate equally in the discussions to eliminate fears. When new discordant partners join the group, the old members introduce themselves as partners each saying his or her names and HIV status, and emphasize the statement that they are *positively living together as husband and wife* despite their discordance state.

Second, the patients aim at pooling resources together to boost their income capacity. This idea stemmed from the fact that many patients are poor and cannot get proper diet. These groups initiated income-generating activities like keeping poultry, goats and grow vegetables along the lakeshore for sale. Like *Abimbo group* members keep the goats and after they have multiplied each person would be given equal share. The group's vision is to buy each member a milking goat that would sufficiently produce milk at a very minimal management cost. At the same time, the group's intention is to reach out to sponsors for financial support through writing proposals. The other groups donated local breeds of chicken and keep them in one cage in a member's home. NGOs are beginning to come up to give support. These include CARE International (Kenya), NEMA, CCFMC and DCCP (Rieko En Ngima). One remarkable support from these organizations is capacity building. The NGOs offer education on management of various economic activities the groups had started.

The third main objective of the support groups is to continue creating awareness about HIV/AIDS. Some of these groups go to chiefs' meetings, declaring their status and teaching people more about the disease. Just like CHWs, these clients approach the villagers who seem sickly and advise them to go for the HIV test. Likewise some villagers with ill health but have not gone for the test also consult them since they see these *clients* who were once down are tremendously regaining good health. In fact, each group member was counting at least three people they had talked to and convinced to go for the HIV test. They also teach caretakers how to provide the necessary care and safety required. They also urge other patients to adhere to drugs despite the on-and-off illnesses they experience. Many patients despair when they see sickness continue in spite of the treatment they get.

Despite the good intentions and progress that the support groups are making, they also face a lot of challenges. Several group members cannot manage to pay monthly contributions required to sustain the projects. This makes many members boycott meetings, which consequently engender ill feelings among the committed ones. They blame each other all the time. The members have even tried tightening rules and issuing threats of dismissal for members who miss meeting for three consecutive months. This was in a bid to enhance commitment. In reaction to such threats, the absentees instead just requested for refund of their contributions. For example, Nyang'oma CCFMC patient support group had 32 registered members but only 14 members were active. On the same note, the projects of poultry keeping and farming are still staggering.

Several organizations keep on giving empty promises, except CCFMC that had begun to help the patients attached to them even though too slowly. CCFMC volunteered to construct poultry houses and prepare the farmland near Uyawi beach, as the group members agreed to provide physical labour. It took the NGO about three years to make a meaningful step when a poultry cage was put up at last. Each group member brought a hen. And since the management was in the hands of the members, the group also donated some small amount of money and local feeds like maize and sorghum. By the end of the

study the birds had not begun laying eggs, though other birds also died from diseases. However, distance is a major limitation in this income generating activity. The members could not work in turns as was earlier planned. The group approached the NGO to employ somebody to do management on its behalf, but this request did not go through due to financial limitations. The NGO on the contrary felt that it was the group to participate or employ a person to guarantee sustainability of the project.

Farming was not different from the poultry business. The group owned one vegetable garden, which included all the members from various locations in the division. CCFMC also promised to fence the plot with barbed wire and asked the group bring fencing posts and clear the area. In spite of their ill health the group members dug a two metre deep trench all round the plot to keep away hippopotamuses from the lakeshore. But the group never enjoyed any fruits of their labour in this garden. It took two years before any planting was done here. *To-KO* and some other group members got various serious attacks illnesses after the long toil and the few others who remained got discouraged. The NGO also failed to do fencing. The owner finally decided to throw the *support group* out of the plot. All efforts of this poor *support group* went to waste.

The *discordant support group*, on the other hand, suffered a big set back when a majority of the men who were HIV negative remained reluctant to attend meetings and group activities organized in the villages. Neither did they want to go to Nyang'oma dispensary, the group's usual meeting place, saying *people who go there for treatment would suspect them as being HIV positive*. Some HIV negative husbands also insisted that the infected wives must do the necessary household duties like cooking for them and the children before leaving for the meetings at 10.00 a m. Such women delayed for the meetings all the time. As a result, the support groups lost the original vigour and only the infected individuals attend meetings.

CHAPTER FIVE

PATIENTS AND CARE MANAGEMENT GROUP

In this chapter, the findings of the study regarding HIV/AIDS patients and the care management groups, including the caretakers living with patients in same home as well as those who sent support like food and money while staying far, are presented.

5.1 Care management group

HIV/AIDS patients in this study area were cared for by a constellation of people, who are here collectively referred to as *care management groups* (CMGs). In essence, the CMGs encompass the patients themselves and all caretakers including close relatives, friends and CHWs who support in one way or another. A total of 48 (68.6%) of all patients who participated in the study were linked to the CHWs.

The effort put by the infected persons is also not ignored because many of them were regaining and supporting themselves. Among the patients interviewed, 49 of them had regained good health and could do some daily chores. However, this does not undermine the fact that at certain times the patients become seriously sick and continue to rely on other people.

Although, the CMG profile put as Appendix 1 only includes a few CHWs who cared for HIV infected persons in their own households, the rest of the CHWs are still considered as very important part of the CMGs. This is because many patients maintained close link with the CHWs who then acted as a fallback in terms of physical support. For instance, 11 out of the 30 married patients were concordant HIV positive and whenever both partners were seriously sick they sent the children to call the CHWs to come and help them.

Indeed, the *clients* and CHWs visit each other. And in the process of informal conversations the patients digress and mention shortage back at home. *You know, "my sister", I slept hungry last night and still don't have what to cook for today.* Of course, the CHW sympathizes and gives out something because the patient is a *client*. But this act

of begging cannot guarantee such patients continuous supply of food because the CHWs as well live in abject poverty. The patients themselves were also feeling ashamed of the habit and thought that they were becoming a bother in the community.

Table 5.1 below gives a summary of Appendix 1 showing the dynamics of CMGs, although it excludes the 11 patients who offered self-care. The CMG categories show the number of caretakers around a patient.

Table 5.1 Care management group (CMG) dynamics

CMG categories	Number of patients	
	Stable	Unstable
1 (single caretaker)	5	6
2 (double caretakers)	15	23
3 (triple caretakers)	2	5
4 and above caretakers	0	3
Total	22	37
Grand Total	59	

Stable - patients with regular care and support from their caretakers.

Unstable - patients with no regular care and support from caretakers.

As contained in Table 5.1 above, 11 (18.6%) patients had single caretakers while a total of 38 (64.4%) patients had double caretakers. And the remaining patients, 7 (11.9%) had three caretakers while only 3 (5.1%) had up to four caregivers. However, Table 5.1 further indicates that only 22 (37.3%) patients had stable caretakers, meaning that the caretakers always provided for their needs, while the remaining 37 (62.7%) patients received support occasionally from their caretakers.

Focus group discussions and in-dept interviews clearly show that the number of caretakers around a patient changed as patient's ill health advanced. As per Table 5.1, in situation requiring more caretakers the caretakers were more likely to be unstable. The number of the caregivers around a patient was more than one just at the initial stages but

continued to diminish with time and in the long run leaving close blood relatives to provide care as contained in the next section.

5.2 Relatedness and caring for HIV/AIDS patients

Relatedness featured as a major determinant in the flow of support for HIV/AIDS patients in the Luo community. A majority of the CMGs were blood relatives. According to the focus group discussions, *"The issue of this "disease of today" (HIV/AIDS) is very complex such that if not just a person of your own blood (children), mother or your brother or sister then you just die without anybody coming even to see you "*. The complexity of HIV/AIDS as captured in the above statement is with regard to the awful ailment process and the resource demanding nature of the pandemic. The CHWs stated, *"Taking care of HIV/AIDS patients requires time, money and other material resources.* On the other hand, the patients lamented that,

"You ail for a long time until people dislike you. People have no hope once it attacks you. What they see in you is death ". (Ja-Abi, a 45 yr-old woman)

The community has given HIV/AIDS a dreaded face. People refer to HIV/AIDS with phrases like "the big one", "the strong one", and "the dangerous disease". Others call it "take your flesh and leave my skeleton", "close the gate and bring the keys". All these names portray danger and massive deaths once a family is infected. Coupled with modes of transmission, taking care of HIV/AIDS patient is like "taking a risk ". People have intense fear that they may also contract the virus by caring for a person suffering from the disease. The infected persons are stigmatized. Unless directly affected, no one wants to come into contact in any way with an infected person. As soon as a patient begins to look thin and show symptoms like frequent diarrhoea and other opportunistic infections, people start to withdraw.

The pattern is the same even among the married partners where the blood relatives are still noted as the main support providers for their infected relatives. The presence of HIV virus in the family generated a lot of tension and a feeling of betrayal between spouses. The uninfected spouses accuse the infected of infidelity. Both discordant and physically strong concordant HIV positive partners exhibit indifference and unconcern for the ailing

spouses. Observations, in-depth interviews and focus group discussions indicate that a majority of male spouses told their wives, "*go back to your maternal home so that your people can also try for you*" once the wives became too sick to support themselves. For example, only two out of thirteen men in the study cared for their wives. Among the remaining eleven husbands, one of them who had two wives decided to abandon the first wife who was then seriously sick under the care of a 16-year-old son and he migrated to Mombasa where he joined his second wife who works there. Three other husbands transferred their wives from different towns where they lived together to come and be cared for by the mothers-in-laws and a co-wife in the rural homes. In the latter cases, the two mothers-in laws were over 70 years old. The two ailing women later moved back to their natal homes to seek support.

Some parents took six other women to their maternal homes when their health conditions got worse. However, these six women kept moving back and forth from the family of procreation to the family of orientation whenever they were seriously sick. I called this movement *care migration* as will be discussed later. Lastly, one woman, *Juci-Ko*, who stayed on with her discordant husband later got support from a brother-in-law's wife who sympathized with her.

On the other hand, the female spouses seemed from outside to care for their husbands since they stayed together. As depicted in Table 4.3, apart from the five women who separated after their male spouses tested HIV positive, the remaining fourteen women stayed on with their husbands. However, just like in the case of male partners above, female partners exhibit signs of arrogance and negligence to their husbands. The mother *oiAlf-Nya*, now 71 years old, took over the care of her 38-year-old son and wonders what has gone wrong with the "*women of today* who do not care for their husbands when they fall sick. The female spouses often put pressure on the parents and siblings of the infected partners to support them because *they are their persons*. The phrase "their persons" is with reference to blood attachment. The CHWs concluded that only wives with "good hearts" take care of HIV infected husbands. More details will come in the section containing patterns of discordance and concordant positive couples.

In this shift of attention to blood relatedness, women, especially widows and orphans were the most affected. As the orphans living with HIV/AIDS moved to maternal grandmothers, widows also sought support from parents and siblings. More details will also be covered in the section on *care migration*. But it is emphasized here that children are the main caretakers of their widowed mothers and sisters. In the study there were a total of 15 PLWHA under the care of children between 12 and 18 years old. But only one PLWHA was a man who had lost all his relatives including his wife. This is approximately 21.4% of all HIV/AIDS patients interviewed. The girl-child more often provides nursing care while boys look for food and money.

The children caretakers get some support from the mothers' friends, especially those from merry-go-round and religious groups. The welfare members are basically women who hail from various common birthplaces locally known as *nyi pinje*. It is noticeable in their terms of address as *nyimine* (sisters), which connotes some blood relationship. The infected widows mainly rely on such networks of friends to whom they send their children for all sorts of assistance. Like the CHWs, friends are also limited in many ways. Apart from the geographical gap, they have limited financial capacity to guarantee continued material support. They thus help the patients while keeping an eye on *anyuola* (close lineage members) who according to them should have taken up the responsibility as it has been in the past.

In addition, the friends and the CHWs did not want to run the risk of being left with the whole burden should the patient die. Focus group discussions revealed that there were incidences in the community where certain families abandoned their dead family members because they were not incorporated right from the beginning of ill health. The CHWs and friends thus retreat when a patient's condition get worse. They instead approach *anyuola* of these patients to step in and assist. But many of these kin members are not always willing to do so because of the fear of contracting the HIV virus as was noted earlier. For instance, *Ja-abi*, narrates the reaction of her brother-in-law's wife about

her ill health as the brother-in-law himself spreads rumours of her imminent death as follows:

"Eh! My brother-in-law's wife", she calls me. "I don't want to cheat you. You look frightening. I don't even want to see you. When I come to you like this I fear greeting you with my hands. It is not that I dislike you 'my sister' but I have a lot of fear in my heart. I don't know even how to begin". You know, she tells me all these while her husband who is my brother-in-law also tells people how I'm dying soon. And imagine, he has never come to me ever since I became sick. The villagers he talks to again come and tell me everything he says. (*Ja-abi*, a woman aged 39 years)

Sometimes the patients longed for people to chat with but could just see them from far as they went about their daily activities. But even when they paid visits they did not take reasonable time with the patients. However, a few people from *anyuola* who care for patients at least must have had some friendly relations. The patients say they were close to each other even long before the illness began.

5.3 Gender and the care for HIV/AIDS patients

Although, blood relatives are noted as the key support providers for HIV/AIDS patients in the study area, gender also plays a role in determining the nature and place where support is provided. Female relatives including mothers, sisters and daughters as well as grandmothers, offered nursing care, except in a few cases where four young boys assisted their mothers with whom they lived alone and one father who took care of his adult son who was deserted by his wife after he tested HIV positive. This son had also lost his mother when he was 5 years old, and the stepmother he lived with since then has now become unconcerned most probably because of his illness.

In certain situations the infected persons greatly feared their fathers and did not want to request them for any support. Six out of the nine PLWHA expressed intense grief over abuses the fathers often hurl at them after going on drinking sprees. Some patients expressed the sentiment, saying "*my father has lost hope in me and many occasions he tells me in the face that I have wasted myself*".

For that reason, "mothers are everything". One male patient, *Josi-wa*, described a mother as "*oliep* (a big acacia tree) upon which all kinds of birds perch". According to him every person runs back to the mother to find rest in case of adversity. CHWs during focus group discussions maintained that since the mother is the one who experiences labour pain, she feels pinched any time her child falls sick. The CHWs also asserted that women are very sympathetic, understanding and caring unlike men. Fathers begin to quarrel, saying, "*Didn't I tell you to take care? You have contracted disease and now you are coming back here. That is up to you with your mother*". So, when a son or daughter is sick it becomes difficult for him or her to approach the father because of the anticipated reaction.

For HIV positive women whose mothers had died, it is like the relationship with the maternal home is waning too. They rather go to their sisters married in other places. For example, in this study there were five infected widows who had come to live with their sisters. They travelled from as far as Rachuonyo District in the southern part of Nyanza province. There was also a case where one young girl was sent by her father from Rarieda, a neighbouring division to come and help her elder sister who did not bare any child.

However, brothers are supportive mainly on the line of therapy consultations, and transport. For example, brothers took their ailing sisters to various hospitals for the serology test and arranged for their transport for subsequent clinic attendance. But they did not accommodate the sick for long. This is because the brothers' wives are not very free to stay with the infected sisters-in-law. Since mainly females cook and wash clothes among other household duties, it is not very easy for brothers to offer such help. The infected sisters too, do not want to bother their brothers' wives. Instead, the brothers support by sending them food and other material necessities as children of the sick take up the responsibility of providing nursing care. Some children were conditioned to migrate to schools near their homes so that they could go and come back to prepare food for the sick parents. A 12-year-old boy was withdrawn from a boarding school where he

had been sponsored by a certain NGO to come and live with his sick mother. When the mother gets some relief he goes to a day school nearby.

On the other hand, where there are boys and girls as caretakers, the girl-child is more disadvantaged. The boys leave nursing care on the girl-child no matter her young age. Boys are mainly concerned with ways of getting money like charcoal burning or doing bicycle taxi business. One morning I observed a case where a sick mother complained to her sons that her little girl, 12 years old, did not fix her some good tea the previous day. But the boys did not take the responsibility to do the cooking themselves. Instead the boys quarrelled the young sister and threatened to beat her if she did not learn to cook properly. I sat down to enjoy some stories together with the patient but very keen to observe the breakfast the little girl was beginning to make on an open hearth outside the house. The poor little girl poured approximately one litre of milk into a saucepan full of water, which I guessed was more than four litres. The firewood that she was using kept on producing thick smoke that covered the whole cooking area. She kept on blowing the fire and all the dust from the ashes poured into the tea. Finally, she brought the tea to the table. Of course, I was served some cup but it was too bitter because of that smoke. The sick mother sipped it once and just nodded in disapproval. She never commented loudly again but pretended she was getting nauseated. She then left and went into the bedroom to sleep. From my own observation, this ailing mother was starving not for lack of food but because nobody could prepare it properly for her to enjoy.

Key informants held that in the Luo community from time immemorial men did not take care of the sick. Instead they were charged with the responsibility of looking for food, specifically hunting and defending the community against any external attacks. The Luo kept livestock besides fishing and thus moved from one place to another in search of pasture. In the process clashing with other ethnic groups they came into contact with. They also had intra-ethnic conflicts as the clans expanded and needed bigger pieces of land. As a result men were required to be free of any condition considered unclean, because it could make them vulnerable in times of war and get killed. Thus all domestic duties were left in the hands of women.

5.4 Patterns of discordance and concordant positive partners

In the study there were 14 PLWHA in a discordant relationship, a condition where one partner is HIV negative. Among them were six men and eight women. Only two families were polygynous, where in one family only the husband was HIV positive while his two wives were both HIV negative. In the other family, only one wife was infected with HIV virus. The study also included ten concordant positive partners among whom two families were polygynous. One man lived with his two wives in the rural home as the other man had a second wife in Mombasa while the first wife lived at home.

For these families, continuous ill health of one or both of them prompted the partners to go for voluntary counselling and testing except in one, the family of *Ogo-Uyo*. *Ogo-Uyo* had two wives, but the second wife ran away after internal squabbles with her co-wife but later returned. She stayed away for three years and on her return she re-united with her husband without any blood test. However, after three months *Ogo-Uyo* got worried about this second wife whom he thought must have had relationships with other men the time she was away. The fact that the woman came back with one child born out of wedlock was a clear proof. *Ogo-Uyo* decided to go secretly for a serology test in Kisumu where he found that he was still HIV negative. *Ogo-Uyo* then gathered courage to tell this second wife that they go for couple counselling and testing at Bondo district hospital. Like the rest of the discordant partners, *Ogo-Uyo* was surprised to find himself HIV negative while the second wife was infected. "*How come and we have been having unprotected sex?*" *Ogo-Uyo* wondered.

The reality of discordance remains a mystery even to the health providers whom I had contact with during my fieldwork. They described discordance as a "*time bomb that can explode any moment. May be the virus is still hidden somewhere unknown in the blood*" they asserted. In fact, one man and his wife tested concordant HIV positive two years later when they went for another HIV test. It was a double tragedy for the family since their last-born daughter, now one and half years old, also tested HIV positive. The family now looks helpless as the care burden increases to cover three people. The husband

complains that he feels too weak to carry the wife and the child to a health facility for **ARVs** regularly as required.

It was never an easy ride for concordant positive women like *Na-Uya*. *Na-Uya*, whose husband was very sick, complained a lot that her parents-in-law insult her saying she infected their son with HIV virus because she comes from Kisumu town. The parents-in-law believed that ladies from urban areas are sexually promiscuous. All the time I visited this family, she told me she wanted to leave for her maternal home to find peace. She finally disappeared after my third visit.

However, among polygynous concordant positive families rivalry and blame intensified among the co-wives as the husbands skewed towards one of the wives. One husband migrated to live with the second wife in Mombasa after his retirement as was noted in the previous section. The other family lived here in the rural area but the husband just supported the first wife whom he used to carry on a bicycle to Nyang'oma dispensary. The second wife trekked while carrying her young infected child. The man claimed that both wives and their two last-born children were all sick, and he could not manage to earn' all of them to a health facility to pick medicine considering that his health condition was also deteriorating. This second wife decided to stop going for medicine and threatened to go back to her maternal home.

Male and female discordant partners expressed almost similar post-test reactions to the partner's HIV status. Although various factors still tied together these partners with mixed serostatus, it is significant to note that news of the HIV virus caused a lot of instability in these families. One female partner ran away after the husband tested HIV positive. The other five HIV negative wives could not leave the husbands simply because they had tested HIV positive, though in part children were the cementing factor. *"Nowhere the children would be accepted if I leave"*, one of them said. While other HIV negative female spouses did not want to breach their nuptial vows, some of them feared that the husbands would haunt them if they failed to provide them with good care.

Bride-wealth was also another strong binding force. Half of the HIV negative female spouses had at one point attempted to go to their maternal homes. But their maternal relatives always insisted that they return since it would look bad if they abandoned their husbands when they are sick. Relatives of the husbands also followed and pleaded with them to come back. Key informants explained that among the Luo if marriage breaks the groom or his paternal relatives have an authority to demand for the return of either the woman escaping or reclaim bride-wealth that was paid to the bride's family.

Nonetheless, it was never smooth for these discordant partners. One HIV negative wife separated as some of them disclosed the status of the husbands without their consent. Others nagged the infected husbands and sometimes threatened not to give them food. *Onya-Wa*, the husband of two HIV negative wives recounts the turn of things in his house, when his first wife yelled at him in front of his two sons, 16 and 18 years old, when he requested her for food. It was such deafening shout, he recalls:

"Did you bring something to be cooked for you? If you know you didn't, then you'd rather keep quiet. I give you when I wish. I didn't tell you to walk aimlessly", she told me. I almost fainted but got courage since I had told the sons about my status. I didn't utter even a word. I simply went to sleep. I tell you, I took two days on bed without eating. And since the incident occurred on a Sunday, the following Monday the sons also went to school. While the second wife as usual thought everything was normal since I was within the home and the incident happened when she was away. What surprised her was why I was ever in-doors and the elder co-wife says nothing about it. She braved on and came straight to me and found me crying. She got shocked but just told me to stop crying. She wiped my tears, then lifted me up by the hands and told me to go with her to her house where she offered me porridge to drink, after which she bathed me. I had become too frail to do anything. I tell you, I almost died of stress and hunger. But I have to appreciate the salvation I have. I know, I could have "acted like a man" (*could have beaten the wife*). (*Onya-Wa*, a 55-year-old man)

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Other HIV negative wives always threatened to live. But there were some identified probable reasons behind the threats. First, they feared for their lives as some infected male spouses coaxed and coerced discordant female partners into unprotected sex saying *they had been living like that in the past before they knew their status and there was no transmission of the virus yet*. The victims reported some of these cases to counsellors at the VCT sites. But whenever the husbands adhered to the use of condoms these HIV

negative women did not fear having occasional coitus. Furthermore, there was more hope, especially where the wife was HIV negative. They further opened businesses for the HIV negative sister-in-law to stabilize the affected household financially. Other kin members working away from home promised to send their financial support every month. The also encouraged the sick not to fear because "*many people now take medicine and live longer*".

In contrast, there is quite a lot of uneasiness where husband is HIV negative. First, they doubted VCT results. Six of the discordant husbands walked to various VCT sites to verify the HIV results. For example, *Ogo-Uyo* went to seven VCT centres. He began in Kisumu where he visited the New Nyanza General Hospital and other two centres. After one month he went to Bondo district hospital. He proceeded to another health facility in Rarieda division, called Matangwe, but he was not yet satisfied with the results. Lastly, he visited the two local health facilities, Nyang'oma and Uyawi, each at an interval of two months.

The discordant husbands strongly demanded an explanation from their wives concerning the source of infection. The counsellors at VCT sites said that certain husbands right away narrated how they had suspected their wives of having extra marital affairs. Some of these husbands turned very violent and simply looked for flimsy excuses to beat the infected wives. *Le-Wa* narrates the brutality of her husband after she confessed to him that they got married when she had known her HIV status but did not tell him because she feared he would not marry her. This followed her previous experience when two men declined to marry her after she went for the blood test with each of them.

Le-Wa and her discordant husband each remember their six years of marriage before going for couple counselling and testing as was full of love. Now it has turned sour. The man complains *Le-Wa* spoiled his relationship. Despite the fact that the husband is HIV negative, *Le-Wa* explains "*the man is isolated; he does not interact with friends as before and always expresses anger at me. We no longer chat as a family. I live on commands;*

"do this, do that". The man does not allow me to talk because I'm HIV positive. He says, "I m already dead".

What now holds *Le-Wa* and her husband is their daughter, two and a half years old. Given that *Le-Wa* had known her status, when she got pregnant she simply cheated the husband that she had some complications and needed the attention of a private doctor. She went to Kisumu where she attended her prenatal care till delivery. She adhered to PMTCT instructions and did not even breastfeed the little child, whereas the husband believed all these practices were because of the complications the wife told him. Finally, the child tested HIV negative. Like the rest of the men, *Le-Wa's* husband always threatened to send her away and marry a new wife.

Moreover, five of the discordant husbands expressed fears and did not want even to stay in the same house, let alone sharing a bed with the infected wives. For example, *Ogo-Uyo* thought his wife could prick him with a sharp object and infect him. Since he worked away from home where the wives were, he did not want to go there because his first wife could suspect him if he failed to spend some nights in the house of the second wife, the one who was infected. And like *Ogo-Uyo*, all these other discordant men could not dare have even protected sex with the infected wives, unlike the case with women. After a short while some husbands went back to the counsellors saying they wanted to marry new wives. Indeed one man went ahead and married a new wife although others still feared that they might get women who are also infected. They did not desire to go back for the test since they thought the test could prove them HIV positive this time round.

In terms of care, just one husband consistently took his wife for medical support. Some ignored their infected wives' healthcare needs and did not want to provide any fare or money required to buy medicines for opportunistic infections. These abandoned HIV positive women walked on foot to Bondo district hospital and Nyang'oma dispensary despite the long distances. And when one of the HIV positive women became too sick the husband instead requested his brother's wife to help her. This brother's wife as was

mentioned earlier, felt ashamed to let the man take care of the wife while she was in the same home.

Unlike the female spouses who were HIV negative, only two men joined the *discordant support group* with the infected wives. The rest of the HIV negative male partners just attended one seminar organized by a certain NGO in a Bondo hotel. Thereafter they did not want to identify with the group anymore. They often boycotted all the meetings arranged by the infected partners in the village. Follow-up studies show that these men did not want to "tarnish their names, and wondered what the community would think of them when they learnt of such a health problem in their families. "*It's shame* ", the men said.

Inasmuch as some of these women wanted to go public in order to eliminate rumours surrounding their health status, the husbands neither revealed nor permitted the wives to disclose to their friends and relatives. For example, *Le-Wa's* husband explained that it is impossible to disclose the status of his wife to his parents and other relatives following circumstances that preceded their marriage. One factor was that, "*my parents forbade me from marrying this woman because they doubted her chastity. She was very beautiful and many men also fought to get her. But I defied the parents' conditions and married her. I can't go back and tell them that she is HIV positive. So. she is now "my elephant head"*, meaning it was his own fault and he has to bear the burden alone. Although he appreciates being in the *patient support group*, he says it is like advertising the problem to everyone. There is no way he can convince his parents that he is HIV negative and the wife is HIV positive.

5.5 Care migration and its implications

In the previous sections we saw movements of patients especially widows from one location to another in a bid to get support and care from relatives. At the same time, there were cases where married daughters came back to care for their sick parents. This section moves a step ahead to look at the implications of the movements both on the patients and the caretakers.

To begin with, a total of nine widows and two orphans living with HIV/AIDS were involved in transfers, migrating into the study area as others went outside the division where maternal relatives lived. But there was a lot of anxiety about the stay of the patient in these places. This was because death could occur and in part create other complications besides unplanned expenses to transport the body to its rightful place for burial. In the Luo community, if a married woman dies she is buried in her marital home. It is believed that if such a woman was buried in her maternal home she would haunt the coming generations of girls in the family and sometimes hinder them from getting married.

As a result, when such a patient developed any serious complications, the caretakers always got nervous and hurriedly returned the patient to her marital home without considering the care she needs at this critical time. *Jan-Nya*, a victim narrates her story of how her brother censured her mother for keeping her and would give the family problems when she dies. *Jan-Nya* was attacked by Tuberculosis. Because *Jan-Nya* did not have a house and her husband had also died, the brother and other lineage members then decided to take her to her sister's home. However, her sister had a big household and at that time there was serious food scarcity in the area. *Jan-Nya* says she almost died of hunger instead of disease. Immediately she got some relief she escaped and came back to her mother.

"Take me back I go die in my house. I don't want to give you problems ", some patients also demanded. These patients were losing hope and did not want to die away from their own houses. The caretakers too despaired once the patients insisted on returning to their home. What comes into their minds is the expense they will incur should the person die. This follows some previous experiences in the community where husbands' relatives refused to bear the transport costs of bringing back the body of such women when they died wherever they had gone to seek for care. It did not matter whether the deceased was separated or not, though it depended on whether there was an agreement at the time she was leaving. I observed three cases in the area, although not part of the study participants,

where some women who came back died and the maternal family members bore the burden of taking the bodies back for burial. But according to the CHWs only women who had strained relationships with their in-laws or had separated were disowned. The husbands' relatives provided only the graveyard as the maternal kin were conditioned to bear every burden, including food they would eat during burial.

Ne-Nya and five other widows relied on their daughters who had been married in other places who from time to time came back to take care of them and return when the ailing parents got some relief. The daughters described this situation of operating in two places as "too difficult". This is because they have their children and spouses far away, and when they come back, they are new people in the area. The daughters have to rely on the food or money they carried along from their own houses. *Atis*, *Na-Nya's* daughter, desperately explains how she has spent all her savings in travelling and helping her sick mother. *'To and fro journey costs me around two thousand Kenya shillings because I have to use more than three vehicles on the way'*. The mother's condition forces *Atis* to check on her almost every month. Other married daughters, like *Atis*, lament that the situation is already causing tension between them and their husbands, whom they depend on for more support. This is because these daughters are not settled and cannot do any productive activities to generate income to sustain the demands at hand. The husbands also feel bad as they are always left to take care of children, which also limit their search for livelihood.

5.6 Secrecy and difficulties in the care process

The findings show that 40 (57.1%) of patients had not disclosed their HIV status to the caregivers. Even among the remaining 30 patients who claimed disclosure, 8 of them did so when they were totally bedridden as others revealed partially to spouses leaving out parents and other close relatives like children.

The patients gave varied explanations for delaying to break the news of their HIV status. First, some did not want to shock their kin members because the families had lost several close relatives to the disease. It could certainly make them think of another death soon

befalling the family. Others kept silent to save their children from beginning to experience orphanhood prematurely. Those with spouses felt they could be accused of promiscuity and be deserted as a result. Patients feared they could be seen as sexually immoral.

But the weight of the matter was fear of being abandoned. One of them said, *"it is a precautionary measure to deliver this message of HIV status to a relatively few people "*. This suggests that these clients were trying to maintain their caregivers around them by keeping silent about their HIV status.

In the process of concealing their HIV status these patients faced a lot of challenges. These patients took medicines secretly both at home and from the health facilities. At the health facility the patients sometimes hid when they saw around somebody who knows them. Such patients were always worried about villagers taking the message back. At home they kept medicine in their pockets. Under these circumstances, it was difficult for the patients to strictly adhere to the time for taking medicine. For example, when other family members stayed around the whole day the patient avoided taking the medicine even when time was due.

Sometimes when the patient was too sick nobody knew what to do. When the patient goes to hospital he or she explains malaria instead of the exact illness already diagnosed. For example, a maternal cousin took *Alf-nya*, to Chulaimbo, a hospital renowned for HIV related medication in the western region of Kenya, hoping that he would open up and tell the health personnel his problem. The cousin did not know that *Alf-nya* was already on ART at Nyang'oma dispensary. The cousin just suspected his status for *Alf-nya* had been sickly for along time. Besides, the time *Alf-nya* was being taken to Chulaimbo hospital his clinic day was due and he was supposed to take medicine for the new month. *Alf-nya* insisted on malaria and that is what he was treated for and he returned home without HIV related medicines. Yet, here at home he was taken care of by an old mother over 70 years and he knew there was nobody to take him to Nyang'oma dispensary again. The nephew that he had told his status lived in Homa Bay and that month he did not turn up. He

defaulted for three months and later he went to Bondo where he pretended that he had not gone for HIV test. So he began the whole process a fresh.

The CHWs also feared visiting the patients regularly because the family members of the sick would be suspicious. The patients too were also not open to let the CHWs come to see them. Instead the patients secretly went to the CHWs' homes. Some visited the CHWs at night to avoid curious villagers and relatives. But it was impossible when the patient was too sick to walk. Above all, the CHWs could not advise caretakers on safety measures.

The patients, on the other hand, feel ashamed to emphasize on diet as advised at the health facilities. *Jo-Ma*, a young man in his early thirties who was deserted by his wife had to split from his own mother's household to cook for himself in his *simba*, to ensure that he ate well and in time. Before the split, he explained, "*I used to feel very hungry and I could cry for food like a child after taking drugs on an empty stomach*". The mother used to prepare breakfast at 10.00 a.m, which was too late for him because he had to take the medicine at exactly 8.00 a.m. This alone, never spared *Jo-Ma* from being ridiculed in the village as *a man who cooks for himself* Traditionally, a Luo man is not allowed to go into the kitchen to cook, more so in his own *simba* (son's hut) when wife is away.

Some concordant positive partners expressed great shock and grief when they realized their partners concealed their status from them. One female and four male spouses among the concordant families began to sicken and went for HIV test but kept the results confidential from their partners who thought that they suffered from "normal" sickness. But as sickness persisted they got suspicious and demanded to know what the problem was all about. The ailing partners dodged but finally broke the news remorsefully. But this did not spare them blame and accusation. Consequently, the partners exhibited no commitment towards the care of the ailing spouses unlike before. Follow-up with the CHWs show that when the sickly partners demanded attention, the partners became too rude to them.

Fre-PB for a long time did not want his mother to know about his health problem. But he opened up immediately he and his wife went for couple counselling and testing. The test proved the wife was HIV negative. The mother narrated the agony she had gone through over the previous years because her son had refused to go for the HIV test. The parents of *Fre-PB* had taken him to faith healers as well as folk specialists and no positive change had been realized. The family then gave up. But the day he opened up, all family members came in full support. The family organized a fund-raising and opened for the wife a business in order to make the family stable financially.

It was this time that I learned from the mother that *Fre-BP* had had poor health since 1994, the year he sat for his fourth form examination. At the time of this research *Fre-BP* had lived with the virus for over twelve years. *Fre-BP* opened up when he had a second serious attack of tuberculosis. He was then put on both ARVs and IB treatment while he had a CD4 count of only 7. In his face there was hope but his health continued to worsen. He finally died three months later. According to the family and health providers, had he accepted his status and gone for medical support in time he would not have died that prematurely. This conclusion was based on the fact that he managed to regain some good health after he was linked with ICROSS, where he got some nutritional supplements and medicine for minor opportunistic infections. But he delayed to start ARV given that he did not want to go hospital and no family member knew what was happening.

5.7 Disclosing HIV/AIDS status to child caretakers

In the study there were 21.4% of PLWHA cared for by children between 10-19 years old. The ages of the children caregivers ranged from 12 to 18 years old with 12 as the mode. Since the PLWHA were advised by health providers to disclose test results to a "treatment buddy", who could either be a friend or a family caretaker, the clients had no choice but to tell their children who happened to be the main care providers. Remember that in the earlier chapters it was mentioned that the *care management group* was effective but very temporary, leaving only close blood relatives to bear the burden of care. Of course, not all clients revealed their HIV status as discussed in section 5.7, except five clients who disclosed to their children.

However, it was like these five clients opened a can of worms. They had to deal with several questions that kept flowing from the children, especially how they will obtain their education and where they will go to live after the parents' death. These were not easy questions for the HIV infected parents to explain satisfactorily to their inquisitive children. As a researcher who had also become like a family friend, the children did not hide their anxiety. Some sneaked to come and ask me, while others could pretend to escort me whenever I visited them. Similarly, the infected parents often requested me to affirm to the children they are stable since they had been put on treatment. In all cases the children sought an assurance about the future of their parents.

According to these parents, disclosure of HIV status was meant to prepare the children to come to terms with the disease instead of keeping them unaware and relying on guesswork. *"Children are taught about HIV/AIDS at school and also read about it"*. Some children asked the parents why they take drugs daily and what the drugs treat. While others could ask what the "doctor" said the disease is. Parents' disclosure also meant to let the children caretakers know how to help and whom to consult, especially whenever the sick parents developed serious health complications. For example, the children kept close contact with CHWs, whom they also requested for any material assistance like food when they did not have.

5.8 Lack of food and poor drug adherence

Interviews with primary caretakers, patients and CHWs show that a majority of the patients do not access proper nutrition, which according to the health providers prevents the patients from getting better. One HIV/AIDS patient said:

Nutrition is really affecting us. How do you take medicine without food? You know, we are advised to take balanced diet but we can't get it. The area is always very dry and food is very expensive and scarce in the markets around. At the same time we are advised to take drugs at least after eating something. Sometimes food is not there. We are forced to forgo certain meals like breakfast and wait for either lunch or super. And when I take drugs on an empty stomach, I feel very hungry. The drugs are overwhelming. Now I find it difficult to take drugs according to the doctor's prescription because what is required first is not there. That one even

brings delays, because I'm tempted to postpone taking the drugs till I get what to eat.

(*Fre-PB*, a 35-year-old man)

This lack of food caused patient's poor adherence to drug regimen. Ten patients explained a similar case where they intentionally skipped taking medicine as per their timetables specifically because there was no food. A personal communication with a health provider in a local health facility shows that HIV/AIDS patient's nutritional intake is almost double the ration of a normal person. And the needed drugs are too powerful to be taken on an empty stomach, lest they cause fatal effects on the patient. The person needs proper feeding for the drugs to work effectively.

However, lack of food was a result of unstable sources of income for HIV/AIDS patients. In terms of daily livelihood, the findings indicate that 42% of these infected and the caretakers mainly depended on subsistence farming as illustrated in Figure 5.1 below. Crops mainly grown include sorghum and maize as the staple food crops. The crops sometimes do well when there is enough rainfall like the time of this research when good harvest was realized. But this good season just benefited a few families that did reasonable and timely planting. Almost all the affected families delayed because they do manual hoeing. They neither own any bulls nor have money to hire a tractor to tilling land for them.

In-depth interviews reveal that the families had sold all the animals they possessed to meet medical costs and the funeral expenses of their close relatives that had occurred in the recent past. Among the seventy HIV infected persons visited only three have some few goats. *To-ko*, like other *clients*, wonders how he will fend for his family since his ill health cannot allow him to do any duty that requires physical effort like hoeing that his family depends on.

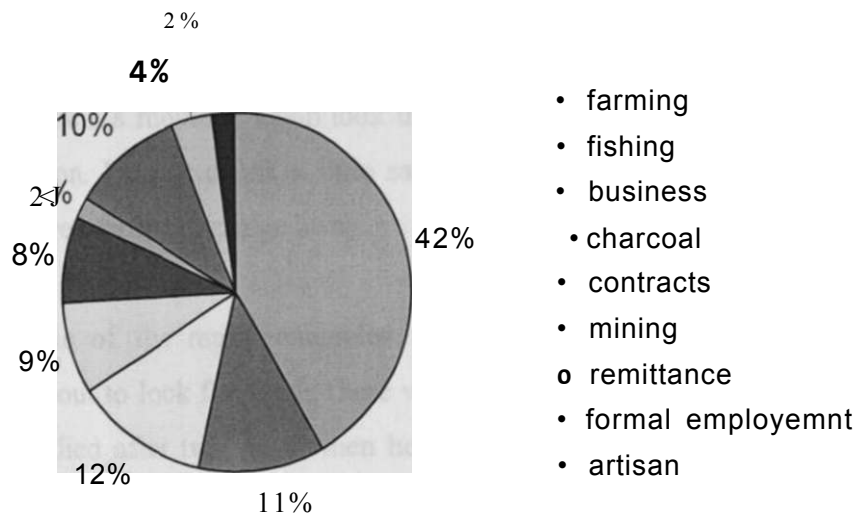


Figure 5.1: Sources of livelihood for people living with HIV/AIDS.

Other affected families combine farming with several income generating activities like business, charcoal burning and contracts on people's farms during planting and weeding seasons. Whereas six of the patients relied on contracts like being housemaids as one of them temporarily worked at a local fish industry. One informant who did self-care operated a shop in a market centre. Other patients stocked shop items at home from where the village customers came to buy the goods.

The rest were vegetable sellers and fishmongers. Some caretakers who do the business of selling fish went to the beaches very early in the morning to buy fresh fish from fishermen immediately they came from their nightlong collection in the lake. The fishmongers took fish, dried it and sold to other retailers who proceeded with the business in far areas like Kisumu and other towns in Western province of Kenya.

In this fish business, some caretakers could take a whole day at the beaches while the patient stays hungry at home. I observed in one family where the wife prepared porridge and put it in a jug for the sick husband to drink when he woke up. This man, *Alf-Nya* was very weak and could not walk. He called his young boy, 5 years old, to give him a mug of

porridge next to the bed where he was lying. But the porridge had thickened, and the child did not even shake it well. When he took the porridge to drink the whole of it flowed and some poured covering his nose. He slowly put down the mug. I sympathized and stood to help him wipe his mouth. I again took the mug and shook it well and gave him to drink using a spoon. He just drunk a little saying he had lost appetite. He then called the son to take the remaining porridge away.

Alf-Nya was just but one of the many examples who suffered simply because the principal caretakers went out to look for food. There was another case where a client, *Jo-Mbu* was rained on and died after two days when he was put on the garden to prevent squirrels from destroying germinating crops as his wife went to do *amali*, the contract of digging in other people's gardens for wages. This suggests that even the sick had to be included in the daily activities as other family members also go out in search of food. Note that *Jo-Mbu* was very sick and even his voice had become so dim to produce sound that could scare the animals. He was just put there as a scarecrow. Unfortunately, that fateful day the rain began a little early in the day before the wife came back.

Some of the HIV positive women enlisted their young children into the income generating activity of cutting and burning charcoal. The children did paid job over the weekends while some did it during school going days. And when the parents were too sick the children did not go to school at all, which actually affected their performance academically. It was a big problem to girl-child caretakers who could neither burn charcoal nor do any other income generating activity in order to support the sick parent. The patients under the care of young girls depended solely on remittances and donations from well-wishers and close relatives who visited occasionally. Three girls got pregnant and dropped out of school and the sick parents highly suspected that certain men lured them into sexual activities with promises of financial support.

Mining also takes place around Wagusu and Abimbo and employed two caretakers. While four caretakers had formal employment, two patients were shoe cobblers.

In sum, many of these HIV/AIDS patients and families have low-income levels and the patients could not get a balanced diet. This aspect of food led to a lot of psychological stress observed among caregivers who then complained that patients only demanded *"sweet things like fish, meat and if it was vegetables then milk had to be put in it or else they rejected it"*. But the caretakers could not afford all these ingredients. It became like a tendency that the patients did not want to eat meals prepared by the primary care providers, and when a different person came to visit them with food the patient ate so well. This habit was stressful to caretakers as it implied that they were failing in their duty.

In addition, the caretakers could not find enough time to look for food because patients needed their attention all the time. Husbands in particular, sometimes did not want their wives to take much time away from home. The wives complained that their husbands often suspected them of looking for other men. In such instances, it was devastating for the caretakers as the sick quarreled them whole night. Sometimes when a new person came, especially a close relative, the patient told him or her very negative stories about the principal caregiver. Upon enquiries, the visitor finds exact opposite of what he or she had been told. However, focus group discussions suggest that some patients had developed *mental impairment*.

5.9 Caring for children with HIV/AIDS and the fear of infection

Apart from the problems of food and inaccessible healthcare support for children living with HIV/AIDS, it was a more risky and disastrous venture for families supporting them.

I report here a real story

(At 9.00 a m my cell phone rang. Oh! The caller was a caretaker of my little friend, a young boy 8 years old living with HIV/AIDS. When I picked up the phone the caretaker just said, "come, your friend". And she began to cry. I thought the young boy was seriously sick or dead. I took my bicycle and went. I found the young mother of two children weeping painfully. I was shocked. But I tried to console her and she began to narrate the story).

"Your friend was caught molesting my little girl yesterday". *How? I asked in a low tone.* "He was caught 'sleeping' with my daughter in their room". *(She broke in tears again. The handkerchief she had in her hand was totally soaked. After a few seconds she composed herself well again ready to talk).* "You know, yesterday when I went to work in the afternoon, I left the children playing behind the house. They were together with the neighbour's child. All over sudden there was silence and the neighbor couldn't see them any more, except the youngest child, one and a half years old, who sat by the door. The neighbour assumed that they were around. But the silence went on too long. She got scared and went to my house to check. She peeped through a window and saw the two copulating. When they saw the neighbour they got scared and ran to hide under the bed. She just called them softly to come out. She held them by their hands and went with them to her house to do investigations. The little daughter 'innocently' narrated that the boy had been doing to her such things for some time but always warned her not to tell mom, because mom would beat her. The boy said he had seen another schoolmate doing the same thing with another girl on their way from school. So, he was also trying. He mentioned he had done it thrice. So, when I came in the evening I just cooked for them and ate. But when I was just about to sleep the neighbour came to me and broke this news. I tell you, I cried and I was totally confused. She took the young boy to her house to sleep. The following morning I woke up and found that the young boy had escaped very early in the morning to go to his maternal grandmother. The home is barely two kilometres away from here. My little girl was then rushed to the District hospital for post-exposure prophylaxis (PEP). (The caretaker, uncle's wife, 26 years old)

This incident caused pain and anxiety in this young family. They had to let the boy stay away with the grandmother whom they then gave medicines to give him. After a short time when I followed the boy and observed that care in this new place was not proper. The boy had developed a lot of rashes all over his body. Two months later he got hospitalized and did not sit his end-term exams. Though this maternal uncle's family supported from far because it was the uncle's mother who then took the responsibility of caring for the boy, the uncle's family was extremely afraid to risk inviting the boy back for the safety of their children. The neighbours who also heard the story did not want to see him around.

This story is just but an example illustrating how certain behaviours of patients lead to their stigmatization and neglect by their caretakers. It also suggests that great care must be taken to ensure the safety of all family members whenever a family lives with an infected person.

CHAPTER SIX

PERCEPTIONS AND PRACTICES

This chapter captures cultural beliefs like *chira*, spirit possession and witchcraft. They are here presented in the context of delays before going for the HIV test and enrolment into the home-based care programme as well as interferences in the provision of nursing care and lack of adherence to the drug regimen.

6.1 Witchcraft and spirit possession

I started feeling sick in 1994. At that time I was too sick and the White man who sponsored my education took me to a hospital in Nairobi. I got some treatment but the illness did not clear. So, I just stayed like that, going for treatment little by little until I did my fourth form examination. After that I came back to my parents. They also tried for me (seeking treatment). As you know, we, people of Luo community have some funny beliefs that once an illness has "defeated" hospital treatment we can go and try the traditional medicine. In fact, I'm not afraid to say that even "witchdoctors" we consulted trying to find out what was happening because my parents thought that I could have been bewitched for a reason that some white man sponsored my education. But all these did not help. When it reached April 1997, some aunt of mine advised me that we go and try somewhere else. She took me to "*Roho*" church and I was really prayed for and in fact, it was miraculous that I got "healed". Everybody could not believe what happened because it had reached a time that people had said, "this man cannot survive, he must die". But from the prayers my health improved to the extent that even me I became surprised. Since that day I accepted Jesus Christ as my personal saviour. I even went to look for employment in Nairobi. I stayed there and got married in 1999. Soon after marriage, I started feeling the problem again and it resumed full blast in the year 2001. I prayed but there was no improvement. My mother suggested that I go for HIV test, but I did not go because I thought if it were HIV/AIDS I could have died long time ago. I just believed somebody had caused the calamity in me. I never went for VCT until November 2005 when I got serious attack of tuberculosis. (*Fre-PB, a man in his early 30s*)

The above excerpt is a case showing how cultural belief in witchcraft among the Luo delayed uptake of VCT and subsequent enrolment into the programme of home-based care. In this case, it took *Fre-BP* almost eleven solid years to know his status. However, *Fre-BP* explains very clearly that he went to hospital before finally going for traditional and faith healing. And his delay also came in part because of the fact that those days doctors could not suggest VCT for patients. Not him or his parents were told about the need for such a test. Even long after VCT had become an open exercise, *Fre-PB* still stuck to the belief that somebody had caused the ill health in him. His mother explained that she almost separated with her husband over *Fre-PB's* illness. The father too,

believed his son was bewitched and he did not want to hear anything like going to hospital.

This belief did not stop even after a patient is initiated on ART. Some HIV/AIDS patients who continued to experience complications despite taking ARVs claimed that there is someone responsible for their ailments. The caretaker of *Kon-PB* explained that the patient she took care of decided to abandon taking medicine because she had seen no improvement. The patient complained that her colleagues with whom she started treatment the same time had become strong while she grew thinner and thinner. She decided to go to a faith healer who told her that her former husband "picked her" (cast magic spell) to kill her because she deserted him. The faith healer gave her concoctions as an antidote to go and bathe with. She was further instructed to go back to the home where she was formerly married to bring some of her clothes and soil from there to help in her subsequent treatment. The caretaker says that from then the patient rejected ARVs. The faith healer did not encourage *Kon-PB* to continue with ARVs irrespective of the fact that *Kon-PB* disclosed to her that she had also tested HIV positive.

Other HIV/AIDS patients believed that they were possessed by ancestral spirits. *Aki-Bo*, a woman in her early twenties strongly insisted that she was possessed by evil spirits even after her husband disclosed to a CTIW that she had tested HIV positive at Kenyatta National Hospital in Nairobi. Her husband was working in Nairobi where they lived together before she became sick. The husband transferred her home to stay with her mother-in-law. Before he returned to Nairobi, he requested *Jo-Mak* to link her to an NGO for further support. *Aki-Bo* had turned deaf due to ill health and I could not communicate with her easily, though the CHW had known how to talk with her because they come from the same village.

Since the CHW had not told her about my research intentions, he just began to explain to her that I was part of the NGO he had told *Aki-Bo* about. I did not have even a chance to utter a word. *Aki-Bo* picked on *Jo-Mak*, "I told you I don't have HIV/AIDS. My illness is because of lang 'o (ancestral spirits). The other time you came here with people from

Bondo and I told you the same", *Aki-Bo* retorted. *Jo-Mak* replied, 'i didn't say that you have AIDS, but suggested that you go to Bondo hospital. As CHWs, we help people suffering from various ailments, not just HIV/AIDS'. This argument continued for a little while before I intervened and told *Jo-Mak* that every thing is voluntary. However, amid this confusion I learnt that *Aki-Bo* believed so much in spirit possession. She was in "*Roho*", the Holy Spirit church as was revealed by the cloth she put on her head, which bore the name of the church stitched on it.

6.2 *Chira*, Wasting illness as a result of violating traditional rules

In this community, *chira*, is a wasting illness resulting from several sources but mainly from failure to fulfill or follow the traditional rules (*chike*). Here are two cases to illustrate the point of *chira*. This does not mean that only two people found themselves in the dilemma of *chira*. There were three others more. All these five people had gone for the HIV test and were HIV positive. But because of the belief in *chira*, they were not consistent in taking their medicine. They threw all their weight in treating *chira* and neglected ARVs.

When my father died, we remained with our mother. But the mother did not get a levir to stay with again. So, I remained here as my elder brother used to work in a town centre. Then, when planting and harvesting were done, it was me "finishing all these rules". Since my brother's house had collapsed he used not to sleep here in the home, though he used to eat here. As a result "the cold" (*chira*) attacked me. I was then told to "try outside" and that is why I established this new home. Now I continue with *manyasi*, a concoction to clear the taboo causing *chira*. I had also gone for HIV test, though I missed to go for drugs last month and I don't have any now. (*Oke-Ye*, a man in his early 40s)

Out of the five the HIV/AIDS patients, three had a case where they fulfilled rules of the home, which they had no capacity to do because they were not the owners of the home (*weg dala*, pi.). As sons, they were considered too young to "carry the burden of the da/a" as they put it. After the death of the father (the owner of the home), the *dala* was said to be "improper" or "not good" until the widow is "taken" (inherited). Till then, it was taboo for the sons to continue doing planting and harvesting. Since the sons lived with their wives and fulfilled their conjugal rights as husband and wife they were considered to have fulfilled the rituals. Having sexual intercourse within the *dala* at such

a time fulfills rules. And this was considered wrong and it brings "cold" (*chira*). When illness began the sons were advised to move out of the homes, either by establishing new homes or going to a shopping centre to stay there.

Oke-Ye decided to have a new home during the dry month of February 2006. On the first day he stayed in a "tent" made of large polythene sheets. The construction of the main house was to commence the following day but nobody turned up. *Oke-Ye* laments that he is sick and the ground is very hard but nobody is willing to help him dig holes for the house. It was almost the month of March when the rains are expected in the area. *Oke-Ye* expressed fear that the rains would kill him in this "tent". Next to his bed in the "tent" he put a tin containing the concoction, *manyasi* that he drinks to clear *chira*. The caretaker says *Oke-Ye* abandoned medicine he was given at Bondo hospital.

Below is another case, illustrating how two men similarly claimed they married new wives whose husbands had died and unknowingly "broke the cord".

I married a second wife. But seemingly she had been married somewhere else and she did not disclose that to me. The go-betweens likewise never told me about it. I just welcomed her but she "followed me with bad air" (*chira*). Now I began to feel unwell. I went to Nyang'oma dispensary and I was diagnosed with HIV and I was given medicine. However, I took medicine and saw no improvement. My knees were paining, I was fatigued and I felt a lot of cold all the time. I decided to go to faith healers, who revealed to me that I had "broken a certain cord". That my second wife had lost her former husband and she did not finish the rituals of death before she came to me. I was then given some *manyasi*, to clear the taboo and illness. After a short while I began to realize some good improvement. (*Dom- fVA*, a man in his early 30s)

The "cord" as used in the case above is symbolic. In the past, widows tied around their waist cords made from banana fibres (*okola*) to symbolize the period of mourning and widowhood. So, the act of having sexual intercourse with a woman for the first time after burying the former husband is referred to as "breaking the cord", *okola or kode* ", which *Dom-Wa* has become a victim of. It was not until *Dom-Wa* became ill that he learnt that the problem was more than HIV that he had been diagnosed with. Continued fatigue, wasting, and the boils that attacked him were because of *chira* as the faith healer he consulted told him. *Dom-Wa* was given *manyasi* to drink and bathe with. After using

<*nanyasi* for some time *Dom-Wa* says he regained strength to walk and the boils were healing. Since the wife also ran away as it had turned that she is the cause of the ailment, *Dom-Wa* did not regularly take ARVs. The record at the dispensary shows that he had stopped taking drugs long time ago. Two months later *Dom-Wa* suffered a serious stroke that paralyzed the whole of his left side of the body.

Chike and *kweche* abound in the practices of the Luo community. The next section continues to illustrate the implications of such rules on housing conditions.

63 Traditional rules, poor housing conditions and difficulties in nursing care

Like in the above section, *chike* and *kweche*, respectively mean rules and taboos that define practices among kin members. In this small section I want to talk about a few areas where unfulfilled *chike* of *ter* (rules of inheritance) engendered poor living conditions among widows, who in this study were the majority. The section further highlights instances where beliefs in taboos also restricted certain family members from giving care to their sick kin.

During my field trips I observed cases where certain sick widows lived in poor housing conditions. Bigger chunks of grass that were used to thatch the houses had fallen down, and the houses were leaking terribly. The earthen floors were pathetic when it rained. *Simbu*. a client lived in a house in which one side of the walls had fallen off and replaced with some old mat from inside to cover the open wall. In the centre of the house there was a "tent" made of a large polythene sheet to shield the bedding from rain. Seven other widows had the same problem.

The underlying reason behind the poor housing conditions was that the widows had not been "inherited". After a husband's death, the house and the widow is considered *mogak*, (unclean) until the widow gets *jater*, (a man to inherit her) who would literally build her a new house. It is a taboo to repair the old house, which belonged to the deceased husband. The widow's children are also prohibited from contributing any materials or participating physically in the building of their widowed mother's new house. It is the responsibility of

the widow and the new husband to look for building posts and other necessities that many **of these** infected widows could not manage due to their ill health. Once the materials are **ready the** inheritor puts the first post in the holes of the house for it to be called in his **name. The** widow's brothers-in-laws and other villagers could assist.

However, the situation is complicated by the fact that none of these widows wants to get "an inheritor" due to their HIV status. At the VCT centres they were also warned against engaging in sexual activities with other men in order to minimize chances of re-infection in **order** to prolong their lives. *Mi-Ako*, a client is very sad about the issue of *ter*. And according to her, the bad state of her house "increases the stigma people have attached to her because she refused to get *ajater*". Again no man is willing to inherit them because they are suspected to be HIV positive since their husbands died after a long period of ill health.

If a widow built a new house and occupied it without an "inheritor", she had gone against *chik*, and this could cause *chira* in her or her children. The married sons were compelled to go and stay either at shopping centre or with their uncles (fathers' brothers). According to the elderly informants the sons have no capacity to fulfill all the rites in their father's *dala*, especially during planting and harvesting when the mother has no *jater* as the head of the home. *Odhis*, a young man in his thirties, migrated to a nearby shopping centre called Wagusu, from where his wife cooked and took food to his mother. *Odhis* is also forbidden from doing any farming activities even from the shopping centre where he lives. He feared that the food he grows would go to the mother's home and she would unknowingly eat it, which is *kwero* (prohibited). *Odhis*, thus has to depend on small contracts and business activities that are not very rewarding. It has become too difficult for him to feed his family plus the sick mother.

Some parents are not able to provide nursing care to their sick married sons and their wives in their *simba*. Likewise married sons are not very free to nurse their sick parents. They cannot go up to the sleeping areas of each other. They instead peep at the door to see how the sick fares on. Food is given to children to forward it to the sick. It is more

complicated for bedridden patients. The caregivers are forced to call upon other people who relational[^] correspond to the sick in the kinship structure. Like for sons grand parents, brothers, or brothers' wives to help. But this external support is occasional. The patient can take too long in their sleeping places when such people are away. They are not bathed nor are their cloths cleaned regularly. There is always unpleasant smell from the sleeping areas, which is not conducive for the sick, as one patient observed:

These beddings of mine are very dirty. The smell from them stifles me. I really feel bad about it. My brother-in law's wife was to come to change them for me but she has not arrived yet. Perhaps she is still busy with her domestic duties".
(*Ne-Nya*, an infected widow, 45 years old)

Based on that background a boy, 17 years old was forced to marry in order to get a wife who could help him nurse his mother. The boy had turned 19 years while his wife was 17 years old at the time of this study. According to the sick mother, *Ja-Abi*, it was a blessing in disguise to have her son married at such a tender age. And to break barriers of *chik*, she decided not to get a *jater*, as her late husband and villagers advised her. The elderly informants said that as long as a woman is still sexually active, her daughters-in-law are restricted from entering her bedroom. But once she declares non- engagement in sexual relations they are free to walk into her inner room and support her in any way, including bathing her. *Ja-Abi's* **daughter**-in-law was then free and took good care of her.

Whereas **in-depth** interviews show that sons could be taken back to their parents' house and cared for from the sitting room when they become too sick as was observed in one case throughout the study, this was only possible for sons who had not established their own homes. But **daughters**-in-law could not be taken to the mothers-in-law's houses when **too** sick.

Others areas where *Chike* and *kweehe* applied include a case where two men whose parents and the elder brothers could not visit because they established homes before the elder brothers did. The wives of these two men bore the whole burden of nursing the husbands alone until they both died. The mothers never stepped into these homes even during the burial sessions of their sons in order to protect the other elder sons from *chira*.

Nevertheless, patients with Christian background had broken away from the traditional beliefs. Christians attended to each other without restrictions because the blood of Jesus Christ "finished it all". This implies that they are no longer under any bondage of the traditional norms. Widows built houses without *joter* (pi.), and encouraged their colleagues to join churches and abandon the customs. In the study there were six widows who were helped by various churches to build new houses. Church leaders blessed the grounds where the houses were built and the "sisters in Christ", helped spend the first night in the new home to ensure no man invaded as *ajater*. But the only question that the villagers commonly ask is, "how will the sons build their *simba* or establish homes?" This comes as a concern that not all the boys would be Christian converts and should that be the case then *chira* would have to attack them.

CHAPTER SEVEN

DISCUSSION

In this chapter, the findings are interpreted to show how they relate to similar studies done elsewhere.

7.1 Discussion

The study shows that government, various NGOs and the local community strive to provide health care support for PLWHA in the study area. Based on the understanding that prevention of HIV and management of AIDS involves a series of multi-faceted social processes, these stakeholders combine efforts in order to strengthen resource capacity, which Bourdieu and Wacquant (1992) refer to as the capital. Capital, in this sense did not only include money that facilitate the trainings of health providers, but also the supply of medicine and other necessary home-based care kits like gloves as well a health care personnel trained specifically on ART. Other NGOs provide nutritional supplements and occasionally give blankets to *clients*.

The partnership approach adopted in the home-based care programme has led to a scenario where HIV/AIDS patients in the study community were cared for by a constellation of people, collectively referred to as the *care management group* (CMG). The CMG is akin to the therapy management group (TMG) that Janzen (1978) describes about medical pluralism in Lower Zaire, where various kinsmen, and occasionally friends and associates exercise a brokerage function between a sufferer and a specialist. However, the CMG is a broader version and conversely facilitated by health providers and brings together the HIV/AIDS sufferers, the family caretakers and CHWs in the care process.

More importantly, the PLWHA have founded social clubs known as *patients support groups*, which is based on their shared biological affliction. The *patients support group* is an additional resource base. It serves the role of "psychosocial therapy", which is similar to what Nguyen (2005) writes about a "talking group" in Ouagadougou, Burkina Faso. When more members join the group, they develop a feeling of "after all it is not just me

but with many others". They cheer up overcome awkward silence and fear and begin to have lively discussions about the vicissitudes of everyday life.

The group injects energy and most of the infected persons "go public". They attend public meetings and confess their HIV status, which then has become a step forward towards reaching out to other people who still fear going for HIV test. Each support group member counted at least two people who went for VCT out of such collective efforts. The support group members visit each other for pas-time and also help colleagues when too sick or bereaved. *Support group* members have taken the place of kinship relations, especially for those clients whose relatives have abandoned. They now have "new brothers and sisters".

These support groups are also formed as self-help ventures. The group members pool resources to run joint income-generating activities like keeping goats, poultry and horticulture. The patients further use the group as a social movement to lobby for their needs and interests. For example, the groups request for financial support from donors by writing proposals via NGOs. Already several NGOs like CARE International, among others, were coming up to offer trainings on management of income-generating activities as well as on how to boost their economic base through savings and loaning.

Nonetheless, the *patient support groups* are just but part of the second wave of programmes aimed to address the HIV pandemic by stressing the direct involvement of affected communities, especially the infected persons. Achieving "greater involvement of people living with HIV/AIDS" or GIPA as the approach came to be known after the 1994 Paris Summit on AIDS, encouraged PLWHA to take leadership roles and actively respond to the problems affecting them. This background stimulated formation of such support groups albeit some of which were not out of heartfelt desire to participate in self-help groups (Nguyen 2005).

Bourdieu and Wacquant (1992) argue that in any game or practice for that matter, adequate capital (resources) and practical disposition enable players to be effective in

order to achieve the intended goals. In spite of the expanded social network, home-based care programme in this study area face a lot of challenges due to limitations related to facilities and other socio-cultural aspects. In spite of the fact that people fear going for serology test, inadequate VCT sites and counselors in part delay entry of patients into home based care programme. In the long run, they seek VCT services when too sick and wasted, which then slow down their recovery process as observed by health care providers in the area.

One health facility that provides ARVs is already over stretched by the number of patients. The other health facility still has to refer patients to Bondo that is inaccessible due to lack of fare. Even in Bondo district hospital patients sometimes get medicine that can only last them for a few days. This means many patients are at risk of drug resistance (Mombe 2004).

At the same time, there is a disproportionate doctor-patient ratio. In relation to the estimated population of the division as per the last census conducted in the year 1999 (CBS 1999) the ratio comes to 1 health provider per 34,790 inhabitants. Patients queue for so long while waiting for services. The shortage makes the clinical officer also to spend very little limited time with each patient, who in the contrary requires a lot of time to express all problems.

The NGOs that deal directly with HIV/AIDS patients also face the challenge of limited resources. They are conditioned to consider very few *clients* for support. The NGOs thus provide support based on "social calculus", where patients who contribute most, especially by declaring their HIV status in public are favoured. In other words, only those who can translate their improved health for the good of others benefited more (Nguyen 2005). The patients are in a way part of the playing team. They are used in creating more awareness. Those who cannot go public are of course left out of this therapeutic economy.

However, the NGOs lack consistency in their supplies of material and healthcare support even to those patients selected as beneficiaries. Neither do they visit the *clients* regularly because of staff shortage, nor do they fulfill promises of financial support to the support groups. This has triggered patient migration to other NGOs still considered stable in terms of resources. But the patient migration generates tension between the losing and receiving NGOs, which also interferes with free flow of support to patients. The affected patients get tossed back and forth as some of them are completely abandoned in the process.

On the other hand, there is a growing recognition of the importance of CHWs as part of social capital in this era of HIV/AIDS and home-based care. Kenya's health care system has always relied on the CHWs in many aspects of community-based health care services, and it was assumed that these CHWs could still volunteer and remain effective as in the past. But the voluntary approach cannot be taken for granted considering the social and economic background of the volunteers and the demanding nature of caring for a person suffering from HIV/AIDS. The CHWs even need materials to attract and maintain clients (Carsten 2000). The study has shown high attrition rates among CHWs aged 40 years and below. And the prime driving force behind the dropout is lack of payment or incentives. They consider it a "waste of time" to work as volunteers, while there are a lot of family needs. The clients also have high expectations from the same CHWs and they cannot afford it. The situation is further complicated by the moral principle that "it is unacceptable to visit the sick bear-handed".

The CBOs are also financially poor to offload the burden on the individual CHWs. Most of the groups are basically welfare, the *nyoluoro* groups (Ouko 1998), where the money collected at each rotation is given to the member hosting the association at that time. The monthly savings do not even exceed twenty Kenya shillings per person, hence too little to meet extra needs like helping a needy family. The programme also makes the CHWs poor since they take a lot of time out of their productive duties.

More importantly, many of the CBOs are "resource capture" driven. They are not formed out of the desire to take up the responsibility to help PLWHA, but to target donor support. There is a widely spread rumour in the community that groups helping HIV/AIDS patients are heavily funded. The CBOs are thus formed and registered but literally have no income-generating activity for sustainability. The NGOs also promised to award the CHWs some token in the near future, which did not materialize. The CHWs thus scramble for trainings in order to benefit from allowances, such as transport reimbursements and lunch allowances provided during trainings. While in the villages patients stay for a long time without any attention of the CHW.

Stigma and confidentiality is of concern in home-based care in the study area. Erving Goffman (1963) in his classic book, *Stigma: notes on spoiled identity*, defined stigma as "an attribute, which is highly discrediting". Instead of recognition, the stigmatized are met with disapproval. In the Luo community, HIV/AIDS evokes stigma because of its known mode of transmission, the ailment process and the fact that it has no cure. PLWHA experience blame, rejection, bitterness, expulsion, insufficient care and neglect (UNAIDS 2002; Save the Children 2001; Cabrera *et al.* 1996). As a result, many people are afraid of being tested for HIV. A few others agree to undergo VCT when completely wasted and ravaged by opportunistic infections. Almost 16% of the patients who participated in the study died soon after they were introduced to ARVs perhaps because of drug load because there were several other opportunistic infections treated alongside HIV/AIDS and all the medicines were taken each day.

Other patients also fear that the local health facilities cannot keep their secrets and thus seek treatment from hospitals outside the study area. But traveling is too expensive for such patients. They sometimes miss to go for drugs on time for lack of fare. Again these patients do not benefit from the support of CHWs, except for a few who were lucky to have friends as CHWs.

At family level, HIV/AIDS patients face the dilemma of disclosure; to tell or not to tell the caretakers about their status. Some patients had only told the CHWs they were linked with. The silence was a defense mechanism to guard against stigma, although some parents took it as a way of saving their children from beginning to think of themselves as orphans. But one major problem with patients' silence is lack of adherence to drug regimen. This is perhaps because the caretakers have no knowledge of what is going on and what to do. The CHWs cannot also monitor them on a regular basis. In contrast, total compliance was observed among the patients who had shared their HIV status with family caretakers. The caretakers maintain close contact with health providers such that whenever there is any complication the patient is rushed for a check up. More so, there is comparatively good social and material support for the infected persons from other friends who they had told about their status. And these patients showed very good health improvements. Loustaunau and Sobo (1997) had also noted that family empathy and support increased compliance in alcoholism treatment, and hastened the recovery progress in stroke victims and patients with severe orthopedic disabilities.

Although it is necessary to disclose HIV status to caretakers, children suffered a lot of distress after their mothers broke the news to them. The children kept on asking the ailing mothers what they would do when they die. The children wanted to know whom they would live with and how they would go to school. It was a hard task for these infected mothers to convince these children that they would not die soon. The fact that the mothers were regaining some good health and strength was not satisfactory evidence to convince them otherwise. Such children confessed that the class performance dropped as a result of trauma they were undergoing.

Inasmuch as CMG exists, mainly blood relatives look after their sick kin members (Cabrera *et al.* 1996). The blood relatives include parents, siblings and own children, either young or adult. The CHWs and friends chip in occasionally. But the presence of the HIV virus caused a lot of tension among married couples, which degenerated into life characterized by accusations of infidelity, violence and neglect. Some wives ran away from their husbands after they tested HIV positive. Likewise, the male spouses returned

their ailing partners to their maternal homes. Although children still tie the parents together, the discordant husbands always want to marry new wives. In general many HIV negative spouses withdraw their support and feel less concerned about the care for the infected.

The study also noted that the extended family system, which has been evoked in a number of contexts as a "safety net" no longer holds in this era of HIV/AIDS and home-based care. The extended family members living nearby keep away from the HIV infected persons. Infected widows and orphans were most affected. Mainly maternal grandmothers absorb the infected orphans, as the infected widows mostly get support from their own children, parents or siblings.

The shift towards blood relatives led to *care migration* where infected widows and orphans migrate to maternal families, while others rely on daughters already married in various places who return from time to time to care for them. Some young girls are sent to look after their widowed sisters.

Nonetheless, *care migration* is complicated by the custom, which requires that a woman must be buried beside her house when she dies. So, when a woman goes to her maternal relatives to get support, the moment she develops serious health complications, she is returned to her home where mainly children are left to take care of her. As a result many child caregivers were observed to drop out of school at alarming rate.

Lack of food is a major problem facing PLWHA. Consequently, many PLWHA ignored taking medicine saying, "*That the drugs are overwhelming if taken on an empty stomach*". Health providers also noted poor nutrition as the main cause of "poor prognosis" among patients (NACC 2005). A majority of the affected families rely on farming, which is mostly affected by persistent droughts in the district (Central Bureau of Statistics 2005). The caretakers also take much of their time with the sick at the expense of productive roles as well as increased expenditures on healthcare (UNICEF 2002). In other situations, patients forced themselves into economic activities like charcoal burning

in order to fend for their families. But engagement in such difficult economic activities resulted in persistent chest problems.

Cultural rules and taboos abound in the everyday practices of the Luo (Prince 2004) and cause a lot of complications in the care process. Rules of widow inheritance engender poor housing conditions for several widows because they had not been set free for growth (Prince 2004). But these widows were not willing to enter into sexual unions because of their HIV status. Furthermore, men feared these widows following long illness of their deceased husbands. In this case, there was a blockage in the life pathways of these widows and their homes (see Prince 2005). No house could be built for such a widow without *jater*. However, there is relief among Christian widows, who have broken away for the traditional norms. They constructed new houses without *jater* despite negative talks from the community.

Likewise, unfulfilled ritual, in turn blocks the sons to build their houses in the same homes. Instead they are forced to migrate out of such homes leaving the widowed mothers alone in their homes. And providing care for such widows from a distance is too difficult.

Similarly, belief systems delay going for VCT and influence how patients interpret their continued experience of complications despite being on ART. Some patients claimed that they suffer from *chira*. They variously attribute the conditions to circumstances in their living arrangement and fulfillment of rules within the homes. Other patients also ascribe their sickness to sorcery and witchcraft. They consequently opt for traditional practitioners who provide concoction, *manyasi*, as antidote to clear the culture-bound syndrome. Some patients abandon ART as well despite knowledge of their status.

Although anthropologists have recognized the worth of traditional practitioners as part of therapeutic options (Cabrera *et al.* 1996), there seems to be some missing link with the professional sector. The traditional practitioners appear not to encourage the *clients* to continue with ART alongside the concoctions they provide to the sick. There is need to

bring them to light of HIV/AIDS and the necessary therapeutic process in order to help the sufferers.

7.2 Conclusion

This study found that the government and NGOs mobilized and trained CHWs as part of the expanded social capital to extend skilled management of PLWHA in the villages. The partnership approach adopted in the home-based care programme has led to establishment of CMG, in which relatives, friends and the CHWs teamed up to help PLWHA.

Despite the expansive social capital mobilized, there is inadequate health care support for HIV/AIDS patients in the study area. Throughout the division only one health facility, provides ARVs, while the rest refer patients for ARVs in Bondo district hospital, which many patients cannot reach easily due to distance and lack of fare. The support from NGOs is inconsistent and reaches a small number of PLWHA. Patients thus migrate to other NGOs considered stable in terms of resources. But the exodus generates tension between NGOs and interferes with free flow of support for such patients.

CHWs specifically aged 40 years and below drop out of the programme at an alarming rate for lack of payment and high expectations from the affected families. Blood relatives of patients especially children bare the brunt of taking care of their sick parents.

Almost 50% still go to far places for treatment despite transport burden. They fear that their status would be revealed when they go to local health centers where they are known. As well a total of 31.3% remained unlinked with CHWs and thus did not benefit from the expanded social network.

Many patients often ignore taking medicine when there is no food saying that the drugs are overwhelming if taken on an empty stomach. Health providers also blame malnutrition as the main cause of poor prognosis observed in the patients. Other challenges include cultural beliefs and practices that not only delay going for VCT but

make patients to re-interpret physical discomfort in terms of folk illness and interpersonal malevolence, and they subsequently abandon antiretroviral therapy.

7.3 Recommendations

- There is need to scale support services and made accessible to PLWHA.
- The supporting NGOs need to strengthen teamwork
- Some small token for the CHWs, if possible, need to be tailored into home-based care as a policy in order to increase their retention in the programme.

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APPENDICES

APPENDIX 1.

Patient details and the Care Management Group profile

Names	Gender	Marital status	Status of spouse	Sickness duration	Care-giver (& age)	Disclosure of status	Link to NGO
Flo-Uya (34 yrs)	Female	Married	Discordant	2 yrs	Self	Yes	No
Omb-Ula (25 yrs)	Male	Widowed		lyrs	Self	No	No
Sip-Mbu (38 yrs)	Female	Widowed		4yrs	Self	No	Yes
Ali-Bo (25 yrs)	Female	Widowed		1yr	Self	Yes	Yes
Bea-Nya (38 yrs)	Female	Widowed		3 yrs	Self	No	No
Sip-Uya (45 yrs)	Female	Widowed		2yrs	Self	No	Yes
Nao-Uya (23 yrs)	Female	Widowed		6yrs	Self	Yes	No
Ja-KD (45 yrs)	Female	Widowed		3 yrs	Self	Yes	Yes
Mil-Ako (36 yrs)	Female	Widowed		2yrs	Self	No	Yes
Dol-Mbu (45 yrs)	Female	Widowed		lyrs	Self	No	No
Ndo-KD (38 yrs)	Female	Married	Concordant HIV+	3yrs	Self	No	No
Mil-Bo 30 yrs	Female	Widowed		2 yrs	Self	No	Yes

Patients with single caretakers							
Names	Gender	Marital status	Status of spouse	Sickness duration	Care-giver (& age)	Disclosure of status	Link to NGO
Ati-Ma 38yrs	Male	Separated	Concordant positive	5 yrs	Brother 45yrs	No	Yes-transfer
Wa-Ye (42 yrs)	Male	Married	Concordant HIV +	2yrs	Wife (30 yrs)	Yes	Yes
Car-Onyi (25 yrs)	Female	Widowed		2yrs	Daughter (12 yrs)	No	No
Ndo-KD (43 yrs)	Male	Married	Concordant HIV+	3 yrs	Wife (38 yrs)	Yes	Yes
Josi-KD (25 yrs)	Male	Married	Discordant	2 yrs	Wife (25 yrs)	Yes	No
Do-KD (26 yrs)	Male	Separated	Discordant	2 yrs	Mother (62 yrs)	No	No
Jo-Mbu (56 yrs)	Male	Married	Not tested	2 yrs	Wife (47 yrs)	No	No
Sar-SDA (38 yrs)	Female	Widowed		4 yrs	Dgt (13 yrs)	Yes	No
Mi-Da (16 yrs)	Female	Unmarried 16 yrs old		2 yrs	Mat-Gr-mom (71 yrs)	Yes	No
Moni-Ko (45 yrs)	Female	Widowed		3 yrs	Daughter (23 yrs)	No	(Abandon)
Odu-Og (36 yrs)	Male	Widowed		3 yrs	Son (12 yrs)	Yes	Yes
Mag-Mbu (42 yrs)	Female	Widowed		2yrs	Siz (47 yrs)	Yes	No

Names	Gender	Marital status	Status of spouse	Sickness duration	Care-giver (& age)	Disclosure of status	Link to NGO
Le-Wa (30 yrs)	Female	Married	Discordant	9yrs	Husband(35 yrs) not stable	Yes	No
Tre-Uya (8 yrs)	Female	Unmarried 8yrs		5yrs	Pa-Aunt (55 yrs)	Yes	Yes-transfe r
Ro-Go 45 yrs	Female	Married	Concordant positive	1yr	Son 17 yrs	No	No
Jos-Nya (38 yrs)	Female	Widowed		4yrs	Cousin-in law (-)	Yes	Yes
Alf-wi (25 yrs)	Female	Married	Concordant HIV+	1yr	Mo-in law (73 yrs))	No	No
Isa-Abi (43 yrs)	Male	Married - (polygyny)	Concordant HIV+	1yr	Wife (25 yrs)	Yes	No
Euni-Abi (25 yrs)	Female	Married (polygyny)	Concordant HIV+	3 yrs	Husband(43 yrs))	Yes	No
Ma-Ma (26 yrs)	Female	Married	Discordant	1yr	Husband (28 yrs)	Yes	No
Ma-Wa (25 yrs)	Female	Married	Discordant	1yr	Husband (36 yrs)	Yes	No
Ma-Uyo (30 yrs)	Female	Married	Discordant	1yr	Husband (Fear) (46 yrs)	Yes	No
To-KO (37 yrs)	Male	Married	Discordant	5 yrs	Wife (25 yrs)	Yes	Yes-transfe r
Docu-Uya (23 yrs)	Female	Married	Discordant	2yrs	Husband (28 yrs)	Yes	No
SaG 38 Y	Female	Remarried	Not tested	4yrs	Levir (-)	No	No

Names	Gender	Marital status	Status of spouse	Sickness duration	Care-giver (& age)	Disclosure of status	Link to NGO
An-Wa (43 yrs)	Female	Married	Not tested	5yrs	Bro(-)	No	No
Rom-Ola (43 yrs)	Male	Separated	Not tested	9yrs	Mother (65 yrs)	No	Yes
Onge-Uya (55 yrs)	Male	Married	Discordant	1yr	Wife-conflict (29 yrs)	Yes	No
Jud-Ako 48 yrs	Female	Widowed		4 yrs	Daughter 15 yrs	No	No
Sam-Nya (8 yrs)	Male			5 yrs	Maternal grand mother	Yes	No
Ro-Ase	Female	Widowed	-	3 yrs	Siz 13 yrs	No	No
Patients with double caretakers							
Ajo-Bo (25 yrs)	Male	Married	Concordant (HIV+)	4 yrs	Wife (24 yrs) Mom (56 yrs)	Yes No	Yes (transfer)
Onya-KD (57 yrs)	Male	Married (polygyny)	Both wives Discordant	4 yrs	2 Wives (55 yrs & 34 yrs)	Yes	Yes (transfer)
Agn-Nya (38 yrs)	Female	Widowed		6 yrs	Daughter (17 yrs) Bro-in law (-)	Yes Yes	Yes (transfer)
Jan-PB (45 yrs)	Female	Widowed		4 yrs	Daughter (14 yrs) Mom (70 yrs)	No No	No (abandon)
Ari-Bo (25 yrs)	Female	Married	Doesn't know	3 yrs	Husband Mo-in law 70	No No	Yes

Names	Gender	Marital status	Status of spouse	Sickness duration	Care-giver (& age)	Disclosure of status	Link to NGO
Luc-Ako (18 yrs)	Female	Unmarried (17yrs, has child)		3 yrs	Mom (43 yrs) Pat-gr-mom (over 70 yrs)	Yes Yes	Yes (abandon)
Frans-KR (56 yrs)	Female	Widowed		5 yrs	Dght-in law (30 yrs) Son (32 yrs)	No No	Yes No
Jul-Ako (57 yrs)	Female	Widowed		2 yrs	Co-wife (56 yrs) son (17 yrs)	No No	No
Dol-Mbu (60 yrs)	Female	Widowed		4 yrs	Siz (45yrs)(married in village) & Son (-)	No	Yes (abandon)
Oki-Lu (30 yrs)	Female	Widow		4 yrs	Son (12 yrs) & bro (-)	Yes	No
Math-KO (65 yrs)	Female	Widowed		4 yrs	Son & dght (16 & 14 yrs)	No	No
Caro-Ako (25 yrs)	Female	Remarried		1 yr	Levir (-)& bro-in law's wife (43 yrs)	No	Yes (abandon)
Sali-Ati (24 yrs)	Female	Married		1 yr	Husb (37 yrs)& mother (53 yrs)	To husband only	No
Juci-KO (23 yrs)	Female	Married		1yr	Husb (37 y)& bro-in-law's wife (30 yrs)	Yes	No
Bent-Nya (27 yrs)	Female	Remarried	Discordant	2 yr	Levir (-)& aunt (45 yrs)	Yes	Yes

Names	Gender	Marital status	Status of spouse	Sickness duration	Care-giver (& age)	Disclosure of status	Link to NGO
Mika-Wa (50 yrs)	Female	Widowed		5 yrs	Bro (-)& friend (CHW) (47 yrs)	Yes	No
Sar-Ako (40 yrs)	Female	Widowed		3 yrs	Son (14 yrs)& bro (-)	Yes	Yes
Dor-KR (21 yrs)	Female	Widowed		3 yrs	Grndmom, step mom	Yes	No
Ste-Uya (25 yrs)	Male	Separated		3 yrs	Father, step- mom	Yes	Yes
Josh-KR (23 yrs)	Male	Separated		2yrs	Mother and friend	No	No
Alf-Lu (38 yrs)	Male	Married		7 yrs	Mother and wife	No	Yes
Patients with triple caretakers							
Okw-KD (47 yrs)	Female	Widowed		3 yrs	Dgt 12 y, sons 25 & 18 yrs	Yes	Yes
Ja-Abi (45 yrs)	Female	Widowed		5 yrs	Dgt-in law 17 y, son 18 yrs & Siz 56 yrs	Yes	Yes
Ne-Nya (50 yrs)	Female	Widowde		5 yrs	2 Dgt 17 & 25 yrs & son 19 yrs	Yes	Yes (transf er)

Names	Gender	Marital status	Status of spouse	Sickness duration	Care-giver (& age)	Disclosure of status	Link to NGO
Patients with multiple caretakers							
Jef-Mbu (63 yrs)	Female	Widowed		3 yrs	2 Dgt (23 & 26 yrs)& Sons (-)	Not	
Abu- Ore (45 yrs)	Male	Married	Not tested	2 yrs	Bro (60 yrs), nephew (26 yrs)& wives (35 & 37 yrs)	To 1 wife & nephew	
Fre-PB (35 yrs)	Male	Married	Discordant	12 yrs	Wife (29 yrs), mom (58 yrs), bro (-)& siz (-)	Yes	Yes

APPENDIX 2
DATA COLLECTION INSTRUMENTS

Interview Guide for HIV/AIDS patients

1. When did you begin to feel sick?
2. History of health care seeking:
 - Process of seeking treatment since illness began.
 - Have you gone for voluntary counseling and testing? (When?)
 - Current place of health care support? (How far)
3. What problems do you face when seeking health care?
4. Which NGOs are you linked with for further care and support?
 - Are you linked with CHWs from the community?
 - How are you related with the CHW?
 - What kinds of support do you get from the CHWs?
5. Family support
 - Who takes care of you here at home?
 - How are you related with the caretaker?
 - What kinds of support do you get from the extended family members?
6. What problems do you experience while being taken care of at home?
7. What cultural taboos hinder some of your relatives from helping you?

Direct observation

Housing conditions

1. Describe the condition of the house where the patient lives
(Roofing materials and the walls)
2. Observe cleanliness of the house and compound
3. Record physical state of the patient. (Able to walk or bedridden)

Survey Questionnaire for HIV/AIDS patients

1. Age group of the patient
 - (a) 0-09
 - (b) 10-19

- (c) 20-29
 - (d) 30-39
 - (e) 40-49
 - (f) 50 and above
2. Marital status
- (a) Single
 - (b) Married
 - (c) Separated/divorced
 - (d) Widowed
3. Sex
- (a) Male
 - (b) Female
4. Religion
- (a) Catholic
 - (b) Protestant
 - (c) African inland churches
 - (d) Islamic
5. What is your main source of livelihood?
- (a) Farming
 - (b) Business
 - (c) Formal employment
 - (d) Remittance
 - (e) Others (specify)
6. Where do you get health care support_
7. What is the relationship between you and the caretaker
- a) Daughter
 - b) Son
 - c) Mother
 - d) Father
 - e) Grandmother
 - f) Others (Specify)

8. What is the age of your principal caretaker?
9. Did you disclose your HIV status to the caretakers or close relatives?
 - a) Yes
 - b) No
10. How often do you receive support from the extended family members?
 - (a) Very frequently
 - (b) Frequently
 - (c) Not frequently
11. How many NGOs are you been linked to since your entry into home-based care
 - (a) None
 - (b) One
 - (c) Two
 - (d) More than three
12. How often does the CHW you are linked to visit you
 - a) Very often
 - b) Often
 - c) Not often
13. In relation to your home, how far does the CHW come?
 - a) Very far
 - b) Far
 - c) Not far

Checklist for monthly follow-ups with patients

1. Describe the physical state of the patient (Able to walk or bedridden).
2. What remarkable physical changes are observed since last visit?
3. Who now take(s) care of the client?
4. What is the relationship between the patient and the new caretaker?
5. What is the age of the new caretaker?
6. What additional source of income or assistance from outside the household since last visit? (From a friend or extended family)
7. Has the patient changed to a new place to seek care and support?

- a) Yes (if yes, to where? Specify)
 - b) No
8. Has the CHW visited the client in the last four weeks?
- a) Yes (if yes, how many times?)
 - b) No
9. Did the patient go to collect medicine for the month?
- a) Yes
 - b) No (Why?)
10. Has the patient transferred from the original health facility to another?
- a) Yes (Why?)
 - b) No
11. Has the client transferred to a new NGO?
- a) Yes (To which NGO? And why?)
 - b) No
12. Does the client and spouse if married, attend support group meetings?
- a) Yes
 - b) No (why?)
13. Describe the condition of the house where the patient lives (Roofing materials and the walls)
14. Observe cleanliness of the house and compound

Interview Guide for caretakers

1. Socio-demographic information
 - Age of the informant
 - Sex
 - Marital status
 - Level of education
2. What economic activities do you do for a living?

3. How are you related to the patient?
4. History of patient's ill health.
 - When did the patient begin to feel sick?
 - When did the patient go for VCT?
 - Where does the patient get treatment?
5. Caretaking
 - Who has (have) been taking care of him/her since the beginning of ill health?
 - What problems do you experience while taking care of the patients.
 - Which NGOs have been supporting the patient?
 - What kinds of support does the patient receive from the NGOs?
 - What is the contribution of extended family towards care of the patient?
6. What cultural taboos hinder you or other relatives from caring for the patient?

Interview Guide for CHWs

1. Socio-demographic information
 - Age of the informant
 - Sex
 - Marital status
 - Level of education
 - What is your religious affiliation?
2. What do you do for a living?
3. Home-based care programme.
 - When did you begin this volunteer service?
 - What motivated you into the programme?
 - Which NGOs or health care institutions are you linked with?
 - What kind of activities do you do as a CHW?
4. Link with clients
 - How many clients do you have as at now?

- How do you did you come to identify the clients?
5. What problems do patients face in the process of being taken care at home?
 6. What kind of assistance do the patients get from their relatives?
 7. What cultural taboos hinder some relatives from providing care to their sick?
 - Who then provides care?
 8. How do you help patients without any relative to assist?
 9. What problems do you experience as a CHW in home base care programme?

Focus Group Discussion Guide for CHWs

1. Which category of people takes care of the sick family members?
 - Why?
2. What problems do HIV/AIDS patients face while being taken care of at home?
3. What kinds of support do the extended family give HIV/AIDS patients?
4. What cultural taboos hinder some relatives from taking care of a sick kin?
 - In the event of such taboos, who then takes the responsibility to assist?)
5. How do you approach and enroll clients into the programme?
6. Why are some HIV/AIDS patients not linked with CHWs from their own villages?
7. What problems do CHWs experience as volunteers?
8. Why do some CHWs drop out of home-based care programme?

Interview Guide for Key Informants (Elderly Persons)

1. Which members of the family were charged with the responsibility of caring for sick family members in the traditional past?
 - *(Could you know why)*
2. What problems did they face during care provision?
 - *(How did they deal with the problems?)*
3. How have expectations from extended family networks in relation to supporting sick relatives changed over time?
 - *(What can you attribute these changes to?)*

4. Could you tell me some cultural taboos that were preventing some relatives from providing nursing care to a sick member?
 - *Do they still exist?*
5. From your experience, what do you think can be done to help families caring for their sick members at home?

Interview Guide for NGOs

1. When did you begin this work of home-based care in this area?
2. How many places do you cover in this area?
3. How do you link with HIV/AIDS patients in the villages?
4. How many patients do you have as at now?
5. What is the community's general response towards the programme?
6. What kind of support do you provide for HIV/AIDS patients?
7. What kind of challenges does the organization face in the process of providing home-based care?

Interview Guide for Religious Leaders

1. Could you please tell me something you know about HBC for people living with HIV/AIDS in the area?
2. What programmes does the church have in relation to taking care of people living with HIV/AIDS at home?
3. What particular group of people does the church target with its programmes?
(Church members only or everybody irrespective of denomination)
4. From your own observation, what problems do the sick experience while being taken care at home?

Interview Guide for Health Providers

1. How you do home base care for people living with HIV/AIDS?
2. What kinds of services do you provide with regard to HBC?
3. What problems do you see as a hindrance to the effective provision of this programme in the area?
 - Stigma

- Lack of adherence to regimen (why?)
- Lack of commitment on the part of CHWs
- Inadequacy of drugs as compared to the number of patients registering

Compared to the past, what strengths do you see since the introduction of this programme

As a key participant in this programme, what do you think could be done to improve its effectiveness?

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